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**Prenatal testing and reproductive autonomy:
defending against disability discrimination concerns**

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Abstract

Arguments have been forwarded that terminating a pregnancy affected by a congenital abnormality discriminates against those living with disabilities and makes negative judgements about their lives.

For the clinical geneticist these arguments raise questions as to whether their practice is ethical. In this thesis I aim to consider these concerns primarily from the position of the clinical geneticist by addressing ethical arguments. I argue that the fetus does not have full moral status equivalent to a person and therefore terminating a disabled fetus is not comparable with ending the life of a disabled person, and so does not imply that the lives of disabled persons are not worth living. I further argue that the decision to carry out prenatal testing and abortion should not solely rely on disability and on the objective opinions of healthcare professionals. Central to this argument is that when considering whether or not prenatal testing and abortion are justifiable, it is important to take into account the specific and unique circumstances of the family, particularly the parents and pre-existing children. Parents' reproductive autonomy therefore needs to be considered as well as the harm having a disabled child could cause; both to the future child to and those directly affected by their existence.

I conclude that prenatal testing and abortion does not discriminate against those living with disabilities. Despite this, however, reproductive autonomy is not being respected in current approaches to prenatal testing as late termination of pregnancy can only be legally permitted where two healthcare professionals agree to it. Therefore, in order to enhance reproductive autonomy I have made recommendations whereby the supportive role of the clinical geneticist can be further developed by their acting as an advocate for prospective parents when justifications for late termination of pregnancy are being considered by healthcare professionals.

Key words: prenatal testing, disability, discrimination, abortion, moral status, reproductive autonomy, clinical genetics

Contents

1.	Introduction	1
1.1	Aims and introduction	1
1.2	Genetic and genomic medicine	5
1.3	Prenatal testing and the clinical geneticist	7
1.4	Moral status, reproductive autonomy & disability discrimination	18
2.	The Abortion Act 1967: moral status of the fetus	23
2.1	Introduction	23
2.2	Moral status	25
2.2.1	What is it to have ‘moral status’?	27
2.2.2	Being human	29
2.2.3	Sentience	31
2.2.4	Personhood	32
2.2.5	Fetal viability	39
2.2.6	Birth – the transition from fetus to neonate	44
2.2.7	Moral status as a continuum	48
2.3	Disability and Abortion law	49
2.4	Abortion: women’s rights arguments	60
2.5	Summary and conclusions	65
3.	Reproductive autonomy	68
3.1	Introduction	68
3.2	Autonomy as an overriding principle	69
3.3	Personal autonomy	75
3.4	Social and relational autonomy	79
3.5	Respecting autonomy	82
3.5.1	Paternalism	86

3.6	Reproductive autonomy	91
3.7	Autonomy and prenatal testing	94
3.8	A response to anti-autonomy arguments surrounding prenatal testing	101
3.9	Equality and reproductive freedom	108
3.10	Summary and conclusions	114
4.	Harm, health, disease and disability	117
4.1	Introduction	117
4.2	Harm, health, disability and disease	119
4.2.1	Models of disability	121
4.2.1.i	The Medical Model of disability	122
4.2.1.ii	The Social Model of disability	126
4.2.2	Health	129
4.2.2.i	Theories of health	133
4.3	When death or non-existence may be a preferable option	138
4.4	Other reasons to support prenatal testing - minimising disability after birth	143
4.5	Summary and conclusions	148
5.	Responding to disability discrimination arguments	150
5.1	Introduction	150
5.2	The Disability Critique and the effects of discrimination	154
5.2.1	Advances in genetic and genomic medicine	154
5.2.1.i	Reducing the number of disabled people in society	157
5.2.1.ii	Reinforcing hostile social attitudes	160
5.2.2	Does prenatal testing devalue disabled people?	162

5.2.3	Does prenatal testing influence parental expectations?	171
5.3	Are those with disabilities providing a representative voice?	180
5.4	Summary and conclusions	186
6.	The promotion of reproductive autonomy in future policy	188
6.1	Introduction	188
6.2	Fetal Management	189
6.3	Implications for reproductive autonomy	193
6.4	Difficulties in decision making and harm to others	194
6.5	Considering the reality of termination	199
6.6	Is adoption a viable alternative?	201
6.7	Psychological impact on healthcare professionals	202
6.8	Involving prospective parents in fetal management	205
6.9	Summary and conclusion	207
7.	Summary and concluding remarks	209
	Bibliography	216

Chapter 1

Introduction

“The goal [of counselling] is to promote client autonomy, [to help clients] understand their options and choose a course of action that is most appropriate to them in view of their risk and their family goals and act in accordance with that decision.”¹

1.1 Aims and introduction

Prenatal diagnosis has revolutionised reproductive medicine giving couples an insight into and allowing more control over the health of their future child, either by preventing the birth of a child affected by a condition or by maximising treatment options by having information available prior to birth. As with many advances in the field of medicine, and particularly reproductive medicine, there are ethical concerns about whether or not these new technologies create more harm than benefit. Advances in reproductive technology, for example, heighten concerns about abortion and add to the ongoing debates on this subject.² Objections are raised due to concerns about disability discrimination and how this may suggest that if termination of a disabled fetus is deemed acceptable then infanticide may follow.^{3,4} Although it will not be a feature of this thesis there are also those who are concerned that advances in reproductive technology will allow us to not only select against

¹ Fraser AC (1974) ‘Genetic counselling’, *American Journal of Human Genetics* **26**, pp 636-659

² Savulescu J (2013) ‘Abortion, infanticide and allowing babies to die, 40 years on’, *Journal of Medical Ethics* **39**, pp 257-259

³ Singer P (2013) ‘Discussing infanticide’, *Journal of Medical Ethics* **39**, pp 260

⁴ Giubilini A and Minerva F (2013) ‘After-birth abortion: why should the baby live?’, *Journal of Medical Ethics* **39**, pp 261-263

certain features but also select for those characteristics which we may find more desirable,⁵ such as intelligence or superior sporting abilities.

The overall purpose of this thesis is to address two important questions which are relevant to those working in prenatal medicine where decisions are made in relation to terminating pregnancies which are affected by a fetal anomaly. These two questions are relevant for the practising clinical geneticist to consider in order to satisfy themselves that their practice is ethical. The first question is whether specific prenatal testing discriminates against those living with disabilities as the detection of an abnormality may result in termination of the affected pregnancy. Where termination is decided, based solely on the existence of an abnormality in the fetus, there are arguments that this makes judgements about the lives of disabled people, suggesting they are not worth living.⁶ This is one of the reasons why abortion has always been controversial and continues to be a topic for ethical debate.^{7,8} The second question is whether the existing decision making process regarding termination of pregnancy due to disability supports reproductive autonomy. This second question is influenced by the fact that additional justification for a termination is needed where this takes place late in pregnancy and the current law dictates that two medical practitioners must make this justification.

In this initial chapter, I will explain the aims of my thesis, and make clear that these are to be understood with respect to the role of the clinical geneticist in supporting and advising prospective parents with decision making during the prenatal period. In addressing these two questions, the overall aims are to argue that prenatal testing does not discriminate

⁵ Wilkinson S (2010) *Choosing tomorrow's children: the ethics of selective reproduction*, Oxford University Press, p186

⁶ Shakespeare T (1995) 'Back to the future? New genetics and disabled people' *Critical Social Policy* **15**, pp 22-35

⁷ Savulescu J (2013) 'Abortion, infanticide and allowing babies to die, 40 years on', *Journal of Medical Ethics* **39**, pp 257-259

⁸ Giubilini A and Minerva F (2013) 'After-birth abortion: why should the baby live?', *Journal of Medical Ethics* **39**, pp 261-263

against those living with disabilities and also to consider the implications current practice has for reproductive autonomy, which I argue should be of paramount importance. I base my arguments not only on the implications a prenatal diagnosis has on the fetus but also the future child within the context of its family. The ethical framework that informs this thesis is the Four Principles developed by Beauchamp and Childress.⁹ This has been described as a culturally neutral approach to thinking about ethical issues in the healthcare setting and is based on four common basic moral commitments,¹⁰ these being the respect for autonomy, beneficence, non-maleficence and justice. It is appropriate to use this as an ethical framework for this thesis because it is precisely the framework most used by those engaged in healthcare practice¹¹ and this thesis is addressing issues from that perspective.

As this thesis is considering the issues of disability discrimination and reproductive autonomy from the perspective of a practising clinical geneticist it is important to outline their role, which is to provide prospective parents with support and information that will allow them to make reproductive decisions.¹² These prospective parents are generally those who have been identified as being at higher risk or who have a relevant family history, and are referred to the clinical genetics service by their general practitioner (GP) or obstetrician. These decisions may include whether to start a family at all, increase their existing family or to decide whether or not to continue a pregnancy due to it being affected by a physical abnormality or genetic condition. Prospective parents can be provided with knowledge about a particular condition that their future children may be at risk of and what the level of risk is for them personally. Investigations such as ultrasound scans and tests to identify genetic mutations and chromosomal changes can be performed to identify more specific

⁹ Beauchamp TL, Childress JF (2001) *Principles of biomedical ethics* (5th ed), Oxford University Press.

¹⁰ Gillon R (1994) 'Medical ethics: Four Principles plus attention to scope', *British Medical Journal* **309**, p 184

¹¹ Page K (2012) 'The Four Principles: can they be measured and do they predict ethical decision making?', *BMC Medical Ethics* **13**(10), pp 1-8

¹² Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed), BMJ Publishing Group, pp 10-11

risks and abnormalities. It may be on the basis of the results of these tests that prospective parents decide to terminate an affected pregnancy.

It is important to note at this stage that having a child with a disability is not inevitably a negative experience or something that should be viewed as such. As I will discuss in chapters four and five, what constitutes a disability is very subjective and whilst it is generally accepted that prospective parents would prefer their child not to be born with a disability, it should not automatically be viewed as bad news. Prospective parents are still likely to want to gain more knowledge about the effects of the disability and how this may affect their future child's life, and their own, just as many other parents gain information and knowledge about having a child generally so they can prepare themselves. There is evidence that having a disabled child can have a positive impact on a family, for example, in terms of parents and carers having an increased sense of purpose, personal growth and extended personal and social networks.¹³ Having a disabled child may expose families to other aspects of life that add quality, which they would not otherwise have had the opportunity to experience. I am conscious therefore that my thesis may appear biased towards the negative aspects of disability. This is not deliberate but rather a reflection of the fact that it is generally only going to be those prospective parents who do view the disability in their child in a negative way who may ultimately decide to terminate the pregnancy. As the central focus of my thesis relates to prenatal testing and abortion, particularly late in gestation where currently healthcare professionals have the final say, negative views of disability and the harm it may cause to the future child, and to the interests of the wider family, are inevitably more prominent.

¹³ Stainton T (1998) 'The positive impact of children with an intellectual disability on the family', *Journal of Intellectual & Developmental Disability* **23**(1), pp 57-70

What follows in this introductory chapter is an overview of the development of the use of genetic and genomic investigations in reproductive medicine and fetal management and a brief summary of the arguments I put forward to address the aims of the thesis.

1.2 Genetic and genomic medicine

Genetic medicine is very topical at the moment with the development of the Department of Health's '100,000 Genomes project'¹⁴ and great emphasis being placed on the importance of genetics in mainstream medicine.¹⁵ This will inevitably lead to more and more genetic discoveries and more conditions that can be identified before birth. It is likely therefore that the number of genetic tests that can be offered to prospective parents will increase, both those offered as part of standard antenatal screening and those tests which are specific to a couple's personal circumstances. As the discovery of an abnormality during pregnancy may result in the prospective parents choosing to terminate the pregnancy, there is also a concern that abortions on the basis of disability will increase.¹⁶ This will understandably fuel the concerns raised by those who oppose prenatal testing and abortion on the grounds of disability that believe these actions are discriminatory. It is important, therefore, as a clinician working with patients undergoing prenatal testing to be satisfied that the decision to have testing, and the decisions that then follow, are justifiable particularly where the outcome is termination of a pregnancy where the fetus has an abnormality.

¹⁴ Genomics England (2015) *Genomics England is delivering the 100,000 Genomes Project* (www.genomicsengland.co.uk as cited on 21 October 2015)

¹⁵ Clayton-Smith J, Newbury-Ecob R, Cook J, Greenhalgh L (2015) *The Evolving Role of the Clinical Geneticist: A summary of the workshop hosted by the Clinical Genetics Society*, 23rd-24th November 2014, p 8

¹⁶ McGovern C (2016) 'New prenatal testing could drastically increase abortion rate', *National Catholic Register* Oct. 2

Genetic factors play a significant role in disease with approximately three percent of neonates having at least one major congenital anomaly and two percent having a chromosomal or single gene mutation.¹⁷ Genetic causes are thought to be responsible for approximately fifty percent of severe mental retardation disorders, childhood deafness and blindness. When considering these along with congenital anomalies they account for forty to fifty percent of childhood deaths.¹⁸ Clearly then genetic diseases have a significant impact on the health of the population and resources within our society. Research in genetics has been particularly prominent over the last few decades with the Human Genome Project being at the forefront. This was officially inaugurated in 1990 with a projected time span of fifteen years.¹⁹ Its purpose was to acquire fundamental information about our genetic makeup allowing increased understanding of human genetics and the role of various genes in health and disease.²⁰ The project was completed early in 2003. Part of the remit of the project was to ensure that people had access to advice about the social and ethical issues associated with human genetics in order to ease public anxiety,²¹ recognising the fact that there are concerns about how genetic information will be used. This has now been followed by the aforementioned '100,000 Genomes Project' which aims to sequence 100,000 genomes from around 70,000 people with rare diseases and their families, and patients with cancer.²² The aim is to create a new genomic medicine service for the NHS, which it is hoped will transform the way in which patients are cared for.²³

¹⁷ Metcalfe K, Kingston H (2002) 'Who should be referred for genetic consultation?', *The Obstetrician and Gynaecologist* **4**[2] April, pp 64-68.

¹⁸ Fraser AC (1974) 'Genetic counselling', *American Journal of Human Genetics* **26**, pp 636-659

¹⁹ Strachan T, Read A (2003) *Human Molecular Genetics* 3, London & New York, Garland Science, p 208

²⁰ Fraser AC (1974) 'Genetic counselling', *American Journal of Human Genetics* **26**, pp 636-659

²¹ Department of Health (2003) *Our Inheritance, Our Future: realising the potential of genetics in the NHS*, DOH: London

²² Genomics England (2015) *Genomics England is delivering the 100,000 Genomes Project* (www.genomicsengland.co.uk as cited on 25 October 2016)

²³ Genomics England (2015) *Genomics England is delivering the 100,000 Genomes Project* (www.genomicsengland.co.uk as cited on 25 October 2016)

These advances in genetic research mean that an ever-increasing number of conditions can now be diagnosed with more specific genes being identified.²⁴ The results of genetic based tests have far reaching implications, not only for the individual tested but also for other members of their family who may also find that they too are at risk. With regards to prenatal testing this will not only have implications for the fetus but also the prospective parents and wider family, not only in terms of their potential genetic risk but also in terms of the effect having a disabled child in the family may have on them. It is essential therefore that patients understand the consequences of the decisions they make and they are empowered to make decisions that are appropriate for them and their own personal circumstances by the establishment of a supportive relationship with the clinical geneticist and other members of the clinical team.

1.3 Prenatal testing and the clinical geneticist

I will concentrate my discussion on specific prenatal testing which is carried out for those prospective parents who for some reason have been identified as being at risk of having a child with a genetic condition, rather than standard antenatal screening which is offered to all women who are pregnant. I will explain the differences that exist between these, the latter being that in which clinical geneticists play a role, and give my reasons for limiting my discussions to specific prenatal testing below.

Standard antenatal screening involves an offer of a test to a pregnant woman because she is pregnant and not because she, as an individual, is at any particular risk of having a disabled child.²⁵ Some women may be identified as being at a higher risk of having a child with a

²⁴ Lucassen A, Parker M (2001) 'Revealing false paternity: some ethical considerations', *The Lancet* **357**(9261), pp 1033-1035

²⁵ Harper P (2004) *Practical Genetic Counselling* (6th ed), Arnold Publishing, London, pp 363-364

chromosomal abnormality by virtue of their age but generally there is no distinction between women who are offered these tests. Improvements in antenatal tests have led to the introduction of standard antenatal screening programmes with all pregnant women now being offered testing for conditions such as Down syndrome (Trisomy 21) and neural tube defects, regardless of any prior risk.²⁶ The conditions screened for can be extended for those at risk of particular genetic conditions such as screening for Tay Sachs syndrome in people of Ashkenazi Jewish origin.²⁷

Screening tests, therefore, are performed to identify those who may be at risk of having a disabled child and who will then be offered further more specific prenatal diagnostic testing, such as the analysis of specific genes to look for mutations.²⁸ Standard tests include ultrasound scans to identify structural abnormalities and blood tests to identify certain chemicals in the pregnant woman's blood, which when compared with other factors such as gestation and maternal age provide a risk of the baby being affected by a chromosomal or physical abnormality.²⁹ For example, elevated levels of alpha fetoprotein indicate an increased risk of a fetus being affected by a neural tube defect, and a low level may suggest a chromosomal change such as that seen in Down syndrome.³⁰

Standard antenatal screening therefore differs to specific prenatal diagnostic testing. Clarke summarises genetic testing in the following way:

²⁶ National Institute for Health & Care Excellence (2016) *Antenatal Care for uncomplicated pregnancies* [guidance CG62], NICE (www.nice.org.uk as cited on 4 October 2016)

²⁷ Harper P (2004) *Practical Genetic Counselling*, Arnold Publishing, London, p 367

²⁸ Graves AE, Freeman S et al (2009) 'Maternal age and risk for trisomy 21 assessed by the origin of chromosome nondisjunction: a report from the Atlanta and National Down Syndrome Project', *Human Genetics* **125**(1), pp 41-52

²⁹ Harper P (2004) *Practical Genetic Counselling*, Arnold Publishing, London, pp 365-366

³⁰ Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed), BMJ Publishing Group, p 75

“Genetic testing may be carried out in many different contexts. It is helpful to distinguish these contexts because the ethical issues that arise can be very different. Genetic testing can be offered to individuals because of their specific family histories or other circumstances, or it can be offered to large groups, to populations or subpopulations (eg all newborn infants or pregnant women). The first type of testing is specific to the individual or the family context; the second type of testing is termed population screening.”³¹

At the outset, therefore, it is important to identify the distinct differences between standard antenatal screening and specific prenatal diagnostic testing. As mentioned above, standard antenatal screening is offered to all pregnant women regardless of any prior risk, whereas specific prenatal testing is a diagnostic test offered to pregnant women due to the risk of her pregnancy being affected by a condition, either because the couple have a previously affected child or due to a known family history of the condition.³² Alternatively, they may have no prior history but an abnormality has been found during their pregnancy, for example, a physical anomaly identified on routine antenatal ultrasound scanning of the fetus which may be suggestive of a genetic abnormality.

Standard antenatal screening may be diagnostic. For example, the anomaly scan offered to pregnant women at approximately twenty weeks of gestation may diagnose a neural tube defect or congenital heart defect. However, other tests such as the testing of levels of alpha fetoprotein may provide a *risk* of the fetus being affected. If the risk is above the defined threshold further diagnostic tests can be offered.

³¹ Clarke A (1998) ‘Genetic Counselling’ in Ruth Chadwick (ed) *Encyclopaedia of Applied Ethics* volume 2, San Diego, Academic Press, p 394

³² Harper PS, Clarke AJ (1997) *Genetics Society and Clinical Practice*, Bios Scientific Publishers, Oxford, p 75

On reviewing the literature relating to standard antenatal screening there is evidence to suggest that such tests were motivated by the benefits it brought to society generally, rather than being aimed at the pregnant individual and her own interests. Some believed that testing was more to do with the benefits to others than it was to the potential child.³³ One of the ways in which the success of these policies was measured was by the reduction in the incidence of certain conditions. Whittle referred to the positive impact antenatal testing had by noting the steady fall in the incidence of babies born with open neural tube defects.³⁴ As advances in fetal therapy have not kept pace with developing diagnostic techniques many conditions identified before birth cannot be cured or treated. The only way, therefore, for a reduction in incidence to occur would be by terminating affected pregnancies. This suggests that a measure of success was the prevention of the birth of an affected fetus as opposed to the information gained from the tests being used for other purposes, such as preparation for the birth or in-utero treatment.

A document produced by the Department of Health and Social Security in 1977 refers to the burdens imposed on society in caring for those with ‘handicaps’ and also discusses the cost benefit of antenatal testing.³⁵ Relating to antenatal testing it states:

“.....because caring for the handicapped can impose great burdens on our society the prevention of handicaps in addition to its other benefits may save money. The costs of providing amniocentesis for all expectant mothers over the age of 40 years, and maternal serum AFP screening for all pregnant women, would be more than offset

³³ Aksoy S (2001) ‘Antenatal screening and its possible meaning from the unborn baby’s perspective’, *BMC Medical Ethics* 2:E3, Epub May 22

³⁴ Whittle MJ (1991) ‘Antenatal diagnosis of fetal abnormalities’ in Drife J, Donnai D (eds) *Routine Fetal Anomaly Screening*, London: Springer-Verlag London Limited, p 35

³⁵ Department of Health and Social Security (1977) *Reducing the risk: Safer pregnancy and childbirth*, HMSO: London, p 48

by the economic benefits in terms of savings of expenditure on children and adults with Down's syndrome and spina bifida."³⁶

A little over ten years later the Royal College of Physicians provided further evidence for the motivation of antenatal screening policies:

“Unless prenatal diagnosis is to be devoid of practical application when it reveals a major defect in the fetus, a responsible doctor must discuss with the parents the option of terminating that pregnancy and must in some circumstances provide information that may deter them from further reproduction.”³⁷

Other authors refer to the ‘tangible benefits’ of such a screening policy, quoting avoided health service expenditure, education services expenditure, other public services expenditure and lifetime consumption by the child of other goods and services,³⁸ confirming that such policies were assessed in terms of their resource consequences.

Another problem that has been associated with standard antenatal screening is that it is performed by healthcare professionals, such as midwives and obstetricians, in a busy antenatal clinic environment where there is little time or training given in order to ensure prospective parents understand the implications of having these tests done. Some have argued that this diminishes the choices of prospective parents and forces them down a route they may not otherwise have taken if they had had sufficient information.³⁹ By contrast,

³⁶ Harper PS & Clarke AJ (1997) *Genetics Society and Clinical Practice*, Bios Scientific Publishers, Oxford

³⁷ Royal College of Physicians (1989) *Prenatal Diagnosis and Genetic Screening: Community and service implications*, RCP: London

³⁸ Henderson JB (1987) ‘Economic evaluation of screening for fetal and genetic abnormality’ in *Screening for fetal and genetic abnormality*, London, King’s Fund consensus development conference, programme and abstracts

³⁹ Bennett R (2001) ‘Antenatal Genetic Testing and the right to remain in ignorance’, *Theoretical Medicine and Bioethics* 22(5), pp 461-471

prenatal testing aimed specifically at those who are known to be at risk, and therefore referred to specialist clinical genetics centres, is aimed at enhancing an individual's or couple's reproductive choices, whether their decision is to continue a pregnancy or opt for a termination. This is the type of prenatal testing I will discuss in chapter three, with regards to reproductive autonomy.

Fortunately there is now greater recognition for the importance of informed consent with respect to standard antenatal screening and the provision of information to pregnant women. For example, Public Health England has produced specific guidance for women regarding the availability of tests that are offered.⁴⁰ This guidance explains to pregnant women and their partners that such screening tests will identify those who may be at risk of having a pregnancy affected by a disabling condition, but it is not diagnostic. Those identified as having an increased risk will be offered further testing, should they want it, in order to try to establish a diagnosis. The guidance makes it clear that screening tests are a personal choice and acknowledge that they may not be right for everyone. Information is provided about the conditions that screening can identify a risk of, such as, the more common chromosomal abnormalities and physical problems that can be identified by ultrasound scan, for example spina bifida. The aim of this guidance is to alert pregnant women that screening is available to them during pregnancy and to reassure them that whether or not screening is accepted is a personal choice, as are the decisions taken as a consequence of the results. Whilst the guidance encourages women to seek more information about screening and encourages them to ask questions, this will still generally be provided by obstetricians and midwives in a busy antenatal clinic and, therefore, there may be limitations as to the quality of this information and the support that pregnant women receive.

⁴⁰ Public Health England (2014) *Screening tests for you and your baby*, NHS

As I will discuss in chapter 3 (section 3.8), those who are known to be at risk of having a baby affected by a disabling condition can be referred to a specialist in clinical genetics and fetal management. This will include specially trained counsellors and clinicians who can discuss the implications of prenatal tests with them in detail. Research has shown that obstetricians, who are more likely to be discussing the results of standard antenatal screening with women, are more likely than genetic counsellors to direct their patients down a particular route.⁴¹ Counselling provided by those working in clinical genetics is said to be non-directive, however, whether such counselling can be truly non-directive has been the subject of debate.⁴² Just because the genetic counsellor ultimately leaves the decision as to what action to take to the parents, this does not mean that the information they have provided to the parents has not been biased in some way by their own attitudes towards the condition, or to termination of pregnancy generally. There are also other individuals involved in such processes including those where decisions about a late termination of pregnancy are made and decisions by parents are likely to be influenced, or even overruled, at other stages of the process. I will develop this area of discussion in chapter six of my thesis with regard to fetal management and the decision-making around late termination of pregnancy. This being an area where I recommend developing the role of the clinical geneticist with respect to their professional relationship with the prospective parents.

During genetic counselling the availability of further tests can be discussed and the accuracy to which they may provide results, as well as an opportunity to discuss the options available to the prospective parents should the result be unfavourable. Whether or not these discussions are truly non-directive the prospective parents using these services do have the benefit of being provided with information about the condition being tested for and how it may affect them personally, and should ultimately be able to make the decision which best suits them

⁴¹ Bernhardt BA, Geller G, Doksum T et al (1998) 'Prenatal genetic testing: Content of discussions between obstetric providers and pregnant women', *Obstetrics and Gynecology* **91**, pp 648-655

⁴² Clarke A (1991) 'Is non-directive genetic counseling possible?', *The Lancet* **338** (8773), pp 998-1001

and their particular circumstances, ideally with no pressure from those providing the information. More importantly the decision that they do make is based on a more substantial amount of information and deliberation than they would otherwise have received in a routine antenatal clinic.

As well as those patients referred following the identification of a problem during standard antenatal screening, a clinical geneticist will also be involved where prospective parents have prior knowledge of a risk and may therefore want to consider prenatal diagnostic testing. For these prospective parents the geneticist will be involved in their care from a very early stage, possibly even before they contemplate a pregnancy. Prenatal testing itself involves investigations during pregnancy which may be carried out on the woman or on the fetus directly in order to gather diagnostic and prognostic information.⁴³ It is influenced greatly by advances in reproductive and genetic technology and will become of more relevance to increasing numbers of people as more conditions can be tested for, and therefore will have wider implications for the pregnant population. The information that is gained can then be used in a number of ways.

Depending on the severity of the condition a couple may choose to terminate an affected pregnancy or, alternatively, the information gained may be used to inform those caring for the mother and fetus as to what the most suitable mode of delivery may be and what immediate treatment may be most appropriate to enhance survival or minimise ongoing neurological and physical impairment. In-utero treatment may also be an option for a limited number of conditions allowing an abnormality to be corrected or its effects to be minimised, for example, the use of fetal surgery to repair some neural tube defects.⁴⁴

⁴³ Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed), BMJ Publishing Group, p 11

⁴⁴ Johnson MP, Sutton LN et al (2003) 'Fetal myelomeningocele repair: short-term clinical outcomes', *American Journal of Obstetrics and Gynecology* **189**(2), pp 482-487

Prenatal testing can also be used to determine the sex of the fetus where there is concern that a male fetus may be affected by an X-linked condition⁴⁵ carried by the unaffected mother. Should the fetus be found to be female no further testing would be required. However, should the fetus be male then further genetic or metabolic tests can be offered to allow the parents to discover whether or not the male fetus is affected. As I will discuss in chapter four (section 4.4), with particular reference to conditions such as Congenital Adrenal Hyperplasia (CAH), the availability of specific genetic tests can benefit the fetus by allowing the condition to be identified and treated, for example, by the use of prophylactic medications given to women with at-risk pregnancies.⁴⁶

Prenatal testing does not only include genetic tests but also ultrasound scanning at certain points in gestation which can provide information about the physical condition of the fetus, often in great detail.⁴⁷ Neural tube and brain defects, facial clefts and heart and limb abnormalities can all be identified by ultrasound scanning, as well as many other congenital anomalies.⁴⁸ Even very subtle physical differences can alert clinicians to the possibility of a congenital condition, such as thickening of the soft tissue at the nape of the neck (nuchal fold) and an increased space between the first and second toes, indicating a possible diagnosis of Down syndrome or other chromosomal abnormality.⁴⁹ Often a combination of these different types of tests is used to provide clinical information about the fetus and its prognosis, some of which will have been performed during standard antenatal screening, before the pregnant woman is referred to the clinical genetics service.

⁴⁵ Females have two X chromosomes whereas males have an X and a Y. In an X linked condition the mother has a faulty gene on one X chromosome, but also has a normal copy and is therefore an unaffected carrier of the condition. Should that mother have a male child, there is a fifty percent risk of that child inheriting the X chromosome carrying the faulty gene. A boy with an affected X chromosome will be affected by the condition, as he will have no normal X chromosome to compensate.

⁴⁶ Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed) BMJ Publishing Group, pp 100-101

⁴⁷ Salomon LJ, Alfirovic Z, Berghella V et al (2011) 'Practice guidelines for performance of the routine mid-trimester fetal ultrasound scan', *Ultrasound in Obstetrics & gynecology* **37**(1), pp 116-126

⁴⁸ Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed), BMJ Publishing Group, p 75-76

⁴⁹ Harper PS (2004) *Practical Genetic Counselling* (6th ed), Arnold Publishing, London, pp 122-123

Whilst there are a variety of different investigations available in the antenatal period some findings can create uncertainty with respect to the risk they impose. This might, for example, include ‘soft’ markers in ultrasound scanning.⁵⁰ These markers are considered to be variants of normal but are known to increase the risk of there being an underlying fetal chromosomal abnormality. For example, choroid plexus cysts in the brain can be a normal variant which disappear during the course of the pregnancy, or they can indicate the presence of Edward syndrome (Trisomy 18).⁵¹ These markers, however, are not diagnostic. Where two or more soft markers are present the risk of an underlying pathological cause increases. It is not difficult to see how the presence of these soft markers can cause difficulties for obstetricians, and anxiety for prospective parents, who will need to decide whether to take a ‘watch and wait’ approach or whether to engage in further testing, such as by amniocentesis, which could put the pregnancy at risk,⁵² bearing in mind that this could well be a normal pregnancy.

These uncertainties are not restricted to standard tests performed during routine antenatal care. As genomic medicine advances more of the genome is being tested, as opposed to individual genes. This provides much more prenatal genetic data and, therefore, on the face of it would appear to place those parents who want information about their fetus in a better position. However, where a specific gene mutation is found a diagnosis can confidently be made whereas genome sequencing can sometimes give unexpected results that may be of uncertain significance.⁵³ The detection of these variants of unknown significance within the

⁵⁰ Van den Hof MC, Halifax NS (2005) ‘Fetal soft markers in obstetric ultrasound’, *Journal of Obstetrics & gynecology of Canada* **27**(6), pp 592-612

⁵¹ Gupta JK, Cave M, Lilford RJ, Farrell TA, Irving HC, Mason G, Hau CM (1995) ‘Clinical significance of choroid plexus cysts’, *Lancet* **346**(8977), pp 724-729

⁵² Akolekar R, Beta J, Picciarelli G, Ogilvie C, D’Antonio F (2015) ‘Procedure-related risk of miscarriage following amniocentesis and chorionic villus sampling: a systematic review and meta-analysis’, *Ultrasound in Obstetrics & Gynecology* **45**(1), pp 16-26

⁵³ Donley G, Chandros Hull S, Berkman BE (2012) ‘Prenatal whole genome sequencing: Just because we can, should we?’, *Hastings Center Report* **42**(4), pp 28-40

genome also present problems for those involved in prenatal testing of pregnant women as a clear diagnosis, and therefore prognosis, cannot be discussed with the prospective parents. For the purposes of my thesis I will limit my arguments in that they will only apply when there is certainty about the presence of disability. This is particularly relevant for prenatal testing which results in late termination of pregnancy, as this currently cannot be performed unless that certainty exists.

Once a diagnosis has been established ethical problems arise when one considers how prospective parents then use the information gained by such investigations; as there are essentially two alternatives. The first would be to use this information in preparation for the birth of a child who may have a congenital abnormality or debilitating genetic condition, ensuring that the child was born at an appropriate treatment centre or that specialised treatment was commenced as soon as possible after or even before birth. The other option is for parents to use this information to make reproductive choices as to whether they wish to continue with such a pregnancy or choose to terminate it. The clinical geneticist's role at this point is crucial in supporting couples to ensure they make well-informed decisions based on balanced information. It is also essential that couples are made aware of the limitations on their choices that may exist, for example, where termination would need to occur late in gestation. It is the use of prenatal testing for the purposes of terminating an affected pregnancy which attracts the most controversy largely due to the long standing arguments against abortion,⁵⁴ but also due to the implications terminating such pregnancies may have for those living with disabilities caused by the very same conditions.⁵⁵

Those representing disabled people and those living with disabilities argue that investigating for, identifying and then terminating pregnancies affected by a disability encourages

⁵⁴ Gillon R (2001) 'Is there a 'new ethics of abortion'?', *Journal of Medical Ethics* **27**, pp ii5-ii9

⁵⁵ Parens E & Asch A (2003) 'Disability rights critique of prenatal genetic testing: Reflections and recommendations', *Mental retardation and developmental disabilities research reviews* **9**, pp 40-47

discriminatory attitudes and sends out negative messages about the value of their lives.⁵⁶ It is the ability of prenatal testing to identify a fetus with a disability that is the focus of this thesis in that this very fact allows a choice to be made regarding termination of an affected pregnancy. However, as I will discuss in chapter four, it can also provide benefit and avoid harm, not only to the fetus but also to the wider family. Whilst showing that disability discrimination concerns are unfounded, based on arguments about the moral status of the fetus, I will also argue as to why reproductive autonomy should be of overarching importance particularly where the birth of the child will result in harm, not only to the child themselves but also to the interests of other family members. I will also move this debate on by considering what happens in reality when the management of a fetus affected by an abnormality, which is discovered late in gestation, is discussed by the clinicians involved in the care of the prospective mother, and how these decisions may not ultimately be made based on the arguments I have put forward. Taking this in account, I will also make recommendations as to how practice can be improved by encouraging communication between prospective parents and the clinical team, and how this can be achieved by enhancing the role of the clinical geneticist, particularly in view of the supportive role they establish with prospective parents at an early stage during the prenatal period.

1.4 Moral status, reproductive autonomy & disability discrimination

In order to begin to answer my first question as to whether specific prenatal testing discriminates against those living with disabilities, I will initially consider the moral status of the fetus in chapter two. I will begin by discussing the moral status of the fetus as compared to a person who has been born. If the fetus has full moral status equivalent to that of a person who has been born, and it is wrong to kill a person, it follows that we have a

⁵⁶ Shakespeare T (1995) 'Back to the future? New genetics and disabled people', *Critical Social Policy* **15**, pp 22-35

strong *prima facie* reason to consider that it is also wrong to terminate a pregnancy, as this will involve killing the fetus. This is, therefore, of great importance when discussing abortion under any circumstances.⁵⁷ Where a distinction is made between fetuses based on whether they are disabled or non-disabled moral status arguably becomes a greater issue. The Abortion Act 1967 does distinguish between such fetuses. The Act allows severely disabled fetuses to be aborted throughout gestation, up to the point of birth, but does not allow the same for what is regarded as a normal fetus (unless the woman's life is at risk). It is understandable therefore that this raises concerns about a discriminatory attitude towards disability. I will argue that the fetus does not have full moral status and therefore cannot be compared to a person who has already been born, as they do have full moral status in the relevant sense (not that they are fully responsible moral agents). More importantly consideration needs to be made as to whether the disabled fetus has the same moral status as a non-disabled fetus and how we can reconcile the fact that late terminations are performed only under very specific circumstances, including the presence of severe disability. I will argue that the disabled fetus does have the same moral status as a non-disabled fetus and that it is not the existence of an abnormality in itself that justifies termination but the implications that abnormality has for the future child in the context of the family, including the prospective parents and pre-existing children.

In order to support my argument that the disabled fetus has the same moral status as a non-disabled fetus, and with regards to my second question with respect to reproductive autonomy, I will argue in chapter three that autonomy is of paramount importance due to the personal nature and gravity of the decisions that are being made. As reproductive decisions, whether it is to continue or terminate a pregnancy, will have far-reaching implications for those who are directly affected it is essential that healthcare professionals involved in this process engage with families so that they have a full understanding of these

⁵⁷ Warren MA (1973) 'On the moral and legal status of abortion', *The Monist* 57(1), pp 43-61

implications. Healthcare professionals should not base their views and decisions solely on the clinical status of the fetus or the effects a disability may have on the future child alone, but should also take into account the effect on that child within the context of their family and the effects on the family itself. This is particularly relevant where late termination of pregnancy is being considered, as it is the doctors who are going to perform the procedure who decide whether it can be justified, rather than the decision being made by the prospective parents themselves.

Throughout my thesis, but particularly in chapter four and five, I have referred to the concept of harm. This relates not only to the harm to the interests of the future child but also to the interests of the wider family. As I will discuss in chapter four (section 4.2), harm is said to occur when someone has been made worse off than they would otherwise have been.⁵⁸ These harms need to be balanced with the positive aspects of having a child with a disability so that the overall position can be evaluated. From the point of view of the family consideration needs to be given to the fact that they already have established interests to which harm could occur, and account needs to be taken of this by the clinical geneticist when counselling couples and by those arbitrating decisions about late termination of pregnancy.

Before discussing the arguments put forward by those representing disabled people, who largely oppose prenatal testing and termination of pregnancy based on finding a disability in the fetus,⁵⁹ I will discuss the current models of disability and the problems these create in chapter four (section 4.2.1). I will discuss the concepts of health and disease (section 4.2.2) and what it means to be harmed in order to support my arguments in chapter three that

⁵⁸ Reznek L (1987) *The Nature of Disease*, Routledge & Kegan Paul: London and New York, p 134

⁵⁹ Saxton M (2000) 'Why members of the Disability Community oppose prenatal diagnosis and selective abortion' in Parens E, Asch A (eds) *Prenatal Testing and Disability Rights*, Georgetown University Press/Washington DC, pp 148-149

reproductive autonomy ought to be respected as harm may occur not only to the future child, but also to the wider family and those who have a higher moral status than the fetus.

Following on from my arguments that the fetus does not have full moral status and building on my discussion of disability and harm in chapter four, I will discuss in chapter five the arguments as to whether prenatal testing and subsequent termination of pregnancy does discriminate against those with disabilities, which are put forward by those representing disabled people.⁶⁰ They argue that terminating a pregnancy based on the presence of disability is the result of judgements being made about the quality of the lives of disabled people and reinforces discriminatory attitudes towards them.⁶¹ I will argue that it is harm to the interests of the future individual child and those directly affected by the birth of a disabled child, such as the prospective parents and pre-existing children, which needs to be taken into account and this harm needs to be acknowledged by the clinicians responsible for the care of the mother and her fetus. It is with regard to this that the clinical geneticist, in addition to providing the couple and the clinicians involved with information about the genetic condition, can ensure that those who ultimately make decisions about late termination of pregnancy take into account the harm to the interests of not only the future child, but also other directly affected individuals.

Having then argued that prenatal testing does not discriminate against those with disabilities, but enhances reproductive autonomy, I will then discuss in chapter six the problems that prospective parents face in reality when they discover that their pregnancy is affected by an abnormality and the challenges they face. I will discuss the way in which decisions in my experience as a clinical geneticist are made and how these are often counter to the arguments in support of prenatal testing and late termination of pregnancy. Finally, I will put forward

⁶⁰ Shakespeare T (1995) 'Back to the future? New genetics and disabled people', *Critical Social Policy* **15**, pp 25-35

⁶¹ Gillott J (2001) 'Screening for disability: a eugenic pursuit?', *Journal of Medical Ethics* **27**, pp ii21-ii23

recommendations on how this area of practice can develop in order to support reproductive decision-making better. These recommendations include placing greater emphasis on considering the harms to the interests of the wider family when prospective parents are counselled, and to take these potential harms into account when deciding whether or not late terminations can be justified, rather than focusing on the clinical findings of the fetus. There should also be increased involvement of the prospective parents, and where appropriate other family members, in a supportive and sensitive way during the process to assist healthcare professionals in justifying their decisions. The supportive role of the clinical geneticist can be further developed as an advocate for prospective parents to ensure that their views are also taken into account.

Chapter 2

Moral status of the fetus and Abortion

2.1 Introduction

One of the reasons why there is opposition to prenatal testing is because a possible consequence of it is termination of pregnancy, and it is this that causes most controversy and debate.^{1,2} Those who oppose abortion often argue against it on the basis of the moral status of the fetus. A clinical geneticist advises and supports prospective parents who may opt for a termination and, therefore, it is important for them to be comfortable with this potential outcome for the fetus so that they can give pragmatic advice and appropriate information. In this chapter, I will discuss the moral status of the fetus with particular reference to those identified as having some form of congenital anomaly. In doing so I conclude that decisions to terminate a pregnancy affected by a disability, particularly late in gestation, whilst needing greater justification do not in themselves discriminate against the disabled fetus or those living with disabilities.

The foundation of my argument is that the fetus does not have the same full moral status as an adult human and, therefore, a disabled fetus does not have the same moral status as a person already living with a disability. I also argue that the disabled fetus does not have lower moral status than a non-disabled fetus. The concern that a disabled fetus has a lower moral status arises where termination of pregnancy is said to be justifiable on the basis that the fetus has, or is at serious risk of having, a severe disability. This is also reflected in the current legislation

¹ Savulescu J (2013) 'Abortion, infanticide and allowing babies to die, 40 years on', *Journal of Medical Ethics* **39**, pp 257-259

² Marquis D (1989) 'Why abortion is immoral', *Journal of Philosophy* **86**, pp 183-203

on abortion,³ the limits of which are influenced by arguments about the moral status of the fetus.⁴ This tends to relate to terminations that take place after twenty-four weeks of pregnancy where termination of a normal fetus would not be permissible unless it was threatening the life of the mother.

In order to do this I will discuss a range of arguments as to whether the fetus has moral status, and whether this is full moral status equivalent to that of an adult person. It is generally accepted that it is wrong *ceteris paribus* (to exclude, for example, self-defence) to kill an entity that has full moral status and, therefore, those who argue that the fetus has full moral status also believe that it is wrong to terminate a pregnancy.⁵ However, there are certain possible exceptions to this line of reasoning in the case of abortion, such as considerations as to the rights of a woman as presented by, for example, Judith Jarvis Thomson.⁶ Whilst I recognise the complex array of arguments that exist in this area, the line of argument concerning the moral status of the fetus remains one of the most widely referred to central arguments in this debate and addressing it directly is important for any position that seeks to justify abortion on certain grounds. I argue that the fetus, although a moral entity and deserving of some protection, does not have full moral status and therefore termination of pregnancy can be morally justified.

The fetus is something that we may have moral obligations towards due to its importance to other people, but also due to its own future interests. I will develop the position that moral status increases throughout gestation as the fetus acquires more characteristics of a person who has full moral status. It therefore follows that as pregnancy progresses the protection that we should afford to the fetus increases, meaning that greater justification to end a pregnancy is needed the closer toward term the fetus reaches. This is reflected in current clinical practice

³ Abortion Act 1967, HMSO: London

⁴ British Medical Association (2014) *The Law and Ethics of Abortion: BMA reviews*, BMA

⁵ Griffith S (2004) 'The Moral Status of a Human Fetus: A Response to Lee', *Christian Bioethics* **10(1)**, pp 55-62

⁶ Thomson JJ (1971) 'A defence of abortion', *Philosophy and Public Affairs* **1(1)**, pp 47-66

where greater justification is needed before clinicians will agree to perform late terminations of pregnancy. This does, however, impact on certain freedoms of choice that a woman may wish to exercise as part of their autonomous reproductive decision-making, as I will discuss in chapter six. One problem with this justification is that healthcare professionals tend to focus on the clinical condition of the fetus and the potential disability that may ensue. These decisions, however, should also consider the fetus in the context of the wider family and take into account the potential harm to their interests as well.

One justification offered for ending a pregnancy late in gestation, therefore, is where there is a substantial risk of severe disability in the fetus. There are, however, concerns that this discriminates against those living with disabilities, suggesting that they have a lower moral status than those without disabilities. I will argue that this is not the case and that the disabled fetus does have the equivalent moral status to any other fetus, and as such a disabled person has the same moral status as one that has no disabilities.

2.2 Moral status

When considering moral status this will be with reference to the characteristics that human moral agents such as ourselves attribute to other entities like the fetus. Moral status is relevant where an entity matters morally to us for its own sake. If something has moral status we cannot act in any way we please and we have moral obligations toward it, not because of any benefit this may derive to ourselves or other persons but because the entity has moral significance in its own right.⁷ Another corollary of this is that it is important to consider that entity's well-

⁷ Warren MA (1997) *Moral Status: Obligations to persons and other living things*, Oxford University Press, pp 3-5

being and its continued existence.⁸ It is, of course, not only those of the human species that have moral status. It is generally accepted that non-human animals have moral status and we should not treat them in any way we please, although it is also generally accepted that non-human animals have a lower moral status than human beings. As such we can kill a non-human animal (humanely) but not a human person.⁹

There are many theories as to when the fetus acquires full moral status, if at all. These views range from the conservative, often favoured by religious figures,¹⁰ to the view that the fetus only becomes a (full) moral being once born.¹¹ I will discuss a number of theories in relation to what it means to have moral status and that two of the main theories, interest views and the acquisition of sentience, do not in themselves confirm full moral status on a fetus. This distinction between moral status and full moral status is important to my thesis, as I argue that whilst the fetus does have moral status, this develops over time with the fetus becoming more morally significant as gestation progresses. This is particularly relevant when considering the difference between a disabled fetus and a disabled person who has been born. I will discuss the concept of being human in comparison to the concept of personhood in section 2.2.2 and the views that rely on psychological continuance as opposed to the physical characteristics that humans possess.

⁸ Dwyer JG (2010) *Moral Status and Human Life: The Case for Children's Superiority*, Cambridge University Press, pp 9-26

⁹ Spedding C (2000) *Animal Welfare*, Earthscan Publications Ltd, London & Sterling, VA, p 12

¹⁰ Ohara N (2003) 'Ethical consideration of experimentation using living human embryos: the Catholic Church's position on human embryonic stem cell research and human cloning', *Clinical and Experimental Obstetrics and Gynaecology* **30**(2-3), pp 77-81

¹¹ Gross M (2002) 'Abortion and Neonaticide: Ethics, Practice and Policy in four Nations', *Bioethics* **16**(3), pp 202-230

2.2.1 What is it to have ‘moral status’?

An entity with moral status is entitled to be treated with respect for their autonomy (should they have it) and self-interests.^{12,13} They are the subject of moral concern and should be respected and protected from harm. Objects that do not have moral status have only instrumental value whereas, by contrast, human beings have intrinsic value in their own right and cannot therefore be treated in the same way as objects. But what is it that gives them moral status?

Between entities with full moral status and inanimate objects with no moral status there are beings for which it is more difficult to assign what degree of moral status they have. This includes not only different species of non-human animals but also embryos and fetuses. If these beings have full moral status they are deserving of the same protection as adult human beings. If this were the case, just as killing an adult human being would be morally wrong, it would be equally as wrong to terminate a pregnancy. If, however, fetuses do not have moral status then abortion would not be wrong on these grounds and if this applied to a fetus at any stage of development abortion at any gestation of pregnancy, from conception to birth, would not be impermissible by appeal to its moral status.

Warren puts forward the following view on moral status:

¹² Kant I (1964) ‘The groundwork of the metaphysics of morals’ in Paton HJ (ed) *The Moral Law*, Hutchinson University Library, p 43

¹³ Galvin RF (2008) ‘Noonan’s argument against abortion: probability, possibility and potentiality’, *Journal of Social Philosophy* **19**(2) pp 80-89

‘To have moral status is to be morally considerable, or to have moral standing. It is to be an entity towards which moral agents have, or can have, moral obligations. If an entity has moral status, then we may not treat it in just any way we please; we are morally obliged to give weight in our deliberations to its needs, interests, or well-being. Furthermore, we are morally obliged to do this not merely because protecting it may benefit ourselves or other persons, but because its needs have moral importance in their own right’.¹⁴

Therefore according to Warren, for an entity to have moral status it must have interests in its own right. A non-human animal has these interests, it can feel pain and pleasure and has self-awareness and therefore has moral status. A human person has higher function and greater interests than a non-human animal and, as such, has a higher moral status. However, just because something does not have moral status on this basis we may still have moral obligations towards it due to the importance of it to the interests of those considered to have moral status.^{15,16}

For example, a family heirloom such as a piece of furniture has no moral status in itself. It has no interests of its own and cannot experience pain or pleasure. However, it is likely that it creates interests for a person with full moral status and they could be harmed (financially or emotionally, for example) if that item was destroyed or damaged. It is the harm to the interests of this person with full moral status that leads us to have moral obligations towards the object.¹⁷ Even if therefore, arguments that say that the fetus does not have moral status at all are accepted it does not follow that we do not owe moral obligations to that fetus.

¹⁴ Warren MA (1997) *Moral Status: Obligations to persons and other living things*, Oxford University Press, p 4

¹⁵ Wrigley A (2013) ‘Limitations on personhood arguments for abortion and ‘after-birth abortion’, *Journal of Medical Ethics* **39**, pp 15-18

¹⁶ DeGrazia D (2007) ‘The harm of death, time-relative interests, and abortion’, *Philosophical Forum* **38**(1), pp 57-80

¹⁷ Warren MA (1997) *Moral Status: Obligations to persons and other living things*, Oxford University Press, p 4

2.2.2 Being human

Roman Catholic theory relies on moral status being bestowed upon those who are members of the human species.^{18,19} All living human beings from the beginning to the end of their lives are morally equal and have an equal right to life. One problem with this theory is that the point of becoming 'human' is still an issue for debate.²⁰ If it is agreed that this takes place at the point of conception then arguably all terminations of pregnancy are morally wrong other than those exceptions, for example, when the mother's life is at risk. Others, however, argue that being regarded as human occurs later, for example, when neural (nerve) tissue develops.²¹

There is no doubt that an embryo and early fetus created by the fusion of gametes from adult human beings is a member of the human species. It has its own human genetic code and if left undisturbed will usually develop into a human person. This does not, however, mean that this confers moral status on that developing embryo and fetus which is equivalent to that of a fetus later in pregnancy, or to the person who is eventually born. There is more to moral status than simply having the correct genetic make-up or being part of a particular species. I agree that being human does have special significance, for example, in view of the importance of our role in the development of society and our capacity for reasoning and self-consciousness.²² However, in order to be considered to have full moral status equivalent to an adult human being certain qualities and characteristics need to be present, and it is for this reason that I argue that the personhood view of moral status, which I discuss in section 2.2.4, is the most convincing. It is certain capacities that mark out a being as having full moral status. In order for a human

¹⁸ Jones D (2001) 'A theologian's brief: on the place of the human embryo within the Christian tradition and the theological principles for evaluating its moral status', *Ethics & Medicine* **17**(3), pp 143-153

¹⁹ Jones D (2005) 'The human embryo in the Christian tradition: a reconsideration', *Journal of Medical Ethics* **13**(12), pp 710-714

²⁰ Jones D (2005) 'The human embryo in the Christian tradition: a reconsideration', *Journal of Medical Ethics* **13**(12), pp 710-714

²¹ Donceel FJ (1970) 'Immediate animation and delayed hominization', *Theological studies* **31**, pp 76-105

²² Diamond C (1991) 'The importance of Being Human', *Royal Institute of Philosophy supplement* **29**, pp 35-62

person to matter more than any other sort of thing in moral consideration it has to have qualities that no other organism has. It is not enough, therefore, to consider such things as the ability to form family relationships, problem solving or expressing emotions, as these abilities have been shown to exist in non-human animals.^{23,24} It has been necessary, therefore, to identify why human beings are unique from other non-human animals by identifying certain capacities and capabilities. As I will discuss, the notion of personhood encapsulates this uniqueness.

Similarly, Warren argues that it is not genetic human beings who have a special moral status and a right to life but persons.²⁵ As I will discuss in section 2.2.4, in order for an entity to have interests in its own right, and therefore moral status, it must have consciousness, for example, the ability to feel pain. It must have self-awareness and be motivated by its own self-interest. Whilst the fetus does possess consciousness and the ability to feel pain at a certain point in gestation it does not possess the other qualities required for it to be regarded as having full moral status, such as an adult human being would have. Adult human beings generally have all of those qualities mentioned above and, furthermore, are rational and able to make their own autonomous decisions. I argue, therefore, that the fetus does not have full moral status, just like a non-human animal does not, but it does possess some characteristics meaning that it does have some moral status. Even if one argues, however, that the fetus does not have moral status, it is morally significant due to the nature of it in that it is human and belongs to someone with full moral status, and therefore we do have moral obligations towards it and it is deserving of protection.

Therefore, at one end of the spectrum we have inanimate, non-sentient objects and at the other end we have adult human beings with full moral status. The difficulty clearly lies with assigning moral status to those beings in between, such as the fetus. Whilst I have agreed that

²³ Bekoff M (2000) *The smile of the dolphin: Remarkable Accounts of Animal Emotion*, Discovery Channel Books.

²⁴ Goodhall J (2000) *In the Shadow of Man*, New York: Houghton Mifflin Co, pp 140-141

²⁵ Warren MA (1973) 'On the moral and legal status of abortion', *The Monist* **57**(1), pp 43-61

simply being part of the human species does not confer full moral status, I have argued that it does have some special significance. Therefore, whilst an embryo should not be afforded the same moral status as, for example, a viable fetus or term neonate, it does have a degree of moral status and as such we cannot do whatever we please with human embryos or pre-viable fetuses.

2.2.3 Sentience

Utilitarian theorist Jeremy Bentham argued that a being's capacity to experience pleasure and pain is what is important when considering moral status.²⁶ He argued that we have a moral obligation not to kill or inflict pain or suffering upon such beings without good reason. Our status in moral consideration according to Bentham is entirely reflective on our capacity to suffer. As humans have a great capacity to suffer they tend to be more significant in utilitarian calculations governing our moral actions. However, it is the sum total of pleasures versus pain that is of relevance and suffering of any organism, human or not, can count towards this calculation. This means that non-human animals have equivalence to humans inasmuch as their suffering is considered equally morally relevant, but they do not suffer as much. Based on this he believed that any moral obligation we have to protect humans also applied to non-human animals. His theory did not place importance on whether a being could 'reason' but whether it could 'suffer'. I do not intend to consider all of the arguments in relation to this as it is generally accepted within our society that non-human animals, whilst having moral status, are not morally equivalent to humans and the way in which at least some non-human animals behave is not morally equivalent to the way in which humans behave in their communities.²⁷

²⁶ Bentham J (1907) *An introduction to the principles of morals and legislation*, Oxford: Clarendon Press (reprint of 1823 edition) (www.econlib.org as cited on 17/03/2013)

²⁷ The problem with this line of Utilitarian thought was highlighted by Nozick R (1974) 'Anarchy, State, and Utopia', *Libertarian Review* 3(12), p 1. If a monster took such great pleasure in eating people that it outweighed our suffering in being eaten, we would all be morally obliged to feed ourselves to it.

For the fetus it would mean moral status would develop over time as the physiological and anatomical developmental changes took place and as the nervous system developed, and, therefore, there would be very little difference between a fetus in the final stages of gestation and a neonate. This theory, however, does not currently help us to decide when during gestation a fetus becomes sentient and, therefore, according to this theory attains moral status, as there is no consensus as to when the fetus does begin to feel pain^{28,29} and this is a complicated concept. I do not intend to consider this here as I do not argue that there is a specific defined time in gestation when the fetus attains moral status, but that moral status increases over time as gestation progresses. However, it is important to recognise that in establishing when a fetus feels pain it does not only depend on physiology and anatomy and the development of the nervous system, but also what is meant by ‘experiencing pain’ and the fact that different individuals may have different perceptions of and tolerance to pain, as well as the question of how we know when pain is being experienced³⁰ and how this can be measured.

2.2.4 Personhood

Locke was the originator of personhood as a moral concept. He described a person as “a thinking intelligent being that has reason and reflection and can consider itself as itself, the same thinking being in different time and place; which it does only by that consciousness which is inseparable from thinking and as it seems to me essential to it.”^{31,32} His theory provided the concept of a person as having the properties of being conscious, self-aware and rational. Kant

²⁸ Lowery C, Hardman MP, Manning N, Hall RW, Anand KJ and Clancy B (2007) ‘Neurodevelopmental changes of fetal pain’, *Seminars in perinatology* **31**(5), pp 275-282

²⁹ Coghlan A (2010) ‘Briefing: New law claims a fetus can feel pain’, *New Scientist* (www.newscientist.com cited on 17/03/2013)

³⁰ Steinbock B (2011) *Life before birth: The moral and legal status of embryos and fetuses* (2nd ed), New York, Oxford University Press, p 46

³¹ Helm P (1979) ‘Locke’s Theory of Personal Identity’, *Philosophy* **54**(208), pp 173-185

³² Locke J (1975) *Essay concerning human understanding*, P H Nidditch (ed), Oxford University Press, 1690/1975, p 9 (reprinted 1975)

also talked about rational beings that existed as an end in themselves rather than merely being in existence solely for the benefit of others.³³ Locke's theory of personal identity related to identity over time where we are the same person insofar as our consciousness in the present time is the same as it was in the past. Other philosophers have discussed and defended Locke's theory,^{34,35,36} however, this means that not all living humans would be regarded as persons, including neonates, infants and very young children and those with learning difficulties or dementia. A human would not become a person until these qualities had been achieved and may then lose the recognition of being a person due to aging, disease or trauma, and it is this that makes such a theory unattractive as defending it results in the conclusion that what applies to the fetus also applies to neonates and severely incapacitated adults. This led to Giubilini and Minerva concluding that if abortion is permissible so too is infanticide and the reasons which make abortion permissible should also apply to terminating the life of a neonate.³⁷

The personhood theory only takes into account the psychological aspects of being a person and does not take into account any physical attributes. It reflects and supports the view that the fetus does not have the full moral status of a person.

Steinbock describes personhood as:

³³ Kant I (1785) *The Groundwork for the Metaphysics of Morals* (Mary J Gregor), Cambridge University Press, 1997 (plato.stanford.edu as cited on 29/06/2015)

³⁴ Parfit D (1984) *Reasons and Persons*. Oxford University Press, pp 321-345

³⁵ Shoemaker S (1984) 'Personal identity: A materialist's account' in Shoemaker S, Swinburne R (eds) *Personal Identity: Great debates in philosophy*, Oxford: Clarendon Press, pp 67-132

³⁶ Garrett B (1988) *Personal identity and self-consciousness*, Routledge, pp 5-6

³⁷ Giubilini A, Minerva F (2013) 'After-birth abortion: why should the baby live?', *Journal of Medical Ethics* **39**, pp 261-263

“Beings that have moral status must be capable of caring about what is done to them. They must be capable of being made, if only in a rudimentary sense, happy or miserable, comfortable or distressed. Whatever reasons we have for preserving or protecting non-sentient beings, these reasons do not refer to their own interests. For without conscious awareness, beings cannot have interests. Without interests they cannot have a welfare of their own. Without a welfare of their own, nothing can be done for their sake. Hence, they lack moral standing or status”.³⁸

This particular definition, however, does not clearly define human beings from other creatures. Other definitions of personhood are problematic. For example, Harris believes those who are capable of valuing their own existence can be recognised as persons.³⁹ This adds an extra dimension to Locke’s theory as it includes the ability to look forwards and to have control over and value one’s future. However, the same problems occur in that if that human being loses that capacity they no longer remain a person. Again, it would imply that a neonate or even young infant who does not appreciate the value of their existence would also not be regarded as persons and it would also suggest an individual in a persistent vegetative state (PVS) would not be classed as a person with full moral status. However, in the case of a neonate or child, they could reasonably be expected to gain capacity in the future with increasing age, unlike those who lose capacity due to an ongoing illness.

The fact that this theory suggests that if a fetus can be killed, as it does not have full moral status, then it should also be possible to kill a neonate or adult in a PVS seems intuitively wrong. As a society we do generally agree that other people should not be killed and this has raised much debate about the ethics of euthanasia, even where an adult person with capacity decides for themselves that they no longer wish to live. Whilst it is not a purpose of this thesis to discuss

³⁸ Steinbock B (2011) *Life before birth: The moral and legal status of embryos and fetuses*, (2nd ed) Oxford University Press, p 5

³⁹ Harris J (1991) *The value of life: An introduction to medical ethics*, London: Routledge & Kegan Paul, p 18

the ethics of euthanasia I do agree that any decision made about the fetus, in view of me arguing that moral status is based on the personhood view, does also apply to neonates. Although based on my view a neonate does not have full moral status, it does not mean that we can do as we wish to it. It has moral status and is morally considerable but this is not equivalent to that of an adult human being (except one in a PVS for which the same arguments apply) and, therefore, I do agree that under very strict circumstances a neonate's life could be ended, for example, if they were severely disabled and destined to have a life of pain and suffering or their survival was already limited by illness. This, however, is based on views about access to euthanasia for neonates rather than arguments about them not having full moral status. The arguments I discuss throughout my thesis, therefore, could apply just as readily to the position of a severely disabled neonate, just as they do to a severely disabled fetus. However, as I have previously stated, even if it were argued that the fetus or neonate did not have moral status at all they are important to those with full moral status and as such we would still have moral obligations towards them, and this would need to be considered in the actions we take against them.

Returning to Warren, she also concludes that the special moral status that is associated with personhood is defined in terms of what psychological characteristics and cognitive functions a person has. This may include self-consciousness, self-motivation, self-awareness and reasoning. An entity without such characteristics cannot be regarded as a person. This means that the early fetus is not a person and a fetus later in gestation will also have fewer of the person-associated characteristics than some non-human creatures. Based on this Warren comes to the conclusion that it is therefore 'morally neutral' to have an abortion and makes the controversial comparison of terminating a pregnancy with having a haircut.⁴⁰ I agree that as gestation progresses the features of personhood develop and as such the moral status of the fetus is enhanced. The fetus may not have *full* moral status but this does not mean that it is not worthy of protection and as such I do not agree with Warren that terminations of pregnancy are

⁴⁰ Warren MA (1973) 'On the moral and legal status of abortion', *The Monist* 57(1), pp 43-61

‘morally neutral’. It is generally regarded that persons have a *prima facie* right to life due to them having full moral status, however, this does not automatically mean that it is morally insignificant to destroy something that does not have full moral status; justification would still be needed.⁴¹ In arguing that moral status increases over time as pregnancy progresses this means that greater justification to end a pregnancy is needed later in gestation. In early pregnancy when the fetus is completely dependent on the mother for survival this justification can be provided by the woman’s rights over her own body.^{42,43} However, as the fetus develops and acquires increasing characteristics and capacities more significant justification to perform a termination is required, such as it being a threat to the mother’s life or severe fetal disability that would cause harm to the future child or those with full moral status who would be directly affected by its birth. As well as the clinical condition of the fetus and the potential harms to it as a result of this, the clinical geneticist involved in supporting the prospective parents must take these latter considerations into account during counselling, and ensure that those clinicians who are responsible for justifying their decision to perform a late termination, also consider the fetus in the context of the wider family and the potential harm to their interests as well.

Steinbock⁴⁴ is particularly concerned about Warren’s view of personhood as she describes it as justifying infanticide as a neonate is not significantly different to a late fetus in terms of the characteristics it has which relate to personhood. Whilst this is true, the fetus is, however, still in-utero and therefore whilst it is morally significant the pregnant woman has full, and therefore superior, moral status. There is a difference, therefore, between a fetus and a neonate which is no longer physically associated with a person who has higher moral significance.

⁴¹ Wrigley A (2013) ‘Limitations on personhood arguments for abortion and ‘after-birth abortion’’, *Journal of Medical Ethics* **39**, pp 15-18

⁴² Wrigley A (2013) ‘Limitations on personhood arguments for abortion and ‘after-birth abortion’’, *Journal of Medical Ethics* **39**, pp 15-18

⁴³ Thomson JJ (1971) ‘A defence of abortion’, *Philosophy and Public Affairs* **1**(1), pp 47-66

⁴⁴ Steinbock B (2011) *Life before birth: The moral and legal status of embryos and fetuses* (2nd ed) Oxford University Press, p 54

Due to the problems with the personhood view, in that it excludes neonates and those adults with severe mental disabilities or in a PVS, there is another theory. The Animalist or Biological Species account of personhood relies on us being a member of a particular species and places importance on the physical and biological properties a member of that species has, rather than psychological abilities and functioning.^{45,46} Reliance on this theory would mean that if a person became permanently unconscious they would, by virtue of their physical being, still be a person and the same person as they had previously been. It is the continuance of our biological functioning that maintains our personal identity according to this theory, not whether or not psychologically we continue to function. A person would cease being a person when they were physiologically dead and when the biological processes, for example respiration, had stopped or following brain stem death.⁴⁷

On the face of it, this would mean that an anencephalic infant or an adult in a PVS is just as deserving of being protected as a person who is conscious, can feel pain and could suffer both physically and emotionally by being harmed or killed. It is by appeal to these being members of a species whose members *typically* possess the properties that gives them personhood status. Species membership means that not every individual needs to possess the features of being a person, only a typical member of the species.

I prefer to regard a person from the psychological perspective rather than basing what it is to be a person on their genetic makeup or biological functioning. However, rather than suggesting that it is only those with interests that have full moral status I also wish to argue that the fetus

⁴⁵ Wiggins D (2001) *Sameness and substance renewed*, Cambridge University Press, pp 193-222

⁴⁶ Olsen ET (2003) 'An argument for animalism' in Martin R, Barresi J (eds) *Personal Identity*, Blackwell: Oxford, pp 318-334

⁴⁷ Olsen ET (2003) 'An argument for animalism' in Martin R, Barresi J (eds) *Personal Identity*, Blackwell: Oxford, pp 318-334

and neonate have some moral status which is of significance in that they do have some interests as well. Wrigley,⁴⁸ following DeGrazia,⁴⁹ refers to these as time-relative interests (TRIs).

These interests mean that the fetus does have moral status and as such justification is needed to kill them, although these interests are not enough to give the fetus the full moral status that a fully sentient and psychologically developed person would have. The concept of TRIs introduced by McMahan is described as an interest in continuing to live and includes a consideration of the amount of good the future of that individual may hold and also the psychological link between current interests and the future.⁵⁰ In order to have TRIs one must have a psychological relationship between future and past self. An infant will have weaker TRIs in continuing to live than a grown adult in view of the fact that the infant has very little awareness of its future self. A patient with dementia will have weaker TRIs as they are less likely to be able to invest in their future self.

The concept of TRIs is used as a defense of abortion arguing that the fetus, at least in its early stages, does not have TRIs.⁵¹ However, it can also be used to explain why greater justification for terminating a pregnancy is needed as gestation proceeds. As the fetus develops and goes beyond the pre-sentient stage arguably it will develop some, although weak, TRIs. Comparing the TRIs of an adult human to that of a fetus at any gestation does distinguish between the morality of killing a fetus and killing a person who has been born, and this is important when comparing a disabled fetus to a disabled adult and considering discrimination. The concept of TRIs has been used as a justification for early abortion,⁵² where abortion takes place before the

⁴⁸ Wrigley A (2013) 'Limitations on personhood arguments for abortion and 'after-birth abortion'', *Journal of Medical Ethics* **39**, pp 15-18

⁴⁹ DeGrazia D (2007) 'The harm of death, time-relative interests, and abortion', *Philosophical Forum* **38**(1), pp 57-80

⁵⁰ McMahan J (2002) *The Ethics of Killing: Problems at the Margins of Life*, Oxford University Press, pp 80, 170-174, 183-188

⁵¹ DeGrazia D (2003) 'Identity, Killing, and the Boundaries of Our Existence', *Philosophy and Public Affairs* **31**, pp 413-442

⁵² McMahan J (2002) *The Ethics of Killing: Problems at the Margins of Life*, Oxford University Press, pp 80, 170-174, 183-188

fetal brain acquires the capacity to support consciousness. It is thought that consciousness develops between the twentieth and twenty-eighth week of gestation⁵³ and, therefore, after twenty-eight weeks the fetus will have TRIs, albeit weak ones, and hence the justification for abortion is greater.

If we consider moral status to be related to a subject having interests in itself, rather than indirect interests to others, the embryo and early fetus have lower moral status than the viable fetus and that in turn has lower moral status than the fetus just prior to delivery. In applying this theory, therefore, the fetus does have lower moral status, at all points during gestation, to the mother and her rights therefore outweigh that of the fetus. That is not to say, however, that the fetus does not have any moral status but that it has not yet attained full moral status. It also confirms that as gestation progresses and TRIs become greater moral status increases and, therefore, greater justification to terminate a pregnancy is required the later in gestation this takes place.

2.2.5 Fetal viability

In this section I discuss fetal viability due to its importance with regard to late termination of pregnancy. This is of particular relevance when considering fetal abnormality and disability discrimination. Whilst I have argued that the fetus does not have the equivalent moral status to an adult viability has been identified as a significant point in gestation with regards to moral status.⁵⁴ Viability is described as the point at which the fetus can survive independently outside the mother given appropriate intensive care.⁵⁵ This could be different for a fetus that is affected by a congenital abnormality and, therefore, I will assume that this is only applicable to those

⁵³ McMahan J (2002) *The Ethics of Killing: Problems at the Margins of Life*, Oxford University Press, pp 267

⁵⁴ Campbell AV (1985) 'Viability and the moral status of the fetus', *Ciba Foundation Symposium* **115**, pp 228-243

⁵⁵ Gillon R (2001) 'Is there a 'new ethics of abortion'?', *Journal of Medical Ethics* **27**, pp ii5-ii9

fetuses that have nothing about them that would hinder their ability to survive. One consequence of this is that it gives a twenty-four week fetus the same moral status as a twenty-four week neonate,⁵⁶ who, apart from now being outside the uterus, is comparable in every other way to its in-utero counterpart.

There are several problems, however, with identifying viability as significant in relation to moral status. With respect to its position of independence should this be a basis on which moral worth is assessed? Some argue that all adults have full moral worth regardless of their physical or mental condition.⁵⁷ I have shown in section 2.2.4 that the psychological account of personhood identifies why this is not the case. Even if it were assumed that all adults did enjoy full moral status there are a number of reasons why an adult may not continue to survive independently of other factors, just like a fetus of less than twenty-four weeks could not survive outside the mother's body.

A person with chronic renal failure can continue to live a full and active life. However, this is on the condition that they have regular renal dialysis, something on which their life is dependent. Similarly there are respiratory illnesses which may require a person to have overnight ventilation to enable their continued survival. Whilst these examples show that even adult humans can be dependent on something for their continued existence this does not in any way lower their moral significance or worth. Why then does the dependence of the fetus on its mother limit its moral status?

The fetus is part of the mother until it is born and is said to be dependent on the mother for its survival until the point of viability. However, I have already argued that she has a higher moral status than the fetus and therefore her rights are of greater importance.⁵⁸ However, it is not with

⁵⁶ Singer P (1993) *Practical Ethics*, Cambridge University Press, p 139

⁵⁷ Stainton T (2003) 'Identity, difference and the ethical politics of prenatal testing', *Journal of Intellectual Disability Research* 47(7), pp 533-539

⁵⁸ Brazier M, Cave E (2011) *Medicine, patients and the law*, London: Penguin Books, p 411

the mother's moral status that I am comparing, but that of a pre-viable versus viable fetus. The independence theory of viability does not automatically confer moral status at that particular point in gestation; just as losing one's independence does not result in the forfeiting of one's moral status. Independence or potential independence in itself does not suddenly mean that moral status should be granted, just as it should not be removed if independence is lost.

A further argument against viability as a point at which the fetus gains moral status is the effect that medical technological advances have had on the viability of neonates.⁵⁹ In 1967 when the Abortion Act was created long-term survival of preterm babies born prior to thirty-two weeks gestation was unusual.⁶⁰ However, with advances in fetal and neonatal medicine, particularly neonatal intensive care, survival of neonates born at twenty-four weeks gestation is now frequent.⁶¹ If viability were to be taken as the time at which the fetus becomes morally significant this would mean that the moral status of a twenty-four week fetus now would be greater than a fetus forty years ago. This alone, however, does not exclude viability as an argument for moral status. It is not difficult to find other examples in history where the moral status of other groups has changed over time.⁶² Having lower moral status in the past does not affect their moral status now.

However, what may be more relevant are the inequalities in neonatal intensive care which exist not over different time periods but in different geographical locations during the same era. For example, whilst there may be a good chance of survival in the western world of a fetus born prematurely, this may not be the case in developing countries.⁶³ Does this mean that a fetus elsewhere in the world, where survival rates are lower and therefore the point of viability is later in pregnancy, has lower moral status? If that were the case it could also be extended to

⁵⁹ Gillon R (2001) 'Is there a 'new ethics of abortion'?', *Journal of Medical Ethics* **27**, pp ii5-ii9

⁶⁰ Wyatt J (2001) 'Medical paternalism and the fetus', *Journal of Medical Ethics* **27**, pp ii5-ii20

⁶¹ Wyatt J (2001) 'Medical paternalism and the fetus', *Journal of Medical Ethics* **27**, pp ii5-ii20

⁶² Hosken, FP (1981) 'Towards a Definition of Women's Rights', *Human Rights Quarterly*, **3(2)**, pp. 1–10.

⁶³ Singer P (1993) *Practical Ethics*, Cambridge University Press, p 140

other areas of medicine. Cancer survival rates are better in developed countries due to diagnostic techniques and treatment.⁶⁴ This does not mean those adults with cancer in developing countries are of lower moral status because their chances of survival are lower. Even within the United Kingdom different neonatal units will have different survival rates.⁶⁵

Therefore, identifying viability as the point of attainment of full moral status would not comply with the general belief that all persons are equal in worth⁶⁶ and would suggest that some people have higher moral status than others (I have already talked about those in whom changes in their psychological attributes may affect them being classed as a person, but I am assuming here that those I refer to are psychologically a person). If this is unacceptable for adult persons why should it be acceptable for the fetus? I do not accept therefore that the fetus has full moral status once it reaches the point of viability, as this point is too variable between different fetuses depending on their own intrinsic development and health, but also depending on their external environment once they are born. A fetus with a disability, such as a congenital heart or lung abnormality, may not be viable at twenty-four weeks but may be at a later stage in development. This would suggest that the fetus with a disability at twenty-four weeks has lower moral status than the fetus without the anomaly at the same stage of gestation, which would be discriminatory and, therefore, morally impermissible.

Some argue that the justification for third trimester abortion should be based on whether or not the fetus is a patient.⁶⁷ If it is, then, as with any other patient, a physician cannot legally and

⁶⁴ Kanavos P (2006) 'The rising burden of cancer in the developing world', *Annals of Oncology* **17**(8), pp viii15-viii23

⁶⁵ Koh THHG, Harrison H, Casey A (2000) 'Prediction of survival for preterm births', *British Medical journal* **320**, p 647

⁶⁶ Edwards SD (2005) *Disability, definitions, value and identity*, Oxford: Radcliffe, p 136

⁶⁷ Chervenak FA, McCullough LB, Campbell S (1995) 'Is third trimester abortion justified?', *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

intentionally kill it, *ceteris paribus*.⁶⁸ Chervenak et al⁶⁹ argue that the fetus is a patient when it becomes viable but accept that viability may occur at different gestational ages depending on various factors including the existence of a congenital abnormality, and therefore the cut-off point may in fact be later than twenty-four weeks gestation, which is generally regarded as the point of viability.⁷⁰ Curiously, Chervenak et al conclude that ‘any attempt to establish limitations on third trimester abortion on the basis of claims about the independent moral status of the third trimester fetus is bound to end in intellectual deadlock’.⁷¹ However, they then go on to say that the fetus as a patient has a form of dependent moral status and appear to rely on this to support their arguments that late termination of pregnancy should only occur where the anomalies in the fetus mean that death is a certain or near certain outcome or that there is an absence of cognitive developmental capacity which is ‘tantamount to death’.⁷² They argue that conditions which fall short of these criteria, such as spina bifida and most cardiac abnormalities, should not result in a decision that a pregnancy should be terminated late in gestation and to agree to a termination under these circumstances would be counter to the doctor’s professional integrity.⁷³ They do not appear to take into account the potential pain and suffering which conditions such as spina bifida and some congenital heart malformations can lead to. In more severe cases it is likely that the child, from a very early age, will need extensive surgery and in-patient hospital care and may suffer significant morbidity throughout their life. They also do not take into account the harm to the interests of the wider family that may occur. It is accepted by them, however, that respect for a pregnant woman’s autonomy is a fundamental principle in

⁶⁸ This is because there might be exceptions; for example, ‘self-defence’ might still be an option for intentionally killing the fetus if the life of the mother is threatened by the continued pregnancy, even if the fetus is considered to be a patient.

⁶⁹ Chervenak FA, McCullough LB, Campbell S (1995) ‘Is third trimester abortion justified?’, *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

⁷⁰ Greaves D, Evans M, Morgan D et al (1992) ‘Bioethics in the United Kingdom and Ireland: 1989-1991’ in Lustig BA (ed) *Bioethics Yearbook* **2**, Kluwer Academic Publishers, Dordrecht, pp 127-152 as cited in Chervenak FA, McCullough LB, Campbell S (1995) ‘Is third trimester abortion justified?’, *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

⁷¹ Chervenak FA, McCullough LB, Campbell S (1995) ‘Is third trimester abortion justified?’, *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

⁷² Chervenak FA, McCullough LB, Campbell S (1995) ‘Is third trimester abortion justified?’, *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

⁷³ Chervenak FA, McCullough LB, Campbell S (1995) ‘Is third trimester abortion justified?’, *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

obstetric ethics, although, they go on to argue that this can be limited by the physician's obligations to the fetal patient,⁷⁴ unless it threatens the life of the mother.

One problem with this argument is that if the fetus, after the point of viability, is to be regarded as a patient but can be killed if it has a severe abnormality as they describe, it would also follow that a neonate in the same condition can also be killed (infanticide). Similarly, an adult patient who is affected by a condition which will soon result in death can also be killed (euthanasia). Chervenak et al are silent on this point and one argument to distinguish these situations from that of the fetus would be to consider the location of the fetus within the mother's body. This is a point which has also been noted by Savulescu,⁷⁵ who also makes reference to the fact that the point and age of viability is affected by technology.⁷⁶

2.2.6 Birth – the transition from fetus to neonate

Birth is another point at which the fetus is said to gain full moral status.⁷⁷ According to my argument that moral status develops as gestation progresses I agree that at birth moral status is higher than it was at, for example, twenty-four weeks of gestation. Under certain maternal and fetal conditions a termination of pregnancy can be performed legally without time limit.⁷⁸ A termination performed after twenty-one weeks and six days of gestation must involve feticide to overcome the problems of viability and survival⁷⁹. As feticide is acceptable under these circumstances but infanticide is not this would suggest that the law recognises some

⁷⁴ McCullough LB, Chervenak FA (1994) *Ethics in Obstetrics and Gynaecology*, Oxford University Press, New York (cited in Chervenak FA, McCullough LB, Campbell S (1995) 'Is third trimester abortion justified?', *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

⁷⁵ Savulescu J (2001) 'Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion', *Journal of Medical Ethics* **27**, pp 165-171

⁷⁶ Savulescu J (2001) 'Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion', *Journal of Medical Ethics* **27**, pp 165-171

⁷⁷ Bermudez JL (1996) 'The moral significance of birth', *Ethics* **106**(2), pp 378-403

⁷⁸ Abortion Act 1967, HMSO: London, Section 1(1)(b), 1(1)(c) and 1(1)(d)

⁷⁹ Brazier M & Cave E (2011) *Medicine, patients and the law*, London: Penguin books, p 407

significance relating to birth. This is not only of legal significance where an entity is not recognised legally as a person until it is physically born, with the fetus having no recognised legal rights, but it is also said to be of moral significance.⁸⁰ Steinbock, however, argues against birth as being a morally significant stage in fetal development:

‘There is not much difference between a newborn moments after birth, and a foetus moments before it is born. How can a change merely in location have such a drastic effect on moral status?’⁸¹

Warren, however, argues that as well as the change in location of the fetus, from inside the mother to outside, there are also changes in the biological connection to the mother which make birth significant. Once delivered the fetus can exist independently and no longer potentially threatens the life of the mother.⁸² Whilst pregnancy is associated with risks to the mother it does not generally threaten her life. Obviously there are some situations where continuing to be pregnant can threaten a woman’s life, and this is one of the justifications for termination of pregnancy, including late termination. However, in general, without specific indication most fetuses do not confer any significant threat to a woman’s life, so is this a good enough reason to give the fetus a lower moral status than its delivered counterpart?

Thomson argues that killing the fetus in self-defence is a justification for terminating a pregnancy⁸³ and therefore a threat to a woman’s life may justify termination up to birth for such a situation. Thomson, however, talks of self-defence as a reason to allow a woman to terminate a pregnancy even in the face of arguments that suggest that the fetus has the same moral status as a neonate, and therefore should not be killed. Thomson uses an analogy to justify her

⁸⁰ Bermudez JL (1996) ‘The moral significance of birth’, *Ethics* **106**(2), pp 378-403

⁸¹ Steinbock B (1992) *Life before birth: The moral and legal status of embryos and fetuses*, Oxford University Press, p 330

⁸² Warren MA (2000) ‘The moral difference between infanticide and abortion: A response to Robert Card’, *Bioethics* **14**(4), pp 352-359

⁸³ Thomson JJ (1971) ‘A defence of abortion’, *Philosophy and Public Affairs* **1**(1), pp 47-66

position. She describes a villain throwing a fat man towards you as you sunbathe on a deck beneath the cliff he is being thrown from.⁸⁴ If the man lands on you, you will be killed, however, he will survive as you cushion his fall. To complicate matters further you are immobile with your leg in traction and therefore have no chance of being able to move out of the way before he hits you. The only option you have to prevent your own death is to impale the man on your parasol. This, Thomson argues, is justified. The fat man is innocent but will kill you if he hits you. You have the right, therefore, to take action to save your own life, even if this does result in the fat man's death. Thomson then goes on to compare this to the situation faced by women whose lives are threatened by their pregnancy. On this basis, therefore, whilst the fetus is an innocent party it is threatening the life of the mother and as such she is justified in ending the life of the fetus in order to save herself. This argument of course only works when we consider the situation where the woman's life is at risk.

This argument would not justify the termination of those pregnancies which are affected by a fetal abnormality, but which do not threaten the mother's life. Legally a seriously disabled fetus can be aborted but a seriously disabled neonate cannot actively be killed. Ethically birth is also seen as a significant point in development with Warren arguing that infanticide, based on severe neonatal abnormality, cannot be justified, stating:

‘...since it is possible to do more than ever before to enable people with disabilities to lead good lives’.⁸⁵

This argument could, however, also be applied to seriously handicapped fetuses and would serve as an argument against abortion on the grounds of fetal abnormality. Warren's argument implies that disability is not a good enough reason to allow infanticide and, therefore, one could

⁸⁴ Thomson JJ (1971) ‘A defence of abortion’, *Philosophy and Public Affairs* **1**(1), pp 47-66

⁸⁵ Warren MA (2000) ‘The moral difference between infanticide and abortion: A response to Robert Card’, *Bioethics* **14**(4), p 352-359

deduce from this that abortion on the grounds of disability could also not be justified. These fetuses could be treated following delivery, or even in-utero. Therefore, if abortion is acceptable but infanticide is not this suggests that the neonate has a higher moral status than the fetus.

Gillon also considered this arbitrary distinction between the born and unborn, describing it as 'biological geography':

“... (a) human being does not have a right to life if it lies north of the vaginal introitus but has a right to life once it has passed south.”⁸⁶

A thirty-eight week fetus is as fully developed and one would assume as sentient as a thirty-eight week gestation neonate. There are slight changes from fetal to neonatal physiology as the baby takes its first breath, but these could not be considered significant biological changes as to bestow moral status as many premature neonates, who are generally regarded as having full moral status in addition to full legal status, do not undergo these changes without medical intervention. Apart from its in-utero position and its umbilical attachment to its mother there is no difference. In section 2.2.4, I stated that the mother, being a person, has higher moral status than her fetus and in the event of her life being threatened a termination is justified up until birth.⁸⁷ In the case of terminating a pregnancy, and therefore killing the fetus, one justification of this is the rights of a woman over her own body.⁸⁸ However, if a fetus with congenital abnormalities or a condition that is going to result in a disabled person once born is not threatening the life of the mother, is it morally justifiable for this pregnancy to be terminated up to the point of birth when this is not an option in a normal pregnancy which is not threatening

⁸⁶ Gillon R (2001) 'Is there a 'new ethics of abortion'?', *Journal of Medical Ethics* **27**, p 10

⁸⁷ Newnham H (2003) 'Mother vs fetus: who wins?', *Australian Journal of Midwifery* **16**(1), pp 23-26

⁸⁸ Thomas JJ (1971) 'A defence of abortion', *Philosophy and Public Affairs* **1**(1), pp 47-66

the mother's life? Does this suggest that a disabled fetus has a lower moral status than one that is regarded as normal? This is an issue which I will subsequently discuss in section 2.4.

2.2.7 Moral status as a continuum

Having considered what it is to have moral status and discussed the arguments as to when this occurs during fetal development, I have concluded that a fetus does not become morally significant at what is regarded as the point of viability or at birth, or for that matter any other discrete point in gestation. The development of moral status is something that is continually evolving during gestation as the fetus attains more of the properties and characteristics associated with personhood. The attributes of a person put forward by Warren do not suddenly develop at a particular point in gestation, but are achieved and developed gradually over time and they may not all appear at the same time. As personhood develops so too does moral status, with full moral status being achieved once the attributes of a person have been reached. Glover⁸⁹ supports this view that becoming a person is a matter of degree and abandons the view that there is an abrupt transition. He describes a one-year-old child being more a person than a neonate or fetus just before birth, but that each of these is more a person than an embryo. Glover acknowledges that this theory does not resolve the issues surrounding moral status of the fetus completely as there is likely to be disagreement as to the rate at which acquiring moral status increases and when it is completed. This will depend on which aspects of personality makes a human a person.⁹⁰

This view of moral status being on a continuum avoids the problems encountered by having a sharp distinction as to when abortion under certain circumstances is and is not acceptable. It implies that abortions become increasingly morally wrong as pregnancy progresses meaning

⁸⁹ Glover J (1997) *Causing death and saving lives*, Penguin Books, p127

⁹⁰ Glover J (1997) *Causing death and saving lives*, Penguin Books, p128

that stronger justification for ending a pregnancy later in gestation is needed. This enhanced justification may become clearer for the medical practitioners agreeing to perform the termination when they fully engage with the prospective parents in order to understand their reasons for requesting a termination, and the impact having a disabled child will have on them as well as the future child, which I discuss in chapter six. The clinical geneticist, as part of the support they provide to prospective parents, should play a pivotal role in ensuring that the justifications for these decisions includes consideration of the interests of prospective parents and other family members, and that they are not solely based on clinical information about the fetus.

Strong refers to the above view of moral status as having ‘considerable intuitive plausibility’,⁹¹ with abortions earlier in gestation being less ethically problematic than those that take place late in gestation. This, however, does not assist in deciding on the issue of whether a termination, for any reason, can take place at any time during gestation or whether this should be confined to certain extenuating circumstances, as defined in the Abortion Act. If we are to accept that the fetus does have moral status and that this increases as gestation progresses there needs to be acknowledgement that with increasing gestation comes the need for increasing protection.

2.3 Disability and Abortion Law

The advent of prenatal testing and diagnosis has led to the increased identification of fetuses with abnormalities, both physical and mental. Ultrasound scanning during pregnancy has also become much more sophisticated with detailed physical imaging revealing an increasing

⁹¹ Strong C (1997) ‘The Moral Status of pre-embryos, embryos, fetuses and infants’, *The Journal of Medicine and Philosophy* **22**, pp 457-478

number of anomalies in fetuses.⁹² Advances in genetic medicine have led to the identification of more and more genes that cause disease and for which prenatal testing is available. Offering such tests to pregnant women provides them with the opportunity to terminate an affected pregnancy if so desired. Some abnormalities, however, cannot be identified until later in gestation resulting in the need for terminations to take place closer to term, around which there is additional controversy. This is reflected in law in the form of the Abortion Act⁹³ where, as well as for reasons of maternal interest, termination of pregnancy for fetuses considered to have a serious abnormality can take place *after* the point at which the fetus is considered viable (currently twenty-four weeks gestation). Applying this time limit, either in legislation or ethically speaking, does have implications with respect to the moral status of those identified as being at substantial risk of ‘serious handicap’. If a fetus that is considered ‘normal’ cannot be terminated after the point of viability, unless it is threatening the life of the mother, why is it acceptable or justifiable to terminate a pregnancy where the fetus has been identified as having significant or serious abnormalities?

On the face of it, therefore, the Abortion Act does appear to differentiate between and discriminate against those fetuses that have congenital abnormalities that would result in the birth of a disabled person. Women who choose to have prenatal tests performed are able to use the information this provides to make decisions about their pregnancy. If an abnormality is identified a woman may consider having a termination, however, the law imposes limitations on this. It is sometimes the case that abnormalities cannot be identified before twenty-four weeks or some serious conditions may not develop until later in pregnancy. Late termination (after twenty-four weeks) may allow pregnant women to continue to make choices about their pregnancy as relevant information becomes available to them, and may provide them with the options that are available to those women who receive information about the health of their

⁹² Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London, p 1

⁹³ Abortion Act 1967, HMSO: London, Section 1(1)(b), 1(1)(c) and 1(1)(d)

fetus earlier in gestation. I will discuss in chapter six the limitations that may be placed on women later in pregnancy due to the need for a late termination to be medically justified, and how developing the role of the clinical geneticist may assist prospective parents and healthcare professionals reach these decisions.

The question of when the fetus becomes a moral agent affects what can be considered to be morally justifiable with respect to termination of pregnancy. Pro-life arguments against abortion rely on the initial premise that it is wrong to kill a human being and on the second premise that a fetus has full moral status, therefore, concluding that it is wrong to kill a human fetus.^{94,95,96} In order to counter-argue these claims I have argued that the fetus does not have full moral status equivalent to the adult human person based on the personhood view and due to the fact that an adult has TRIs which are greater than that of a fetus. However, this does not address the problem of permitting termination of pregnancy after a point in gestation due to serious disability, but not allowing the termination of a 'normal' pregnancy after the same point.

If we consider abortion law to have developed by firstly considering the ethical principles, we can then consider the moral implications of this legislation.⁹⁷ The current abortion law is not totally permissive or totally prohibitive and it is the presence of serious disability in the fetus that I am interested in. As previously stated, the Abortion Act allows termination of pregnancy up to twenty-four weeks of gestation. The ethical basis for this is that twenty-four weeks gestation is also regarded as the point at which the fetus is viable in that it could survive independently of the mother, although not necessarily without significant disability.⁹⁸ Certain

⁹⁴ Singer P (1993) *Practical Ethics*, Cambridge University Press, p 138

⁹⁵ Marquis D (1999) 'Why abortion is immoral' in Kuhse H, Singer P (eds) *Bioethics: An anthology*, Blackwell Publishers, pp 46-57

⁹⁶ Wertheimer R 'Understanding the abortion argument', *Philosophical and Public Affairs* 1(1), pp 67-95

⁹⁷ Radcliffe Richards J (1994) *The Sceptical Feminist: a philosophical enquiry*, Penguin Books, Chapter 8

⁹⁸ Moore T, Hennessy EM, Myles J et al (2012) 'Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies', *British Medical Journal*, December 4, p 345:e7961

maternal and fetal criteria, as outlined by the Act, will also sanction abortion up to birth, another significant point in fetal development and one in which others regard as morally significant.⁹⁹ Whilst obviously all terminations involve feticide, a termination after twenty-two weeks must involve additional procedures that ensure that the life of the fetus has been ended before the termination procedure takes place¹⁰⁰. This is to avoid the delivery of a live born infant and the anguish for the neonate, parents and staff that is inevitably associated with this.¹⁰¹

Some argue that the fact that a termination may be permissible up to birth if the fetus has a severe disability, but not if the fetus is said to be 'normal', discriminates against those with disabilities who live in our society¹⁰² and that a common time limit should be adopted for all pregnancies.¹⁰³ Abortion law has been developed over time taking into account ethical opinions regarding the treatment of the fetus at various points during gestation.^{104,105} This has led to the time limit of twenty-four weeks for abortion other than those performed under certain circumstances, including fetal disability. On the face of it this does suggest that the law is unethical as it does distinguish between disabled and non-disabled fetuses and, therefore, discriminates against those with disabilities.

There are two ways in which this could be seen to be discriminatory. One is that terminating pregnancies due to fetal abnormality or disability at all confers lower moral status on those living with disabilities, suggesting that they would have been better off not to have been born. The second is that if one extends the argument that a normal fetus, or one with minor

⁹⁹ Jensen D (2015) 'Birth, meaningful viability and abortion', *Journal of Medical Ethics* **41**, pp 460-463

¹⁰⁰ Prior to the termination procedure, an ultrasound scan directed injection is given into the fetal heart or vessels containing potassium chloride. This stops the fetal heart, causing death.

¹⁰¹ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London, p 29

¹⁰² Gillott J (2001) 'Screening for disability: a eugenic pursuit?', *Journal of Medical Ethics* **27**, pp ii21-ii23

¹⁰³ Shakespeare T (1998) 'Choice and Rights: Eugenics, genetics and disability equality', *Disability and Society* **13**(5), pp 665-681

¹⁰⁴ British Medical Association (2014) *The Law and Ethics of Abortion: BMA Views*, BMA

¹⁰⁵ Gleeson K (2007) 'Persuading Parliament: Abortion law reform in the UK', *Australasian Parliamentary Review* **22**(2), pp 23-42

abnormalities, cannot be terminated after twenty-four weeks gestation but a fetus with serious abnormalities can be, suggesting there is a difference in their moral status,¹⁰⁶ then this would also apply to individuals already born with disabilities. This would, therefore, appear to discriminate against those living with disabilities and suggest they too have lower moral status than their non-disabled counterparts. This could then have implications for those living with disabilities, for example, with respect to medical treatment and the impact this may have on resources within society generally.

With respect to the first argument, terminating a disabled fetus does not discriminate against those living with disabilities any more than terminating a fetus for social reasons alone does for a non-disabled person. I have already established that the fetus, disabled or otherwise, does have a lower moral status than a person who has been born and, therefore, the two cannot be compared. However, one can also see why it is not unreasonable for those representing disability groups to be concerned that such termination decisions will be considered to express discriminatory attitudes towards disability, especially as disabled and non-disabled fetuses at the same gestation are treated differently.

This leads to the question of whether we ought to legislate to prevent such attitudes from being expressed in reproductive choices based on the argument that such attitudes may mould the sort of people who are allowed to live in society. However, during my discussion of the arguments I intend to show that such terminations do not discriminate against those with disabilities. Parental and reproductive autonomy should not be overruled when a serious abnormality exists on the basis that it discriminates against disabled people.

The second argument, however, is more difficult to refute on moral grounds. If disabled individuals have the same moral standing as those without disabilities why can a disabled fetus

¹⁰⁶ Savulescu J (2001) 'Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion', *Journal of Medical Ethics* 27, pp 165-171

be terminated after twenty-four weeks of gestation but a physically and mentally unimpaired fetus cannot?

Those already living with disabilities have the same moral status as other individuals and so too does the disabled fetus have the same moral status as the fetus that is considered to be normal. The fact that some form of disability exists does not affect moral standing. The permissibility of late terminations where serious disability exists is not justified on the basis that the disabled fetus has a lower moral status, but based on the quality of life the future child would be expected to have if they were born, and the implications this may have for other close family members, and the harm it may cause to the interests of those who have full moral status. One could even argue that morally it is unacceptable to allow a baby to be born knowing it will have such severe disabilities as to have a life which is not worthwhile.^{107,108} However, if terminations are permitted on the basis of reducing suffering this would imply that infanticide and even euthanasia at any age should be allowed.

Gillon agrees that if human fetuses are people and therefore disabled fetuses are disabled people it is morally unacceptable to kill such fetuses, as it would be to kill similarly affected adults.¹⁰⁹ However, Gillon argues that justifying abortion on the grounds of disability and rejecting the claim that fetuses are people with full moral status is not discriminating against those living with disabilities. I have already discussed why the fetus does not have full moral status, having based my arguments on the personhood view. Gillon argues that such abortions can be justified by providing the choice to pregnant women not to continue a pregnancy which would result in a disabled person. He argues that if the fetus is not regarded as having full moral status then aborting an abnormal fetus does not discriminate against those living with disabilities, who have the same full moral status as other people who have been born. As Gillon states:

¹⁰⁷ Harris J (1990) 'The wrong of wrongful life', *Journal of Law and Society* **17**(1), pp 1-16

¹⁰⁸ Warren MA (1978) 'Do potential people have moral rights?' in Sikora RI, Barry B (eds) *Obligations to future generations*, Philadelphia, Temple University Press, p 25

¹⁰⁹ Gillon R (2001) 'Is there a 'new ethics of abortion'?', *Journal of Medical Ethics* **27**, pp ii5-ii9

“...if they do not yet have full moral status including a right to life, then there is simply no logical connection between making abortion available to prevent the creation of a disabled person and discriminating adversely against disabled people.”¹¹⁰

As a clinician it is important to be able to reconcile the concerns about disability discrimination with the fact that the advice being given to prospective parents may ultimately result in the termination of a disabled fetus. The decision to request and agree to a late termination will not only depend on the implications of continuing the pregnancy for the future child, but also the harm to the interests that is likely to occur to those with full moral status who are directly affected by the birth of the child. The decision is also made with a view to promoting parental autonomy, which I discuss in chapter three. Greater justification for ending a pregnancy should be sought as gestation progresses, particularly in the case of late terminations, for the reasons I have given above about moral status developing as gestation progresses. The clinical geneticist can play an important role in ensuring that all of these harms are considered when justifications are made.

The decision as to whether or not a termination can take place, therefore, is based on the degree of suffering that is going to occur to the future person once born and the consequential harm to the interests of the parents and other close family, such as siblings. I will discuss the issue of harm in chapter four.

Medical practitioners and specialists who have knowledge of the condition, parents with experience of it and adults who are affected can inform the decision as to whether or not a late termination can be justified. My concern with viability being chosen as the point after which late terminations for serious disability are allowed is that viability does not mean survival

¹¹⁰ Gillon R (2001) ‘Is there a ‘new ethics of abortion’?’, *Journal of Medical Ethics* 27, pp ii5-ii9

without serious complications. Babies born at twenty-four weeks gestation now have a reasonable chance of survival but at this gestation there is also a serious risk of disability.^{111,112} If it is the detrimental consequences of serious disability that we are trying to avoid, and the harm caused by it, it would seem more appropriate to move this back to twenty-eight weeks which is a point in gestation where survival is likely and the risk of disability as a result of premature birth is much lower.

The law on abortion is silent on the level of seriousness that is required to fulfil the criteria for a late termination. There is no legal definition as to what level of substantial risk of serious handicap is needed for a late termination for fetal disability to be allowed. Whether a risk is considered to be substantial may vary depending on the nature and the consequences of the abnormality and the disability that it causes. The Royal College of Obstetrics and Gynaecology (RCOG) state that an assessment of seriousness should be considered on a case-by-case basis, taking into account all of the *clinical* information that is available.¹¹³

As previously mentioned above, as well as justifying late termination of a disabled fetus due to the effect the abnormality will have on its quality of life, it is also important to consider what effect having a disabled child will have on the parents and their own interests, something which tends to be neglected in current decision-making, with clinicians concentrating on the clinical findings and prognosis for the future child.¹¹⁴ I have already established that adult persons have full moral status whereas the fetus does not, and, therefore, the parents, being autonomous full moral agents, should be able to decide for themselves what impact continuing a pregnancy

¹¹¹ Moore T, Hennessy EM, Myles J et al (2012) 'Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies', *British Medical Journal* December 4, p 345:e7961

¹¹² Saigal S, Doyle LW (2008) 'An overview of mortality and sequelae of preterm birth from infancy to adulthood', *Lancet* **371**(9608), pp 261-269

¹¹³ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London, p viii

¹¹⁴ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London, p viii

affected by a severe disability will have on them and their future quality of life. This is something only they can decide and reflects the importance of establishing a supportive relationship with the clinical geneticist and other relevant healthcare professionals to ensure they are able to reach the best decision for them. Having a higher moral status than the fetus, the parents are in the position to take precedence over that of the fetus when considering harms and benefits to either party. Parents who, through no fault of their own, find out late in pregnancy that their future child is affected by a disability should not be disadvantaged as compared to those parents who find out before twenty-four weeks that their future child will have serious abnormalities and are therefore able to have a termination of that pregnancy.

With technological advances in fetal medicine more information than ever can be obtained about an individual pregnancy and more predictions can be made about the clinical effects an abnormality can have. No two pregnancies are likely to be the same and even those pregnancies affected by the same condition may result in different outcomes. A fetus with Down syndrome, for example, may result in a child with relatively mild learning difficulties and no life threatening physical anomalies, whereas another pregnancy affected by the same condition could result in a child with profound learning difficulties and severe heart and digestive tract abnormalities, requiring extensive surgical procedures. These differences in the phenotype cannot be identified by simply performing a genetic test to look at the child's chromosomes (such as following amniocentesis). Specialised antenatal scanning can, however, help to predict the level of disability and ongoing care that may be needed in order to assist parents in making a decision about continuing or terminating their pregnancy.

To set specific criteria for what substantial risk means or what type of abnormality or condition is serious enough to warrant abortion may result in some terminations taking place where the disability may not have been particularly detrimental to the person's life, or denying termination to some women whose child will have significant postnatal problems. The RCOG express the view that at a minimum serious handicap would require 'the child to have physical or mental

disability which would cause significant suffering or long-term impairment of their ability to function in society'.¹¹⁵ As well as clinical implications of the abnormality, therefore, it is important to consider its wider effects. The current guidance, however, refers to the impact on the fetus and does not make any reference to others who will be directly affected. I will discuss harm in chapter four and the implications that having a pregnancy affected by a serious abnormality has not only on the future child but also other members of the immediate family. Healthcare professionals who care for prospective parents in these circumstances should not only consider the clinical implications of the condition on the fetus but also take into account factors which affect the family generally, such as their financial and social situation, how emotionally robust they are to cope with a future with a severely disabled child and whether or not the parents themselves are in good health, how many other children they have and what their state of health is. Bearing all this in mind does make it clear that specific criteria cannot be put forward by which late termination can be justified. It also highlights the importance of not only clinical geneticists and counsellors engaging with prospective parents, but also those who will ultimately decide whether or not a late termination of pregnancy can be justified.

The impact of having a child with a serious disability on the wider family can only be established by effective interaction between the prospective parents and the whole healthcare team. This view does not discriminate against the fetus because it has some intrinsic difference about it; rather, it focuses on the implications, which, despite medical and social interventions after birth, cannot be overcome. It is possible that other pregnancies not affected by disability may also be seen to cause harm to the same degree. If this can be established by healthcare professionals engaging with prospective parents it may mean that late termination can also be justified for reasons other than disability. This would, therefore, require a change in the law as it stands now. It may, however, be difficult to find the appropriate justification to end the pregnancy of a non-disabled fetus, as it is more likely that any extrinsic factors, such as poverty

¹¹⁵ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London, p 8

and social deprivation or the risk of neglect, could be addressed once the child is born. This highlights the fact that it is not the disability *per se* or the existence of an abnormality itself that justifies the termination, but the impact it will have once the child is born on the future person and close family members.

To illustrate the point that the justification for a late termination is not based on the fact that the fetus has a disability, I will use an analogy relating to a non-disabled fetus. I have previously said that it is difficult to see how one can justify terminating a pregnancy late in gestation when there is no intrinsic problem with the fetus, even where the potential future may consist of neglect or social deprivation. These problems could be overcome with appropriate support and the future child could still have a life without harm or suffering. Where there is an abnormality in the fetus which will cause significant harm with pain and suffering and, if after discussion, it is decided that this cannot be overcome for the future child or family this may justify late termination. On the face of it, it may seem that the decision has been made based on the existence of disability. I disagree, however. The decision has been based on harm to the future person and their direct family and the impact of this can only be established by supporting parents and respecting their reproductive autonomy.

Imagine a couple who have received the much anticipated and welcome news that they are expecting a baby. All is well and they progress through their pregnancy and make plans for the future. A civil war breaks out in their country and the people who live there are exposed to unimaginable terror and violence. They witness the suffering of others and may even see death or injury to their pre-existing children. Direct threats are made to their family including to their new baby, which is due imminently. The situation is such that there is nothing they can do to change this and the civil war will continue for the life of the future child. The couple decide that despite this being a much wanted pregnancy they do not want to inflict this sort of life on their child if they can avoid doing so and do not want to see their child inevitably suffer and be

harmed. They have seen their other children suffer terribly and do not want to experience further harm by seeing this child meet the same fate.

Adoption is discussed but the child could only be adopted by a family within the same war torn country and therefore the future child would suffer the same harms. The couple would only contemplate adoption if the child could be taken out of the situation and not suffer. Adoption in their case would not prevent harm to the child and the couple would still suffer harm knowing their child was being brought up in the same environment but with the added distress of not knowing what had happened to him or being able to try to protect him themselves.

Justifying late termination in this case would be similar to justifying it when a disability has been identified. Not because of the disability but because of the harms to the future child and family. As with termination due to the presence of a disability, this scenario emphasises the importance of respecting reproductive autonomy as only this woman/couple can make the decision as it will inevitably have implications of its own and won't be an easy decision to live with. The harms of the decision will need to be weighed against the harms caused by continuing the pregnancy.

2.4 Abortion: Women's rights arguments

I have considered the arguments in relation to the moral status of the fetus from the perspective of whether or not the fetus is a human being or is to be regarded as a person. I will now look at the arguments put forward by women's rights advocates to see whether these provide any further assistance in supporting my argument that termination of pregnancy is morally acceptable under certain circumstances. This is based on the account that the moral status of the fetus develops over time towards full moral status afforded to persons. My thesis is concerned with prenatal testing and, therefore, it is necessary to consider abortion as

termination of pregnancy can be the outcome of receiving an unfavourable result following testing. This clearly has implications for impaired fetuses and whether or not it is morally acceptable for there to be different rules in this situation when considering termination.

Those who support termination of pregnancy for any reason generally rely on women's rights arguments and claim that a woman should be allowed to terminate a pregnancy regardless of the reason and at any time during gestation.¹¹⁶ Many of these arguments relate to women having control over their own bodies and being able to decide what happens to them without intervention from others.¹¹⁷ Other advocates talk about a woman's right to self-defence.¹¹⁸

The first theory I will consider is one which is well rehearsed within the literature, that of Judith Jarvis Thomson.¹¹⁹ Whilst not necessarily agreeing with it herself Thomson starts her arguments by assuming that the fetus is a person and has a right to life. Whilst the mother has a right to decide what happens to her own body, this does not necessarily supersede the right to life of the fetus. This therefore suggests that abortion is morally wrong.

From this Thomson then creates the scenario of the 'unconscious violinist'. This scenario supposes that a famous unconscious violinist has been connected to your kidneys in order to save their life from a serious ailment. You are the only person who can save them. To unplug the violinist would be to kill them and you are told that he will have to be connected to you in this way for the next nine months, although Thomson also poses the question as to what if this was for nine years or even for the rest of your life? The violinist is a person and therefore has a right to life, but is the right greater than the right you have to say what happens to your own

¹¹⁶ Smith S (2004) 'Abortion is every woman's right', *Socialist Worker*, April 23, pp 6-7 (socialistworker.org as cited on 23/06/2015)

¹¹⁷ Varden H (2012) 'A feminist Kantian conception of the right to bodily integrity: The cases for abortion and homosexuality' in Crasnow S, Superson A (eds) *Out of the shadows: Analytical feminist contribution to traditional philosophy*, Oxford University Press, pp 39-47

¹¹⁸ Thomson JJ (1971) 'A defense of Abortion', *Philosophy and Public Affairs* **1**(1), pp 47-66

¹¹⁹ Thomson JJ (1971) 'A defense of Abortion', *Philosophy and Public Affairs* **1**(1), pp 47-66

body? Are you obliged to allow them to stay connected to you? The scenario unfolds in that the dependent violinist eventually starts to cause damage to the body of the woman he is connected to and if he continues to be attached to her she will die. Does she have the right to save her own life by disconnecting him even though this will result in an innocent person's death? This is where the self-defence argument comes into play and is the analogy to a pregnant woman's life being threatened by continuing her pregnancy. Thomson argues that it is permissible to save one's own life by killing someone else, if necessary and despite their innocence.

I agree with Thomson in that the self-defence argument does support the woman's right to end a pregnancy but this is only in the situation where her life is threatened. It does not assist the argument regarding a woman ending her pregnancy due to unfavourable social circumstances or due to serious fetal abnormality. Thomson does go on to discuss situations where the life of the mother is not threatened. Glover¹²⁰ refers to this as the priority argument and Thomson also reduces the severity of the violinist's dependence by making this for only one hour. She concludes that whilst it may not be the kindest act to unplug the violinist in this new scenario, the violinist does not have any right to the use of the woman's body and therefore it is not unjust for her to refuse to continue to support him, just as the fetus has no right to her body either.

Ultimately, my view that abortion is permissible under certain circumstances is supported by Thomson. In terms of the acceptability of late termination this would include a threat to the mother's life (self-defence) and severe fetal abnormality which would lead to a life of pain and suffering and harm to the interests of the fetus and parents. The example that Thomson uses to support her conclusion is that it would be acceptable, and indeed indecent not to, to allow a pregnancy to be terminated in the case of a fourteen year old girl having been raped. What would not be appropriate is for a woman, in her seventh month of pregnancy, to decide that

¹²⁰ Glover J (1977) *Causing death and saving lives*, Penguin Books, p 132

being pregnant is no longer convenient to her. In the latter case the woman has accepted responsibility for the fetus by having already reached her final trimester having presumably found out about her pregnancy much earlier. She has now reached the stage where terminating a pregnancy of a normal fetus cannot be justified on this basis alone as it has higher moral status at this stage in pregnancy and deserves protection. Much greater justification is needed to allow termination of the pregnancy to take place at this stage, such as a risk to the life of the mother or the identification of a serious abnormality in the fetus, which is likely to cause future harm to the person born and relevant others with full moral status. If the mother no longer wants to have a child, having progressed this far through the pregnancy, other options are available to her such as adoption.

Warren,¹²¹ considering Thomson, accepts that abortion may be acceptable in the case of rape, but has concerns about Thomson's arguments where a pregnancy happens as a consequence of the woman's carelessness or where the woman has intentionally become pregnant and then changes her mind. This would then suggest that the woman has assumed responsibility for the fetus she is carrying. However, in response to this my view is that although the woman has, through her own fault or actions, become pregnant and, therefore, consented to the fetus being in her uterus and being dependent on her, it is possible that her decision may have been different had she known that her pregnancy would be affected by an abnormality that would lead her to have a child with serious disabilities. Warren ultimately resolves her dilemma by concluding that the fetus is not a person and does not have full moral status, which is a conclusion I have also previously reached.

When Thomson published her paper in 1971 prenatal testing was not part of antenatal care and therefore she was not in a position to consider this in relation to a fetus with abnormalities. In the situation where parents have had prenatal testing it is likely that this is a very much-wanted

¹²¹ Warren MA (1973) 'On the moral and legal status of abortion', *The Monist* 57(1), pp 43-61

pregnancy of a woman who is engaging with antenatal care. As she is at a stage where she has not previously opted for a social termination one can assume that this is a much wanted child. It is not the concept of being pregnant and having a fetus dependent on her that is an issue here, but the reality of the potential child having serious disabilities which will not only affect the future child's life, but that of the woman's and other important people in her life. In chapter four, I consider the impact this situation may have on the fetus and woman and the implications that prenatal testing has for those living with disabilities.

Davis¹²² talks about abortion in terms of discontinuing life support. She argues that as the fetus is dependent on the woman to continue to live ending this support is analogous to discontinuing life support in other situations, providing there are sound reasons for doing so. Davis does not, however, define what she means by sound reasons and presumably, therefore, this will be a matter for the woman to decide and discuss with her clinician, but may include the presence of a fetal abnormality. This argument could be said not to apply to those fetuses which have reached twenty-four weeks of gestation and are, therefore, likely to be viable should they be independent of the mother. However, they will still require medical support in the form of mechanical ventilation, intravenous fluids and other clinical interventions to help them to stay alive or to minimise the disability they may suffer as a result of prematurity. The life support provided by the mother, therefore, has simply been replaced by other interventions once the fetus is outside the womb.

I rely on my previous position that the moral status of the fetus develops and progresses during the gestation period thus making termination of the pregnancy less acceptable as time goes by, with the need for greater justification the closer the fetus approaches term. It would not be appropriate to discontinue a person's life support if there was a good chance that they would recover once they were over the period of time that life support was required. If the recipient

¹²² Davis N (1984) 'Abortion and self defense', *Philosophy and Public Affairs* **13**(3), pp 175-207

of the life support was going to recover to lead a fulfilling and worthwhile life, it should be without question that it should be continued. However, decisions are frequently made in clinical practice whereby life support, or life sustaining treatment, is not continued because there is no prospect of recovery.¹²³ These are patients who are never going to recover, it being futile to continue with life support, or whose life will be of very poor quality. There are other similar scenarios where treatment may be withheld due to the quality of life that the person is likely to have should they continue to survive. For example, antibiotics may be withheld from a person with severe dementia and who is completely immobile and lacking capacity when they develop a life threatening pneumonia. After discussion between the close family and physicians a decision is often made that it would be kinder not to treat them and let nature take its course. I mention these situations in support of termination of pregnancy when an impairment has been identified in the fetus which is going to result in death in-utero or during the neonatal period, or lead to the birth of a child who is going to be blighted by a life of immense pain and suffering. Terminating a pregnancy removes the life support that is being provided by the mother and allows the fetus, who would otherwise have died later in utero or soon after birth, or had a life of immense suffering, to die.

2.5 Summary and conclusions

The time limitations set by the Abortion Act, if we assume that these are based on the moral status of the fetus, do discriminate between non-disabled and disabled fetuses. If the fetus is regarded as having the same full moral status as a person who has already been born this would also discriminate against those already living with disabilities. Having initially discussed the arguments as to what it is to have moral status I have argued in this chapter that the fetus does not have full moral status at any point during gestation. The fetus, therefore, has a lower moral

¹²³ *Airedale NHS Trust v Bland* [1993] AC 789

status than a person already born. One cannot, therefore, compare killing a fetus with a disability to killing an adult with a disability.

I have also discussed certain points during gestation that have important significance particularly in relation to termination of pregnancy. Whilst a fetus at the point of viability has a higher moral status than one earlier in pregnancy, and a fetus at the end of the gestation period has a higher moral status still, viability and birth are not points where the fetus reaches full moral status. This supports my overall position that prenatal testing does not discriminate against those living with disability.

I have argued that fetal moral status develops as gestation progresses and, therefore, greater justification is needed in order to perform a termination later during pregnancy. One justification may be a threat to the mother's life. A more controversial reason is the existence of a serious abnormality. I have argued that this does not suggest that a disabled fetus has lower moral status than a 'normal' fetus, but that this decision is based on the harms that may occur to the future child and the prospective parents and others that may be directly affected. If these harms cannot be overcome this may justify terminating the pregnancy. However, this justification can only be achieved when healthcare professionals engage with prospective parents so that all parties fully understand the implications for the fetus in the context of the family, as opposed to considering only the clinical information about the fetus and potential effect the disability will have solely on them.

Late terminations are not carried out without discussion between healthcare professionals and prospective parents and it is important to note that they account for only 1% of all terminations.¹²⁴ The disability has to be very serious and one which will impact negatively on the life of the future child. However, my concern is that where an abnormality has been

¹²⁴ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London, p 1

identified, either by physical in-utero examination of the fetus or by genetic or metabolic tests, those who ultimately decide whether a late termination can be justified do not consider the implications to the wider family. Not allowing late terminations, particularly for those identified as having abnormalities late in pregnancy, would mean the worst affected pregnancies and those with the greatest potential to cause harm to the future child and wider family would continue, whereas less severely affected pregnancies identified before twenty-four weeks, could be terminated. The clinical geneticist is not ultimately responsible for justifying agreement to perform a late termination, but should take an active part in discussions with those clinicians responsible, to ensure that the harm to the interests of all relevant parties is taken into account.

The arguments that I have discussed in this chapter help to underpin my position in the next chapter, where I argue for the promotion of reproductive autonomy in that those who will be affected by the birth of a disabled child are best placed to make decisions about prenatal testing and its consequences. Many of the arguments I have made in this chapter will be further supported through my discussion of the concepts of disability and harm to the interests of the fetus and those close to it in chapter four.

Chapter 3

Reproductive Autonomy

3.1 Introduction

In this chapter I will argue that autonomy, and more specifically reproductive autonomy, with the ability to control our own reproductive choices should be respected due to the importance society places on us having control over our own lives. This chapter utilises my conclusions from chapter two, in that the fetus does not have full moral status equivalent to that of a person and, therefore, as a clinical geneticist one can begin a meaningful dialogue with the prospective parents having dealt with the concerns about the morality of abortion (which may result as a consequence of prenatal testing where the fetus has a disability). In chapter four, I will then go on to discuss the nature of disability and harm, particularly in relation to the harm to one's interests that can only really be evaluated by the autonomous individual themselves. This will lead on to chapter five, where I challenge the arguments that claim prenatal testing should not be permitted as it discriminates against those with disabilities. I will look at the arguments in favour of and against the claims that reproductive autonomy makes prenatal diagnosis morally acceptable.

My arguments are based on the premises that, firstly, autonomy in respect to making decisions regarding one's own life is of utmost importance and, secondly, that decisions regarding reproduction and having children are of such profound importance to an

individual.¹ As such, reproductive autonomy should be afforded the same degree of respect as autonomy concerning other decisions, for example and probably of most relevance, those relating to decisions regarding healthcare and medical treatment.² I will also look at the concerns that are raised in relation to external pressures that are said to be applied to couples when considering prenatal testing, and the limitations that are placed on autonomy particularly in reproductive medicine due to clinicians being the final arbitrators with regards to late termination and the concerns that these limitations raise. I argue, however, that rather than these concerns be a reason to discourage prenatal testing, they highlight the need for deliberative discussion between prospective parents and the healthcare team, which the clinical geneticist should be heavily involved with, to ensure that the autonomy of prospective parents is respected and that clinicians not only consider the interests of the fetus, but also the wider family.

3.2 Autonomy as an overriding principle

The term ‘autonomy’ is derived from the Greek word *auto* meaning ‘self’ and *nomos* meaning ‘law’ or ‘rule’. Therefore ‘autonomy’ literally means ‘self-rule’. In biomedical ethics this is the common understanding of autonomy,³ however, on reviewing the literature there appears to be no consensus on the precise meaning that the word is intended to convey. As a consequence, literature specifically relating to autonomy tends to cite several of the different interpretations of the word used by philosophers.⁴

¹ Glover J (2006) *Choosing Children: the ethical dilemmas of genetic intervention*, Oxford: Clarendon Press, p 37

² It is beyond the scope of my thesis to consider the arguments in relation to genetic enhancement and reproductive autonomy, where parents wish to make choices to enhance the attributes of their future children.

³ Varelius J (2006) ‘The value of autonomy in medical ethics’, *Medicine, Health Care and Philosophy* **9**, pp 377-388

⁴ Dworkin G (1988) *The Theory and Practice of Autonomy*, Cambridge University Press, pp 5-6

Although the founding of the concept of autonomy relates back to ancient Greek philosophy, Kant developed the idea of ‘moral autonomy’ with respect to having authority of one’s own actions.⁵ Kant put forward the idea that rather than people being governed by factors external to their control, such as emotional responses to the world or decisions made by others, such as by political or religious leaders or society, which he referred to as ‘heteronomy’, we should abide by our own self-imposed laws, which he called ‘autonomy’.

Kant argued that it was possible to develop a consistent moral system using reason alone, and that people would realise that moral laws existed which all rational beings had to obey in a manner which they could work out for themselves what was right or wrong through appeal to a consistent, necessary principle of rational thought. He called this basic principle ‘The Categorical Imperative’, which he intended to be the basis of rules governing our moral conduct, as it would provide a rational basis for determining any action-guiding rule that would hold true in all circumstances. This is, for Kant, the supreme principle of morality. The Categorical Imperative has three different formulations which Kant believes all amount to the same thing. The first formulation, often that which is most referred to, is as follows:

First formulation (The Formula of Universal Law): “Act only on that maxim through which you can at the same time will that it should become a universal law [of nature].”

This means that in order to determine what we should and shouldn’t do; we subject maxims to the Categorical Imperative by asking whether we could rationally will that the maxim be universal. These maxims are the principles of reason that a particular individual has for performing a certain action. An example of where this might be applied to determine an action would be where a person asks themselves ‘should I save that child who is about to run into the traffic?’ A universal law may then be generated from a maxim by asking whether

⁵ Kant I (1996) *The Cambridge edition of the works of Immanuel Kant: Practical Philosophy*, Edited and translated by Mary Gregor, Cambridge University Press, pp 37-39

all rational people should do the same in similar circumstances. If the maxim can rationally be made universal (“Everyone should always try to save children from running into traffic”) then it imposes a moral duty on us to act according to it. By adhering to this approach, all individuals in a community would provide action guiding principles in their own right rather than simply follow laws and this, according to Kant, means that they can be respected as ends in themselves. It is important to know what the maxim is for an action as the same action could be done for very different reasons. It is the intention behind the action that allows the only unconditional good to be identified and for a person to abide by their duty simply for duty’s sake.

Kant described a second formulation of the Categorical Imperative which relates to treating others as an ‘end in itself’ and not merely as a ‘means’. This recognises that a person’s inherent value does not depend on anything else that someone might consider valuable, for example, whether they enjoy their life or make other people’s lives better. Instead, it means that we should not treat someone simply as a means to satisfying our own projects and desires, but must remember that they have ends or ‘goals’ of their own too. They exist so they have value and are not there for the benefit of others. Kant, however, excluded emotions, feelings, habits and other non-intellectual factors from the decision making process and relied upon our ability to determine rationally what it is to act morally, thus referring to this as ‘moral autonomy’. From Kant’s perspective, therefore, moral autonomy included freedom and responsibility where individuals submit to self-imposed laws, rather than being subject to the will of another.⁶

John Stuart Mill, however, emphasised the importance of individuality and the importance of emotions over reason and the development of a unique self.⁷ Rather than autonomy being

⁶ Wolff PR (1970) *In Defense of Anarchism*, New York: Harper & Row, p 14

⁷ Mill SJ (1956) *On Liberty*, Indianapolis and New York: The Liberal Arts Press, (Originally published 1859) pp 103-105 (Gutenberg.org e-book as cited on 11/12/2013)

influenced by moral motivation it was seen as an expression of one's self and allowing the development of an individual identity. The possession of this autonomy brings with it certain moral obligations notably to respect autonomous decisions of others, which I will discuss further in section 3.5.

Dworkin offers a theory of autonomy rather than simply specifying a set of necessary and sufficient conditions to form a definition.⁸ This aims to offer a more solid specification of the general concept of autonomy in a way that will encompass its importance as a political, moral and social ideal. Dworkin offers an account of autonomy which applies to people leading lives of a certain quality. He is interested in 'what it means to be an autonomous person, to have a certain capacity and exercise it'.⁹ Autonomous persons are motivated by principles, desires and goals which are their own. Self-rule is therefore linked to the ideas of self-creation and self-authorship. He goes on to talk of autonomous people as defining their own nature, giving meaning and coherence to their lives and taking responsibility for the kind of people they are. In this way autonomous people control the formation of their own character, values and beliefs and then structure their lives accordingly. Autonomy is an ideal of character, rather than it being a feature of acts or choices.¹⁰ He explains that he is not attempting to analyse the notion of autonomous acts themselves, but of what it means to be an autonomous person and to have a certain capacity and to exercise it.¹¹

Contemporary philosophers have also contributed to the literature with regards to what constitutes autonomy. John Harris describes autonomy as follows:

⁸ Dworkin G (1988) *The theory and practice of autonomy*, Cambridge University Press, p 7

⁹ Dworkin G (1988) *The theory and practice of autonomy*, Cambridge University Press, p 20

¹⁰ Dworkin G (1989) 'The concept of Autonomy' in Christman J (ed) *The Inner Citadel: Essays on Individual Autonomy*, Oxford University Press, p 26

¹¹ Dworkin G (1988) *The theory and practice of autonomy*, Cambridge University Press, pp 19-20

“Autonomy is, strictly speaking ‘self-government’, and people are said to be autonomous to the extent to which they are able to control their lives, and to some extent their destiny, by the exercise of their own faculties.”¹²

Similarly, Raanan Gillon refers to autonomy as:

“...(literally, self rule) is, in summary, the capacity to think, decide and act on the basis of such thought and decision freely and independently and without, as it says in the British passport, let or hindrance.”¹³

My thesis pertains to women and couples who have capacity and these definitions assume that the subject has the mental capacity to make decisions that meet their own needs and interests. It is not necessary for my thesis, therefore, to discuss in any detail those who lack capacity to make certain decisions for themselves. These individuals will to some extent have decisions made on their behalf in what is hoped to be their best interests. This element of autonomy and decision-making is reflected in the definition provided by Beauchamp and Childress:

“The autonomous individual freely acts in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets its policies. A person of diminished autonomy, by contrast, is in at least some respect controlled by others or incapable of deliberating or acting on the basis of his or her desires and plans.”¹⁴

¹² Harris J (1991) *The Value of Life: An introduction to Medical Ethics*, London: Routledge & Kegan Paul, p 195

¹³ Gillon R (2002) *Philosophical Medical Ethics*, Chichester: John Wiley & Sons, p 60

¹⁴ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p58

This definition acknowledges that others, for example parents and other relatives, may assist with decision making based on what they know to be the interests of the person before they gained or lost capacity. This is relevant to my thesis in as far as the fetus is not in a position to make decisions for itself. Decisions that are made during pregnancy may affect the life of the child that is eventually born and depending on what is decided, this may limit the choices that person can later make for himself or herself.

What these definitions do not mention, however, is that decisions are influenced by the expectation that they are made within the law. A person can obviously autonomously choose to act in an illegal way, but they must be prepared to accept the consequences of this. Dworkin describes higher-order autonomous desires to obey the law so that decisions are restricted to those that are legal, and therefore don't violate one's autonomy. This is also why people can take a principled stance against what they view as unjust laws by not adhering to them.¹⁵

Patients can refuse to have treatment should they so wish even if it is felt not to be in their best interests, providing they have the mental capacity to do so.¹⁶ This is exactly what Mill claimed about autonomy stating 'The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant'.^{17,18} This may arise, for example, when a competent adult who is a Jehovah's witness declines potentially lifesaving blood products. In this case the patient does not refuse medication due to a wish to die but due to their religious convictions. They may consent to other methods of treatment that are available, accepting that these might not be as effective. This differs from a patient

¹⁵ Dworkin G (1988) *The theory and practice of autonomy*, Cambridge University Press, pp 19- 20

¹⁶ General Medical Council (2013) *Personal Beliefs and Medical Practice: Patients who refuse treatment*, GMC: London, paragraph 24

¹⁷ Mill SJ (1956) *On Liberty*, Indianapolis and New York: The Liberal Arts Press, (Originally published 1859) pp 103-105 (Gutenberg.org e-book as cited on 1 February 2016)

¹⁸ Arneson RJ (1980) 'Mill versus Paternalism', *Ethics* **90**(4), pp 470-489

with a life limiting or severe illness, who refuses treatment knowing this may shorten or end their life. This places doctors in a very difficult position but ultimately we allow patients to make these decisions due to the importance that we place on a patient's autonomy and their right to make decisions for themselves.¹⁹

3.3 Personal Autonomy

Personal autonomy can be regarded as the decision-making process which is purely internal to the individual and particular to them. Personal autonomy does not follow any particular set of established values or principles but is consistent with the individual's own values. Personal autonomy should allow meaningful choices to be made by the individual without influence from others, or more relevantly without any limitations, such as inadequate understanding or knowledge.²⁰ Decisions about reproduction, including prenatal testing, are very personal decisions and it is for those individuals who are affected to make reproductive decisions as they know better than anyone what serves their own interests.

The ability to make autonomous decisions is an important aspect of a person's life regardless of the impact that decision may have, or regardless of how that decision is perceived by others.²¹ The ability to make one's own choices is important because it is only that individual who can make the right decision for themselves at that time. For example, a highly intellectual person with ambition and drive would not find life particularly fulfilling or rewarding if a career was chosen for them which did not reflect their intellectual needs. This could have a profound effect on their life, well-being and interests. It is, therefore, important

¹⁹ General Medical Council (2008) *Consent: patients and doctors making decisions together*, GMC: London, paragraph 43

²⁰ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p58

²¹ *Re C* (Adult, refusal of treatment) [1994] 1 All ER 819

to recognise that different individuals have very different needs, and if these needs are not recognised and fulfilled it could cause harm to their interests and have a detrimental effect on the quality of their whole life. This principle could apply to almost any aspect of a person's life, with choices being made by others having lasting and detrimental consequences. This would include placing restrictions on a person's ability to make reproductive decisions, including the decision whether or not to utilise prenatal testing. This highlights the importance of constructive dialogue taking place during the prenatal process between the clinical geneticist and prospective parents so that they can make their own choices. In addition to this, other healthcare professionals involved in the process must also take into account the interests of all of those who will be directly affected by any decisions that are made.

On recognising that people are autonomous individuals and are best placed to consider what action is most appropriate for their own needs to be met, it is important that they are involved in the decision-making processes which affect them and that they have enough information to make informed decisions. Not providing sufficient and appropriate information may result in a person making the wrong or an inferior choice, which is not ultimately in their best interests or does not serve their needs adequately. This could have just as much a detrimental effect as not being in a position to make one's own choices in the first place. A person's ability to consent to something, therefore, depends upon what information they are given and their understanding of it.

For example, assume a person buys a new car and seeks expert advice in order to buy the safest car available to adequately protect their family. The salesman is aware of three cars with varying degrees of safety features. The best is also the most expensive and the salesman makes a judgement that the customer would not want to pay the price for that particular vehicle and therefore informs him only of the two cheaper models. The customer chooses the safest and most expensive out of the two. He is not concerned with cost but with

providing his family the safest vehicle he can. Sadly, the vehicle he has bought is involved in an accident and his family are all killed leaving him as the sole survivor. Had he bought the most expensive vehicle, about which the salesman chose not to inform him, his family would have been spared. Had the customer been aware of this car he would have happily borne the additional expense in order to save his family. However, he could only make his decision based on the information he had been provided with by the salesman and this ultimately meant that he did not make the decision that was right for him, with devastating consequences that will affect the rest of his life from that moment. The point is that not only is it for the individual to decide whether or not they make a particular decision, and whether this is the right one for them, but it is also essential that the individual has the right information so that they can make a valid choice. As explained in section 1.3 of chapter one, I have limited the scope of my thesis in that my arguments only apply where there is certainty as to the presence of disability when prenatal testing is carried out, but have acknowledged the difficulty that can arise where ‘soft markers’ and variants of unknown significance are identified during antenatal testing and genome sequencing. The above analogy will of course only work when considering prenatal testing where the diagnosis is certain, and enough information can be provided about the prognosis for the future child and the disability that may ensue.

Informed consent in clinical practice is generally held to be the key to respecting a patient’s autonomy,²² and the General Medical Council provide extensive guidance to doctors to ensure that, wherever possible, patients are involved in the decisions that are made about their care.²³ Good practice dictates that patients (or parents in the case of children) should be provided with appropriate information to enable them to make a decision about their care

²² O’Neil O (2003) ‘Some limits of informed consent’ *Journal of Medical Ethics* **29**, pp 4-7

²³ General Medical Council (2008) *Consent: patients and doctors making decisions together*, GMC: London, paragraphs 7-27

and any decisions should be free of coercion. Walker²⁴ talks of two elements to consent, one in relation to information that needs to be provided, and another in relation to information that also needs to be understood. He argues that the expectation that all information given to a patient is also understood by them, rather than merely disclosed to them, makes the taking of consent overly onerous for healthcare professionals. He argues that there is some information that is needed in order for a person to make the decision as to whether they are going to consent (C1), for example, to a medical procedure being performed on them, and then other information that is needed in order for a person to make an *informed* choice (C2) about whether or not to consent. Walker states that the obligation to ensure a patient understands the information only applies in the case of C1. The patient needs to understand what procedure is being carried out and what this will entail. If the patient does not understand what they are consenting to any consent that they do give will be defective. As part of the information provided to the patient in C1, it would seem appropriate to ensure that the patient is aware of the risks of the procedure. In the case of prenatal testing the patient will need to understand and appreciate the possibility of an unfavourable result and what this may mean to them and their future child.

Walker argues that it is not always wrong to do something to someone without their consent if they are to benefit from it. Establishing a benefit may be relatively straightforward in the case of a surgical procedure that will save the life of the patient or enhance their quality of life. However, whether or not something is of benefit to a patient is subjective and this is even more so when considering a person or couple who are contemplating prenatal testing. Some couples may receive an unfavourable result in a way that makes them feel empowered to take some control, whereas others may prefer not to have this information about their pregnancy and deal with any consequences if and when the need arises. For this reason informed consent is particularly important in prenatal testing because whether or not the

²⁴ Walker T (2012) 'Informed consent and the Requirement to Ensure Understanding' *Journal of Applied Philosophy* 29(1), pp 50-62

individual benefits from it cannot be presumed. Making such a decision on behalf of a patient, no matter how well intentioned, could harm their interests and have implications for the decisions they would then have to make in the future.

Clinicians are under an obligation to disclose adequate amounts of information to patients, although there is no consensus as what an adequate amount is.²⁵ Manson and O’Neil argue that informed consent requires clinicians to disclose as much information as possible to patients as this allows them to make self-governed decisions about their care.²⁶ However, it is questionable as to whether an autonomous decision can be made when a person is provided with as much information as possible.²⁷ Providing people with too much information may overwhelm them and make it difficult for them to process and comprehend, thus undermining their ability to make an autonomous decision.²⁸ This highlights the importance of clinicians involved in prenatal care engaging with prospective parents so that appropriate amounts of information are given to them in a form that they can understand, and so that they have the opportunity to ask questions in order to address their specific concerns in relation to how they personally will be affected by the consequences of having a disabled child.

3.4 Social and relational autonomy

I have talked about moral autonomy, which refers to a person’s ability to formulate and follow moral laws, and personal autonomy which deals with a person’s ability to make self-governed

²⁵ Lomelino PJ (2015) *Community, Autonomy and Informed Consent*, Cambridge Scholars Publishing, p 98

²⁶ Manson NC, O’Neill O (2007) *Rethinking Informed Consent in Bioethics*, Cambridge University Press, pp 36-37

²⁷ Manson NC, O’Neill O (2007) *Rethinking Informed Consent in Bioethics*, Cambridge University Press, pp 36-37

²⁸ Mossman J (2014) ‘How much information is too much for patients?’ *Journal of Risk Research*, Nov 18, pp 1-4

choices as to the way they act so that it contributes to their overall well-being. However, these concepts of autonomy may not truly reflect what happens in clinical practice, particularly for the clinical geneticist where the patient, as well as being an individual, is also a prospective parent and possibly already a parent to other children, in addition to having other family members such as a partner, with which she interacts. Not only this, she is also part of a society and possibly a particular religion or culture. One purpose of my thesis is that it aims not only to consider the clinical features and prognosis of a fetus that is affected by an abnormality which may lead to a disability, but also the effect this will have in the context of the wider family. In acknowledging this it is important to also recognise that this may influence the decisions that the pregnant patient is likely to make.

Walter and Ross refer to the 'in-control agent' model of autonomy which assumes that a patient will avoid the influence of others or emotional persuasion during decision-making.²⁹ In this case the role of the clinician is viewed as an expert whose role it is to provide information to allow individual patients to make their own healthcare decisions.

An alternative model, however, is that of relational autonomy which acknowledges the role of others in the decision-making process, including the clinician. This model involves engaging with the patient's emotional experiences.³⁰ Rather than accepting that choices are based on individual autonomy it views the person making the decision as a relational being that is part of and influenced by other interconnected relationships and, therefore, their values and interests also depend on their social environment.³¹ This relational view doesn't see us as autonomous individuals like those referred to in the in-control model but as heirs to those who have formed us or cared for us, with personalities being formed by relationships to

²⁹ Walter JK, Ross LF (2014) 'Relational Autonomy: Moving beyond the limits of isolated individualism' *Pediatrics* **133**(1), pp 16-23

³⁰ Walter JK, Ross LF (2014) 'Relational Autonomy: Moving beyond the limits of isolated individualism' *Pediatrics* **133**(1), pp 16-23

³¹ Mackenzie C, Stoljar N (eds) (2000) *Relational Autonomy: Feminist perspective on autonomy, agency, and the social self*, Oxford University Press, p 4

others.³² This model regards an individual's interest and beliefs as things that are constantly changing due to their relationships with others as well as their traditions and even history.³³ It is important for clinicians involved in the care of pregnant women to recognise this because as well as influencing the woman's decisions, it may also influence the way in which information is given and the kind of choices that are available to the patient. In the prenatal setting it is not uncommon for women to include their partners and other family members in their decision making and this model of autonomy does not conflict with the patient making an autonomous decision. They are not abdicating their autonomy by the fact that they are asking for advice and opinion from others.³⁴

There are those, however, who express concern about relational autonomy in that women accept prenatal screening or testing because it is something that is promoted by the society that they live in. For example, Vassy argues that prenatal screening has been developed by the medical profession for its own purposes, rather than the demand for it by women.³⁵ She argues that women are tested without much regard for informed consent and screening becomes normalised as part of routine antenatal care and, therefore, this screening is not supported by the value of autonomy.³⁶ As mentioned in chapter one, my thesis is limited to prenatal diagnostic testing rather than standard antenatal screening, however, this does highlight how a woman's relationship with the society in which she lives may impact on her decisions and limit her autonomy. It also emphasises the importance of engagement between

³² Baier A (1985) *Postures of the Mind: Essays on Mind and Morals*, Minneapolis, MN: University of Minnesota Press, p 84

³³ Walter JK, Ross LF (2014) 'Relational Autonomy: Moving beyond the limits of isolated individualism' *Pediatrics* **133**(1), pp 16-23

³⁴ Walter JK, Ross LF (2014) 'Relational Autonomy: Moving beyond the limits of isolated individualism' *Pediatrics* **133**(1), pp 16-23

³⁵ Vassy C (2006) 'From a genetic innovation to mass health programmes: The diffusion of Down's Syndrome prenatal screening and diagnostic techniques in France' *Social Science & Medicine* **63**, pp 2041-2051

³⁶ Vassy C (2006) 'From a genetic innovation to mass health programmes: The diffusion of Down's Syndrome prenatal screening and diagnostic techniques in France' *Social Science & Medicine* **63**, pp 2041-2051

clinicians and prospective parents to ensure that both parties think carefully about the decisions they make and the consequences these may have.

Relational autonomy recognises that emotional responses are just as important as rational ones. When considering relational autonomy in the context of prenatal diagnosis, as well as clinicians providing factual information about the clinical condition of the fetus and the prognosis parents should expect, they should ensure that couples engage in emotional dialogue about the implications their future child's disability may have on not only the child, but on them and other family members. Couples should be encouraged to look beyond the clinical information that they receive and acknowledge the emotional aspects of the decisions that they make. Interestingly, where a child is not going to reach adulthood and therefore will never become an autonomous adult, Walter and Ross suggest that it may be appropriate for a child's interests to be given less importance when their decisions conflict with that of the interests of the family as a whole.³⁷ What is also important, however, is that clinicians also take into account the emotional impact decisions have on a family particularly when it is the clinicians who are currently the ones ultimately having to justify whether a late termination of pregnancy due to disability can take place. Taking into account only the clinical facts and prognosis for the future child may place limits on those justifications.

3.5 Respecting autonomy

It is widely accepted, therefore, that respect for autonomy is a vital principle in medical ethics³⁸ and it is generally accepted that one ought to respect and not interfere with autonomous decisions. There are compelling ethical reasons why respect of autonomy is of

³⁷ Walter JK, Ross LF (2014) 'Relational Autonomy: Moving beyond the limits of isolated individualism' *Pediatrics* **133**(1), pp 16-23

³⁸ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p57

such importance.^{39,40,41} Respecting autonomy in the healthcare arena allows patients to make their own decisions regarding the treatment or management they should receive. It allows them to decline treatment. Autonomy is such an important principle in biomedical ethics due to the recognition that competent people want to be able to live their own lives as they see fit and not have decisions made for them by others, no matter how well meaning they may be.

Gillon⁴² goes as far as to say that autonomy is of such importance that respect for it should outweigh the importance of the three other principles in this particular approach to medical ethics, namely beneficence, non-maleficence and justice. He argues that autonomy is morally very precious and should not only be respected but actively encouraged.⁴³ Gillon argues that beneficence and non-maleficence both require respect for autonomy because what are benefits and harms vary from person to person as well as between cultures. It is therefore for the individual to decide for themselves what will promote or harm their own interests and reflects the need for them to make their own autonomous choices. This may happen, for example, where a patient chooses not to have treatment for a condition that others, including their family and healthcare professionals, may feel is in their best interests.

Holm also outlines some of the reasons why respect for autonomy is important:

³⁹ Gillon R (2003) 'Ethics needs principles-four can encompass the rest-and respect for autonomy should be 'first amongst equals'', *Journal of Medical Ethics* **29**, pp 307-312

⁴⁰ Callahan D (2003) 'Principlism and communitarianism', *Journal of Medical Ethics* **29**, pp 287-291

⁴¹ Entwistle VA, Carter SM, McCaffery K (2010) 'Supporting patient autonomy: The importance of clinician-patient relationships', *Journal of General Internal Medicine* **25**(7), pp 741-745

⁴² Gillon R (2003) 'Ethics needs principles-four can encompass the rest-and respect for autonomy should be 'first amongst equals'', *Journal of Medical Ethics* **29**, pp 307-312

⁴³ Gillon R (2003) 'Ethics needs principles-four can encompass the rest-and respect for autonomy should be 'first amongst equals'', *Journal of Medical Ethics* **29**, pp 307-312

- “1. The first line of argument sees autonomy as the basis for moral standing, and thereby the necessary and perhaps sufficient condition for the ascription of right. [...] A common form of this argument states that we have a basic interest in shaping our own life, and that being autonomous and having our autonomy respected are necessary conditions for being able to fulfil this interest.

2. The second line of argument is basically consequentialist [...] Autonomy is here seen as a good thing, either in and of itself [...] or more frequently because being autonomous promotes the creation of good things in the life of the person in question. Autonomy is thus valuable primarily as a means to the creation of that which is intrinsically valuable (preference satisfaction, pleasure etc).

3. The third line of argument proceeds from the premise that we are all moral strangers. Each person has his own way of life and own moral principles. Persons have no right to impose their way of life on others, and have no right to limit the expression of other people’s way of living as long as it is not harmful to anybody. We cannot say whether autonomy is itself valuable (because that would be to adopt the view of one specific moral community), but we have to respect the choices of others as a procedural constraint.”⁴⁴

In the first point, Holm supports the view that being able to make our own decisions enables us to protect our interests. With regard to reproduction these interests may include having a child without a disability and the consequences this may have for the child itself, the

⁴⁴ Holm S (1998) ‘Autonomy’ in Chadwick R (ed) *Encyclopedia of Applied Ethics, Volume 1*, San Diego: Academic Press, p 270 as cited in University of Manchester, MA Health Care Ethics & Law distance learning materials 2003

parents and siblings. These interests can be harmed if our autonomy is not respected. I will consider the concept of harm in Chapter 4 (sections 4.2).

The general availability of prenatal testing may be regarded as reassuring for prospective parents, particularly those who have a known risk of having a child with a severely disabling condition. The fact that they can have testing and, therefore, have a choice as to whether they have a child who is affected by the condition increases their choices and puts them in a better position to have the family they desire. Just like the reassurance of knowing that there are treatments for medical conditions the availability of prenatal testing can promote an overall good for prospective parents. This is reflected in Holm's second line of argument.

Holm's final point is particularly important. It acknowledges that not all individuals share the same desires, beliefs and interests and, therefore, it is not acceptable to force others to make choices that are not appropriate for them. We do not all aspire to the same outcomes for our lives and our moral beliefs are not the same. It is the difference in these moral beliefs that give rise to the debate about prenatal testing and abortion and Holm's third point reflects the fact that prospective parents do have different views on pregnancy, antenatal intervention, delivery and parenthood, including the type of children they wish to raise. This latter point will be the subject of chapter four, when considering the implications of having a child with a disability. It is important to recognise that some parents will deal well with the prospect of having a severely disabled child and will cope admirably with the consequences of this. Others, however, will know from their own personal experiences that the effect on the value of their own life (whether that be due to the direct effect of having a disabled child or whether it be due to them having to indirectly experience the pain and suffering of their child and the affect their disability will have on them) of having a disabled child will be such that they will not want to begin or continue an affected pregnancy if no intervention to prevent or reduce the effects of the impairment can be offered.

Whilst it is generally accepted in healthcare that a competent patient's autonomy should be respected,^{45,46} is this always the case?

3.5.1 Paternalism

I discuss paternalism in this section because where an abnormality is found late in gestation additional justification is needed to terminate the pregnancy. A couple may decide that they do not want to carry on their pregnancy but ultimately this decision will be made by clinicians involved in the termination process. Currently this decision is based on the degree of disability and the prognosis for the future child with very little or no consideration given to the fetus in the context of and to the wider family. Where prospective parents decide they want to terminate a pregnancy late in gestation the medical professionals who ultimately have to justify the procedure may overrule this. More consideration should be given to the autonomous wishes of the parents and where their reasons for opting for this outcome relate to the harm that having a disabled child may cause to their interests, this should be taken into account alongside the clinical implications of the disability identified in the fetus.

One influential definition of paternalism is that it

‘...is the intentional overriding of one person's known preferences or actions by another person, where the person who overrides justifies the action by the goal of benefiting or avoiding harm to the person whose preferences or actions are overridden.’⁴⁷

⁴⁵ Tweeddale MG (2002) ‘Grasping the nettle – what to do when patients withdraw their consent for treatment: (a clinical perspective on the case of Ms B)’, *Journal of Medical Ethics* **28**, pp 236-237

⁴⁶ Brock DW, Sartman SA (1990) ‘When competent patient make irrational choices’, *New England Journal of Medicine* **322**, pp 1595-1599

⁴⁷ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p178

There are those who argue against autonomy and consider the acceptability of paternalistic intervention.⁴⁸ Paternalism, therefore, is the interference of an individual's (such as a patient's) decision making by a third party (for example a doctor) and is motivated by that third party thinking they know what is best for the patient and in an attempt to avoid them any harm. Paternalism arises in many aspects of our lives, for example, the mandatory wearing of seatbelts by the enacting of legislation. I am going to concentrate my discussion on paternalism specifically within the healthcare field. Doctors may make decisions which are paternalistic in order to spare patients or relatives feelings, for example, by minimising the suffering that a loved one may have suffered before they died. When obtaining consent from a patient for treatment the doctor may restrict a patient's decision by only providing information about one particular treatment over others, because the doctor has a preference for this or feels the patient would be better off having that treatment. Doctors generally are in a position of having greater knowledge when they speak to patients and, therefore, there is a potential for patients to be influenced by the information they are given. Even if a patient specifically asks, there is no guarantee that the doctor will give them additional information and as they may not fully understand the technicalities of what they are being told a patient's decision may not be truly autonomous.

Throughout the history of medical ethics beneficence and non-maleficence have been important ethical principles both of which provide a basis on which paternalism can be justified.⁴⁹ In the past paternalism was prominent in healthcare with doctors having an attitude of knowing what was best for their patients and patients deferring to the superior knowledge of their physician.⁵⁰ This led to the information given to patients about their own

⁴⁸ Conly S (2012) *Against Autonomy: Justifying Coercive Paternalism*, Cambridge University Press, p 3

⁴⁹ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p179

⁵⁰ Henderson LJ (1935) 'Physician and Patient as a Social System', *New England Journal of Medicine* **212**, pp 819-823

health being limited to what the doctor thought they ought to know and the avoidance of providing them with information that the doctor felt would be harmful. Although paternalism is not generally regarded as best practice in medicine now there are different accounts of paternalism, some of which may be more acceptable than others. Feinberg talked of strong and weak paternalism (later referred to as hard and soft).⁵¹ Weak paternalism arises when the doctor interferes with a person's decision making on the basis of beneficence or non-maleficence and to protect the person from themselves. Feinberg referred to a patient's 'non-autonomous actions'⁵² due to the patient not being adequately informed. This might arise where a patient is severely depressed preventing rational thought and decision-making.⁵³ This occurs therefore where the patient's mental capacity is affected in some way and the doctor acts in what they believe are in the patient's best interests. This type of paternalism is generally accepted in medical decision-making and this is now enshrined in the Mental Capacity Act 2005,⁵⁴ and even some opponents of paternalism do not object to this.⁵⁵ Feinberg argues that what we think of as 'weak paternalism' is not really paternalism at all.⁵⁶ The subject is not in a position to weigh up the information and make an appropriate decision for himself and, therefore, the decision is taken out of his hands but is made in his best interests.

Strong paternalism arises where the doctor intervenes in the patient's decision-making despite the fact that the patient is competent to make his own voluntary and autonomous decisions, although these may not accord with the doctor's version of what is sensible and rational.⁵⁷ In these cases the doctor may choose to limit the amount of information given to

⁵¹ Feinberg J (1986) *Harm to Self* (volume 3) of *The Moral Limits of the Criminal Law*, New York: Oxford University Press, p 4

⁵² Feinberg J (1971) 'Legal paternalism', *Canadian Journal of Philosophy* 1, pp 105-124

⁵³ Feinberg J (1971) 'Legal paternalism', *Canadian Journal of Philosophy* 1, pp 105-124

⁵⁴ Mental Capacity Act 2005, HMSO: London, section 4

⁵⁵ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p182

⁵⁶ Feinberg J (1986) *Harm to Self* (volume 3) of *The Moral Limits of the Criminal Law*, New York: Oxford University Press, p 14

⁵⁷ Feinberg J (1971) 'Legal paternalism', *Canadian Journal of Philosophy* 1, pp 105-124

the patient in order to influence their decisions or even override the patient's choice. It is strong paternalism which creates the most controversy as this involves overriding the choices of a competent person's autonomous decisions, bearing in mind that they should be in a position to know what is best for them and best able to take into account all of their own circumstances and values. In the prenatal setting this may occur where a woman wants to end her pregnancy due to a disability but the doctors who ultimately make the decision as to whether this is justified disagree.

There may be situations where a doctor acts paternalistically toward a patient in what they believe to be in their best interests and this may be justified even though the patient is competent.⁵⁸ A doctor may decide not to give all of the information they have about a 'bad news' diagnosis to a patient, preferring to provide this piece-meal in order to help the patient come to terms with the news. Similarly, telling a patient who has been badly injured at the scene of an accident and unlikely to survive that help is on its way and everything will be all right may be seen as the kindest thing to do under the circumstances, rather than telling them they will die. There are likely to be many scenarios where doctors do act paternalistically towards patients because the doctor has made the decision that this is best for them. I agree that this approach can be appropriate under certain circumstances but should a competent patient specifically ask searching questions or ask for more information they should not be denied this, as this may prevent them from making an autonomous decision or may limit decisions they make later.

There has to be a balance between the principles of autonomy, beneficence and non-maleficence when communicating with patients and seeking their consent. If a patient does not have the competence to make a particular decision for themselves at the time it needs to be made it is appropriate for those with knowledge of their illness and the available treatment,

⁵⁸ Sokol DK (2007) 'Can deceiving patients be morally acceptable?' *British Medical Journal* 334(7601), pp 984-986

and knowledge of the patient (such as carers and close relatives), to make decisions on their behalf in what is believed to be their best interests.

There are also situations where a patient may specifically request a particular treatment which their doctor will refuse. The patient is competent and can understand the risks of undergoing this particular treatment and the reasons for the doctor not recommending it or specifically advising that they do not have it, but wishes to continue regardless. This may occur where a doctor does not believe that the patient will receive any benefit and the treatment is futile or may even cause the patient more harm. Rather than this being active paternalism which occurs where a patient prefers not to have a particular intervention, this is referred to as passive paternalism.⁵⁹ The doctor has made a decision not to allow the patient to receive the treatment they want based on what they believe is in the best interests of the patient. This may be a procedure which is known to be high risk and where a second opinion from a colleague is likely to yield the same opinion. It is well known and accepted that doctors have a professional and moral obligation to act in their patient's best interests, they do not, however, have a professional obligation to comply with a patient's specific wishes if the treatment they are requesting is out with normal medical practice.⁶⁰ Denying a patient treatment for this reason can also be justified on consequentialist grounds and consideration that needs to be given benefit to the population generally. If a form of treatment is futile and will not be of any benefit to the patient, or may even cause further harm to the patient, there is not only the personal cost of this but also other costs. Resources are used in providing the treatment including hospital resources and funds and the time of the medical practitioners and supporting staff involved, in addition to addressing any complications that arise as a result of the treatment. The time and money spent on this futile treatment could have been better spent caring for other patients whose treatment is

⁵⁹ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p191

⁶⁰ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, p191

appropriate and beneficial to them. Respect for autonomy does not mean always giving someone what they want. There may be limits to this, for example, should there be risk of harm to a third party. Freedom and respect do not always imply a positive duty to act, even if they do not always imply a negative duty not to interfere.

3.6 Reproductive autonomy

Decisions that individuals and couples make in relation to reproduction are particularly important. These decisions affect not only the individuals concerned but also their future and present children. The consequences of these reproductive decisions last throughout their lifetime and have a major impact on their interests. It is for this reason that autonomy in relation to reproductive decisions is of particular significance and why the role of the clinical geneticist in supporting prospective parents is so important.

Beginning a family is a decision that has fundamental importance and is one of the most important and significant decisions an individual can make, with far reaching consequences. Even before consideration is made in relation to the new life that will be brought into the world there is the decision as to when to start a family and with whom, as well as the pregnancy to contend with and the limitations this might place on a woman and her partner. In addition to this is antenatal care and decisions in relation to information that the couple might want to obtain during the pregnancy, decisions about the mode and location of the birth and how many children to have. This is only the tip of the iceberg as the decisions that are ultimately made will then impact on virtually every aspect of the ongoing lives of the parents, siblings and future child. As well as these considerations of course is the decision whether or not to have prenatal testing and the consequences that this may lead to.

Purdy describes reproductive autonomy as:

“...the power to decide when, if at all, to have children; also, many – but not all – of the choices relevant to reproduction.”⁶¹

Purdy does not tell us what choices relevant to reproduction fall within the scope of this description of reproductive autonomy. Similarly, Robertson, although using the term ‘procreative liberty’, refers to this as ‘freedom in activities and choices related to procreation’ and recognises that this does not specify which activities are relevant.⁶² I, therefore, prefer the term ‘reproductive freedom’ where reference is specifically made to individuals taking advantage of prenatal techniques if they wish.⁶³ The moral basis of this is autonomy and self-determination,⁶⁴ believing that an individual’s decision to employ genetic information to assist with reproductive decisions should not be interfered with, where preventing individuals from obtaining information relevant to them would be limiting their reproductive freedom.⁶⁵ Buchanan et al argue that reproductive freedom should include the choice of what kind of children to have, but acknowledge that this is one of the most controversial components of this freedom and will no doubt become more so as the knowledge of human genetics increases along with improved genetic and medical techniques.⁶⁶

Reproduction and issues surrounding it are clearly and without argument very sensitive and emotive and it is generally accepted that it is up to the individual or couple to make their own

⁶¹ Purdy L (2006) ‘Women’s reproductive autonomy: medicalisation and beyond’, *Journal of Medical Ethics* **32**, pp 287-291

⁶² Robertson JA (1986) ‘Embryos, Families and Procreative Liberty: The Legal Structure of the New Reproduction’, *Southern California Law Review* **59**, p 955

⁶³ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*, Cambridge University Press. p 210

⁶⁴ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*, Cambridge University Press. p 214

⁶⁵ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*, Cambridge University Press. p 208

⁶⁶ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*, Cambridge University Press. p 209

decisions with respect to starting a family. It is acknowledged that reproductive freedom makes an important contribution to an individual's well-being and their welfare.⁶⁷ The decision whether or not to have a family has a major impact on not only the individual's life, but also on the lives of those close to them. As such, reproductive decisions should be afforded the same degree of autonomy as other decisions which have such a significant impact on a person's life, with competent individuals being the best judges of what reproductive choices will best promote their happiness.⁶⁸

However, as I have discussed in section 3.2, the extent to which people can make autonomous choices can be limited. This may be, for example, where third parties may be harmed or where acts would be outside the law. Reproductive autonomy is no exception. An individual's moral view will influence their decision and legal limitations may restrict the decision they are able to make taking into account their statutory obligations (set out in the Abortion Act⁶⁹ and Human Fertilisation and Embryology Act).⁷⁰ Reproductive autonomy is therefore restricted by current legislation but it is important to note that it is also limited by the actions and views of clinicians looking after the mother and fetus. Prospective mothers can choose to have prenatal testing but whether or not they can terminate a pregnancy late in gestation due to fetal abnormality depends on the agreement of the doctors looking after her and her fetus, who not only have to abide by the law but who may also have their own moral views about the appropriateness of termination for that particular fetus. This is something I will explore further in chapter six.

One argument against the view that reproductive choice is of such significance is that respecting an individual's autonomy, for example, when they choose not to have lifesaving

⁶⁷ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*, Cambridge University Press. p 214

⁶⁸ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*, Cambridge University Press. p 219

⁶⁹ Abortion Act 1967, HMSO: London

⁷⁰ Human Fertilisation and Embryology Act (HFEA) 1990, HMSO: London

surgery, is that it will only be their own life and interests that could be potentially lost or damaged.⁷¹ Affording the same degree of respect to autonomous decisions for reproductive reasons may result in the loss of life, not of the individual making the decision, but of the fetus they are carrying and the future person they will become. However, allowing competent adults to make autonomous decisions regarding the way in which they live their lives does affect the lives of others and can have a detrimental effect on another person's quality of life and may, therefore, also harm the interests of others. Despite this autonomy of the individual still prevails. If a person chooses to smoke they detrimentally affect their own health. This will in turn have a detrimental effect on the quality of life of their loved ones who may be dependent on them and will also witness their suffering and possible demise, not to mention the effects of passive smoking on their own health. Similarly, if a person chooses not to accept lifesaving or life changing treatment this will not only impact on their own quality of life but also on that of others dependant on them or close to them. In this way, therefore, allowing competent adults to make autonomous decisions is comparable to those wishing to make such decisions about their reproductive status and should be treated in exactly the same way, both deserving of the same degree of respect.

3.7 Autonomy and prenatal testing

Priaultx discusses the impact of the genetic revolution on reproduction and the impact this has had on parenthood.⁷² Prospective parents are now not only in a position to consider how many children they wish to have but also what kind of children to have. Whilst this could form the basis of a discussion on genetic enhancement and choosing what 'normal'

⁷¹ Beauchamp TL & Childress JF (2001) *Principles of Biomedical Ethic* (5th ed), Oxford University Press, p 126

⁷² Priaultx N (2007) 'Beyond health and disability: Rethinking the 'foetal abnormality' ground in abortion law' in Horsey K, Biggs H (eds) *Human Fertilisation and Embryology: Reproducing Regulation*, London & New York, Routledge Cavendish, pp 205-229

characteristics a parent would wish their child to have, I will discuss it only in the context of choosing not to have a child with a severe disabling condition for which testing is available, either by prenatal genetic diagnosis or other antenatal tests such as ultrasound scanning. As Priaulx points out, there are those who argue that this is promoted by the avoidance of paying out extensive costs in caring for those with disabilities and others who argue that it confirms a public hostility to those with disabilities.⁷³ I will discuss the latter issue in chapter five.

Glover discusses the decisions that parents can make to promote the chances of having a healthy child. This may involve choosing a partner known not to carry the same recessive gene mutation, such as Thalassaemia, or choosing not to smoke in pregnancy.⁷⁴ It is normal practice in some populations for individuals to have genetic screening for conditions that are prevalent in their community before they find a suitable partner to marry and start a family with, in order to minimise the risk of having a child with an autosomal recessive condition. One example of this would be screening for Tay Sachs disease carriers in the Ashkenazi Jewish population.

It is to be presumed that the child whose mother does not smoke will be grateful for this and for the fact that they have not suffered as a consequence of her actions during pregnancy. However, this relates to action that prevents the disability from developing rather than eliminating disability that is already present. Whilst it is presumably preferable to be born without a disability, and hence decisions to act in such a way before or during pregnancy which prevents the development of a disability is to be encouraged, it does not necessarily follow that it is preferable to not be born at all rather than be born with a disability. This again is an issue I will consider in chapter four. The arguments against prenatal testing,

⁷³ Barnes C, Mercer G, Shakespeare T (1999) *Exploring Disability*, Oxford: Polity Press, p 122

⁷⁴ Glover J (2006) *Choosing children: the ethical dilemmas of genetic intervention*, Oxford: Clarendon Press, p42

therefore, are not related to the prevention of disability *per se*, but in terminating a pregnancy and preventing the continued development of the fetus because of its disability or abnormality.

It would appear, therefore, to be acceptable, and is indeed encouraged, to prevent disability proactively, for example, by taking folic acid during the first trimester of pregnancy and leading a healthy life style and by the use of seat belts in cars. As I go on to argue in chapter five, this does not lead to criticism regarding discrimination against those with disabilities and it does not lead to claims that in acting to prevent such disabilities society will withdraw support for those already living with disabilities. The purpose of proactively preventing disability once a pregnancy has started prevents harm to individuals. Prenatal testing based on reproductive autonomy and consideration of those individuals directly involved does not disparage those other individuals who are already living with disability or reduce their value in society.

Whilst reproductive decisions may ultimately result in a termination of a pregnancy affected by a severely disabling condition and the end of the life of the fetus, the decisions surrounding reproductive autonomy have such a profound effect on the life of not only the individual carrying the fetus but other members of their family, that they should receive as much respect as decisions made in relation to other matters which have serious consequences, such as treatment decisions. It is important, however, to clarify that whilst I have stated that autonomous decisions in relation to reproduction should be respected due to the innate importance of such decisions and also due to the familial consequences, this does not justify killing another human being, for example, a severely disabled individual whose existence also has consequences for his or her family. Termination of pregnancy, particularly in the later stages of gestation, does require moral justification, however, this justification is less demanding than that for a living human being with full moral status. I have discussed my arguments in relation to the moral status of the fetus in chapter two, and

how this is lower than that of a human being who has been born. Termination of pregnancy is not a morally negligible decision and my arguments about the importance of reproductive autonomy provide sufficient moral justification.

From the point of view of prenatal diagnosis, those who are seeking it often have first-hand knowledge of the condition for which they require testing. They may have had a child previously who was affected and are, therefore, fully aware of the implications this may have for themselves, their other children and family members and for the future child. They will be in the best position to decide whether or not they are able to bring to life a person with such a condition and to be able to cope with all of the implications this would hold for them. They may have an awareness of the degree of suffering which the child may endure due to their previous experiences. Just as young children cannot make autonomous decisions about issues of significant importance for themselves the fetus cannot make decisions and, therefore, in both cases decisions are made on their behalf. However, that decision will not only be influenced by what is felt to be in the interests of the fetus but also the effect that having a severely disabled child will have on the mother, father and other members of the family will be taken into account. These decisions are likely to be influenced by the parent's ability to care for a child with a significant disability and also the effect on the lives of other children, as their quality of life will also be affected. Non-maleficence is an important principle here with respect to preventing harm to those already born (the family) but for the fetus the disability is already present and so continuing the pregnancy does not cause that particular harm, as that already exists. From the point of view of the fetus it is a case of doing what is thought to be best for it and acting in a beneficial way, even though this may result in the future child never coming to exist.⁷⁵ Allowing those

⁷⁵ I acknowledge that Derek Parfit refers to the non-identify problem where he raises the question about the ability to identify the specific individual that would be the recipient of the harm. He argues that being born cannot harm a person with a disability, as their only other option is non-existence. I have not considered his arguments as my thesis focuses on potential harm in the context of the wider family, not just to the person who will be born with the disability. I argue that

individuals affected to make such decisions allows account to be taken of different people's views and abilities. Some parents may be much better placed emotionally, mentally, financially or otherwise to be able to manage and care for a child with a severe disability and find it a hugely positive and rewarding experience. Sadly, others may not and, therefore, only those individuals who will be directly affected can make an appropriate decision. All of this needs to be taken into account by the clinicians supporting these families and not just the implications the disability will have for the future child.

The decision to terminate such a pregnancy, therefore, may not be based solely on the fact that the resulting child will be disabled in itself but more the additional financial, practical and emotional consequences of this. The majority of terminations are based on such 'social' factors; it just so happens that these factors may have more significance if the fetus is disabled. Whilst financial and practical support may be available emotional support is difficult to provide as the needs of the individual parents and their family are so variable.

For those parents who have not had first-hand experience of caring for a child with such a condition, or who have not witnessed the consequences of the condition, it is clearly important that they are provided with enough information to allow purposeful dialogue to take place so they can make an autonomous decision as to whether they want prenatal testing and if so, what they wish to do based on the results. Useful information can be sought from experienced healthcare professionals who care for people with the relevant condition, from clinical geneticists and counsellors who can provide information about the way in which a condition can be inherited and also from families and carers of children who have been born with and possibly died from the condition in question.⁷⁶ Those who suffer from a serious condition, but one which is compatible with life, may also be in a position to offer advice to

it is not only the future child that clinicians should take into account when justifying decisions about termination of pregnancy but other relevant individuals.

⁷⁶ Asch A (1999) 'Prenatal diagnosis and selective abortion: a challenge to practice and policy', *American Journal of Public Health* **89**(11), pp 1649-1657

prospective parents about the way in which they live their lives. Paediatric specialists can also provide information about the clinical needs of the child and the natural history of the condition their child has. This again is no different from a person making a lifesaving or life changing decision about a serious operation, for which they have no personal knowledge, but have been provided with the information from their healthcare team or from other patients who have suffered from similar condition. Based on this it is recognised that life changing decisions should be made by the individual who is the subject of the decision assuming they have the capacity to do so. Reproductive decisions have a major effect on people's lives and as such are deserving of the same respect.

In order for people to utilise their reproductive autonomy they need to have appropriate information to make a genuinely informed choice⁷⁷ about the risks and benefits of prenatal testing and whether this is right for them. If they chose to have it prenatal testing can provide them with information about the physical and mental health of the fetus. Those prospective parents may be informed by their own past experiences or may need more information provided to them to allow them to decide what action they wish to take.

The availability of prenatal testing promotes parental and reproductive autonomy by providing this information should prospective parents wish to receive it. It is hoped that the genetic counselling and support they receive will then allow them to make their own decisions about the future of their pregnancy. The reproductive autonomy of prospective parents, with regards to late termination of pregnancy, can be limited, however, by the actions and decisions of the healthcare professionals involved in their care.

Under the current law, where late terminations of pregnancy for a substantial risk of severe fetal disability are concerned, two medical practitioners must agree that the termination is

⁷⁷ Walker T (2012) 'Informed consent and the Requirement to ensure understanding', *Journal of Applied Philosophy* 29(1), pp 50-62

appropriate. This not only needs to be in discussion with the healthcare professionals involved but also with the prospective parents. I have already discussed in chapter two (section 2.4) that there are no strict criteria which can be applied with regards to what a severe disability is and, therefore, this decision comes down to the opinion of the medical practitioners, having taken into account the clinical and prognostic nature of the abnormality. Ultimately, therefore, the mother's reproductive autonomy is limited by the fact that it is not her decision as to whether a termination in the later stages of pregnancy can be justified. This, therefore, is a further case of passive paternalism where a procedure or management option is being denied to the patient. However, this differs in that it is not due to consideration of what is in the mother's best interests but what is thought to be in the best interests of the fetus. My conclusion that the fetus has lower moral status than those who have been born, such as the mother and other family members, is obviously very relevant here. The doctors need to consider the mother's wishes and what outcome she is hoping for, and also consider the harm that may occur to the future child and family if the pregnancy were to continue. Just as prospective parents make decisions to avoid harm to their unborn baby, such as ensuring they do not smoke or expose their fetus to other harmful substances to ensure it is not harmed once born, the doctors consider what harm the disability will have on the future child. The doctors need to satisfy themselves that the disability will be severe enough to result in enough pain and suffering to justify preventing the child from being born. This decision, therefore, will be influenced by the doctors' own knowledge and experiences and personal opinion. There are likely to be certain conditions which affect the fetus which medical practitioners working in fetal medicine will accept justify late termination of pregnancy, such as Thanatophoric Dysplasia and Anencephaly, but there will also be anomalies which will be more contentious and that could potentially lead to criminal prosecutions of the doctors making the decision to terminate a pregnancy after twenty-four weeks of gestation.⁷⁸

⁷⁸ The Crown Prosecution Service (2005) 'CPS decides not to prosecute doctors following complaint by Rev Joanna Jepson' (cps.gov.uk as cited on 7/07/2015)

3.8 A response to anti-autonomy arguments surrounding prenatal testing

There are also arguments *against* prenatal diagnosis based on the principle of autonomy.⁷⁹ Whilst some consider the availability of prenatal testing enhances a person's reproductive autonomy others argue that it puts pressure on those couples who may otherwise have preferred not to have had such information.⁸⁰ Haker raises concerns that the availability of prenatal tests limits a woman's reproductive autonomy.⁸¹ Haker argues that rather than the availability of prenatal tests promoting women's reproductive autonomy by giving them the choice as to whether they want to have testing done, it actually puts more pressure on them to have the tests due to the social-ethical implications,⁸² and may possibly even make them feel regarded as being irresponsible by not doing so.⁸³ They may feel that they are jeopardising the health of their child if they choose not to accept such testing.⁸⁴ Any decision to utilise prenatal testing, therefore, may not be an autonomous choice. Although the introduction of such testing was aimed at preventing the births of disabled children,⁸⁵ notably by the same society that objected to discrimination against disabled people, there is concern that it has 'assumed a health-related obligation to "prevent" giving birth to a child with serious health

⁷⁹ Shakespeare T (1998) 'Choices and rights: eugenics, genetics and disability equality', *Disability & Society* **13**, pp 665-681

⁸⁰ Shakespeare T (1998) 'Choices and rights: eugenics, genetics and disability equality', *Disability & Society* **13**, pp 665-681

⁸¹ Haker, H (2006) 'Reproductive Autonomy in Light of Responsible Parenthood: with new science comes the need for a new ethical discourse', *Harvard Divinity Bulletin, Harvard Divinity School* **34(1)** (www.bulletin.hds.harvard.edu as cited on 8/07/2015)

⁸² Haker, H (2006) 'Reproductive Autonomy in Light of Responsible Parenthood: with new science comes the need for a new ethical discourse', *Harvard Divinity Bulletin, Harvard Divinity School* **34(1)** (www.bulletin.hds.harvard.edu as cited on 8/07/2015)

⁸³ Harris J (1998) *Clones, genes and immortality*, Oxford University Press, p 117

⁸⁴ Bennett R (2001) 'Antenatal genetic testing and the right to remain in ignorance', *Theoretical Medicine* **22**, pp 461-471

⁸⁵ Whittle MJ (1991) 'Antenatal diagnosis of fetal abnormalities' in Drife J, Donnai D (eds) *Routine Fetal Anomaly Screening*, London: Springer-Verlag London Limited, p35

risks or symptoms of disability.⁸⁶ The consideration of these issues will become more important as new ways of providing treatment in-utero emerge. One such condition that current research is likely to impact on is Down syndrome.⁸⁷ Therapies being investigated aim to reduce the symptoms of the condition but will not eliminate it or change the chromosomal pattern associated with Down syndrome and would, therefore, avoid the ethical problems associated with germline genetic manipulation.⁸⁸ It is hoped that such treatment would improve the quality of life of those with the condition and reduce the morbidity and mortality associated with it. These outcomes appear to be consistent with in-utero treatment for other conditions, such as Congenital Adrenal Hyperplasia (CAH), and also with post-natal treatment. Concerns may be raised, however, if the purpose or use of this in-utero intervention is to ensure that a person conforms to society's view of an ideal standard.

This may potentially be true if it were the case that an abnormality could be identified that could be corrected before birth or if it informed the clinicians of any precautions that needed to be taken at birth. However, it would not be the case if nothing could be done following the diagnosis being made. If their fetus had an abnormality it would still be there whether they had testing or not. Their decision not to have testing has not *caused* the abnormality. It is argued that, in this situation, the couple's autonomy is not protected as they make choices based on external pressures.⁸⁹ One of those choices may be to terminate an affected pregnancy, which when left to their own devices they may have continued, or not had testing to establish its status in the first place. However, rather than this being an argument against prenatal diagnosis it highlights the importance of healthcare professionals considering each

⁸⁶ Haker, H (2006) 'Reproductive Autonomy in Light of Responsible Parenthood: with new science comes the need for a new ethical discourse', *Harvard Divinity Bulletin*, *Harvard Divinity School* **34**(1) (www.bulletin.hds.harvard.edu as cited on 8/07/2015)

⁸⁷ Das I, Park J-M, Shin JH, Jeon SK, Lorenzi H, Linden DJ, Worley PF, Reeves RH (2013) 'Hedgehog Agonist Therapy Corrects Structural and Cognitive Deficits in a Down Syndrome Mouse Model' *Science Translational Medicine* **5**(201), pp 201ra120

⁸⁸ Guedj F, Bianchi DW, Delabar JM (2014) 'Prenatal treatment of Down syndrome: a reality?' *Current Opinion in Obstetrics & Gynecology* **26**(2), pp 92-103

⁸⁹ Bennett R (2001) 'Antenatal genetic testing and the right to remain in ignorance', *Theoretical Medicine* **22**, pp 461-471

individual couple and the need for them to have meaningful discussions in order to make a decision about whether or not to have prenatal testing in the first place, and if they do, what options are available to them once the result is known. It also depends on the healthcare professionals engaging with the prospective parents to gain an understanding of how the outcome of the pregnancy will affect them, within the context of the family. This argument emphasises why it is important to ensure that all reproductive decisions made by a couple are informed throughout the prenatal process, from initial counselling to termination, if that's what they choose and the clinical geneticist should be in a position to support this and contribute to the discussions that take place.

Prospective parents who are known to be at risk of having an affected pregnancy can be referred to a clinical genetics department and be seen by a dedicated team of healthcare professionals, including clinical geneticists and counsellors. Such patients will have the opportunity to discuss fully the nature of the condition which is affecting their pregnancy, or which their pregnancy is at high risk of being affected by. The exact nature of the condition and its phenotypic variability can be discussed so that the couple can decide for themselves whether it is a condition which they could cope with. Counselling is designed to be non-directive⁹⁰ in order that it enhances a couple's autonomy, providing them with information and support to allow them to make informed decisions which will best suit them. Whether or not non-directive counselling is attainable is unclear.⁹¹ Whilst directive counselling is aimed at influencing a patient's behaviour, non-directive counselling tries to influence the patient's thought processes before ultimately reaching a decision.^{92,93} During counselling the

⁹⁰ Harper P (2004) *Practical Genetic Counselling* (6th ed), Arnold Publishing, London, p 15

⁹¹ Elwyn G, Gray J, Clarke A (2000) 'Shared decision making and non-directiveness in genetic counselling', *Journal of Medical Genetics* **37**, pp 135-138

⁹² Kessler S (1992) 'Psychological aspects of genetic counselling. VII. Thoughts on directiveness', *Journal of Genetic Counseling* **1**, pp 164-171

⁹³ Wolff G, Jung C (1995) 'Non-directive and genetic counselling', *Journal of Genetic Counseling* **4**, pp 2-25

availability of further tests can be discussed and the accuracy to which they may provide results, as well as an opportunity to discuss the options available to the prospective parents should an anomaly be found. The benefit, therefore, for those who are in a position to use such services is that it is ultimately hoped that they are able to make a decision which best suits them and their particular circumstances, with support and advice from those providing the information.

Prenatal genetic testing for those at a particular risk of a genetic condition is, therefore, a service which is available should a couple want this. With non-directive counselling it is hoped that the couple will be able to make informed decisions about whether or not they want testing during pregnancy and will also be aware of what the potential outcomes could be, including, but not exclusively, the possibility of termination of an affected pregnancy.

Clinical geneticists are also able to provide support and reassurance to prospective parents as prenatal diagnosis does not only provide couples with the option of identifying whether or not they are carrying a disabled fetus, it can also allow couples to begin a family when they may not have otherwise done so. Prior to the discovery of the gene mutation causing Duchenne Muscular Dystrophy (DMD),⁹⁴ women who knew that the gene existed in their family due to the presence of affected individuals, but did not know whether or not they were a carrier, would often choose not to have children due to the fear of having an affected son. Others would embark on a pregnancy but on finding that the fetus was male would opt for a termination, having had first-hand experience of what it would be like to have a son with the condition, and having to witness a deterioration in their health from a young age to their premature death. This is despite the fact that they did not know whether they did actually carry the gene fault, thus giving them a risk of twenty-five percent of having an affected boy

⁹⁴ DMD is an X-linked condition in which females are unaffected carriers but are at 50% risk of having an affected son. It is a progressive neuromuscular condition resulting in delayed motor milestones and death usually by the age of twenty.

and a seventy-five percent chance of the fetus being unaffected. This meant that a large proportion of the terminations carried out were of normal healthy boys.⁹⁵

The advent of prenatal testing for DMD, and similar conditions, has meant that those women can now be carrier tested and know exactly what their risk is. This meant that many of the women who had either opted not to have children or who had had terminations of male fetuses could now go on to have the family they desired, either by being able to have genetic testing or because they knew they were not at risk. The lack of availability of prenatal testing meant that a large number of pregnancies carrying normal males were terminated. This highlights the fact that, taking into account a family's personal experiences of a condition, they will take drastic action to prevent the birth of an affected child. At least with the option of prenatal testing lives of future children can be saved, as those pregnancies that are not affected are able to continue.

Prenatal diagnosis does not always have to result in termination of pregnancy. The information gained by prenatal testing may be empowering to an expectant couple allowing them to prepare for the birth of their child, which will also be of benefit to the child itself. Preventing people who want this knowledge from gaining it could be detrimental to them as well as the developing child. The uncertainty of whether or not the pregnancy is affected by a particular condition could place a great burden on the pregnant woman and her partner. This in itself could affect their relationship and family in a negative way, in addition to the effect it may have on the pregnancy.

There are also further benefits of prospective parents engaging with clinical genetics services and being able to discuss how they can mitigate the risks associated with starting a

⁹⁵ Friedman Ross L (2006) 'Research Review: Screening for conditions that do not meet the Wilson and Jungner criteria: The case of Duchenne Muscular Dystrophy', *American Journal of Medical Genetics* **140**(A), pp 914-922

family. Not testing a high risk pregnancy may mean that an assumption needs to be made that the pregnancy is affected by a condition and certain interventions may need to take place as a precaution. This in itself could be harmful to the fetus and to the mother. For example Congenital Adrenal Hyperplasia is an autosomal recessive metabolic condition. Both parents can be unaffected carriers of the mutated gene, which is responsible for causing the condition, with a twenty-five percent chance of them having a child affected by the condition.⁹⁶ Males and females can be affected, but in the case of a female fetus, due to the hormonal imbalances that occur, over masculinisation of the female fetus can occur during gestation resulting in a genetic female with ambiguous genitalia at birth.⁹⁷ This is a seriously disabling condition not only physically but also psychologically for both child and parents.⁹⁸ This may be particularly problematic, and is the subject of debate,^{99,100} where a child is born with a 46XX karyotype but is severely masculinised at birth. Despite having a female karyotype these children may be assigned male gender at birth, as ease of surgical correction has to be considered and there is controversy as to whether this is the correct approach to take.¹⁰¹ The child will need to undergo often multiple plastic surgery procedures and long term medical follow up.¹⁰² The condition can be fatal in some situations. One way of reducing the damaging effects of CAH is for the mother to take Dexamethasone, a steroid, during early pregnancy.¹⁰³ However, this treatment is not without its side effects and can

⁹⁶ Warrell DA (2005) *Oxford Textbook of Medicine*, Oxford University Press, p 261

⁹⁷ McAnulty RD, Burnette MM (2006) *Sex and Sexuality, Volume I*, Greenwood Publishing Group, p 165

⁹⁸ Meyer-Bahlburg HFL, Dolezal C, Haggerty R, Silverman M, New MI (2012) 'Cognitive outcome of offspring from dexamethasone-treated pregnancies at risk for congenital adrenal hyperplasia due to 21-hydroxylase deficiency', *European Journal of Endocrinology* **167**(1), pp 103-110

⁹⁹ Lee PA, Houk CP (2010) 'Review of outcome information in 46,XX patients with congenital adrenal hyperplasia assigned/reared male: What does it say about gender assignment?' *International Journal of Pediatric Endocrinology* **2010**(1), p 1

¹⁰⁰ Kipnis K, Diamond M (1998) 'Pediatric ethics and the surgical assignment of sex' *Journal of Clinical Ethics* **9**, pp 398-410

¹⁰¹ Lee PA, Houk CP, Husmann DA (2010) 'Should male gender assignment be considered in the markedly virilised patient with 46,XX and congenital adrenal hyperplasia?' *Journal of Urology* **184**(4), pp 1786-1792

¹⁰² Milunsky A, Milunsky J (2010) *Genetic Disorders and the Fetus: Diagnosis, prevention and treatment*, John Wiley & Sons, p 600

¹⁰³ Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed), BMJ Publishing Group, p 74

also cause some harm to the fetus. The risks and benefits have to be considered and weighed in the balance.¹⁰⁴

Without prenatal testing the parents and their healthcare advisers have a difficult choice to make. There is a twenty-five percent risk of them conceiving an affected child and a seventy-five percent chance of the fetus not being affected. Should they start the prophylactic treatment or not? If they do there is a chance that they could cause harm to an otherwise healthy fetus. But if they do not choose to treat they risk depriving an affected fetus of a chance to development normally and avoid unnecessary pain and suffering once born.

Allowing parents to consider their options and choose whether or not to have testing may avoid the harm of uncertainty for the couple and also the harm to the fetus. Once the genetic status of the fetus is established a decision regarding treatment can be made, which is known to be in the best interests of that particular fetus and not based on risks and probabilities. Having clinicians engage with couples early, preferably before conception or at least in early pregnancy, to discuss their genetic risks and the risks and benefits of testing and potential treatment allows the couple and their pregnancy to be viewed individually, with their specific needs considered in isolation and hence the enhancement of their autonomy with respect to reproductive decision making.

This example further highlights the benefits of prenatal testing and emphasises the fact that terminating an affected pregnancy is only one possible outcome and by no means the ultimate goal of testing and prenatal diagnosis. I will discuss in chapter four (section 4.5), the benefits that prenatal testing can bring to the fetus, which would not otherwise have been available had testing not been done.

¹⁰⁴ Kingston HM (2002) *ABC of Clinical Genetics* (3rd ed), BMJ Publishing Group, p 74

3.9 Equality and reproductive freedom

Another basis for the importance of reproductive freedom is the principle of equality.¹⁰⁵ This argument relates to the fact that regardless of whether someone is male or female, they should have the same opportunities to live their life the way they see fit. It is believed that reproductive freedom neutralises the unfair disadvantages women face in relation to reproduction due to their gender. The decision whether or not to continue a pregnancy which is affected by a disability has an impact on both parents, although clearly the pregnancy and possible termination will have the greatest impact, physically and emotionally, on the mother. It may appear, therefore, that the issue of inequality, with respect to gender, is not relevant when considering prenatal testing (as opposed to termination of pregnancy) as testing will determine a longer term consequence which will affect not only the mother. However, it is argued that the greatest impact of the birth of a disabled child, and its future upbringing, places most burden on the mother as it is generally the mother who will be responsible for the child's upbringing.¹⁰⁶ Whilst some care may be available it is unlikely that both parents of a severely disabled child will be in a position to work as the child may well require twenty-four hour care which is unlikely to be compatible with a position of employment outside the home, even when support is available. It is argued, therefore, that reproductive freedom, with the opportunity to utilise prenatal testing with or without termination of pregnancy, provides women with the opportunity to decide whether or not they want to fulfil the role of carer for a severely disabled child rather than the life they may otherwise have chosen. Many women of course will choose to continue with an affected pregnancy and accept their future role in relation to this. Others, however, will be in a position to choose, just like their male counterparts.

¹⁰⁵ Buchanan A, Brock DW, Daniels N, Wikler D (2001), *From Chance to Choice: Genetics & Justice*. Cambridge University Press, p 214

¹⁰⁶ Buchanan A, Brock DW, Daniels N, Wikler D (2001) *From Chance to Choice: Genetics & Justice*. Cambridge University Press, p 221

Purdy refers to the ability to control our own bodies as ‘a keystone of liberal society’ and that just as men do, women want to be able to control what happens to and within their bodies.¹⁰⁷ The provision of abortion services has allowed women to gain some control over their reproductive freedom and, as Bender puts it, ‘freeing themselves from male dominance’.¹⁰⁸ The availability of contraception and abortion has allowed women to develop an identity which is separate to reproduction and has given them control over their lives which is similar to that of their male counterparts. Prenatal testing has allowed women to gain information about their pregnancy so that they can make decisions on behalf of their future child taking into account how the abnormality found will impact on that child, but also on their own life. Access to abortion particularly in the late stages of pregnancy is restricted of course with the ultimate gatekeepers being the medical professionals who arbitrate over whether or not a disability is serious enough. As I have argued in chapter two, as the woman has higher moral status than the fetus a woman should be allowed to make the choices that serve her own needs, to a point. I have also argued that as pregnancy progresses the moral status of the fetus increases and, therefore, there does have to be some control over what women are able to do under limited circumstances, such as when the pregnancy threatens her life or in the event of very serious fetal disability. Purdy focuses on the judgements in legal cases that have resulted in a woman’s decision being overridden in the interests of the fetus, including giving doctors permission to perform caesarean sections on women who have refused to consent to this.¹⁰⁹ I have discussed the importance of autonomy and how this should be respected and as Purdy describes, these types of actions are highly unlikely to be taken against ‘the average middle-class white man on the street’,¹¹⁰ or even a

¹⁰⁷ Purdy L (1999) ‘Are Pregnant Women Fetal Containers?’ in Kuhse H, Singer P (eds) *Bioethics: An Anthology*, Blackwell Publishers, pp 71-81

¹⁰⁸ Bender L (1993) ‘Teaching feminist perspectives on health care ethics and law: a review essay’, *The University of Cincinnati Law Review* **61**, pp 1251

¹⁰⁹ Gallagher J (1987) ‘Prenatal Invasions and Interventions: What’s Wrong with Fetal Rights’, *Harvard Women’s Law Journal* **10**, p 9

¹¹⁰ Purdy L (1999) ‘Are Pregnant Women Fetal Containers?’ in Kuhse H, Singer P (eds) *Bioethics: An Anthology*, Blackwell Publishers, pp 71-81

competent woman who is not pregnant. What is it then that creates the situation whereby a pregnant woman is treated differently to those women who are not pregnant, and their male counterparts?

There is clearly the issue of moral status. Those who argue that the fetus does have full moral status equivalent to that of the mother will undoubtedly argue that the fetus is deserving of as much protection as the mother. Any action that is needed to protect the fetus, assuming it does not harm the mother, should therefore be permitted even if this against the mother's wishes. This may arise, for example, if there is a clinical need to deliver a baby by caesarean section because vaginal delivery could result in serious harm to the baby or even death. There may only be minimal risk to the mother in having a caesarean section and therefore her refusal, at the expense of the child, may seem unreasonable. I agree that I too would struggle with this situation and would hope that the mother would choose the option that was in the best interests of her future child, however, if she has a higher moral status than the fetus her decision should be respected assuming she fulfils the criteria for having mental capacity and is competent to make such a decision. Denying women the choice in these cases limits their reproductive autonomy and is a retrograde step from the point of view of what the feminist political agenda has been fighting for. Under any other circumstances a person could not undergo a procedure that they had not consented to, such as surgery, because this would be counter to their autonomy even if it was felt that this decision was irrational or not in their best interests. There are those who argue that in this situation, providing the woman's own health is not being seriously compromised, her autonomy should be disregarded in order to save the fetus, as ultimately this will not cause any physical harm to the woman^{111,112}. The risk here of course is that this could create an adversarial relationship between the woman and fetus/future child as the woman's

¹¹¹ Kluge E-K W (1988) 'When Caesarean Action Operations Imposed by a Court are Justified', *Journal of Medical Ethics* **14**, pp 206-211

¹¹² Parness J (1986) 'The Abuse and Neglect of the Human Unborn', *Family Law Quarterly* **20**, pp 197-212

fundamental rights have been challenged.¹¹³ It is interesting to note that if a child is harmed, for example born with brain damage, due to a delay in the performance of a caesarean section by doctors the child's rights will be protected by the Congenital Disabilities (Civil Liability) Act 1976. A breach in duty to the mother that results in injury to the child creates rights for both the mother and child.¹¹⁴ If, however, the child suffers harm because the mother has refused to consent to a caesarean section that doctors have advised, the child will not be able to sue the doctor because the doctor is not liable to the mother. The Act also provides immunity to the mother so that the child cannot make any claim against her. This legal position seems consistent with the ethical position that the mother has a higher moral status than the fetus and, therefore, her autonomous choices take precedence over that of the fetus and its well-being.

In the latter scenario, the only way by which the doctor could act in the best interests of the fetus and future child would be to override the autonomy of the mother. It was ruled by the Court of Appeal in *St George's Healthcare NHS Trust v S*¹¹⁵ that a caesarean section, or any other form of obstetric procedure, could not be performed on a woman who refused to consent and was competent to make her own decision. It was ruled that pregnancy and labour did not impact on the importance of a patient being able to make their own healthcare decisions. In those cases that have resulted in judgements that have permitted such procedures being carried out on pregnant women who have refused, the woman's mental capacity has been called into question.^{116,117,118} The legal situation, therefore, is that if a woman has mental capacity at the time the decision needs to be made her autonomy cannot be overridden. The decisions made in case law are confirmed by the Department of Health

¹¹³ Johnsen DE (1986) 'The creation of fetal rights: Conflicts with women's constitutional rights to liberty, privacy and equal protection', *The Yale Law Journal* **95**, pp 599-626

¹¹⁴ Brazier M, Cave E (2011) *Medicine, Patients and the Law*, Penguin Books, p 340

¹¹⁵ *St George's Healthcare NHS Trust v S* [1998] 3 All ER 673

¹¹⁶ *Re S* [1992] 4 All ER 671

¹¹⁷ *Rochdale Healthcare NHS Trust v C* [1997] 1 FCC 274

¹¹⁸ *Tameside & Glossop Acute Services Trust v CS* [1996] 1 FLRC 762

which refers to decisions to refuse treatment being respected if they are made by an adult with capacity even if this may ‘result in the death of the person (and/or death of an unborn child, whatever the stage of the pregnancy)’.¹¹⁹

As the fetus is part of the woman’s body and its future interests are therefore dependent on her actions how do we resolve this moral problem? Purdy suggests comparing the relationship between the mother and fetus with that of the relationship between other relatives. This provides us with the opportunity to compare and consider a similar scenario but with a relationship between a non-pregnant woman or male person and a close relative, such as their child. If, for example, a child needed a kidney transplant and the only match was their parent (mother or father) would they be required to undergo surgery in order to save or improve the life of their child? Whilst one would hope that a parent would proceed in order to save the life of their child, assuming there was little risk to themselves, would they be morally obliged to do so? There is a natural expectation that parents will do their best for their children and will make sacrifices for them. Parents have children generally knowing that this will have a significant impact on their own life, affecting their financial status, their career, as well as the physical and emotional effects of having a child. Whilst it is argued that parents are morally obliged to care for their children¹²⁰ this does not necessarily mean that they should put themselves at risk for their children. Whilst there may be a moral obligation to provide basic care such as food and shelter to one’s children, this does not mean that this should extend to donating a kidney to a child. If a parent refused to do this their autonomy, as a competent person who has the right to make decisions for themselves, would not be overridden. Donating an organ could put the parent’s life at risk, for example, from post-operative complications such as sepsis or haemorrhage or they may have an adverse reaction to the anaesthetic. If something happened to that parent not only would

¹¹⁹ Department of Health (2009) *Reference Guide to Consent for Examination and Treatment* (2nd ed), DOH: London, chapter 1, paragraph 44

¹²⁰ Eekelaar J (1991) ‘Are parents morally obliged to care for their children?’, *Oxford Journal of Legal Studies* **11**(3), pp 340-353

this impact on their future but possibly on the future of others, such as other children that may already exist to whom the parent also has moral obligations. There are many reasons why a parent may refuse to help their own child in this way and, therefore, why then should a pregnant woman be required to undergo an invasive procedure in order to save the life of her fetus? This view is shared by others^{121,122} and Annas argues that the relationship between the mother and fetus is actually less demanding than the relationship between a mother (or father) and a child who has already been born in that the fetus is not yet a person and as such has lower moral status than the parent and the child.¹²³

I agree with Annas' point that the fetus has lower moral status than that of the child and as such the mother does not owe any more duty to the fetus than she does to the child, however, one would hope that the mother would act in such a way as to protect her fetus as she would her child. Just as we would generally expect parents to follow the advice of health professionals in preventing illness and disability in their child it seems reasonable to expect the same for their fetus, assuming this does not cause harm to the mother. Examples may include refraining from smoking, taking illicit drugs and drinking alcohol during pregnancy or positive actions such as taking Folic Acid to reduce the risk of neural tube defects. Other examples that may be more difficult to reconcile may include changing from one anti-epileptic medication to another less effective one, which does not have teratogenic side effects. This latter example may be a fine balancing act between the mother's interests (in not suffering from an epileptic seizure, which may in itself harm the fetus) and the interests of the fetus in not developing congenital abnormalities secondary to the effects of the anti-epileptic medication. However, as Purdy argues if parents are not expected to undergo

¹²¹ Kolder VEB, Gallagher J, Parsons MT (1987) 'Court-ordered obstetrical interventions', *New England Journal of Medicine* **316**(19), pp 1194

¹²² Annas GJ (1982) 'Forced cesareans: The most unkindest cut of all', *Hastings Center Report* **12**(3), p 17

¹²³ Annas GJ (1982) 'Forced cesareans: The most unkindest cut of all', *Hastings Center Report* **12**(3), p 17

invasive procedures against their wishes for the sake of their children then there should be no expectation for the mother to do so for the benefit of the fetus.¹²⁴

When considering equality and what is fair it is also important to consider whether or not denying an ‘at risk’ couple prenatal testing can be justified. Couples who are known to be at risk of having a disabled child are already disadvantaged by that risk and it would appear unfair to deny them the opportunity to put themselves on an equal footing as other couples who are at a low risk of having a pregnancy affected by an abnormality.

Even if one concludes that the information provided by prenatal diagnosis does enhance reproductive autonomy, in that it allows couples to decide whether or not to continue an affected pregnancy, there are still those who argue that despite this enhancement of autonomy prenatal diagnosis is still morally wrong. I have addressed arguments relating to the moral status of the fetus in chapter two, however, the main focus of my thesis has been to look at the arguments relating to prenatal diagnosis and the claim that it discriminates against those living with disabilities, which I will discuss in chapter four and five.

3.10 Summary and conclusions

Autonomy is clearly of utmost importance in our society and with respect to healthcare, with autonomous adults being generally encouraged to make decisions for themselves. These decisions, for various reasons, are, however, sometimes limited for example by existing laws, or in the case of healthcare by the cost and availability of treatment. A person’s autonomy with respect to healthcare may also be restricted by the healthcare professionals looking after them if the care the patient is requesting is felt not to be clinically appropriate

¹²⁴ Purdy L (1999) ‘Are Pregnant Women Fetal Containers’ in Kuhse H, Singer P (eds) *Bioethics: An Anthology*, Blackwell Publishers, pp 71-81

or justified. I have discussed the fact that whilst paternalism is discouraged passive paternalism does still play a part in the provision of modern healthcare.

If a patient does not have capacity to make their own decisions we act in what we believe to be their best interests taking into account all of the circumstances. When prospective parents make decisions about reproduction they do so taking into account the impact any decisions will have on their fetus, but also by considering what is in their own best interests and that of their other immediate family.

I have argued that as decisions about reproduction are so important in how they affect a person's life (the prospective parents, the future child and others with a close personal connection) the respect for reproductive autonomy is of particular importance. All reproductive decisions, whether this be a decision to start a family or not or when and how many children to have, have a profound impact even before consideration is given to whether or not the future child may be born with a disability. This disability may require the prospective parents to consider additional care the future child may need and the need to take into account the wider reaching impact this may have on their own future lives. The extent to which the fetus may suffer due to its condition and the treatment of it will also play a significant role in determining what parents may decide to do. They can be greatly assisted in making these decisions by having a supportive relationship with relevant healthcare professionals which could start before conception or during the prenatal period.

I have argued that it is because of the profound effects these decisions have on the lives of those involved that interference in them should be avoided as much as possible. As with other decisions that we wish to make autonomously, however, and despite their profound effect, there are still restrictions on what prospective parents may be in a position to decide. Healthcare professionals again are the final arbitrators of whether or not a couple

can ultimately terminate a pregnancy if an anomaly is found later during gestation and I will explore this in more detail in chapter six.

Chapter 4

Harm, health, disease and disability

4.1 Introduction

The purpose of this chapter is to discuss what is meant by harm, health, disease and disability and the significance this has as to whether a person, or those close to them, can be harmed by being born with a disability and the issues surrounding existence and non-existence which this creates. This will then enable me to discuss in chapter five the arguments against prenatal testing that claim it discriminates against those with disabilities. In arguing against this position I conclude that the underlying reasons for prenatal testing and termination of pregnancy, including late terminations, should be to prevent harm. The presence of an abnormality in a fetus, which is going to affect the life of the future person, may cause it harm. It is not, however, only the fetus and future person it will become who may be harmed by the abnormality but also people who already exist, such as the prospective parents and other children that they may already have.

Prenatal testing is performed in order to determine whether or not a fetus is likely to be born with a disability. Prospective parents who receive such a finding may choose to terminate that pregnancy. When making this decision consideration needs to be given not only to the potential harm to the future child but also potential harm to the interests of the wider family. I will therefore discuss what constitutes harm itself and harm to interests, but also whether a person who is going to be disabled, can be harmed by being born when the only other option is that of non-existence.

As mentioned in my introductory chapter, I am conscious that my thesis may create a negative impression of having a child with a disability. This is not intentional but a reflection of the fact that where prenatal testing is followed by termination it is likely that the prospective parents will have viewed the disability in their particular child as something that will be detrimental to their interests and, possibly, to the interests of the wider family.

When talking to prospective parents it is important for them to understand the implications that the condition their fetus will be affected by will have on the future child. This will include asking questions such as: How will it affect their health? What limitations could it place on them and how might they overcome these? It is important for prospective parents to have the opportunity to deliberate on what they consider to be harm, not only to the future child but to their own interests, and whether they believe that their future child's health and level of disability is going to affect them all enough to consider terminating the pregnancy. This discussion clearly needs to be balanced and the positives of having the child also need to be recognised to ensure that the prospective parents make the right decision for them. Both prospective parents and those supporting them need to have an understanding of the concepts of harm, health and disability so that they can determine what it means for them.

There are well rehearsed models of disability in the literature^{1,2} and I will discuss how these do not always provide adequate definitions of disability when considering the types of impairment that are often identified by prenatal testing, particularly those that result in severe disability and may lead to late terminations of pregnancy.

¹ World Health Organisation (1976) 'International Classification of Impairments, Disabilities and Handicaps: A manual of classification relating to the consequences of disease' Published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976, p 47

² Shakespeare T (2013) 'The social model of disability' in LJ Davis (ed) *The disability studies reader*, Routledge: New York & London, p 214

I will also discuss the definitions of health and disease and the difficulties with these definitions, including the Naturalist and Normativist theories of health, and how the Normativist theory takes into account the interests of the individual and what allows a person to lead a worthwhile life. The Normativist account supports my arguments in chapter three regarding the importance of reproductive autonomy, and how decisions should be made by those whose interests may ultimately be harmed by the birth of a disabled child.

4.2 Harm, health, disability and Disease

One of the aims of my thesis is to emphasise the need to consider the fetus in the context of the family, as not only may the fetus be harmed by the presence of a disability but also harm may occur to the interests of other relevant individuals. It is, therefore, important to consider what is meant by harm. Reznick considers the concept of harm from the point of view that an object is harmed if it is made worse off.³ This would imply that the object being harmed had a ‘good or well-being’ that could be impaired in the first place. This point would be particularly relevant to prospective parents and pre-existing children who will already have an established life with interests of their own which could potentially be harmed. From the point of view of human harm we need, therefore, to consider what it is to have human good or welfare. Reznick talks of a person being harmed if they are in a worse state than they otherwise would have been had they not suffered the harm.⁴ This is not always straightforward. In medicine particularly it may be necessary to expose a person to side effects of a drug thus causing them harm, but without this treatment their overall condition would be worse. The person is, therefore, actually better off having taken it. Not taking the drug would result in more overall harm to them. Reznick overcomes this problem by considering the concept of ‘some harm’.⁵ In this case the drug has made the person better off overall but has caused some harm to them. Overall the person has benefitted.

³ Reznick L (1987) *The Nature of Disease*, Routledge & Kegan Paul: London and New York, p 134

⁴ Reznick L (1987) *The Nature of Disease*, Routledge & Kegan Paul: London and New York, p 134

⁵ Reznick L (1987) *The Nature of Disease*, Routledge & Kegan Paul: London and New York, p 134

Harm therefore occurs where a person is worse off than they would otherwise have been. Whether a particular type of harm, or harm caused to particular interests, is sufficient to impact significantly on a person's life is for them to determine. People may accept some harms when these are balanced by benefits. From the perspective of parents and pre-existing children who have interests that could be harmed it is important, therefore, to consider the possible harms to those interests that having a disabled child in the family could bring with the positive benefits to allow their overall position to be evaluated. This is why deliberative discussion is needed before prospective parents make reproductive discussions. Taking this approach may also assist medical professionals in making decisions when faced with the need to justify the appropriateness of late termination of pregnancy.

Diagnosis and treatment of patients is closely associated with our understanding of what constitutes health; theories of which I will discuss in section 4.2.2.i. Health is defined as the 'optimum capacity of a person to fulfil the requirements for performing various roles and tasks within society'.⁶ When considering the principle of beneficence and non-maleficence and our *prima facie* duty to prevent others from being harmed, this arguably means that we have a duty to assist those who are unhealthy as they are subjected to harm by being made worse off than their optimum state of health would otherwise be. The importance of this in relation to prenatal testing is that identifying an abnormality that has the potential to cause harm in the fetus may allow us to intervene and prevent or reduce that harm.

When healthcare professionals decide whether or not to offer prenatal testing, and before a couple decides whether or not to accept it, they will inevitably make judgements about the life they believe the

⁶ Talcott Parson (1981) 'Definitions of health and illness in the light of American values and social structure' in Caplan AL, Engelhardt Jr HT, McCartney JJ (eds) *Concepts of Health and Disease: Interdisciplinary perspectives*, London, p 69

future child will have. This will be based on their own personal experiences, information they receive and their own personal views about life and disability and, for the parents, their own aspirations. It will not only be the life of the future child that will be affected. The parent's lives and the lives of any other children they have are also likely to be affected in some way. For some families this may be a positive experience and they may approach the news of a difference in their future child with a positive attitude about what this may bring. Others, however, may think more negatively about the consequences of having a disabled child on their own lives and their existing children and they may feel that the negatives outweigh the positives. This will depend on the way in which they believe their future child, existing children and they themselves will be harmed and what their personal views on disability are. How the birth of a disabled child will affect them will depend on their own unique set of circumstances. This is likely to be different for every couple and every family; just as what *disability* means to them will also differ depending on their own views and interests.

4.2.1 Models of disability

As mentioned above, the view as to how a disability is likely to affect the person directly or how it will affect those close to them may vary from one person to another. There are models of disability which provide a framework for understanding the way in which people with impairments experience disability. They also provide a reference for society as laws, regulations and structures are developed that impact on the lives of disabled people. There are two main models that have influenced modern thinking about disability: the medical model and the social model.

4.2.1.i The Medical Model of Disability

In the medical model it is the disability that is seen as the problem. The physical or mental abnormality that the person has is seen to be causing their impairment and the restrictions that are placed upon them, rather than their environment. In this model the person with the impairment needs to adapt to the surrounding circumstances, if possible, in order to remove or reduce their disability, rather than society needing to make any adjustments.

In the late 1970s the World Health Organization (WHO) devised a new classification system for disability.⁷

- *Impairment*: any loss or abnormality of psychological, physiological or anatomical structure or function.⁸
- *Disability*: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.⁹
- *Handicap*: a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.¹⁰

⁷ World Health Organisation (1976) 'International Classification of Impairments, Disabilities and Handicaps: A manual of classification relating to the consequences of disease' Published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976, p 47

⁸ World Health Organisation (1976) 'International Classification of Impairments, Disabilities and Handicaps: A manual of classification relating to the consequences of disease' Published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976, p 47

⁹ World Health Organisation (1976) 'International Classification of Impairments, Disabilities and Handicaps: A manual of classification relating to the consequences of disease' Published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976, p 143

¹⁰ World Health Organisation (1976) 'International Classification of Impairments, Disabilities and Handicaps: A manual of classification relating to the consequences of disease' Published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976, p 183

This definition suggests that disability is essentially seen as problematic and the ‘responsibility’ of the person with impairments and is not related to the way in which society is organised. Any social consequences for the disabled person are said to be due to the physical limitations they experience and not the fault of society.^{11,12} I do not accept that disability is solely the result of the biological impairment, as there clearly are impairments that can be overcome by society adapting and, where this does not happen, some losses of function can be made into disabilities, or made more disabling, due to the physical construct of society.^{13,14,15} The definitions were strongly opposed by organisations controlled and run by disabled people because they promoted a view that individual impairments are the determining factor in explaining both disability and handicap. The model was argued to give an impression that disability must be prevented due to the fact that disabled people are unable to function normally within our society.¹⁶ The World Health Organisation currently consider disability to be reflected by the following definition, now taking into account the impact of the environment as well as a person’s physical or mental impairments.

“Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.”¹⁷

¹¹ Asch A (1989) ‘Reproductive Technology and Disability’ in Cohen S & Taub N (eds) *Reproductive laws for the 1990s*, Clifton, NJ Humana Press, p 73

¹² Brisenden S (1986) ‘Independent living and the Medical Model of Disability’ *Disability, Handicap and Society* **1**(2), pp 173-178

¹³ Gillam L (1999) ‘Prenatal diagnosis and discrimination against the disabled’ *Journal of Medical Ethics* **25**, pp 163-171

¹⁴ Asch A (1989) ‘Reproductive Technology and Disability’ in Cohen S & Taub N (eds) *Reproductive laws for the 1990s*, Clifton, NJ Humana Press, p 73

¹⁵ Shakespeare T, Watson N (2002) ‘The social model of disability: an outdated ideology?’ *Research in Social Science and Disability* **2**, pp 9-28

¹⁶ Asch A (1989) ‘Reproductive Technology and Disability’ in Cohen S & Taub N (eds) *Reproductive laws for the 1990s*, Clifton, NJ Humana Press, p 98

¹⁷ World Health Organisation website (www.who.int/topics/disabilities/en/ as cited on 20 June 2013)

Impairment may not result in disability as the loss or abnormality may not in itself affect a person detrimentally. A person who is born with one kidney can function perfectly well and may not even be aware of this anatomical anomaly until they are investigated for a completely unrelated matter. Impairments alone therefore are not always significant. What is 'within the range considered normal for a human being' (see definition of disability above) is not defined and could mean different things to different people and to different couples. The medical model does not provide an adequate or useful definition of disability when considering the benefits and disadvantages of prenatal testing. A person may be considered disabled by others as they may be unable to do the things that others can do, but from their own personal point of view any difference about them is insignificant and does not have any major detrimental impact on their life.

The medical model is problematic in that it does not take into account the personal experiences of those with an impairment who may not consider themselves to be disabled, even where the medical model defines them as such. Scully argues that consideration needs to be given to experience and perspective.¹⁸ This supports my view that a difference in the fetus should not solely be evaluated in clinical terms but also based on the impact it will have on the future child and family, which may not necessarily be negative. There is a danger that in looking only to the clinical facts in terms of the physical and intellectual characteristics, the needs of each individual are not taken into account.¹⁹ The medical model also does not differentiate between those who have acquired their disability later on in life, such as through accident or illness, from those with congenital impairments resulting in disability from birth.²⁰ Where a disability is present from birth it can form an important part of that person's identity and if that disability were taken away they would no longer be that person.²¹ This is particularly

¹⁸ Scully JL (2004) 'What is a disease?' *EBMO reports* 5(7), pp 650-653

¹⁹ Brisenden S (1986) 'Independent living and the Medical Model of Disability' *Disability, Handicap and Society* 1(2), pp 173-178

²⁰ Scully JL, Rippberger C, Rehmann-Sutter C (2004) 'Non-professionals' evaluations of gene therapy ethics' *Social Science & Medicine* 58, pp 1415-1425

²¹ Scully JL (2004) 'What is a disease?' *EBMO reports* 5(7), pp 650-653

noticeable in those who are deaf and part of a 'Deaf culture'.²² Proponents of this Deaf culture view that being deaf is not a disability but a culture, highlighting the fact that what constitutes an abnormality or harm is not always obvious.

Expectations of prospective parents as to what impairments may result in disability or handicap are likely to be influenced by what they have achieved in their own lives and what they hope to achieve from having a family. Educational achievement, for example, may be extremely important to a prospective parent who is very academic themselves, and to find that her pregnancy is affected by a neurological or genetic condition that is going to result in her child having severe learning difficulties might be devastating for them. Another person, however, may not be troubled particularly by this providing the child is physically well and not experiencing any significant pain or suffering. This is one reason why good quality genetic counselling is necessary to ensure that prospective parents fully understand the potential outcomes for their future child if an anomaly is identified, so that their expectations can be addressed with the possibility of their fears being allayed and the many advantages the child will bring being highlighted and ensuring that they are aware of the type of support that can be provided. This also highlights the need for healthcare professionals involved in the care of these women to take into account not only the effects the anomaly will have on the future child, but also on the interests of those people directly involved and what potential harm they feel it could cause to them.

²² Stern SJ, Amos KS, Murrelle L, Welch KO, Nance WE, Pandya A (2002) 'Attitudes of deaf and hard of hearing subjects towards genetic testing and prenatal diagnosis of hearing loss' *Journal of Medical Genetics* **39**, pp 449-453

4.2.1.ii **The Social Model of Disability**

The difficulties that the medical model has in establishing whether or not a particular physiological or mental condition has any negative or undesirable impact on someone's life has led to the development of the social model of disability which distinguishes between impairment and the disabled experience.²³ The Union of the Physically Impaired against Segregation (UPIAS) was an early disability rights organisation in the United Kingdom which helped to create this social model and make a distinction between impairment and disability.²⁴ In this model the barriers that exist within society and the way in which society is organised cause disability, with those affected being denied the same access to their society as non-disabled people.²⁵ This model reflects the view that society discriminates against people with impairments, where, according to the WHO definition, impairment is 'any loss or abnormality of psychological, physiological or anatomical structure or function',²⁶ and excludes them from involvement and participation. However, one could argue that it is not only psychological, physiological or anatomical reasons that may give rise to impairment but also other causes, such as a person's financial position which may prevent them from participating in certain activities that they may have an interest in. With this in mind one could therefore be disabled not only by impairment as it is currently defined, but also by other factors that may be regarded as a disadvantage.

Oliver also describes a social model of disability²⁷ stating that it is not the impairment an individual suffers which has an impact, but the influence society has on their impairments which prevent them from living their life in the same way a person without such physical or intellectual differences would.

²³ Scully JL (2004) 'What is a disease?' *EBMO reports* 5(7), pp 650-653

²⁴ Shakespeare T (2013) 'The social model of disability' in LJ Davis (ed) *The disability studies reader*, Routledge: New York & London (2013), p 214

²⁵ Zola IK (1979) 'Healthism and disabling medicalization' in Lee P, Brown N & Red I (eds) *The Nation's health*, San Francisco, California, Boyd and Fraser, pp 101-110

²⁶ World Health Organisation (1976) 'International Classification of Impairments, Disabilities and Handicaps: A manual of classification relating to the consequences of disease' Published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976, p 47

²⁷ Oliver M (1991) 'The Politics of Disablement', *International Journal of Rehabilitation Research* 14, pp 185-186

This model also reflects the Union of Physically Impaired Against Segregation (UPIAS) definition of disability views.

‘Disability is the disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have [physical] impairments and thus excludes them from the mainstream of social activities.’²⁸

By this definition disability is a result of environmental and social factors as opposed to the physical impairments that exist. Research carried out by Scully in relation to congenital abnormalities (and therefore present from birth) showed that a person’s impairment formed an important part of their identity and that the problems they faced were not always intrinsic to the condition but due to the reluctance of society to adapt (for example, Scully uses the example of installing light switches lower down to take into account people with shorter stature).²⁹ According to the social model disabled people are people with impairments who are disabled by barriers in society. However, I do not accept that this is the case with all disability and that there are some conditions which would result in limitations and cause suffering no matter what the social setting was.³⁰ I will consider later (section 4.3) those impairments that are so severe that they are not amenable to social intervention, for example, those that result in profound learning difficulties or severely limited survival. This problem highlights the inadequacies of the social model and how it does not consider individuals with the most severe impairments, those of whom are often the subject of late termination of pregnancy.

²⁸ UPIAS (1975) ‘The UPIAS and The Disability Alliance discuss fundamental principles of disability’ Being a summary of the discussion held on 22nd November, 1975 and containing a commentary from each organization, (disability-studies.leeds.ac.uk as cited on 8 August 2015))

²⁹ Scully JL (2004) ‘What is a disease?’ *EBMO reports* 5(7), pp 650-653

³⁰ Gillam L (1999) ‘Prenatal diagnosis and discrimination against the disabled’ *Journal of Medical Ethics* 25, pp 163-171

The contentious nature of disability is reflected in these descriptions and debate that continues. As people are individuals they will have their own view on what they regard as a disability or impairment and this will depend on their own interests and the harm that may result to those interests as a consequence of the impairment or disability. A person who does not enjoy sport may not be bothered by their moderate asthma whereas a keen athlete may find his limited respiratory function disabling, placing limits on what he is able to achieve. Whether or not a physical or mental abnormality or disease, therefore, causes disability depends on the view of the individual and for those who are not yet born may depend on the view of their prospective parents who may or may not have experience of the condition their fetus is affected by. The decision, therefore, as to whether an abnormality will be significant enough to warrant prenatal testing, or indeed termination of an affected pregnancy, should be dictated by those who are going to be affected by it personally. This supports my arguments in chapter three where I discuss the importance of enhancing reproductive autonomy.

Those who have personal experience of a condition, or who have had a previously affected child or family member, will obviously be well placed to fully understand the implications such a diagnosis will have for them and their future child. It is essential for those with no prior experience of a disabling condition to be provided with the necessary information they need to be able to make an autonomous decision about prenatal testing and its consequences. This will avoid decisions being made based on negative assumptions about a disabling condition. It should not be for those with disabilities or their advocates to decide when prenatal testing and termination of pregnancy should be allowed, nor should it be for the healthcare professionals to decide alone, particularly in the case of late terminations. It is only those who will be directly affected who can truly know what impact having a disabled child will have and the harm this may cause to their interests. Whilst the life of the future child should always be an important consideration in making these decisions, it should not be the only consideration. The interests of those who are already born, and who have full moral status, should also play an important

part in the decision-making process, and the clinical geneticist may be well placed to ensure that this happens, as I will discuss in chapter six.

4.2.2 Health

As previously mentioned, when considering prenatal findings of abnormality whether this is physical, mental or biochemical, it is important to consider the impact this will have on the family in addition to the future individual. Health and disease have a significant impact on our well-being generally and I will consider the harm that may arise from a condition that results in a serious disability and the affect this may have on that person's interests, in addition to the interests of its parents and wider family. In doing so I will consider the different accounts of health that have been put forward. This is important to my discussion on reproductive autonomy as it highlights how the identification of a disability in-utero, and the prospect of having a disabled child, may affect the lives of other autonomous people with their own interests.

Generally the actions and interventions taken by healthcare professionals are aimed at promoting health and normal functioning. In addition, doctors have a professional ethical duty to promote patient care and to act in the patient's best interest.³¹ What is in a person's best interests, however, can be open to debate and will depend on the individual circumstances and this reflects why autonomy is so important. I have discussed autonomy briefly in chapter one (section 1.4), and considered this further in chapter three (section 3.2) and specifically in relation to reproductive autonomy (section 3.6). This reflects the importance of allowing those with the capacity to decide for themselves what actions may or may not be in their own best interests, whether or not this accords with the view of those caring for them.³² When making decisions about whether or not to offer prenatal testing and termination of pregnancy the

³¹ General Medical Council (2013) *'Good Medical Practice'*, GMC: London

³² General Medical Council (2008) *'Consent: patients and doctors making decisions together'*, GMC: London

health of the future individual is considered and also what harm they are likely to experience as a result of their disability. Just as with defining disability, there are problems with attempting to provide a definitive account of what 'health' is. It is also likely to mean different things to different people in a similar way that disability does. For example, the World Health Organisation (WHO) definition of health is:

'Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity' (WHO Constitution 1946)

This definition is very broad and does not define the meaning of disease or infirmity, or for that matter, social well-being. At the time this definition was introduced it was felt to be ground breaking, overcoming the previous negative definitions of health as being the absence of disease.³³ This definition of health was felt to benefit from the inclusion of physical, mental and social domains. However, if this definition is to be applied to all individuals one would find that very few people could be regarded as truly healthy. The word 'complete' in the definition would suggest that even minor ailments constitute a lack of health and even a minor physical abnormality could render someone impaired, despite this having very little impact on their day to day life or well-being. As a result of this the definition has subsequently faced criticism but has never been adapted.³⁴

Most people have some physical or mental difference about them, no matter how minor, that would exclude them from being healthy in terms of this definition. A person with asthma or diabetes can lead a fully independent life, and provided they are compliant with the appropriate treatment and have a

³³ Huber M (2011) 'How should we define health?', *British Medical Journal* **343**, d 4163 (www.bmj.com as cited on 7 June 2013)

³⁴ Larson JS (1999) 'The conceptualization of health', *Medical Care Research & Review* **56**, pp 123-136

‘healthy lifestyle’ they may not be bothered by their condition at all. The current WHO definition could result in the threshold as to who could be described as disabled being lowered and it could encourage medical intervention or screening of ‘conditions’ that in reality are not of any real significance. With an increasingly aging population and better treatments allowing those who may once have not survived live longer, there will be more and more people who fall foul of this definition.

A further consideration with regards to this definition is that with health comes social well-being. A person can be physically and mentally healthy but may be in a difficult social situation. For example, they may have good physical health but be financially insecure or in an abusive relationship. They may have a lonely existence which may then have a negative impact on their interaction with society. Similarly, a person with a medical condition can still have social well-being and a good support network despite their illness. Social well-being may be influenced by unemployment rather than an illness and, therefore, arguably ‘unemployment’ would be a health problem resulting in the risk of living in poverty or feeling excluded from society and one’s peers. As well as considering the physical and mental health of the future person the fetus will become it is also important to consider these other factors which are likely to be influenced by the prospective parents and the type of life the future child will be born into.

Due to the criticism that the WHO definition has faced others have put forward their own theory of what health is. Bircher has described health as ‘a dynamic state of well-being characterised by a physical and mental potential, which satisfies the demands of life commensurate with age, culture and personal responsibility.’³⁵ For the purposes of my thesis this definition has its advantages as it takes into account other variables as well as the physical and mental components of health. These other variables may be influenced by an individual’s own belief systems, aspirations and interests and,

³⁵ Bircher J (2005) ‘Towards a dynamic definition of health and disease’, *Medicine, Health Care and Philosophy* **8**, pp 335-341

therefore, what one person may consider to impair their health, another may not. These differences in perceptions of health highlight the importance of encouraging deliberation and autonomous decision-making and support the arguments I made in relation to reproductive autonomy in chapter three.

It is important to consider these concepts of health and disease when considering the ethical issues that accompany decisions made by healthcare professionals and parents when contemplating the use of prenatal testing. The concepts have a profound effect on medical practice and the formation of health care policy, including the provision of prenatal testing and screening. Whether or not a condition is considered to be a disease will affect whether or not funding is available for treatment or screening and whether preventative measures are taken to limit the condition or reduce its effects, as healthcare services aim to keep people close to normal functioning and preserve their ability to participate in society.³⁶ With respect to prenatal testing, what one person may consider being a disease for which they would want testing, another person may not. Different people will have different perceptions of what harm a condition may cause and this in turn is likely to influence their reproductive decisions. It is for these reasons that when making decisions about offering prenatal testing and subsequent abortion healthcare professionals engage with the prospective parents throughout the entire process, particularly where late termination of pregnancy is being considered. Consideration needs to be made as to what health means to them and how the existence of a disability is going to impact on the future child's life within the parameters of that particular family. The impact it is going to have on the health and well-being of the parents and pre-existing children needs to be considered, taking their own personal circumstances into account.

³⁶ Daniels N (2001) 'Justice, Health and Healthcare', *The American Journal of bioethics* 1(2), pp 2-16

4.2.2.i Theories of health

Debate about the concept of disease has led to the idea of health being a natural concept or alternatively a normative concept concerning the role of values. These theories of health include Naturalists³⁷ who believe that whether or not a person is healthy depends upon biological or physiological factors and then those who argue that health is a 'normative' or 'evaluative' issue.³⁸ In the latter case health and disease are regarded as concepts of 'welfare' or 'well-being'.

Normativists consider health and disease to be at least partly socially constructed and value laden.³⁹ If a person is ill they conclude that they have a condition that is harmful to them and they define disease in terms of harm. This theory is important when considering prenatal testing as it takes into account what will enable us to lead a good or worthwhile life. It considers a person's interests and how someone can be made worse off by having these interests impaired.⁴⁰ This means that rather than a disease or abnormality itself being considered harmful it takes into account how that disease or abnormality may affect the individual concerned. Being colour blind may be considered to cause harm to a person by preventing them from fulfilling their ambition of becoming a pilot, thus harming their interests, whereas it may be of no consequence to another person whose inability to distinguish between certain colours does not cause them any disadvantage. This then allows consideration to be made of the effect that a condition has on the subject, rather than assuming something is harmful because it prevents completely normal functioning. It takes into account whether that functioning really matters to the subject. As Reznick puts it 'Harm only consists in the malfunction of systems worth having, or the frustration of worthwhile pleasures, or the frustration of worthwhile desires'.⁴¹ This is important when we consider

³⁷ Boorse C (1975) 'On the distinction between disease and illness', *Philosophy & Public Affairs* **5**, pp 49-68

³⁸ Engelhardt H T Jr (1975) 'The concepts of health and disease' in Engelhardt Jr HT, SF Spicker (eds) *Evaluation and Explanation in Biomedical Sciences*, Dordrecht: D Reidel, pp 125-141

³⁹ Hamilton RP (2010) 'The concept of health: beyond normativism and naturalism', *Journal of Evaluation in Clinical Practice* **16**(2), PP 323-329

⁴⁰ Van Hooft S (1997) 'Disease and subjectivity' in JM Humber, RF Almeder (eds) *Biomedical Ethics Review: What is disease?*, Springer Science + Business Media LLC, New York, p 295

⁴¹ Reznick L (1987) *The Nature of disease*, Routledge & Kegan Paul: London and New York, p 152

prenatal testing. Consideration needs to be made as to how that individual future child will be affected by that particular impairment and potential disability. Whilst the specific abnormality and the disability that it is known to cause would need to be taken into account (which may be based on the lives of those living with such disability) emphasis needs to be placed on the circumstances of the individual and how it will affect them specifically. However, whilst healthcare professionals give consideration to the future child it is also important to consider the impact of the disability on the prospective parents and other close family members. The existence of this child will inevitably impact on their interests too, with the potential to cause them harm. If the interests of the fetus, who does not yet have full moral status, are to be considered then so too should the interests of those already in existence, who do have full moral status.

Naturalists view the concepts of health and disease as being objective and value free rather than being socially constructed.⁴² For example, a Naturalist would argue that whether an organ was diseased or healthy is an objective opinion, for example, made by a doctor. Whether or not this diseased state is of value is a completely separate matter.⁴³ Boorse has written extensively on this issue and defends the Naturalist position, emphasising the importance of function.^{44,45,46,47} Boorse discusses the more biological theory of health, where health is a scientific concept rather than a moral one. In this theory health equals the absence of disease and disease is any condition that causes an organism, or part of it, to function below 'normal'.⁴⁸ This takes into account the age and gender of a species when considering what normal function is, but limiting this theory is the fact that it only considers normal function in relation to individual survival and reproduction. This would mean that a person who could not have

⁴² Kovacs J (1998) 'The concept of health and disease', *Medicine, Health care and Philosophy* **1**, pp 31-39

⁴³ Ruse M (1997) 'Defining disease: The question of sexual orientation' in Humber JM, Almeder RF (eds) *What is disease?*, Springer Science + Business Media, LLC, New York, 1997, p 147

⁴⁴ Boorse C (1987) 'Concepts of health' in Van De Veer D, Regan T (eds) *Health Care Ethics: An introduction*, Philadelphia, pp 359-393

⁴⁵ Boorse C (1976) 'What a theory of mental health should be', *Journal of the theory of social behavior* **6**(1), pp 61-84

⁴⁶ Boorse C (1977) 'Health as a theoretical concept', *Philosophy and Science* **44**(4), pp 542-573

⁴⁷ Boorse C (1975) 'On the distinction between disease and illness', *Philosophy and public affairs* **5**(1), pp 49-68

⁴⁸ Boorse C (1975) 'On the distinction between disease and illness', *Philosophy and Public Affairs* **5**(1), pp 49-68

children for some biological reason would be regarded as having a disease.⁴⁹ If that person, however, had never wanted children and, therefore, the biological reason for their infertility was irrelevant it is then difficult to conclude that this has harmed them. In fact a person may never be aware of this biological dysfunction if they never tried to have children and therefore would never be regarded as unhealthy.

As well as considering what it is to be healthy it is also important to consider what constitutes disability and whether this results in harm. From a Normativist point of view this would depend on whether the interests of that person had been impaired by the condition that results in the disability. With regards to prenatal testing and the decisions about the fetus that may follow, I agree with this theory as it takes into account how the physical abnormality found within the fetus may affect its future interests, and also how it may affect the current and future interests of those directly affected who have full moral status. It doesn't assume that impairment will inevitably result in a disability or harm.

It is clear that different approaches can offer very different accounts of health and disease and it is important to establish which one is most pertinent to my argument that prenatal testing does not discriminate against those with disabilities. I have agreed with Reznek's view of harm and the Normativist theory of health in that harm occurs when the interests of an individual are interfered with, and harm is therefore at least partly subjective. A condition that is classified as a disease due to, for example, loss of the functioning of an organ, body system or a metabolic pathway may not necessarily result in harm to the individual. It would very much depend on how the disease process affected that individual's interests and desires and this would therefore be different for different people. Arguably the difficulty faced, however, is that with regard to prenatal testing it is a future person that is being

⁴⁹ The WHO has recently classified infertility as a disability according to their website www.who.int *Infertility definitions and terminology* (as cited on 28 October 2016) and reported in the Daily Express 'Failure to find a sexual partner is now a DISABILITY says World Health Organisation' 24 October 2016

considered and, therefore, one which has limited interests. When parents make decisions about their unborn child they do not know what specific interests that child will have and how their congenital abnormality may affect them personally, or whether it will cause them harm. It is necessary, therefore, to make decisions on behalf of the fetus and this is similar to the way in which parents make decisions on behalf of young children who do not have the capacity to make decisions for themselves. There are, however, interests that generally all human beings share. We have an interest not to be in pain or to be suffering and we have an interest in perceiving and experiencing pleasure. An abnormality that interferes with these interests therefore may be one that parents would opt to have testing for so that the harm to these interests can be avoided. This may either be by termination of the affected pregnancy, thus preventing that child's existence at all, or if possible, by treating the condition in-utero or immediately after birth.

As prenatal testing results in the provision of information about a future person I would like now to address the issue of harm in relation to whether or not a future person, who is found to have an impairment once prenatal testing has been performed, can be harmed by being brought into existence. On the face of it, it would appear that the answer would be in the affirmative depending on the severity of the abnormality found. If the pregnancy continues and one assumes that the impairment will cause significant pain and suffering the future person would be harmed by being born. This intuitive response reflects the views of Harris⁵⁰ and Savulescu⁵¹ who argue that there is a moral obligation to bring to existence the best children we possibly can. They do this from society's perspective and from the point of view the negative effect having a disability has on the world generally. Harris also talks of 'the wrong of bringing avoidable suffering into the world'.⁵² However, one needs to consider that this person

⁵⁰ Harris J (1985) *The value of life: An introduction to medical ethics*, London: Routledge & Kegan Paul, pp 146-149

⁵¹ Savulescu J (2001) 'Procreative Beneficence: Why we should select the best children', *Bioethics* **15** (5/6), pp 413-426

⁵² Harris J (1998) *Clones, Genes and Immortality: Ethics and the Genetic Revolution*, Oxford University Press, p 111

was never going to be born without a disability. The options for this person were to be born with a disability or not to be born at all.

The question, therefore, is whether the future person is better off being born with the disability as opposed to not being born or coming into existence at all.⁵³ This may depend on the severity of the disability but may apply to other fetuses that have no disability. A child with a significant mental or physical impairment could be born into a loving supportive environment and be given all that he or she should need in the form of emotional and welfare support. Despite the disability the child will be offered the best life that it is possible for them to have. On the other hand, a child with no such disability could be born following an unwanted pregnancy into a life of poverty and abuse and feel that their life is so terrible as to be not worth living. This person has arguably been worse off than the loved and nourished child with a disability. It is for these reasons that it is necessary to not only consider the physical or mental disability that may result from the abnormalities found in the fetus, but to also consider the wider implications and the circumstances in which the future child will be born. This information also needs to be sought by healthcare professionals when considering whether or not prenatal testing and, more significantly, termination of pregnancy should be made available on the basis of fetal abnormality. Fetuses with the same abnormality, but born into different circumstances, may have very different experiences, as may their families whose interests also need to be taken into account.

As there is a potential for prospective parents to request a termination of pregnancy due to the discovery of a fetal anomaly consideration needs to be made as to how this anomaly is going to cause harm. This is harm not only to the future child but also to those who will be directly affected by it, such as the parents and pre-existing children. The disability or physical anomaly should not necessarily be considered in isolation with regards to the fetus alone or based only on how the anomaly has impacted

⁵³ Parfit D (1984) *Reasons and Persons*, Oxford University Press, p 356

on similarly affected individuals, as experiences vary between different people and different families. In view of the fact that harm can be caused to others decisions are better made based on how they will affect all of the subjects involved, taking into account their views, needs, interests and their own personal circumstances and how these may be harmed.

4.3 When death or non-existence may be a preferable option

In this section I only consider the impact of a disability on the future person when deciding whether or not prenatal testing and termination are justifiable and leave aside the impact on other family members. In considering the future person only we need to think about how the disability is going to affect them and whether or not its effects will result in a life that is so blighted by pain and suffering that it would be better not to have continued. This is something that those healthcare professionals working in fetal management consider when discussing the appropriateness of offering testing and more importantly when making the difficult decision as to whether they will sanction a late termination of pregnancy based on fetal abnormality.⁵⁴

Buchanan et al describe a life that is not worth living as one which is not just worse than the lives of most other people, or a life with substantial burdens, but from the perspective of the person whose life it is so burdensome and without any benefits to compensate for this as to make death a preferable option.⁵⁵ How this is qualified in reality is very difficult.⁵⁶ Having a disability does not necessarily mean that a person's life will not be worth living and what worth a life has is very subjective and will

⁵⁴ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England and Wales: Report of a working party*, London: RGOG, pp 8-10

⁵⁵ Buchanan A, Brock DW, Daniels N, Wikler D (2000), *From Chance to Choice: Genetics & Justice*, Cambridge University Press, p 224

⁵⁶ There are certain examples of extreme disorders and diseases that are often referred to in the literature, such as Tay Sachs disease, where the short and terrible life of the individual would be so bad as to make the concept of a life worth living meaningless in such a context. I acknowledge that there may be some very extreme cases but that many other cases will be much more difficult to judge.

not only relate to a person's physical or mental well-being but also financial and emotional well-being, amongst other things. Many people with disabilities have very rewarding and fulfilling lives contributing much to society and in some cases much more than their non-disabled counterparts. Positive accounts from those living with disabilities reinforce the arguments put forward by those representing disabled people that oppose prenatal testing as devaluing the lives of people with disabilities. These accounts are very persuasive and rightly raise the question as to whether or not the presence of disability is a good enough reason to seek out abnormalities in the antenatal period, with the possibility of ending a pregnancy which is shown to have some form of mental or physical difference. These accounts, however, may not be representative. Some of those whose opinions and views are put forward in support of the disability argument are those who have positive life experiences⁵⁷ and, therefore, whilst important, these views may have only limited value. This is an issue which I discuss in more detail in chapter five (section 5.3) in arguing that prenatal testing does not discriminate against those with disabilities. The other concern is that positive life experiences that are put forward by those who have the intellectual capacity to do so. Those with disabilities who argue against prenatal testing and termination of pregnancy are therefore a selective group, and what we often do not have the benefit of is the views of those who do not survive long enough, or those who do not have the necessary mental capacity, to put their views forward. For these individuals the only views we are able to obtain are those of the people who care for them, such as the healthcare professionals, parents and other family members. Healthcare professionals may be able to provide objective information and clinical evidence to inform decisions about whether or not a life may be worthwhile. Parents on the other hand, and those close to the disabled person, are better placed to give subjective views and hence judgements on the quality of life of their loved one and, importantly, how it has also affected their own life and interests and what harm they may have come to as a result of having a severely disabled member of their family.

⁵⁷ Wilkinson M (2009) *Defying disability: The lives and legacies of nine disabled leaders*, London: Kingsley, pp 79-98

Feinberg⁵⁸ acknowledges that there are those people in adult life who, due to their personal circumstances, feel that they would be better off dead. In doing so they are not suggesting that ‘non-existence’ is another option along with true existence as a living person but that not to exist is preferable to the life they are experiencing.⁵⁹ Similarly, there may be situations where views may be expressed that a neonate, by reason of its severely anomalous congenital mental or physical condition, would be better off not having been born. Non-existence is felt to be preferable to the life the person is going to have if they are born, and in these cases any medical treatment may be withheld.

The fact that there are people, however, who are willing to end their lives or argue that they should never have been born due to the physical effects a medical condition may have on them, provides evidence to support the fact that sometimes life can be so unbearable that it is better not to exist. Those who are able to end their own lives make this decision themselves based on the harm their condition is causing to their own interests. However, decisions to discontinue the life of a fetus and prevent the existence of the future child can only be authorised by third parties. In order to ensure that these decisions are made appropriately all parties need to be sufficiently informed about the potential harms or benefits that continuing the pregnancy may have for the future child and those with full moral status who already exist and will be personally affected.⁶⁰ These need to be deliberative discussions which focus not only on the clinical findings and difficulties that may subsequently arise but also the positive aspects of having this child. The prospective parents need to have an opportunity to properly consider what life would be like in view of the disability, not only from the perspective of the healthcare professionals but also from those with such a disability and those who have cared for them or grown up

⁵⁸ Feinberg J (1992) *Freedom and fulfilment*, Princeton University Press, p 17

⁵⁹ Feinberg J (1987) ‘Wrongful life and the counterfactual element in harming’, *Social Philosophy and Policy* 4(1), pp 145-178

⁶⁰ A more controversial view is that of David Benatar. In response to Feinberg, Benatar argues that to consider whether or not a life is worth *starting*, in other words a future life, is very different to considering whether a life is worth *continuing* or not, that is a present life. Benatar’s problem with this is that judgements are being made about a future life based on the standards of a present life. As Benatar points out the threshold for both can be very different.

with them, and whose interests may also have been affected either negatively or, just as importantly, positively.

If a congenital abnormality is identified in pregnancy, whether or not it is compatible with life or even a life that despite the abnormality has value, parents may choose to have that pregnancy terminated. However, an adult with that same abnormality, for example an absent limb, is unlikely to feel that ceasing to exist would be preferable to continuing their life without their limb. It is likely, depending on the circumstances, that they have got on with life reasonably well despite this. This takes us back to the subject of the moral status of the fetus which I considered in chapter 2 (section 2.3), and the fact that one cannot compare ending the life of a fetus with that of an adult, who has full moral status.

Some argue that after delivery a person has full moral status,⁶¹ in addition to full legal worth. Euthanasia is not legally permitted in the UK. Prior to birth, however, debate continues as to when the conceptus, embryo or fetus becomes a moral agent; arguments that I will not repeat here.^{62,63} There is an acknowledgement in the Abortion Act that thresholds should be different depending on development or gestation of the fetus. According to the Act congenital abnormalities that are not deemed to be severe enough (although severity is not defined by the Act) in the opinion of two medical professionals cannot be used as a reason to terminate a pregnancy after twenty-four weeks of gestation. An absent limb, for example, is unlikely to fall into this category of allowing a late abortion, whereas a condition that resulted in severe mental handicap or a severe life limiting condition such as Thanatophoric Dysplasia⁶⁴ would. The justification for a late termination of a pregnancy for those conditions that are deemed to

⁶¹ Finnis J (2013) 'Capacity, harm and experience in the life of persons as equals', *Journal of Medical Ethics* **39**(5), pp 281-283

⁶² Jones D (2001) 'A theologian's brief: on the place of the human embryo within the Christian tradition and the theological principles for evaluating its moral status', *Ethics & Medicine* **17**(3), pp 143-153

⁶³ Jensen D 'Birth, meaningful viability and abortion', *Journal of Medical Ethics* **41**, pp 460-463

⁶⁴ Thanatophoric Dysplasia is a form of severe dwarfism resulting from a gene defect. The rib cage is so badly affected that the lungs cannot develop in-utero. The vast majority of affected pregnancies result in death in-utero. In others death generally occurs at or very soon after birth.

be severe enough is based on information and judgements made largely by medical professionals who have clinical knowledge of such conditions. There are, therefore, those abnormalities that are not felt to justify preventing the future person from existing, just as there are those conditions that do not justify an existing person with a present life from wanting it to cease. What healthcare professionals do not tend to take into account is the impact that specific abnormality or condition will have on the future child when born into the circumstances that it will find itself, or the impact on other close family members. As I will discuss in chapter six my concern is that rather than considering that individual future child it is the specific abnormality or abnormalities and the disabling condition that it may lead to, and what is known about this clinically, that informs the decision as to whether a termination on the basis of severe disability should be allowed.

For those adult individuals who feel that their life is not worth living⁶⁵ death may be preferable to existing due to their own personal circumstances. The fetus cannot consider this option itself and, therefore, this is done on its behalf based on the life they are expected to have. There are those who, all things considered, would prefer not to exist at all as evidenced by the fact that euthanasia is available in some countries and is used by those who no longer wish to live. These individuals provide evidence to support the view that non-existence can in fact be preferable to living if the view is that the life that exists is not worth living and death is a preferable option.

⁶⁵ Feinberg J (1987) 'Wrongful life and the counterfactual element in harming', *Social Philosophy and Policy* 4(1), pp 145-178

4.4 Other reasons to support prenatal testing –

minimising disability after birth

Although termination of pregnancy is one outcome following prenatal testing it is not the only outcome. Prenatal testing can bring benefits to the prospective child and their family, whose interests may also be affected, by preventing or limiting disability. This can occur without terminating the life of the fetus just as medical interventions after birth can assist those already living with disability, and thus both may improve the lives of disabled people. Prenatal testing in this context therefore does not discriminate against those living with disabilities, just as treatment after birth is not considered to be discriminatory.⁶⁶

Opposition to prenatal testing is due to the possibility of termination of pregnancy being a consequence of finding a congenital abnormality, thus preventing a disabled person being born. Those representing disabled people argue that reproductive selection to terminate future children with abnormalities sets an agenda for devaluing those with disabilities, particularly if this is due to a condition that is not amenable to treatment.⁶⁷ Prenatal testing itself, however, can provide information that may result in other outcomes that may be of benefit not only to the parents but the future child themselves. Had prenatal testing not taken place in these cases a child would have been born with a disability that could otherwise have been limited or avoided altogether. Without prenatal testing, therefore, as well as the child being denied the opportunity of being born without an abnormality, or at least a less severe one, by being denied the benefits which in-utero treatment can bring, avoidance of harm to the interests of the wider family would also have been prevented. In this section I will consider what benefits prenatal testing can provide in terms of avoiding or minimising disability in the future person. I argue that prospective parents should not be denied the opportunity to gain information about their pregnancy that

⁶⁶ I acknowledge that there is debate over the use of Cochlear implants in Deaf people who do not regard deafness as a disability and not something that needs to be treated.

⁶⁷ Saxton M (2013) 'Disability Rights and Selective Abortion' in David LJ (ed) *The Disability Studies Reader*, Routledge, pp 87-90

can in turn deny them the opportunity to prevent congenital anomalies from harming the future child and from making autonomous decisions in relation to reproduction.

Prenatal testing can avoid or limit disability where an abnormality is identified in a developing fetus for which it may be possible to treat in-utero and consequently result in a healthy baby with little or no residual disability. Alternatively, testing could provide vital information to allow the birth to take place in an appropriate obstetric or surgical environment so that treatment can be provided at birth to minimise any immediate or ongoing risk to the child. Diagnosis of a diaphragmatic hernia,⁶⁸ for example, picked up on antenatal scan could allow appropriate specialised resuscitation to be given at birth rather than standard resuscitation techniques that could be potentially be harmful to a neonate with this particular type of abnormality. A metabolic condition diagnosed antenatally by genetic or metabolic testing could be treated immediately after birth to prevent significant neurological damage or the pregnant woman could amend her diet during the pregnancy to minimise the effects of the condition on the fetus. Congenital Adrenal Hyperplasia is a recessive genetic condition which results in ambiguous genitalia and in a male fetus can cause a life threatening electrolyte disturbance and dehydration if not detected early. Identifying this condition during pregnancy provides the woman with the opportunity to take steroids resulting in a significantly reduced possibility of the phenotype developing. These examples support the use of prenatal testing in the best interests of the fetus and future person and the additional benefit of avoiding costly ongoing treatment that would be necessary had any of these conditions been present after delivery.

Giving parents the opportunity to have prenatal testing under these types of circumstances not only protects the interests of the fetus but also the interests of the parents and other family members. Intervention may be possible that prevents or reduces harm to the fetus by reducing the impact of the

⁶⁸ Diaphragmatic hernia occurs where the diaphragm does not develop properly allowing the abdominal contents to herniate into the thorax thus preventing normal lung expansion at birth. Normal resuscitation techniques are ineffective putting the neonate at risk of anoxia and neurological damage.

disability on their future life and by reducing or preventing pain and suffering that they may otherwise have experienced. The parents and wider family experience less harm in that their own interests have been preserved. The parents will not have to face the emotional distress and financial burdens of raising a disabled child (or experiencing its shortened survival) and the lives of other children in the family will not be impacted upon by having a sibling with a disability.

Following prenatal testing and intervention the same person will be born who would have been if this had not taken place. Prenatal testing in these circumstances, as opposed to it being followed by abortion, will result in the birth of a person whose personal identity remains unchanged. Rather than comparing life with non-existence we are comparing life with a disability, in the absence of prenatal testing, and a life without disability after prenatal testing and when appropriate intervention has taken place. Harm has been reduced or avoided and as a consequence the same individual has benefitted from prenatal testing being performed.

Whilst this highlights the potential benefits of prenatal testing inevitably not all prospective parents are going to be in a position where the abnormality identified in their pregnancy is amenable to treatment. Some are going to be faced with the fact that the abnormality that has been found cannot be treated and if the condition is compatible with an ongoing pregnancy their child will be born with an impairment which may or may not result in disability. Again, genetic counselling and input from other healthcare professionals or families of affected children may have some influence on what the parents may decide. The decision to terminate that pregnancy is only one option.

Prenatal diagnosis of a condition may benefit the future child in other ways. A child with a chromosomal abnormality, for example Klinefelter's syndrome,⁶⁹ can have a much better outcome if it is identified in the antenatal period rather than as an adult when it is often diagnosed incidentally during investigations for infertility. If a child is known to have this chromosomal change intervention can be taken early from an educational point of view to allow them to reach their full potential. Testosterone therapy can begin at a prescribed time to allow appropriate development of male secondary sexual characteristics and aid fertility.⁷⁰ Similarly, in another sex chromosome abnormality, 47XYY syndrome, a male has an additional Y chromosome. There is empirical evidence to show that men with this additional chromosome have behavioural and intellectual difficulties.⁷¹ If this is detected in-utero allowance can be made with regard to the child's behaviour and support given to the family and child to minimise this and improve behaviour and educational attainment. This is another example of prenatal testing providing an opportunity to improve the quality of life of a child who, without it, would have been unaware of why they had been faced with the challenges that they had in life, and therefore promoting their interests.

Even where treatment is not available being aware of an abnormality in the child before birth will also allow expectant parents and other family members, such as siblings, to prepare themselves emotionally, practically and financially for the arrival of a child who may have special requirements. Similarly, if the fetus is diagnosed with a life limiting condition in-utero, rather than the time spent immediately after the birth being marred by intrusive and painful investigations in an attempt to establish why the neonate is unwell, it can be used more appropriately to allow the family to spend quality time with the

⁶⁹ Klinefelter's syndrome is caused by an additional X chromosome in a male fetus (47XXY). Males born with this condition have low levels of testosterone and fertility problems. They may also suffer from osteoporosis and have some mild learning difficulties.

⁷⁰ Lanfranco F, Kamischke A, Zitzmann M, Nieschlag E (2004) 'Klinefelter's syndrome', *The Lancet* **364** (9430), pp 273-283

⁷¹ Baker D, Telfer MA, Richardson CE, Clark GR (1970) 'Chromosome errors in men with antisocial behavior: Comparison of selected men with Klinefelter's syndrome and XYY chromosome patterns', *The Journal of the American Medical Association* **214**(5), pp 869-878

child and possibly take the child home to die in a dignified way, preventing a clinical death in hospital.⁷² This type of scenario is one that is not taken into account by the social model of disability or by those opposing prenatal testing. No amount of social or environmental change could avoid this outcome. If testing does not take place the child will not survive but may have been exposed to medical interventions that are ultimately futile. The child may have suffered as a result of this and have been harmed, despite the best intentions of those caring for them. No doubt the parents and wider family would also have suffered emotionally. No benefit will have been gained and resources that could have been used more appropriately by others have been wasted.

Not having had prenatal testing under these circumstances would not cause the harm (the impairment) from occurring but it would not have allowed the harm to be at least minimised. Although the positive aspects of prenatal testing are therefore clear from the point of view of the treatment options and benefits it can bring, this does not address the concerns raised by those representing disabled people. Prenatal testing, as well as bringing the benefits I have described, does in other cases lead to termination of pregnancy and therefore the arguments relating to discrimination still exist. Representatives of disabled people could argue that prenatal testing could be permissible but only if it did not lead to abortion. It seems implausible to enact such a policy and may be rebuttable as an ethical position in itself. It is difficult to see how a policy, which may promote prenatal testing so that treatable conditions can be identified, can also limit parental choice for those pregnancies where an untreatable condition is diagnosed. I have argued in chapter two that the fetus does not have full moral status and, therefore, terminating a pregnancy cannot be compared with ending the life of a person with a disability. I have also argued for the overwhelming importance of reproductive autonomy in chapter three. Taking both of these arguments into account in addition to the harms that can be caused to others, such as the

⁷² Testing in the neonatal period could have been performed, such as Whole Genome Sequencing, to establish a reason why the child had been born with an abnormality but this would not have allowed the parents or doctors to be prepared before the birth. Prior to the neonatal result being available the baby may have been subject to intensive medical intervention before a diagnosis was established. In circumstances where such treatment is futile and this information is known before birth, this intervention can be avoided in the immediate postnatal period and the family can be left to spend quality time with their child.

prospective parents, and potential benefits prenatal testing can bring, I argue that prenatal testing is ethically preferable even if it does lead to some terminations and their concomitant potential for disability groups to argue that this is discriminatory. I will discuss the concerns about the discriminatory nature of prenatal testing further in chapter five.

4.5 Summary and conclusions

In this chapter I have discussed the models of disability and have identified that these models do not offer assistance when considering disability and prenatal testing. The medical model does not take into account those who have impairments but are not affected in any significant way by them or those who have an impairment or loss of functioning that can easily be overcome providing society responds to their needs. The social model, which is advocated by those with disabilities, does not take into account those people who are so severely affected by their impairments that any amount of social modification cannot remove or diminish their disability.

I have discussed the complex issue of harm and whether or not an affected fetus can be harmed by being brought into existence. I have agreed with the Normativist view with regards to harm in that it is at least partly subjective. Harm should be considered with respect to the implications it has on a person's interests, rather than the physical or mental abnormality itself which may be of no, or very little, significance. I have concluded that whilst a fetus with a congenital abnormality could only ever either not exist or exist with a disability (the third option of living without disability not being available) there are circumstances where the life of the future child may be so affected by pain and suffering that termination of that pregnancy and, therefore, non-existence may be preferable. In taking these issues into account it is important to reflect back on the relevance of reproductive autonomy and allowing those whose interests are going to be affected by the birth of a disabled child to take precedence.

There is often the assumption that prenatal testing will inevitably lead to abortion. I have provided clear examples where this can be avoided and where, in fact, prenatal testing can bring advantages and benefits to the fetus and family. This may be by treating the condition prior to or immediately after birth or by allowing conditions to be identified so that behaviour toward the future child and adult can be modified so that the consequences of the condition are reduced. Prenatal testing with the identification of a genetic condition gives parents the opportunity to gain information from those who are in a position of knowledge and able to help them decide whether they personally can cope with what the future holds. In addition to my arguments about reproductive autonomy in chapter three, I have discussed why it is the parents and those who would be close to the affected child if it were born who are best placed to make decisions after prenatal testing has taken place. I have discussed the implications of disability with respect to harm to the interests of the fetus and other third parties and how this can only be truly determined by those directly affected, supporting my arguments for reproductive autonomy. In order to ensure that these interests are considered during the decision-making process, particularly by the doctors whose role it is to establish the justification for late termination, it is important for constructive dialogue to take place between all parties, including the prospective parents. As the clinical geneticist is involved with the prospective parents from an early stage in the process they will be well placed to establish a supportive relationship with them and be in a position to put their views forward during discussions about fetal management. I will discuss this further in chapter six. In the chapter that follows I will review the representations that are made by, and on behalf of, those living with disabilities and the concerns that they have that prenatal testing, where it is followed by selective termination, is discriminatory and the implications this may have for disabled people. I will use my arguments in relation to the moral status of the fetus in chapter two and reproductive autonomy in chapter three to support my view that prenatal testing does not promote discriminatory attitudes towards disabled people or disability.

Chapter 5

Responding to disability discrimination arguments

5.1 Introduction

In July 2013 abortion on the grounds of disability was subject to a parliamentary inquiry. The report that followed stated that ‘The vast majority of those who gave written evidence believe that allowing abortion up to birth on the grounds of disability is discriminatory’.¹ The inquiry heard views and opinions from a number of groups including healthcare professionals, disability support groups, parents of disabled children and those who had been through the experience of prenatal testing. Therefore clinical geneticists, as well as satisfying themselves that abortion is not morally wrong, also need to satisfy themselves that abortion on the basis of fetal abnormality is not discriminating against those with disabilities.

In chapter two, I discussed the arguments around the moral status of the fetus, particularly in relation to discrimination towards the disabled fetus and the fact that abortion on the basis of disability is permitted up to birth if this is felt to be serious enough. There are those who argue that ending the life of a fetus due to it being affected by an anomaly that is likely to cause disability discriminates against those already living with disabilities.² However, I argued that the fetus does not have full moral status whereas a person living with a disability does and, therefore, terminating the life of any fetus, whether disabled or not, cannot be compared to ending the life of a person who is already in existence.

¹ Parliamentary Inquiry into Abortion on the Grounds of Disability (2013) (www.abortionanddisability.org as cited on 17 September 2015)

² Gillott J (2001) ‘Screening for disability: a eugenic pursuit?’, *Journal of Medical Ethics* **27**, pp ii21-ii23

I also discussed the argument that the fetus itself (regardless of whether it has the same moral status as a living person), if disabled is discriminated against as compared to a non-disabled fetus, due to the fact that termination of a pregnancy affected by a severe abnormality can take place up to birth, whereas termination of a pregnancy where no condition has been identified in the fetus cannot take place beyond twenty-four weeks.³ Relevant legislation therefore uses the point of viability of the fetus (24 weeks) as a limiting factor for terminating a pregnancy where the fetus is not affected by a serious congenital condition. In chapter two, I identified the inherent problems with this legislation with respect to the implications it has for being discriminatory against those with disabilities. As well as their own ethical views and considerations, specialists in fetal management will rely on the legislation to influence and inform their decision-making when considering whether or not a late termination of pregnancy on the basis of severe disability is justifiable. It is important for specialists to make their decision not only in response to the legislation, but also to be able to justify their decision morally and ethically. Not being able to do so may make them vulnerable to the criticisms of those representing disabled people. My arguments in support of prenatal testing, particularly where it leads to late termination of pregnancy, reinforce the fact that doctors working in this area need to carefully consider the decisions they are making and ensuring that prospective parents feature heavily in the process.

On the face of it late termination of pregnancy due to severe disability does suggest that a disabled fetus has less worth, as its life can be ended at any point during gestation, whereas the non-disabled fetus is protected once it reaches twenty-four weeks. This arguably expresses discriminatory attitudes towards disability. However, in response to this I argued in chapter two (section 2.3) that the decision to terminate the pregnancy of a disabled fetus is not based on this fetus having a lower moral status to that of an non-disabled fetus but is based on the predicted quality of life the future

³ Abortion Act (1967), HMSO: London, section 1(d)

child may have and the harm it, and those directly affected by it, may suffer. This led to my discussion in chapter three about the need for those who would be directly affected by the birth of the disabled child to make decisions for themselves and for their reproductive autonomy to be respected. I have discussed the concepts of harm toward the future child and to those who are directly affected by its birth in chapter four (section 4.2.2i).

In this chapter, I will concentrate on those disability rights arguments which object to prenatal testing and selective termination of pregnancy on the grounds that it discriminates against those people with disabilities.⁴ Here, discrimination is said to occur when one group of people (non-disabled), assume what the life of another group (disabled) must be like and assume that if their lives are not like theirs, they are disadvantaged in some way.⁵ Discrimination can also be regarded as making judgements about people purely based on a particular group they are a member of which is seen as inferior by society,⁶ and where people are denied equal opportunities.⁷

I agree with these definitions in that assumptions are often made about the way in which impairment affects a person's life. There is a danger of non-disabled people comparing their own lives with that of a disabled person and assuming it is less worthwhile than their own because there are inevitably things that a disabled person may not be able to do, despite modifications to society. However, this in itself should not devalue a person or suggest that their life has lower value. People adapt to the situation they are in and may compensate in different ways. If someone has never been able to walk and has learnt to adapt to this, they may not feel that their life would necessarily be

⁴ Buchanan A (1996) 'Choosing who will be disabled: genetic intervention and morality of inclusion' *Social Philosophy and Policy* **13**(2), pp 18-46

⁵ Shakespeare T (1998) 'Choices and Rights: Eugenics, genetics and disability equality', *Disability and Society* **13**(5), pp 665-681

⁶ Campbell T, Heginbotham C (1991) *Mental illness: prejudice, discrimination and the law*, Dartmouth Publishing Co Ltd, pp 3-29

⁷ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled' *Journal of Medical Ethics* **25**, pp 163-171

any better if they did have the use of their legs. Only that individual is in a position to comment on the quality and value of *their* own life.

However, as I have mentioned in chapter 4 (section 4.2.2.i) there are some aspects of life that we can generally expect people to want and value, such as happiness and the avoidance of pain and suffering. Brock refers to ‘human functions that are necessary for, or at least valuable in, the pursuit of nearly all relatively full and complete human life plans’.⁸ There are some severely disabling conditions which inevitably impact on these aspects and, therefore, a non-disabled person may be just as well placed to have a view on this. The point is that general assumptions should not be made about the type of life a person will have if they are born with an impairment. Where this involves decisions about a future person adequate deliberation and discussion should take place between the prospective parents, whose interests will also be impacted by the existence of the future child, and the healthcare professionals with knowledge of the impairment and the disability it may cause, and the impact this will have on the life of the future child. Those who have first-hand knowledge of the impairment and potential disability in question should inform these discussions, where possible.

My position is that prenatal diagnosis does not in itself discriminate against individuals who have been born with or live with any form of physical or mental disability. Those who rely on the argument that prenatal testing discriminates against those with disabilities believe that performing procedures during pregnancy in order to identify abnormalities makes a negative judgement about the future life with a disability and suggests that life will not be worth living.⁹ However, as I will discuss, the claim that prenatal testing assumes that the lives of those with disabilities are of less value than a non-disabled person or that their lives are not worth living cannot be supported by the

⁸ Brock D (1993) ‘Quality of life measures in health care and medical ethics’ in Sen A, Nussbaum M (eds) *The Quality of Life*, Oxford: Oxford University Press, p 127

⁹ Shakespeare T (1998) ‘Choices and Rights: Eugenics, genetics and disability equality’, *Disability and Society* 13(5), pp 665-681

disability arguments. I will provide argument and evidence to show that rather than devalue the lives of those individuals, prenatal testing offers vital information which may be in the interests of the fetus and future person, as well as promoting parental reproductive autonomy, with the potential of preventing harm, not only to the fetus but also the wider family.

5.2 The Disability Critique and the effects of discrimination

Arguments put forward by those representing disabled people in relation to prenatal testing appear to make the assumption that it will lead to termination of that pregnancy if an anomaly is found. However, it is important to note that this is not the only outcome and I have previously discussed in chapter four (section 4.4) what potential benefits prenatal testing can bring in the form of in-utero or immediate postnatal treatment and that termination is not the only outcome, or purpose, of testing. That said, those representing disability groups do have some strong arguments against prenatal testing where it is followed by selective abortion. I will be addressing the major arguments in turn in the following sections and conclude that prenatal testing does not discriminate against those with disabilities but promotes reproductive autonomy and aims to prevent harm to the interests of the future individual and their wider family.

5.2.1 Advances in genetic and genomic medicine

Those representing disabled people who raise their concerns about prenatal diagnosis do so for a number of reasons. One major concern is that the extensive work that has been carried out in genetics in order to sequence the human genome, whilst increasing the number of genetic mutations that can now be identified, has not enjoyed the same success when it has come to gene therapy.¹⁰ This means that whilst an increasing number of disabling conditions can be picked up, they cannot

¹⁰ Shakespeare T (1995) 'Back to the future? New genetics and disabled people', *Critical Social Policy* 44(5), pp 22-35

all be treated. In these cases the information provided by prenatal testing is likely to be used by healthcare professionals and prospective parents to inform decisions about whether or not to continue an affected pregnancy. These advances in genomic medicine have led Stempsey to refer to the ‘geneticization’ of diagnosing disability, where disability is explained in terms of gene action rather than focusing on other factors that cause or contribute it.¹¹ This is despite the fact that only about ten per cent of disabilities are caused by defective genes, with the majority of disabilities being caused by trauma, aging and illness.¹²

As technology advances further it will allow multiple disorders to be tested simultaneously, cheaply and quickly.¹³ This will allow women to be tested earlier in pregnancy and for a wider range of disabling conditions. These tests are likely to be based on non-invasive prenatal testing (NIPT) on maternal blood,¹⁴ rather than by invasive tests on the fetus which could put a normal pregnancy at risk,¹⁵ and may therefore be more attractive to prospective mothers.

It is understandable that this adds to the concerns of those opposed to prenatal testing due to discrimination. Their concern is that the expansion of testing during pregnancy, and the fact that these will prevent the birth of a disabled baby, will be seen as a positive one, fuelling the negative attitudes towards those with disabilities.¹⁶ However, it should be noted that at this stage NIPT is intended only for those who are known to be at higher risk following current primary screening and

¹¹ Stempsey WE (2006) ‘The geneticization of diagnostics’ *Medicine, Health care and Philosophy* **9**, pp 193-200

¹² Scully JL (2008) ‘Disability and genetics in the era of genomic medicine’ *Nature Reviews Genetics* **9**, pp 797-802

¹³ Freshwater S (2013) ‘Fetal genome screening could prove tragic: unborn children will soon have their genes mapped. Without proper guidance for parents, the test could prove calamitous’, *Scientific American* **308**(2), (www.scientificamerican.com as cited on 15 October 2015)

¹⁴ Note that the UK National Screening Committee, in January 2016, recommended an ‘evaluative implementation’ of such testing in order to assess what impact this would have for the NHS antenatal screening programme (www.legacy.screening.nhs.uk cited on 11 November 2016)

¹⁵ Seeds JW (2004) ‘Diagnostic mid trimester amniocentesis. How safe?’, *American Journal of Obstetrics and Gynecology* **191**(2), pp 607-615

¹⁶ Lippman A (1991) ‘Prenatal genetic testing and screening: Constructing needs and reinforcing inequities’, *American Journal of Law and Medicine* **17**(1-2), pp 15-50

NIPT is not diagnostic. Invasive tests would still be required in order to obtain a definitive diagnosis.¹⁷ One benefit of NIPT is that it is hoped that it will ultimately reduce the number of women being offered invasive tests which carry a small risk of miscarriage.

Genetic and genomic medicine provides information about the biological status of the developing fetus and promises to offer an increasing number of ways in which it can help to diagnose, cure or prevent disability.¹⁸ This increasing information will inevitably be used to improve the availability of prenatal diagnosis for an increasing number of genetic conditions. One concern that arises in relation to prenatal testing and selective abortion is that it reinforces the medical model of disability¹⁹ in that it is the physical abnormality which presents the problems experienced by disabled people, and not the fault of society. These arguments are centred upon the fact that specifically selecting a pregnancy for termination based on the presence of a disability sends out a negative message about the lives of disabled people. As there is increasing investment in genetic research it is important to understand these reservations and try to reassure the disabled community that these advances will help to contribute to a better understanding of disability.²⁰ I will now consider what the concerns are with respect to the implications of raising discriminatory attitudes may be towards disabled people.

¹⁷ UK National Screening Committee (2016) 'UK NSC non-invasive prenatal screening (NIPT) recommendation' *phescreening.blog.gov.uk* (www.legacy.screening.nhs.uk as cited on 11 November 2016)

¹⁸ Scully JL (2008) 'Disability and genetics in the era of genomic medicine' *Nature Reviews Genetics* **9**, pp 797-802

¹⁹ Saxton M (2000) 'Why members of the Disability Community oppose prenatal diagnosis and selective abortion' in Parens E, Asch A (eds) *Prenatal Testing and Disability Rights*, Georgetown University Press/Washington DC, pp 148-149

²⁰ Scully JL (2008) 'Disability and genetics in the era of genomic medicine' *Nature Reviews Genetics* **9**, pp 797-802

5.2.1.i Reducing the number of disabled people in society

One consequence of discrimination that concerns the disabled community is that prenatal testing and selective abortion is aimed at reducing the number of disabled people who live in society.²¹ This is evidenced, for example, by the fact that the success of some screening programmes, like that for Cystic Fibrosis (CF), is measured by the reduction of the incidence of the condition in the population.²² Prenatal testing will inevitably result in some children who would have lived with disabilities not being born and as a consequence this will have the effect of reducing the number of individuals born with disabling conditions.²³ CF is not a condition that is routinely tested for in pregnancy, although newborns are screened soon after birth to allow early diagnosis and treatment.²⁴ Those who do have testing in pregnancy are likely to have sought this out due to knowledge of their particular risk (they may, for example, be known carriers of the condition) and possibly knowledge of the impact of caring for a child with this condition. To reassure those who believe that genetic testing is comparable to eugenic activities of the past,²⁵ only those pregnancies that are tested and found to be homozygous²⁶ for the defective gene, and therefore will develop the condition, are subject to termination, if that is what the prospective parents decide. Those found to be heterozygous²⁷ carriers, and therefore have only one copy of the defective gene, are not terminated. This means that the gene mutation is not likely to be eradicated from society. The purpose, therefore, is not to attempt to eliminate the CF mutation completely, but to give prospective parents the choice as to whether they want to continue their pregnancy, knowing their

²¹ Houghton H (1994) 'Does prenatal diagnosis discriminate against the disabled?' in McKie J (ed) *Ethical issues in prenatal diagnosis and termination of pregnancy*, Melbourne: Centre for Human Bioethics, pp 97-102

²² Beaudet A L (1990) 'Invited editorial: carrier screening for cystic fibrosis', *American Journal of Human Genetics* **47**, pp 603-605

²³ Ettore E (2000) 'Reproductive genetics, gender and the body: 'Please Doctor, may I have a normal baby?''', *Sociology* **34**(3), pp 403-420

²⁴ Wilcken B, Brown ARD, Urwin R, Brown DA (1983) 'Cystic Fibrosis screening by dried blood spot trypsin assay: Results in 75,000 newborn infants', *The Journal of Pediatrics* **102**(3), pp 383-387

²⁵ Hubbard R (1986) 'Eugenics and prenatal testing' *International Journal of Health Services* **16**, pp 227-242

²⁶ A person who is homozygous for a gene mutation has two copies of the faulty gene and will therefore be affected by Cystic Fibrosis

²⁷ A person who is heterozygous for a gene mutation has one normal copy and one faulty copy of the gene. This means they are a carrier of Cystic Fibrosis but are not affected by the condition themselves.

child will have the condition and this decision should only be made after the couple have benefited from having had counselling. As genetic technology has improved a number of different mutations for CF have been identified and therefore it may be possible to give parents more information about how their child will be affected by the condition. Different mutations cause different clinical phenotypes with some being more severe than others.²⁸ This advance in technology, therefore, could potentially result in some pregnancies that would previously have been terminated continuing as parents are reassured that the particular mutation in their fetus is not one of those causing severe symptoms. This suggests, therefore, that advances in genetic testing for prenatal diagnosis may actually reduce the number of terminations in some circumstances.

Down syndrome is a condition that people often associate with standard antenatal screening tests during pregnancy, which are offered to all women (as mentioned in chapter one). The success of the introduction of screening for Down syndrome was measured by the decrease in the number of births of children with the condition.²⁹ This obviously lends support to the argument of those representing those with disabilities that prenatal testing is designed to reduce the incidence of disability in society. Prenatal testing for Down syndrome is particularly controversial for other reasons.³⁰ It is a very variable condition with respect to physical and mental disability and is often associated with a good quality of life.³¹ This variability cannot necessarily be predicted simply based on a genetic test that identifies the extra chromosome 21.

²⁸ Koch C, Cuppens H, Rainisio M et al (2001) 'European Epidemiologic registry of Cystic Fibrosis (ERCF): Comparisons of major disease manifestations between patients with different classes of mutations', *Pediatric Pulmonology* **31**(1), pp 1-12

²⁹ Whittle MJ (1991) 'Antenatal diagnosis of fetal abnormalities' in Drife J, Donnai D (eds) *Routine Fetal Anomaly Screening*, London, Springer-Verlag London Limited, p 45-47

³⁰ Reynolds TM (2003) 'Down's syndrome screening is unethical: views of today's research ethics committees', *Journal of Clinical Pathology* **56**, pp 268-270

³¹ Reynolds TM (2003) 'Down's syndrome screening is unethical: views of today's research ethics committees', *Journal of Clinical Pathology* **56**, pp 268-270

In order for women to make informed and autonomous choices about whether or not to accept screening for Down syndrome they need to understand what the test can achieve and its limitations. Ultrasound scans may identify other medical problems associated with it such as brain malformations, congenital heart defects or bowel abnormalities and give an indication as to the extent of care the future child may need. It is these additional features of the condition that may influence a healthcare professional's decision as to whether a late termination of pregnancy can take place based on a diagnosis of Down syndrome, but it is also important for prospective parents to also have this type of prognostic information as early as possible. I will discuss the implications of this further with regard to parental expectations in section 5.2.3.

Although there is concern that prenatal testing and selective termination of pregnancy will reduce the incidence of disability in society,^{32,33} it is important to note that congenital disease is not the only cause of disability.³⁴ The majority of disabilities are due to a combination of those acquired through accident or due to medical conditions that develop later in life as well as other conditions such as cancer, dementia and lung disease.^{35,36} The age of the population is increasing and with this comes more morbidity and consequentially an increase in the number of people living with disability and the increased requirement for more social support and adaptation of society. There have been changes in the law to reflect this with the introduction of the Disability Discrimination Act 1995 and the Equality Act 2010. Prenatal testing will not have any impact on these aetiologies and, therefore, any argument that prenatal testing will have a negative effect on the number of disabled people as a whole in society, by reducing their number, is weakened. With increased

³² Blumberg L (1994) 'Eugenics v Reproductive Choice', *The Disability Rag and Resource*, (January – February), p 15

³³ King DS (1999) 'Preimplantation genetic diagnosis and the 'new' eugenics', *Journal of Medical Ethics* **25**, pp 176-182

³⁴ Saxon SV, Etten MJ & Perkins EA (2010) *Physical change and aging: A guide for the helping professionals* (5th ed) Springer Publishing Company, p 263

³⁵ Saxon SV, Etten MJ & Perkins EA (2010) *Physical change and aging: A guide for the helping professionals* (5th ed), Springer Publishing Company, p 264

³⁶ Scully JL (2008) 'Disability and genetics in the era of genomic medicine' *Nature Reviews Genetics* **9**, pp 797-802

survival rates for certain conditions and age acquired disability there will always be a need for society to adapt to the needs of disabled people. This point does not of course address the argument that prenatal testing and subsequent termination of pregnancy is discriminatory towards individuals with the condition by which the fetus is affected, or the suggestion by those opposing prenatal testing and abortion that it devalues the lives of disabled people.³⁷ These arguments are often made by those living with disabilities who therefore have first-hand knowledge of the impact disabling conditions may have. However, as I will argue in section 5.3, whilst their arguments may be valid others, such as carers, parents and siblings of severely disabled people, may be better placed to offer a strong case in some circumstances as to whether such devaluing is taking place through testing.

5.2.1.ii Reinforcing hostile social attitudes

There has been significant progress in Western society with respect to attitudes towards people with disabilities and this has been enhanced by legislation rightly giving disabled people equal rights³⁸ and prohibiting discrimination.³⁹ One criticism of prenatal diagnosis is that it will jeopardise this progress and change social attitudes towards disability.⁴⁰

With the advent of prenatal testing came a choice for prospective parents as to whether they wanted to bring a disabled child into the world. Prior to this having a disabled child was not something parents could avoid or necessarily predict, unless there was already a family history of disabling genetic condition. Now that various forms of prenatal testing are available to couples they do generally have a choice and may even be seen as irresponsible if they decide not to terminate an

³⁷ Shakespeare T (1995) 'Back to the future? New genetics and disabled people', *Critical Social Policy* **15**, pp 22-35

³⁸ Equality Act 2010, HMSO: London

³⁹ Disability Discrimination Act 1995, HMSO: London

⁴⁰ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled', *Journal of Medical Ethics* **25**, pp 163-171

affected pregnancy.⁴¹ One argument that follows this is that disabled people, particularly those with impairments that could have been detected antenatally, are seen as ‘accidents’ and something that could have been avoided, resulting in a change in social attitudes and increased discrimination.⁴² Gillam, for example, refers to stigmatisation against those with disabilities and the risk that they could be seen as a burden on society and may become marginalised.⁴³ Asch reinforces the view that prenatal testing and selective termination give an impression that disability is so terrible that the birth of such individuals should be avoided, a message that we would not deliberately want to give to those who have such disabilities.⁴⁴

One cannot deny the feelings of those with disabilities that find the provision of prenatal diagnosis and selective termination demoralising or offensive. However, even those representing disabled people believe it is possible to be able to contemplate prenatal diagnosis without reaching the conclusion that disability is painful and burdensome for all of those affected by it.⁴⁵ Prospective parents who make the decision to terminate an affected pregnancy should do so for their own personal reasons (assuming that this does not include reasons of prejudice) once they have had the opportunity to weigh up all of the benefits and potential disadvantages of having a disabled child. These deliberations should include the clinical features of the disability, but this should not be the only consideration. They need to consider the impact the disability will have on the future child in terms of, for example, function and the extent of pain and suffering, but they should also be given an opportunity to fully consider what the impact will be on their own interests and those of other members of the family, such as the future child’s siblings. When considering a termination in this way they are not making judgements about the lives of those with the same disability, as it is very

⁴¹ Wertz DC, Fletcher JC (1993) ‘Feminist criticism of prenatal diagnosis: a response’, *Clinical Obstetrics & Gynaecology* **36**(3), pp 541-547

⁴² Gillam L (1999) ‘Prenatal diagnosis and discrimination against the disabled’, *Journal of Medical Ethics* **25**, pp 163-171

⁴³ Gillam L (1999) ‘Prenatal diagnosis and discrimination against the disabled’, *Journal of Medical Ethics* **25**, pp 163-171

⁴⁴ Asch A (1989) ‘Can aborting “imperfect” children be immoral?’ in Arras JD, Rhoden NK (eds) *Ethical issues in modern medicine*. Mayfield Publishing Co, p 319

⁴⁵ Kaplan D (1988) ‘Disability rights perspectives on reproductive technologies and public policy’ in Cohen C, Taub N (eds) *Reproductive laws for the 1990s*. Humana Press, pp 241-247

unlikely that they will be comparing like with like when all of the circumstances are taken into account. In addition to emphasising the need for the prospective parents to weigh up all of the issues, it also emphasises the importance of the clinicians involved, especially where late termination needs to be justified, weighing up these same factors. The risk of discrimination should not result in objections to prenatal diagnosis but should promote the need for communication with disabled people and to ensure that social attitudes continue to improve. As Gillam states, any moral disadvantages of discrimination need to be assessed against the advantages of prenatal testing, where one such advantage is individual reproductive autonomy (which I have discussed in chapter three).⁴⁶

5.2.2 Does prenatal testing devalue disabled people?

The Expressivist argument⁴⁷ against prenatal testing states that it is wrong to select out disease and disability because it sends out a negative message about disabled people and the value of their lives and particularly about those people who have the specific disability that is being selected against.⁴⁸ Proponents of this position claim that selection against such genetic impairments is discriminatory.⁴⁹

Those living with disabilities argue that a judgement is made about their life which suggests that it is not worth living and, as a result, prenatal testing is performed in order to prevent the existence of an individual with an impairment who will become disabled.⁵⁰ This argument, however, also has the tendency to create a negative impression of the prospective parents and makes assumptions

⁴⁶ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled', *Journal of Medical Ethics* **25**, pp 163-171

⁴⁷ Buchanan A (1996) 'Choosing who will be disabled: Genetic intervention and the morality of inclusion', *Social Philosophy and Policy* **13**, pp 18-46

⁴⁸ Edwards S (2004) 'Disability, identity and the "Expressivist Objection"', *Journal of Medical Ethics* **30**, pp 418-420

⁴⁹ Shuster E (2007) 'Microarray genetic screening: a roadblock to life?', *Lancet* **369**, pp 526-529

⁵⁰ Shakespeare T (1998) 'Choices and rights eugenics, genetics and disability equality', *Disability and Society* **13**(5), pp 665-681

about people who opt for prenatal testing. It does not take into account that individual's own personal circumstances or individual reasons for having testing. It is unreasonable to assume that because a person has testing, possibly followed by a termination, that this is suggesting that the life of a person who is affected by the condition has no value.

If a couple terminated a pregnancy for social reasons, for example, due to the fact that their relationship had ended, this decision, whilst it may be frowned upon by some, would not be seen to send out a message that the lives of children from single-parent families are valueless or in any way not worth living. The decision was based on not wanting to bring that particular child at that time into that specific set of circumstances, and not due to a wider assumption about children with estranged parents. In the same way, deciding to end a pregnancy where impairment exists in that particular fetus does not make assumptions about the lives of others with that same impairment. In fact this particular couple may have very good personal reasons for not wanting to have this child now that they are no longer together. This decision would be based on their own autonomous choice and the parent's own personal circumstances and not based on any discriminatory attitude toward others in a similar position. The point is that it is important to recognise that reproductive decisions run deeper than simply deciding that they do not want a particular pregnancy to continue. In the same way, a decision to terminate a pregnancy, for example with Achondroplasia (dwarfism), does not make any comment about a person already born with Achondroplasia, or about their parents who may or may not have decided to have prenatal testing themselves and are likely to have different interests from other parents in the same position.

The problem, however, is that although technically no message other than that in support of parental choice should be given, the very fact that policies and legislation are in place to control the reasons and time limits by which termination of pregnancy can take place seem to endorse discriminatory views. I have discussed the problems with current abortion legislation in chapter two and the concern that this could be seen to discriminate against those with disabilities. A termination of pregnancy of a normal fetus cannot take place according to the Abortion Act, assuming it is not

threatening the life of the mother, after twenty-four weeks gestation but the termination of a fetus with a serious abnormality can. I have argued in chapter two, however, the reasons why this distinction is important when considering late terminations. Allowing late terminations of pregnancy where a serious abnormality exists can be justified on the basis of avoiding harm that would have otherwise been caused to that future person and their wider family if the pregnancy were to continue, and is not based on an assumption about those living with a disability in general.

There are other steps prospective parents can take to prevent or at least reduce the risk of having a child with certain types of impairments. Folic acid, for example, is known to significantly reduce the incidence of neural tube defects, such as spina bifida and anencephaly in fetuses, particularly those who are at high risk due to a genetic predisposition.⁵¹ Whilst there is a big difference between preventing disability by treating the causes as opposed to preventing disability by terminating a pregnancy, and hence preventing the existence of that particular individual with a disability, the overall outcome is that a disability has been avoided. This does not, however, send out a message that people with the conditions that this intervention is designed to prevent have any less worth or value than anyone else.

Wilkinson similarly challenges the Expressivist Argument by looking at the circumstances of the message that is being both sent and received.⁵² Wilkinson talks of the imperfections of human communication and how the message from the sender (the person offering/choosing prenatal testing) and the recipient (the person with a disability) often diverge. Glover also talks of the importance of sending out a clear message, that decisions about prenatal testing are not because of

⁵¹ Oakley GP Jr (2008) 'Elimination of folic acid-preventable neural tube defects', *American Journal of Preventative Medicine* **35**(6), pp 606-607

⁵² Wilkinson S (2010) *Choosing tomorrow's children*, Clarendon Press: Oxford, pp 171-173

a negative or 'ugly' attitude toward those with disabilities.⁵³ Similar to the example of the use of Folic Acid, Glover also compares the use of prenatal testing to avoid disability with other medical programmes.⁵⁴ In his example he talks of defeating cancer, not out of our lack of respect for people who have and live with cancer, but with our desire to prevent what effect cancer has on people. However, whereas eliminating disability is seen by some as discriminatory treatment for other 'conditions' is seen as a positive step and in fact causes public outcry if people are denied treatments that may cure them.⁵⁵ Glover argues that if communication were improved and based on the fact that prenatal testing is not making any value judgements about the disabled, the Expressivist Objection is obsolete.⁵⁶

Choosing to offer and receive prenatal testing is about providing prospective parents with the option to make very personal choices and is not in any way an expression of negativity towards those with disabilities. The counter argument to this would be that whilst treating people for cancer and other illnesses with the hope of providing a cure may eliminate the disease in that person who continues to exist, prenatal testing might only be able to prevent disability by termination of an affected pregnancy and thus prevent the existence of a future person. I have, however, discussed in chapter 4 (section 4.4) that in-utero or postnatal treatment following prenatal testing can result in disability being reduced or avoided in the person who is ultimately born.

Those representing disabled people are concerned that selecting out disability sends the message that the world would be a better place if those with disabilities did not exist. Wilkinson evaluates this view, making the point that selecting against an embryo (or fetus in the case of prenatal testing) with a particular condition does not extrapolate to meaning that it would also be acceptable to

⁵³ Glover J (2006) *Choosing Children: the ethical dilemmas of genetic intervention*, Oxford University Press, pp 33-35

⁵⁴ Glover J (2006) *Choosing Children: the ethical dilemmas of genetic intervention*, Oxford: Clarendon Press, p 35

⁵⁵ *Woman wins Herceptin court fight* (www.news.bbc.co.uk/1/hi/health/4902150.stm, as cited on 10 November 2008)

⁵⁶ Glover J (2006) *Choosing Children: the ethical dilemmas of genetic intervention*, Oxford: Clarendon Press, pp 33-35

murder a person who is already living with that same condition.^{57,58} When we select against disability in preference for an embryo or fetus without the disability we are choosing to create a child which is expected to have a better quality of life. The decision is not suggesting that a person with the same condition does not themselves have a worthwhile life and nor should it devalue their existence. The fact is that when parents decide to start a family they generally want to have a child with the best possible quality of life.

In chapter three, I argued for the importance of reproductive autonomy due to the personal nature of decisions around reproduction. These arguments were supported by my discussion about harm in chapter four. What the Expressivist Argument does not consider is the harm to the interests of other directly affected third parties, such as the prospective mother. Gillam acknowledges that justification for termination that takes into account the best interests of the mother-to-be does not involve any direct quality of life assessment of the disabled child, and she regards this justification as most defensible because it relies on the same factors that are referred to when abortion is justified in other contexts, one of those factors being autonomy.⁵⁹ However, it could be argued that the promotion of prenatal testing also sends out a negative message about the lives that the parents and siblings of a disabled person must also have. Whilst those with disabilities who argue against prenatal testing may be in a position to comment on how it affects their lives, they are not in a position to comment on how it affects the lives of others. The harm to the interests of other third parties can only really be assessed by those third parties themselves. It is of course important that they are provided with information to help them assess the impact of having a disabled child, but ultimately they are the only ones who can really evaluate what their future may be like and how their interests may be affected. Again, this supports the arguments I have made in chapter three

⁵⁷ Wilkinson S (2010) *Choosing tomorrow's children*, Oxford University Press, pp 173-176

⁵⁸ In addition to this, I have discussed in chapter 2 that the fetus does not have full moral status and therefore killing a fetus cannot be compared with killing a person, with full moral status, who has already been born.

⁵⁹ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled' *Journal of Medical Ethics* **25**, pp 163-171

with respect to promoting reproductive autonomy and also emphasises the need for harm to the interests of third parties to be taken into consideration by clinicians who find themselves in the position of having to justify a late termination of pregnancy.

When we consider how a disability might affect an individual we try to put ourselves in their position and imagine what life would be like. One theoretical way of doing this is to evaluate their 'Quality of life' (QOL).⁶⁰ This could include the fetus in relation to prenatal testing and screening for disabilities where the quality of the predicted life is evaluated and compared to a minimum quality, below which prospective parents would choose to terminate the pregnancy.⁶¹ Similarly, these evaluations are likely to influence clinicians who are required to justify late abortions. These analyses are used to inform decisions about distribution of healthcare resources and in informing the development of health policy.⁶² For the purposes of my thesis, however, I am only focusing on the use of QOL assessments in as much as they influence decisions about the provision of prenatal testing and the arguments that this is discriminatory against those with disabilities in that it is making judgement about their lives. One important point to make is that this QOL assessment for the purposes of selective abortion assumes that the fetus is not equivalent to a person. This means that killing a fetus which is predicted to have a low quality of life is not the same as suggesting it would be permissible to kill a person living with disabilities who may be assessed as having a low quality of life.⁶³

⁶⁰ Prutkin JM, Feinstein AR (2002) 'Quality of life measurements: origin and pathogenesis' *Yale Journal of Biology and Medicine* **75**, pp 79-93

⁶¹ Mackenzie C, Scully JL (2007) 'Moral imagination, Disability and Embodiment' *Journal of Applied Philosophy* **24**(4), pp 336-351

⁶² Wachbroit R (2005) 'Assessing quality of life: Clinical versus Health Policy Users' in Wasserman D, Bickenbach J, Wachbroit R (eds) *Quality of Life and Human Difference: Genetic testing, health care and disability*. Cambridge University Press, pp 27-42

⁶³ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled' *Journal of Medical Ethics* **25**, pp 163-171

Criticisms of the QOL assessments relate to the fact that they involve an observer's view of what kind of life is worth living,⁶⁴ and this view may not have been open to challenge.⁶⁵ This is relevant to my thesis in that others make evaluations with respect to the QOL a fetus is expected to have if it is born with an impairment that is likely to cause disability. Mackenzie and Scully rightly question whether it is feasible for people without impairments to make judgements about the quality of life of someone with impairment.⁶⁶ This is also something I will consider further in section 5.3 with respect to people living with disabilities making judgements about the lives of future individuals with impairments.

Mackenzie and Scully argue that health professionals who make these judgements are unlikely to have an adequate understanding of the lives of people with disabilities and those with the disability are likely to be underrepresented when healthcare decisions are made.⁶⁷ There is also the problem of what level of importance is placed on different aspects of a person's life. A person who has never had a particular biological function is less likely to miss it, as compared to a person who had it at birth and for a significant portion of their life but then loses it, or at least imagines what it would be like to do so. It does appear that there are certain questions about QOL that can only be answered by a similarly affected individual. Shakespeare acknowledges that every impairment, and also every family and every life, is different and, therefore, states that it is dangerous to generalise about the experience of impairment.⁶⁸ However, based on this one could also argue that it is difficult to see how a person with a disability can evaluate the quality of life of parents of a disabled child, whose QOL should also be taken into account when reproductive decisions are

⁶⁴ Shakespeare T (2005) 'The social context of individual choice' in Wasserman D, Bickenbach J, Wachbroit (eds) *Quality of Life and Human Difference*, Cambridge University Press, pp 217-36

⁶⁵ Mackenzie C, Scully JL (2007) 'Moral imagination, Disability and Embodiment' *Journal of Applied Philosophy* **24**(4), pp 336-351

⁶⁶ Mackenzie C, Scully JL (2007) 'Moral imagination, Disability and Embodiment' *Journal of Applied Philosophy* **24**(4), pp 336-351

⁶⁷ Mackenzie C, Scully JL (2007) 'Moral imagination, Disability and Embodiment' *Journal of Applied Philosophy* **24**(4), pp 336-351

⁶⁸ Shakespeare T (2005) 'The social context of individual choice' in Wasserman D, Bickenbach J, Wachbroit (eds) *Quality of Life and Human Difference*, Cambridge University Press, pp 217-36

made. This may be a general problem when making QOL decisions when there is a difference in the experiences and understanding of those making the judgements and we may not require a perfect understanding in order to make a reasonable determination. However, it is important to consider the individual set of circumstances that any parent finds themselves in that means they, and only they, are in a position to make an adequate judgement as to the overall impact of QOL. The parents are the only ones able to make the fullest and, therefore, most important judgement about QOL issues in these circumstances.

Gillam also notes that terminating certain pregnancies is justified on the basis of the QOL the future child is predicted to have, taking into account the effects of the disability and by comparing it with the QOL of a possible future non-disabled child.⁶⁹ In making this assessment one person makes a judgement about how life will be affected by a certain disability, from that person's point of view. Where the positives and negatives are weighed in the balance a decision may ultimately be made that a termination can be justified in the best interests of the future child. What these QOL assessments do not tend to take into account is the QOL in the context of the wider family and how the disability may affect the interests of others.

Those representing disabled people argue that these evaluations are misinformed and make judgements about the quality of their lives that are unduly negative. However, as well as the QOL of the disabled individual, that of the prospective parents and other close family members also need to be considered. The people in the best position to make these decisions are those who are going to be directly affected by the birth of the child following balanced discussions to support their decisions, which would benefit from the inclusion of views from disabled people. It is only those who are going to be directly affected who are able to make an overall judgement as opposed to

⁶⁹ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled' *Journal of Medical Ethics* **25**, pp 163-171

those who may only be able to consider specific aspects of QOL judgements. Similarly, clinicians making decisions about late termination of pregnancy should not only consider the QOL of the future child but also other relevant third parties, taking into account their personal views and the potential harm that may be caused to their interests. In view of the relationship that prospective parents have with the clinical geneticist, they would be well placed to act as an advocate for prospective parents who may find it difficult to express their views at such a difficult time.

Gillam also makes the point that making these QOL judgements does not equate to a moral judgement about that person and as such it is not discriminatory.⁷⁰ We consider the quality of a person's life in a number of different situations, particularly in healthcare. Gillam refers to the patient with cancer who is in intractable pain. Just because a person's QOL is lowered by illness does not lower their moral worth.⁷¹ We still have moral obligations to them, particularly with respect to addressing the pain they are suffering. Similarly, a patient with dementia resulting in physical and intellectual impairment may have a lower quality of life than someone who is active and capacious but this does not mean we should withdraw care or treat them badly. As I have discussed in chapter two (section 2.2.4) when considering the moral status of the fetus, humans who may lack various capacities are still morally significant and we continue to have obligations towards them. Assessing their QOL has not been carried out with the intention or result of making a judgement about their moral worth. In assessing the affects an impairment may have on a future individual's interests, and that of their wider family, we are not making any negative moral judgement about those who live with disabilities.

⁷⁰ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled' *Journal of Medical Ethics* **25**, pp 163-171

⁷¹ Gillam L (1999) 'Prenatal diagnosis and discrimination against the disabled' *Journal of Medical Ethics* **25**, pp 163-171

5.2.3 Does prenatal testing influence parental expectations?

A further argument put forward by those representing disability groups is the Parental Attitude Argument.⁷² No distinction appears to be made as to whether the objections about testing in pregnancy relates to standard antenatal screening or diagnostic prenatal testing or the types of conditions that are tested for. I assume that the argument relates to any testing that is capable of identifying a difference in the fetus that is likely to be regarded as abnormal and causing what would be regarded as a disability according to the medical model. This argument suggests that parent's expectations of what their child should be like are unrealistic. It suggests that parents want some form of guarantee that their child will be perfect.⁷³

According to Asch prenatal testing creates a first and incomplete impression of the future child and this includes the decision never to learn about what the entire future person may be like after birth.⁷⁴ She refers to prenatal diagnosis as being “morally problematic” and “misinformed” in relation to disability.⁷⁵ Asch talks of ‘specific individual characteristics’⁷⁶ that are allowed to overpower any other positive qualities the fetus or future child may have.

Concerns are raised that wanted pregnancies are being ended following prenatal testing due to something being learned about that particular child.⁷⁷ However, it is too simplistic to say that the decision is based on information gained only about that child. A prospective parent's decision to

⁷² Parens E & Asch A (2003) ‘Disability rights critique of prenatal genetic testing: Reflections and recommendations’, *Mental Retardation and Developmental Disabilities Research Reviews* **9**, pp 40-47

⁷³ Asch A (1989) ‘Reproductive technology and disability’ in Cohen S, Taub N (eds) *Reproductive laws for the 1990's*, Clifton, NJ Humana Press, pp 69-124

⁷⁴ Asch A *Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements*, (www.faculty.law.miami.edu/mcoombs/documents/asch.pdf, as cited on 21 January 2013) p 234

⁷⁵ Asch A *Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements*, (www.faculty.law.miami.edu/mcoombs/documents/asch.pdf, as cited on 21 January 2013) p 234

⁷⁶ Asch A *Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements*, (www.faculty.law.miami.edu/mcoombs/documents/asch.pdf, as cited on 21 January 2013), p 235

⁷⁷ Asch A *Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements*, (www.faculty.law.miami.edu/mcoombs/documents/asch.pdf, as cited on 21 January 2013) p 234

terminate may be based on experience of the condition by which the child is affected and the impact this may have on them both. Indeed, the initial decision to have prenatal testing in the first place may be based on a couple's previous experience of a particular condition. The decision, therefore, is based on previously known information about the abnormality and not about that particular child. The information may be from health professionals experienced in caring for people with the condition. In the case of couples who are referred to clinical genetics services for testing of very specific conditions, it is information gained first hand from possibly having had a previously affected child who may have experienced much pain and suffering, or a sibling who was similarly affected, that will inform their decisions. For prospective parents who do not have first-hand experience it is also possible for them to speak to a person who has the condition themselves or parents with an affected child. It may also be that one of the parents has the condition themselves if it is dominantly inherited and compatible with life and fertility is not affected.

The Parental Attitude Argument seems to make a general assumption that most parents would not want a disabled child as it would impact on what their idea of being a parent is all about. What the argument does not take into account is the personal reasons that a couple may have for choosing not to have a disabled child. Rather than only considering the impact it may have on them personally, they may be considering what they believe to be in the best interests of the future child or other members of the family, such as pre-existing children. They may already have, or have had, a child with the same condition and therefore have first-hand experience of the condition and its impact on the child. It may be the child's interests that they are considering when they choose to have prenatal testing, rather than just being concerned about their own interests or ideals.

I have limited my thesis to prenatal testing where a risk is known, however, I acknowledge that with regards to standard antenatal screening, where there is no prior risk to a pregnancy, Asch's arguments are more difficult to refute and there is evidence that some women do take up the offer

of standard antenatal screening due to concerns about having a 'socially unfit' child.⁷⁸ Those parents who have first-hand knowledge and experience of having a disabled child, however, might be better placed to make reproductive decisions based on the impact the disability may have on the child and the wider family. What Asch's arguments highlight is the importance of ensuring that deliberative discussions take place between the prospective parents and clinicians to allow all aspects of having a disabled child with the given abnormality to be considered. Focus should not only be on the clinical and physical aspects of the impairment that has been identified but also on the support and treatment that may be available to the family and future child, and the positive aspects that having that child will bring. This is particularly important for those couples who do not have previous experience of having a child with the condition. Whilst I am advocating that the doctors ultimately making the decision about late terminations consider the impact on the wider family, and not just the clinical features of the disability, prospective parents also need to be given the opportunity to consider the positive aspects having this child will have on the wider family and again discouraged from focusing solely on the clinical and physical difference.

As I will discuss in more detail in section 5.3, whilst there are those who live with disabilities who are able to express their views there are other disabled individuals who, due to the severity of their impairment, are not able to express how they feel about life with disabilities and whether or not they feel that their lives are worth living. It would seem that the only people who are best placed to comment on their behalf are those who are most closely associated with them, for example, their family or their carers. Those making these comments, for example, the parents of children who have such severe disabilities, will no doubt love and care for their child as a parent of any other child would. Their child is already born and therefore prenatal testing is not an issue or a consideration for them. Their comments can be made purely on the basis of what they feel about their child's life and the quality of it, which will be influenced by many things including the positive experiences the child may have and also the pain and suffering and need for medical intervention.

⁷⁸ Remennick L (2006) 'The quest for the perfect baby: why do Israeli women seek prenatal genetic testing?' *Sociology of Health & Illness* **28**(1), pp 21-53

These parents, in the absence of the child being able to do this themselves, are best placed to weigh up the positives and negatives in that child's life to decide whether their particular circumstances would accord with those arguments put forward by the members of disability groups.

Healthcare generally is an area where a society's attitude to the quality of life is clearly expressed. Gillot argues that decisions made in the sphere of healthcare can demonstrate the value that we place on one another's lives,⁷⁹ however, as discussed earlier in this chapter, it is not a judgement we are making about the moral value or worth of a person, but what quality their life has and this is what we base healthcare decisions on. Decisions are made with respect to withholding and withdrawing treatment from terminally ill patients and from those in a PVS, these decisions being influenced by the quality of life those individuals are expected to achieve,⁸⁰ not because we believe they have any less moral worth. Prenatal genetic diagnosis is another important area from this point of view. Lives can be regarded as valuable in a variety of ways. With respect to the arguments against prenatal testing I am considering not an extrinsic value of another's life measured in terms of benefits to others or to society, but a value which is intrinsic to the individual in question and independent of others' need for or view of that individual. This value indicates the existence of moral status, which has previously been considered in chapter two (section 2.2.4). When we consider the quality of a person's life to be negatively affected by a disability, it does not follow that we devalue them in any way or suggest they are morally inferior.

If it is accepted that women may choose not to have babies for social reasons, such as the effect it may have on their career or due to their financial situation, it must be accepted that some women may also not wish to have babies with impairments, which may be due to the fact that these children will have more complex needs in relation to both their care and cost of upbringing.⁸¹ Nelson also

⁷⁹ Gillot J (2001) 'Screening for disability: a eugenic pursuit?', *Journal of Medical Ethics* **27**, pp ii21-ii23

⁸⁰ *Airedale NHS Trust v Bland* [1993] AC 789

⁸¹ Shakespeare T (1998) 'Choices and rights eugenics, genetics and disability equality', *Disability and Society* **13**(5), pp 665-681

acknowledges that a person's reasons for choosing to utilise prenatal testing and ending pregnancies is varied.⁸² A prospective parent may doubt their own ability to care for and bring up children with impairments. They may not be prepared to accept the challenges this brings. As Nelson points out based on these feelings some choose not to have children at all.

Those living with disabilities argue that a judgement is made about their life which suggests that it is not worth living and as a result, prenatal testing is performed in order to prevent the existence of an individual with an impairment who will become disabled.⁸³ This argument, however, is made by disabled people who are in a position to raise such concerns and who do have a life that is clearly worthwhile. They would not be putting these arguments forward otherwise. Those who offer, and those who choose, prenatal diagnosis are not making their decisions based on the lives of those with a similar condition within society, they are making the decision based on what they believe to be the future for the individual fetus in question, and based on the parent's and family's own personal needs and circumstances. These decisions are not to be taken lightly and require appropriate counselling to ensure that they are made following consideration of the best interests of all relevant parties.

The arguments that prenatal testing discriminates against those living with disabilities because it makes judgements about their lives and devalues their worth arises when one group (non-disabled) fail to appreciate that the other group (disabled) have lives that are as rewarding and fulfilling as their own.⁸⁴ I have talked about prenatal screening for Down syndrome and the fact that in my experience prospective parents don't always have the benefit of genetic counselling and decisions

⁸² Nelson JL (2000) 'Prenatal Diagnosis, Personal Identity, and Disability', *Kennedy Institute of Ethics Journal* **10**(3), pp 213-228

⁸³ Shakespeare T (1998) 'Choices and rights eugenics, genetics and disability equality' *Disability and Society* **13**(5), pp 665-681

⁸⁴ Asch A *Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements* (www.faulty.law.miami.edu/mcoombs/documents/asch.pdf, as cited on 21 January 2013)

may be made based on, often outdated, assumptions as to what the life of the disabled child will be like. As those representing disabled people say, this may be based on misinformation about what they can achieve in their lives, despite their disability.⁸⁵ As far as chromosomal abnormalities are concerned Down syndrome is one of the most common⁸⁶ and the one that most people will have some awareness of. Obstetricians and midwives may feel more comfortable about telling a prospective mother that her fetus is affected by Down syndrome without the need to refer to a specialist genetics centre for counselling, as they would for other chromosomal abnormalities with which they are less familiar. Prospective parents themselves may feel that they know what Down syndrome is and therefore do not need to discuss their situation with anyone other than the antenatal team looking after them. Sadly, the knowledge they believe they have may be based on negative stereotypes and biased information about having a child with the condition. Screening for Down syndrome began in an era when higher morbidity and mortality arose from it and therefore life expectancy was shorter with fewer opportunities for relieving some of the clinical problems associated with it, and there was less support for those living with disabilities.⁸⁷ Times have now changed and conditions such as Down syndrome may have less of a negative impact on the person affected and their family as they once had. I agree that in these circumstances there is a danger that these women will make decisions that are not as fully informed as they could be or based on outdated views and information. Assumptions will be made about what a child with Down syndrome will be like and what impact it will have on the parents and other pre-existing children.⁸⁸ There is a danger that these women will follow a path that, with more informative and non-directive counselling, they may not have followed. This emphasises the need for prospective parents to have balanced information, and in the case of Down syndrome information about its variability, so that they can make an informed decision about their pregnancy that best suits them. Reproductive

⁸⁵ Brostrand HL (2006) 'Tilting at Windmills: Changing Attitudes Toward People with Disabilities' *Journal of Rehabilitation* **72**(1), pp 4-9

⁸⁶ Kingston H (2002) *ABC of Clinical Genetics* (3rd ed) BMJ Publishing Group, p 18

⁸⁷ Peterson M (2012) 'Disability Advocacy and Reproductive choice: Engaging with the Expressivist Objective', *Journal of Genetic Counseling* **21**, pp 13-16

⁸⁸ Clapton J (2003) 'Tragedy and catastrophe: contentious discourses of ethics and disability', *Journal of Intellectual Disability Research* **47**(7), pp 540-547

autonomy is not being respected where a couple is told that their fetus is affected by a particular condition without being given appropriate information about how the condition is affecting their particular fetus and the postnatal support that is available and throughout the person's life. There may be some pregnancies affected by Down syndrome that have been terminated that could otherwise have been spared had the prospective parents been furnished with a balanced view about their future child's prognosis, rather than simply giving them a diagnosis. This adds further support to the arguments about reproductive autonomy that I put forward in chapter three, and the need for constructive dialogue between healthcare professionals and the prospective parents.

There is a danger, therefore, that these assumptions and misinformation may result in judgements being made about the life the future child may have which are unfounded, particularly if they focus only on the disability and not on the complete circumstances that the future child will find themselves in. Not only do the clinical aspects of the condition need to be considered (the medical model of disability) but also the social aspects and how the future child and their family can be best helped to overcome any difficulties. Having taken all of this into account the views of the prospective parents and how their lives will be affected also need to be considered. Because there is so much to consider, a lot of which is very personal to the couple involved, it is important that those who are going to be affected are involved in the decision making process as much as possible. As I will discuss in chapter six, there are limitations, however, placed on prospective parents where late termination of pregnancy is being considered as the decision as to whether such a termination can be justified lies with the clinicians who will perform the procedure, and not with the prospective parents.

There are some physical and mental disabilities that no amount of adaptation in society will allow a person to function in the same capacity as a non-disabled individual. Some disabilities can be compensated for, for example, a person suffering from visual or hearing impairment may feel no less disadvantaged than a person with fully functioning hearing and vision as they can learn new

methods of communication and stimulation so that life can be enjoyed to the same extent. However, a person with quadriplegia cannot do many of the physical activities that a non-disabled person can do, despite the best efforts of society and the community. That said, this does not prevent them from living a fulfilling life. That person may be able to do many things another non-disabled person might not. They may have, for example, superior intelligence or other abilities that are not hindered in any way by their physical disability.⁸⁹ There are clearly differing degrees of disability and, therefore, the ability of society to accommodate those with impairments is limited by the severity of the original physical disability from which the individual suffers and in some circumstances no amount of adaptation will allow a person with a disability or disabilities to do everything that a non-disabled person can do.

It is this lack of ability by society to be able to help some disabled people overcome their impairment that may be taken into account by some prospective parents and clinicians when contemplating whether or not to continue a pregnancy. It is likely that this situation will arise where impairment is very severe (either physically or mentally) and may be associated with significant pain and suffering. I discussed the moral status of the fetus in chapter two, and how this develops gradually over time. In view of this, greater justification for terminating a pregnancy is needed as gestation progresses. Where late terminations are concerned such justification is likely to be influenced by the level of support and adaptation society can offer where a disability is so severe that pleasurable experiences are outweighed by pain and suffering, despite appropriate medical intervention.

When information is given to prospective parents when an abnormality has been identified antenatally it is this spectrum of disability which needs to be discussed so that parents are fully aware of the impact the abnormality will have on the life of their future child and them and their

⁸⁹ Professor Stephen Hawking for example, although physically disabled is the Dennis Stanton Avery and Sally Tsui Wong-Avery Director of Research at the Department of Applied Mathematics and Theoretical Physics and Found of the Centre for Theoretical Cosmology at Cambridge University (www.hawking.org.uk as cited on 19 November 2015)

family. What a particular family can cope with will vary and, therefore, each case must be treated individually so that an autonomous decision can be made by the couple concerned. The decision made by a family may be influenced by their own values, ability to cope, pre-existing family and support structure and their financial situation. It is therefore important for the impact of anomalies to be understood and how these may impair a person's life and their interests, as I have discussed in chapter four (section 4.2.2i). The perspective of people living with such disabilities is invaluable in this sense and often parents are encouraged to talk to and get advice from those living with the same condition, their parents and the healthcare professionals who care for them and see the range of severity a specific condition can have. It is for this reason that charitable organisations such as Contact a Family⁹⁰ and other support groups for specific conditions, which are often genetic, have been created.

Some people with a disabling condition may themselves choose to have prenatal testing as they wish to avoid having a child with the condition they have suffered from personally. They may seek genetic counselling in order to understand what reproductive options are open to them, allowing them some control over the type of child they will have.⁹¹ Similarly, some people with a specific anomaly may not abort a pregnancy affected by the same condition but may abort a pregnancy affected by something else which they feel would affect the child's life in a way that makes termination of pregnancy preferable.⁹² Some parents who already have a child with a condition that could be tested choose not to have testing in a subsequent pregnancy as the condition itself has become irrelevant.⁹³ They may feel that having such a test, with a view to terminating an affected pregnancy, would send out a negative message to the child they already have. Others, however, in the same situation, who value and support their existing child, would choose to have a test to avoid

⁹⁰ Contact a Family (CAF) www.cafamily.org.uk

⁹¹ Peterson M (2012) 'Disability Advocacy and Reproductive choice: Engaging with the Expressivist Objective', *Journal of Genetic Counseling* **21**, pp 13-16

⁹² Wertz DC (1992) 'How parents of affected children view selective abortion' in Holmes H (ed) *Issues in Reproductive Technologies I*, New York: Garland Publishers, pp 161-92

⁹³ Wertz DC, Fletcher JC (1992) 'Sex selection through prenatal diagnosis: a feminist critique' in Holms HB, Purdy LM (eds) *Feminist perspectives in medical ethics*, Bloomington: Indiana University Press, pp 240-253

having another child with the same condition.⁹⁴ This shows that the decisions that are made are very personal and emphasises the importance of allowing couples control over the outcome.

Those who rely on the Parental Attitude Argument to oppose prenatal testing, therefore, do so partly because they believe parents base their decisions on misinformation.⁹⁵ Rather than support the opposing arguments this promotes the need for reproductive autonomy and the need for prospective parents to be well informed about the condition their pregnancy is affected by. Parents should not be in a position where they are making important life changing decisions based on misinformation and stereotypes. They should be given the opportunity to speak to others who are or have been affected by the same condition so that they can consider what the implications will be for their future interests, and the future interests of their fetus. This argument, therefore, lends support to my arguments for the promotion of reproductive autonomy and the need to consider what harm may occur to the interests of the fetus and others that will be directly affected.

5.3 Are those with disabilities providing a representative voice?

It is without doubt that many people with various disabilities do have rewarding and successful lives, many more so than some of their non-disabled counterparts. This can be confirmed by those who talk on behalf of disabled people, and are disabled themselves, and those who as a consequence of this evidence and opinion claim that prenatal testing and subsequent termination of pregnancy infers a judgement has been made about their quality of life. Empirical data has been collected in order to show that those living with disabilities can and do have valuable lives.^{96,97}

⁹⁴ Peterson M (2012) 'Disability Advocacy and Reproductive choice: Engaging with the Expressivist Objective', *Journal of Genetic Counseling* **21**, pp 13-16

⁹⁵ Asch A *Why I haven't changed my mind about prenatal diagnosis: Reflections and refinements*, (www.faculty.law.miami.edu/mcoombs/documents/asch.pdf, as cited on 21 January 2013) p 234

⁹⁶ Wacker DP, Harper DC, Powell WJ, Healy A (1983) 'Life outcomes and satisfaction ratings of multihandicapped adults', *Developmental Medicine and Child Neurology*, Oct **25**(5), pp 625-631

⁹⁷ Bertsson L, Berg M, Brydolf M, Hellstrom AL (2007) 'Adolescents' experiences of well-being when living with a long-term illness or disability', *Scandinavian Journal of Caring Science* **21**, pp 419-425

This I do not dispute, however, there are those who are not able to represent themselves or others with disabilities due to the severity of the impairments that they have.

A study by Wacker et al⁹⁸ sought the opinions of 180 'multihandicapped adults'. These views were obtained by questionnaire that took into account aspects of the subject's life, such as, social situation, living circumstances, physical status, education, vocational training and employment. Most reported that they were satisfied with their life outcomes and very satisfied with their social activities. The variable which was reported to most strongly relate to life outcome and satisfaction was functional status. Another study supporting this is one that involved adolescents rather than adult subjects. This study also concluded that 'adolescents with long-term illness or disabilities experience well-being when they are allowed to prepare for living a normal life integrated in society.'⁹⁹

This type of data is invaluable, particularly for determining which aspects of a disabled person's life can be improved if necessary and also as evidence to prospective parents of a disabled child that life with disability can be very rewarding. It does not take into account, however, those who have such severe disabilities that it prevents them from participating in this type of research and analysis. This may include those with severe intellectual disabilities, which may or may not be accompanied by physical disabilities, or those who are too young to provide any comment, or those who have very limited survival. This important point is also noted by Abberley¹⁰⁰ who observed that 'there are impairments which cause suffering, pain and premature death', and as a consequence these individuals cannot take part in such studies.

⁹⁸ Wacker DP, Harper DC, Powell WJ, Healy A (1983) 'Life outcomes and satisfaction ratings of multihandicapped adults', *Developmental Medicine and Child Neurology* **25**(5), pp 625-31

⁹⁹ Berntsson L, Berg M, Brydolf M, Hellstrom AL (2007) 'Adolescents' experiences of well-being when living with a long-term illness or disability', *Scandinavian Journal of Caring Science* **21**, pp 419-425

¹⁰⁰ Abberley P (1987) 'The concept of oppression and the development of a social theory of disability', *Disability, Handicap and Society* **2**, pp 5-19

Hubbard argues against the suggestion that all disabled people should be grouped together 'as though all disabilities were the same and always devastating and as though all people who have one were alike'.¹⁰¹ This is a valuable point to make and again highlights the importance of deliberative discussions between prospective parents and clinicians to ensure that decisions are made based on the particular difference in their future child and how it may affect them and their family personally and not based on a general view of the disability in question.

With regards to Hubbard's comments, those who argue against prenatal testing are doing exactly what he argues against but with the converse view that they can speak on behalf of all of those suffering from impairment and subsequent disability. Shakespeare, who has the genetic condition Achondroplasia, acknowledges that impairment is not the defining characteristic of being a person with disabilities in view of the fact that not everyone experiences the same degrees of illness or impairment.¹⁰²

Shakespeare also argues that disabled people are not consulted on the very matters that affect them.¹⁰³ He is concerned that decisions made about factors that affect them are done so by unrepresentative parties, without referring to the 'best experts on life as a disabled person'.¹⁰⁴ I agree that those with disabilities, who are able to do so, should be consulted about matters that affect them, however, the problem that Shakespeare highlights is exactly what those with disabilities are doing to those who cannot voice their opinion due to the severity of their disability or due to their limited postnatal survival. It needs to be accepted that there are disabled individuals who cannot speak for themselves and about whom other disabled people cannot provide a representative voice. In fact it is likely that those best placed to make decisions on behalf of

¹⁰¹ Hubbard R (1997) 'Abortion and disability: who should and who should not inhabit the world?' in L Davied (ed) *The Disability Studies Reader*, New York, Routledge, p 74

¹⁰² Shakespeare T (1998) 'Choices and rights: eugenics, genetics and disability equality', *Disability & Society* 13(5), pp 665-681

¹⁰³ Shakespeare T (1998) 'Choices and rights: eugenics, genetics and disability equality', *Disability & Society* 13(5), pp 665-681

¹⁰⁴ Shakespeare T (1998) 'Choices and rights: eugenics, genetics and disability equality', *Disability & Society* 13(5), pp 665-681

someone with impairments who cannot speak for themselves and who are best placed to make any form of judgement about their life and its quality are their parents or carers.

However, Shakespeare goes on to say that being a parent of a person with an impairment is different from being that person themselves.¹⁰⁵ Whilst I do agree with this sentiment the same could be said for anyone else who makes judgements about those aforementioned individuals who have severe or life limiting impairments, including those disabled people who are able to voice an opinion. Can anyone really stand in the shoes of another person and make true judgements about their life just because they too happen to be physically impaired?

Shakespeare, however, argues that it is important to recognise the ‘collective voice of disabled people’.¹⁰⁶ When considering issues on policy I agree that this is important for the voice to be representative so that the maximum number of people can benefit, however, where important personal decisions, such as those relating to prenatal testing are taking place, an overall voice may not be the most appropriate and it is the voice of those who are going to be directly affected that needs to be considered. Whilst it can never be ideal for another person to make decisions or judgements about another’s life or needs, this is often necessary in a health and welfare setting when patients do not have the capacity to make decisions for themselves¹⁰⁷ and particularly so where those with parental responsibility make decisions for their children before they reach an age where they are competent to make their own decisions.¹⁰⁸ This principle is based on the fact that generally parents will act in the best interests of their children¹⁰⁹.

¹⁰⁵ Shakespeare T (1998) ‘Choices and rights: eugenics, genetics and disability equality’, *Disability & Society* 13(5), pp 665-681

¹⁰⁶ Shakespeare T (1998) ‘Choices and rights: eugenics, genetics and disability equality’, *Disability & Society* 13(5), pp 665-681

¹⁰⁷ Mental Capacity Act 2005, HMSO: London, section 4

¹⁰⁸ General Medical Council (2007) *0-18 years: Guidance for all doctors*, GMC: London

¹⁰⁹ Beauchamp TL, Childress JF (2001) *Principles of Biomedical Ethics* (5th ed), Oxford University Press, pp 102-103

With regards to prenatal testing and termination of pregnancy the fetus cannot make the decision itself as to whether it wants to exist with a disability or not exist at all. The fetus, therefore, is in a similar position to those living with disabilities who do not have the mental capacity to form or voice their views. This leaves the prospective parents, who will be ultimately responsible for this future person if they are born, to make those decisions on their behalf. Better placed to make these decisions are those prospective parents who have experience of the condition in question, either directly from having had a previously affected child, or indirectly from knowing another affected family member.

In addition to those whose disabilities are so severe that that cannot express their views prenatal testing can also identify fetuses that may have impairments which have implications for a short period of time due to limited survival. Generally speaking, for this group impairments will only have limited effect because the condition is one of such severity that it is not compatible with long-term survival. Again, these neonates do not have the opportunity to experience any of the pleasures in life which those living with disabilities experience and who argue against prenatal testing, and it is not currently possible to gain any measure of this. However, due to the nature of their illness it is likely that they will experience at least some pain and suffering whilst they are alive. Those who argue against prenatal testing on disability grounds do so without reference to these neonates.

Another group that should be considered are those who have such severe physical congenital impairments as to not survive pregnancy and die in-utero. If a prospective parent is unfortunate enough to discover that their pregnancy is affected by a condition which will inevitably result in death before gestation is complete, but perhaps at a stage of pregnancy which will still require a natural delivery, it must be for that parent to decide whether or not the pregnancy be terminated at an earlier stage. The outcome for the fetus would be the same. Without prenatal testing providing this information a woman would be faced with only finding out there was a problem once she had gone through her pregnancy and delivery. The outcome of this situation is the same whether or not prenatal testing takes place from the point of view of the fetus. When considering parental

autonomy and discrimination against those with disabilities it would seem that under these circumstances discrimination is not an issue and, therefore, whether or not prenatal testing takes place in this case should be based on what the pregnant woman may feel is in her best interests and that of her fetus.

It is clearly essential that whomever is making the decisions does so with the best interests of the future child in mind and any decisions will generally be made by a number of parties acting together to further these interests, for example, parents and healthcare workers. Supporting my argument that even those with disabilities cannot be completely representative, Shakespeare himself acknowledges the existence of disabled people who cannot speak for themselves, the example referred to, is those with severe intellectual impairments such as Fragile X syndrome.¹¹⁰ In these circumstances, Shakespeare concedes that it may perhaps be appropriate for family and other advocates to contribute to any decisions made.

This supports the overall arguments of my thesis in that rather than the decisions being made with regards to prenatal testing and termination of pregnancy being discriminatory against those with disabilities, they are made with the best interests of the future child within the context of its wider family based on individual circumstances, and not based upon the opinions of others as to how disability more generally may affect a person's life. It also further emphasises the arguments in chapter three, supporting the importance of respecting reproductive autonomy where decisions are being made on behalf of a future disabled child.

¹¹⁰ Fragile X is an X-linked condition carried by the mother. If this is passed on to a male fetus it will result in moderate to severe intellectual impairment and behavioural problems. Prenatal testing is available for this condition for those know to be at risk of transmitting this gene mutation on to their offspring.

5.4 Summary and conclusions

In this chapter I have reviewed arguments against prenatal testing put forward by those representing the interests of people with disabilities and those who oppose prenatal testing on the grounds that it is discriminatory. I have discussed the importance of not regarding a fetal abnormality as an isolated finding but also by the impact it will have on the interests of the future person, the prospective parents and others who will be directly affected.

I have argued against the claims that the effect of prenatal testing will be to reduce the number of people with disabilities in society or negatively impact on the provision of support that is offered. In fact, with an aging population and medical technological advances improving support to disabled people will be more important than ever, and rightly so.

I have discussed the Expressivist and Parental Attitude Arguments and concluded that prenatal testing, whether or not this is followed by termination of an affected pregnancy, does not make judgements about the lives of those with disabilities or suggest that their lives are not worthwhile. The disability discrimination arguments do not take into account the many reasons that influence a couple as to whether they decide to have their pregnancy tested. Not only do the physical and/or mental impairments of the fetus need to be considered but also the impact this has for the future child in terms of harm to their interests, including the experience of pain and suffering, but also the wider implications to the interests of others including the parents and pre-existing children.

The decision to have a pregnancy tested does not say anything, negative or otherwise, about those living with disabilities but is a very personal decision which takes into account the desires, interests and circumstances of the individuals involved. Whilst the views of people living with disabilities is undoubtedly important in this debate it is by no means representative particularly when considering those pregnancies for which late termination of pregnancy is an option.

Disabled people who are able to put their views forward may be no more representative of very severely disabled people, especially those with very severe mental impairments, than anyone else.

I argue that the parents are best placed to make these decisions and that parents should be able to make autonomous reproductive decisions based on information that they are able to gain throughout the process. Others argue that it is the disabled community who are in the best position to speak out against prenatal testing and abortion. The fetus is not in a position to consider its own future and I have argued that there is no single person alone who can categorically decide what is in the future child's best interest. Therefore, the prospective parents are in a better position than anyone, providing any decisions they make are based on balanced information which is relevant to their particular circumstances, and hence promoting the importance of reproductive autonomy.

Chapter 6

The promotion of reproductive autonomy in future policy

6.1 Introduction

In my previous chapters, I advocated and supported the use of prenatal testing by arguing that allowing such testing, with or without termination of pregnancy, promotes and respects reproductive autonomy. I also argued that prenatal testing does not discriminate against those with disabilities and does not make judgements about the lives of people who live with disability. This is also supported by my argument that the fetus does not have full moral status and therefore terminating the life of a disabled fetus cannot be compared to ending the life of a person with a disability.

I have argued that it is not only the life of the future child that should be considered when deciding whether or not termination of pregnancy following prenatal testing is justified, but also the harm that could be caused to the interests of the prospective parents and other people, who have full moral status, that are directly affected by a disabled child's birth.

The purpose of this chapter is to highlight the problems with the current decision making processes around prenatal testing and termination of pregnancy, particularly late in gestation, by fetal medicine specialists and their multidisciplinary teams, and to use my arguments to promote a change in the context of these discussions so that not only the potential harm to the fetus is considered, but also the harm to other relevant parties. This is important because these individuals, as persons, have full moral status¹ and should be afforded the opportunity to make autonomous reproductive decisions about matters which will affect them directly, and where

¹ I discussed the concept of personhood and moral status in chapter 2 (section 2.2.4)

harm to their interests may occur. This change will need to involve the prospective parents more in the decision-making process and more consideration of their interests, and provide them with an opportunity to support medical professionals in justifying their decision to allow a late termination of pregnancy to proceed. As the clinical geneticist is involved in the prospective parent's care from an early stage in the process, when prenatal testing is initially being considered, and they maintain a supportive role throughout the decision-making process, they would be well placed to enhance the involvement of prospective parents and, where necessary, act as an advocate for them.

6.2 Fetal Management

Although I have argued in support of prenatal testing, which may subsequently result in parents opting to terminate an affected pregnancy, in that it promotes reproductive autonomy, this does not correlate with what happens in reality, in my experience, when fetal medicine and other specialists meet to discuss the future management of such cases. Those prospective parents who may wish to end a pregnancy, particularly late in gestation, may not be provided with the opportunity to do so. Ultimately, two healthcare professionals need to agree that a late termination can be justified based on the fetus having a substantial risk of serious handicap due to the presence of a physical or mental abnormality if it is born.² This decision will be based on clinical information but also on the subjective opinion of the doctors and may be influenced by their own moral views.

Whilst prospective parents may have had the opportunity to take advantage of prenatal testing during their pregnancy this does not guarantee them ultimately being able to exercise their reproductive choices, as the medical professionals act as gate keepers at this late stage of

² Abortion Act 1967, Section 1(d), HMSO: London

pregnancy. Presumably those working within the field of fetal medicine and clinical genetics advocate the use of prenatal testing and are not explicitly opposed to the idea of termination of pregnancy. Clinical geneticists and counsellors provide advice and information about prenatal testing and the potential outcomes, including termination of affected pregnancies, and it can therefore be reasonably assumed that they do not conscientiously object to the procedure itself or else they would not work in an area where it is an integral requirement. Similarly, those obstetricians who work within the subspecialty of fetal medicine offer and perform terminations, including those up to birth. Whilst there are some obstetricians who do not offer terminations, it would not be possible for those who subspecialise in fetal medicine to function in their role if they did not perform abortions, including those that require feticide. However, if parents find out that their pregnancy is affected by a congenital abnormality later in gestation their choices may be limited by the judgements of these same healthcare professionals.³

If information about their fetus only becomes available close to or after twenty-four weeks of gestation greater justification is needed to end a pregnancy. However, a decision to terminate a pregnancy due to a given abnormality before this point may have been permitted. This greater justification is due to the current abortion legislation and will also be influenced by the healthcare professionals own ethical framework,⁴ and what they consider to be a serious enough abnormality. Many argue that this should be the case as the fetus is now said to be viable,⁵ necessitating the need for feticide before the pregnancy is terminated. In reality, this is more likely to be an issue from twenty-two weeks of gestation when feticide is generally employed to ensure that the fetus is born dead.⁶

³ In practice this will generally be after 22 weeks gestation as feticide will be required.

⁴ Statham H, Solomou W, Green J (2006) 'Later termination of pregnancy: law, policy and decision making in four English fetal medicine units' *British Journal of Obstetrics & Gynaecology*, **113**(12), pp 1402-1411

⁵ Chervenak FA, McCullough LB, Campbell S (1995) 'Is third trimester abortion justified?', *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

⁶ Graham RH, Robson SC, Ranking JM 'Understanding feticide: An analytical review', *Social Sciences and Medicine* **66**(2), pp 289-300

Fetal medicine specialists need to work within the law and need to be able to justify agreeing to the termination of such a pregnancy. There is no agreed list or criteria as to what constitutes an abnormality that is serious enough to justify ending a pregnancy after twenty-four weeks,⁷ and, therefore, there are no clear legal definitions or clear limits on permissibility.⁸ This, therefore, depends on the judgement of the healthcare professionals involved,⁹ and is likely to be influenced by their own experiences and values.

In my experience working as a clinical geneticist and with fetal medicine specialists pregnancies affected by abnormalities that are picked up later in gestation are discussed amongst healthcare professionals in fetal management meetings, generally in specialist tertiary hospitals. The purpose of these meetings is to discuss the nature of the abnormality and how it might be managed, whether that is by some form of in-utero treatment (such as using nephrostomy drains in a fetus whose kidneys are shown to be obstructed) or by allowing the parents to end the pregnancy should they wish, assuming this is agreed to by two healthcare professionals. Those attending the meeting generally include obstetricians with a special interest in fetal medicine, and who are likely to be the people agreeing to the abortion, signing the forms and performing the procedure, in addition to specialist midwives and clinical geneticists. The role of the geneticist in these discussions is to provide advice and information on the condition or abnormality itself with regards to what is known about the condition and its prognosis.¹⁰ The geneticist may also have a role in confirming the diagnosis based on test results and physical findings picked up on fetal ultrasound scans and more specialised magnetic resonance imaging. It is ultimately the fetal medicine specialists, however, who decide whether or not they are prepared to perform the procedure. They are legally responsible for this with the

⁷ Royal College of Obstetrics & Gynaecology (2010) *Termination of pregnancy for foetal abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London

⁸ Rodeck CH, Bewley S (1994) 'Late abortion for fetal abnormality' in Bewley S, Ward RH (eds) *Ethics in Obstetrics and Gynaecology*, RCOG Press, London, pp 262-267

⁹ Lilford R (1994) 'Decisions about severe abnormality, damage and death' in Bewley S, Ward RH (eds) *Ethics in Obstetrics and Gynaecology*, RCOG Press, London, pp 277-284

¹⁰ Marteau TM (2005) 'Towards informed decisions about prenatal testing: A review', *Prenatal Diagnosis* **15**(13), pp 1215-1226

risk of prosecution if a termination is felt to have been performed inappropriately.¹¹ The patient does of course have the option of a second opinion if the termination is refused at this stage; however, there is obviously no guarantee that the outcome will be different.

As mentioned above, there is no professionally recognised guidance list of conditions that are thought to be serious enough to allow late termination of pregnancy. One concern about drawing up such a list is that it would identify certain conditions and send out a negative message specifically about them.¹² All conditions are variable regarding the extent to which they cause disability or suffering. Spina bifida, for example, can range from being relatively mild to a seriously disabling condition¹³ and therefore there would be problems with having this referred to generally within a list. There is concern that a proscribed list would be unworkable for this reason and may result in reduced patient care.¹⁴ There is also a danger that parents whose pregnancy is affected by a particular condition that does happen to fall within the agreed conditions may feel pressured to terminate their pregnancy, and may even feel irresponsible for not doing so.¹⁵

A role of the clinical geneticist that I believe should be enhanced is that of advocate for the family. Having established a supportive relationship with the prospective parents the clinical geneticist is well placed to not only provide clinical information about the fetus, based on test results and knowledge of the diagnosed condition, but also represent the prospective parents in putting forward their views about the potential impact having a disabled child will have on their

¹¹ Statham H, Solomou W, Green J (2006) 'Later termination of pregnancy: law, policy and decision making in four English fetal medicine units' *British Journal of Obstetrics & Gynaecology*, **113**(12), pp 1402-1411

¹² Savulescu J (2001) 'Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion', *Journal of Medical Ethics* **27**, pp 165-171

¹³ Dennis M, Landry SH, Barnes M, Fletcher JM (2006) 'A model of neurocognitive function in spina bifida over the life span' *Journal of the International Neuropsychological Society* **12**(2), pp 285-296

¹⁴ Statham H, Solomou W, Green J (2006) 'Later termination of pregnancy: law, policy and decision making in four English fetal medicine units' *British Journal of Obstetrics & Gynaecology*, **113**(12), pp 1402-1411

¹⁵ Korenromp MJ, Page-Christiaens GCML, van den Bout J, Mulder EJH, Visser GHA (2006) 'Is there pressure from society to terminate pregnancy in case of a fetal anomaly?', *Prenatal Diagnosis* **26**(1), pp 85-86

own interests, and on the interests of other children they have who may also be affected by the same condition. The clinical geneticist may have supported this family through similar circumstances before due to previously affected pregnancies or affected children, who may or may not still be alive. They may be in the unique position, therefore, of knowing this family better than anyone else from a personal clinical perspective. The importance and nature of this role is something that I will develop in subsequent discussions in this chapter.

6.3 Implications for reproductive autonomy

Where parents undergo prenatal testing and are informed that their pregnancy is affected by a disabling condition later in gestation the freedom of their reproductive choices may be limited. For example, a couple who find that their fetus is affected by Achondroplasia, which for some reason had not been picked up earlier in gestation, may decide they want to end the pregnancy. In my experience this is not a condition that clinicians would consider serious enough to justify late termination as the future child, although of short stature and with some physical restrictions, would be able to function well in society and have normal intelligence. This may appear unfair on the grounds that time rather than the nature of the disabling condition and future welfare of the child is the determining constrain upon their reproductive autonomy. Where a mild abnormality is discovered earlier in pregnancy a termination is likely to be an option for the parents but not late in gestation where a more serious (but not severe enough) abnormality may be found. A normal pregnancy can also be ended at this earlier stage. However, if parents are unfortunate enough to find out there is an abnormality after twenty-two weeks the option of a termination cannot be guaranteed. It is important that parents are aware of this when making decisions about prenatal testing at this point in pregnancy.

Parents should be given the opportunity to discuss the potential outcomes with a fetal medicine specialist in advance of testing and have an indication as to when a termination may be

permissible, and when it is not. Again, the role of the clinical geneticist is pivotal in this regard and when discussing the option of prenatal testing for these types of conditions early referral to a fetal medicine specialist should be considered. Some parents may choose not to have testing if a termination is not an option. Others may still decide to go ahead knowing that any information testing provides may aid delivery and immediate after care. If prospective parents make a decision about prenatal testing based on the premise that a termination is possible, when in fact it is not, this not only limits their reproductive autonomy in not allowing them to ultimately take the action they want, but it also means that the original decision to have had prenatal testing is also flawed as it was based on erroneous information. Some prospective parents may have made the decision not to have prenatal testing if they could not ultimately decide to end their pregnancy and this, therefore, raises issues around consent and whether or not it was fully informed and therefore valid. Early engagement and discussion between the fetal medicine specialists and clinical geneticist is essential therefore, rather than this only taking place once prenatal testing has been performed and a late termination has been requested by the parents, which then needs justification by the clinicians responsible for it.

6.4 Difficulties in decision making and harm to others

The difficulty for healthcare professionals is in deciding on what is serious enough with regards to a disability or abnormality to permit a late termination of pregnancy. Whilst fetal medicine specialists are extremely unlikely to choose to develop their careers in this particular area of obstetrics if they objected to ending pregnancies for whatever reason, the decisions they make are likely to be influenced by their own moral views, as well as being made within the confines of the current abortion law. It is natural that different people have different views and ideas as to what constitutes a serious disability and what they would regard as appropriate to allow a pregnancy at that stage to be ended. It is difficult to see how these doctors can be truly objective about these decisions and not allow their own personal beliefs to influence them. There is

evidence of individual differences between healthcare professional's attitudes towards abnormalities in addition to a shift in attitudes over time, with regards to conditions that would fulfil the legal criteria.¹⁶

There is plenty of literature discussing the impact of termination of pregnancy on women and the psychological impact this has on them.^{17,18,19,20} It is important to remember that women and couples who contemplate late termination of pregnancy due to an abnormality do so as a last resort. By this stage in pregnancy women will, under normal circumstances, have had their routine antenatal tests, including screening blood tests which predict their risk of conditions such as Down syndrome and other chromosomal abnormalities, and a detailed anomaly ultrasound scan at around twenty weeks of gestation. All of these tests may have been reassuring and for some reason new concerns have arisen later, resulting in further testing. The news of a problem with their fetus at this stage must be devastating and a decision to end the pregnancy will not be one taken lightly or without much thought and anguish. The prospective parents will have been looking forward to the birth of their child and may have started to make preparations for its arrival. Other children and relatives will be looking forward to the addition of a new member to their family.

Discussions within fetal management meetings tend to focus on the congenital abnormality in the fetus and the disability that is likely to result as a consequence of it. It is the clinician's views on that disability and the impact it will have on the life of the future child that will

¹⁶ Statham H, Solomou W, Green J (2006) 'Later termination of pregnancy: law, policy and decision making in four English fetal medicine units' *British Journal of Obstetrics & Gynaecology*, **113**(12), pp 1402-1411

¹⁷ Korenromp M (1992) 'Termination of pregnancy on genetic grounds: coping with grieving', *Journal of Psychosomatic Obstetrics & Gynaecology* **13**, pp 93-105

¹⁸ Blumberg BD, Golbus MS, Hanson KH (1975) 'The psychological sequelae of abortion performed for a genetic indication', *American Journal of Obstetrics & Gynecology* **122**, pp 299-308

¹⁹ Korenromp M, Christiaens GCML, van den Bout J, Mulder EJH et al (2005) 'Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross sectional study: Retrospective study in women', *Prenatal Diagnosis* **25**, pp 253-260

²⁰ Davies V, Gledhill J, McFadyen A, Whitlow B, Economides D (2005) 'Psychological outcome in women undergoing termination of pregnancy for ultrasound-detected fetal anomaly in the first and second trimesters: a pilot study', *Ultrasound Obstetrics & Gynecology* **25**, pp 389-392

influence the decisions as to whether to allow a late termination of pregnancy to be performed. If a fetus is found to have anencephaly or Thanatophoric dysplasia, both of which are associated with stillbirth or very limited postnatal survival, it is very unlikely that a late termination would be denied.²¹ However, where a condition may cause a physical abnormality but is not associated with limited survival or intellectual difficulties doctors may not agree to allow a late termination to proceed on the basis that the future person will have a reasonable life in their opinion, despite their physical or intellectual difficulties. This judgement is based on the doctor's views on the prognosis of the condition. It is important to bear in mind that they themselves will not be the one responsible for the child for the rest of its life. This links to my arguments in chapter four (section 4.2.2.i) regarding the discussion of harm caused by disability in the fetus to the interests of, not only the future child, but also other directly affected individuals. As I have discussed in chapter two, those individuals have full moral status, whereas the fetus does not. The harm to the interests of those individuals and how their lives may be affected should also be taken into account in addition to the direct assessment of the severity of the medical condition in the fetus.

Whilst I have agreed that the fetus has moral status, which increases over the course of the pregnancy, it is not the same as the full moral status enjoyed by the mother. The mother has already been born and already has established interests, as do others close to her, such as her partner and other children. I have argued that due to the increasing moral status of the developing fetus greater justification to terminate a pregnancy is needed as term approaches, however, it is not only the anomaly itself which needs to be considered but also the harm that may be caused to relevant others. The decision to terminate a pregnancy, therefore, especially late in gestation, can only be made in conjunction with the prospective parents, whose interests must also be considered.

²¹ Chervenak FA, McCullough LB, Campbell S (1995) 'Is third trimester abortion justified?', *British Journal of Obstetrics & Gynaecology* **102**, pp 434-435

In chapter three, with respect to reproductive autonomy, and in chapter four and five, with respect to disability and the potential harms it can cause, I have reiterated the point that it is not only the future person who is affected by the anomaly and subsequent disability, but also the parents and others close to and directly involved with the future person. How a disability in the fetus affects those directly involved will vary from one family to another and will inevitably have a variable impact between different people. This will depend on their views of that particular disability and also on the interests that they currently hold and the interests they hope to have in the future.

Clinical geneticists counselling couples who find their pregnancy is affected by an abnormality should not only focus on the condition affecting their fetus and the physical or intellectual disability this will result in, but should also offer advice and potential solutions. It is hoped that this may address some of the concerns they have about the impact having a disabled child will have on that child, but also on their own interests. Parents need a balanced picture of how the disability will affect them and their child in order to make the difficult decisions they face in this situation. Parents should be afforded the opportunity to meet other people affected by the condition (either directly as the person with the condition, or indirectly by those living with that person, whose lives are also affected). They should be made aware of the care and support that is available and ways in which the condition can be managed, not just medically but emotionally and practically, so that they have a full understanding of the impact the condition will have and what adjustments may need to be and can be made. The provision of this type of information may have different outcomes. It could result in some couples who may not have understood the seriousness of the condition opting for a termination when they otherwise would not have, or it may mean that other couples feel more reassured and decide to continue a pregnancy that they would otherwise have ended. Either way, they have made a decision based on balanced information that has taken their interests and needs into account, and that of any other family members that may be affected.

However, even where prospective parents are given this information to help them reach a decision, if the abnormality is detected late in pregnancy the decision to terminate is not one that they have full control over. This is left with the healthcare professionals who discuss their 'case' with respect to how it will affect the future child. Whilst prospective parents should be given the opportunity to discuss their situation with other parties who can assist them in reaching a decision, healthcare professionals should also seek appropriate impartial advice and this may, for example, include approaching their clinical ethics committee to allow the complex ethical issues involved in such decision-making to be fully explored.²²

In my view, there needs to be more involvement with the prospective parents when decisions are made about late termination of pregnancy. Healthcare professionals make decisions based on the clinical findings of the tests performed on the fetus and what is known about the condition generally, rather than how the abnormality may affect this particular fetus and those with full moral status who will have the responsibility of caring for and supporting the future child, and may also have other children to consider in addition to their own interests. I have discussed in chapter four how the interests of others may be harmed by the birth of a disabled child and how it is those who will be affected that should be in a position to make a decision about the impact this will have on them. It may be that by having a greater opportunity to express the views of prospective parents during discussions at management meetings different decisions may be made, which are tailored more towards the particular family who will be affected. The impact on the prospective parents and other children can be taken into account when considering what harms may occur as a result of the fetal abnormality, but also a more rounded sense of how the life of the future child may be affected and influenced by those around it. The parent's emotional resilience can be taken into account, their ability to care for the child and how it may also affect their lives and future interests can be considered. A more holistic view of the life of the future child, and not just taking into account the potential disability,

²² McLean SAM (2007) 'What and who are clinical ethics committees for?' *Journal of Medical Ethics* 33(9), pp 497-500

should be considered and used to inform the decision-making process and this is something that the clinical geneticist should promote and encourage. This will also assist the healthcare professionals involved as their decisions will also be better informed, being based on more extensive relevant information.

The role of the clinical geneticist is pivotal at this point in the process, not only in terms of providing clinical information about the fetus and the prognosis in order to assist fetal management specialists in justifying whether or not a later termination can take place, but also in acting as an advocate for prospective parents. The current format of fetal management meetings is to consider the clinical facts of a particular case and what the appropriate action should be based on those facts. The geneticist, having been involved in the prospective parent's care from the outset and having had the opportunity to have in-depth discussions with them about their anxieties, may be well placed to relay this to the rest of the team so that this can also be taken into account when decisions are made.

6.5 Considering the reality of termination

Whilst the termination process will be discussed with the patient and her consent sought it is easy to talk about late termination of pregnancy as a medical process from an academic perspective without taking the time to consider what it means, both practically and from an emotional perspective for those directly involved. Feticide is performed by ultrasound-guided injection of a chemical, such as potassium or lidocaine, into the fetal heart. This procedure is undoubtedly stressful and painful for the pregnant woman. It is then necessary to wait until the fetal heart stops beating and this may involve the pregnant woman leaving the hospital to go home, knowing her fetus is dying or dead, to return the next day to complete the process. A termination at this gestation is a very different procedure to those that occur earlier in

pregnancy.²³ In the case of late termination of pregnancy, once fetal death is confirmed by ultrasound, labour is induced and the woman has to go through labour and give birth vaginally, just as she would have done had her pregnancy been normal. It is easy to discuss late termination of pregnancy without considering these facts and the obvious psychological and physical trauma this will inevitably cause. The process will be explained to the prospective parents before they make their decision and before their informed consent can be obtained as it is for any medically invasive procedure. Some parents may choose not to terminate a pregnancy on receiving this information. This may be the case, for example, when the neonate is likely to die soon after birth and the outcome will be the same regardless of whether active steps are taken to terminate the pregnancy or whether it is continued. Either way the prospective parents will have to face the prospect of going through labour and delivery. Psychological sequelae following termination are well known²⁴ and as well as counselling prior to termination this is also available to couples after the procedure has taken place.²⁵

Other parents may opt for a termination rather than have to cope with the psychological impact of continuing a pregnancy, possibly to full term, knowing what the outcome will be. They may prefer to expedite the inevitable outcome and take some control of the situation. It really is a very personal decision and it is only those directly affected and who have to live with the decision that can really know what is in their own best interests in this situation. This emphasises the importance of reproductive autonomy and, particularly for these types of cases, it highlights the fact that decisions are not made on the basis of discriminating against those with disabilities.

²³ In early pregnancy a medical termination is possible which involves taking medication in the form of mifepristone and prostaglandin which induce a miscarriage. From seven weeks a surgical termination is performed by vacuum aspiration or suction termination to remove the fetus from the womb under local or general anaesthetic. In both procedures, the patient does not go through labour or normal delivery.

²⁴ Canario C, Figueiredo B, Ricou M (2011) 'Women and men's psychological adjustment after abortion: a six months prospective pilot study,' *Journal Of Reproductive And Infant Psychology*,**29**(3) pp 262–275

²⁵ Organisations such as the British Pregnancy Advisory Services offer counseling in the UK (www.bpas.org)

6.6 Is adoption a viable alternative?

There are those who argue that where an abnormality will not result in very limited survival, but may result in severe physical or intellectual disability, adoption of the child is an ethically preferable alternative to a termination.²⁶ This would relieve the parents of the burden of caring for a disabled child but would not deny the child of its existence and having a future of its own. This view may or may not take into account the effect of the disability on the future child, but it is unlikely to take into account the harm to the interests of the prospective parents, in terms of both their own psychological welfare and that of any family members, which may arise from having the child adopted. It is one thing to have a child adopted who is unwanted; this may relieve the parents of any guilt they may have over not wanting the child and allows them to ensure that the child has the best chance of as good a future as possible. Biological parents may be able to reassure themselves that they have done the best thing for the child and that it will have a life that it would not otherwise have had. Despite this, however, there is evidence that biological parents do suffer grief and a sense of loss after having had a child adopted which can lead to significant psychological problems.²⁷

The circumstances where disability is concerned are very different, however. Where an abnormality has been detected late in pregnancy prospective parents have begun to imagine life with their much-wanted child and have begun to make plans for the future. Other siblings may also be looking forward to the birth of their brother or sister. I have argued in chapter four (section 4.2.2.i) that decisions about prenatal testing and termination of pregnancy should also take into account the harm to the interests of others directly affected, and so too should decisions

²⁶ Hare RM (1993) 'The abnormal child. Moral dilemmas of doctors and parents' in Hare RM (ed) *Essays on Bioethics*, New York: Oxford University Press, pp 185-191

²⁷ Condon J (1986) 'Psychological disability in women who relinquish a baby for adoption', *Medical Journal of Australia* **144**, pp 117-119

about adoption due to the emotional and psychological effects it could have on those making the decision (the parents) and other family members who would also inevitably have emotional ties to the child.²⁸ Prospective parents may make a decision to end a pregnancy due to the impact the disability will have on their child and their desire not to see their own child suffer, in addition to the harm it may cause to them and others close to them. Making a decision to have a child adopted under these circumstances does not remove the harm that is caused to their future child. In addition to this, the harm to their own interests in having to support and cope emotionally with having a disabled child will be replaced with having to manage the emotions that are associated with knowing that the child, who was much anticipated, is now being cared for elsewhere by someone else. This could potentially cause more harm to the parents than having had the pregnancy terminated.²⁹ Adoption, whilst being a viable option, cannot be a mandatory alternative to having a termination due to severe disability. If it is chosen it needs to be a decision that is made by the prospective parents and not one that is enforced on them if they make the decision that they do not want to care for a disabled child. Any such policy would in itself restrict the reproductive freedom of prospective parents.

6.7 Psychological impact on healthcare professionals

I have mentioned that literature exists which discusses the emotional impact terminating a pregnancy has on women undergoing a termination. There is very little literature, however, on the psychological impact it has on healthcare professionals who perform these procedures, which has been described as ‘agonizingly difficult’³⁰ and a ‘heavy emotional burden’.³¹ Whilst

²⁸ Logan J (1996) ‘Birth mothers and their Mental Health: Unchartered Territory’, *British Journal of Social Work* **26**(5), pp 609-625

²⁹ Giubilini A, Minerva F (2013) ‘After-birth abortion: why should the baby live?’, *Journal of Medical Ethics* **39**, pp 261-263

³⁰ Lilford R (1994) ‘Decisions about sever abnormality, damage and death’ in Bewley S, Ward RH (eds) *Ethics in Obstetrics and Gynaecology*, RCOG Press, London, pp 277-284

³¹ Lilford R (1994) ‘Decisions about sever abnormality, damage and death’ in Bewley S, Ward RH (eds) *Ethics in Obstetrics and Gynaecology*, RCOG Press, London, pp 277-284

they may not conscientiously object to abortion in itself they will have their own views as to when termination is and is not appropriate based on their own moral judgements. There are those who believe that termination of pregnancy should be allowed for all pregnancies,³² regardless of the reason. If a woman wants to end her pregnancy she should be entitled to do this and for her to have control over her own bodily integrity.³³ Again, it is one thing to put these arguments forward but we also need to consider the fact that the procedure itself has to be performed by another person with their own moral views and beliefs.

Termination of pregnancy, whether or not it involves feticide by injection, involves killing a member of the human species. Whether or not one argues that the fetus has full moral status, or whether or not the fetus is a person, it is understandable that termination is unlikely to be seen as a neutral act. People choose a career in medicine for many reasons but generally they have a desire to help people. There tends to be a general assumption, particularly by the public, that the role of doctors is to save lives.³⁴ In fact a more accurate description of a doctor's role is to act in the best interests of their patient.³⁵ For example, sometimes it is more important to ensure that a patient has a comfortable and dignified death rather than to try to keep them alive. This is recognised by the development of specialities such as palliative care and the introduction of 'Do Not Attempt Resuscitation (DNAR)' orders. It is inevitable that doctors will have a view on abortion, just like anyone else, and those who object to it will avoid specialities that involve it. However, even those doctors who do go into relevant medical specialities are likely to have their own limits as to what they believe is acceptable. These beliefs will inevitably affect the decisions they make with regards to late termination and disability. Whether a woman is allowed to have a late termination, therefore, may depend on the healthcare professional she

³² Purdy L (1999) 'Are Pregnant Women Fetal Containers?' in Kuhse H, Singer P (eds) *Bioethics: An Anthology*, Blackwell Publishers, pp 71-81

³³ Purdy L (1999) 'Are Pregnant Women Fetal Containers?' in Kuhse H, Singer P (eds) *Bioethics: An Anthology*, Blackwell Publishers, pp 71-81

³⁴ Reyes EA (2013) 'More in U.S. say doctors should try to save lives, no matter what', *Los Angeles Times* November 21, (www.articles.latimes.com as cited on 2 January 2016)

³⁵ General Medical Council (2013) *Good Medical Practice*, GMC: London, p 2

sees, and it is possible that she could have received a different decision had an alternative doctor been involved in her care.³⁶ There is evidence of professionals having a difference of opinion when considering what abnormality is severe enough to justify termination of pregnancy and, therefore, the options that are open to a patient is determined by the subjective values of those caring for them.³⁷ Presumably this is partly why two healthcare professionals have to be involved in the decision making process, to ensure some objectivity. It is difficult to see how this issue can be overcome. Doctors who perform terminations have to be able to justify their decisions, not only in terms of complying with the law, but also for themselves personally. They too are likely to be psychologically affected by the decisions they make and forcing doctors to perform terminations that they themselves do not feel comfortable to perform could cause harm to their own interests and well-being. Forcing doctors to undertake such procedures against their own personal views could potentially discourage doctors from going into this branch of medicine, which could ultimately then limit the availability of terminations particularly in the late stages of pregnancy. If a list of criteria existed as to what makes a late termination justifiable this may make it easier for doctors as the decision would not be based on their own personal judgements but on set guidance. However, I have discussed the reason why having such criteria, or a list of conditions, would not be appropriate.

While doctors have to perform feticide and be involved in the process of late termination it is difficult to see how this situation can change. However, there are ways of ensuring that as much consideration is given to the parent's interests as possible. In order to respect the doctor's autonomy and aid them in making decisions they too need to weight up all the relevant information. Therefore, rather than doctors basing their decisions solely on the condition of the fetus, they should also ensure they have a full understanding of the views of the prospective parents.

³⁶ Chervenak FA, McCullough LB, Campbell S (1999) 'Third trimester abortion: is compassion enough?', *British Journal of Obstetrics & Gynaecology* **106**, pp 293-296

³⁷ Savulescu J (2001) 'Is current practice around late termination of pregnancy eugenic and discriminatory? Maternal interests and abortion', *Journal of Medical Ethics* **27**, pp 165-171

Just as for DNAR orders for patients for whom resuscitation is deemed inappropriate those directly affected by ending the life of the fetus should be included in the decision-making process. Before a DNAR order is placed on a patient good practice dictates that a discussion takes place with the patient (assuming they have the appropriate mental capacity) and their close relatives (with the patient's consent).³⁸ Whilst discussions do obviously occur with the prospective parents, usually with their obstetrician who advises them about the termination process and with a clinical geneticist who will advise them about the condition, they do not play a part in the fetal management meeting where decisions about the justification of termination are discussed. Parents should be afforded the opportunity to explain why they feel a termination of pregnancy is appropriate under the circumstances so that the healthcare professionals who ultimately have to justify their decision to proceed can take this information into account.

6.8 Involving prospective parents in fetal management

I have argued about the importance of reproductive autonomy in chapter three, and why this needs to be of overriding importance. In this chapter, I have highlighted how this may be limited when decisions are being made as to whether a late termination should be allowed (particularly as doctors have to take into account the current legal limitations). I argue that placing greater emphasis on reproductive autonomy by considering the harm that can be caused to prospective parents and their pre-existing children will help healthcare professionals to reach a decision which takes into account the best interests of those who already exist, and who will be affected for the rest of their lives. As it stands at the moment abortion law does allow termination of pregnancy up to birth if it is necessary to prevent 'grave permanent injury to the physical or

³⁸ General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*, GMC: London, paragraph 14, p 14

mental health of the pregnant woman'.³⁹ Again, as with serious handicap, there is no definition of what this means. However, the best way of this being assessed with regards to late termination of pregnancy is for the healthcare professionals involved including and involving the prospective mother in their decision-making processes. This will allow them to be in a position to assess exactly what impact having a disabled child may have on her future health and well-being in view of the impact caring for such a child may have on her future interests and the potential harm it could cause to her.

As things currently stand late termination of pregnancy is restricted by the law, by arguments about the moral status of the fetus and due to concerns about disability discrimination. Although these arguments will prove highly difficult to resolve in light of the continuing debate about prenatal testing and termination of pregnancy the purpose of this chapter has been to argue how it is possible to enhance reproductive autonomy by involving parents more in fetal management decisions and by taking into account the harms that can occur to those other than the fetus and future person itself. In this age of enhancing personalised medicine, with the introduction of genomics and pharmacogenetics, so too should decisions about prenatal testing and termination be personalised to ensure that they are made in the best interests of all of those who will be affected, and not based on views and decisions by those who are not ultimately going to have to live with the consequences of the decision that is made.

Prospective parents should be allowed to contribute to fetal management meetings to ensure that the decisions made take all of these important factors into account. It is important to acknowledge, however, that having prospective parents attend these particular meetings could have a very detrimental effect upon them and this prospect alone may deter them from seeking a late abortion, even where this would be the best outcome for them in terms of their QOL considerations. Prospective parents may not feel able to articulate their views to a group of

³⁹ Abortion Act (1967), HMSO: London, section 1(b)

professionals when they are facing such difficult circumstances and are emotionally fragile. The clinical geneticist, having already established a supportive relationship with them and having discussed their concerns and established the effect having a disabled child will have on them personally, can act as an advocate, putting their views forward in a measured way having ensured that the prospective parents have had the opportunity to weigh up the positives and negatives of their situation. Where prospective parents do want to be directly involved in discussions consideration could be given to a specially convened fetal management meeting in a supportive environment with a more limited number of professionals.

6.9 Summary and conclusions

Having established in chapter two that the fetus does not have full moral status and having argued for the importance of reproductive autonomy in chapter three, I concluded that prenatal testing does not discriminate against those with disabilities following my discussions in chapters four and five. Having satisfied myself of this, in this chapter, I have discussed the limitations that are then placed on prospective parents in terms of their decision-making in relation to late termination of pregnancy.

In order to address this I have provided suggestions as to how the role of the clinical geneticist can be enhanced in order to ensure that parents understand these potential limitations at the outset, but also to ensure that decisions made by healthcare professionals when justifying late termination are made following deliberation not only of the clinical findings in the fetus and future disability, but also the impact on the interests to the wider family. Where prospective parents do not feel able to articulate their views personally, in view of current format of fetal management meetings, I suggest that the geneticist is best placed to act as an advocate for families, having established a supportive relationship with them prior to prenatal testing taking place. This will not only assist healthcare professionals in justifying their decisions to allow a

late termination to take place, but it will also ensure that reproductive autonomy is promoted where decisions about prenatal testing are made.

Chapter 7

Summary and concluding remarks

As a clinical geneticist supporting prospective parents through the prenatal decision-making process it is important to be able to satisfy oneself that this area of practice is ethical. In order to do this the aim of my thesis has been to answer two specific questions. The first is whether specific prenatal testing discriminates against those living with disabilities and, the second question, whether the existing decision-making process regarding termination of pregnancy due to disability supports reproductive autonomy or could be improved. The latter question is based on the fact that where late termination of pregnancy is being considered due to fetal abnormality, rather than it ultimately being a decision for the prospective parents, the justification for this will lie with the clinicians involved.

I have addressed these questions throughout my thesis with the important consideration of the position of the clinical geneticist, as this has not been a significant part of the debate on this topic to date. As well as arguing in response to the above questions that this testing is not discriminatory, I have acknowledged that reproductive autonomy, whilst of paramount importance, may not be being respected where late termination is requested. This has led me to make recommendations with regards to enhancing the role of the clinical geneticist in supporting prospective parents in an advocacy role so that as well as considering the clinical disability in the fetus and potential harm to the future child, consideration is also given to the potential harm to the interests of the wider family.

In order to establish my position on these questions, I have discussed a range of relevant ethical and practical considerations. I have argued that based on the personhood view of moral status the fetus does not have full moral status and as such has a lower moral status than a person

already born and living with a disability. One cannot, therefore, compare killing a fetus with a disability to killing an adult with a disability. However, this conclusion did not address the apparent discrimination which exists when one considers that there are only certain circumstances where late termination is permissible, the most notable of which is severe disability. This late termination is after the point of viability, which is currently regarded as twenty-four weeks gestation. A pregnancy where a severe disability has been identified in the fetus can be terminated after this point but one that has no or lesser abnormalities cannot be, unless it is threatening the life of the mother. I concluded that the decision to terminate a pregnancy based on the presence of disability was not discriminatory against those living with disability, but was based on the harm that may be caused to the interests of the future child and the wider family, and it is these interests that also need to be considered in addition to the clinical status of the fetus.

I also argued that although the fetus does not have full moral status, its moral status does increase as gestation progresses meaning that greater justification is needed for a termination to take place as pregnancy advances. Although this justification may still be based on the finding of disability this is not due to any discriminatory attitudes towards disabled people. This led to my discussion about the importance of respecting reproductive autonomy, as well as the importance of prospective parents being fully involved in decision-making throughout the whole process, particularly as their future interests also have the potential to be harmed.

If decisions are made on behalf of a competent adult their interests may be harmed and they may be prevented from living the life they may have wanted. I discussed the importance of being able to make our own autonomous decisions because not everyone shares the same beliefs and desires and we do not all aspire to the same outcomes. Reproductive decisions are part of this autonomous decision-making process and, therefore, affect not only the fetus but also other people who will be closely connected to the future child, making these decisions of utmost importance. Despite arguing for the importance of this, however, I have identified that

reproductive autonomy can be limited in some circumstances by those healthcare professionals who are offering prenatal testing as an option for prospective parents. Where the outcome of testing reveals a severe abnormality late in gestation the choice of prospective parents may be limited by the fact that this is ultimately a decision made by clinicians who tend to focus on the clinical findings of the pregnancy and potential disability to the future child, rather than taking a holistic view of the fetus in the context of the wider family and considering the potential harm to the interests of other relevant third parties. In order to ensure that reproductive autonomy is promoted as much as possible, I recommended that the role of the clinical geneticist include acting as an advocate for prospective parents during fetal management meetings to ensure that their views were fully considered.

I have discussed the models and definitions of disability and harm and have considered these in terms of the individual who will be born with a disability and also in terms of other directly affected third parties. I have concluded that harm is not simply caused by defective functioning of anatomy or physiology but occurs where a person's interests are interfered with in a negative way. A disability, therefore, may cause harm in differing degrees to different people and conclusions about the harm a disability may cause cannot be made on a general basis or be assumed to apply to everyone in the same way.

Harm to interests is a very individual issue and only those who are going to be harmed can articulate this. Disability means different things to different people and therefore this highlights the importance of promoting reproductive autonomy and providing prospective parents with the information they need to make informed decisions about their pregnancy and future child. The clinical geneticist is perfectly placed to ensure that prospective parents not only receive clinical, diagnostic and prognostic information about their future child, including the benefits the child may bring, but also have the opportunity to take part in deliberative discussions about how their own interests may be affected.

Having considered the moral status of the fetus and the importance of promoting and enhancing reproductive autonomy, I discussed the arguments put forward by those representing disabled people who are of the view that prenatal testing discriminates against those with disabilities. I argued against the Expressivist Argument which claims that prenatal testing devalues disabled people and makes negative judgements about them. This was on the grounds that the Expressivist argument did not take into account others who will be directly affected by the birth of a disabled child or the harm to their interests, bearing in mind that these third parties have a higher moral status to the fetus. I also argued against the Parental Attitude argument which, I concluded, does not fully take into account why parents might not wish to have a disabled child in their family. This may not only be for their own interests, which are not insignificant bearing in mind any decision will have a major impact on those interests, but also the interests of the future child and any pre-existing child, who may themselves be disabled by the same condition which is being tested for.

What the Parental Attitude argument did highlight was the need for promoting reproductive autonomy in that it is essential to ensure that prospective parents do not base their decisions on misinformation and that they have balanced information to make autonomous decisions and to ensure that their reproductive choices are respected. This balanced information needs to be gathered from a number of relevant sources so that they do not only have a diagnosis for their future child but also some form of prognosis, and to ensure that the positive benefits of having their child are also highlighted and discussed. Rather than discriminate against those with disabilities, I concluded that prenatal testing and appropriate information-giving and counselling may encourage some parents to continue a pregnancy that would otherwise have been ended based on misinformation and misguided attitudes to disability.

I argued that those living with disabilities are not necessarily in any better position to represent other disabled people than prospective parents, or those parents who have or are caring for disabled children themselves. In addition to ensuring that prospective parents have balanced

information it is equally important that healthcare professionals looking after them also take into account the interests of prospective parents and those of others, such as siblings, in order to make decisions with respect to late termination of pregnancy. Again, the clinical geneticist, having established a supportive relationship with the prospective parents early on in the process, is well placed to act as an advocate for them to ensure that their interests are also taken into account when clinicians are considering the justifications for late termination.

I have concluded that prenatal testing does not discriminate against people living with disability, based on the fetus having a lower moral status than people already born, and based on the need to consider the harms caused to third parties who have full moral status. However, with regards to reproductive autonomy, whilst I am satisfied that this is of utmost importance and its promotion is essential to ensuring appropriate decision-making and avoiding discrimination in prenatal testing by preventing decisions being based on misinformation, I have highlighted problems with the current practices involved in late termination of pregnancy.

In chapter six, I discussed these problems and the fact that ultimately it is the healthcare professionals who decide whether or not a late termination of pregnancy, based on the finding of a severe abnormality in the fetus, is justified. There is no legal or professional guidance as to what constitutes severe disability and therefore this assessment is made by healthcare professionals involved in the care of the mother and fetus. They are the ultimate gate keepers as to whether a termination of pregnancy can proceed. My concern is that these decisions are taken after discussion within a multidisciplinary team that does not include the parents or consideration of the parent's justifications for deciding to request a termination. Whilst fetal medicine specialists and clinical geneticists will speak to the parents about testing that is available during pregnancy, this will be more in the form of providing them with information about the physical condition to help them decide whether they want to go ahead with prenatal testing with the aim of establishing a diagnosis. It needs to be made clear to prospective parents at this point that, depending on the findings, their reproductive autonomy may then be limited

as a late termination will require two healthcare professionals, one of whom will perform the termination, to agree to it.

Whilst it is unlikely that this position will change and the law will continue to require this gate keeping in view of the emotive nature of prenatal testing and termination of pregnancy, reproductive autonomy can be enhanced as can the decision-making of the doctors. Clinicians also need to understand the views of the prospective parents and the potential harms to their interests in order to make an autonomous decision about how to proceed, and they should not only focus on the clinical picture presented before them. If this is so then there is every reason why the considerations and arguments I have presented in this thesis should be incorporated into professional thinking and guidance for doctors working in this area.

If the implications of having a disabled child are taken more into account with regards to the impact this will have on the harm to the interests of other family members, including the parents, this may assist doctors in being able to justify a late termination. They will not only be taking into account the physical abnormality identified in the fetus and its potentially disabling effects on the future child, but they will also take into account the harm that may be caused to the life of others who have current interests and have full moral status. All of these factors are relevant to the assessment of the permissibility of late terminations under these circumstances.

Whilst this thesis has sought primarily to help guide professional thinking about the role of reproductive autonomy and disability discrimination, in order for it to be incorporated into medical practice and to change the attitude of the relevant healthcare professionals, it is necessary for the issues raised and argued in this thesis to be incorporated into the training received by medical students, and to be revisited in more depth for those who choose to specialise in the field of clinical genetics and reproductive medicine. This will ensure that future doctors have a good knowledge of medical ethics in relation to autonomy, reproductive

choice and potentially affected fetuses. Further, this thesis adds to the current guidance issued by the Royal College of Obstetrics and Gynaecology for medical practitioners in the UK¹ when late termination of pregnancy is being considered. Moreover, GMC guidance on consent,² which applies to all registered medical practitioners in the UK, and relates to doctors and patients making decisions together, would be another official channel through which these points could be applied to enhance future practice in this area.

¹ Royal College of Obstetrics & Gynaecology (2010) *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales: Report of a working party*, RCOG: London

² General Medical Council (2008) *Consent: Patients and doctors making decisions together*, GMC: London

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