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'The Prevention of Disabled Lives through the use of Reproductive Genetic Technologies'

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ABSTRACT

FACULTY OF LAW, ARTS AND SOCIAL SCIENCES

Doctor of Philosophy

THE PREVENTION OF DISABLED LIVES THROUGH THE USE OF REPRODUCTIVE GENETIC TECHNOLOGIES

by Lindsey Victoria Brown

This study examines the underlying assumptions that influence attitudes towards the prevention of disabled lives through the use of reproductive genetic technologies.

I consider the models of disability and demonstrate that the way in which we think about disability is important in the 'real world.' As my analysis shows, the debate about models of disability is relevant to law because legal provisions adopt these models. I highlight the dominance of the medical model, and suggest that the law pays insufficient regard to the interests of disabled people because a flawed model is being used.

I explore the expressivist argument advocated by disability rights supporters. This argument holds that assumptions are implicit in the accepted practice of prenatal testing and the selective abortion of foetuses with detected impairments. Disability is a complex social construct and the way society constructs disability communicates signals regarding the value society places on its disabled members. The Abortion Act 1967 s1(1)(d) is focused on as an example of the expressivist nature of law arguing that it reflects societal values that construe aborting a 'disabled' foetus as more justifiable than aborting a 'normal' one.

This study demonstrates the link between the way disability is perceived and the laws that result from those attitudes. It is also clear that when the law takes a disablist position, it encourages people to share these assumptions about the lives of disabled people. It has been possible to identify consistent expression of values all based on the medical model and therefore disablist because they rely on negative assumptions. By analysing a variety of contexts, I draw attention to the way values infiltrate different spheres of life. I highlight the disablist nature of prenatal diagnosis, exploring the way in which disablist values are expressed in law making processes and professional rhetoric.

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Glossary and Abbreviations

AC	Amniocentesis Traditionally amniocentesis has been performed at about the fifteenth and sixteenth weeks of gestation. A careful ultrasonographic examination is performed and a needle-insertion site is selected, this will correspond to an optimal pocket of amniotic fluid. The needle is then inserted and some of the amniotic fluid is taken. There is a risk of miscarriage and damage to the baby. This is then tested and can provide information about the health of the foetus.
ANH	Artificial Nutrition and Hydration If a patient is unable to swallow because of a medical problem, he or she can be given fluids and nutrition in ways other than by mouth. This is referred to as artificial hydration and nutrition.
BPS	Biopsychosocial
CVS	Chorionic villus sampling The only established method of prenatal diagnosis in the first trimester and appears to be as safe as midtrimester amniocentesis. It can be performed as early as the sixth week of pregnancy. This method involves the aspiration of villi and the mesenchymal cells are then cultured are then tested for abnormalities. Studies to detect chromosomal abnormalities are the most common reason for CVS. There are risks of spotting/bleeding, fluid leakage, infection, fetomaternal haemorrhage, perinatal complications and foetal loss.
DALYs	Disability-Adjusted Life Years A measure of quality of life developed by the World Health Organisation and the World Bank.
DDA 1995	Disability Discrimination Act 1995
DDA 2005	Disability Discrimination Act 2005
DDB 2005	Disability Discrimination Bill 2005
DLA	Disability Living Allowance
DPI	Disabled Peoples' International This is the world disabled people's movement, raising awareness of disability issues and campaigning for full equality and participation in society.
DRC	Disability Rights Commission The Disability Rights Commission (DRC) is an independent body established in April 2000 an by Act of Parliament to stop discrimination and promote equality of opportunity for disabled people.
EU	The European Union
FBS	Foetal blood sampling

	When foetal blood is drawn from the umbilical cord by a needle and tested for abnormalities. This method is preferred for evaluation of foetal haematologic disorders and identification of foetal infection.
GMC	General Medical Council The GMC sets the standards of what the public can expect from their doctors. It is also responsible for disciplinary procedures within the medical profession.
HFEA	Human Fertilisation and Embryology Authority A statutory body established in Britain, under s.5 HFE 1990, to govern the practical implementation of the provisions of the HFE 1990.
HFE Act	Human Fertilisation and Embryology Act 1990
HGC	Human Genetics Commission This body is the UK Government's advisory board on the new developments in human genetics and how they impact on individual's lives.
HIV	Human Immunodeficiency Virus
IDM	Informed decision making
ICIDH	International Classification of Impairment, Disability and Handicap
ICD	International Classification of Disease
ICF	International Classification of Functioning
IVF	*In Vitro* Fertilisation
MP	Member of Parliament
MSAFP	Maternal serum alpha-fetoprotein screening (also known as Maternal Serum Screening – MSS) An abnormally high level of AFP may indicate neural tube defects (e.g. spina bifida, anencephaly), and abnormally low amount may indicate Down's syndrome. Blood sampling is recommended, optimally at sixteen weeks. If the result is outside the 'normal' range, the mother will be referred for further tests such as AC or CVS.
NHS	National Health Service
NICE	National Institute for Clinical Excellence NICE is the independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.
PGD	Preimplantation Genetic Diagnosis This technique uses IVF treatment to create embryos. When the embryo consists of 8 cells, a biopsy will be performed removing up to 2 cells for tests. Various tests are then performed, depending on the nature of the

	genetic disease they are screening for. Only the embryos that show no signs of genetic abnormalities will be implanted into the woman.
PND	Prenatal diagnosis Is the term used to describe the tests performed in order to identify and diagnose conditions in an unborn foetus.
PNS	Prenatal screening Describes tests offered to all pregnant women in order to identify those ‘at risk’ from having a disabled child. This group will then be offered prenatal diagnosis.
QL	Quality of Life
RCOG	Royal College of Gynaecologists The RCOG is dedicated to the encouragement of the study and the advancement of the science and practice of obstetrics and gynaecology.
RCOP	Royal College of Physicians The Royal College of Physicians aims to ensure high quality care for patients by improving standards and influencing policy and practice in modern medicine. It sets standards for clinical practice, conducts examinations, defines and monitors education and training programmes for physicians, supports doctors in their practice of medicine, and advises the Government, public and the profession on healthcare issues.
RGTs	Reproductive genetic technologies Umbrella term to include all technologies used to assist pregnancy or diagnose conditions of the embryo/ foetus.
SMA	Spinal Muscular Atrophy
UPIAS	Union of Physically Impaired Against Segregation A former organisation of disabled people that aimed to have all segregated facilities for physically impaired people replaced by arrangements that enable full participation in society.
Ultrasound:	A form of PND. Offered to most women at the optimal gestations of 11-14 weeks and 20-24 weeks. It allows an examination of the external and internal anatomy of the foetus and the detection of not only major malformations but also of subtle markers of chromosomal abnormalities and genetic syndromes.
WHO	World Health Organisation The United Nations specialized agency for health established in 1948. The WHO's objective, as set out in its Constitution, is the attainment by all peoples of the highest possible level of health.

Chapter one: Introduction

Prenatal diagnosis (PND) has been seen as largely benevolent by health professionals but controversial by disability rights activists. This thesis aims to explore this dichotomy of opinions. There is a need to develop a greater understanding of the underlying assumptions that influence our attitudes towards these procedures and technologies. It is hoped that, following from this research, it will be possible to understand which of these perspectives is more convincing.

PND is not regulated by law,[1] although there are guidelines from the National Institute for Clinical Excellence on good clinical practice with regards to prenatal testing.[2] If PND reveals an abnormality with the foetus, there is rarely any treatment available.[3] The only choice the parents have is whether to continue with the pregnancy or have an abortion. Abortion in the United Kingdom is regulated by the Abortion Act 1967 as amended by the Human Fertilisation and Embryology Act 1990.[4] Most prenatal tests are available on the NHS if a doctor agrees they are necessary. If a woman requests a test that doctors believe to be unnecessary there is the possibility of seeking private treatment. Prenatal diagnosis is not a new development in medicine. Yet the procedures and techniques used have developed along with our knowledge of the genetic causes of some conditions. These developments have improved the safety of the procedures which has lead to all pregnant women being offered some form of PND.

There have been several arguments suggested by disability rights activists, against the use of PND and selective abortion. To summarise these, they are:

a) *The expressivist argument*: this argument holds that there are practices and policies that express values, and that some values can be damaging to certain members of society. In the context of PND and selective abortion, the argument contends that assumptions are implicit in the accepted practice of prenatal testing and the selective abortion of foetuses with detected impairments. Disability is a

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[1] Although the general laws of consent and negligence in carrying out the procedures still apply.

[2] National Institute for Clinical Excellence *Antenatal Care: Routine care for the healthy pregnant woman* (London, NICE, 2003) available at http://www.nice.org.uk/pdf/CG6_ANC_NICEguideline.pdf.

[3] Foetal surgery is possible, but only for a limited number of conditions; the usual decision to be faced after positive diagnosis of a disability following PND is whether or not to have an abortion.

[4] This is discussed in more detail in the 'Introduction to the Expressivist argument' chapter (chapter 3).

complex social construct and the way society constructs disability communicates signals regarding the value society places on its disabled members. People make the psychological links between reproductive genetic technologies and the value we place on disabled people. This does not have to be intentional on the part of parents making choices for the accumulative effect to be disablist.

b) *Eugenics:* Reproductive genetic technologies[5] are often labelled as 'eugenic.' This term is used to describe a social philosophy which advocates the improvement of human hereditary traits through social intervention. In this context, it is suggested that PND is used to prevent the lives of disabled people, thereby improving the human race.

c) The *Loss of Support argument* contends that the use of genetics reduces the number of disabled people and one consequence of this will be that public support for the remaining disabled people will dwindle. Screening is all about what society deems acceptable and unacceptable. This argument holds that there will always be disabled people irrespective of the model of disability that is used, that is inherent in the definition of disability itself. Removing the impairment will not remove the segregation in a disablist society.

d) Proponents of genetics argue that genetically based disabilities, like other disabilities, impair opportunity and that a commitment to equal opportunity requires genetic interventions to prevent disabled lives. The *Justice trumps Beneficence* argument asserts that while only beneficence, not justice, speaks in favour of genetic intervention to prevent disabilities, the widespread use of genetic interventions to prevent disabilities puts disabled people at risk of suffering grave injustices. This argument is made more explicit by Buchanan *et al* who break the argument down into the following assertions:

    a. "Genetic intervention to prevent disabilities is not required by justice but only by the value or principle of beneficence.

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[5] I use the term reproductive genetic technologies here, because although the focus of this study will be PND and selective abortion, I believe that the arguments and approaches used in this thesis could be used to argue against preimplantation genetic diagnosis (PGD) as well. The same could be true for any method that involves post-conception attempts to prevent the birth of disabled lives.

b. The widespread use of genetic intervention to prevent disabilities would create a serious risk of injustice to disabled people.
c. Justice trumps beneficence (when the pursuit of beneficence creates a risk of serious injustice, the avoidance of injustice should take precedence).
d. Therefore, widespread genetic intervention to prevent disabilities ought not to be undertaken." [6]

This thesis will focus upon the first of these arguments: the expressivist argument. In concentrating on this argument, as already mentioned, I intend to develop a greater understanding of the assumptions that influence our attitudes towards the prevention of disabled lives through the use of reproductive genetic technologies. I will also reflect on the ways that those assumptions (prejudices) are expressed in the regulatory processes that govern such technologies. Regulation is used here to embrace the legal, professional and cultural frameworks within which the technologies are applied. It is important to study this area because it is suggested that disabled people are harmed by the use of these technologies. Furthermore, it is suggested that these technologies perpetuate such disablist attitudes. This implies that these technologies, policies and attitudes have real implications for disabled people. It is becoming increasingly recognised in our society that disabled people are entitled to equality. This was demonstrated by the Disability Discrimination Act 1995 and subsequent laws. That this ethos could be undermined by health care policies requires exploration.

1.1 Terminology

Before reading this thesis, it is important to understand some issues of terminology, in order to highlight the problems encountered with framing the question. Firstly, this study will refer to 'disabled people' rather than 'people with disabilities.' This was decided after much deliberation because I wanted to emphasize that disablement is the social process of preventing individuals with certain characteristics from being accepted as ordinary people are. American disability activists speak of 'people with disabilities' to emphasize that disablement does not reduce the essential inner person, however much it oppresses the contingent social person. The disabled community objects to the medical

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[6] Buchanan, A., Brock, D.W., Daniels, N., Wikler, D. *From Chance to Choice* (Cambridge, Cambridge University Press, 2000) at p270.

model of disability (discussed in more detail later)[7] and so it seems logical to me, when deciding which term to use, to reflect the social model and the process of disablement.

Another distinction that requires further explanation is the distinction between 'impairment' and 'disability'. The variety of ways in which impairment is distinguished from disability still confuses scholarship in this field. To put it simply, this thesis will describe a physical or mental anomaly as 'impairment,' and when impairments occasion substantial limitation in major life activities, they are 'disabling.' Another way of understanding this distinction is to "conceptualize impairment as pertaining to individuals' anomalous physical, sensory or cognitive performances, whereas disablement characterizes the way in which their environment reduces such individuals' functionality."[8] Attempts to define 'impairment' and 'disability' are discussed in great detail in the models of disability chapter, and it is impossible to do justice to a discussion of the different terms here.

Finally, many of the arguments in this thesis around informed consent relate to both prenatal diagnosis (PND) and prenatal screening (PNS) and as such both may be referred to, and examples taken from both PNS and PND will be used to illustrate the arguments put forward in this thesis. However, it is important to recognise and clarify at this stage the differences between the two. For the purposes of this study, PNS is offered to all women and is used to identify those 'at risk' of carrying a disabled child. PND is then offered to those women categorised as 'at risk' by PNS in order to investigate and diagnosis the disability.[9]

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[7] See chapter two: models of disability.

[8] Silvers, A., Wasserman, D., Mahowald, M.B. *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy* (Oxford, Rowman & Littlefield Publishers, 1999) at p9.

[9] The different procedures used are briefly explained in the glossary.

1.2 The approach taken in this thesis

The structure of the thesis will be explained later in this chapter, in order to highlight the way the arguments of this thesis have been developed. However, first it is necessary to briefly explain the general methodology behind this research. The broad intention here is to make transparent how the research unfolded, from design through to data collection, analysis and recommendations. The aim is a transparent and persuasive research narrative that makes the whole process more accountable and understandable to the reader.[10] This thesis will utilise 'disability rights' or 'disability studies' as a perspectival theory. In other words, the issues discussed in this paper will be viewed from the perspective of a social model of disability.[11] This does not mean that other perspectival theories will not be included at some junctures, such as Marxist and Feminist approaches. Indeed, the 'disability rights' perspective owes a lot to contributions from these theories.

An approach to research that utilises different concepts will be taken. Social constructionism will be an umbrella for the approach, in an examination of power/knowledge of doctors: using Derrida's 'différance' and Foucault's 'biopower.' Social constructionism is demonstrated in the focus on language and attitudes that produce and shape reality. This approach is evident in the small-scale research projects completed as part of this research: textual analysis of media, leaflet and Hansard.[12] As Corker explains, "Post-structuralist discourse on disability does not "reject" the social model. Rather it suggests that, since disability is now located in a postmodern world, it is appropriate to begin to look at the relationship between the individual and society rather than to focus on the individual or society."[13] This is the approach that this thesis has tried to adopt. The emphasis of social constructionism has been to disregard medical

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[10] Mies, M. 'Towards a methodology for feminist research' in Bowles, G., Klein, R.D. (eds) *Theories of Women's Studies* (London, Routledge & Kegan Paul, 1983), pp117-39; Stanley, L. Wise S. *Breaking Out Again: Feminist Ontology and Epistemology* (London, Routledge, 1993); Maynard, M. 'Methods, practice and epistemology: the debate about feminism and research' in Maynard, M., Purvis, J. (eds*)* *Researching Women's Lives from a Feminst Perspective* (London, Taylor and Francis, 1994), pp10-26.

[11] This will be explained in detail in the next chapter.

[12] Methodological considerations of these projects are included in Appendices A-C.

[13] Corker, M. 'Disability Discourse in a Postmodern World' in Shakespeare, T. *The disability reader social science perspectives* (London, Cassell, 1998) at p232.

accounts of the body as 'capturing' its underlying reality, and to explore instead how meaning is created by use of a particular language (or discourse) and for what purpose.[14]

In order to recognise the importance of cultural processes and discourses in the generation of disability and disablism, the postmodern trend will be useful to draw on an understanding of how the socially fragmented yet inter-connected and high tech post-modern world offers opportunities as well as constraints (e.g. for disabled people to become a niche market, and an effective minority pressure group). Post-modernism is utilised in this doctorate by questioning the dominant hegemony of science and medicine. This approach is evident in the chapters focusing on models of disability, decision making and quality of life judgements.[15]

This project is definitely multi-disciplinary in nature, or perhaps more accurately described as 'trans-disciplinary.' This is because the subject matter chosen i.e. disability and genetics cross many subject boundaries. It would be an inadequate research project if strict boundaries as to what constituted as 'law' were adhered to. The main premise of this thesis is that there are negative assumptions made about disability, therefore medical texts were employed to demonstrate this in a health care context; sociological texts were utilised in order to discuss different models of disability; and psychology texts were useful in understanding the way in which decisions are made and the factors that are relevant in prenatal decision making. It is maintained that only by understanding all these concepts could an effective theoretical framework be developed which would allow thorough analysis of the issues.

Although it could be argued that "when law borrows from scientific disciplines or practices it appears to do so as it sees fit, taking what it deems useful, on its own conditions, for its own purposes."[16] It is seen as important to employ a trans-disciplinary approach in this project because it is concerned with both how law is produced by society

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[14] Barnes, C., Mercer, G., Shakespeare, T. *Exploring Disability: A Sociological Introduction* (Cambridge, Polity Press, 1999) at p65.

[15] See chapters two, four and five.

[16] Cotterell, R. 'The Significance of a Concept of Law Not Restricted to State Law' in Cotterell, R. *Law's Community – Legal Theory in Sociological Perspective* (Oxford, Clarendon Press, 1995).

and with the way 'society' is produced by law.[17] For this reason a sharp line between the legal and the social can no longer be drawn; a 'more holistic understanding' is required.[18]

A substantial amount of the literature relied on for this thesis was written and published in the United States of America. Whilst it is important to note that the USA has different laws relating to disability, and a very different health care system, it was realised early on in this project that much of the debates about the issues relevant in this thesis were more advanced across the Atlantic. Where such texts are relied upon in this thesis, it is because the arguments employed by them were equally as relevant in this country, irrespective of these differences.

In the area of social research, the choice of a particular research method to study disability has been increasingly recognized as critical beyond methodological appropriateness because that choice in itself may predetermine the results. Guba and Lincoln elaborate the rationale behind such comments, by noting that "values permeate every paradigm that has been proposed or might be proposed, for paradigms are human constructions, and hence cannot be impervious to human values."[19] It is possible to identify the influence of many cultural theories throughout this thesis, in relation to methodology and in the way disability is perceived. Because this work is based in theory of the social model of disability, the methodology needs to reflect that. The orthodoxy among British disability writers has been that the 'adoption of the social model of disability' provides 'the ontological and epistemological basis for research production.'[20] In this context, ontology is taken to mean 'what is the nature of reality?'; epistemology as 'what is the relationship between the knower/researcher and knowledge?' and methodology as 'how does the knower/researcher go about obtaining knowledge about the social world?'[21]

This thesis adopts an interpretive approach that centres on the social construction of reality and the existence of multiple versions (ontological pluralism). It highlights

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[17] Nelkin, D. 'Beyond the Study of Law and Society? Henry's *Private Justice* and O'Hagan's *the End of Law*' (1986) *Am Bar Foundational Research Journal* 323-38 at p323.
[18] Cotterell, n. 16 above.
[19] Guba, E.G., Lincoln, Y.S. *Fourth Generation Evaluation* (Newbury Park, CA, Sage, 1989) at p65
[20] Priestley, M. 'Who's research? A personal audit' in Barnes, C., Mercer, G. (eds) (1997) *Doing Disability Research* (Leeds, Disability Press) pp88-107.
[21] Guba, n. 19 above. pp105-17.

everyday experiences and understandings. The theoretical and research orientation is shifted from establishing causal explanations to exploring the situation-specific interpretation of social action.[22] The constructivist paradigm has typically been associated with qualitative research designs and is described as "contextual, inclusive, experimental, involved, socially relevant, multimethodological, and inclusive of emotions and events as experienced."[23]

1.3 Reflexivity – situating myself in the research experience

It seems important to include a discussion of reflexivity at this juncture, as the researcher can never be 'outside' discourse[24] and hence research findings will necessarily be constructed in and through personal and theoretical perspectives. I will therefore now attempt to situate myself in the research experience. The following brief explanation focuses on my disability and my experiences of living with a disability, which inevitably affects the way in which I perceive disability issues. There may well be other facets to my character which have influenced my research, but I am not conscious of them, after all, I am not solely defined by my disability. As Doucet and Mauthner explain:

> "It is with hindsight, as well as time and distance from our doctoral projects, that we have both been able to understand and articulate how our research was the product of these multiple influences."[25]

It is also suggested that a reader would probably be unaware of these and so it is necessary to justify my approach in relation to them.

I became disabled at 18 years old, and that proved to be a life-altering experience. Prior to the development of epilepsy, I had been studying Physiotherapy, an ambition I had held since I had to choose my options for my GCSEs. As a result of my diagnosis, I was

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[22] Mercer, G. 'Emancipatory Disability Research' in Barnes et al n.14 above at p231.

[23] Mertens, D.M., McLaughlin, J.A. *Research methods in Education and Psychology* (Thousand Oaks, CA, Sage, 1995) at p5.

[24] Gordon, C. (ed) *Power/Knowledge: Selected Interviews and Other Writings* (Brighton, Harvester, 1980); Weedon, C. *Feminist Practice and Poststructuralist Theory* (Oxford, Blackwell Ltd, 1987).

[25] Doucet, A., Mauthner, N. 'Knowing Responsibly: Linking ethics, research practice and epistemology' in Mauthner, M., Birch, M., Jessop, J., Miller, T. *Ethics in Qualitative Research* (London, Sage, 2002) at p135.

informed I was no longer suitable to study physiotherapy, as I could be endangering patients in my care. At that time there was no protection for students with disabilities in higher education from discrimination. I was, and still am, angry at the way the school dealt with my case. As it happened, a career change into studying law has turned out brilliantly. I have a great life and I become frustrated when people cannot see past my disability or seem to portray me as a 'super-crip' who is inflicted with a tremendous burden.

My health continues to be unstable, and so I spend a lot of time in hospitals and in the company of health professionals and students. It is still unclear as to whether or not epilepsy is a genetic condition, however in my case it is thought not to be. It is currently not possible to diagnosis epilepsy prenatally. Studying genetics for my doctorate was not out of self interest in that way, rather it was a way in which I could test out assumptions I believed health professionals, and the public hold about disability. Having experienced discrimination and ignorance from others, not just in the Faculty of Medicine, but almost every time I walk into a pub, get a taxi or go shopping with my assistance dog, I strongly advocate the social model of disability.

I do however concede that there is a need to recognise 'impairment.' After all, even if society could change and remove all access and attitudinal barriers to me, I would still have seizures that affect my life. Yet when I become frustrated with my disability it is rarely due to 'impairment effects' but as a result of stigma and ignorance, and other people's attitudes towards my disability. As a result of my experiences, I have come to believe that the media has an important role to play in challenging the public's perceptions about disability;[26] that Members of Parliament have an obligation to pass effective laws to ensure equality for disabled people;[27] that doctors need to adjust the way they think about disability as they are very influential in our society;[28] and that it is crucial that discussion of disability is not dominated by a medical hegemony.

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[26] Discussed in more detail in the introduction to the expressivist argument chapter (chapter 3).

[27] Discussed in more detail in the models of disability chapter (chapter 2).

[28] Discussed in more detail in the informed decision making chapter (chapter 4) and the quality of life chapter (chapter 5).

1.4 The structure of this thesis

I will explore the expressivist nature of PND and selective abortion by firstly examining the different approaches there are to thinking about 'disability'. This examination will take place in chapter two. There have traditionally been two contrasting models of disability presented in debates: the 'Medical Model' and the 'Social Model'. In the first chapter of this thesis, these models will be examined in detail in order to understand the differences in approaches. Examples of the models 'in use' will be presented to highlight the affects the approach taken to considering disability can have. This discussion is important because laws adopt these models. Through such discussion it will become apparent that the medical model is flawed and results in disablist policies and laws. Whilst there has been recognition by lawmakers of the limitations of the medical model, it has proved difficult to incorporate an entirely social model. The 'Biopsychosocial' model has been put forward as an attempt to synthesise the dichotomy the original models present. It is suggested that failure to make progress away from the medical model indicates the degree to which the current law expresses disablist values. This could be avoided more effectively than they currently are, even if neutrality remains difficult to achieve.

Having discussed the different approaches taken to considering disability, I will then focus on the nature of the expressivist argument in more detail in chapter three. This analysis will be situated within the context of PND and selective abortion. Having argued that the law governing abortion for foetal abnormality[29] is vague, I will introduce the Joanna Jepson case to demonstrate that termination for a disability can express disablist attitudes about how society values people with that condition. This case also drew attention to the lack of clarity in the law for the term 'serious handicap.' The guidance provided by the Royal College of Gynaecologists (RCOG) on this matter will be included in order to illustrate how vague laws enable disablist guidance to creep in to offer recommendations. I will also include some media analysis to highlight the values expressed therein. This chapter will incorporate a discussion of some of the influences that affect private decision making, in order to demonstrate that decisions made by

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[29] The Abortion Act 1967 s1(1)(d).

prospective parents are not wholly private, because they are not insulated from these wider issues. I will also draw attention to a number of areas in which disablist attitudes are expressed which prevent private decision making from being value neutral.

The focus of chapter four moves on to consider the various factors that affect decision making in more detail. The aim is to explore the expressivist nature of individual decisions and the pressures women are under in the context of PND. Whilst prospective parents are making their own decisions, there are many spheres of influence that a) allow the choices to be made and b) affect the decisions made. This chapter focuses on the information provided to couples/women about PND. The role of professionals will be concentrated upon using a Foucauldian analysis to demonstrate the effect of knowledge and power on both the patient-professional relationship, and the relationship between professionals and disabled people. The information provided by professionals will be explored including the context of the information, the actual information provided and the way in which the information is presented. PND is always justified as offering couples/ women reproductive choices. I will argue that the rhetoric of choice is little more than a marketing strategy to avoid eugenic criticisms by illustrating that: nondirective counselling does not work in practice, many prenatal tests are offered as part of routine care, the offer of the technologies in itself is not value neutral, societal constraints restrict women from rejecting PND and the information provided is inadequate to allow for informed choice. This final point will be illustrated by drawing upon results from analysis of some NHS PND leaflets.

Chapter five of this study will focus on quality of life (QL) judgements made by professionals. People make negative assumptions about impairment and disability. These assumptions can be invoked in making 'quality of life' judgements and are often based on the medical model of disability. These judgements are used by lawmakers and doctors and I argue that such judgements are subjective and based on cultural norms and values and on the approach taken to considering disability. Previous chapters have demonstrated that attitudes towards disability can influence policies. It is therefore important to explore the basis of QL judgements, the ways they are used in practice, and the implications they have for disabled people.

Finally, the concluding chapter of this thesis will draw together the main themes and findings of my research. The three appendices include discussion of the methodological considerations for the three small-scale research projects carried out: Times work analysis; Leaflet analysis and Hansard analysis.

To reiterate, this thesis focuses on the underlying assumptions that influence attitudes towards the prevention of disabled lives through the use of reproductive genetic technologies. This analysis begins in chapter two with a discussion about the varying approaches that can be taken to considering disability and the affects the different approaches can have on law, and on the lives of disabled people.

Chapter 2: Models of Disability

2.1 Introduction

The models of disability explored in this chapter, represent different ways of thinking about disability. It is hoped the following chapters in this thesis relating to 'quality of life' and 'informed decision making' will demonstrate why the way we think is important 'in the real world.' Within the scope of this doctorate it has been possible to identify consistent expressions of values which are based on a medical model of disability, and can be perceived to be disablist because they are based on negative assumptions about disability. The proceeding chapters will demonstrate the invisible and insidious impact of the medical model. The role of this chapter is therefore to explain the different models of disability and to identify attempts to utilise the range of models. This will establish the frame of reference by which the discussion of reproductive genetic technologies will take place later in the thesis.

Law has an impact on disabled people, it can act as a barrier to access and services, or it can remove them; it dictates the welfare benefits to be awarded; it can prescribe treatment disabled people receive in employment and education. Doctors have a 'gate-keeping' role in this respect, and their influence over disability policies is one of the key themes of this thesis that will be revisited several times. There is an intrinsic connection between law and societal values. When a set of values or a model is enshrined in law it can have a fixed coercive effect that stigmatises disabled people. It is necessary to explore the way in which disability issues are framed by Parliament as they make laws. It will be demonstrated that it is possible for the law to approach the issues from a more social model of disability, however so far in the UK this has not happened. The reasons behind this will be explored.

The approach taken to considering disability[1] can also have a psychological impact on disabled individuals. This is as a result of 'stigmatization' that can result, *inter alia*, from labelling and deviance. Opinions differ radically on the root causes of stigma and

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[1] i.e. the model of disability adopted. The main models (social and medical) are explained in detail below, however these preliminary points are included here in order to explain the importance behind studying them in relation to this thesis.

disadvantage. Some see the social construction of disablement to be the inherent product of the acquisition of power by groups of professionals in the health and human services industries who required a dependent and devalued people who will always be in need of their services.[2] Others argue that the formation of the disability minority group arose during the ascendancy of capitalism with its need for dependable and interchangeable workers. Since people with impairments were unable, rather than unwilling, to enter the labour force, they needed to be separated off, viewed as sick and inferior and put under the control of professionals.[3] Others emphasise the role of culture in creating 'disabling images' found throughout literature and communications media.[4] It cannot be denied that individuals with physical impairments often feel socially stigmatised as a result of the way they are viewed and treated by society at large. In addition, feelings of social stigmatisation are usually compounded by the fact that the stigmatised individual is seen to be to blame for his or her own stigmatisation, as in the medical model. Hence, Goffman states that physically impaired individuals are more likely to feel negative about themselves and experience feelings of shame.[5] In contrast, the development of the social model has resulted in a shifting of blame (as to the cause of disability) away from the individual and towards society instead. Finkelstein argues that the social model has been influential, in a very positive way, in the formation and operation of organisations that provide support and advice for individuals with impairments which have positive effects on the self esteem of disabled people.[6]

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[2] Stone, D. *The Disabled State* (London, Macmillan, 1984); Wolfensberger, W. 'Human service policies: the rhetoric versus the reality' in Barton, L. (ed) *Disability and Dependence* (Lewes, Falmer, 1989) at p23; Albrecht, G. *The Disability Business* (London, Sage, 1992).

[3] Hunt, P. *Stigma* (London, Chapman, 1966); Finkelstein, V. *Attitudes and Disabled People: Issues for Discussion* (New York, World Rehabilitation Fund, 1980); Oliver, M. *The politics of disablement* (Basingstoke, Macmillan, 1990).

[4] Hevey, D. *The Creatures that Time Forgot: Photography and Disability Imagery* (London, Routledge, 1992); Shakespeare, T. 'Art and Lies? Representations of disability on film' in Corker, M., French, S. (eds) *Disability Discourse* (Buckingham Philadelphia, Pa, Open Uni Press, 1999) pp164-173; Peters, S. 'Transforming disability identity through critical literacy and the cultural politics of language' in Corker, M., French, S. (eds) *Disability Discourse* (Buckingham Philadelphia, Pa, Open Uni Press, 1999) pp103-116; Barnes, C., Mercer, G., Shakespeare, T. (ed*) Exploring the Divide: illness and disability* (Leeds, the Disability Press, 1996) p182-210; Marks, D *Disability: controversial debates and psychosocial perspectives* (London, Routledge, 1999) p137-153; Hevey, D. 'The Enfreakment of Photography' in Davis, L.J. (1997) The Disability Studies Reader (New York, Routledge, 1997) pp332-348; Mirzoeff, N. 'Blindness and Art' in Davis, L.J. (1997) The Disability Studies Reader (New York, Routledge, 1997) pp382-401. This point will be explored further in the analysis of the media included in the introduction to the expressivist argument chapter (chapter 3).

[5] Goffman, E. 'Selections from stigma' In Davis, L.J. (1997) The Disability Studies Reader (New York, Routledge, 1997).

[6] This is achieved by a) increased the range of choices available to individuals who are disabled, (b) provided opportunities for confidence building and the development of new skills, (c) encouraged the portrayal of a more positive self-image of the disabled individual that is in direct opposition to that

In this chapter, disability literature is reviewed in order to explain the research paradigm within which this research is situated. It is not possible to understand the legal events discussed in this thesis without consideration of other approaches. Therefore much of this chapter focuses on texts from the fields of disability studies, sociology and psychology. The medical and social models of disability are discussed widely, yet often misinterpreted. Both models are flawed and a new model is required to take discussion of disability rights forwards. Recent attempts to fuse the two models will be discussed. However, it is concluded that a unifying theory of disability constructed out of the different terms of diverse disciplines would depend on the resolution of enormous problems of translation, and any claim to success must be treated warily.

It is not necessary to recapitulate a detailed history of these different definitions and their conceptual characteristics. For the purposes of this thesis, however, the dominant ways of thinking about disability need to be explored. The point is that disability can be placed within a number of different frames. These frames can be seen as methodological: tools for helping us to understand what is there in the world. They can also be seen as ontological: mechanisms or practices whereby things that we cannot see because they are taken for granted, or things that are too blurred to see are brought into being, created, or constructed. This ontogenetic capacity of the frames we employ also makes those frames political because they have the power to make us see disability in one way rather than another. As Williams states "Disability is something – if it is actually anything at all – that is framed in a number of different ways with very different implications for our knowledge, policies and practices."[7]

However, it is important to bear in mind Mike Oliver's comment that:

> "... models are merely ways to help us to better understand the world, or those bits under scrutiny. If we expect models to explain, rather than aid understanding, they are bound to be found wanting... we cannot assume that

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depicted by the medical model (which portrayed people with impairments as inherently dependent on charity and functionally passive), and (d) allowed disabled people to exercise more control over the support systems they use.

[7] Williams, G. 'Theorizing Disability' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p127.

models in general and the social model in particular can do everything, that it can explain disability in totality."[8]

2.1.1 Structure of this chapter

The medical model of disability will be examined first. It will be explained, criticised and examples of the model 'in use' will be demonstrated. Particular attention will be given to examples of eligibility criteria that are based on the medical model. Discussion of the social model of disability will then follow the same structure, this section will then focus on the reasons why the social model is yet to be realised in legislation in the UK. A recent evolution of the social model will be examined, which demonstrates the need to 'bring the body back' into discussion of disability in order to explain that perhaps it is not possible to translate a purely social model into law. Attempts to integrate the models of disability to produce a 'hybrid' model are explored as well as an examination of disability as a universal human condition as an alternative approach.

2.2 The 'medical model'

The medical model of disability (also known as the 'individual model') places a particular emphasis on the individual and their impairment, defining disability as almost an entirely medical problem.[9] Indeed, this model appears to imply a direct causal link between impairment and disability. Consequently it sees problems that people with physical disabilities experience as being directly related to their physical impairment.[10] It has been suggested that a bio-medical understanding of disability reduces impairment to categories of the diseased body and "focuses on the patient not the person."[11] Furthermore, this approach strongly relies on the notion of physical normality. Disability is viewed as deviant physiology that needs to be corrected, eradicated or normalised, for the benefit of both the impaired individual and for society as a whole.[12] Impairment

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[8] Oliver, M. *Understanding Disability: From Theory to Practice* (Basingstoke, Macmillan Press, 1996) at p40.

[9] Brisenden, S. 'Independent Living and the Medical Model of Disability' (1986) 1(2) *Disability, Handicap & Society* 173.

[10] Oliver, M., Sapey, B. *Social work with disabled people* (2nd ed.) (London, Macmillan, 1999); Johnston, M. 'Models of disability'. (1996) 9 *The Psychologist* 205-210.

[11] Nettleton, S. *The Sociology of Health and Illness* (Cambridge, Polity Press, 1995) at p34.

[12] Swain, J., French, S. 'Towards an affirmation model of disability' (2000) 15 *Disability & Society* 569-582.

signifies "disorder, indiscipline, unreliability"[13] and, as such, it is perceived as "undesirable, something to be cured, overcome or hidden."[14] This perspective sees the impaired person as the one who needs to adapt to the world and not vice versa.[15] According to this model, disability can be defined in terms of any restriction or lack of ability (resulting from impairment) to perform an activity in a manner (or within the range) considered normal for a human being.[16]

The medical model reflects wider cultural assumptions around individuality, personal autonomy and self-determination within a society in which great value is placed upon 'standing on your own two feet,' 'staying one step ahead,' 'standing up for yourself,' 'walking tall' and 'making great strides.'[17] This is then reinforced through wider cultural representation of disability and disabled people.[18] The medical model reflects a framework of thinking about disability that has been and continues to be imposed by 'non-disabled' people upon disabled people. It reflects and reinforces dominant ideas about individuals and their roles within society; it values conformity and asserts the significance of self-reliance.[19]

There has been a perceived need to define 'disability.' The administrative perspective suggests an emphasis on the individual and the categorization of the individual as a member or non-member of the disabled class or category.[20] For administrative purposes, disability is usually defined as situations associated with injury, health, or physical conditions that create specific limitations that have lasted (or are expected to last) for a

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[13] Davis, L.J. Enforcing Normalcy: Disability, Deafness and the Body (London, Verso, 1995)

[14] Swain, J., French, S., Cameron, S. *Controversial Issues in a Disabling Society* (Buckingham, Open University Press, 2003) at p23.

[15] Hasler, F. 'Developments in the disabled people's movement' in Swain, J., Finkelstein, V., French, S., & Oliver, M.(eds.*)* *Disabling barriers – enabling environments* (London, Sage, 1993) pp.278-284.

[16] World Health Organisation *International classification of impairments, disabilities, and handicaps* (Geneva, WHO, 1980).

[17] Keith, L. 'Tomorrow I'm going to rewrite the English Language' in Keith, L. (ed) *Mustn't Grumble: Writing by Disabled Women* (London, The Women's Press, 1994) at p57.

[18] For discussion of cultural representation of disability see, *inter alia*: Barnes, C. 'Images of disability' in French, S. (ed) *On Equal Terms: Working with Disabled People* (Oxford, Butterworth-Heinemann, 1994); Thomson, R.G. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, Columbia University Press, 1997); Shakespeare, T. n.4 above; Barnes, C., Mercer, G., Shakespeare, T. *Exploring Disability: A Sociological Introduction* (Cambridge, Polity Press, 1999) p182-210 and p315-382.

[19] Swain, J., French, S., Cameron, S. n.14 above, at p23. The role of the medical profession in this process will be discussed in detail later in this thesis in both the IDM chapter (chapter 4) and the QL chapter (chapter 5).

[20] This will be discussed in more detail later in this chapter.

named period of time.[21] In an attempt to quantify the effect of what is identified as the 'burden' of disability in a way that could be used for cost-effectiveness analysis;[22] work was commissioned by the World Health Organisation (WHO) and the World Bank. This lead to a composite measure known as Disability-Adjusted Life Years (DALYs) being developed for use as a health outcome measure to provide a basis for comparisons across multiple national populations.[23] DALYs measured the sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability. Clinical definitions have their basis in the authority that is attached to medicine and are carried out by medical specialists.[24]

Oliver and Sapey note that despite long-standing criticisms of the medical model and the fact that disabled people have largely rejected it in favour of the social model, the medical model still remains dominant.[25] Ungar suggests that despite the growing opposition to the medical model, its resilience is due to the pre-eminence of the views of the medical profession in our society.[26] The legal, economic, educational and civil structures by which populations are bound are organized in ways which confirm and give legitimacy to the version of reality that has been sanctioned by those with power. We are embedded in a complex network of social relations. The subject is not something prior to politics or social structures, but is constituted in and through specific socio-political arrangements. This thesis aims to identify the 'constitutive mechanisms of truth and knowledge' within scientific and social discourses, policy and medico-legal practice which produce it and sustain it.[27]

Writers such as Tom Shakespeare[28] and Mairian Corker[29] have argued that much of the disability literature seriously downplays the importance of cultural processes and

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[21] Altman, B.M. 'Disability Definitions, Models, Classification Schemes, and Applications' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p98

[22] *Ibid,* at p99.

[23] Murray, C.J., Lopez, A.M. *The Global Burden of Disease* (Boston, Harvard University Press, 1996). See www.who.int/entity/mental_health/ management/depression/daly/en/

[24] Altman, B.M. n.21 above, at p99.

[25] Oliver, M., Sapey, B. n.10 above, at p26.

[26] Ungar, S. 'Applied social cognition 3: Disability' retrieved October 14, 2002 from http://www.lgu.ac.uk/psychology/staff/ungar/sun/LectureNotes/ASC3_Disability/

[27] Tremain, S. 'On the Subject of Impairment' in Corker, M., Shakespeare, T. (eds*) Disability/ Postmodernity – Embodying Disability Theory* (London, Continuum, 2002) at p45.

[28] Shakespeare, T. 'Cultural representation of disabled people: dustbins of disavowal?' in Barton, L., Oliver, M. (eds) *Disability Studies: Past, Present and Future* (Leeds, Disability Press, 1997).

[29] Corker, M. *Deaf and Disabled, or Deafness Disabled?* (Buckingham, Open University Press, 1998); Corker, M., French, S. (eds) *Disability Discourse* (Buckingham Philadelphia, Pa, Open Uni Press, 1999).

discourses in the generation of disability and disablism. Culture, then, is a process that shapes our expectations and experiences. The culture we grow up in provides the 'coloured glass' through which we understand our social world and ourselves. Personal identity and the identity of 'others' are grounded within the ways of thinking and doing within that culture.[30] However, culture is also a distorting activity. Dominant (or mainstream) cultures will always reflect the interests of those within particular social groups of societies who have the power to define situations and the resources with which to ensure that their own definitions are accepted as true. Those whose interests conflict with those of the powerful are represented, to various extents, as uncivilized, degenerate, immoral, inadequate or incapable.[31] Knowledge is thus culturally relative and changes over time.[32]

Foucault maintained that there is no outside of power, that power is everywhere, that it comes from everywhere.[33] If more than one set of beliefs about a particular phenomenon exist within a society, the explanatory model of the most powerful group will be validated as 'true' and superior to the explanatory models of others. Tremain argues that "the production of seeming acts of choice on the everyday level of the subject makes possible hegemonic power structures."[34]

Accounts inspired by Foucault[35] have demonstrated how the medical discourse (like others) is grounded in specific power relations and ideological interests, and in turn contributes to them.[36] A Foucauldian perspective on disability might then argue that a proliferation of discourses on impairment gave rise to the category of 'disability.' Though these discourses were originally scientific and medical classificatory devices, they subsequently gained currency in judicial and psychiatric fields of knowledge. 'Disabled people' did not exist before this classification although impairment and impairment-related practices certainly did. Thus Foucault shows us that social identities are effects of the ways in which knowledge is organized, but his work is also significant

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[30] Swain, J., French, S., Cameron, S. n.14 above, at p21.

[31] Saraga, E. *Embodying the Social: Constructions of Difference* (London, Routledge, 1998).

[32] Swain, J., French, S., Cameron, S. n.14 above, at p30.

[33] Foucault, M. *The History of Sexuality, Vol 1: An Introduction* (New York, Random House, 1978) at p93.

[34] Tremain, S. n.27 above, at p36.

[35] Foucault, M. 'The Eye of Power' in Gordon, C. (ed) *Power/Knowledge: Selected Interviews and Other Writings* (Brighton, Harvester, 1980).

[36] Barnes, C., Mercer, G., Shakespeare, T. n.17 above, at p65.

for its explanation of the links between knowledge and power. Foucauldian notions of the self-disciplining of the body in the shadow of powerful medical and welfarist discourses on impairment are seen to offer ways of understanding the subordination experienced by disabled people.[37] A key contribution of critical social theory was that it reinterpreted many seemingly 'personal troubles' as more appropriately understood as 'public issues' that have their origins in wider social structures and processes. Moreover, successful knowledge claims were linked with dominant interests and social relations in specific social and historical contexts.[38] Foucault argued that this objectification of the body in eighteenth century clinical discourse was one pole around which a new regime of power – biopower – coalesced.[39] Foucault's concept of biopower refers to the strategic tendency of relatively recent forms of power/knowledge to work towards an increasingly comprehensive management of life: both the life of the individual and the life of the species.[40] Foucault regarded 'normalization' as the central component of the regime of biopower.[41]

The power and status of doctors will be examined further in the decision making chapter.[42] The purpose of including a preliminary discussion of this point here is to demonstrate a possible explanation for the dominance of the medical model in law and medicine. The argument here is that as a result of the traditional hegemony of medicine, disability has been defined in medical and biological terms referring to the individual. This became known as the medical model. This is an important tenet of the argument of this thesis. It is now necessary to examine the ways the medical model has been translated into use. Firstly in the form of the World Health Organisation's document, the *International Classification of Impairments and Handicaps* (ICIDH), then in the way the model has been adopted by UK law in the form of the Disability Discrimination Act 1995 (DDA 1995) which aims to protect disabled people from discrimination. Measures that directly affect entitlements of disabled people are also examined in the form of the eligibility criteria for the Disability Living Allowance (DLA) and for travel concessions.

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[37] Price, J., Shildrick, M. 'Uncertain thoughts on the dis/abled body' in Barnes, C., Mercer, G., Shakespeare, T. *Exploring Disability: A Sociological Introduction* (Cambridge, Polity Press, 1999).
[38] Barnes, C., Oliver, M., Barton, L. *Disability Studies Today* (Cambridge, Polity Press, 2002) at p231.
[39] Foucault, M. n.33 above.
[40] Allen, B. 'Disabling Knowledge' in Madison, G., Fairbairn, M. (eds) *The Ethics of Postmodernity* (Evanston, Northwestern University Press, 1999).
[41] Tremain, S. n.27 above, at p36.
[42] See chapter 4.

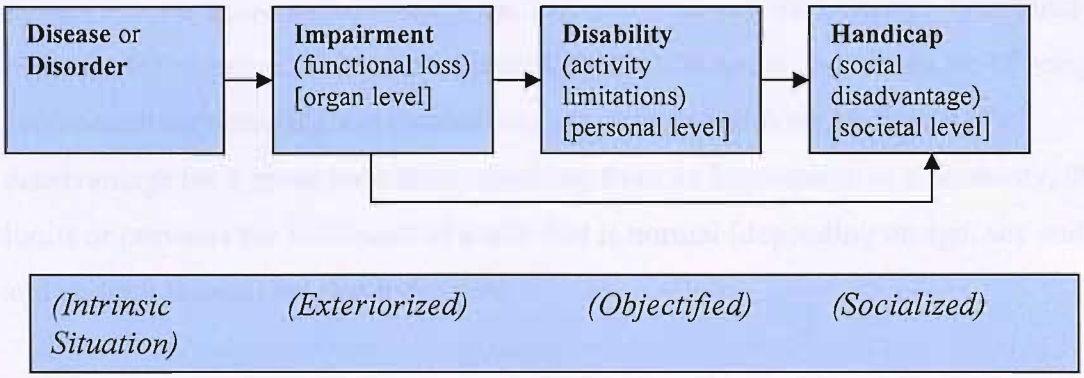
2.2.1 The medical model 'in use'?

It is impossible to find an example of the medical model of disability in use *per se*.[43] Not even a medical text book of any worth would argue that disability is a problem solely for the individual and not society. Whilst the ICIDH (1980), did not intend to follow the medical model of disability, when compared to other models such as that proposed by the Union of Physically Impaired Against Segregation (UPIAS 1976) it is clear it does not fully embrace the social model of disability.[44]

The first WHO model and ICIDH were offered as frameworks to facilitate the provision of information that was seen as essential to decisions that needed to be made for those concerned with health and welfare. The purpose of the development of the ICIDH was "to provide a classification scheme similar to the *International Classification of Disease (ICD)* with the intent to facilitate study of the consequences of disease."[45]

2.2.1.1 The ICIDH (1980)

Fig. 1. The International Classification of Impairment, Disability and Handicap[46]



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[43] The non-intentional reliance on the medical model is discussed in more detail later when it is demonstrated that attempts to utilise the social model have traditionally failed and resulted in a reliance on the medical model.

[44] The UPIAS statement will be explored in more detail in the section relating to the social model of disability.

[45] World Health Organisation n.16 above, at p35.

[46] *Ibid.*

The WHO's ICIDH appeared to embody the insights of the social model. Yet, despite its promise, almost from its first appearance, critics have argued that the ICIDH and the model of disablement it projects are deeply flawed.[47] In the ICIDH, disablement is modelled as a sequence of levels of health experience consequential upon some aspect of morbidity (disease, trauma, mental illness and chronic or age-related conditions). An initial pathological change, which need not be observable or experienced, may lead to awareness of 'abnormalities of body structure and appearance and of organ or system function.' This is called an *impairment*, defined in the ICIDH as "any loss or abnormality of psychological, physiological, or anatomical structure or function." Impairments involve parts of bodies or body systems; they are temporary or permanent differences of structure or function. More accurately, they are deviations from biomedical norms that are statistically grounded. They are observable and measurable.[48]

Following this model, should impairment adversely affect the person's range of activities, how he or she actually acts or behaves, then the person will experience a limitation on the activities he or she can perform. This is a *disability*, defined as "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."[49] Finally, impairments and disabilities may disadvantage the individual by limiting or preventing the fulfilment of six important 'survival goals:' orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency. When that happens, the negative social consequences, that is, the social disadvantages of being a person with impairments and disabilities, constitute a *handicap*, defined as "a disadvantage for a given individual, resulting from an impairment or a 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."[50]

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[47] For example, Fougeyrollas, P. 'Documenting environmental factors for preventing the handicap creation process: Quebec contributions relating to ICIDH and social participation of people with functional differences' (1995) 17 *Disability and Rehabilitation* 145.

[48] Bickenbach, J.E., Chatterji, S., Badly, E.M., Ustin, T.B. 'Models of disablement, universalism and the international classification of impairments, disabilities and handicaps' (1999) 48 *Soc Sci & Med* 1173-1187 at p1175.

[49] World Health Organisation n.15 above.

[50] *Ibid.*

At the levels of disability and handicap, the ICIDH recognises the role of social environment factors in the production of disablement.[51] However despite the attempts to offer a non-medical model of disablement, the promise was never fully, or clearly, realized. As Bickenback *et al* explain:

> "The root problem was a subtle ambiguity of language that undermined the intended model. Try as drafters might to insist that disabilities exist because of social expectations of normal performance and that handicaps are socially constructed disadvantages, they persisted in using language that suggest a very different picture."[52]

This can be seen in the following passage of the ICIDH:

> "Disadvantage accrues as a result of [the individual] not being able to conform to the norms of his universe. Handicap is thus a social phenomenon, representing the social and environmental consequences for the individual *stemming from the presence of impairments and disabilities*."[53]

Although presumably not intended, this passage suggests that people are disadvantaged *because of their disabilities alone,* and that handicaps are *caused by* impairments and disabilities. In this passage, it is for the individual to conform and not for the universe. The underlying model does not clearly acknowledge that the presence of social barriers and the absence of social facilitators play any sort of role in the creations of the disadvantages that a person with a disability experiences.[54] A traditional view would therefore see that the social model of disablement is only partly adopted.[55]

This study will now progress to examine existing English law to see the extent to which it incorporates the medical model. The eligibility criteria for a person to be defined as 'disabled' for various purposes will be examined and three examples will be used to

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[51] Bickenbach, J.E., et al. n.48 above, at p1175.
[52] *Ibid* at p1175.
[53] World Health Organisation n.16 above, at p29 (emphasis added).
[54] Bickenbach, J.E et al. n.48 above, at p1175.
[55] *Ibid,* at p1176.

illustrate this: The Disability Discrimination Act 1995, the Disability Living Allowance, and for travel concessions.

2.2.1.2. Disability Discrimination Act 1995

The DDA 1995 was based on the Americans with Disabilities Act 1990.[56] Disability was defined in s1(1) as:

> "a person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities."

The following table includes a breakdown of the definition of disability and explains the separate elements and any special provisions relating to that element:

Fig. 2. Table to demonstrate the definition of disability as in DDA 1995

Elements of definition	**Explanation of element**	**Special provisions relating to element**
a mental or physical impairment		- cancer, HIV infection and multiple sclerosis are covered effectively from the point of diagnosis.[57] - people who have had a disability in the past but are no longer disabled are covered by certain parts of the DDA.[58]
this has an adverse effect on your ability to carry out normal day-to-day activities	- mobility - manual dexterity - physical co-ordination - continence - ability to life, carry or move everyday objects - speech, hearing or eyesight - memory, ability to concentrate, learn or understand - understanding of the risk of physical danger[59]	- if your impairment has substantially affected your ability to carry out normal day-to-day activities, but does not any more, it will still count as having that effect if it is likely to do so again - if you have a progressive condition and it will substantially affect your ability to carry out normal day-to-day activities in the future, you will be regarded as having an impairment which has a substantial adverse effect form the moment the condition has some effect on your ability to carry out normal day to day activities.
the adverse effect is		

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[56] Disability Rights Commission *Definition of Disability: consultation document* (London, DRC, 2006).

substantial		
the adverse effect is long-term	meaning it has lasted for 12 months, or is likely to last for more than 12 months or for the rest of your life.	

The definition incorporated into the DDA makes no reference to barriers or stigmatisation that would indicate recognition of the social model. In order to receive protection under the DDA, one must therefore provide evidence (usually medical) of the impairment and the effects that impairment has on your life. This needs to be done before the issue of whether or not there has been unfavourable treatment can be considered. It is not therefore the experience of disabling barriers which brings someone within the remit of the legislation but the nature and level of impairment.

The DDA uses the term 'disability' to mean 'impairment.' The legislation only offers protection from discrimination to those who can prove they have an impairment and that it has significantly adverse effects on certain 'normal day to day activities.' The DDA does however contain an important element of the social model of disability in that it requires reasonable adjustments to be made – thus addressing 'disabling barriers.' However, this entitlement to reasonable adjustments is limited to those who fall within certain categories and levels of impairment. The negative connotations of the present definition (with its emphasis on establishing that someone is unable to participate in 'normal' day-to-day activities) are at odds with its role in an anti-discrimination statute, because the ethos of anti-discrimination is achieving equality, whereas the DDA highlights difference.

The DDA requires a definition of disability in order to decide who is eligible for protection from discrimination. Whenever rights are conferred, a definition is needed in order to distinguish those who are entitled to the rights. Anti-discrimination laws do not commit the State to any particular expenditure. They ensure that people do not act in a way that interferes with the rights of others, known as 'negative liberties.'[60] This puts into practice John Stuart Mill's harm principle which says that the only time the state is

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[57] As a result of the Disability Discrimination Act 2005 (discussed in more detail later in this chapter).
[58] DDA 1995 s2.
[59] *Ibid,* Schedule 1.
[60] Berlin, I. *Liberty* (Oxford, Clarendon, 2002).

justified in interfering with a person's freedom of action is when the action harms another person.[61] In this context, it means that disabled people are not to be harassed, discriminated against or treated less favourably. Bearing this in mind, it could be seen that the DDA only confers negative liberties – the law limits the way in which others may treat the rights-bearer, without obliging others to bestow any resources or benefits upon the rights-bearer, i.e. there is no distributive justice element. The rights protected in the DDA (e.g. employment and transport) are universal rights i.e. every citizen is entitled to them; therefore it could be possible to have a broad definition of disability. There is, however, another way of interpreting the DDA, and perhaps employers and service providers would agree with this alternative approach. It could be said that the law gives disabled people the right to demand changes from others to enable disabled people to participate fully in society i.e. there is a positive right to accommodation. Thus the DDA could be seen to confer 'positive liberties.' When positive liberties are conferred, a more narrow definition of disability is required. These positive rights are curtailed further by the restriction of 'reasonableness' to ensure the cost is not too high (for example on business or the taxpayer), and this, in turn, makes them politically acceptable.

I will now consider other examples of eligibility criteria for disabilities. In these cases, it is indisputable that these schemes confer positive liberties.

2.2.1.3. Disability Living Allowance[62]

This benefit stems from the Social Security Act 1975, amended by the Disability Living Allowance and Disability Working Allowance Act 1991. You are eligible to claim Disability Living Allowance if you are aged below 64[63] and have needed help for three months because of a severe physical or mental illness or disability,[64] and you are likely to need it for at least another six months.[65] There are two strands to assessment of disability under the DLA: care needs and mobility needs.

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[61] Mill, J.S. *On Liberty* (Harmondsworth, Penguin, 1982).

[62] Information from www.direct.gov.uk. For a much more insightful analysis of social security law in relation to disability, see Wikeley, Ogus, Barendt *The Law of Social Security* (5th edn) (London, Butterworths, 2002). In particular, pp675-712, p749-761 and p781-785; Wikeley, N. 'Social Security and Disability' in Harris, N. *Social Security Law in Context* (Oxford, Oxford University Press, 2000).

[63] Social Security Contributions and Benefits Act (SSCBA) 1992 s75. Children under 16 qualify for DLA albeit with extra conditions.

[64] SSCBA 1992 s72 (2) (a).

[65] *Ibid*, s72 (2) (a).

To receive DLA, you are considered to have care needs if:

- you need help in connection with bodily functions – this includes things such as eating and using the toilet[66]
- you need help washing
- you need supervision to stop you being a danger to yourself or to others[67]
- you are terminally ill[68]

To receive DLA, you are considered to have mobility needs if:

- you are unable or virtually unable to walk[69]
- you are both deaf and blind[70]
- you are severely mentally impaired with severe behavioural problems and qualify for the highest rate of care component[71]
- you need help getting around out of doors[72]

Some people who make a claim for DLA may be asked to have a medical examination. This is usually because more information about their disability or illness is needed before a decision on their claim can be made. This highlights the reliance on medical evidence in order to qualify as disabled. Benefits can be seen to be positive liberties because people are actually receiving money for a reason, in this case to compensate for their disability. Such positive liberties are only politically sustainable because the narrow definition employed means the benefits are only available to discrete groups of individuals who could not otherwise be self-sufficient because of the additional expenses incurred because of disability (for example, carers, specialised transport). Having doctors to regulate this makes it even more politically acceptable to the tax payer. It is therefore apparent that doctors have a role as 'gate-keepers' deciding who is 'disabled' and what level of benefits people receive. Furthermore, if an applicant appeals a decision regarding their DLA entitlement, a doctor always sits on the appeals panel. It should be

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[66] *Ibid,* s72 (1).
[67] *Ibid,* s72 (1)(b)(ii) and (c)(ii).
[68] *Ibid,* s72 (5).
[69] *Ibid,* s73 (1)(a).
[70] *Ibid,* s73(2)(a).
[71] *Ibid,* s73(3).
[72] *Ibid,* s73(4).

noted that the third member of the panel is always either a disabled person or a carer.[73] Whilst this can be seen as recognition of the social model, the 'carer' is often an occupational therapist and therefore a health professional.

2.2.1.4. Disabled Persons' Railcard[74]

You qualify for a Disabled Persons Railcard if you:

- are registered as visually impaired
- are registered as deaf
- have epilepsy, and are disabled by repeated attacks even though you receive drug treatment
- receive Attendance Allowance
- receive Disability Living Allowance (in the Higher Rate for help with getting around, or in the Higher or Middle Rate for help with personal care)
- receive Severe Disablement Allowance
- receive War Pensioner's Mobility Supplement
- receive War or service Disablement Pension for 80% or more disability
- are buying or leasing a vehicle through the 'Motability' scheme.

By listing specific conditions to define who is eligible for the railcard, this adopts the medical model as it is the impairment that makes the person disabled rather than society. The conditions listed are ones that would prevent someone from being able to drive[75] so it can be seen that the rail ticket concessions are meant only for those who cannot drive and have to rely on public transport. The criteria also refer to assessments by social security as to whether they are entitled to other allowances as a result of disability; again these are decided by doctors. To prove eligibility for a railcard it is necessary to provide medical evidence – in the case of epilepsy, this is a copy of the medical exemption

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[73] For information on appeal tribunal panel composition see The Social Security and Child Support (Decisions and Appeals) Regulations SI 1999 No. 991 and The Social Security and Child Support (Decisions and Appeals) (Amendment) Regulations, SI 1999 No. 1466. The phrase used in SI 1999 No. 991s36 is that there will be a "panel member with a disability qualification."

[74] Information taken from National Rail *Rail travel for Disabled Passengers* (Association of Train Operating Companies, 2005).

[75] For information about the Driver and Vehicle Licensing Agency (DVLA) Guidelines on medical rules, see http://www.dvla.gov.uk/drivers/dmed1.htm.

certificate for prescription charges and a photocopy of a prescription for anti-convulsants, again this is within the parameters of control of doctors.

2.2.1.5. Disabled Persons' Bus Pass

The seven categories of disabled person include any person who:-

a) is blind or partially sighted
b) is profoundly or severely deaf
c) is without speech
d) has a disability, or has suffered an injury, which has a substantial and long-term effect on his ability to walk
e) does not have arms or has long-term loss of the use of both arms
f) has a learning difficulty, that is, a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning
g) would, if he applied for the grant of a licence to drive a motor vehicle under Part III of the Road Traffic Act 1988, have his application refused pursuant to s92 of the Act (physical fitness) otherwise than on the ground of persistent misuse of drugs or alcohol.

That the conditions for bus concessions are not the same as rail concessions demonstrates how complicated defining disability is and how complicated and difficult it can be for a disabled person to know what assistance they are entitled to. For example, a person with Long QT syndrome[76] would be eligible for protection under the DDA, possibly not eligible for help under the DLA, she would be eligible for a rail card but not a bus pass. This complicated system is not even as a result of different models of disability being adapted, as all the above eligibility criteria demonstrate the traditional reliance on the medical model.

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[76] Long QT syndrome is a rare inherited disorder of the heart's 'conducting' or 'electrical' system. 'QT' refers to one of the intervals that characterise a normal heart beat cycle. In people with long QT syndrome, this interval is sometimes longer than usual, which has the potential to trigger a disturbance of the heart's rhythm. People with this disorder may experience attacks of fast heart rhythm which on some occasions could be life-threatening. For more information see the British Heart Foundation website at www.bhf.org.uk.

Having considered the elements of the medical model, and demonstrated its use in theoretical models and English Law, it is now necessary to explain why disabled people see the medical model as problematic and have put forward alternative models.

2.3 So what is wrong with the medical model?

While the approach of the medical model may be appropriate when considering impairment, when discussing disability, the false notion of normality assumed and the resulting emphasis on making impaired people as normal as possible, have a variety of negative implications for individuals with impairments. Indeed, Brisenden suggests that the impossible demands made on impaired individuals by this norm, against which they are measured and found to be lacking, are at the root of their oppression.[77]

Brisenden emphasises a number of general problems with the medical model.[78] Firstly, it assumes that the impaired person can be defined by their impairment. Secondly, it reinforces the established view that impaired people are passive and lack control over their lives, while 'non-impaired' people are active and in control of their lives. Thirdly, it creates an image of the impaired person as being inadequate, weak, pathetic, and in need of sympathy. Finally, if disability is always considered within a medical context, disability will always be seen principally as a set of physical dysfunctions and little else. Brisenden highlights the inequality in the way that society, influenced by a culture permeated by the medical perspective views the 'non-impaired' compared to the way it views individuals with impairments. He suggests that while 'non-impaired' people are usually regarded in terms of both their mental and physical abilities, impaired persons are often defined solely by what are perceived to be their inabilities. He states that in order for societal inequality to be redressed, society needs to make every effort to respond to impaired individuals, by not defining them on the basis of their impairment, but on the basis of their common aspirations with 'non-impaired' people, of seeking to lead full and interesting lives.[79]

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[77] Brisenden, S. n.9, above, at p173.
[78] *Ibid.*
[79] *Ibid.*

A variety of other authors have also criticised the medical model. For example, Ungar suggests that the model implies that impairment is a bad thing and that when medical labels and definitions are carried over into wider cultural contexts they tend to reproduce stereotypes of individuals with impairments as unfortunate and/or tragic.[80] Brisenden states that labelling disabled people with inappropriate medical categories are "nothing more than terminological rubbish bins into which all the important things about us as people get thrown away."[81] Swain and French argue that physically impaired individuals are subjected to many disabling expectations by the medical model, including expectations that individuals with impairments should desire to be 'independent' and 'normal,' and should want to 'adjust to' and 'accept' their situation.[82] Abberley believes the medical model does no more than to pathologize disability and 'blame the victim' for their condition.[83] At its worst, in the nineteenth century, the medicalization of disability dovetailed with what Foucault called "the racisms of the state,"[84] with the Darwinist and eugenicist perspectives which promised to cleanse the social body of impurity, imperfection, degeneracy and defectiveness.[85] The dominance of such ablest practices infers institutional, social, cultural and even emotional responses to disabled people.[86]

Reindal[87] and Newell[88] argue that not all people with losses, diseases, illnesses etc experience disablement, and so disability cannot be caused by the impairment, otherwise this would not be the case. They argue that if people with impairments are not the victims of social exclusion, they are not disabled. If this were the case, it would be difficult to distinguish those entitled to Disability Living Allowance and other benefits, or those entitled to protection from the law against discrimination, and those who are not. It is arguably more difficult to prove social exclusion than it is to prove impairment. This is where there is some strength to the medical model, when it comes to creating

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[80] Ungar, S. n.26, above.

[81] Brisenden, S. 'Independent living and the medical model' in Shakespeare, T. *The disability reader social science perspectives* (London, Cassell, 1998) at p21.

[82] Swain, J., French, S. n.12 above.

[83] Abberley, P. 'The concept of oppression and the development of a social theory of disability' (1987) 2 *Disability, Handicap and Society* 5.

[84] Foucault, M. *Discipline and Punish* (Harmondsworth, Penguin, 1979) at p54.

[85] Hughes, B. 'Disability and the Body' in Barnes, C., Oliver, M., Barton, L. *Disability Studies Today* (Cambridge, Polity Press, 2002) at p61.

[86] *Ibid,* at p62.

[87] Reindal, S. 'Disability, Gene Therapy and Eugenics: A Challenge to John Harris' (2000) 26 *Journal of Medical Ethics* 89.

[88] Newell, C. 'The Social Nature of Disability, Disease and Genetics: A response to Gillam, Persson, Holtug, Draper and Chadwick' (1999) 25 *Journal of Medical Ethics* 172.

definitions, and proving whether or not someone is 'disabled' it is much easier to prove with medical evidence that there is impairment. Taking the easiest option is not an acceptable justification, nor does it necessarily result in the best laws.

As a result of the traditional hegemony of medicine, disability has been defined in medical and biological terms referring to the individual. The examples of the medical model 'in use,' included in this section, highlight, and also contribute to, the continuing dominance of the hegemony of medicine in this area, for example the need to provide medical evidence to prove disability. The rejection of the medical model and the ICIDH is an important historical moment, marking the divide between those who see disability as an emergent property of the interaction between person and society and those who see it as an expression of social oppression.[89] It is now necessary to explore the nature of the social model; the reasons disability activists advocate it, and the ways in which it has been adopted to define 'disability.'

2.3 The social model

The social model of disability provides a critique from which disabled people can argue that the social exclusion they have experienced has gone on for too long. The importance of the social model of disability lies in providing an alternative understanding of the experience and reality of disability. In this way, it has given disabled people a basis on which to organise themselves collectively.[90] The social model of disability proposes a radical split between impairment and disability where disability is viewed as the social consequence of a disabling environment[91] rather than the inevitable consequence of an individual's impairment.[92] Unlike the medical model, the social model does not imply a direct causal link between impairment and disability; instead it assumes disability to be a social construct. Indeed, the Union of the Physically Impaired Against Segregation

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[89] Williams, G. n.7 above, at p134.

[90] Swain, J., French, S., Cameron, S. n.14 above, at p24.

[91] Finklestein, V. 'Disability: A social challenge or an administrative responsibility?' in Swain, J., Finkelstein, V., French, S., & Oliver, M.(eds.) *Disabling barriers – enabling environments* (London, Sage, 1993) pp34-43.

[92] French, S. 'Disability, impairment or something in between?' in Swain, J., Finkelstein, V., French, S., & Oliver, M.(eds.) *Disabling barriers – enabling environments* (London, Sage, 1993) pp17-25.

(UPIAS) advocate that disability is a distinct form of social oppression.[93] This view has been reiterated by Hasler: he suggests that the problems faced by physically impaired people constitute a specific social oppression rooted in the systematic exclusion of them from everyday life.[94] Brisenden takes this idea further by arguing that a hostile social environment directly oppresses individuals with impairments.[95] Williams argues that disability and dependency are caused by society.[96] Thus, in contrast with the medical model, the social model no longer sees impaired people as having something wrong with them,[97] but understands that the causes of disability are rooted in external social factors.[98] This model therefore challenges both the assumption of physical normality[99] and the notion that inability is a result of deficiencies in the impaired individual.[100]

According to the social model, disability can be defined in terms of the disadvantage or restriction of activity caused by a contemporary social organisation, which takes little or no account of people with physical impairments, thus excluding them from mainstream social activities.[101] According to this perspective, individuals with physical impairments are excluded from society, or 'disabled' as a result of the social and physical barriers they face in a world constructed for non-impaired living.[102] There are many types of barriers faced by disabled people, these include:

- "attitudinal, for example among disabled people themselves and among employers, health professionals and service providers;
- policy, resulting from policy design and delivery which do not take disabled people into account;
- physical, for example through the design of the built environment, transport systems, etc.; and

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[93] Union of Physically Impaired Against Segregation. *Fundamental principles of disability* (London: Union of Physically Impaired Against Segregation, 1976). This is advocated further in many academic commentaries including Tremain, S. n.27 above, at p41.
[94] Hasler, F. n.15 above, at p.278-284.
[95] Brisenden, S. n.9 above.
[96] Williams, G. n.7 above, at p135.
[97] Oliver, M., Sapey, B. n.10 above.
[98] Brisenden, S. n.9 above.
[99] Hasler, F. . n.15 above, at pp.278-284.
[100] Oliver, M., Sapey, B. n.10 above.
[101] Union of Physically Impaired Against Segregation. n.92 above.
[102] Oliver, M., Sapey, B. n.10 above; Finklestein, V. n.90 above, at pp34-43.

- those linked to empowerment, as a result of which disabled people are not listened to, consulted or involved."[103]

Accordingly, adjustment within the social model is seen as a problem for society, rather than a problem for impaired individuals, with the onus being on society to adapt to the impaired individual, rather than vice versa.[104] Rioux actually subdivides elements of the "new" paradigm into environmental and human rights approaches.[105] In the environmental approach, the research focus would be placed on the arrangements of the environment and their impact on persons with disabilities.[106] The human rights approach would analyze how society marginalized people with disabilities and how the social environment could be changed.[107] Thomas argues that "Disability is a form of social oppression involving the social impositions of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being."[108] It is therefore clear that this model encourages society to focus both on removing the social and physical barriers that people with impairments face,[109] and on adapting environments to ensure that the needs and rights of people with impairments are met.[110]

Now the theory of the social model has been explained, this study will now consider examples of the social model 'in use.' This will begin with a description and analysis of the UPIAS statement and will continue to explore attempts to incorporate the social model into law.

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[103] Prime Minister's Strategy Unit *Improving the life chances of disabled people* (London, PMSU, 2005).

[104] Hasler, F. n.15 above, at p.278-284; French, S. n.91 above, at pp17-25.

[105] Rioux, M.H. 'Disability: The Place of Judgement in a World of Fact' (1997) 41(2) *Journal of Intellectual Disability Research* 102-11.

[106] Bercovici, S. *Barriers to Normalization: The Restrictive Management of Retarded Persons* (Baltimore, University Park Press, 1983).

[107] Oliver, M. 'Changing the social relations of research production' (1992) 7(2) Disability, *Handicap and Society* 101-14.

[108] Thomas, C. *Female Forms: Experiencing and Understanding Disability* (Buckingham, Open University Press, 1999); Swain, J., French, S., Cameron, S. n.14 above, at p24.

[109] Finkelstein, V. n.91 above, at pp34-43.

[110] Oliver, M., Sapey, B. n.10 above; French, S. n.92 above, at p17-25.

2.3.1 The social model 'in use'

2.3.1.1. UPIAS/ DPI (1976)

This model published by Disabled People's International (DPI) in 1981, was based on a proposal presented by the Union of Physically Impaired Against Segregation in 1976.[111] It adopts the following definitions:

> *Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment.
>
> *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.[112]

Disabled people are therefore those with impairments who experience disability as a collection of socially-created restrictions, which are discriminatory because they limit opportunity for full and equal participation.[113] This turns our attention to the social environment and makes an implicit political argument for change.[114] This model was seen as a political challenge to health care professionals who, as already demonstrated, have historically dictated who qualifies as a disabled person and what social response is appropriate.[115] They argued that justice demands the removal of these socially-created barriers: anything less being discriminatory.[116]

Less clear is what this model says about the relationship between impairments and disabilities. Since the definition of disability makes no reference to impairments or any physical or mental condition, arguably the model makes no connection at all.[117] It aims

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[111] Williams, G n.7 above, at p134 explains that the theoretical driver of the early statements of principle was a neo-Marxism that defined itself in opposition to welfare-Fabianism and well-meaning liberal-functionalist sociology.
[112] Union of Physically Impaired Against Segregation n.93 above, at pp3-4.
[113] Bickenbach, J.E., et al n.48 above, at p1176.
[114] *Ibid,* at p1176.
[115] Abberley, P. n.83 above; Oliver, M. n.3 above; Barnes, C., Oliver, M. 'Disability rights: rhetoric and reality in the UK' (1995) 10 *Disability and Society* 111.
[116] Bickenbach, J.E., et al n.48 above at p1176.
[117] *Ibid.*

therefore to avoid the criticisms of ICIDH and the way the model used arrows to link the concepts. This is not satisfactory though because it avoids the criticism by avoiding the issue altogether. It could be argued that the fact there is a definition of impairment included in the UPIAS/DPI model at all demonstrates that disabled people remain defined by their impairments which was exactly what people criticised the ICIDH for doing. This questions the possibility of developing a purely social, yet workable definition of disability and is an argument that will be revisited later on in this chapter.

It has already been demonstrated in this chapter that proponents of the social model are often reluctant to highlight biological differences that might be used by others to argue for the inequality of people. Demands to end social inequality and discrimination require those who have been disadvantaged to be identified, and that can only be done by drawing attention to their difference, yet, if difference is ignored or downplayed to support the claim of equality, then the different needs of people may also be ignored.[118]

Topliss argued that:

> "While the particular type or degree of impairment which disables a person's full participation in society may change, it is inevitable that there will always be a line, somewhat indefinite but none the less real, between the able-bodied majority and a disabled minority whose interests are given less salience in the activities of society as a whole."[119]

It seems therefore, that there will always be people who are labelled as 'disabled' irrespective of the model of disability used, but because of the nature or definition of disability itself. It will be demonstrated later, that this is not necessarily the case if one adopts a universalistic approach to disability. Ways in which the social model of disability can be translated into law will now be explored, relying on the area of EU law.

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[118] *Ibid.*

[119] Topliss, E. *Social Responses to Handicap* (Harlow, Longman, 1982) at pp111-112.

2.3.2. Translating models of disability into law

As previously demonstrated in relation to the DDA , there has traditionally been a reliance on the medical model of disability. Even when it has been attempted to incorporate the social model, the medical model has always seemed to creep in. It is important to discover whether or not this is an inevitable part of drafting law. EU law will be focused upon here, the only European Directive to prohibit disability discrimination being the *EC Equal Treatment in Employment Directive 2000.*

2.3.2.1. Examples from EU Law

The *EC Equal Treatment in Employment Directive 2000*[120] prohibits direct or indirect discrimination in employment of grounds of disability, age, religion or belief. The directive means that failure to provide a reasonable accommodation (termed reasonable adjustments within the DDA) for a disabled person can constitute discrimination. This directive required that all EU countries must have civil anti-discrimination legislation protecting disabled people in employment by November 2003, irrespective of employer size.[121] The Directive did not define disability so it is likely that the European Court of Justice will be asked to develop, probably through a piecemeal approach, a European definition.[122] It is not possible to predict with any certainty the approach the ECJ will take, however if one looks at other documents relating to disability from the European Union it becomes clear that there is an acceptance of the social model.

Firstly, in a *Communication from the Commission to the Council and the European Parliament of 24 January 2003, "Towards a United Nations legally binding instrument to promote and protect the rights and dignity of persons with disabilities"*[123] it was stated that

> "People with disabilities are often marginalised because they develop in an environment which is unaware of the consequences of their disabilities. They encounter many physical, technical and social obstacles to the enjoyment of their

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[120] EU Directive 2000/78/EC.
[121] See www.europa.eu.int.
[122] Disability Rights Commission n.56 above, at p29.
[123] Summary at http://europa.eu.int/scadplus/leg/en/cha/c11911.htm.

> rights in all regions of the world (even if this situation is more accentuated in the developing countries)"

This can be seen to be a recognition of the social model because it is accepted that disabled people face barriers which prevent participation. The Communication continues to describe the nature of the difficulties experienced by disabled people:

> "Human rights violations against disabled people generally take the form of indirect discrimination, including the creation and maintenance of barriers preventing disabled people from enjoying full social, economic and political participation in the life of their communities. Countries generally have a narrow understanding of human rights *vis-à-vis* disabled people and make do with abstaining from measures which have a negative impact on them."

This implies that it is not enough to merely ensure policies and environments do not have an adverse impact on disabled people, but that positive steps should be taken to include disabled people in all areas of community life. This approach goes further than the DDA which (unlike legislation for race and sex discrimination) does not protect the disabled person from indirect discrimination.[124]

In June 1999, an *EC Resolution on equal employment opportunities for people with disabilities* was passed. Member States were called upon to place particular emphasis on the promotion of employment opportunities for disabled people, within the framework of their national employment policies, and develop policies to assist their integration into the labour market. This can be seen to be a forerunner to the 2000 Directive and as such provides guidance of the model of disability intended by the Directive. In this resolution, the Council specifically recognised "the need to provide appropriate support in areas such as workplace accommodation, such as technical equipment, workplace access, qualifications and skills required at work, and access to vocational guidance and placement services."[125] This can be seen to be encouraging a more social model of disability by encouraging support to enable disabled people to participate in the

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[124] This may change when the Equality Bill (creating the Single Equality Act) is passed through Parliament.

[125] See www.europa.eu.int.

workplace. That this resolution encouraged Member States to provide support could be interpreted as conferring positive liberties on disabled people.

In 1996, both the Commission and the Council took the first steps towards developing a global disability policy, and recognising the social model of disability. The European Commission produced a document a *Communication on Equality of Opportunity for People with Disabilities.* This was the first comprehensive European Community strategy produced by the Commission. It was inspired by the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Although these rules are not compulsory, they are capable of becoming customary rules when applied by a large number of states. The rules imply a strong moral and political commitment on behalf of Member States to take action to equalise opportunities for people with disabilities. States are tasked with the responsibility of removing barriers to participation, in active partnership with individuals with disabilities and representative organisations.[126] The explicit reference to the removal of barriers indicates an acceptance of the social model and as such marked a major step forward in the Commission's thinking. Its aim was to give "a renewed impetus towards the right-based equal opportunities approach to disability." The Communication was widely praised by disabled people at the time. The Council then produced *EC Resolution of the 20 December 1996 on equal opportunity for people with disabilities* which provided an even more explicit adoption of the social model. As this Resolution was not just in relation to employment, its recommendations were broader. The Resolution called on Member States to consider whether national policies work toward empowering disabled people for participation in society; mainstreaming the disability perspective into all relevant sectors of policy formulation; enabling people with disabilities to participate fully in society by removing barriers; and nurture public opinion to be receptive to the abilities of disabled people.[127] These developments demonstrate a clear change in policy from 1975 when the *Declaration on the Rights of Disabled Persons* which called for national and international action to protect the rights of disabled people defining a 'disabled person' as any person unable to ensure by himself/ herself the necessities of a normal individual and/or social life, as a result of deficiency in his/her physical or mental capabilities.[128]

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[126] See www.un.org.
[127] See www.europa.eu.int.
[128] See www.unhchr.ch.

Up until 1996, one could argue that the international community's approach to disability was based on the medical model of disability. Disabled individuals were expected to adapt to the prevailing norms and standards in society. Where this was not possible, society provided charitable support for those disabled individuals who are unable to support themselves through employment. The medical model dominated the formulation of disability policy within European countries and provided a theoretical justification for practices such as the institutionalisation and segregation of disabled people. In the sphere of employment, the model led to an almost exclusive focus on rehabilitation and vocational training, and income maintenance for people who were classified as unable to work. More recent developments in European law demonstrate a basis for a strong argument that Europe has begun to advocate a social model of disability. However it is arguably easy for Europe to make grand statements in non-binding documents based on the social model of disability which are not necessary translated into law. If it was attempted to translate these resolutions into law they would have faced the additional barrier of having to persuade Member States to agree on ways of thinking about disability as well as drafting law that incorporates that way of thinking. It is potentially less politically acceptable to base laws on the social model of disability as this could involve costly changes to society and the environment rather than assuming disability is located within the individual.

2.3.2.2. Back to the United Kingdom

There has been a recent recognition from UK Legislators that anti-discrimination laws for disability need improving. The Disability Discrimination Act 2005 (hereafter the DDA 2005) extends the definition of disability of the DDA 1995 to provide protection against discrimination for at least another 175,000 people. It covers more people diagnosed with the progressive conditions of HIV, multiple sclerosis and cancer and removes the requirement that mental illnesses be 'clinically well recognised.' The reason for extending the definition in this way was due to an acceptance of the stigma that can be attached to these conditions which can lead to discrimination before the condition affects daily functioning.[129]

The 2005 Act was a result of widespread recognition of the failings of the existing law. The Disability Rights Commission (DRC) criticised the current definition for being too narrow and quoted research that shows that in 16% (one in six) of decided cases applicants lost because tribunals ruled that they had not met the statutory definition of disability. This was the most common reason for a claim to fail. As a result, it had become increasingly common for respondents in disability discrimination case to challenge the applicant's status as a disabled person under the terms of the DDA.[130]

A major issue in the passing of the Disability Discrimination Bill 2005 (hereafter the DDB 2005), in both houses, was that MPs across the political divides wanted the Bill passed before the general election. For that to happen it was difficult to amend the Bill following debates. The concern was that if it was not passed in that Parliamentary sitting, it was unknown when it would next make it onto the Parliament agenda. Therefore, many MPs and organisations (including the DRC) accepted the Bill to ensure it was passed swiftly. However this means that further amendments will probably be necessary in time, but it was important to start the process and get some amendments on the statute books.[131]

The DDB 2005 provides a good opportunity to explore the way in which decisions about legislating for disability are framed, and the Hansard debates provide examples to demonstrate the shift that has occurred towards the social model. Baroness Hollis of Heigham explained that "Disabled people face greater difficulties than most. They encounter institutional ignorance and misunderstanding, individual prejudice and the all-too-familiar barriers to access in every walk of life. That can have a devastating effect on

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[129] For example see Baroness Murphy, House of Lords Hansard Debates for 6 December 2004, Column 689.

[130] Leverton, S. Monitoring the Disability Discrimination Act 1995 (Phase 2) a study carried out on behalf of the Department for Work and Pensions (London , Department for Work and Pensions, 2002); Hurstfield, J., Meager, N., Aston, J., Davies, J., Mann, K., Mitchell, H., O'Regan, S., Sinclair, A. *Monitoring the Disability Discrimination Act, 1995, Phase 3* (London, DWP, 2004).

[131] For example of a comment expressing such concern see Lord Ashley of Stoke, House of Lords Hansard Debates for 6 December 2004, Column 683 when he stated that "we do not want any undue delay even though we want to put forward suggestions for improving the Bill".

their opportunities and self-esteem."[132] Thus she did not explain disability as a result of impairment, but as a result of societal barriers and attitudes. Some members of the House of Lords failed to adopt the social model. For example, Lord Carter stated that "Disabled people are people first, disabled second and discriminated against in their various activities third. It therefore follows that, despite their disabilities, whether mental or physical, they should not be put in a more advantaged position than able-bodied people."[133] In this quote, Lord Carter recognises that disabled people are people but then prioritises their disabilities (second) over the way in which they are discriminated against (third). This demonstrates a prioritisation of medical model elements of disability over the social.

The debate between the two models was even explicitly recognised. For example, it was said that "The definition of disability and mental illness illustrates the whole question of whether the definition of disability should be based on the social model or the medical model, as in the 1995 Act and in this Bill. The social model attempts to define disabling barriers rather than medically defined impairment… The social model recognises that environment produces discrimination – the medical model merely describes impairment."[134] And Baroness Hollis of Heigham explained that "The first big issue… was about the medical model and the social model"[135] and that the approach they had taken was to be pragmatic. She said "there is no tidy read-across between the degree of impairment and the degree of disability or discrimination that someone may suffer as a result of that impairment. One moves from a medical model through to a social one as a result."[136] Indeed due to the time constraints, it almost seemed that discussion of the social model was a distraction to passing the Bill. For example Paul Holmes MP worried that "we are in danger of going off into the long debate about the social and medical models of disability."[137]

Both Houses recognised the possibility to change the approach of the law from focusing on individual impairment to focusing on proving discrimination – a more social model approach. Lord Salisbury explicitly states this when he said: "In particular [I welcome]

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[132] House of Lords Hansard Debates for 6 December 2004, Column 655 per Baroness Hollis of Heigham.
[133] *Ibid,* at Column 672 per Lord Skelmersdale.
[134] *Ibid,* at Column 680 per Lord Carter.
[135] *Ibid,* at Column 705 per Baroness Hollis of Heigham.
[136] *Ibid,* at Column 705 per Baroness Hollis of Heigham.
[137] House of Commons Hansard Debates for 23 March 2005, Column 922 per Paul Holmes.

the opportunity to express the hope that the shift of disability anti-discrimination legislation should be on the act of discrimination, rather than on the nature and the extent of a person's impairment – that is to say, the 'social' rather than the 'medical' focus."[138]

It can therefore be seen that the approach taken (i.e. social or medical) by legislators is to some extent a matter of choice. In which case, it has to be asked why is there still such a dominance of the medical model in the statute books? One explanation for this, already touched upon, is that the Bill was an amendment to, and based on, the DDA 1995 and as a result the MPs were restricted in the approach they could take. As Baroness Hollis of Heigham stated "We will not be altering the fundamental and familiar DDA concepts which are increasingly understood and working."[139] The Minister therefore wished to change the definition as little as possible, believing this would avoid confusion amongst disabled people, the courts and people with duties under the DDA.

Again time constraints played a role in continuing the dominance of the medical model. As Lord Carter said: "The Joint Select Committee recognised all the advantages of adopting the social model but we took the pragmatic view that it would be difficult to use this Bill, which is based on the medical model, to insert a general and a social model of disability into the Bill, thereby almost certainly delaying its introduction substantially."[140]

The Joint Committee considering the draft DDB 2005 concluded that "if the DDA was based on the social model of disability, it would offer protection to anyone who could prove less favourable treatment (discrimination) on the grounds of impairment. This is the same type of protection from discrimination provided by the Race Relations Act 1976 (RRA) and the Sex Discrimination Act 1975 (SDA)."[141] They therefore recommended the adoption of the social model of disability because "If people with impairments are to experience equality of opportunity, they not only require protection from discrimination on the grounds of impairment, they also require additional action to be taken to address

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[138] House of Lords Hansard Debates for 6 December 2004, Column 681 per Lord Bishop of Salisbury.
[139] House of Lords Hansard Debates for 6 December 2004, Column 656 per Baroness Hollis of Heigham.
[140] *Ibid,* at Column 680 per Lord Carter.
[141] Joint Committee on the Draft Disability Discrimination Bill *Draft Disability Discrimination Bill Report* (London: Stationary Office Ltd, 2004) at p21.

the disabling barriers they face."[142] They considered that the focus of anti-discrimination legislation should be on the extent and nature of discrimination, not on the extent and nature of impairment. They therefore preferred the social model approach.[143] Yet it is clear from the report by the Joint Committee that although the idea of a social model definition was advocated, no one seemed to know how to draft one. The Joint Committee therefore asked the DRC to research and consult on this.

The British Council of Disabled People[144] criticised the DDA and the draft bill for not using the social model. They saw the need to add specific conditions (as in the draft bill) as proof that the current definition was unhelpful and excluded people who suffered discrimination. In the end it argued, "the detailed definition of disability will read like a legal and medical dictionary," but will not prevent people who are clearly discriminated against from being excluded from protection because their impairment is not adequately covered by that definition.[145] It added that the question of who is covered by the DDA is becoming "a legal minefield which needs expensive lawyers and doctors to interpret it and act as arbiters." The BCODP argued that the law should not concentrate on level and type of impairment: it should concentrate instead on discrimination, and suggested the following definition of who would be covered by the legislation: "... the person has a disability for the purposes of this Act if he has a physical or mental impairment or is in any way associated with such an impairment." Yet this definition of disability is still using the medical model, it is just the emphasis of the law would be different: focusing on the unfavourable treatment an individual was subjected to rather than whether or not their impairment meant they would be considered as disabled under the Act. Yet the broader definition they suggest would ensure more people were offered protection under the law. They thought that such a definition would not lead to frivolous claims because discrimination and its link to impairment would still need to be proved.[146]

The DRC said it favoured using the social model of disability as the basis of a definition, but only in the longer term. Using this model would be complex requiring a significant

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[142] *Ibid.*
[143] *Ibid,* at p23.
[144] hereafter referred to as the BCODP.
[145] Joint Committee on the Draft Disability Discrimination Bill n.104 above, at p21 referencing Mr Rickell of BCODP Evidence before the Committee.
[146] Joint Committee on the Draft Disability Discrimination Bill n.140 above, at p22.

amount of consultation, and would inevitably delay the bill.[147] Some recognised practical problems in the adoption of a social model approach in the current bill and thought improvements could be made to the current definition while further consideration was given to the move to a social model of disability. Others wanted a social model definition to be introduced immediately.[148]

In the end, the Joint Committee took what they believed to be a more pragmatic approach and argued that it would be difficult to use this bill to insert a general social model definition of disability into the framework of the DDA. They therefore limited their recommendations concerning who is covered by the DDA to amendments which they thought were achievable within the current framework of this bill. However they also clarified that the current inadequacies in the DDA definition must be addressed.[149] Yet arguably the result of the two amendments to the DDA 1995 is that the legislation as a whole is difficult to comprehend. The current definition, with its various elements, exceptions, and exemptions is difficult to understand and has led to extended legal arguments, requiring expensive medical reports and long, stressful litigation.[150] The present definition creates uncertainty and in the vast majority of cases the only way to definitively determine whether a person is disabled under the Act is to go to tribunal.[151]

This shift towards the social model is not only evident in the debates around the DDA 2005. The recent Government Green Paper on Welfare Reforms recognises that disabled people have skills and can make contributions to the workforce and society if given the support needed to get into work.[152] The paper also recognises that there is a need to work to change the prevailing attitudes held towards people with illness or disability among other key stakeholders, particularly GPs and employers,[153] and a need to continue

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[147] *Ibid.*
[148] *Ibid,* at p23.
[149] *Ibid,* at p23.
[150] Disability Rights Commission n.56 above, at p12.
[151] *Ibid.*
[152] For example, see Department for Work and Pensions *A new deal for welfare: Empowering people to work* (London, DWP, 2006) at p3 which states that "there are groups of people locked into long-term dependency on benefits who have been denied the opportunities that work can bring. In a modern, dynamic economy, we cannot afford to be denied the skills and contributions of those who have the potential to work."
[153] Department for Work and Pensions n.151 above, at p28.

challenging any discrimination in employment that exists against long-term sick and disabled people.[154]

The Welfare Reforms are part of an existing policy by the Labour Government to improve the lives of disabled people. In a publication by the Prime Minister's Strategy Unity it was recognised that disabled people looking for work face a range of barriers – discrimination, policy design and delivery, physical and environmental barriers, and a lack of empowerment. That there is a "need to change the current culture and raise the expectations of employers, health professionals and disabled people themselves that these barriers can be overcome."[155] This recognises a social model of disability.

For the purposes of that report, disability was defined as:

- "disadvantage experienced by an individual…
- …resulting from barriers to independent living or educational, employment or other opportunities
- … that impact on people with impairments and/or ill health."[156]

The content of this definition is interesting because it highlights that disability is a disadvantage incurred as a result of social barriers. The order of this definition demonstrates an acceptance of the social model because it highlights the social elements as the cause of disability, impairments or ill health being secondary in recognising disability. This can be contrasted with Lord Carter's quote previously mentioned in this chapter where he prioritised the medical elements over the social. There was also an understanding that "a clear distinction needs to be made between disability, impairment and ill-health. Impairments are long-term characteristics of an individual that affect their functioning and/or appearance. Ill health is the short-term or long-term consequence of disease or sickness. Many people who have an impairment or ill health would not consider themselves to be disabled."[157]

Yet despite this recognition of the social model by the government and Parliament, UK legislators have not improved at drafting definitions. As French and Swain explained,

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[154] *Ibid,* at p30.
[155] *Ibid,* at p49.
[156] Prime Minister's Strategy Unit n.102 above.
[157] *Ibid.*

"Power relations and structures are, by their nature, deeply ingrained, and cosmetic changes often mask a lack of fundamental change."[158] However, as a result of the DDB 2005, the Joint Committee asked the Disability Rights Commission[159] to consult on and make recommendations to the Government on developing a social model definition of disability for the DDA (or the Single Equality Act), focusing on challenging discrimination on grounds of impairment and removing barriers. It will be interesting to see results of the consultation and the ways the results are dealt with by law makers.[160] The chief advantage of such a change to the definition would be to shift the focus of attention from the medical condition of an individual to a consideration of whether or not discrimination is occurring.

The DRC consultation document explains that the goal of a disability discrimination law is to reduce the prejudice, disadvantage and discrimination that has historically been associated with disability by eliminating discrimination and taking action to promote inclusion and participation:

> •"The definition should function to promote these changes in attitude and actions.
>
> •It should facilitate both the promotion of good practice and the enforcement of rights.
>
> •It needs to be clear, since the easier it is to understand the easier it is for those whose attitude and behaviour needs to change to know what is expected of them.
>
> •The definition also needs to be credible in the eyes of stakeholders, in order to mobilise the support that is needed to take forward the necessary social change."[161]

An alternative definition based on the social model would represent a radical reformulation of the law, addressing the issue from a completely different direction. It would be much closer to the way in which people are protected from other types of discrimination. As with other discrimination laws, the focus would be on the act of

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[158] French, S., Swain, J. 'The Relationship between Disabled People and Health and Welfare Professionals' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p751.

[159] hereafter referred to as the DRC.

[160] Further exploration of the way legislators think about disability when focusing on reproductive genetic technologies can be found in the QL chapter (chapter 5).

[161] Disability Rights Commission n.56 above, at p18.

alleged discrimination, rather than the personal characteristics (i.e. extent of impairment) of the individual.[162] As well as addressing the problems with the existing definition a wider definition might, more generally, bring a more positive approach, encouraging a more systemic approach to change and to the removal of barriers. Shifting the approach to definition would have the significant advantage of bringing the law in alignment with best practice.[163] However a major concern is that adopting this much broader approach to disability would diminish credibility and trivialise disability rights.[164] Some have argued that the changes might open the DDA to abuse, and therefore discredit it.[165] The different legal and institutional frameworks and cultural contexts could influence the way in which disability discrimination law operates.[166]

The question remains, is it possible to develop a purely social, yet workable, definition of disability? It has been shown, by the Prime Minister's Strategy Unit that it is possible to prioritise social elements of a definition over the medical ones. Yet, would this change the practical operation of the Act? As the definition still includes reference to impairment, respondents may still focus on that element. However it has been shown in this chapter that it is necessary to include a reference to impairment in order to make the law a) workable and b) politically acceptable. There are examples in Europe, of countries that have found ways of incorporating a more social model style: the Belgian Act to Combat Discrimination does not define disability at all. Alternatively in Ireland, because the definition in the Equality Acts is so wide, the focus of the case is simply on whether the respondent has treated the complainant less favourably than a person without a disability in similar relevant circumstances, based on the disability, or has failed to provide reasonable accommodation to the extent required by the disability.[167] This is an example of changing the emphasis of an Act from the definition of disability to a focus on the less favourable treatment. Yet it can be seen that in the Employment Equality Act 1998 and Equal Status Act 2000, disability is still defined due to impairment:

> "(a) the total or partial absence of a person's bodily or mental functions, including the absence of a part of a person's body,

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[162] *Ibid.*
[163] *Ibid* at p20.
[164] *Ibid* p22.
[165] *Ibid* at p22.
[166] *Ibid* at p24.
[167] Employment Equality Act 1998 and Equal Status Act 2000.

> (b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness,
> (c) the malfunction, malformation or disfigurement of a part of a person's body,
> (d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction
> (e) a condition, disease or illness which affects a person's thought processes, perception of reality, emotions or judgement or which results in disturbed behaviour."[168]

The broadness of the approach taken in Ireland comes from their approach to defining discrimination. Their definition of discrimination on the ground of disability is: "For the purposes of this Act discrimination includes a refusal or failure by the provider of a service to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities, if without such special treatment or facilities it would be impossible or unduly difficult for the person to avail himself or herself of the service."[169]

There could be a potential problem with legislating within a purely social model framework. As shown in previous examples, even when organisations try to develop policies from a more social model, the issue of impairment continues to creep in, causing criticisms that elements of the medical model have remained. Perhaps it is inevitable that elements of the medical model need to be included. Within the field of 'Disability Studies' this argument has become known as 'bringing the body back in.'

2.4 Attempts to 'Bring the Body Back'

Barnes believes that 'disabled people' refers to "all those with impairments, regardless of cause, who experience disability as social restriction."[170] This definition shows that disablement is essentially, conceptually linked to a health status (or a perception of a health status). A social theory of disablement therefore risks incoherence if it cannot make the link (let alone explain the link) between impairments and the socially-created

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[168] Irish Equal Status Act s2(1) available from www.irishstatutebook.ie.
[169] *Ibid,* s4(1).
[170] BARNES, C. (1991) Disabled People in Britain and Discrimination (London: Hurst and Co.) at p2.

disadvantages of disablement. Indeed it is argued that most social modellists have paid insufficient attention to the ways in which different forms of impairment come to be associated with different forms or manifestations of disablism.[171] Thomas argues that models of disability have to engage with impairment in order to get on with the main task – theorizing and exposing disability, and thus clarifying the political terrain for challenging disablism.[172] Some have gone so far as to say that seeing as only people who *have*, or are *presumed to have*, an impairment are counted as disabled, "the strict division between the categories of impairment and disability which the social model is claimed to institute is in fact a chimera."[173]

If impairment is located in a different sphere of knowledge than disability, and disability is socially constituted, then impairment must be biologically constituted. Impairment must, therefore, be taken to refer to the fleshly object that constitutes the subject matter of medical science. It follows that impairment must be devoid of social meaning and separate from the self. As such, impairment could make claim to epistemological validity only as a form of biological dysfunction, and could be identified solely by the authority of the medical gaze.[174] Paul Abberley has long argued against this social modellist naturalization of impairment and the way it leaves impairment to the realm of the biological or to medical hegemony.[175] Bill Hughes and Kevin Paterson have pointed out, for example, that although the impairment-disability distinction demedicalizes disability, it renders the impaired body the exclusive jurisdiction of medical intervention.[176]

There are, however, further objections from social theory modellists to bringing the body back in. For those who equate disability with 'restricted activity,' the notion that impairment restricts activities in important ways[177] is particularly problematic. They are

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[171] Thomas writing in Thomas, C., Corker, M. 'A Journey around the Social Model' in Corker, M., Shakespeare, T. (eds*) Disability/ Postmodernity – Embodying Disability Theory* (London, Continuum, 2002) at p20.
[172] *Ibid*, at p24.
[173] Tremain, S. n.27 above, at p42.
[174] Hughes, B. n.85 above, at p67.
[175] Abberley, P. n.82 above; Abberley, P. 'Work, Utopia and Impairment' in Barton, L. *Disability and society emerging issues and insights* (New York , Longman, 1996) pp61-79.
[176] Hughes, B., Paterson, P. 'The social model of disability and the disappearing body: towards a sociology of impairment' (1997) 12(3) *Disability and Society* 325-40 at p330.
[177] Notion proposed by many theorists including Morris, J. (ed) *Encounters with strangers: Feminism and Disability* (London, The Women's Press, 1996); Crow, L. 'Including all of our lives: renewing the social

of the opinion that by blurring the distinction between impairment and disability, 'bringing impairment in' clouds the crucial question on causality, and the source of disability, as well as obscuring the most appropriate targets for political action.[178] An emphasis has been placed on holding on to the UPIAS formulation for reasons of political strategy.[179] Mike Oliver insists that, while disablement *is* nothing to do with the body, impairment is nothing less than a description of the physical body.[180] Opponents of theorizing impairment argue that much of the apparently new work, which tries to bring impaired bodies back in, is really going over old ground rather than building on what has gone before. They reiterate that the consequence of too much emphasis on diversity and difference in impairment, is that the boundaries between impairment and disability as social oppression become blurred.[181]

Such objections have not prevented many working in disability studies from developing theories of disability which include and embrace impairment. For example, Thomas has argued that it is important to acknowledge the reality of what she refers to as 'impairment effects:' "These are the direct effects of impairment which differentiate bodily functioning from that which is socially constructed to be normal or usual."[182] She explains that this is not because impairment is 'the cause' of that disablism (in a medical model sense) but because disablism (discrimination, exclusion, prejudice) often expresses itself in direct response to the features of impairment of the individual disabled person (or their perceived group).[183] 'Impairment effects' are traditionally focused upon at the expense of what really troubles most people who live with impairment – disability.[184]

Derrida was concerned with ways of thinking about how meanings are established, specifically that meanings are organized through difference in a dynamic play of presence and absence. Meaning includes identity (what it is) and difference (what it is

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model of disability' in Barnes, C., Mercer, G. n4. above; French, S. n.92 above; Wendell, S. *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York, Routledge, 1996).

[178] Finklestein, V. 'Outside: "Inside Out"' (1996) April, *Coalition*, 31-6; Oliver, M. 'Defining Impairment and Disability: Issues at Stake' in Barnes, C., Mercer, G. (eds) n.4 above.

[179] Shakespeare, T. 'A response to Liz Crow' (1992*) September Coalition* 40-2 at p40.

[180] Oliver, M. n.8 above, at p35.

[181] Williams, G. n.7 above, at p138.

[182] Thomas, C. n.170 above, at p20.

[183] *Ibid,* at p24

[184] Thomas, C. 'Disability Theory: Key ideas, Issues and Thinkers' in Barnes, C., Oliver, M., Barton, L. *Disability Studies Today* (Cambridge, Polity Press, 2002) at p44.

not) and is therefore continuously being deferred. Derrida invented a word for this process, combining difference and deferral – *différance.*[185] A Derridean perspective on disability would argue that though they are antagonistic, 'normativism' needs 'disability' for its own definition: a person without an impairment can define him/herself as 'normal' only in opposition to that which s/he is not – a person with an impairment. Disability is not excluded from 'normativism;' it is integral to its very assertion. Moreover, when 'normativism' is privileged, 'disability' becomes a derivative, *cultural* arrangement that imposes on the taken-for-granted, *natural* status of the 'normal.' This strategy for revealing the underpinnings of a particular binary opposition is called *deconstruction.*

Derrida argues that we are always within a binary logic and, whenever we try to break out of its stranglehold, we reinscribe its very basis. Thus, in addition to making sense of the manner in which 'normativism' is itself a social construct, he might be concerned with the way in which an adoption of (a 'positive,' 'proud' and 'visible') 'disability identity' reinscribes the 'sick role' produced through the normal/impaired binary.[186] This is important because of the large number of people with impairments who identify as neither 'normal' nor 'disabled,' but nevertheless are individually engaged in resisting the hegemony of normativism in their everyday lives. Derrida would therefore explain that in order for 'disabled' people to be defined, 'non-disabled' people have to be defined, and it is only in relation to each other that the two categories can exist. In this way, it is necessary to use binary logic to reiterate the importance of being able to define those who are disabled and therefore entitled to protection under the law, or certain benefits; in doing so, it is also possible to identify who is not entitled to such protection or benefits. The one thing that distinguishes disabled people from non-disabled people is impairment – as non-disabled people can face oppression too. However the point of anti-discrimination laws in relation to disability is that oppression because of an impairment is unlawful.

Social constructionism and postmodernism offer an alternative approach to the impairment-disability issue. Such approaches see the distinction between disability (as social) and impairment (as biological, of the body) as a product of modernist,

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[185] Derrida, J. *Writing and Difference* (Chicago, University of Chicago Press, 1978).
[186] Corker, M., Shakespeare, T. 'Mapping the Terrain' in Corker, M., Shakespeare, T. (eds*) Disability/ Postmodernity – Embodying Disability Theory* (London, Continuum, 2002) at p7

'essentialist,' dualistic thinking.[187] In this view, both impairment *and* disability are discursively constructed social categories, the former having no relationship to a supposedly underlying biological reality, itself another construct.[188] Impairment is produced through a myriad of social production and other processes: accidents and injury in the work places; accidents in transportation; medical mistakes, drug therapies and surgical advances (extending the life of many people with impairment); wars, street and domestic violence, and so forth. Thus impairment is as much social as it is biological.[189] The proposition that impairment is simply a medical concern is rejected. And it is argued that over time the perception of the body has changed: it has a history, and has become increasingly medicalized.[190] Concepts of 'normality' and 'abnormality' are not delivered in an unmediated form by biology. The biological data with which we are presented is interpreted through existing understandings of the body and in accordance with cultural standards.[191] As Locker explains:

> "The extent to which functional limitations and activity restrictions constitute a problem, or are otherwise handicapping, is not only variable historically and culturally but is also somewhat dependent upon more immediate contexts; their meaning is not the same across different social and environmental settings."[192]

Hughes and Paterson use a Foucauldian analysis: they argue that Foucault does not deny the materiality of the body; rather Foucault's argument is that the materiality of the body cannot be dissociated from the historically contingent practices that bring it into being, that is, objectivize it.[193] Further, it seems politically naïve to suggest that the term 'impairment' is value-neutral, that it is, 'merely descriptive', as if there could ever be a description which was not also a *prescription* for the formulation of that to which it is

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[187] Shildrick, M., Price, J. 'Breaking the boundaries of the broken body' (1996) 2(4) *Body and Society* 93-113; Price, J., Shildrick, M. n.37 above; Corker, M. n.29 above; Corker, M., French, S. n29 above.
[188] Thomas, C. n.184 above, at p51.
[189] *Ibid*, at p52.
[190] Barnes, C., Mercer, G., Shakespeare, T. n.36 above, at p93.
[191] Leach Scully, J. 'A Postmodern Disorder: Moral Encounters with Molecular Models of Disability' in Corker, M., Shakespeare, T. (eds) *Disability/ Postmodernity – Embodying Disability Theory* (London, Continuum, 2002); Paterson, K., Hughes, B. 'Disability studies and phenomenology: the carnal politics of everyday life' (1999) 14(5) *Disability & Society* 597-610.
[192] Locker, D. *Disability and Disadvantage* (London, Tavistock, 1983) at p5.
[193] Paterson, K., Hughes, B. n.191 above, at pp333-4.

claimed innocently to refer. Truth-discourses which purport to describe phenomena contribute to the construction of their objects.[194]

Recent poststructuralist, neo-Foucauldian analysis attempts to bring the body back in by conceptualising it as the object of knowledge and the target of power. In Hughes and Paterson's terms, "Post-structuralism can be useful in theorizing impairment without a medical frame or reference."[195] This leads to a confrontation where contemporary molecular medicine's epistemological assumption that modernist science provides objective knowledge about 'how the body really is' runs into the postmodern claim that all forms of knowledge, including knowledge about and of the body, are subjectively situated and discursively produced.[196]

It has been argued that impairment and its materiality are naturalized effects of disciplinary knowledge/power.[197] The foundational premiss of the social model (impairment) is an historical artefact of this regime of knowledge/ power.[198] Instead, those allegedly 'real' impairments must now be identified as the incorporated constructs of disciplinary knowledge/power that they are. As effects of an historically specific political discourse (biopower) impairments are materialized as unitary and universal attributes of subjects through the iteration and reiteration of rather culturally specific regulatory norms and ideals about human function and structure, competency, intelligence, and ability.[199] As universalised attributes of subjects, furthermore, impairments are naturalized as an interior identity or essence on which culture acts in order to camouflage the historically contingent power relations that materialized them as natural.[200]

From a Foucauldian position, the impaired body is inseparable from the power that is visited upon it. As a discursive construction, impairment is culturally complex. It is a product of the intense disciplinary practices that produce it.[201] Thus, it would seem that,

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[194] Tremain, S. n.27 above, at p34.

[195] Paterson, K., Hughes, B. n.191 above, at p33.

[196] Leach Scully, J. n.191 above, at p51.

[197] Tremain, S. n.27 above, at p34.

[198] *Ibid.*

[199] Amundson, R. 'Against normal function' (2000) 31 Studies in History and Philosophy of Biological and Biomedical Sciences 33-53.

[200] Abberley, P. n.83 above; Thomas, C. n.108 above.

[201] Hughes, B. n.85 above, at p69.

in so far as proponents of the social model claim that disablement is not an inevitable consequence of impairment, they misunderstand the productive constraints of modern power. For it would seem that the category of impairment emerged and in part persists in order to legitimize the disciplinary regime that generated it in the first place.[202]

Social constructionism and postmodernism have provided a way of recognising that impairment is socially constructed too. As such, it is evident that impairment is also rooted in the medical hegemony. Although traditionally thought of as biological and medical, it is in fact as much social as it is medical. Foucault believed it was naïve to think of impairment as just descriptive because it cannot be disassociated from the historical hegemony that has defined it that way. Whilst these are valid arguments, it remains to be seen how this can be translated into a legal definition of disability.

So far in this chapter I have demonstrated the need to combine elements of the social and medical models in order to achieve a workable legal definition of disability. There has been an attempt to integrate the two polar models of disability: The 'Biopsychosocial model.' This will now be discussed in order to discover whether it is possible to promote a hybrid model of disability.

2.4.1 The Biopsychosocial Model (BPS)

This model is an attempt to synthesise the medical and social approaches to disablement. This synthesis is a response to the over-medicalisation of the ICIDH and the tendency for the social model to "detach disablement from its biomedical foundations."[203] BPS views the health of the population in its physical, mental and social environments and rejects any attempts to reduce an understanding of functioning and health to any one of its three core components. It therefore rejects both the medical and social models on their own and seeks to combine them.

Whilst it has long been recognised that both the medical and social models of disability were inadequate on their own, the origins of BPS and its exact composition seem unclear. Armstrong suggests that the development of BPS was a response to the way that in the

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[202] Tremain, S. n.27 above, at p43.
[203] Bickenbach, J.E et al n.48 above, at p1185.

1960s, psychiatry was being simultaneously pulled towards both a biological reductionist view of mental illness, and approaches which stressed the role of social factors in influencing mental health.[204] It is obvious how this dilemma links into disablement theory. BPS was a way of integrating these two approaches into a more holistic framework by recognising the influences of both the biology and sociology of mental health.

Although BPS is seen as a middle way through the divergent discourses of disability, the way in which this approach treads this precarious path remains unclear. It would seem as if Armstrong's explanation comes the closest when he discusses the 'interlocking systems' of society where physiological, personality, social and cultural all operate on the same level and are interrelated rather than in a hierarchy where one takes dominance over the others.[205] However, as Imrie explains, this theory runs the risk "of maintaining a conceptual separation, or where debate will never move beyond arguments about which perspective is more important and therefore more powerful than the other."[206] This could prove to be a real problem, indeed much disability literature still does not include BPS, instead preferring to focus on the polarised views expressed by the medical and social models. This is perhaps understandable as by taking an extreme view of an approach to exploring disability, it is far easier to then demolish those models as unworkable or prejudiced. It is difficult to argue against BPS because it seems a compromise, and one that remains, as yet, unclear.

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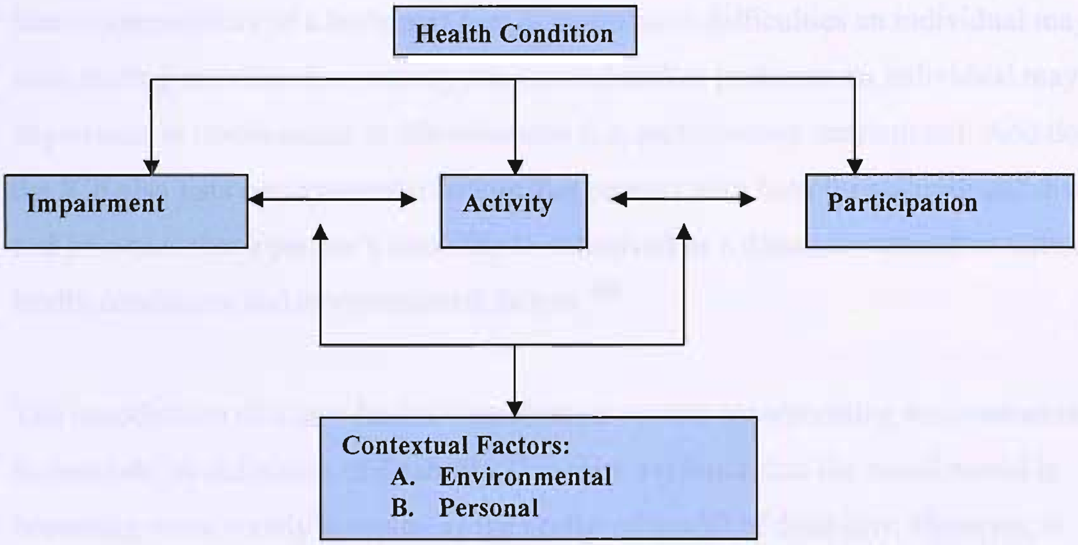
[204] Armstrong, D. 'Theoretical tensions in Biopsychosocial medicine' (1987) 25(11) *Social Science and Medicine* 1213-18.

[205] *Ibid* at p1213.

[206] Imrie, R. 'Demystifying disability: a review of the International Classification of Functioning, Disability and Health' (2004) 26(3) Sociology of Health & Illness 287-305 at p299.

2.4.1.1. The BPS 'in use' – The International Classification of Functioning

Fig. 3. A diagram to represent the International Classification of Functioning:[207]



In 2001, the WHO, strongly influenced by the social model, introduced a new health classification called the *International Classification of Functioning, Disability and Health* (ICF). This replaced the ICIDH and its 'consequences of disease' definition of disability.[208] The ICF is comprised of the following definitions:

- Body functions – physiological functions of body systems (including psychological functions).
- Body structures – anatomical parts of the body such as organs, limbs and their components.
- Impairments – problems in body function or structure such as a significant deviation or loss.
- Activity – execution of a task or action by an individual.
- Participation – involvement in a life situation.
- Activity limitations – difficulties an individual may have in executing activities.
- Participation restrictions – problems an individual may experience in involvement in life situations.

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[207] World Health Organisation *International classification of functioning, disability and health* (Geneva, WHO, 2001).

[208] World Health Organisation n.16 above. (Previously discussed in this chapter.).

- Environmental factors – the physical, social and attitudinal environment in which people live and conduct their lives.

This classification system uses the term 'functioning' to encompass all body functions, activities, and participation, while the term 'disability' is used as an umbrella term for the loss or abnormality of a body part (i.e. impairments); difficulties an individual may have in executing activities (i.e. activity limitations) and/or problems an individual may experience in involvement in life situations (i.e. participation restrictions). Additionally, the ICF also lists environmental factors that interact with both functioning and disability, and proposes that a person's disability is conceived as a dynamic interaction between health conditions and environmental factors.[209]

The introduction of a new health classification system incorporating environmental factors into its definition of disability[210] is clear evidence that the social model is becoming more widely accepted as the preferred model of disability. However, it becomes apparent upon close examination that the new ICF system actually reaches way beyond the social model, with a 'components of health' definition of disability that takes a neutral standpoint on the aetiology of disability so that researchers can draw their own causal inferences.[211]

The ICF departs from the ICIDH in a number of ways, foremost, unlike the ICIDH, it does not conceive the body as pre-social, or impairment as beyond socio-cultural influences or conditioning, thus achieving a social constructionist approach to impairment. The ICF embodies the 'Biopsychosocial model,' a synthesis of the medical and social approaches to disablement. Each dimension of disablement is conceptualised as an interaction between intrinsic features of the individual and that person's social and physical environment.[212] The ICF also challenges the tenor of the ICIDH by noting that the presence of impairment "does not necessarily indicate that a disease is present or that the individual should be regarded as sick."[213] In contrast, it proclaims that "the issue is therefore an attitudinal or ideological one requiring social change, which at a political

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[209] World Health Organisation n.207 above.
[210] *Ibid.*
[211] *Ibid.*
[212] Bickenbach, J.E., et al n.48 above, at p1183.
[213] World Health Organisation n.207 above, at p13.

level becomes a question of human rights. Disability becomes, in short, a political issue."[214]

Disablement is now understood as an identifiable variation of human functioning. The three dimensions are called 'impairments,' 'activity limitations' and 'participation restrictions.' The three dimensions are co-equals in significance and are intended as different facets or manifestations of a single emergent phenomenon – disablement.[215] However, as Imrie points out, the ICF fails to specify, in any detail, the content of some of its main claims about the nature of impairment and disability. He says that this "has the potential to limit the ICF's capacity to educate and influence users of the document about the relational nature of disability."[216] This therefore illustrates, that just as the social model of disability was criticised for not explaining the links between disability and impairment, nor does the ICF. Marks claims that the ICF seeks to develop the conception that "mind, body, and environment are not easily separable but rather mutually constitute each other in complex ways,"[217] this could possibly explain the lack of clarity in explaining the relational nature of disability. However the ICF's explanatory and practical utility is likely to be limited unless some of it core concepts and principles are developed further and justified.[218]

Implicit in the three classifications is the view that it is both inappropriate and scientifically inaccurate to characterise disablement in isolation from human functioning, or, for that matter, to characterise disablement in inherently negative and depreciative terms. To the greatest extent possible, neutral, if not positive language is employed throughout the three classifications and explicitly in activity and participation classifications.[219] Disabled people are understandably sensitive to professionals and researchers who presume to classify them and their lives, without having access to the experiences that they are trying to classify.[220]

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[214] *Ibid*, at p25.
[215] Bickenbach, J.E., et al n.48 above, at p1184.
[216] Imrie, R. n.206 above.
[217] Marks, D n.4 above, at p25.
[218] Imrie, R. n.206 above, at p289.
[219] Bickenbach, J.E., et al n.48 above, at p1185.
[220] *Ibid.*

Politically, it is understandable that many disabled people do not want to concede that impairment on a biological level has anything to do with disability. However, (as already discussed in this chapter) it remains to be seen how to define disability in law without reference to impairment (by some description) in order to distinguish between disabled and non-disabled. An alternative approach to the problem, would be to approach disability as a universal human condition rather than as a minority group discrimination issue. This approach will now be discussed.

2.5 Minority group discrimination or universal human condition?

These approaches can be summarised as:

> *Minority group/ civil rights analysis*: characterises disabled people as a social minority group who must seek out their basic civic rights and fight against discrimination in order to correct the injustices of the past and the present.
>
> *Universalism:* insists that disablement is a universal human phenomenon that has been systematically ignored with dire and unjust social consequences.[221]

As a minority group, disabled people are denied the full enjoyment of their civil rights because of institutional or systemic discrimination brought about, in the final analysis, by prevailing attitudes.[222] As a result, theorists like Hahn believe that: "the primary problems confronting citizens with disabilities are bias, prejudice, segregation and discrimination that can be eradicated through policies designed to guarantee them equal rights."[223] As a result, Hahn puts his faith in the legal protection of rights, and in particular the legal protection that antidiscrimination law provides, believing that law stands the best chance of guaranteeing the basic rights of disabled people.[224]

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[221] *Ibid,* at p1179.
[222] *Ibid,* at p1180.
[223] Hahn, H. 'Civil Rights for disabled Americans: the foundations of a political agenda' in Gartner, A., Joe, T. (eds) *Images of the Disabled, Disabling Images* (New York, Praeger, 1987) p181, at p182.
[224] Bickenbach, J.E., et al n.48 above, at p1180.

Hahn states that, "People with disabilities are a minority group because they have been the objects of prejudice and discrimination."[225] This past discrimination reinforces attitudes that are the primary cause of conditions facing disabled people. Hahn thus places "the focus on public attitudes rather than physical limitations as the primary source of difficulties facing disabled people. Other postulates of the minority-group model specify that all facets of the environment are moulded by public policy and that government policies reflect widespread societal attitudes or values; as a result, existing features of architectural design, job requirements, and daily life that have discriminatory impact on disabled citizens cannot be viewed merely as happenstance or coincidence."[226]

Many believe that the minority group analysis and the civil rights or antidiscrimination approach to advocacy misconceive the nature of disablement and will probably have to give way eventually to a more inclusive, and more stable, political analysis – namely universalism – an analysis that can more effectively serve the political and social needs of disabled people in the future.[227] This is because they believe that:

1. The minority group analysis is founded on a forced analogy between racial minorities and disabled people that breaks down at many important points.[228]
2. An advocacy strategy that sets its sights entirely on civil rights and antidiscrimination protection is of limited continuing value to disabled people. Although undoubtedly, there is discrimination against disabled people, and this should be corrected; the condition of inequality that disabled people face cannot always fit into the mould of discrimination.[229]
    a. Discrimination is a wrongful limitation of someone's negative freedom – the creation of an obstacle or barrier to full participation or some other benefit to which the wronged party has a prima facie claim, based on an irrelevant feature of that individual.

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[225] Hahn, H. 'The political implications of disability definitions and data' (1993) 4(2) *Journal of Disability Policy Studies* 42 at p47.
[226] *Ibid* at p46.
[227] Bickenbach, J.E., et al n.48 above, at p1180.
[228] For a more detailed discussion of whether or not the analogy between disability and race and gender is successful or not see Omansky Gordon, B., Rosenblum, K.E. 'Bringing Disability into the Sociological Frame: a comparison of disability with race, sex, and sexual orientation statuses' (2001) 16(1) *Disability and Society* 5-19; Sheldon, S., Wilkinson, S. 'Termination of Pregnancy for Reason of Foetal Disability: Are there Grounds for a Special Exception in Law?' (2001) 9 *MLR* 85.
[229] Bickenbach, J.E., et al n.48 above, at p1181.

b. The salient feature of the condition of inequality among disabled people is that it typically consists of limitation on their freedom to participate in the full range of social roles and ways of living. Their freedom is not usually limited by expressed legal prohibitions (although that can happen) but by failures to provide the resources and opportunities needed to make participation feasible.[230]

The denial of opportunities and resources is an issue, not of discrimination, but of distributive injustice – an unfair distribution of society's resources and opportunities that results in limitations of participation in all areas of social life. The allocation of resources creates a distributive imbalance unfairly disadvantaging some people.[231]

Zola, who is attributed with first thinking of universalism, believes that what is needed "are more universal policies that recognise that the entire population is 'at risk' for the concomitants of chronic illness and disability." As such, we need a strategy that "demystifies the special-ness of disability" because by "seeing people with a disability as 'different' with 'special' needs, wants and rights in this currently perceived world of finite resources, they are pitted against the needs, wants and rights of the rest of the population."[232]

Crow calls for a 'new norm' which carries an expectation that there will be a wide range of attributes within a population, and an acceptance and valuing of difference.[233] A greater acceptance of the diversity that exists among individuals and more appropriate provision for the inclusion of diversity within the mainstream will, she suggests, lead to a lessening of the need to place labels of impairment on individuals. She emphasises the need to bring discussion about impairment into greater prominence in order that the social change that disabled people aim to bring about is genuinely inclusive.[234]

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[230] *Ibid.*

[231] *Ibid.*

[232] Zola, I.K. 'Toward the necessary universalizing of a disability policy' (1989) *67 The Milbank Quarterly* 401.

[233] Crow, L. 'Including all our lives: renewing the social model of disability' in Morris, J. (ed) *Encounters with strangers: Feminism and Disability* (London, The Women's Press, 1996).

[234] *Ibid.*

The sharp divide which formally exists between 'disabled' and 'non-disabled' people does not tally with the actual distribution of impairment:

> "The idea that physicality involves impairment and increasing impairment, and ultimately death may not seem positive, but a view of life which embraced that fact would be healthier, would probably lessen prejudice against disabled people and older people and would certainly warrant doctors radically altering their view of their role, and of what it is to be human."[235]

Universalists argue that any member of the population is at risk of becoming disabled at any point in their lives, and as health care improves and people are living longer, they are often living with disabilities. By taking this stance, proponents of this argument are 'tapping in' to the selfish nature of most people. Most people, if unsure about the hand the 'natural lottery of disability' will deal them, would like to ensure that disabled people are protected and provided for, in case they join that category at some point in their life.[236]

Ironically, the minority group approach finds itself requiring a fixed and dichotomous sense of disability precisely in order to define the minority group of disabled people. However for laws to be effective this is arguably inevitable. For the DDA 1995 to be effective, it is imperative to be able to define disability so that decisions can be made as to who warrants protection under the law. Yet whenever there is a definition of disability, it requires comparison to the 'normal.' The result will probably be stigmatisation. This is a negative experience, but it is the stigmatisation that has lead to political moves to outlaw discrimination. The following diagram aims to illustrate this circular argument:

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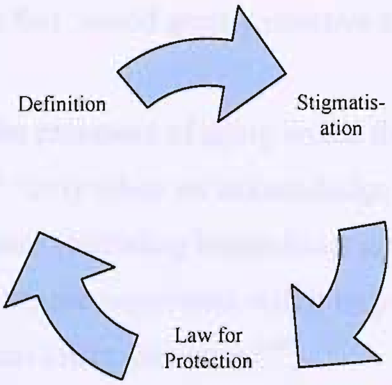
[235] Shakespeare, T. 'Back to the future? New Genetics and Disabled People' (1995) 44(5) *Critical Social Policy* 22-35 at p28.

[236] For a similar argument see the 'veil of ignorance' suggested in Rawls, J. *A Theory of Justice* (Oxford, Clarendon Press, 1972).

Fig. 4. A diagram demonstrating the difficulties of developing a definition of disability in law



One method of resolving this issue would be to specify that the category 'normal,' is understood to be a social construction or something which itself needs to be explained. This will prevent people's prejudices from defining disability in a way that stigmatises. Universalism, in a way solves this problem as proponents of this theory ask for policy that respects difference and widens the range of the normal. Disability is not a human attribute that demarks one portion of humanity from another (as gender does, and race sometimes does); it is an infinitely various but universal feature of the human condition.[237] Advocates of this theory argue for an ability-disability continuum, and then the complete absence of disability, like the complete absence of ability, is a limiting case of theoretical interest only.[238]

If society could be persuaded to adopt the universalism theory, the concept that everybody has limitations, (although the degree of them and their implications on daily life can vary) could be accepted. This could lead to a reduction in health costs for society because rather than spending vast amounts on the prevention of disabled lives, they would be accepted. Instead of striving for ideal health as an essential (and unobtainable) goal to happiness, people would accept the distribution of talents as they are ('accept the hand they are dealt'). Ironically, this utilises a utilitarian argument to improve the quality of life for disabled people: the maximum happiness for the maximum number of people could be ensured by reducing expenditure on healthcare. Rather than this being done by

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[237] Bickenbach, J.E., et al n.48 above , at p1182.
[238] *Ibid.*

preventing disabled lives, it could be done by changing people's ideals so that people were thought of as 'differently abled' rather than 'disabled,'[239] people would not strive to remove their limitations and instead, money could be spent on removing the social and environmental barriers that would greatly improve the quality of people's lives.

Zola pointed out that the processes of aging linked the interests of the 'able-bodied' to those of 'the disabled:' "only when we acknowledge that near universality of disability and that all its dimensions (including biomedical) are part of the social process by which the meanings of disability are negotiated, will it be possible fully to appreciate how general public policy can affect this issue."[240]

In the Netherlands the approach taken by The Dutch Act on the Equal Treatment on grounds of Disability or Chronic Illness (2003) ensures that both disabled and non-disabled people are protected from disability discrimination. Therefore, if an employer refuses to employ a person because she has a disability, this will be discrimination. However, it will also be discrimination if an employer refuses to employ someone because he does *not* have a disability. Discrimination will only exist if one person is treated worse than another person, who does or does not have a disability. This indicates that it is not permitted to treat anyone more or less favourably than anyone else, there is therefore no need to define disability. This could be seen to adopt a universalistic position. However this approach to disability law removes the possibility for reasonable adjustments and positive discrimination – their allowance in the UK being commendable aspects of the DDA 1995 to enable distributive justice.

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[239] See the Introduction to the expressivist argument chapter (chapter 3) for discussion of the effects of changing terminology relating to disability.
[240] Zola, I.K. n.232 above, at p420.

2.6 Conclusions

This chapter has shown that the debate about models of disability is relevant to law because legal provisions adopt these models. I have drawn attention to the way that lawmakers tend to adopt the medical model, and therefore pay insufficient regard to the interests of disabled people because a flawed model is being used. The discussions in Europe and the DDA 2005 indicate recognition of this but relatively little concrete progress. This may be because it is difficult to incorporate social models, as shown by the persistence of medical models in various guises within international documents. I have argued that this is as a result of the traditional hegemony of medicine. I suggested that it is not possible to achieve a purely social, yet workable definition of disability. European examples highlight that it is possible to change the focus of the law but not to exclude impairment. I demonstrated that attempts at convergence into hybrid models can be seen in the disability literature and in the latest WHO model.

The problem seems to be that where positive liberties are concerned, it is necessary to define disability, and this has traditionally resulted in a definition including impairment which is then accused of following the medical model. The DDA 2005 demonstrated a shift towards the social model and the amendments it made ensures the DDA is no longer solely based on the medical model. However, amendments to the existing legislation have resulted in a very complicated legal situation. It remains to be seen how the DRC will develop a social model definition of disability as a result of their consultation and whether or not this is adopted by the legislature. Following the research done here, it seems as if the Government is willing to adopt a more social model of disability (as evidenced in requesting the DRC to do the consultation and the discussions of the nature of disability in the Green Paper on Welfare Reforms) without knowing the best way to proceed. The challenge that remains is to realise the progress away from a purely medical model through more consistent legal provisions. Failure to make that progress indicates the degree to which the current law expresses disablist values which could be avoided more effectively than they currently are, even if neutrality remains difficult to achieve.

The discussion so far has been based on the models of disability as used in anti-discrimination law. These laws are in place to ensure that disabled people are not treated less favourably than 'non-disabled' people because all people regardless of their disability status are entitled to equality. In this context, it has been demonstrated how sensitive laws can be to the approach taken based on the different models of disability. And as already explained, the laws created can have real effects on the lives of disabled people, and can be seen to enshrine values. This thesis will now continue to discuss the expressive nature of reproductive genetic technologies. These technologies are not used to improve the lives of disabled people but to prevent them. In this context then it is important to explore the model of disability used to justify them. It will be seen that quality of life judgements based on negative assumptions grounded in the medical model are prevalent amongst lawmakers and medics. The model of disability used and the values it expresses in the context of reproductive genetic technologies leads to the devaluation of disabled lives.

Chapter 3: Introduction to the Expressivist Argument

This chapter will begin to set the scene for a discussion about the engagement of the law with disability issues in the context of reproductive genetic technologies. This will demonstrate that the way in which we perceive disability is important in the 'real world' and is not merely an interesting academic debate. The focus of this discussion will be section 1 of the Abortion Act 1967. This section of the Act details the reasons for which abortion can be carried out in the UK. Section 1(1)(d) in particular permits abortions where there is "a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped." I will argue that the Abortion Act 1967 s1(1)(d) reflects societal values that construe aborting a 'disabled' foetus as more justifiable than aborting a 'normal' one. In this way, the lives of disabled people are not judged to be equal to those of non-disabled people. This argument is made stronger by the fact there is little clarification as to which disabilities are suitable for PND. The guidance offered by the Royal College of Obstetricians and Gynaecologist (RCOG) relies heavily on a medical model of disability, and is therefore inherently disablist, as demonstrated in the previous chapter. These issues will be explored in more detail later in this chapter.

Initially, the law regarding abortion for foetal abnormality needs to be clarified, and the importance of a recent case brought by Joanna Jepson explained. The expressivist argument will then be outlined in order to explain the structure of the remaining parts of this thesis. This chapter will then continue to examine the argument that although parents perceive their reproductive choices as private decisions, their decisions are influenced by the cultural context and in turn they contribute to that cultural context. Cultures can express societal values which can be damaging to disabled people. Furthermore there is a link between the way disability is perceived and the laws that result from those attitudes. The law takes a disablist position, and this encourages people to share these assumptions about the lives of disabled people. The language with which we refer to people reflects our perceptions of those people and may even influence the way others perceive them. The use of disabling language feeds back to our images of disabled people. When it comes to national media and disseminating information to the public, the way in which disability is portrayed can make a difference. Private decisions are influenced by these debates.[1] Thus, there is a circle of meaning and decision-making created that could either be vicious or virtuous. I aim to show throughout this thesis that because of the disablist attitudes expressed at all stages it is a vicious circle.

3.1. Abortion Act 1967

Abortion in England and Wales was first made illegal in the 19th century by statute. Before then English Common Law had allowed abortion, provided it was carried out before the woman felt the foetus move ('quickening') as it was at this point that it was believed the soul entered the body.[2] Abortions performed after quickening were an offence under Common Law but there were no fixed penalties and the woman having the abortion was not necessarily held responsible. In 1803, the law changed and abortion became a criminal offence from the time of conception with penalties of up to life imprisonment for both the pregnant woman and the abortionist. Section 58 of the Offences against the Person Act 1861 made abortion a criminal offence punishable by imprisonment from three years to life, even when performed for medical reasons. No further legal changes occurred in England until 1929 when the Infant Life Preservation Act was passed.

The Infant Life Preservation Act amended the law so that abortion would no longer be regarded as a felony if it was carried out in good faith, for the sole purpose of preserving the life of the mother. The 1929 Act made it illegal to kill a child 'capable of being born live,' and set 28 weeks as the age at which a foetus was presumed to be able to survive.[3] In 1938, Dr Alex Bourne performed an abortion on a 14 year old girl after a gang of soldiers had raped her. Dr Bourne informed the police and was prosecuted. In court, the judge ruled that Dr Bourne had acted in the 'honest belief' that the abortion would 'preserve the life of the mother.' This opened the way for other doctors to interpret the law more flexibly as it established that preserving a woman's life could mean more than literally preventing her death.[4]

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[1] This will be demonstrated in the IDM chapter (chapter 4).

[2] For more information on the history of abortion law in the UK, see Royal College of Obstetricians and Gynaecologists *A Consideration of the Law and Ethics in relation to Late Termination of Pregnancy for Fetal Abnormality: Report of the RCOG Ethics Committee* (London, RCOG Press, 1998) ; Kennedy, I., Grubb, A. *Medical Law* (London, Butterworths, 2000).

[3] The Infant Life (Preservation) Act 1929 s1.

[4] *R v Bourne* [1939] 1 KB 687 at 694.

The Abortion Act 1967 came into effect on 27 April 1968 and permits termination of pregnancy subject to certain conditions. Regulations under the Act mean that abortions must be performed by a registered practitioner in a National Health Service hospital or in a location that has been especially approved by the Department of Health.[5] The Abortion Act 1967 was amended by s37 of the Human Fertilisation and Embryology Act 1990 (HFE Act 1990). It introduced a time limit of 24 weeks for grounds C and D. Grounds A, B and E are now without limit.[6] Before this change the limit that applied for all grounds was that the foetus was 'capable of being born alive' and this line was drawn at 28 weeks.[7] This Act also changed the numbering of the sections of the Abortion Act 1967. The HFE Act 1990 also confirmed that when a woman had a multiple pregnancy it was legal for a doctor to terminate the life of one or more foetuses leaving others alive.[8] An abortion can be approved providing two doctors[9] agree in good faith that one or more of the following criteria apply:

Fig. 5. The criteria for abortion set out as they are presented in the statutory forms[10]

Criteria in statutory form	Corresponding section of the Abortion Act 1967 as amended by the HFE Act 1990
A. the continuance of the pregnancy would involve risk to the life of the pregnant woman greater than if the pregnancy were terminated;	S1(1)(c)
B. the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman;	S1(1)(b)
C. the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman;	S1(1)(a)
D. the continuance of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of any existing child(ren) of the family of the pregnant woman;	S1(1)(a)

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[5] The Abortion Regulations 1991, Statutory Instrument 1991 No. 499 (which revoke S.I.s 1969 No 636, 1976 No 15, 1980 No 1725).

[6] See fig. 5. for an explanation of the grounds for which abortion is permitted.

[7] the time limit set by The Infant Life Preservation Act (as described above) unless the mother's life was endangered.

[8] s37(5) HFE Act 1990.

[9] s1(1) Abortion Act 1967.

[10] This form is used for data collection and the production of national statistics.

E. there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped; or in an emergency, certified by the operating practitioner, as immediately necessary.	S1(1)(d)

In relation to grounds C and D the doctor may take account of the pregnant woman's actual or reasonably foreseeable environment, including her social and economic circumstances.[11] 97% of abortions are carried out under grounds C or D because the doctor confirms that it would be damaging to the woman's mental health to force her to continue the pregnancy. This is demonstrated in the following a table:[12]

Fig. 6. Table to show the number of abortions carried out under each statutory ground in 2004:

Statutory Grounds	**Number of abortions**	**% of total number of abortions**
All legal abortions	185,415	N/A
A (alone or with B,C or D)	128	0.06
B (alone)	1,192	0.64
B (or with C or D)	482	0.26
C (alone)	176,754	95.3
D (alone or with C)	4,965	2.68
E (alone or with A,B,C, or D)	1,894	1.02

Doctors and other medical staff have the legal right to 'conscientiously object' to taking part in abortions[13] unless this is necessary to save the life or prevent grave permanent injury to the woman.[14]

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[11] s1(2).

[12] Information taken from http://www.dh.gov.uk/assetRoot/04/11/75/74/04117574.pdf.

[13] s4 (1).

[14] s4 (2).

3.1.1 Focusing on the foetal abnormality clause

The Abortion Act 1967 limits the application of the 1929 Act to an abortion carried out outside the circumstances within the 1967 Act. The 1967 Act attempts to balance the interests of the mother and the foetus by imposing a time limit[15] for abortions at 24 weeks. There are, however two exceptions to the 24 week rule: Firstly, that if continuing the pregnancy involves a real and substantial risk to the health or life of the woman, greater than a termination,[16] or, secondly, if "there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped."[17] This study will focus on the latter of these provisions.

The wording of the Act is vague, deferring to the clinical judgement of doctors rather than setting standards elsewhere. The Royal College of Obstetricians and Gynaecologists said it is left to the doctor's discretion over what is considered a "major handicap" in relation to abortion law.[18] As long as two doctors[19] and the mother agree, an abortion can be performed. During the parliamentary debates over the HFE Act 1990, it was evident that many MPs had faith that doctors would always exercise their discretion prudently.[20] Montgomery highlights the Courts' deference to medical discretion[21] and uses Mr Justice Baker's statement in *Paton v BPAS* to illustrate this:

> "not only would it be a bold and brave judge… who would seek to interfere with the discretion of doctors under the [Abortion Act 1967], But I think it would really be a foolish judge who would try to do any such thing, unless possibly there is clear bad faith and an obvious attempt to perpetrate a criminal offence."[22]

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[15] s1(1)(a).
[16] s1(1)(b) and (c).
[17] s1(1)(d).
[18] Royal College of Obstetricians and Gynaecologists n.2 above; Royal College of Obstetricians and Gynaecologists *Criteria for Termination of Pregnancy for Fetal Abnormality* (London, RCOG, 1996). This is interesting because the wording of the Act is 'serious' not 'major' handicap.
[19] s1(1).
[20] This is discussed in more detail in the QL chapter (chapter 5).
[21] Montgomery, J. *Health Care Law* (Oxford, Oxford University Press, 2003) at p382.
[22] Baker P in *Paton v Trustees of BPAS* [1978] 2 All ER 987 at 989.

It would seem that the Crown Prosecution Service (CPS) hold a similar view to Justice Baker. Writing in *The Telegraph*, Joanna Jepson says that the Chief Crown Prosecutor for West Mercia wrote to her to defend his decision not to prosecute the doctors involved in the case.[23] He apparently wrote that he was satisfied that the doctors had acted in "good faith."[24]

3.1.2 Why is this the law?

The idea of a time limit for abortion arises from a 'gradualist' view of the moral status of foetal life, governing how much protection society owes to the foetus. This view gives a lower moral status to the foetus in the first and second trimesters than to the viable foetus, and holds that the newborn deserves protection apart from the interests of the woman and family when circumstances dictate.[25] Although argument still rages on about whether abortion should be permitted merely as a matter of convenience to the woman, the foetal handicap ground is almost universally accepted.[26]

The Lane Committee was asked to report on the workings of the Abortion Act in June 1971 and published its report in 1974.[27] It reported that only 1.1 per cent of all abortions were performed upon the ground of risk of the child being seriously handicapped.[28] They then considered section 1(1)(b)[29] of the Act which legalized abortion where there is "a substantial risk that of the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped." At that stage, no abortion was allowed after the foetus was 'capable of being born alive' (28 weeks) unless the mother's life was endangered. In 1967, research was being undertaken into the antenatal diagnosis of foetal abnormalities, but it is was only possible to diagnose a small number of these abnormalities early enough in pregnancy to perform an abortion. By 1974, with

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[23] This case is explained in detail later in this chapter.

[24] Jepson, J. 'Murder, even in "good faith," is still murder' *The Telegraph*, 20 March 2005.

[25] Fletcher, J.C., Wertz, D.C. 'Ethics and prenatal diagnosis: past, present and future' in Brock, D.J.H., Rodeck, C.H., Ferguson-Smith, M.A. *Prenatal Diagnosis and Screening* (Edinburgh, Churchill Livingstone, 1992) at p746.

[26] This will be demonstrated when the Hansard debates of the 1990 Act are analysed in the QL chapter (chapter 5). In this way abortions for foetal abnormalities are grouped together with abortions following rape or incest. This in itself is offensive to many disabled people because rape and incest are social, moral and legal wrongs.

[27] Lane, Justice *Report of the Committee on the Working of the Abortion Act* Cmnd. 5579 (London: Her Majesty's Stationery Office, 1974).

[28] *Ibid*, at p68. It can be seen in Fig. 6. that the most recent figure (for 2004) is 1.02%.

[29] This became s1(1)(d) when the Human Fertilisation and Embryology Act 1990 was passed.

advances in the techniques of amniotic cell culture and of examination of the chromosomes and biochemical properties of the cells, more of these conditions could be detected at an earlier stage.[30]

The Lane Committee stated that

> "The decision to be made as to abortion under section 1(1)(b) by the mother and father and the medical advisers may be among the most difficult under the Act, for example where it is known that there is a risk but that it is not of a high order. We do not think it would be appropriate to try to define this statutory ground more precisely and we make no recommendation with regard to the working of the subsection.[31]... In referring to these time limits, it should be borne in mind that there is often extreme difficulty in calculating the gestational age with accuracy; many women seeking abortion claim that their pregnancy is at an earlier stage than in fact it is."[32]

The Committee, in agreement at that time, stated that the informed opinion was that a maximum gestational ages of twenty-eight weeks for abortion was too high, having regard to modern methods of sustaining prematurely-born infants, and so it was recommended that the upper time limit for abortions should be reduced to 24 weeks.[33] With relation to the foetal handicap exception, the Lane Committee concluded that:

> "According to evidence received from those concerned with diagnostic amniocentesis, the diagnosis of chromosomal abnormalities in the foetus, although often possible by eighteen or nineteen weeks' gestation, may, in some cases not be made until the end of the twenty-second week. Further, in the detection of bio-chemical abnormalities diagnosis may not be made available until twenty-four weeks' gestation. *Nevertheless, the Committee would not be prepared to recommend an exception to the upper limit for abortion on the sole*

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[30] Lane, Justice n.27 above, at p71.
[31] *Ibid,* at p71.
[32] *Ibid,* at p86.
[33] *Ibid,* at p90.

> *ground of diagnosis of fetal abnormality* and we consider that such an exception would be unacceptable to the medical and nursing professions."[34]

It can be seen from the preceding quote that the Lane Committee considered the beliefs of the medical profession more important than what society at large, or what an individual woman would want.

The time limit for abortion was not actually changed until the Human Fertilisation and Embryology Act 1990 came to be passed. This coincided with Lord Houghton's Private Member's Bill seeking to allow abortions for any reason up to birth. Many did not want abortion included in the HFE Act 1990 debate but despite this the time limit for abortions was reviewed.[35] At that point, the Lane Committee's recommendation of reducing the time limit to 24 weeks was finally accepted. However MPs ensured that an abortion could take place up to birth for a foetal handicap, this was not what the Lane Committee recommended. It seems that 28 weeks was suggested for foetal handicap, to ensure that it was consistent with the 1929 Act.[36] However, the voting in the Commons became very complicated and s1(1)(d) exempting abortions to birth for foetal handicap came about almost inadvertently. This can be seen in the voting processes that took place in the House of Commons.[37] MPs could vote for a series of time limits – 28 weeks, 20 weeks, 26 weeks and 24 weeks. There was concern expressed at the time by several MPs. For example, Mr Dennis Skinner said

> "Yesterday a list of amendments was put in the No Lobby. It showed what type of amendments would be taken today. Even they were complicated. Nevertheless, that is what we expected. Today the agenda is different. I have no doubt that many Members of Parliament here today are working on the principle that what they saw in the No Lobby yesterday will apply. Apparently, that is no longer the case... Furthermore we are dealing with an unusual procedure. It is not normal practice for the House of Commons. In the first place, the idea that the debate will continue until 11pm is unusual. From then on, a series of

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[34] *Ibid,* at p90 (emphasis added).

[35] For example, see House of Commons Hansard Debates for 24 April 1990, Column 170 per Mr Skinner

[36] *Ibid,* Column 179 per Mrs. Bottomley.

[37] For the debates on the 24 April 1990, there were so many options and amendments to vote on, the procedures became very complex. The proceedings became long and protracted and continued late into the evening.

> amendments will be put to the House. In many cases, which one is called will depend on which amendments have been carried."[38]

Many MPs voted in order to achieve a compromise: pro-life MPs could lower the time limit for most abortions if they excluded foetal abnormalities from the 24 week rule. Their aim was to reduce the number of abortions because it was unrealistic to expect that the Abortion Act 1967 would be revoked and all abortions prohibited. For example, Mr Alton stated:

> "Although I disagree on some of these issues, especially on the taking of life because of disability, I tried to move in the direction of those who hold diametrically opposed views so that we could try to reach a sensible arrangement about the upper time limits."[39]

Miss Widdecome provides further support to this point when she said:

> "I do not want to exempt all severe disability from the requirement... Many hon. Members had said that they would vote for a lower limit if and only if severe disability which could be detected by the amniocentesis test was excluded... We have always said that we believe in the exemption of severe handicap from whatever limits the House decides to impose, subject only to the requirements of the Infant Life (Preservation) Act." [40]

The Abortion Act 1967 s1(1)(d) in itself reflects societal values that construe aborting a 'disabled' foetus as more justifiable than aborting a 'normal' one. So much so that it is permissible to allow an abortion up until the birth for a disabled foetus. At 24 weeks the law recognises a constraint on the woman's freedom of action. Yet the law does not recognise the same constraints on the woman's actions if the foetus is disabled. Even using words like 'abnormality,' 'defect,' and 'recurrence risk' in connection with a given trait connotes a value stance.[41] Although the law governing the time limit for s1(1)(d)

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[38] House of Commons Hansard Debates for 24 April 1990, Column 170 per Mr Skinner.

[39] House of Commons Hansard Debates for 24 April 1990, Column 224.

[40] *Ibid*, Column 197.

[41] Kolker, A., Burke, B.M. *Prenatal testing: a sociological perspective* (Westport, CT, Bergin & Garvey, 1998) at p168 This is discussed in more detail in relation to the media analysis, later in this chapter.

came about inadvertently, it does not stop the law from expressing values about life with a disability. Disability is implied to be incompatible with life satisfaction.[42] In more recent parliamentary debates about abortion time limits, the possibility of reviewing the time limit for s1(1)(d) was raised by only one MP.[43] The Joanna Jepson case was used as a way to initiate debate about the lack of clarification of the definition of 'serious handicap' and to highlight the way in which values are reinforced by law.

3.2 The Joanna Jepson case:

In 2003, a Curate named Joanna Jepson pursued a case against West Mercia Police Authority for not prosecuting the doctors who performed an abortion for a cleft lip and palate after 24 weeks. Ms Jepson discovered the abortion whilst looking through the National Statistics on abortions.[44] Media reports claim that the abortion was performed on a 28-week-old foetus following a diagnosis of a bilateral cleft lip and palate by Dr Michael Cohn at Hereford County Hospital in December 2001.[45] She brought the case to the attention of West Mercia Police in 2002 believing that the doctors' actions were unlawful and that they should be prosecuted.

The reason given for the late abortion in this case was 'bilateral cleft lip and palate.' The terms 'cleft lip' and 'cleft palate' are often mistakenly used interchangeably, and both conditions are grouped together in official statistics.[46] It would perhaps be more accurate to list them as 'facial clefts' which encompasses both a cleft lip and a cleft palate. Cleft lips and cleft palates can vary enormously in their severity, both in width and length.[47] A cleft lip[48] creates an opening between the mouth and the nose, and can look as though there is a split in the lip. It can range from a slight 'notch' in the coloured part of the lip extending up and into the nose. Some babies who have a cleft lip may also have a cleft

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[42] This argument is explored in more detail in the Quality of Life chapter later in this thesis.
[43] House of Commons Hansard Debates for 19 July 2005, Column 403 per Caroline Flint.
[44] Available from www.statistics.gov.uk.
[45] Day, E. 'Curate postpones cleft palate late abortion action' *The Telegraph*, 09 May 2004.
[46] For example, Table 23 showing Legal abortions – numbers, principal medical condition for those performed under grounds E (s1(1)(d)) alone or with any other, 2000 available at www.statistics.gov.uk/dwnloads/theme_health/AB27/AB_No27_v1.pdf.
[47] Larsen, W.J. (2nd ed) *Human Embryology* (Churchill Livingstone, 1997).
[48] *Oxford Concise Colour Medical Dictionary* (2nd ed) (Oxford, Oxford University Press, 1998) defines a cleft lip as 'the congenital deformity of a cleft in the upper lip, on one or both sides of the midline. It occurs when the three blocks of embryonic tissue that go to form the upper lip fail to fuse and it is often associated with a cleft palate.'

in the gum. Again, that can either be a small split, or a complete division. The palate can also be affected by a cleft. In less severe cases, the soft palate towards the front of the mouth has a small split at the back of the soft palate. In more serious cases, there can be almost complete separation of both the soft and hard palate, further back in the mouth. Cleft palates[49] can also leave a baby with a small lower jaw, which can lead to breathing difficulties, a condition sometimes known as Pierre Robin Sequence. Often, a short operation to repair a cleft lip will take place before a baby is three months. The skin and muscles of the lip are rearranged to repair the split. Operations to repair a cleft palate using the tissues of the palate normally take place before a baby is one-year-old.[50] Some experts also argue that cleft lip and palate may be a marker for a multitude of severe congenital abnormalities.

Joanna Jepson's complaint is that a cleft palate does not constitute a 'serious handicap' and so could not justify a late abortion. She began legal proceedings against the police force after they failed to prosecute the doctors once they had investigated her claims. The police argued that following an investigation they were satisfied that the doctors had discussed the condition with the mother and it was decided that it justified an abortion. A High Court judge rejected the initial application for a judicial review in October 2002, but the application was renewed on 1 December 2003. On this attempt, Lord Justice Rose and Mr Justice Jackson gave Reverend Jepson permission to challenge in court the refusal of the police to prosecute. Mr Justice Jackson said "I am persuaded that this case does raise serious issues of law and issues of public importance which cannot be properly or fully argued in the context of a permission application."[51]

Joanna Jepson was born with a congenital jaw defect and had major surgery at seventeen to fix it. She said "I want to see a clarification of the law so that abortions do not take place for trivial reasons and so that discrimination against the disabled does not become widely accepted… People only see the negative side of disability. You only see

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[49] *Oxford Concise Colour Medical Dictionary* n.48 above, defines a cleft palate as 'a fissure in the midline of the palate due to failure of the two sides to fuse in embryonic development. Only part of the palate may be affected, or the cleft may extend the full length with bilateral clefts at the front of the maxilla; it may be accompanied by a cleft lip and disturbance of tooth formation.'

[50] For more information on this condition, see Wyszynski, D.F. (ed) *Cleft Lip and Palate: From Origin to Treatment* (Oxford, Oxford University Press, 2002); Rohrich R.J., Byrd H.S. 'Optimal timing of cleft palate closure. Speech, facial growth, and hearing considerations' (1990) 17(1) *Clin Plast Surg* 27-36; Ruding, R. 'Cleft palate: Anatomic and surgical considerations' (1964) 33 *Plast Reconstr Surg* 132-47.

[51] *Jepson v The Chief of West Mercia Police Constabulary* [2003] EWHC 3318 at para 16.

something that needs to be eradicated."[52] It seems therefore, that Ms Jepson did not mean to vilify the individual woman or doctor in this particular case, more she was unhappy with the state of the law on this issue. This case also highlights the way that people perceive values expressed by the law and by individual actions, and can see that disablist values can be harmful. By taking this case to court, she successfully introduced these issues into public debate. As a result of this case there has been wide press coverage and also coverage of the wider disability issues.[53] It also seemed for a while as if the government was considering changing the law in this area,[54] as was the shadow cabinet.[55] It is therefore apparent that Ms Jepson has successfully used the law to create a debate and influence the government and society.

Ms Jepson first agreed to postpone the case[56] after a request by the police who re-opened a criminal investigation into the case, and has now decided to drop the case. It has been reported that this was a result of the Crown Prosecution Service deciding that no

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[52] Day, E. 'The law is saying there are reasons why I shouldn't be alive. I look at my life and think: that's rubbish' *The Telegraph,* 23 November 2003.

[53] For example see Batchelor, W. 'Curate: Why I sued Police over 'Cleft Palate' Abortion' *The Scotsman*, 19 November 2003; Anon, 'Life and Limits it is time to look again at the law on abortion' *The Times*, 09 July 2004; Various authors 'Letters to the Editor: Abortion is a clash of rights' *The Sunday Times*, 11 July, 2004; Bale, J. 'NHS funding 'illegal' abortion' *The Times*, 11 October 2004; Bird, S. 'First round to curate in battle over abortion' *The Times*, 02 December 2003; Crompton, S. 'Life begins at...'*The Sunday Times*, 10 July 2004; Day, E. n.45 above; Dobson, R. 'Review of abortion law demanded after abortion for cleft palate' (2003) *BMJ* 327 1250; Driscoll, M., Rogers, L. 'To be or not to be - Does the Abortion Law need changing?' *Sunday Times*, 04 July 2004; Fiddian- Green, R.G. 'Might a morula have cognitive functioning equivalent to that of an adult?' 11 December 2003 Response to DOBSON, R. 'Review of Abortion law demanded after abortion for cleft palate' (2003) 327 *BMJ* 1250; Foggo,D., Edwardes, C. 'British Pregnancy Advisory Service helps women get illegal abortions.' *The Telegraph*, 10 October 2004; Furedi, A. 'Trust doctors on abortion, not lawyers' *The Guardian*, 02 December 2003; Gerard, J. 'Interview: Jasper Gerard meets Joanna Jepson' *The Times*, 07 December 2003; Harries, R. 'To let potential life develop is greater good' *The Times*, 12 September, 2002; Rogers, L. 'Rules may have been twisted in abortion of cleft palate babies' *The Sunday Times*, 11 July 2004; Sieghart, M.A. 'Opinion: Abortion rights and wrongs are all a matter of timing' *The Times*, 09 July 2004; Templeton, S.K., 'Law Review after abortion for harelip' *The Sunday Herald*, 02 November 2003; Templeton, S.K., Rogers, L. 'Abortion has gone too far, says man who changed law' *The Sunday Times*, 04 July 2004; Weyman, A., Scarisbrick, J. 'Pictures give fresh impetus to debate on abortion' The Times, 08 July 2004; Wise, J. 'British Public Supports Legal Abortion for All' (1997) 314 *BMJ* 627.

[54] Day. E. 'Abortion campaigners welcome MPS's change of heart' The Telegraph, 7 December 2003; Rozenberg, G., Nobbs, K. 'Abortion: How MPs' views changed' The Times, 09 July 2004; Webster, P. 'Cross-party abortion move to consider 24 week limit' *The Times*, 09 July 2004; Webster, P. 'Blair backs abortion review' *The Times*, 08 July 2004. However, to date nothing has come form this. The only legislation introduced in this area has been a private member's bill: The Prohibition of Abortion (England and Wales) Act (33).

[55] Jarman, A.B. 'Judicial review is hostage to purely political agendas' *The Times*, 24 May 2005; Hennessy, P., Kite, M. 'Howard pledges Commons vote over abortion time limit' *The Telegraph,* 20 March 2005.

[56] Day, E. n.45 above.

prosecution was warranted.[57] This is interesting because, if Ms Jepson was fighting for a change or clarification in the law, she would be best to take the case to court and having a judge to rule on the meaning of 'serious handicap.' It is probable that her postponing the action is more to do with her *locus standi* in this case. The major part of Ms Jepson's case was that the police had failed to investigate a potentially criminal act, if that is no longer the case following this investigation, it could be an insurmountable obstacle.

If the case had continued through the courts, it could have affected the way in which doctors are policed. Hansard shows that on 21 June 1990, Frank Doran MP told parliament that opponents of the Bill were scaremongering by suggesting that doctors would carry out abortions after 24 weeks for a cleft lip.[58] It is therefore expected that if the judicial review action is restored the lawyers for Jepson will argue in that abortion after 24 weeks for a cleft palate is a misinterpretation of what Parliament intended by 'serious handicap.' This case could have provided greater clarity as to the definition of 'serious handicap.' It also demonstrates how legal activity serves to bring expressed values into public view. The considerable press coverage this case received provides an opportunity for an examination of the image of disability portrayed in the media.[59]

3.3 The Expressivist Argument

Jonathan Glover explains the expressivist nature of selective abortion and PND by asking "What attitudes towards disabled people do these programmes express, and what message do they send to people who already live with these conditions? What does it do to your sense of being a valued member of society to realise that there are people who go

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[57] Gledhill, R. 'Curate loses legal challenge over cleft-palate abortion' *The Times,* 17 March 2004; Jarman, A.B. n.55 above; Jepson, J. n.24 above; Womack, S. 'Vicar loses court battle to prosecute doctors over abortions' *The Telegraph,* 17 March 2005.

[58] House of Commons Hansard debates, 21 June 1990, column 1188 per Frank Doran. Further evidence to support this point can be found in House of Commons Hansard Debates for 24 April 1990, Column 197 when Anne Widdecombe said *'Although we shall support the exemption because we said we would, we want to see the nature of the disability specified on the form, and we shall raise that again on report. On several occasions during the passage of his Bill, my hon, Friend the Member for Mossley Hill claimed that doctors were aborting for hare-lip and club-foot. Everyone sad "Oh nonsense – the medical profession would not do that."'*

[59] This will be discussed in more detail later in the chapter.

to great lengths to avoid the birth of someone like you?"[60] He then refers to a letter written by families of children with Down syndrome which asked:

> "Does British Society really want to make this statement to our children with the syndrome, and the many adults with it who are living independent, fulfilling and wonderful lives, that they shouldn't be here; they are such a burden that they should be eradicated before birth?"[61]

The Expressivist Argument therefore holds that there are practices and policies that express values, and that some values can be damaging to certain members of society. In the context of PND and selective abortion (which is the focus of this study), the argument contends that assumptions are implicit in the accepted practice of prenatal testing and the selective abortion of foetuses with detected impairments. Disability is a complex social construct and the way society constructs disability communicates signals regarding the value society places on its disabled members. People make the psychological links between reproductive genetic technologies and the value we place on people with disabilities. This does not have to be intentional on the part of parents making choices for the accumulative affect to be disablist.

The expressivist argument was first mooted, and disregarded, by Allan Buchanan in his work 'Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion.'[62] He explains it as: "The commitment to developing modes of intervention to correct, ameliorate or prevent genetic defects expresses (and presupposes) negative, extremely damaging judgements about the value of disabled persons."[63] Since then, many authors have become critics of this argument. Yet Buchanan only focuses on the second strand of the expressivist argument. He is not actually focusing on how values are expressed through these practices; instead he is questioning whether or not these values are disablist. Critics seem to break the argument down into components in order

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[60] Glover, J. *Choosing Children: the ethical dilemmas of genetic intervention* (Oxford, Oxford University Press, 2006) pp4-5.
[61] Gravell, C., Boyd, M., Slater, C., Tall, A., Duffin, L., Ridal, J., Robson, S., Ritchie, G., Hedges, R., Buckley, S. and 27 others 'Letter' *Independent,* 24 Oct 2003 referenced in Glover, J. n.60 above, at p33
[62] Buchanan, A. 'Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion' (1996) 13 *Social Philosophy and Policy* 18-46.
[63] *Ibid,* at p28.

to disprove it.[64] Despite these attempts, the argument, in various forms, remains one of the most popular arguments against the use of reproductive genetic technologies on the grounds of their disablist effects. Many disability rights activists still maintain the validity of the argument.[65] Regardless of the methods used to discredit the argument, it is still considered by organisations that consider bioethical issues.[66] The RCOG recognised the argument when it said that:

> "The recognition of seriously handicapping physical or mental abnormalities as a ground for termination of pregnancy does not imply that the life of seriously handicapped people is, like damaged goods, of diminished value or worth. Whatever measures may be justified as clinically necessary, and whatever the impairment which may beset the life of the born child, this intrinsic value or worth, is in no way diminished."[67]

Dr Tom Shakespeare used the expressivist argument when providing evidence for the House of Commons Select Committee for Science and Technology.[68] He said that developing a list of conditions which could be prevented by the use of RGTs "would send a very negative message to the thousands of people who are living with many of those conditions"[69] He went on to discuss abortion for foetal abnormalities and

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[64] For example, see Kittay, E.F., Kittay, L. 'On the Expressivist and Ethics of Selective Abortion for Disability: Conversations with My Son' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p167; Nelson, J.L. 'The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p197

[65] The most notable being Adrienne Asch. See Asch, A. "Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements" in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p234; Parens, E., Asch, A. 'The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) pp3-43; Asch, A. 'Prenatal diagnosis and selective abortion: a challenge to practice and policy' (1999) 89(11) *Am J Public Health* 1649-57; Also see Cameron, C., Williamson, R. 'Is there an ethical difference between preimplantation genetic diagnosis and abortion?' (2003) 29 *J Med Ethics* 90-92

[66] For example, the expressivist argument was rejected by the Nuffield Council on Bioethics report on behavioural genetics. See Nuffield Council on Bioethics *Genetics and human Behaviour* (London, Nuffield Council on Bioethics, 2002). The argument was rejected in the context of non-disease traits such as intelligence or sporting prowess. The validity of the argument was not considered in relation to disabilities.

[67] Royal College of Obstetricians and Gynaecologists n.2 above, at p9.

[68] Evidence given on 10 November 2004 and detailed in Hansard.

[69] House of Commons Select Committee on Science and Technology *Minutes of Evidence, Wednesday 10 November 2004* (London, HMSO, 2004) at Q1040.

> "the symbolic impact of a law which says that, as it were, you get human rights at 24 weeks unless you are disabled, in which case you do not get human rights until you are born and questionably after that, sends out a hugely damaging message to disabled people and to the wide community about the value of babies."[70]

The objection is that PND in this way discriminates against disabled people for various reasons, including their lives not being judged as equal to those people who do not have a disability.[71] These judgements fail to recognise the positive aspects of living with a disability.[72] Even if a disability involves suffering and/or limitations, it does not follow that this makes life not worth living.[73] There are considerable problems in selecting those genetic conditions, identified by testing, that would justify destruction of embryos and foetuses. Such selection necessarily requires that some forms of disability are considered to be more compatible with a worthwhile life than others. By expending substantial resources to determine the genes for some characteristics, but not others, health professionals reinforce society's negative views about what that disability means for life. They endorse the idea that these traits are not acceptable if they can be avoided and that people should not be born with these traits if women and couples have the means to prevent their birth. For example, there are subtle issues, raised by wrongful life cases, about whether the idea of harm or benefit can ever apply to bringing someone into existence. In considering which disorders should be avoided, conditions might be categorised on the basis of features such as whether it is likely to cause fatality at birth; whether treatment or cure is possible; the predicted degree of disability and dependence; the time of onset of symptoms or, alternatively, the period of time during which the individual could expect to be symptom-free; and the extent to which quality of life would be impaired. Other factors such as the cost to the healthcare system, might also be influential, but should not, by themselves, be decisive.[74]

Buchanan argues that for the expressivist argument to succeed as a convincing argument there is a need to demonstrate that the only reason women would opt for selective

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[70] *Ibid.*

[71] Cameron, C., Williamson, R. n.65 above.

[72] A whole chapter is dedicated to the analysis of quality of life judgements (see chapter 5).

[73] This point is explored in more detail in the QL chapter (chapter 5).

[74] Wood-Harper, J., Harris, J. 'Ethics' in Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996) at pp281-2.

abortion is because they do not value disabled lives.[75] It could be argued that there are many reasons for choosing to have a termination following a positive result from PND, hence the action may not be expressing any message except the level of burden that an individual can deal with. For example, some parents may have already had one child with a severe genetic disorder. If the child had a short and painful life, the parents may not want to impose such a life on another child. Or the earlier child may still be alive, and the parents may feel unable to cope with two children with the disorder. Or, parents planning their first child may choose, if possible, to have a child without the problems caused by even a relatively mild disorder.[76] Glover agues that choosing to have a child without certain disabilities need not come from any idea that disabled people are inferior. Nor does it necessarily entail the belief that the world, or the gene pool, should be cleansed of disabled people.[77] Nelson suggests other reasons such as "simply wish[ing] to avoid putting additional pressure on one's marriage or on one's family" or "one may wish to avoid putting additional pressure on limited social resources to support disabled individuals."[78] Yet these arguments still assume that living with a disability is a burden, either on the family or on society. They also assume that the place to look for expressivity is in the minds of the parents. This thesis will be showing that actually it is in the minds, literature and practices of the professionals who constrain parental choice by defining it within a rhetoric or structure of meaning that expresses disablist attitudes.

It is accepted that some women wish to end their pregnancy for reasons that do not seem to involve characteristics of the foetus, and would end any pregnancy. However, other women wish to end a pregnancy on the basis of a characteristic they believe to be possessed by the particular foetus they are carrying. This is the any/particular argument advocated by Adrienne Asch.[79] It is the latter case that is envisaged in the expressivist argument, that a woman, who would ordinarily want that child, rejects it after discovering that child is disabled. That child does not satisfy the criteria, or pass the test of what that couple expected their child to be. It is as if they are saying that this one fact 'trumps' everything else one could discover about the child-to-be, and says that the

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[75] Buchanan, A., Brock, D.W., Daniels, N., Wikler, D. *From Chance to Choice* (Cambridge, Cambridge University Press, 2000).
[76] Glover, J. n.60 above, at p28.
[77] *Ibid.*
[78] Nelson, J.L. n.64 above, at p198.
[79] For example see Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000); Asch, A. n.65 above.

woman/ couple cannot accept into her/their life a child with this characteristic when she/they planned to accept a child. This is an important point, because it is not that the couple do not want to have a child because of any social or economic reasons, or external circumstances. Rather they do not want this child because of something inherent to the child. The reason that determines the decision or tips the balance for having this child terminated is because it is disabled.

John Gillot argues that if parents choose to terminate an affected pregnancy they are making a judgement about impairment, and a guess about the life they, and a child with the particular condition would have, given the existing levels of medical knowledge and social support. That judgement is a *relative* one i.e. that life without the condition is better than life with it. Parents are not, as the caricature sometimes has it, saying that life with a genetic disorder is not worth living or is too terrible to contemplate. And certainly, they do not see themselves as making a moral judgement about the worth or rights of people living with a genetic condition. Rather, they are deciding for their own lives that they will 'try again' for a 'non-disabled' child or that they could not cope with a child with a disability. Parents perceive their choices as private decisions that directly affect their lives.[80]

There is, however, still an underlying assumption that having a disabled child will cost a family a lot more emotionally, financially, and socially. I do not think it is necessary to prove/ disprove the extent to which a child may be more of a 'burden' than a 'non-disabled' child.[81] However I would reiterate that many of the difficulties of disability result from society's inability to accommodate people with disabilities, rather than from an internal characteristic within an individual. If society was better adapted, the lives of disabled people would be easier.[82]

Glover highlights the need to send a clear signal that we do not have 'ugly' attitudes to disability. He says that it is "important to show that what we care about is our children's flourishing: that this, and not shrinking from certain kinds of people, or some horrid project of cleansing the world of them, is what motivates us. To think that a particular

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[80] Gillott, J. 'Screening for disability: a eugenic pursuit?' (2001) 27 suppl II *J Med Ethics* ii21-ii23 at ii22.
[81] QL judgements are discussed in detail in a later chapter (see chapter 5) and will challenge the negative assumptions made about life with a disability.
[82] As already described in the models of disability chapter (chapter 2).

disability makes someone's life less good is not one of the ugly attitudes. It does not mean that the person who has it is of any less value, or is less deserving of respect, than anyone else."[83] He states that one way to reduce the expressivist nature of RGTs in relation to disabled people is to realise that "disability is only one way in which flourishing is impaired. Poverty, bad housing or child abuse can do so at least as much. If we single out disability among the obstacles to flourishing, the ugly attitudes may seem to be lurking there. We have to take the other obstacles just as seriously."[84] Glover argues that this does not mean we should have programmes offering termination of pregnancy to parents who are poor or live in bad housing. He believes there are better ways of dealing with those problems. Yet he does not go so far as to recognise that there are better ways to 'deal with' disability other than abortion. This could be seen as an acceptance of the medical model; because he implies that poverty and bad housing are social problems where as disability is an individual problem. In this way, Glover could be accused of expressing the kind of 'ugly attitude' he warns against.

So far, the focus of this discussion has been demonstrating that the use of RGTs is based on disablist attitudes. It is now necessary to alter the focus slightly, and instead to highlight the way that these attitudes are consistently expressed through the structures of meaning that constrain PND, abortion and other medical services. If one looks at the way in which decisions are made that provide women with the choice whether or not to have PND and then a selective abortion, the expressivist argument can be demonstrated at many different stages of the process. Levels at which the expressivist argument works include:

- Legal Drafting. This has been shown through analysis of the Abortion Act and Hansard Debates.
- PND Policy. This could be explored through the analysis of the NICE guidelines.
- Medical Attitudes. These are expressed through the leaflets given to prospective parents (and are analysed in chapter 4)
- Individual Decisions
- Pressures on Individual Women (this is the basis for the IDM chapter)[85]

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[83] Glover, J. n.60 above, at p35.

[84] *Ibid.*

[85] Chapter 4.

Buchanan, Gillot and Nelson have all suggested that for the expressivist argument to work in practice, it is necessary to demonstrate that disablist attitudes are present in the minds of the prospective parents when they are deciding whether or not to use PND and abortion. They argue that the expressivist argument is true only if "as a matter of fact, one could only be motivated to make this judgement of the person ascribed to the judgement (i.e., that one could not psychologically make the decision if he or she did not believe to be true what the judgement affirms), or one cannot rationally make the decision without believing what the judgement affirms."[86] As an argument against expressivity, it has therefore been suggested that private decisions by women to use RGTs do not affect anyone else. If someone states her view about a life with a disability, she is talking about her *own* life. She does not criticize the standard of people living with that disorder. In other words, she does not pass judgement about what life means to them. She only says that she does not want to change places. Similarly, a woman choosing to use PND and selective abortion does not say that disabled people should not be born – but only that she does not want a disabled child. The practices of prevention look different to the disability community than to doctors and patients who engage in genetic testing. Since the latter will consider the confrontation with genetic disorders from a medical point of view, their focus will be on the limitations that a disabled life may bring. From the point of view of both the users and providers of these medical services, the crucial issue is free reproductive choice for people who want to protect themselves and their children against suffering. One genetic counsellor responding to a HGC consultation document said:

> "We live in a wide society where individuals have varying viewpoints. There will be some people in society who place a lower value on the lives of individuals, but this does not mean that it is a reflection of society as a whole."[87]

Yet private reproductive decisions do have ramifications far beyond the medical context of individual patients consulting their doctors, even if they tend to regard their decisions

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[86] Buchanan, A. et al n.75 above, at p274.

[87] Human Genetics Commission *Choosing the future: Genetics and Reproductive Decision-Making. Analysis of responses to the consultation* (London, HGC, 2005) at p25.

as private.[88] There are two components which explain why these reproductive decisions are not private:

a) the decisions are influenced by their cultural context, and
b) the decisions impact on, and in turn contribute to, that cultural context.

There is considerable evidence to suggest that the majority of women opt for PND and in the event of a positive result; the majority of women chose to have an abortion.[89] The practice of offering PND and selective abortion has built a culture which expresses disablist values: they signal that disabled people are not wanted, and it would be better if they were not born. Individual decisions are influenced by this cultural context and as a result the majority of women opt to use the procedures.[90] Using the uptake figures of the procedures as evidence, PND and selective abortion are seen as something women want,[91] and that health services should provide. As such, it can be seen that individual decisions reinforce a culture that expresses disablist values.

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[88] Reinders, H.S. *The Future of the Disabled in Liberal Society: An Ethical Analysis* (University of Notre Dame Press, 2000) at p75.

[89] For example see Modell, B., Petrou, M., Layton, M., Varnavides, L., Slater, C., Ward, R.H. et al 'Audit of prenatal diagnosis for haemoglobin disorders in the United Kingdom: the first 20 years (1997) 315 *BMJ* 779-84 discovered that 97% of pregnancies with foetuses diagnosed as homozygous (for thalassaemia or sickle cell disorders) were terminated.

Modell, B., Harris, R., Lane, B., Khan, M., Darlison, M., Petrou, M. et al 'Informed choice in genetic screening for thalassaemia during pregnancy: audit from a national confidential inquiry (2000) 320 *BMJ* 337-41discovered that there was an 80% uptake of prenatal diagnosis when offered among British Pakistanis, 35/48 (73%) agreed to prenatal diagnosis in the first trimester with 11/12 affected pregnancies terminated, compared with 11/18 (39%) accepting prenatal diagnosis in the second trimester, with 4/7 affected pregnancies terminated. This study, as well as showing a high proportion of affected pregnancies terminated, demonstrates that women are more likely to take risks in the early stages of pregnancy and find the decision to have a termination 'easier' the earlier in the pregnancy it is.

Ahmed, S., Saleem, M., Sultana, N., Raashid, Y., Waqar, A., Anwar, M. et al 'Prenatal diagnosis of beta-thalassaemia in Pakistan: experience in a Muslim country (2000) 20 *Prenatal diagnosis* 387-83 discovered that 47/53 (89%) of pregnancies affected with beta-thalassaemia were terminated, with 6/53 termination declined for religious reasons. It is important to note, however that this study was carried out in Pakistan.

Wald, N.J., Rodeck, C., Hackshaw, A.K., Walters, J., Chitty, L., Mackinson, A.M. 'First and second trimester antenatal screening for Down's syndrome: the results of the serum, urine and ultrasound screening study' (2003) 7 *Health Technology Assessment* 1-88 identified that of all the cases diagnosed with Down's syndrome, 71 pregnancies were terminated, 4 miscarried after amniocentesis and 26 resulted inn a live birth.

[90] This is demonstrated in the next chapter on decision making (chapter 4).

[91] A view shared by David Steele in his article Steele, D. 'Letters to the editor' *The Sunday Telegraph*, 14 December 2003.

Commitments to alleviate the difficulties arising from chronic illness and disability and efforts to promote healthy lifestyles throughout the population need not necessarily lead to a devaluation of the members of society who do not meet the typical understanding of health. Yet, as Tom Shakespeare explains:

> "I think there is a moral difference between reducing the impact of disability and preventing the birth of disabled people, and that is where lots of disabled people are very anxious and worried."[92]

Furthermore when attempts to prevent disabled lives are set "in the context that people with disabilities have indeed been subject to systematic segregation and second-class treatment in all areas of life,"[93] it is understandable that the choices made to prevent the birth of a child with a disability are seen to display the attitude that disability is negative, should be prevented and that disabled people are not valued in this society.

It was predicted by policy makers that most women would accept the offer of PND and abortion to prevent giving birth to a disabled child. There must have been an assumption that this trend would occur otherwise the technologies would not have been justified on a cost-effective rationale. The way the RGTs are marketed - as providing reproductive choice[94] - avoids the accusation of government interference in the realm of reproductive decision making and to thereby avoid criticisms of eugenics. The constructs of public and private should be seen as normative.[95]

> "Too often those who point to a public/ private dualism do so as if they are two discrete entities – that they are "out there", two almost natural realms – or even that they are fixed categories or value-free. What this ignores is the historical specificity of the conjunction, its relativity to time and place. Indeed different concepts of the private are sometimes used in tandem, and indistinguishably. Thus, it is clear that, in talking of the family as 'private', one is referring both to

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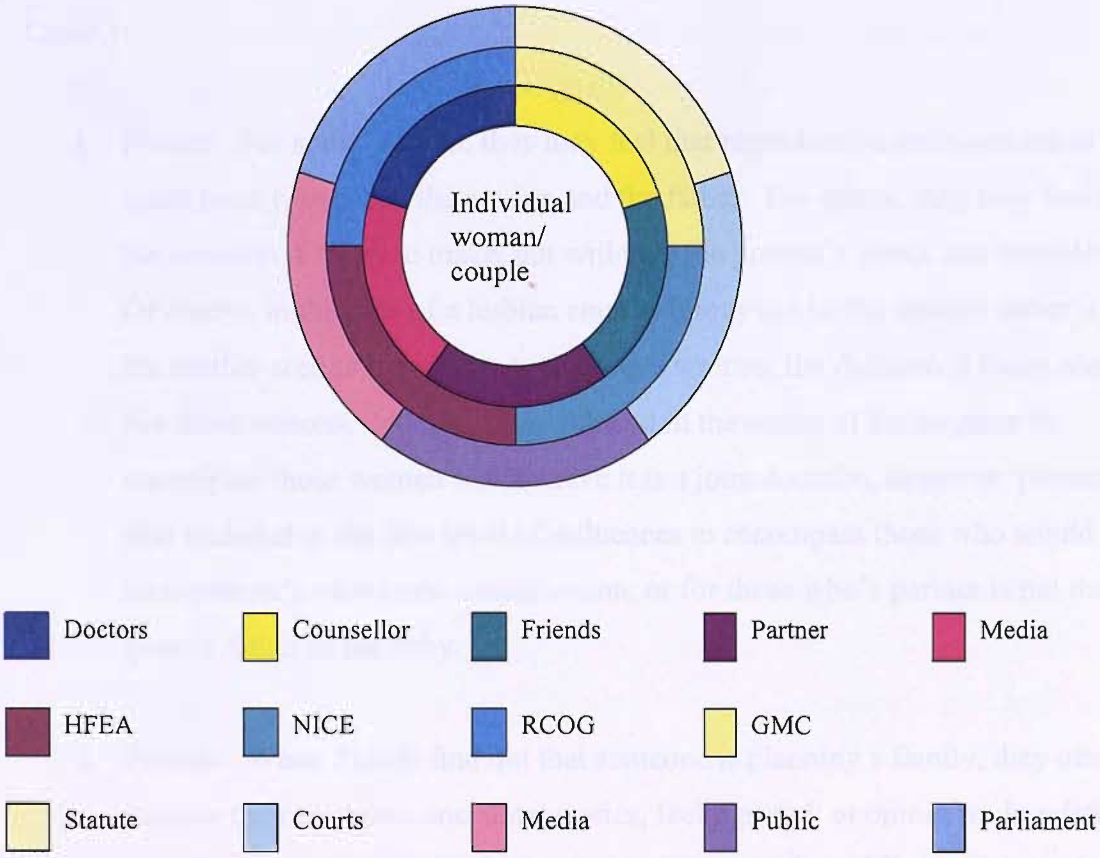
[92] Shakespeare, T. speaking at House of Commons Select Committee on Science and Technology *Minutes of Evidence, Wednesday 10 November 2004* (London, HMSO, 2004) at Q1038.
[93] Asch, A. n.65 above.
[94] The extent to which a real 'choice' is offered is the subject of the IDM chapter.
[95] Freeman, M.A. *Lloyd's Introduction to Jurisprudence* (London, Sweet & Maxwell, 2001) at p1131.

its being (supposedly) outside the authority of the state, and outside the scope of market relations. Neither is true."[96]

Liberals who favour autonomy for the private sphere often rest their case on freedom but, "the freedom of more powerful members... to exercise this power without restriction."[97] In the case of RGTs it is arguably the influence of the medical profession that has made their use unquestionably acceptable.[98] The argument in this thesis is that whilst the woman/ couple make the final decision whether or not to use the procedures, there is a whole series of external pressures that express disablist values and prevent that choice from being neutral.[99] After all, RGTs are offered within the remit of government policy, regulations, legislation and guidance from professional bodies. The following diagram is a simple way of illustrating this:

Fig. 7: influences on a woman/ couple making reproductive choices



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[96] *Ibid,* at p1130.
[97] *Ibid,* at p1131.
[98] This is discussed in more detail in the IDM chapter (chapter 4) and QL chapter (chapter 5).
[99] The IDM (chapter 4) and QL chapter (chapter 5) will prove this argument; this purpose here is to set out the hypothesis that will be tested throughout these chapters.

Explanation of Figure 7:

This diagram demonstrates the many sources of influence there are for a woman or a couple faced with making reproductive choices. The influences on the innermost circle represent those that may directly influence the individual woman or couple. As you move out through the circles, the influences become less direct and instead set the context in which the individual woman or couple makes her decision. The argument in this thesis is that these layers set the context in which individual women/couples make their decisions; the context set by lawmakers and professional rhetoric is disablist. The diagram aims to demonstrate the ways in which, although genetic reproductive choices are promoted as private decisions, many of the spheres of influence, and the ways in which these decisions are regulated are public. Each level of influences will now be examined in more detail. (The layers are again illustrated in the key to the diagram).

Layer 1:

1. Partner: For some women, they may feel that reproductive decisions are to be made jointly, between the mother and the father. For others, they may feel as if the decision is theirs to make, but will take the partner's views into consideration. Of course, in the case of a lesbian couple, it may not be the genetic father's views the mother sees as important, or for single women, the decision is theirs alone. For these reasons, 'couple' was included in the centre of the diagram to encompass those women who believe it is a joint decision, however 'partner' is also included in the first level of influences to encompass those who would take their partner's views into consideration, or for those who's partner is not the genetic father of the baby.

2. Friends: When friends find out that someone is planning a family, they often express their thoughts, anecdotal stories, feelings and/ or opinions. In relation to genetic reproductive technologies, opinions across the public vary enormously, and so it is possible that women or couples may be influenced by how their friends react.

3. Doctor: Doctors have an important role as gate-keepers of information.[100] Doctors/ genetic counsellors are meant to offer 'non-directive advice'.[101]

4. Counsellor: When a woman/ couple have to make a difficult reproductive decision, counselling will often be offered. This could directly influence them.

5. Media: At this level, it is possible to argue that the media portrayal of genetic reproductive technologies could directly influence the reproductive decisions made by women and couples.

Layer 2:

1. HFEA: The HFEA is a non-departmental Government body that regulates and inspects all UK clinics providing IVF, donor insemination or the storage of eggs, sperm or embryos. The HFEA also licenses and monitors all human embryo research being conducted in the UK.[102] The HFEA, through the issuing of licences can control the activities of doctors. This is in turn can affect the decisions made by individual women or couples. The HFEA make decisions on a case-by-case basis and so their decisions can directly affect women or couples. They also develop the code of practice and guidance that influences what services are received and how they are delivered.

2. GMC: The General Medical Council (GMC) was established under the Medical Act of 1858.[103] They have strong and effective legal powers designed to maintain the standards the public have a right to expect of doctors.[104] The GMC therefore sets standards of what the public can expect from their doctors. It is also responsible for disciplinary procedures within the medical profession. There are other professional bodies that have similar roles. For example the Chartered Society of Physiotherapists, the Nursing and Midwifery Council, the Health

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[100] The information given to women or couples, in relation to prenatal testing and screening is analysed as part of the IDM chapter (chapter 4) along with an exploration of the power-relations in the doctor-patient relationship in this context.

[101] The extent to which this is possible will be discussed in the IDM chapter (chapter 4).

[102] see www.hfea.gov.uk.

[103] Now regulated by the Medical Act 1983 (as amended by Statutory Instrument 2002 No. 3135).

[104] see www.gmc-uk.org.

Professions Council. The GMC, is used here as an example of an area of influence, as this diagram is not exhaustive.

3. RCOG: The RCOG is dedicated to the encouragement of the study and the advancement of the science and practice of obstetrics and gynaecology.[105] The RCOG issues guidance to its members, thereby setting standards for what patients can expect from obstetricians and gynaecologists. Again here, the RCOG is used as an example of an area of influence; other groups such as the Royal College of Midwives and the British Medical Association are other examples.

4. NICE: The National Institute for Clinical Excellence works on behalf of the National Health Service and the people who use it. They make recommendations on treatments and care using the best available evidence.[106] This can affect the reproductive decisions made by individuals, for example, NICE decides how many cycles of IVF treatment women should be offered on the NHS.

Layer 3:

1. Media: In this outer layer of the diagram, the media is included to represent the role it can play in setting the climate in which reproductive decisions are made. Until women/couples find themselves having to make these choices, they may have only heard of them through the media (or friends discussed above), this will provide them with the background with which they approach these choices.

2. Public: Society has a large role to play in reproductive decisions, in fact to a certain extent they are public decisions by the way the choices are regulated. This segment of the diagram represents the role the public plays, in electing parliament; in consulting with the regulatory bodies as they gage opinion of how choices should be regulated; in dictating the market for the media i.e. they report what sells papers/ attracts the viewers.

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[105] see www.rcog.org.uk.

[106] see www.nice.org.uk.

3. Parliament: Parliament is where laws are debated and enacted in the form of statutes. In this context Parliament refers to the debates and the influence that these may have an individuals.

4. Statute: Reproductive decisions are regulated by statutes which must be adhered to. This will influence decisions individuals make, because their actions are restricted by the law in this way.

5. Courts: The courts are able to review any government action through judicial review, this would include the decisions made by the HFEA and NICE. In addition cases can be brought against bodies such as the GMC and their guidelines challenged.[107]

The individual woman/ couple are not the only people influenced by the above parties, it is also important to highlight that the various parties influence each other. Not only do the layers have influence over the policy relating to RGTs, but equally as important for the purposes of this study, is an exploration of their attitudes towards and ways of thinking about disability. No matter which party is located in the centre of that diagram, it becomes evident that they are all affected by disablist values expressed in the surrounding layers of influence.[108]

One area of influence that deserves particular attention here, is the guidance provided by the RCOG on the issue of interpreting the term 'serious handicap' in s1(1)(d). This will illustrate how the imprecision of the law gives space for disablist attitudes to be expressed in informal guidance and such guidance can be relied upon by doctors, courts, parliament and all the organisations in level 2.[109]

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[107] As was the case in *R (on the application of Burke) v General Medical Council* [2004] EWHC 1879; [2005] EWCA Civ 1003. This case is discussed in detail in the QL chapter (chapter 5).

[108] This will be seen in the IDM chapter (chapter 4) and the QL chapter (chapter 5) where the values expressed by health professionals and lawmakers are challenged.

[109] The reliance of courts and parliament on doctors' advice will be seen in detail in the QL chapter (chapter 5).

The RCOG interpretation of 'serious handicap'

The term 'serious handicap' has never been defined. In 1996, the Royal College of Obstetricians and Gynaecologists published guidelines called *Termination of Pregnancy for Fetal Abnormality.*[110] This document explored the meaning of the terms in s1(1)(d). The RCOG explains that "the medical practitioners have to judge whether the abnormality would be likely to result in 'serious handicap.'"[111] Yet they recommend that "Judgements should be cautious, recognising that it is not possible to give an authoritative view of the meaning of 'seriously handicapped' as this has not been interpreted by the courts."[112] As already explained, the Joanna Jepson case could have provided authoritative guidance, however this case did not come to court.[113] It is important to explore the guidance provided by bodies such as the RCOG, as if a case did come to court; such guidance could inform the decision.[114] Indeed it is reported that the RCOG guidance was relied on by the CPS when they made the decision not to prosecute the doctors in the *Jepson* case.[115]

In this guidance, the RCOG refer to the WHO's ICIDH.[116] To reiterate, the WHO defined disability as "... 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." Furthermore, they recommend the use of the WHO scale of the severity of disability. Only individuals with disability at the third or higher points of the scale would be considered by most people to be seriously handicapped. Points 3 and 4 are defined as follows:

3. "Assisted performance. Includes the need for a helping hand (i.e: the individual can perform the activity to sustain the behaviour, whether augmented by aids or not, only with some assistance from another person).

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[110] Royal College of Obstetricians and Gynaecologists n.18 above.

[111] Royal College of Obstetricians and Gynaecologists n.18 above, at para 3.3.1.

[112] *Ibid,* at para 3.3.3.

[113] The role of lawmakers in the expression of disablist values is discussed in detail in the QL chapter (chapter 5).

[114] For a discussion of the reliance of the courts on doctors, see the QL chapter (chapter 5).

[115] See newspaper articles already referred to n.49 above.

[116] World Health Organisation *International classification of impairments, disabilities, and handicaps* (Geneva, WHO, 1980) discussed in detail in the previous chapter relating to models of disability (chapter 2).

4. Dependant performance. Includes complete dependence on the presence of another person (i.e. the individual can perform the activity or behaviour but only when someone is with him most of the time)."

The RCOG conclude that

> "A person is only likely to be regarded as seriously handicapped if they need the support described in WHO Points 3 and 4. However, an opinion that a particular abnormality would be associated with serious handicap should be based on a careful consideration of the following factors, not all of which will be relevant in every case.
>
> These are:
>
> - the probability of effective treatment, either *in utero* or after birth;
> - the probable degree of self-awareness and of ability to communicate with others;
> - the suffering that would be experienced
> - the extent to which actions essential for health that normal individuals perform unaided would have to be provided by others"[117]

As already discussed in the previous chapter relating to models of disability, the ICIDH is widely criticised for incorporating the medical model of disability. The WHO has revised their reliance on this model, and developed the ICF in 2001 in an attempt to incorporate more elements of the social model, yet the RCOG has not revised its guidance in line with this shift. Indeed it is clear from the above quote that they situate the problem of disability within the individual. The RCOG published a report from their Ethics Committee in 1998 called *A Consideration of the Law and Ethics in relation to Late Termination of Pregnancy for Fetal Abnormality.* This document provided examples as to when it would be acceptable to perform an abortion under s1(1)(d) *in the interest of the foetus.* From these examples, the following principles can be drawn:

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[117] Royal College of Obstetricians and Gynaecologists n.18 above.

- For conditions that are not lethal, but the outlook for the baby is very poor and would fulfil criteria allowing non-treatment or withdrawal of treatment of handicapped neonates on the basis of "life being so demonstrably awful."[118] If a case fulfils criteria for non-treatment after birth, it would have been reasonable to have considered terminating the pregnancy.[119]

- Down Syndrome is a severely handicapping mental condition with an IQ usually varying between 50-80. Generally, it is not associated with mental or physical suffering on the part of the affected person. Children and adults with Down syndrome can form relationships. Their life expectancy may be as much as 60+ although they are seldom able to live unsupported. As it is the commonest cause of congenital mental handicap, screening programmes are available for women to find out their risk of Down syndrome and to have a diagnosis made. Termination is available for an affected foetus.[120]

- Some specialists in foetal medicine are willing to offer later termination for 'Down Syndrome plus,' for example, if there is an associated cardiac or gastrointestinal abnormality (although these may be correctable). Since a Down Syndrome child would usually be treated as any unaffected neonate and be given life saving cardiac or gastrointestinal surgery, it is questionable, ethically and legally, whether it is acceptable to terminate for 'Down Syndrome plus.'[121]

- The factors of biological variability and medical uncertainty would make it inappropriate to draw up a list of conditions in order of severity that would enable practitioners to know which were seriously handicapping and thus leally or ethically acceptable, and which were not.[122]

- There is an ethical imperative to judge cases on their individual facts and merits.[123] The QL chapter (later in this thesis) will demonstrate the impossibility

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[118] *Re J* (a minor) [1991] Fam 33; *Re C* [1990] Fam 26; *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 W.L.R. 1421.

[119] Royal College of Obstetricians and Gynaecologists n.2 above, at p12.

[120] *Ibid,* at p13.

[121] *Ibid.*

[122] *Ibid.*

[123] *Ibid,* at p14.

of judging QL objectively and that when QL judgements are made prejudicial views inevitably creep in. This is an example of a way in which individual cases are sufficiently interconnected and as such cannot simply be judged solely on individual facts and merits. To do so would be blind to the bigger picture, and in turn contribute to it.

- "There is a difficulty in comparing objective judgement of function with the subjective suffering that might influence parental attitudes. There might be delight at having a child even though handicapped, or there might be despair at having a child with grave problems. Other people's attitudes have influence, and there is always the question whether facilities to help rearing would be available and accessible."[124] This is an interesting paragraph of the guidance for two reasons. Firstly, it recognises that parents may either experience delight or despair at the thought of having a disabled child, yet in the previous sentence there is the assumption of suffering.[125] Secondly, there is a recognition of the social model – evident through the mention of the influence of people's attitudes, and the failure to provide services that disabled people. However, the elements of the social model are then dismissed as not significant.

The Committee also considered that the following factors might influence the ethical weighting which will be involved in decision making:

a) The *suffering of the child.* This might involve pain and repeated operations, poor quality of life in severe cases, and awareness of difference and of discrimination if intelligence is normal. Yet life could be very fulfilling in milder cases.[126] This presumption of suffering is rebutted in the QL chapter.[127]

b) The *suffering of the mother.* Two types of suffering may be considered: on one's own behalf (disappointment, undue strain in caring with the risk of diminished care of siblings, demands of extra work, resentment of unwanted child) and in

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[124] *Ibid,* at p15.

[125] The presumption of suffering is discussed in more detail in the QL chapter later in this thesis.

[126] Royal College of Obstetricians and Gynaecologists n.2 above, at p15. There is a more detailed discussion of the presumption of suffering in the QL chapter.

[127] Chapter 5.

empathy with the child (watching the cumulative operations and observing the struggles and developing self-awareness and apprehension).[128]

c) The *burden on others*, in effect the wider family or the State, can be measured only in relation to the provision made by the community for the assistance of mothers bringing up children with special needs: provision of services or of social or financial support. In a wealthy country, State provision is determined by political will. It might be held that the principle of compassion, as well as the public interest in the preservation of life, should prompt such generosity as would remove the prospect of hardship from the number of adverse factors which lead to a request for termination.[129] That this factor is included and could influence the 'ethical weighting,' undermines the rhetoric of 'choice' which PND is offered under in order to defend against accusations of eugenics.[130]

d) *Severity of handicap*… does not diminish moral worth. It complicates the balance of moral claims by weighting the scale on one side against the other. The new legal liberty of later termination for grave foetal handicap brings more consistency between late obstetric practice and acceptable neonatal practice.[131] Whilst the RCOG is keen to argue that 'handicaps' do not 'diminish moral worth,' this is not consistent in the context of the comment.

Interestingly, the RCOG argue that a diagnosis of foetal abnormality "may lead to psychological harm or mental illness in the mother if she unwillingly continues the pregnancy with a baby that is diagnosed abnormal, delivers an unwanted child, and then has the difficulty of rearing, or sending for adoption, a baby who is handicapped."[132] However this raises the question of whether or not there is any need for s1(1)(d), as abortions to protect the mother's mental health are covered by other sections of the Act.

The way society constructs disability demonstrates the value society places on disabled people. There is an intrinsic connection between law and societal values. The values

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[128] Royal College of Obstetricians and Gynaecologists An.2 above, at p15.
[129] *Ibid.* at p16.
[130] This is discussed in more detail in the IDM chapter (chapter 4).
[131] Royal College of Obstetricians and Gynaecologists n.2 above, at p16.
[132] *Ibid.* at p10.

that are expressed at various stages of the processes already outlined[133] will be considered in detail. This will be done through the analysis of several small research projects, each intended to demonstrate the disablist attitudes of decision makers. This thesis, by using a number of foci, will demonstrate that no matter where the starting point is, it is possible to observe expression of disablist values. Media analysis in the form of analysis of the Times newspaper will be undertaken in order to identify the way in which issues are framed for the public. In the informed decision making chapter, analysis of NHS leaflets provided to prospective parents will be performed in order to explore the information provided about the use of reproductive genetic technologies and the disabilities they seek to prevent. Finally in the quality of life chapter, case law will be analysed to identify the approach taken by the courts and Hansard will be focused upon in order to draw out the way in which MPs approach the issues. The latter has already been demonstrated in relation to models of disability; however it is also imperative for the purposes of this study to focus on the debates around RGTs. These research projects all aim to demonstrate the framework within which private decisions are made, and that it is a framework that remains dominated by the medical model of disability. Whilst this is not necessarily done consciously or deliberately, the prevailing attitudes remain disablist and furthermore, this attitude is then self-reinforcing.

The previous chapter has analysed the academic discussion of models of disability and illustrated the impact the law can have when conceptualising disability into a coherent framework. Media analysis can highlight the way disability is constructed in the context of RGTs by demonstrating the values placed on disability by society. When looking at the image of disability portrayed by the media it becomes apparent that these are general issues in society as opposed to an issue peculiar to commentators. To prove the expressivist argument it may matter just as much what people think is happening than a point of law. As such the 'cultural reception' can reflect society's views of disability. The public debate has been largely shaped around what technology has to offer with regard to genetic disease. This has been based on the medical model of disability which can be demonstrated through an analysis of the disablist language used. The terminology used in the media reflects the cultural perceptions of disability.

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[133] See fig. 7.

3.4 Disability terminology in the media: a comparison of newspaper reports appearing in the Times between 1965 and 2003

3.5.1 Background

This study aims to prove that the expression of disablist values is pervasive. It is hoped that such analysis will demonstrate that this thesis is not just an analytical exercise of legislation; instead, these issues have an impact in the 'real world.' The thesis will then develop to consider the way in which real people's decisions are structured by disablist attitudes in the IDM chapter. In this way, the focus of this study on RGTs will be looking at the 'macro-cultural' context through media analysis as well as 'micro-cultural' context by exploring individual decision making. The way values are indicated in the media helps reveal that wherever you look you can see an expression of disablist values.

The main objective of this media analysis was to identify the changes in the way in which prenatal testing and selective abortion was reported in the popular press over time. The hypothesis was that although the subject matter would stay the same, the context in which it was discussed would have changed. Discussion of the methodology of this small scale study is included in Appendix A.[134] Briefly, the Times newspaper was analysed in five yearly intervals from 1965 to 2003,[135] focusing on articles indexed under certain categories (e.g. abortion). The terms used to describe disability (e.g. deformity) in each article were identified and listed, and specific medical conditions (e.g. Downs Syndrome) referred to were also recorded.

The language with which we refer to people reflects our perceptions of those people and may even influence the way others perceive them. Negative references with regard to disabled people have been termed 'disabling language' as they may serve to perpetuate negative myths and stereotypes. The terminology used to describe disability is important as it can signal to society the value it places on disabled people. There has been an historical trend of using terms to describe disabilities or disabled people, as taunts or insults. For example, someone who fails to notice something important will be called 'blind;' or someone who fails to hear something is 'deaf;' or someone who fails to

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[134] It is situated here to ensure that the argument is not interrupted with discussions of methodology.

[135] Articles therefore taken from the years: 1965, 1970, 1975, 1980, 1985, 1990, 2000, 2003.

understand something is a 'retard.' Such attacks feed back to our images of disabled people because language plays a key role in constituting our perceptions and so using impairments as terms of insult generalises and exaggerates the effect they are seen as having.

It is important to examine the institutional and cultural context in which terms are constituted and used. Labels tend to be used strategically to achieve particular contextually bounded outcomes. For example, in his work *Madness and Civilisation,*[136] Foucault drew attention to the work of professional bodies in constituting a range of pathologies. Such professionals need technological, administrative and architectural resources to perform their tasks of categorising and treating people. Far from engaging in value-neutral procedures for measurement and treatment, psychiatry reflects social and cultural prejudices.[137]

Disabled people have deployed two main strategies in the struggle to resist offensive disablist terminology. These can be described as 'positive naming' and 'defiant self-naming.'[138] Positivist naming deploys terms which either have positive connotations or which confine the negative aspects of terms to a specific impairment – rather than allowing it to engulf the disabled person's whole identity. For example, some disabled people talk of being 'differently abled,' rather than being 'disabled.' Another example of the positive naming strategy can be found in the Spastic Society's decision to change its name to Scope. The reason for this was because the term 'spastic', originally purely a medical description of the condition of Cerebal Palsy, had become contaminated with highly offensive connotations. The term 'handicap' has been rejected by many commentators in favour of impairment because of the patronising connotations of being 'cap-in-hand;' that is, of begging.

Scope offers a list of 'positive' and 'negative' words, for example they suggest that 'people with disabilities' and 'disabled people' are positive whilst 'the disabled' and

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[136] Foucault, M. *Madness and Civilisation: A History of Insanity in the Age of Reason* (London, Tavistock, 1965).

[137] Marks, D *Disability: controversial debates and psychosocial perspectives* (London, Routledge, 1999) at p143.

[138] *Ibid,* at p145.

'cripples' should be avoided.[139] It is arguable that there is no positive way of describing a disability, as people will automatically interpret whatever word is used as confirming their negative preconceptions of what a disability is, usually based on ignorant prejudices. Yet the idea of the positive language debate is that it suggests a change in terminology which alter perceptions of disabled people by focusing on capacities rather than limitation, and differences rather than deviance.[140]

How much of a difference can linguistic alterations really make? For example, as briefly described in the introduction chapter, 'people with disabilities' is preferred in some circles as it is an attempt to put the person first, because it is assumed that the impairment is so negative that it eclipses personhood. It is questionable whether or not a linguistic alteration really overcomes this difficulty. Alternatively, others prefer to refer to 'disabled people' thereby confirming that the person is disabled by the society in which they live. How can journalists be expected to use non-offensive terminology when even the most positive terms may cause offence to some? Is it not naïve to believe that language change on its own can bring about social change? Maybe when it comes to national media and disseminating information to the public, the way in which disability is portrayed and described can make a difference.

If one looks at the history of the term 'special educational needs,' it is possible to track the changes in terminology preferred. Originally referred to as 'subnormal,' then as a 'mental handicap,' this changed to a 'learning disability' and most recently has been changed to 'special educational needs.' At each stage, the preceding terms were seen as oppressive. Changes in terminology can reflect a process of euphemism rather than a change in the underlying assumptions. It is also true that as new policies are developed, new terms are created to help separate the future from the past. This may especially be the case in the field of disability where there is such a strong historical background of suppression, stigmatization and discrimination.

Perhaps the constantly changing terms expresses a desire to make the impairment go away. By changing the term every time we become uncomfortable with the meaning

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[139] For more information see the Scope website: www.scope.org.uk.

[140] This was briefly discussed in the context of 'universalism' in the models of disability chapter (chapter 2).

behind it, we change the term rather than accepting the characteristics of the impairment. The different terms used can become code words, for example 'special educational needs' still refers to mental handicaps, and because of society's prejudices, SEN will soon become a school ground taunt and become contaminated with negative connotations. Indeed it could be seen that there is already a negative connotation involved by using the term 'special.' Instead of changing the language we use to describe disability, we should familiarise ourselves with what disability means and encourage acceptance of it rather than avoidance of the issues.

Throughout history, disabled people have been victims of discrimination and exclusion in various ways, precisely because they were regarded as 'abnormal.' Any major struggle against discrimination in recent history has been a struggle against judgements grounded in reasons of this type.[141] The suggestion that disabled people fail to qualify as normal in the full moral sense of that term contrasts strongly with the goal of accepting them as equally respected members of our society.[142] To obtain this goal society has implemented legal and social policies of integration and normalization. In view of these policies, classifying disabled people as somehow 'defective' is at odds with the moral convictions and beliefs that underwrite them.[143]

Labelling occurs in order to see whether particular people fall under particular regulations or should have access to particular services.[144] The labels given have clearly changed overtime. Even if one is to discard such issues as merely responding to political correctness, they nevertheless testify to the upward mobility of disabled people in the public frame of mind. To change a label such as 'mentally retarded' is to indicate that in using it one betrays a lack of respect for the people so designated. Shifting terminologies are indicative of shifting patterns of inclusion. This is true even though the continuing change in labels is largely a matter of political correctness, since it shows what the publicly accepted standard is: disabled people ought to be treated with equal respect.[145]

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[141] Reinders, H.S. n.88 above, at p71.

[142] As already discussed, this is an objection to s1(1)(d) Abortion Act 1967.

[143] Reinders, H.S. n.88 above, at p72.

[144] This was discussed in the models of disability chapter (chapter 2) in the context of developing a definition of disability.

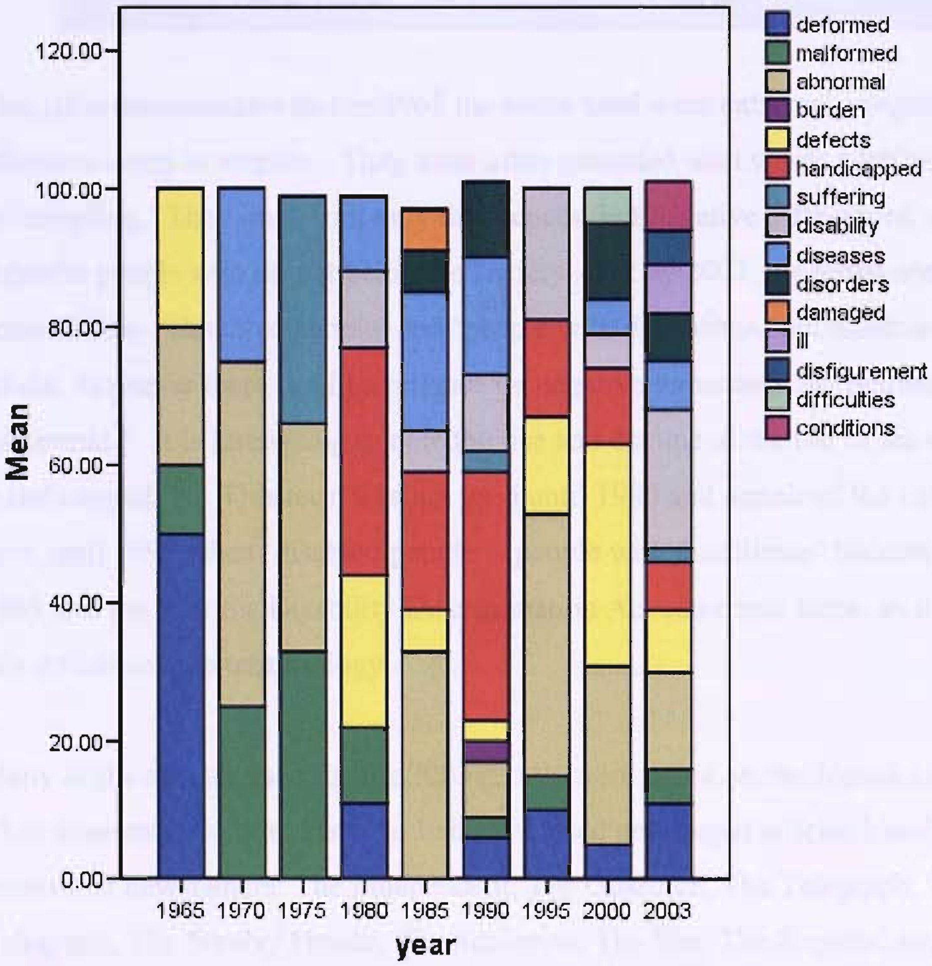
[145] Reinders, H.S. n.88 above, at pp72-3.

3.5.2 Discussion of findings:

Between 1965 and 2003 many different words were used to describe disabled people, or their impairments. The context in which these were terms used was mainly associated with congenital disabilities in the context of abortion, prenatal testing, pre-implantation genetic diagnosis and screening.

There was clearly a dominance of negative terms to describe disability. This can be seen in the following graph:

Fig. 8: A graph to show the % of different descriptions per year
syndrome



The changes in the terms used can be highlighted in the following table that contrasts the terms used in 1965 with those used in 2003:

Fig. 9. Table to show the % of articles using different terms to describe disabilities and disabled people in 1965 and 2003.

Term	**1965**	**2003**
Deformed/ deformities	50	11
Abnormal/ abnormalities	20	14
Defective/ defects	20	9
Malformed/ malformations	10	5
Handicapped	0	7
Suffering	0	2
Disabled people/ people with disabilities	0	20
Diseases	0	7
Disorders	0	7

This table demonstrates that in 1965 the terms used were extremely negative and offensive terms to employ. They were often preceded with words such as 'grave,' 'fatal,' or 'crippling.' They imply not only differences, but negative differences, shameful, regretful people who do not belong to society. Yet by 2003, the terms used had changed considerably. 'Disabled people' and 'people with disabilities' are much more positive labels. However there is still a reliance on negative terms such as 'deformed' and 'abnormal.' It is interesting to note the rise and decline of the use of the term 'handicapped.'[146] This term was not used until 1980 and remained the most common term until 1995 when 'disabled people'/ 'people with disabilities' became more popular. 1995 was the year the Disability Discrimination Act came into force, so it is possible that this influenced the terminology.

Many of the articles used for the 2003 results were based on the Jepson case.[147] This was a key case-study in this thesis, so I also analysed newspaper articles based on this case from other newspapers: The Independent, The Guardian, The Telegraph, The Sunday Telegraph, The Sunday Herald, The Scotsman, The Sun, The Express, and The Daily Mail. The reporting of this case continued in 2004 and 2005 and so these articles were

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[146] As is evident in fig.8.

[147] This case has already been discussed in this chapter. The number of articles in 2003 can be seen in appendix A. Fig. A and the % of those relating to cases can be seen in appendix A. fig. C.

collected and analysed as well. I approached the analysis of these articles as an examination of a social event and an opportunity to examine the way the case was discussed. The case demonstrates how legal activity can bring expressed disablist values to public attention so I was interested to see if the values in the newspaper articles were disablist. The articles referred to in the following discussion aim to be illustrative rather than representative of all newspaper reporting on this case. Many of the articles analysed appeared in *The Telegraph* and *The Sunday Telegraph*.[148] These papers followed the case keenly. However it should be acknowledged that *The Sunday Telegraph* had donated money to Jepson's campaign. A key factor in that decision was that the editor, Dominic Lawson, has a daughter with Down's Syndrome .[149]

I analysed 43 articles about the *Jepson* case.[150] Every article (except one, which was a brief letter from a reader) referred to Ms Jepson's career as a curate. This was interesting because she was not taking the case on behalf of the Anglican church. Abortion is an emotive subject and religious discussion often forms part of the debate. This is possibly the explanation behind the constant references. Ann Furedi (of BPAS)[151] used Jepson's career to imply that this was religious extremism interfering in private decisions.[152] Much was also made of the fact that Jepson herself was born with a congenital jaw defect,[153] and that her brother has Down's Syndrome.[154] Whilst these points, along with her religion may have informed her view of abortions for foetal abnormality, they were arguably not instrumental in the legal case she was initiating.

I was interested to explore the way the newspaper articles dealt with the issues arising from the case. Many reported on the progress of the case with little reference to the implications of it. When the question of whether or not facial clefts constitute a 'serious handicap' was raised, most emphasised the minimal impact of the condition and the way that it could be repaired through surgery. For example some talked of a cleft palate being a "trivial reason"[155] to have an abortion. An article in *The Telegraph* said:

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[148] 18 of the 43 articles analysed for this study.

[149] Womack, S. 'A disfigured child who grew up to defend the right to life' *The Telegraph*, 02 December 2003.

[150] The references can be found in the bibliography at the end of this thesis.

[151] The British Pregnancy Advisory Service, whom offer abortions.

[152] Furedi, A. n.53 above.

[153] Of the 43 articles read, 33 of them mentioned this and some repeated the point several times.

[154] Of the 43 articles read, 26 of them mentioned this.

[155] For example see, Anon, 'Curate wins abortion challenge' *The Daily Mail*, 01 December 2003.

> "It is worth noting that this condition is now easily remediable: the notion that a "serious handicap" now includes facial abnormalities which can be straightforwardly corrected is horrifying."[156]

An article in the Daily Mail reiterated that "with surgery, these children can live perfectly normal lives. It's treatable and it doesn't interfere with their development in later life."[157] One letter from a reader who worked in a neonatal unit said "Most if not all neo-natal units have "before and after" photographs showing the remarkable results of surgery, and these children go on to lead perfectly normal lives of good quality."[158]

This in itself is interesting because they suggest that it is only possible to live a 'normal life' after the surgery. This could be because of the stigmatisation that people with facial disfigurements experience. This is recognition of the social model of disability. Jepson herself was keen to talk about the stigmatisation and negative attitudes towards her that she experienced before her surgery:

> "My teenage years were difficult because of facial abnormality. I live a positive and fulfilling life."[159]

> "All through my teenage years, my self-perception was shaped by my looks. There was a pecking order of attractiveness and I was right down at the bottom. That all changed. I feel like the ugly duckling turned prom queen."[160]

However, although Jepson believes she is challenging society's obsession with physical perfection, she can be seen to perpetuate it by referring to herself as an ugly duckling before surgery, and a prom queen after. In the same article she refers to a photograph of herself before the surgery and says "I look like a chipmunk in that first photo."[161]

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[156] Anon, 'Joanna fights for us all' *The Telegraph,* 30 November 2003.
[157] Laing, L. 'Hope to babies with cleft palates' *The Daily Mail*, 09 December 2003.
[158] Sparshott, M. 'Unpardonable termination' *The Telegraph,* 30 November 2003.
[159] Womack, S. 'Curate's victory on cleft palate abortion' *The Telegraph*, 02 December 2003.
[160] Day, E. n.52 above.
[161] *Ibid.*

Here it becomes clear that one of the reasons for the extensive press coverage was an interest in Jepson herself, not just the case she was pursuing. The press coverage becomes a 'human interest' story: girl with facial disfigurement, bullied as a teenager becomes a beautiful curate on a mission to right the wrongs of the world. Many articles included pictures of her, an attractive lady (in a white collar) smiling. In this way she was portrayed as someone who herself was born with a jaw defect but is now 'normal' after simple surgery. One article said:

> "Her green eyes and girl-next-door appearance belie the facial disfigurement with which she was born and that underscores her attitude to life today."[162]

Another article described part of a meeting the reporter had with Jepson:

> "There are two photographs at the bottom of the dusty shoebox. One of them, its edges curled with age, shows a skinny teenage girl in a white lace blouse. Her mousey hair curls down her back. She has an awkward half-smile. But the profile shot reveals a protruding upper jaw and sunken chin. The second one taken years later of the same girl. She is laughing through long, blonde hair; she has high cheekbones, shining eyes and even features."[163]

Because of the focus on the life opportunities that someone born with a cleft palate can enjoy, the focus of the issue can be seen as a discussion about facial clefts as impairments that need not be disabilities. Although a facial cleft can arguably be a 'physical abnormality'[164] someone with a facial cleft would not necessarily be 'seriously handicapped.'[165]

Jepson believed her campaign was about more than just highlighting one abortion for a cleft palate. She wanted to challenge the way people think about disability. She was reported to have said that "People only see the negative side of disability. You only see it as something that needs to be eradicated."[166]

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[162] Womack, S. n.149 above.
[163] Day, E. n.52 above.
[164] Taken from s1(1)(d) Abortion Act 1967.
[165] The words of s1(1)(d).
[166] Day, E. n.52 above.

One reader understood the wider implications of her argument: "Ms Jepson's views are that many disabled people are only prevented from having a full life by the prejudice of others. If this prejudice results in the termination of foetuses with cosmetic "abnormalities," then we are in trouble as a society. This opinion is not an absolute, but it reflects our law as it stands."[167]

Jepson was also keen to talk about her brother with Down's Syndrome thereby implying Down's Syndrome should be considered similar to facial clefts. For example, she is reported to have said:

> "I find the [government's] decision to screen every pregnant woman for Down's Syndrome very difficult to deal with because it will lead to more abortions of Down's Syndrome children."[168]

This was not a very successful part of her campaign because whilst many articles picked up on her brother having Down's Syndrome, none of them suggested that it would not constitute a 'serious handicap.' Again, this implies it is the possibility of remedial surgery that sets cleft palate abortions aside from those for other disabilities and so receives public support. In this way the media coverage can be seen as not more accepting of disabled people *per se*, but more outraged that an abortion would take place for a condition that can be so easily remedied. Because of this restricted perspective adopted by the media, few articles reported on the potential implications of the case for disability issues. Of the 43 articles read, only five of them took this angle. A common term used in these articles was 'eugenics.'[169]

The coverage of the *Jepson* case focused on people with cleft palates and the life opportunities they can have, rather than medical diagnoses. This shows a shift in society as moving towards a social model. It is arguable that if the case had happened in 1965, there would have been no public outcry which demonstrates that people's opinions of

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[167] Groves, P. 'Moral choice and trust' *The Guardian*, 03 December 2003.
[168] Day, E n.52 above.
[169] For example see Anon, n.156 above.

disabled people are changing. The challenge now is to create laws that reflect this change in attitude.

The media coverage explored in this chapter suggests that the public do not perceive cleft palate to be a 'serious handicap' within the meaning of the Abortion Act 1967. Any late abortions taking place for that reason would therefore be out of line with pubic opinion. A poll carried out by *The Telegraph* suggested that 53% of voters backed a time limit of 20 weeks, with 30% opposing the reduction. When asked whether the current law permitting the abortion of unborn babies suspected of being handicapped at any time up to birth was right or wrong, 42% of voters said it was right, but 40% said that the law was wrong.[170] It is possible that these results have come about because of the *Jepson* case raising the issues in the public arena. Disability can be constructed in different ways.[171] The Jepson media shows a growing recognition of the social model. And a feeling that in deciding what constitutes a 'serious handicap' doctors should not focus solely on the medical diagnoses of the condition and neglect the social context of the conditions. The way society constructs disability signals the value placed on disabled people. It is for this reason that the public were shocked to hear of an abortion after 24 weeks for a 'trivial reason.'

3.6 Can decisions about future people affect existing people?

Arguments have been put forward against the expressivist argument, to show that the use of genetic technologies does not necessarily involve judgements about people who are living with disabilities. For example, the foetus is understood to have low moral status, and thus can legitimately be killed in circumstances which would not justify the killing of a person, therefore prenatal diagnosis and selective abortion are not inherently discriminatory to disabled people. Independent from arguing about the legal and moral status of the foetus, it is clear that there are issues that need to be addressed in relation to disablism. Even when the lives of actual people in existence are not the issue, this does not mean that the lives of these people are not implicated.[172]

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[170] Hennessy, P., Kite, M. n.55 above.

[171] This was explored in the previous chapter about models of disability (chapter 2).

[172] Reinders, H.S. n.88 above, at p57.

Making decisions about PND involves a judgement about what one believes life with disability or with a child with a disability to be. It seems the only way to arrive at this judgement is to look and see what such a life is like. The question is on what basis do we decide to prevent a life with a particular genetic disorder if not on the basis of information about the lives of actual people with the same disorder? In that sense it must be true that a decision to prevent a life with that disorder exemplifies a negative view of the lives of people who are actually living with it. Without such a view this decision would fail to make sense. As part of the decision making process, prospective parents of a disabled child, may look at the lives that disabled members of society lead as a valuable source of information. They may look at (for example) special educational establishments, and the support offered to parents. When this is undertaken they are likely to see how disabled members of society are segregated, stigmatised and devalued. This links to the social model of disability, for if social barriers were removed then perhaps prospective parents would form a different view of disability. Instead the view they form is one of living with a disability in a disablist society.

While it may be true in theory that there is no moral inconsistency between respect for disabled people and attempting to prevent their birth, in the real world, the two issues are intimately related. It is difficult to believe that in a society which has overcome its fears of disability and truly considered disabled people as equal members of the community, there would be such an interest in prenatal screening.[173] All that is required is that a psychological connection is made between women's acts and the value society places on disabled people. This connection is made by many and this explains why so many disabled people object to selective abortion and s1(1)(d) in particular.

3.7 Conclusions

This chapter has set out the legal basis for PND and selective abortion in the UK, focusing on s1(1)(d). I argued that the law places a lower value on disabled foetuses than 'normal' ones, because terminations are allowed up until birth for a disabled foetus, whereas a 'normal' foetus receives protection from the law after 24 weeks.[174] I then

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[173] King, D. 'Preimplantation Genetic Diagnosis and the 'new' eugenics' (1999) 25 *Journal of Medical Ethics* 176-82.

[174] Unless the mother's life is in danger.

moved on to explain the essence of the expressivist argument. To summarise: the expressivist argument holds that there are practices and policies that express values, and that some values can be damaging to certain members of society. In the context of PND and selective abortion, the expressivist argument contends that assumptions are implicit in the accepted practice of prenatal testing and the selective abortion of foetuses with detected impairments, and that this practice expresses disablist values.

The Joanna Jepson case was introduced as an example to demonstrate that termination for a disability can express disablist attitudes about how society values people with that condition. This case also highlighted the lack of clarity in the law for the term 'serious handicap.' The guidance provided by the RCOG on this matter was focused upon to demonstrate how vague laws enable disablist guidance to offer recommendations. A simple concentric circles diagram drew attention to the many influences in this area that affect individual decisions, by both influencing the reproductive decisions that couples are allowed to make, and by influencing the way in which disability is considered. These layers of influence depicted in fig. 7, set the climate in which individual women and couples make their reproductive decisions. I explained that no matter which party is located at the centre of the diagram, it becomes evident that they are all influenced by the disablist values expressed by the others. The RCOG guidance also serves as an example to provide evidence of disablist values expressed by organisations in that sphere of influence.

I contended that although prospective parents perceive their decisions to be private about the lives they wish themselves and their children to have, they do in fact have ramifications outside the private sphere. The individual decisions are influenced by the cultural context in which they are made, and in turn they contribute to that cultural context. The cultural context being described here is one that does not value disabled lives. These decisions affect 'real people' firstly because QL judgements made about conditions are based upon looking at the lives of those with the condition;[175] secondly, the law in this area expresses disablist attitudes;[176] finally, it is can be seen that medics

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[175] This will be demonstrated in much more detail in the QL chapter (chapter 5).

[176] As made evident by the statutory provisions regulating abortion for foetal abnormality discussed in this chapter.

perpetuate these disablist attitudes.[177] The small scale media analysis included in this chapter demonstrated the way that the media can express negative values about disability by the language they use. Furthermore, it was suggested that the values expressed in the media contribute to the disablist climate that prevents reproductive decision making from being value neutral. The media coverage of the Jepson case highlighted a growing recognition for the social model of disability, and a feeling that it is no longer acceptable to follow the medical model and focus solely on the medical diagnoses of a condition to define 'serious handicap' because this ignores the significant life opportunities open to disabled individuals. However this philosophy remained restricted to facial clefts and despite attempts by Jepson to introduce Down's Syndrome into the debate, the media did not seem to accept the same argument for that condition. Rather than an expression of acceptance for disabled people, the media coverage of the case instead focused on late abortions for impairments that are easily corrected after birth. The key point for the expressivist argument is that it is possible to identify the values implicit in the commentaries. Even where the attitudes portrayed do not show greater understanding of disability issues, they still support the basic thesis that values are being expressed in the cultural practices that surround foetal abnormality terminations.

This thesis aims to demonstrate that the values expressed in relation to disability suggest that society does not value its disabled members, and that these values are expressed in many areas of influence. The disablist values expressed on many levels of influence ensure that individual decision making is not neutral. I have highlighted some of the areas of influences involved in developing policy relating to RGTs, and established that this thesis will explore the attitudes expressed about disability within the main areas of influence. The next chapter about informed decision making will consider the 'choices' open to prospective parents and will highlight the many ways in which these 'choices' are undermined in practice. As the disablist values expressed by doctors and lawmakers are analysed closely, it will become evident that an explanation for them is that they are rooted in the medical model of disability.

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[177] As seen by the RCOG guidance in this chapter, yet this will be a recurring theme throughout the next two chapters about IDM (chapter 4) and QL (chapter 5).

Chapter 4: Informed Decision Making

4.1. Introduction

The Patient's Charter states that patients have a right to be given a clear explanation of any treatment proposed, including any risks and alternatives, before they decide whether to agree to the treatment.[1] The UK National Screening Committee suggests that "There is a responsibility to ensure that people who accept an invitation [for screening] do so on the basis of informed choice."[2] The requirements of informed consent require some level of patient engagement with decision making, and the General Medical Council has laid down stringent information requirements for patients to receive.[3]

An informed decision is one where relevant, good quality information[4] about the health alternatives is weighed up and used to inform the final decision: the resulting choice should be consistent with the individual's values[5] and behaviourally implemented.[6] Informed choice presupposes that an individual has sufficient information to optimise his or her choice. This raises the question: 'what is sufficient?' Some definitions of informed choice require that individuals appraise and use all available information.[7] Individuals, however, vary in their need for and interest in information when making a decision.[8]

This chapter will consider the various factors that affect decision making. The aim is to explore the expressivist nature of individual decisions and the pressures women are under in the context of PND. As demonstrated in the previous chapter,[9] with the use of the

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[1] see www.nhs.uk for more information.

[2] Department of Health *Second Report of the UK national screening committee* (London, Dept of Health, 2000).

[3] General Medical Council *Seeking patients' consent: the ethical considerations* (London, GMC, 1999).

[4] Marteau, T., Dormandy, E., Michie, S. 'A measure of informed choice' (2001) 4 *Health Expectations* 99-108.

[5] Bekker, H., Modell, M., Dennis, G., Silver, A., Mathew, C., Bobrow, M., Marteau, T.M. 'Uptake of cystic fibrosis carrier testing in primary care: supply push or demand pull?' (1993) 306 *BMJ* 1584-1586.

[6] O'Connor, A., O'Brien-Pallas L.L. 'Decisional conflict' in McFarlane, G.K., McFarlane, E.A. (eds) *Nursing Diagnosis and Intervention* (Toronto, Mosby, 1989) pp486-496.

[7] Bekker, H., Thornton, J., Airey, M. *et al* 'Informed decision-making: an annotated bibliography and systematic review' (1999) 3 *Health Technol Assess* 1.

[8] Miller, S.M., Mangan, C.E. 'Interacting effects of information and coping style in adapting to gynaecologic stress: should the doctor tell all?' (1983) 45 *J Pers Soc Psychol* 223-36.

[9] See the introduction to the expressivist argument (chapter 3).

concentric circles diagram (see fig. 7.),[10] whilst prospective parents are making their own decisions, there are many spheres of influence that a) allow the choices to be made and b) affect the decisions made. This chapter will focus on the information provided to couples/women about PND. The role of professionals will be examined using a Foucauldian analysis to demonstrate the effect of knowledge and power on both the patient-professional relationship, and the relationship between professionals and disabled people. Earlier discussion in this thesis has already explained the medical model on which medics rely,[11] and the way this translates into disablist quality of life judgements will be explored in the next chapter.[12] The information provided by professionals to prospective parents will be explored including the context of the information, the actual information provided and the way in which the information is presented. PND is consistently justified as offering couples/ women reproductive choices. I will argue that the rhetoric of 'choice' is little more than a marketing strategy to avoid eugenic criticisms by illustrating that: a) nondirective counselling does not work in practice, b) many prenatal tests are offered as part of routine care, c) the offer of the technologies in itself is not value neutral, d) societal constraints restrict women from rejecting PND, and e) the information provided is inadequate to allow for informed choice. The final point will be illustrated by drawing upon results from analysis of NHS PND leaflets.

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[10] See the introduction to the expressivist chapter (chapter 3).
[11] See the models of disability chapter (chapter 2).
[12] See quality of life chapter (chapter 5).

4.2 The Role of Professionals in decision making

4.2.1 Knowledge and Power

Tremain argues that "the production of seeming acts of choice on the everyday level of the subject makes possible hegemonic power structures."[13] This section aims to explore the power structures that exist between doctors and patients; and health professionals and disabled people. Power relations and structures are, by their nature, deeply ingrained in society and cosmetic changes often mask a lack of fundamental change.[14] If more than one set of beliefs about a particular phenomenon exist within a society, the explanatory model of the most powerful group will be validated as 'true' and superior to the explanatory models of others. As Marx said, "the ideas of the ruling class are in every epoch the ruling ideas."[15]

A key contribution of critical social theory was that it reinterpreted many seemingly 'personal troubles' as more appropriately understood as 'public issues' that have their origins in wider social structures and processes. Moreover, successful knowledge claims were linked with dominant interests and social relations in specific social and historical contexts.[16] From the eighteenth century, a new set of procedures and operations – 'technologies' – came together around the objectification of the body. These technologies did not cause the rise of capitalism, but it is believed that they were preconditions for its success.[17] Accounts inspired by Foucault[18] have demonstrated how the medical discourse (like others) is grounded in specific power relations and

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[13] Tremain, S. 'On the Subject of Impairment' in Corker, M., Shakespeare, T. (eds*)* *Disability/ Postmodernity – Embodying Disability Theory* (London, Continuum, 2002) at p36.

[14] French, S., Swain, J. 'The Relationship between Disabled People and Health and Welfare Professionals' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p751.

[15] Marx, K. *The Poverty of Philosophy* (Moscow, Progress, 1955) at p47.

[16] Mercer, G. 'Emancipatory Disability Research' in Barnes, C., Oliver, M., Barton, L. *Disability Studies Today* (Cambridge, Polity Press, 2002) at p231.

[17] Rainbow,P. (ed) *The Foucault Reader* (New York, Pantheon Books, 1984); Gordon, C. 'Governmental rationality: an introduction' in Burchell, G., Gordon, C., Miller, P. (eds*)* *The Foucault Effect: Studies of Governmentality* (Chicago, University of Chicago press, 1991).

[18] Foucault, M. 'The Eye of Power' in Gordon, C. (ed) *Power/Knowledge: Selected Interviews and Other Writings* (Brighton, Harvester, 1980).

ideological interests, and in turn contributes to them.[19] Foucault argued that this objectification of the body in eighteenth century clinical discourse was one pole around which a new regime of power – biopower – coalesced.[20] His concept of biopower refers to the strategic tendency of relatively recent forms of power/knowledge to work towards an increasingly comprehensive management of life: both the life of the individual and the life of the species.[21] Foucault regarded 'normalization' as the central component of the regime of biopower.[22]

Iris Young notes how the demand for social justice has shifted from distributive aims to a wider canvas of decision making, division of labour and culture as well as "the importance of social group differences in structuring social relations and oppression."[23] In her account, oppression comprises five different dimensions: exploitation, marginalisation, powerlessness, cultural imperialism, and violence. It is viewed not only in terms of coercion by the state apparatuses, but as something structural, which is located in everyday routines, values and norms, and in institutional practices. Indeed, following Foucault,[24] there is not necessarily an easily identified, oppressive sovereign power. Instead, liberal institutions such as education, health and welfare services and the production and distribution of consumer goods are all listed as instruments for domination.[25] As Thompson argues, then "an understanding of the workings of power is an essential part of challenging inequality, discrimination and oppression."[26]

Institutional discrimination can be defined as "unfair or unequal treatment of individuals or groups which is built into institutional organisations, policies, and practices at personal, environmental and structural levels."[27] It is also a notion that links the experiences of people from minority oppressed groups together.[28] Disabled people face

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[19] Barnes, C., Mercer, G., Shakespeare, T. *Exploring Disability: A Sociological Introduction* (Cambridge, Polity Press, 1999) at p65.
[20] Foucault, M. *The History of Sexuality, Vol 1: An Introduction* (New York, Random House, 1978).
[21] Allen, B. 'Disabling Knowledge' in Madison, G., Fairbairn, M. (eds) *The Ethics of Postmodernity* (Evanston, Northwestern University Press, 1999).
[22] Tremain, S. n.13 above, at p36.
[23] Young, I.M. *Justice and the Politics of Difference* (Princeton, Princeton University Press, 1990) at p3.
[24] Foucault, M. n.18 above.
[25] Barnes, C., Mercer, G., Shakespeare, T. n.19 above, at p81.
[26] Thompson, N. *Promoting Equality: Challenging Discrimination and Oppression in the Human Services* (Houndmills, Macmillan, 1998) at p43.
[27] Swain, J., Gillman, M., French, S. *Confronting Disabling Barriers: Towards Making Organisations Accessible* (Birmingham, Venture, 1998) at p5.
[28] Thompson, N. *Anti-Discriminatory Practice* (London, Macmillan, 1997).

institutional discrimination in a social and physical world that is driven by and for 'non-disabled' people. This prevents their full access and participation within organisations and within society. Institutional discrimination can be understood in terms of attitudinal, environment and structural barriers.[29] Attitudinal barriers are constructed on environmental barriers that, in turn, are founded on structural barriers.[30] This chapter aims to explore the hegemonic power structures that lead to institutional discrimination in the professions of medicine and lawmakers.

4.2.2 Examining the power and status of doctors

Medicine, despite recent bad press, is still held in esteem surpassing that of other sectors of applied science in our society.[31] Clinical definitions have their basis in the authority that is attached to medicine and carried out by medical specialists.[32] This has raised specific questions about the institutional and policy links between the state and organized medicine, while its practitioners enjoy power, status and material rewards that rank them within the dominant classes.[33] Hugman states, "Social power is an integral aspect of the daily working lives of professionals. The centrality of power in professional work has been increasingly recognized."[34]

Most recent sociological writing now explains medicine's rise to dominance as a historically specific process which involved a power conflict with other interest groups. Crucially, state patronage established orthodox medicine in a dominant position.[35] This has cemented a particular form of occupational control (over other practitioners and patients) within the health sector. However, medicine has had to engage in a continuing political struggle to retain its pre-eminent position, particularly in the health care 'division of labour,' and its control over the 'determination of the substance of its

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[29] These have already been discussed in the models of disability chapter (chapter 2).
[30] French, S., Swain, J. n.14 above, at p741.
[31] Goble, C. 'Controlling Life?' in Swain, J., French, S., Cameron, S. *Controversial Issues in a Disabling Society* (Buckingham, Open University Press, 2003) at p46.
[32] Altman, B.M. 'Disability Definitions, Models, Classification Schemes, and Applications' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p99
[33] Barnes, C., Mercer, G., Shakespeare, T. n.19 above, at p36.
[34] Hugman, R. *Power in Caring Professions* (Basingstoke, Macmillan, 1991) at p1.
[35] Barnes, C., Mercer, G., Shakespeare, T. n.19 above.

work.'[36] As such, doctors are sometimes viewed as agents or representatives of the state or, as in some models, the economic and political elite. [37] Oliver and Sapey developed a model of the relations between the state, professionals, and disabled people with particular reference to social work, [38] although it can be generalised to all health and welfare professions. In this model, professions stand between the state and disabled people, acting as agents of the state, particularly as arbiters of need. Needs are defined within the medical model that asserts the expertise and professionalism of the profession.[39] Pragmatists are concerned with the relationship of knowledge and power and the ways in which discourse, whether in science, politics or ethics, is linked to structures of domination.

It is often thought that the specialist knowledge of professionals forms the foundation for developing philosophies, values and systems of work. Expert knowledge is thought to be essential if professionals are to be autonomous, self-regulating and trusted. Those occupations aspiring to become professions attempt to define their own body of knowledge and to separate it from 'lay' knowledge and the knowledge of other professions. In doing so they lengthen the period of training required, making it more specialized, and undertake research.[40] According to Wilding, one of the effects that distinguish professional control is whatever the supposed priorities of policy-makers, the professionals can substantially determine the way in which the services actually operate.[41]

The 'power' model is an alternative view of professions. It views the claims of professionals, for example expert knowledge and altruistic motives, as nothing more than rhetoric to justify occupational autonomy, privilege and self-interest. According to this model, skills are deliberately mystified (through jargon for example) to widen the gap between professionals and their clients and to increase the dependency of those who seek professional advice.[42] Professionals are therefore seen as powerful groups within

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[36] Friedson, E. *Profession of Medicine: A Study of the Sociology of Applied Knowledge* (New York, Harper and Row, 1970) at pxvii.

[37] Illich, I. *Limits to Medicine* (Harmoundworth, Penguin, 1976).

[38] Oliver, M., Sapey, B. *Social work with disabled people* (2nd ed.) (London, Macmillan, 1999).

[39] Wilding, P. *Professional Power and Social Welfare* (London, Routledge and Kegan Paul, 1982).

[40] Fulcher, J. Scott, J. *Sociology* (Oxford, Oxford University Press, 1999).

[41] Wilding, P. *n.39* above, at pp39-41.

[42] Swain, J., French, S., Cameron, S. *Controversial Issues in a Disabling Society* (Buckingham, Open University Press, 2003) at p133.

society, essentially in pursuit of self-interest, with the mystification, defining, and control of expertise.[43] For Ivan Illich, this destruction of people's capacity for self care and self-responsibility is attributed to a 'medicalisation of life.' He also claims that doctors mystify the real causes of ill health, and exaggerate their own capacity to provide solutions.'[44] This is the basis for the expanding power of medicine, as well as for its augmented role as an agency of social control.[45]

Having considered the nature of the power of doctors, it is now necessary to briefly concentrate the discussion on the relationship between doctors and patients. This will be followed by an examination of the relationship between health professionals and disabled people in particular.

4.2.3. Examining the Doctor- Patient Relationship

There is an unequal power relationship between professionals and their clients. Professionals have the power to assess and label people, to make moral evaluations about them, and to define their problems. Coates and King argue that doctors' knowledge is regarded as reliable, valid, and 'objective;' while that of their clients is thought to be fanciful, dubious and 'subjective.'[46] French[47] takes hierarchical power relations as her starting point:

> "It is an unequal relationship with the professionals holding most of the power. Individual professionals have the power to assess people, define their problems and needs, specify solutions in terms of interventions, and evaluate the effectiveness of solutions."[48]

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[43] French, S., Swain,J. n.14 above, at p736.

[44] Illich, I. *Medical Nemesis: The Expropriation of Health* (London, Marion Boyars, 1975)

[45] Barnes, C., Mercer, G., Shakespeare, Tn.19 above, at p59.

[46] Coates, H., King, A. *The Patient Assessment* (Edinburgh, Churchill Livingstone, 1982).

[47] French, S. 'Disabled People and Professional Practice' in French, S. (ed) (1994) *On Equal Terms: Working with Disabled People* (Oxford: Butterworth-Heinemann).

[48] French, S., Swain, J. n.14 above, at pp735-6.

> "Traditionally, professional workers have defined, planned and delivered the services, while disabled people have been passive recipients with little if any opportunity to exercise control."[49]

It is this that reveals that the relationship between professionals and disabled people is a reflection of the social structures, ideologies, and power relations that disable people with impairments.[50]

4.2.4. Examining the Relationship between Doctors and Disabled People

Disabled people have often been viewed as tragic, deficient and inferior and as a result policies have sought to eliminate them (through abortion), remove them from society (through institutionalization), and to cure or approximate them to 'normal' through surgery, drugs and rehabilitation. Professionals have the power to assess disabled people, to label them as disabled, to define their needs, control the resources made available to them, specify solutions and evaluate outcomes. This, together with a disabling physical and social environment, has kept disabled people in a dependent position within society.[51]

The power of professionals in controlling language, knowledge, and the social response to disability has defined professional-disabled people relations. Illich[52] and McKnight,[53] regard professions as disabling because they diminish people's ability to look after themselves. Professional power has also contributed to the dominant individual definition of disability, defined the identity of disabled people as service users, and dominated the daily lives and experiences of many disabled people.[54] Clinical definitions are associated with the pathology that medical practitioners identify within the individual and the prognosis that the practitioner expects relative to the type of condition and the characteristics of the patient.[55] In this way the discipline of biology has

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[49] French, S. *n.47* above, at p103.

[50] French, S., Swain, J. *n.14* above, at p751.

[51] Oliver, M. 'Disability and dependency: a creation of industrial societies' in Swain, J., Finkelstein, V., French, S., & Oliver, M.(eds.) *Disabling barriers – enabling environments* (London, Sage, 1993).

[52] Illich, I. 'Disabling professions' in Illich, I., Zola, I.K., McKnight, J., Caplan, J. Shaiken, H. (eds) *Disabling Professions* (London, Marion Boyars, 1977).

[53] McKnight, J. *The Careless Society: Community and its Counterfeits* (New York, Basic Books, 1995).

[54] French, S., Swain, J. n.14 above, at p738.

[55] Altman, B. n.32 above, at p100.

served a key role in the expansion of this individuating form of power. Medicine deals with the production of medical knowledge, medical assistance and medical practitioners.[56] Justification for these productive processes is based on the premise of health production and illness eradication. Definitions of the body, its health and its forms of cure vary depending on the historical moment and as a function of the social context.[57] These definitions or forms of understanding constitute strong metaphors with a similar level of reality to the sickness itself.[58] Charlton recognises the importance of acknowledging the oppression of the body within sickrooms dominated by professional experts and developing resistance to it. But it is impossible to do this effectively without understanding it in the context of the distribution of power and status in the broader society.[59]

Professionals have been perceived, by their clients and sociologists alike, as controlling, distant, privileged, self-interested, domineering and the gate-keepers of scarce resources.[60] The Marxist view of professionals is that they are 'agents of social control,' that is people who control and stabilize society on behalf of the state by individualizing social problems. This is achieved by focusing on and blaming the individual rather than dealing with social and environmental factors, like poor housing and lack of education, that promote inequalities in health and social problems such as crime and drug abuse. In this way, French and Swain argue that a doctor may legitimise a few days off work for a stressed employee, or recommend a counsellor, rather than considering the environmental and organizational origins of the stress. In this way the status quo and the interests of powerful groups within society are maintained.[61]

Disabled people have also found that health and caring professionals impinge on wider aspects of their lives. Professionals may be involved, for example, in decisions about employment, education, social benefits, or whether or not other concessions should be

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[56] Jamous, H., Peloille, B. 'Professions as self-perpetuating systems: changes in the French University-Hospital system' in Jackson, J.A. *Professions and Professionalization* (Cambridge, Cambridge University Press, 1970).
[57] Payer, L. *Medicine and Culture* (London, Victor Gollancz, 1990).
[58] Sontag, S. *Illness as Metaphor* (New York, Farrar, Straus & Giroux, 1977); Sontag, S. *AIDS and Its Metaphors* (London, Penguin, 1989).
[59] Williams, G. 'Theorizing Disability' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p140.
[60] Swain, J., French, S., Cameron, S. n.42 above, at p133.
[61] French, S., Swain, J. n.14 above.

given, such as extra time in examinations. In that way the lives of disabled people can become increasingly 'medicalized.'[62] Doctors are at the centre of an administrative-legal system for processing people within the welfare system, for sickness and disability benefits.[63] For example, (as already mentioned)[64] in order to qualify for Disabled Living Allowance, applicants often have to undergo a medical examination by a doctor from the social security department. Supporting medical information from the applicant's specialist is also required. Furthermore, a doctor also sits on the panel of the appeal tribunal.

Oliver argues that the creation of dependency is two-way. Professionals are also dependent on disabled people for their jobs, salaries, status, quality of life, and so on. Furthermore, the construction of disability within the medical model has been contingent on the expanding production of medical and rehabilitative services.[65] Despite the potential for a changing relationship, there is little evidence of recognition that empowerment is essentially a political activity addressing power and control, rather than the development of the capacities of disabled individuals by professional intervention.[66]

Discussion this far has demonstrated the influence doctors have over society in general; patients and disabled people in particular. This dominance of the profession means that their views are very influential. Chapter two (models of disability) showed the invisible and insidious impact of the medical model of disability, and it is becoming clearer how this occurred and continues to happen. Recalling the concentric circles diagram (fig. 7) in chapter 3, it is clear that health professionals can have direct and indirect influence over the reproductive decisions made by individual women and couples. Furthermore, any values expressed by doctors are unequivocally accepted as a result of their power, knowledge and status in our society. Supporters of PND resist accusations of state influence (eugenics) by arguing that PND offers reproductive choice, the reality of this will now be analysed.

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[62] Swain, J., French, S., Cameron, S. *n.42* above, at p135.

[63] Barnes, C., Mercer, G., Shakespeare, T. n.19 above, at p56. For more information on disability benefits see Wikeley, N., Ogus, Barendt *The Law of Social Security* (5th edn) (London, Butterworths, 2002).

[64] For discussion of this see models of disability chapter (chapter 2).

[65] French, S., Swain, J. n.14 above, at p738.

[66] *Ibid,* at p750.

4.3. PND is justified by providing "choice"

4.3.1. Is informed decision making the aim of PND?

Patients generally agree to be tested because, it is said, they see it as one part of the decision making process, allowing an 'informed choice' to be made. The argument promoted by supporters of PND was summarised in the HGC consultation:

> "Providing increased information to parents allows them to prepare emotionally, physically and psychologically for the child, and to learn about the disorder. Alternatively, if they choose to terminate the pregnancy it is argued that they are able to avoid, not only the *suffering* of the child, but social, financial and psychological *costs* that may be associated with having a child with a severe disability. Improved *quality of life* is therefore a key driver behind this perspective, whatever course of action is chosen."[67]

Ford stated that:

> "The results of prenatal tests reduce the anxiety and fears of most pregnant women, and this is a benefit for the mother and foetus. If an untreatable defect is detected, the parents, with appropriate genetic and pastoral counselling, may be able to prepare themselves mentally for the birth of a disabled baby. Prenatal information may also be of benefit to obstetricians for the better management of the pregnancy and the prevention of an unnecessary caesarean delivery. It provides an indication for specialist neonatal staff to be at hand in a well-equipped hospital in case urgent treatment is needed after birth."[68]

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[67] Human Genetics Commission *Choosing the future: Genetics and Reproductive Decision-Making. Analysis of responses to the consultation* (London, HGC, 2005) at p4 (emphasis added).

[68] Ford, N.M. 'Ethical Aspects of Prenatal Screening ad Diagnosis' in Magill, G. (ed) *Genetics and Ethics, An Interdisciplinary Study* (USA, Saint Louis University Press, 2004) at p201.

All women offered screening need to have sufficient knowledge and understanding of the relevant facts and possible consequences in order to make an informed decision. Oral and written information therefore needs to be comprehensive, accurate and clear.[69]

However, as Alderson states:

> "Offering informed unpressured choices to pregnant women is not simply a matter of providing more accurate information about the tests and the conditions tested for, vital though this is. It is also important to be more transparent about the values that underlie screening policies, and to acknowledge valuable ethical principles are complicated and double edged."[70]

Whilst pregnant women have a right to seek and be given accurate information on the state of the health of their foetus for reassurance, whether the prospects are good or not,[71] more emphasis should be placed on women's rights to choose whether or not they want to be tested.

Press explored the goals of maternal serum alpha-fetoprotein screening (MSAFP) and revealed two, logically separate, types of goals. She described them as '*societally approved goals*' and '*controversial goals.*'[72] The societally approved goals of the MSAFP program are generally stated first. They include offering reassurance to pregnant women; providing information to the physicians about the state of the pregnancy; allowing time for parents to prepare psychologically in the case where an abnormality is found; permitting special medical preparation for such a birth; and the possibility of in-utero treatment.[73] She explains that these goals share the following characteristics: (1) they focus on the benefit to the individual or family, rather than to the society; (2) they focus on *joint* good to the mother and foetus, rather than raising the possibility of conflicting interests between the mother and the foetus; and (3) they are, in

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[69] Murray, J., Cuckle, H., Sehmi, I., Wilson, C., Ellis, A. 'Quality of written information used in Down Syndrome screening' (2001) 21 *Prenatal Diagnosis* 138-142.

[70] Alderson, P. 'Prenatal Screening, Ethics and Down's Syndrome: A Literature Review' (2001) 8 *Nursing Ethics* 4.

[71] Ford, N.M. n.68 above, at p202.

[72] Press, N. 'Assessing the Expressive Character of Prenatal Testing: The Choices Made or the Choices Made Available?' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p222.

[73] *Ibid.*

the broadest sense, 'for life.' Fundamentally, they are ancillary because it is so unlikely that the MSAFP test would have become routinized if they were the only, or even the major, goals.[74] These are similar to the goals promoted by supporters of PND detailed above. There are, however, two controversial goals: the ability to terminate pregnancies in cases where the foetus is found to have an anomaly, and the concomitant cost savings to society. These goals, which are so central to public health purposes that make population-based prenatal screening viable, are also so controversial that they are often stated indirectly,[75] or as will be demonstrated later in this chapter, not stated at all. Such encoded language is explicable by the fact that, in opposition to the societally acceptable goals, these controversial goals imply that the interests of society may be in conflict with those of the foetus. These goals also raise the spectre of eugenics in regard to prenatal diagnosis.[76]

4.3.2. Is the talk of 'choice' therefore merely a marketing strategy?

It has been shown that pre-natal screening programmes are justified by claiming to offer reproductive choice. Increased and improved information is said to promote medical autonomy by allowing prospective parents to take "responsibility" for their own reproductive decisions. As the Royal College of Physicians (RCOP) state:

> "If patients are believed to be 'responsible,' they must be given a choice. The patient must be allowed the opportunity to choose and be 'responsible' for that choice." [77]

The language of informed decision making, with heavy reliance on words such as 'control,' 'choice,' and 'reassurance,' certainly makes prenatal diagnosis appear attractive. But while this discourse may be successful as a marketing strategy, it relates a limited and highly selected story about prenatal diagnosis.[78] Some critics claim that most women would not terminate pregnancies after unfavourable prenatal diagnostic findings if they had a 'real choice,' namely, the option of raising the child in a supportive and

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[74] *Ibid.* The extent to which tests have become routinized is discussed in more detail later in this chapter.
[75] *Ibid.*
[76] *Ibid,* at pp222-3.
[77] Royal College of Physicians quoted in Human Genetics Commission *n.67* above.
[78] Lippman, A. 'Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities' (1991) 17 *Am J Law Med* 15.

accepting society.[79] The promotion of the prenatal screening campaign obscures 'its eugenic potential.' Instead it is marketed by emphasizing its ability to reassure a pregnant woman that her foetus is probably free from the particular birth defects the program screens for.[80] This reassurance also contributes to the routinisation of PND that has occurred.[81]

In the context of PND, opportunities to make choices benefit women who unequivocally want an abortion. They do not necessarily help women during a wanted pregnancy; those who are uncertain about accepting a disabled child; cases in which the severity of the foetal condition is unknown; women who would rather accept fate then take on responsibility through choice or who identify parenthood with unconditional acceptance of the child; or those who want to enjoy a fulfilling rather than a tentative pregnancy.[82] The choices parents must make are between terminating and continuing with the pregnancy.[83] Prenatal testing is rarely done so that a condition can be treated in either the mother or the foetus.[84] Where necessary, intrauterine blood transfusions can be made to treat foetal conditions such as anaemia or Rh incompatibility. Various anatomical and developmental foetal defects (e.g. variations in heartbeat) discovered by ultrasound foetal monitoring can be treated by drugs or repaired by means of foetal surgery.[85] Yet these interventions are rare. Usually, the first decision to be made is whether or not to have prenatal tests. Then, in the event of a positive result indicating foetal abnormality, the decision is whether or not to terminate the pregnancy.

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[79] Wertz, D.C., Fletcher, J.C. 'Feminist criticism of prenatal diagnosis: a response' (1993) 36(3) *Clin Obstet Gynecol* 541-67.

[80] Browner, C.H., Press, N.A. 'The Normalisation of Prenatal Diagnostic Screening' in Ginsburg, F.D., Rapp R. (eds*) Conceiving the new world order: the global politics of reproduction* (Berkeley , University of California Press, 1995) at p308.

[81] This will be discussed in more detail later in this chapter.

[82] Rothman, B.K. *The Tentative Pregnancy: amniocentesis and the sexual politics of motherhood* (London, Pandora, 1984).

[83] Statham, H. 'Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences' (2002) 13 *Fetal and Maternal Medicine Review* 213-247.

[84] Bailey, R. 'Prenatal testing and the prevention of impairment: a woman's right to choose?' In: Morris, J. (ed) *Encounters with strangers: Feminism and Disability* (London, The Women's Press, 1996).

[85] For more details, see Copel, J.A., Kleinman, C.S. 'Fetal Arrhythmias' in Fisk, N.M., Moise, Jr, K.J. *Fetal Therapy and Transplacental* (Cambridge, Cambridge University Press, 1997); Ford, N.M. *n.68* above, at p202.

4.4 Factors that undermine "choice"

Having explored the argument that PND offers women reproductive choices, this section aims to explore the reasons why 'choice' is undermined in more detail.

4.4.1. Nondirective counselling does not work in practice

4.4.1.1. What is nondirective counselling?

Nondirective counselling is the pervasive ethos of the genetic counselling profession. The nondirective counsellor is committed to helping clients make a well-informed decision. This goal requires that clients receive as full information as time constraints and their own comprehension permits and that clients be encouraged to explore their values and intuitions about what feels right for them.[86] It is generally agreed among health professionals that decisions concerning termination of pregnancy following diagnosis of a foetal abnormality should be made by the woman and her partner, with the support of, but not the influence of, health professionals.[87] Rather than give advice or guidance, counsellors should lay out the options to patients and give them all the information and support they need in order to be able to make a decision in a neutral and unbiased way. There is a belief that responsibility for decisions rests with the counselee after being given the information.[88] Given the moral significance of the decisions made after prenatal diagnosis, there is little debate but that they should be made by those directly involved with no suggestion of coercion.[89] In theory, non-directiveness is in keeping with the principle of autonomy and is an example of informed decision making in use in a particular context.

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[86] Kolker, A., Burke, B.M. *Prenatal testing: a sociological perspective* (Westport, CT, Bergin & Garvey, 1998) at p167.

[87] Royal College of Physicians *Prenatal Diagnosis and Genetic Screening: Community and Service Implications* (London, RCP, 1989); Royal College of Obstetricians and Gynaecologists *Report of the RCOG Working Party on biochemical markers and the detection of Down's Syndrome* (London, RCOG, 1993).

[88] Wertz, D.C., Fletcher, J.C. 'Ethical Issues in prenatal diagnosis' (1989) 18 *Pediatr Ann* 739-49; Kessler, S. 'Psychological aspects of genetic counselling. VII. Thoughts on directiveness' (1992) 1 J Genet Couns 164-171.

[89] Karp, L.E. 'The terrible question' (1983) 14 *Am J Med Genet* 1-4.

The stress on nondirectiveness in clinical genetics originated partly from a desire to repudiate the abuses of the eugenics movement. Eugenicists, who enjoyed widespread respectability in Western countries after World War II, had sought to persuade individuals to make reproductive choices for the good of society; where persuasion failed, coercive measures were applied.[90] Genetic counselling went beyond repudiating the abuses of eugenics. Grounded in an unbounded faith in the capacity of human beings to make enlightened decisions on the basis of knowledge, it has regarded educating the client as its primary role – imparting full and unbiased information while carefully avoiding influencing the client's decision.[91] Any hint of prescription, whether overt or covert,[92] lays the medical profession open to charges of eugenics.[93]

The concept of nondirective counselling was originally outlined by a committee of the American Society of Human Genetics headed by Fraser in 1974, nondirectiveness meant

> "(1) helping clients understand their options and the present state of medical knowledge, so they can make informed decisions,
> (2) helping clients adjust to and cope with their genetic problems,
> (3) the removal or lessening of patient guilt and anxiety,
> (4) helping clients achieve their parenting goals, and
> (5) the prevention of disease or abnormality."[94]

There is an obvious contradiction here between nondirective counselling and objective (5) listed. It is difficult to see how the prevention of disease or abnormality can be achieved if the prospective parents are given a real 'choice,' for they may chose to give birth to a disabled child. In recent years, the profession has reinterpreted "nondirectiveness" to mean not only providing information in a manner that is as unbiased as possible, but also empathizing with the person(s) receiving counselling and

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[90] Kolker, A., Burke, B.M. n.86 above, at p167 For a more detailed discussion of this point see Kerr, A., Shakespeare, T. *Genetic Politics: From Eugenics to Genome* (Cheltenham, New Clarion, 2002)

[91] Kolker, A., Burke, B.M. *n.86* above, at p167.

[92] Antley, R.M. 'The genetic counsellor as a facilitator of the counselee's decision process' in Capron, A. (ed) *Genetic Counselling: facts, values and norms* (New York, Alan R Liss Inc. for the National Foundation, 1979); Shiloh, S. 'Decision- making in the context of genetic risk' in Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996).

[93] Statham, H. n.83 above.

[94] Fraser, C.F. 'Genetic Counselling' (1974) 26 *American Journal of Human Genetics* 636-661.

offering them guidance.[95] This is demonstrated in the WHO's *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services* in 1998 where nondirective counselling is described as follows:

> "Non-directive counselling has two major elements. The first is the provision of accurate, full and unbiased information that individuals and families may use in making decisions. The second is an understanding, empathetic relationship that *offers guidance* and helps people to work towards their own decisions. In non-directive counselling, the professional avoids purposely slanting information that may lead people to do what the counsellor thinks best. Individuals and families must depend on the counsellor as a source of accurate information, and usually have no way of discovering when information is biased."[96]

There is another potential contradiction within this paragraph. The idea that 'guidance' will be offered, which implies directionality, yet professionals are to avoid 'slanting information' towards a particular outcome.

4.4.1.2. Evidence of existing practice

The extent to which health professionals agree to follow these guidelines is not known.[97] There is some evidence to suggest that some counselling may be more directive than guidelines suggest. In an attempt to explore this, Wertz and Fletcher carried out some research on behalf of the WHO's Human Genetics Programme. They used a questionnaire that listed 21 different genetic conditions or foetal malformations that might be found in prenatal diagnosis. Respondents were asked how they would counsel for each of the conditions. Choices of responses were:

- "Urge parents to carry to term

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[95] Wertz, D., Fletcher, J.C. *Genetics and Ethics in Global Perspective* (The Netherlands, Dordrecht, Kluwer Academic Publishers, 2004) at p37.
[96] World Health Organisation *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services* (Geneva, WHO, 1998) at p5 (emphasis added).
[97] Marteau, T., Drake, H., Bobrow, M. 'Counselling following diagnosis of a foetal abnormality: the differing approaches of obstetricians, clinical geneticists and genetic nurses' (1994) 31 *Journal of Medical Genetics* 864-7.

- Emphasize positive aspects so they favour carrying to term without suggesting it directly
- Try to be as unbiased as possible
- Emphasize negative aspects so they will favour termination without suggesting it directly
- Urge termination
- Not tell them this particular test result"

There were only two conditions for which counselling was optimistic: cleft lip/palate, and child not of desired sex.[98] The following table illustrates some of the results from this study. For a list of conditions, the % of those who would provide unbiased counselling and the % of those who would give pessimistically slanted information.

Fig. 9. A table to show some of the results collected by Wertz and Fletcher[99]

Condition	% in the UK who would provide unbiased counselling	% in the UK who would give pessimistically slanted information (i.e. emphasize negative aspects so they favour termination without suggesting it directly)
Anencephaly	41	Not given
Severe, open spina bifida	63	38
Trisomy 13	61	39
Trisomy 21	84	14
Cystic fibrosis	87	10
Achondroplasia	87	4
Sickle cell anaemia	88	6
Child not of desired sex	27	Not given
Neurofibromatosis	80	Not given
Klinefelter (XXY)	72	0
Turners (45, X)	73	Not given
PKU in foetus	72	7
Severe obesity	65	Not given
Cleft lip/palate	48	Not given
Hurler Syndrome	Not given	23
Huntington disease	Not given	10

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[98] Wertz, D., Fletcher, J.C. n.95 above, at p38.
[99] *Ibid,* at p371.

If nondirective counselling was really universally adopted in practice, these results should be different. Regardless of the condition, unbiased counselling should be provided for 100% of the conditions, and 0% should be providing pessimistically slanted information for any condition. That this is not the case suggests that nondirective counselling has not progressed as much since Fraser's objectives in 1974 as was thought. Furthermore, what people actually do in professional practice may depart considerably from what they say they would do in response to questionnaires. In this way, the results could underestimate the amount of directive, pessimistic counselling. With the dominant ethos behind the profession believing nondirective counselling is the most ethical approach, many professionals may have been reluctant to show open evidence of directiveness.[100] Research has shown that some genetics professionals hold clearly eugenicist views:[101] believing that genetic testing is a good thing because it allows people to have healthy babies instead of unhealthy babies; placing a negative value on people with certain conditions; seeing it as desirable to prevent the births of certain foetuses.[102]

Research conducted by Marteau *et al* demonstrated that a consistently non-directive approach was not adopted for any of the conditions selected.[103] Consensus (defined as agreement between 70% or more of respondents)[104] on the approach to counselling between the groups of professionals (obstetricians, clinical geneticists, and genetic nurses), was evident for just one of the seventeen conditions, cleft lip: where it was reported that parents were counselled in the direction of continuing with the affected pregnancy.[105] None of the groups of health professionals uniformly approached counselling for any of the conditions in a non-directive fashion.[106] Again, there are limitations to this research, as recognised by the authors as the extent to which these self-reported differences are reflected in actual practice is not known.[107] Neither is it known

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[100] Wertz, D., Fletcher, J.C. n.95 above, at p38. It is widely accepted that when people fill in questionnaires, they respond in a socially desirable way. This is termed 'demand characteristics' (because they are ceding to the demands of societal acceptability), and it is difficult to eliminate in a study of this type.

[101] Farrant, W. 'Who's for amniocentesis? The politics of prenatal screening' in Homan, H. (ed) *The sexual politics of reproduction* (London, Gower, 1985) at pp90-177.

[102] Shakespeare, T. 'Choice and Rights: Eugenics, Genetics and Disability Equality' (1998) 13 *Disability and Society* 665.

[103] Marteau, T., Drake, H., Bobrow, M. n.97 above, at p866.

[104] Wertz, D.C., Fletcher, J.C., Mulvihill, J.J. 'Medical geneticists confront ethical dilemmas: cross-cultural comparisons among 18 nations' (1990) 46 *American Journal of Human Genetics* 1200-13.

[105] Marteau, T., Drake, H., Bobrow, M. n.97 above, at p866.

[106] *Ibid*, at p866.

[107] *Ibid*, at p867.

the extent to which the respondents are representative of their profession.[108] Clinical practice for clinical geneticists and in particular genetic counsellors is defined by non-directiveness. The responses of these two groups may therefore reflect knowledge of this value system, rather than reflecting actual practice.[109]

These studies indicate that in practice, nondirective counselling is not always achievable. Possible explanations for the failure to adopt nondirective counselling will now be focused upon. These include the pressure on health professionals, the variation of approach between professionals, the systems and structures of practice, and patient needs. This will enable conclusions to be drawn as to whether or not nondirective counselling is possible.

4.4.1.3. Problems with nondirective counselling

Difficulties have been noted by practitioners attempting to work in a nondirective way.[110] There are several suggested reasons for this that will now be explored: a) the time pressures, b) the training health professionals receive, c) the ways the information is provided, d) the variation in approach between doctors of different disciplines, e) the 'set-up' of the clinics undermines nondirective counselling, and f) nondirective counselling sometimes does not satisfy the patient's needs.

Nondirective counselling creates time pressure on doctors, nurses and counsellors to convey information in a time span that is already limited.[111] In addition, the antenatal setting is viewed by many as highly pressurised. Patients who are offered screening are usually already pregnant, putting significant time pressure on the decision making process, limiting the potential options and placing too much emphasis, according to some,[112] on termination of pregnancy in the event of a positive diagnostic result. Inadequate resources for counselling and achieving informed choice have been

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[108] *Ibid,* at p867.
[109] *Ibid,* at p867.
[110] Williams, C., Alderson, P., Farsides, B. 'Is non-directive counselling possible within the context of antenatal screening and testing?' (2002) 54 *Social Science and Medicine* 339-347.
[111] Human Genetics Commission n.67 above, at p7.
[112] For example, Doctors for Life said *"Often once the service is accessed, the patient is on an assembly line that ends in termination."* in Human Genetics Commission n.67 above, at p27.

consistently recognised as a problem in relation to prenatal screening, even when only one test was being offered.[113]

Pressures such as time constraints and factors including health professionals' training, medical textbook knowledge and traditional ways of giving information, all undermine efforts to shift the way in which information is presented.[114] Williams *et al* identified that there was not enough time in consultations to allow for fully informed choice about detailed scanning and nuchal translucency screening.[115] In another paper, Williams *et al* quote one obstetrician who said that:

> "With scans, the amount of time you would need to give proper informed consent about what a scan can pick up, what the outcomes would be and what is the management of these conditions, it's not feasible before you do a routine list... I don't think we can give patients fully informed consent before we undertake procedures."[116]

Termination of pregnancy is believed to be more likely where counselling is poor, where the patient has not received enough information and/or they have felt under time pressure to make a decision. These difficulties are all set within the context where the offer of a screening test can be seen as a recommendation, and as such, can serve to compromise informed choice.[117] Some argue that termination is 'built into' the system or routine of testing, where some health professionals treat termination as the obvious and most likely next step after testing/diagnosis.[118]

Different approaches have been identified as being used by health professionals of different disciplines. Some doctors will vary and supply more or less directive advice and information than others. There is evidence that obstetricians are more directive than

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[113] Green, J.M. 'Serum screening for Down's Syndrome: experiences of obstetricians in England and Wales (1994) 309 *BMJ* 769-772.

[114] Williams, C., Alderson, P., Farsides, B. 'What constitutes "balanced information" in the practitioners' portrayals of Down's Syndrome?' (2002) 18 Midwifery 230-237. These issues will be explored later in this chapter.

[115] Williams, C., Alderson, P., Farsides, B. 'Dilemmas encountered by health professionals offering nuchal translucency screening: a qualitative case study' (2002) 22 *Prenatal Diagnosis* 216-20.

[116] *Ibid*

[117] Press, N., Browner, C.H. 'Why women say yes to prenatal diagnosis' (1997) 45(7) *Social Science and Medicine* 979-989.

[118] Human Genetics Commission n.67 above, at p23.

geneticists and other doctors.[119] Parents counselled by a clinical geneticist or a specialist paediatrician are more likely to continue a pregnancy affected with a disability than are those counselled by other professionals such as obstetricians.[120] The proportion of women terminating pregnancies affected by chromosomal abnormality is higher among those consulting an obstetrician only rather than among those additionally consulting geneticists or paediatricians.[121] This could be because obstetricians offer outdated information about the condition on the basis of studies of cases which came to the attention of health professionals precisely because they had problems.[122] Alternatively it could be because parents who were undecided about their pregnancies, and perhaps more inclined to continue with the affected pregnancy, were those who sought specialist counselling.[123] It is important to note that obstetricians' attitudes in the UK have been seen to change markedly. In 1993, 34% of a sample of 357 practising obstetricians reported that they required a woman to undertake to terminate an affected pregnancy before they would undertake an amniocentesis[124] compared with 75% of the obstetricians asked the same question in 1980.[125] Yet there is clearly still room for improvement if we are expected to believe that nondirective counselling and the provision of 'choice' are more than merely empty rhetoric and an example of a public relations exercise in marketing. This was demonstrated earlier in this chapter.

Sources of unwarranted variation in prenatal screening uptake include the way testing is conducted and the way the tests are presented by healthcare professionals, perhaps

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[119] Marteau, T.M., Plenicar, M., Kidd, J. 'Obstetricians presenting amniocentesis to pregnant women: practice observed' (1993) 11 J *Reprod Infant Pscychol* 3-10; Marteau, T., Drake, H., Bobrow, M. n.97 above; Bernhardt, B.A., Geller, G., Doksum, T., Larson, S.M., Roter, D., Holtzman, N.A. 'Prenatal genetic testing: content of discussions between obstetric providers and pregnant women' (1998) 91 *Obstet Gynecol* 948-655; Geller, G., Tambor, E.S., Chase, G.A., Hofman, K.J. Faden, R.R., Holtzman, N.A. 'Incorporation of genetics in primary care practice' (1993) 2 *Arch Fam Med* 1119-1125.

[120] Holmes-Seidel, M., Ryynanen, M., Lindenbam, R.H. 'Parental decisions regarding termination of pregnancy following prenatal detection of sex chromosome anomalies' (1987) 7 *Prenatal Diagnosis* 239-44; Robinson, A., Bender, B.G., Linden, M.G. 'Decisions following the intrauterine diagnosis of sex chromosome aneuploidy' (1989) 34 *Am J Med Genet* 552-554; DADA Study Group 'Outcomes of pregnancies diagnosed with Klinefelter Syndrome: the possible influence of health professionals' (2002) 22 *Prenatal Diagnosis* 532-566.

[121] Marteau, T., Anionwu, E. 'Evaluating carrier testing: objectives and outcomes' in Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996).

[122] Hall, S., Abramsky.L, Marteau, T. 'Health professionals' reports of information given to parents following the prenatal diagnosis of sex chromosome anomalies and outcomes of pregnancies: a pilot study' (2003) 23 *Prenatal diagnosis* 535-538.

[123] *Ibid.*

[124] Statham, H. n.83 above.

[125] Farrant, W. n.101 above.

reflecting their attitudes towards the test.[126] Research previously discussed based on self-reporting questionnaires of doctors and genetic counsellors demonstrates that nondirective counselling does not work in practice, and that many professionals provide pessimistically slanted information.[127]

There is also concern about the way information is presented by different health professionals who may come into contact with the same patient.[128] Interview studies with women conducted by Press and Browner suggest that their attitudes towards undergoing tests are shaped in various ways by these health professionals.[129] One possible explanation for this difference is that these groups of health professionals conducted consultations differently, giving parents different descriptions of the conditions, or using different counselling styles. If this interpretation is correct, it suggests that whether a pregnancy is terminated may depend upon which type of health professional a woman consults.[130]

Healthcare professionals with negative attitudes toward disability screening emphasise negative aspects of the screening test to the women who consult them, such as the risk of miscarriage following a diagnostic test. Conversely, those with positive attitudes towards screening may emphasise the benefits of screening by discussing the difficulties of bringing up a child with a disability.[131] Healthcare professionals based at a hospital with higher screening uptake have been found to have more positive attitudes towards screening than healthcare professionals based at the hospital with lower screening

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[126] Boyd, F., Simpson, W., Johnstone, F.D., Goldberg, D., Hart, G. 'Uptake and acceptability of antenatal HIV testing' (1999) 7(3) *British Journal of Midwifery* 151-56; Dormandy, E., Michie, S., Weinman, Marteau, T.M. 'Variation in uptake of serum screening: the role of service delivery' (2002) 22 *Prenatal diagnosis* 67-69; Gekas, J., Gondry, J., Mazur, S., Cesbron, P., Thepot, F. 'Informed consent to serum screening for Down Syndrome: are women given adequate information' (1999) 19 *Prenatal Diagnosis* 1-7; Marteau, T.M., Plenicar, M., Kidd, J. n.119 above; Simpson, W., Johnstone, F.D., Boyd, F. *et al* 'A randomised controlled trial of different approaches to universal antenatal HIV testing: uptake and acceptability' (1999) 3(4*) Health Technol Assess*; Weinans, M., Hujissoon, A., Tymstra, T.J., Gerrits, M., Beekhuis, J., Mantingh, A. 'How women deal with the results of serum screening for Down Syndrome in the second trimester of pregnancy' (2000) 20 *Prenatal Diagnosis* 705-8.

[127] Wertz, D., Fletcher, J.C. n.95 above, at p371.

[128] Human Genetics Commission n.67 above, at p16.

[129] Press, N., Browner, C.H. n.117 above.

[130] This is discussed in more detail in the 'information given to couples' section of this chapter. Marteau, T., Drake, H., Bobrow, M. n.97 above.

[131] Professionals with positive attitudes towards screening for Down's Syndrome have negative views about life with Down's Syndrome. Dormandy, E., Marteau, T.M. 'Uptake of a prenatal screening test: the role of healthcare professionals' attitudes towards the test' (2004) 24 *Prenatal diagnosis* 864-868.

uptake.[132] The attitudes of healthcare professionals might influence systems of care, not just communication with pregnant women.[133] The effect of healthcare professionals' attitudes could be mediated either through the organisation of a screening programme within hospitals or though individual consultations with pregnant women.[134]

There is evidence to suggest that patients may not see nondirective counselling as in their best interests. Patients are often very interested in learning about the physician's experience of how others have resolved the moral dilemmas with which they struggle. Studies of parents attending genetic counselling show that they expect to be offered advice and help with making decisions.[135] Scrupulous non-directiveness could be seen to deprive patients of valuable information and means parents are left to make their decisions in a vacuum because health professionals fear being seen as directive if they fully discuss the available options.[136] In a postal survey of almost 800 families who had received genetic counselling, 42% stated that in addition to the facts, they wanted the counsellor's opinion of what they should do.[137] Often parents want doctors to share in the decision making and show relief when some of the burden of such onerous decisions is taken from them.[138] This is further exacerbated by the patients' expectation that they will be given advice and guidance on medical 'best practice,' which they would be able to follow.[139] Parents often seek direct advice as to what action they should take.[140] This again, reflects the esteemed status in which doctors are held in our society.

Little is known about the readiness of patients to take on decision making responsibility. Evidence exists to show that many patients do have strong treatment preferences,[141] that these are not always predictable,[142] and doctors often fail to understand them,[143] but it is

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[132] *Ibid.*

[133] *Ibid.*

[134] *Ibid.*

[135] Michie, S., Bron, F., Bobrow, M., Marteau, T.M. 'Non-directiveness in genetic counselling: an empirical study' (1997) 60(1) Am J Human Genet 40-47.

[136] Genetic Interest Group *Genetic Testing, Screening and 'eugenics'* (London, GIG, 1999).

[137] Somer, M., Mustonen, H., Norio, R. 'Evaluation of genetic counselling, recall of information, post-counselling reproduction, and attitudes of the counsellees' (1988) 34 *Clinical Genetics* 352-65.

[138] Weatherall, D.J. *The New Genetics and Clinical Practice* (Oxford, Oxford University Press, 1991) at p349.

[139] Human Genetics Commission n.67 above, at p20.

[140] Karp, L.E. n.89 above.

[141] Guadagnoli, E., Ward, P. 'Patient participation in decision-making' (1998) 47 *Soc Sci Med* 329-39.

[142] Richards, M.A., Ramirez, A.J., Degner, L.F., Fallowfield, L.J., Maher, E.J., Neuberger, J. 'Offering choice of treatment to patients with cancers' (1995) 31A *Eur J Cancer* 112-6.

possible some patients may not want to have an active role thrust on them.[144] Some people prefer to defer decision making to the doctor, perhaps because it allows them to avoid responsibility for the consequences of 'wrong' decisions.[145]

4.4.1.4. Is nondirective counselling possible?

While guidelines for practice are clear in stressing the importance of non-directiveness for counselling, they fail to acknowledge how difficult non-directiveness is to achieve in practice. There are many factors that may affect the counselling provided to prospective parents. Nondirective counselling is impossible because counsellors have their own values, and these values tend to creep into the counselling situation however assiduously the counsellor strives to suppress them. Furthermore, most people expect a counsellor to have values. If the counsellor will not discuss values openly, those being counselled may try to discover them through observations of gestures or tone of voice.[146]

Sorenson stated, "To apply knowledge requires making decisions about what to inform people, when to inform them, and how to inform them. These decisions are influenced by values... Genetic counselling probably has never been nor will be value neutral."[147] Genetic counselling by its very nature implies value judgements. Even using words like 'abnormality', 'defect' and 'recurrence risk' in connection with a given trait connotes a value stance.[148] In order to combat this, genetics professionals need to examine their own values and fears about disability, and how these can influence their work.[149]

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[143] Coulter, A., Petro, V., Doll, H. 'Patients' preferences and general practitioners' decision in treatment of menstrual disorders' (1994) 11 *Fam Pract* 67-74.

[144] Coulter, A. 'Paternalism or partnership? Patients have grown up – and there's no going back' (1999) 319 *BMJ* 719-720.

[145] Charles, C., Redko, C., Whelan, T., Gafni, A., Reyno, L. 'Doing nothing is no choice: lay constructions of treatment decision-making among women with early-stage breast cancer' (1998) 20 *Sociol Health and Illness* 71-95.

[146] Wertz, D., Fletcher, J.C. n.95 above, at p36.

[147] Sorenson, J. 'Genetic Counselling: Values That Have Mattered' in Bartels, D.M., Leroy, B.S., Caplan, A.L. (ed) *Prescribing Our Future: Ethical Challenges to Genetic Counselling* (New York, Aldine de Grutyer, 1993) at p3.

[148] Nance, W.E. 'Parables' in Bartels, D.M., Leroy, B.S., Caplan, A.L. (eds) *Prescribing Our Future: Ethical Challenges to Genetic Counselling* (New York, Aldine de Grutyer, 1993).

[149] Saxton, M. 'Born and Unborn: The Implications of Reproductive Technologies for People with Disabilities' in Arditti, A., Klein, R.D., Minden, S. (eds) *Test-tube Women what future for motherhood?* (London, Pandora Press, 1989) at p308.

In Wertz and Fletcher's 1995 survey, close to 100% of geneticists said they agreed with nondirective counselling. More recently, however, many geneticists and genetic counsellors have argued that totally "nondirective" counselling is neither possible nor desirable.[150] There is considerable debate as to whether non-directive counselling is an achievable goal even with trained counsellors.[151] Many respondents to the HGC consultation argued that non-directive counselling is an ideal that can never be achieved in reality. This is not because these respondents believe that health professionals are routinely steering patients down a particular course of action, but that direction is conveyed implicitly by the way that the system is set up (as explained earlier) and by extraneous pressures.[152] In the event of a positive diagnostic result, a large number of respondents to the consultation believe that patients feel pressure to abort the affected foetus. In fact, it is suggested that the majority of patients would not agree to invasive testing if this were not the most likely scenario. The explicit form of pressure exerted by directive counselling is reinforced by more subtle economic and cultural processes.[153] Financial and familial pressures are also said to play a part in driving patients in the direction of termination. Together, it is argued, these factors make the concept of non-directive counselling and of informed value-free choice impossible (in many cases).[154]

4.4.2. Technology is not value neutral

Technologies of normalization are instrumental to the systemic creation, classification and control of 'anomalies' in the social body. Foucault argued that the function of these techniques is to isolate so-called anomalies, which can in turn be normalized through the therapeutic and corrective strategies of technologies.[155] More recently, Abby Lippman argued that a genetic understanding of a condition tends to 'biologize' and localise what should primarily be understood in social and environmental terms.[156] This section

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[150] Clarke, A. (eds) *Genetic Counselling: Practice and Principles* (London, Routledge, 1994); Kessler, S. n.88 above; White, M.T. '"Respect for autonomy" in genetic counselling: an analysis and a proposal' (1997) 6(3) *Journal of Genetic Counselling* 297-314.

[151] Clarke, A. 'Is non-directive genetic counselling possible? (1992) 338 *Lancet* 998-1001; Michie, S., *et al*. n.135 above.

[152] Human Genetics Commission *n.67* above, at p20.

[153] Genetic Interest Group 'Genetic Testing, Screening and 'eugenics'' (London, GIG, 1999).

[154] Human Genetics Commission *n.67* above, at p22.

[155] Rainbow,P. n.17 above.

[156] Jennings, B. 'Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p141.

therefore aims to explore the values inherent in the technologies offered, and what the 'choice' of these technologies means for prospective parents. If it is to be believed (as argued by critics of the expressivist argument) that reproductive decision making is value neutral, the offer of the technology should also be value neutral. This section will demonstrate that this is not the case.

Saxton argues that technologies can only be evaluated within the limits of contemporary culture, and on that basis, they have been and will be used in ways that devalue disabled people.[157] It is important to recognise the ways in which the issue and the moral problem are being framed, both by those writings in the field of bioethics, and, more importantly, by the professionals that shape ideas in our society more broadly – voices from the medical and scientific professions.[158] Scientists play a key role in pushing back the boundaries of acceptability.[159] Technology can be seen as a system of knowledge, a system of social organization, and a system of power.[160] Jennings explores this argument by stating that the trouble with the ethics of prenatal genetic testing is that we fail to recognise the background influence of the reality-constituting power of the technology itself.[161] He contends that there is a "coercive power of the state and the society with its laws, incentive systems, and rewards."[162] And in addition to this it is important to acknowledge the "influence of the surrounding culture and belief systems that affect the individual, including the norms of religion, custom, and tradition, and the pressures of conformity with the behaviour of others."[163] The scientific context in which prenatal testing is located inevitably plays a critical role here too.

One of the main criticisms of the technologies is that they are used because of a pre-existing negative view of disability i.e. something to be avoided.[164] The very offer or availability of the technology is in itself not value neutral. There is an erroneous

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[157] Saxton, M. "Why Members of the Disability Community Oppose Prenatal Diagnosis and Selective Abortion" in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p151.

[158] Jennings, B. n.156 above, at p129.

[159] Shakespeare, T. n.102 above, at p668.

[160] Winner, L. *Autonomous Technology* (Cambridge, Mass. MIT Press, 1977); Elluh, J. *The Technological Society* (New York, Knopf, 1964); Mumford, L. *The Myth of the Machine*, 2 vols (New York: Harcourt Brace Jovanovich, 1964-70).

[161] Jennings, B. n.156 above, at p126.

[162] *Ibid,* at p127.

[163] *Ibid.*

[164] See QL chapter (chapter 5).

assumption that technology is a tool and hence not an appropriate object of ethical evaluation in its own right. When bioethics adopts the frame of individual choice on any given issue involving the use of technology, the default assumption will normally be that the technology, having shown to work and having been made available, is morally permissible. This individual choice frame assumes, in other words, that the technology will naturally and necessarily be in demand, that on balance it is better to have it than not to have it, and that individuals who have a reasonable interest in using the technology should be given access to it, subject to their sharing a fair burden of its cost and maintenance.[165] The assumption is that genetic technology is a morally neutral tool or instrument of individual decision making and choice.

Scientists and medics control the availability of the technologies. This is by deciding research priorities and which technologies to develop. It can therefore be seen that the resulting technologies reflect the values of the scientists and medics involved. Furthermore, reproductive technologies are an industry, and as a result priorities could be decided by profit margins rather than clinical need.

Practitioners should also be aware that women's choices are shaped by the offer of prenatal tests for certain conditions and not for others, as well as by the information provided about these conditions.[166] Some have taken this argument further by arguing that not only is the offer of technology not value neutral, but that the offer of a test for a condition may be perceived as a recommendation that something (i.e. termination) should be done about the condition if found.[167]

It is extremely difficult, if not impossible, for women to choose to reject technologies approved by the obstetric profession. This is because tests offered by doctors can be seen as recommendations. It is a strong-willed parent who can resist having this powerful reality-shaping force become the *only* reality of pregnancy. Those who can do so are those who have a previously affected child perhaps, or those who hold a strong,

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[165] Jennings, B. n.156 above, at p129.

[166] Lippman, A. 'The genetic construction of prenatal testing: choice, consent or conformity for women?' in Rothenberg, K., Thomson, E. (eds) *Women and prenatal testing* (Columbus, Ohio University Press, 1994).

[167] Press, N., Browner, C.H. n.117 above; Clarke, A. n.151 above.

principled commitment not to discriminate against or to undervalue the lives of those with disabilities, or who hold a deep religious conviction against abortion.[168]

Many have argued that the very offer of testing forces women to make decisions. That the technology demands a response; it does not necessarily force any particular choice, but it does force choice in general. It is a commonplace to observe with virtually any technology that once it is available, then, like a genie out of a bottle, it cannot be undone or put out of the sphere of social reality.[169] With testing, everything must be deliberate and everything is a decision. Prenatal genetic testing technology shapes choice by in effect making everything into a choice.

The technologies available not only change the way in which prenatal care is offered to prospective parents, but it can also change the way in which prospective parents think about their pregnancies.[170] As Jennings explains:

> "Genetic tests provide a highly charged and theory-laden form of knowledge that structures our perception of our physical bodies, our social selves, and our temporal futures in selective and distinctive ways. And this form of knowledge also structures the perception of the bodies, selves, and futures of our unborn children."[171]

Choice either way loads women with responsibility, (as well as) potential guilt and blame. To refuse tests may appear to be casual, even callous; to accept the birth of an impaired child, expected or not, can look like selfish extravagance and may become a lonely burden.[172] In this liberal and individualistic society, there may be no need for eugenic legislation. Physicians and scientists need merely provide the techniques that make individual women, and parents, responsible for implementing the society's prejudices, by choice. And once the means to avoid bearing a child with a particular disability are available, women who have medical and financial access to that so-called 'choice' may not feel entitled to refuse. Kolker and Burke argue that the birth of a child

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[168] Jennings, B. n.156 above, at p136.
[169] *Ibid*, at p134.
[170] See Rothman, B.K. n.82 above.
[171] Jennings, B. n.156 above, at p137.
[172] Alderson, P. n.70 above; Marteau, T., Drake, H. 'Attributions for disability: the influence of genetic screening' (1995) 40(8) *Soc Sci & Med* 1127-1132.

with a genetic disability will be placed in the same category that condemns a mother who bears a child with foetal alcohol Syndrome, drug addiction, or any condition attributable to maternal behaviour known to be harmful to a foetus.[173] It appears that in much of the world, women who carry a child with a known genetic 'defect' to term will face social blame, perhaps accompanied by social and cultural pressure to abort.[174] Thus the very existence of prenatal screening programmes puts pressure on individuals to take part due to the perception that the very availability of the test implies that it is desirable.

Weinans *et al* report that one woman stated:

> "This kind of screening has different sides. It is there, you can use it and it is difficult not to use because the procedure is so simple. But imagine that something is wrong and you didn't have this test. During my previous pregnancies the test was not available, making things a lot easier because I didn't have to decide."[175]

Williams *et al* report that such sentiments are also shared with health professionals. One midwife said:

> "You are making moral dilemmas for them because the choice is there, the choice wasn't there before, it was simple… It doesn't mean we shouldn't do it, but I think it has to be acknowledged that life is more difficult because of this."[176]

It is thus important to understand that the technology of prenatal diagnosis does not come about in a vacuum. It develops in the context of all the new reproductive technologies, including those which arrived with much fanfare: IVF and PGD. Others such as amniocentesis and ultrasound have crept in more quietly, but it is part of the whole, occurring in a context in which the prevention of the lives of disabled people is seen as desirable. There are societal norms that exert a pressure over women to comply.

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[173] Kolker, A., Burke, B.M. n.86 above, at p173.

[174] Wertz, D., Fletcher, J.C. n.95 above, at p34.

[175] Weinans, M., *et al.* n126 above.

[176] Williams, C., Alderson, P., Farsides, B. n.115 above.

In a broader sense, it has been shown that genetic counselling cannot be completely neutral or nondirective because the basic grounding of its professional discourse already derives from genetic science and technology. The counsellor can be seen to mediate between the client and the technology.[177] The counsellor is not in a position to make the genetic testing industry accommodate itself more fully to the educational and emotional needs of couples faced with the prospect of rearing a chronically ill or disabled child.[178] The counselling may be neutral as regards the personal beliefs of the counsellor but it cannot be neutral in regards the very context of genetic technology itself.[179]

I have demonstrated this far that doctors are very influential in our society; that nondirective counselling is not possible in practice; and that the offer of technology in itself is not value neutral. That the offer of the technology comes from doctors makes it even more difficult for patients not to see the offer as a recommendation. Furthermore, there is evidence that many women are not making informed decisions because a) they do not understand the nature of the tests i.e. screening or diagnostic, and b) they misunderstand what the results will show.

Many researchers have reported that the respondents of their surveys deemed the information they received as inadequate. For example, in Gekas *et al*'s study 58% of participants deemed the information inadequate and 13% reported that *no such information* was provided.[180] The context that the information is presented in is also important. The first communication to parents is important because it may affect how information presented later is interpreted or even whether it is sought.[181] In Weinan *et al*'s study almost all women felt that they had been well-informed about the serum screening. Nonetheless, about one quarter of them supposed that the serum screening result would tell them whether or not they were carrying a Down Syndrome child. This demonstrates lack of knowledge.[182] Of the 42 women participating in research by

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[177] Bosk, C.I. *All God's Mistakes: Genetic Counselling in a Pediatric hospital* (Chicago, University of Chicago Press, 1992).

[178] Jennings, B. n.156 above, at pp135-6.

[179] *Ibid,* at p136. More discussion of this in technology not neutral section.

[180] Gekas, J., *et al.* n126 above, at p3.

[181] Tversky, A., Kahneman, D. 'The framing of decisions and the psychology of choice' (1981) 211 *Science* 453-8; Marteau, T.M. 'Framing information: its influence upon decisions of doctors and patients' (1989) 28 *Br J Soc Psychol* 89-94; Anderson, G. 'Nondirectiveness in prenatal genetics: patients read between the lines' (1999) *Nursing ethics* 126-36.

[182] Weinans, M., *et al.* n.126 above.

Marteau *et al*, 18 were classified as having made an informed choice, and 24 were classified as having made an uninformed choice.[183] Press found that the women she interviewed did not understand the purpose of screening. The notion that it was to find cases of untreatable birth defects in order to allow women and couples the opportunity to terminate a pregnancy appeared to be obscured from view.[184] To refer to Gekas *et al* again, they discovered that maternal serum screening was introduced to 42.5% of respondents as a recommended test in normal pregnancy follow-up; to 41.5% as an obligatory test in normal pregnancy follow-up and for 16% the test was done without their agreement. Gekas *et al* reported that the purpose of maternal serum screening was misunderstood by 90.5% of respondents.[185] This is backed up by many other studies, that document women's poor levels of knowledge about the tests they are offered.[186] Such findings raise questions regarding the reliability of the informed consent for prenatal screening. This is supported by other studies that often conclude that despite receiving written information, women appear to have little knowledge about prenatal screening,[187] and repeatedly recommended that practitioners need more training in communication skills and increased knowledge about prenatal screening in order to better inform women.[188] There is evidence that for many mothers the requirements of informed consent are not always adhered to for MSS and prenatal diagnosis, even if the mothers thought it was sufficient at the time.[189]

There are two possible reasons to explain the lack of informed consent in PND and PNS:

1. Routinisation of the tests
2. The information provided

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[183] Marteau, T., Dormandy, E., Michie, S. n.4 above.

[184] Press, N. n.72 above, at p219.

[185] Gekas, J., *et al.* n126 above.

[186] Marteau, T.M., Johnston, M., Plenicar, M., Shaw, R.W., Slack, J. 'Development of a self-administered questionnaire to measure women's knowledge of prenatal screening and diagnostic tests' (1988) 32 *Journal of Psychsomatic Research* 403-8; Smith, D.K., Shaw, R.W., Marteau, T.M. 'Informed consent to undergo serum screening for Down Syndrome: the gap between policy and practice' (1994) 309 *BMJ* 776; Chilaka, V.N., Konje, J.C., Stewart, C.R., Narayan, H., Taylor, D.J. 'Knowledge of Down Syndrome in pregnant women from different ethnic groups' (2001) *21 Prenatal Diagnosis* 159-164.

[187] French, S. 'Perceptions of nuchal translucency screening' (2000) 8 *Br J Midwifery* 632-637; Mulvey, W., Wallace, E. 'Women's knowledge of and attitudes to first and second trimester screening for Down's Syndrome' (2000) 107 *J Obstet Gynaecol* 423-436.

[188] Smith, D.K., Shaw, R.W., Marteau, T. 'Lack of knowledge in health professionals: a barrier to providing information to patients' (1994) 3 *Qual Health Care* 75-78; Abramsky, L., Hall, S., Levitan, J., Marteau, T.M. 'What parents are told after prenatal diagnosis of a sex chromosome abnormality: interview and questionnaire' (2001) 322 *BMJ* 463-466.

[189] Statham, H., Green, J. 'Serum Screening for Down's Syndrome: Some women's experiences' (1993) 307 *BMJ* 174.

Each of these explanations will now be focused upon in an attempt to understand why women's 'choices' are being undermined. When the various arguments put forward in this chapter are combined, the suggestion that, in practice, informed consent is not obtained for PND and PNS becomes powerful.

4.4.3 Routinisation

Women are under some social pressure to undergo prenatal screening tests and diagnosis. There is evidence that many of those who agree to participate in screening programs do so only in response to an invitation and may not feel free to decline if the request is made by health professionals.[190] For example, in response to the HGC consultation, the British Medical Association said:

> "Some forms of prenatal screening are offered as "routine" and some women have reported difficulties in declining them... The possibility of declining all forms of prenatal screening and testing should be presented as a reasonable and acceptable option."[191]

Pregnant women and their partners need practical freedom to consent to, or decline, prenatal screening tests and diagnosis without undue pressure from health professionals or government health departments. There is no ethical duty to have them, nor should women be made to feel guilty if they decline.[192] This argument was supported by a report by the National Childbirth Trust published in 1997 that claimed the right of parents not to have ante-natal testing is being undermined by health professionals.[193]

Prenatal screening for foetal abnormalities is now a routine component of modern antenatal care in many countries.[194] Ultrasound scanning is routinely available as both a

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[190] Bekker, H., *et al n.5* above.

[191] Human Genetics Commission *n.67* above, at p21.

[192] Ford, N.M. n.68 above, at p203.

[193] See Dodds, R. Newburn, M. 'The stress of tests in pregnancy: women's experiences.' (1997) 9 *Changing Childbirth Update* 4.

[194] Statham, H. *n.83* above.

screening and diagnostic test.[195] And there is a belief among patients, who are receiving information in the screening context, that the tests they are undergoing are 'routine.'[196] It was Farrant who first drew attention to the dichotomy in attitudes towards prenatal testing between health professionals, who saw testing as means to detect abnormalities, and parents who sought reassurance about the absence of those abnormalities.[197] Such a view can still be found to prevail among many parents who embark upon the 'ritual of reassurance'[198] when they undergo screening tests.[199] Such findings clearly raise questions around whether women who see screening as a means of reassurance are making an informed choice about undergoing tests.[200] Many women therefore approached the scan not as a procedure that may reveal anomalies, but as a routine procedure that allows them to see their baby and to confirm that all is well.[201] Indeed, a third of women in Whynes' study appeared not to appreciate that scans could result in the detection of anomalies.[202] Currently, prenatal screening is too often presented as part of routine care, the purpose of which is purportedly to ensure the health of the baby, rather than as a test for potential disabilities that parents may wish to avoid.[203]

4.4.3.1. Evidence of routinisation

In 2001, the specialist antenatal subgroup of the UK National Screening Committee announced a program of second trimester serum screening to be offered nationally to all

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[195] *Ibid.*

[196] Human Genetics Commission *n.67* above, at p19.

[197] Farrant, W. n.101 above, at pp90-177.

[198] Press, N., Browner, C. n.117 above.

[199] FARRANT, W. n.101 above, at p90-177; Press, N., Browner, C.H. n.117 above; Green, J.M., Snowden, C., Statham, H. 'Pregnant women's attitudes to abortion and prenatal screening' (1993) 11 *J Reprod Inf Psychol* 31-39; Weinans, M., *et al.* n.126 above; Williams, C., Alderson, P., Farsides, B. n.115 above; Green, J.M. 'Women's experiences of prenatal screening and diagnosis' in Abramsky, L., Chapple, J. (eds) *Prenatal Diagnosis: The Human Side* (London, Chapman and Hall, 1994).

[200] Marteau, T. Dormandy, E. 'Facilitating Informed Choice in prenatal testing: How well are we doing?' (2001) 106 *Am J Med Genetics* 158-190; Statham, H., Solomou, W., Chitty, L. 'Prenatal diagnosis of fetal abnormality: psychological effects on women in low-risk pregnancies' (2000) 14 *Balliere's Clin Obstet Gnaecol* 731-47.

[201] Green, J.M., Statham, H. 'Psychosocial aspects of prenatal screening and diagnosis' in Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996) pp140-63.

[202] Whynes, D.K. 'Receipt of information and women's attitudes towards ultrasound scanning during pregnancy' (2002) 19 *Ultrasound Obstet Gynecol* 7-12.

[203] Parens, E., Asch, A. 'The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) pp3-43 at p34.

pregnant women.[204] Clearly, for women over 35, and increasingly for younger women, prenatal testing – with all its consequences – has become the norm. Societal norms exercise their own pressures for compliance. In one way or another, then, the use of prenatal testing affects all pregnancies.[205] Whether the clinician is a genetics professional or (as is increasingly the case) an obstetrician promoting prenatal diagnosis as routine care for pregnant women, the tone, timing, and content of the counselling process cry out for drastic overhaul.[206] Ultrasound screening is performed routinely on almost every pregnant woman appearing for prenatal care early enough in pregnancy. And although ultrasound is not usually labelled as "prenatal diagnosis", it not only belongs under this rubric but was the first form of prenatal diagnosis for which informed consent was not obtained.[207]

Dormandy *et al* report that higher rates of screening are achieved when a test is offered as part of a routine visit or service,[208] partly because particularly in the prenatal setting, the offer of a test can be seen as a recommendation.[209] Whilst high uptake rates of routine first trimester screening have been equated with the screening service being viewed 'very favourably' by women,[210] it remains to be seen whether uptake under such conditions results in the most informed choices.[211] There are doubts about whether mothers are properly informed and whether they understood the true implications of a genetic test.[212]

A study by Jo Green in 1994 demonstrated the number of doctors routinely offering specified tests to all, some, or no women in their care:[213]

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[204] www.doh.gov.uk/nsc/antenatal_screen/antenatal_screen_ind.htm.

[205] Kolker, A., Burke, B.M. n.86 above, at p6.

[206] Asch, A. 'Prenatal diagnosis and selective abortion: a challenge to practice and policy' (1999) 89(11) *Am J Public Health* 1649-57.

[207] Lippman, A. *n.*78 above.

[208] Dormandy, E. 'Better understanding of factors influencing uptake is needed' (1999) 318 *BMJ* 806

[209] Press, N., Browner, C.H. n.117 above.

[210] Spencer, K., Spencer, C., Power, M., Moakes, A., Nicolaides, K. 'One stop clinic for assessment of risk for fetal anomalies: a report of the first year of prospective screening for chromosomal anomalies in the first trimester' (2000) 107 *Br J Obstet Gynaecol* 1271-1275.

[211] Kerr, A., Cunningham-Burley, S., 'On ambivalence and risk: reflexive modernity and the new human genetics' (2000) 34 *Sociology* 283-304.

[212] Jallinoja, P. 'Genetic Screening in maternity care: preventive aims and voluntary choices' (2001) 23(3) *Sociology of Health and Illness* 286-307.

[213] Green, J.M. n.113 above.

Fig. 10. A table to show some of the results from Green's study[214] (% in brackets)

Test	All	Some
Ultrasonography: anomaly scanning	302 (85)	51 (14)
Ultrasonography: dating scan	292 (83)	57 (16)
Serum screening for Down's Syndrome	184(52*)	143 (40)
Serum screening for neural tube defects	252 (71)	53 (15)
Serum screening for toxoplasmosis	6 (2)	167 (47)

* plus 2% who only offer the test privately

This demonstrates that ultrasound is a routine test offered to the majority of women. Serum screening for Down Syndrome is offered to at least some women. It is probable that serum screening for other conditions is not routinely offered initially but only after ultrasound (which is offered routinely) indicates a clinical need for further tests. More recent NICE guidelines state that all pregnant women should be offered an ultrasound scan between 18-20 weeks, and all pregnant women should be offered screening for Down's Syndrome between 11-14 weeks.[215] This indicates that screening is now offered more routinely than the results of Green's survey suggest.

In the recent HGC consultation, there was support for the proposal that screening should not be routinely offered to all pregnant women but, for example, only when recommended by a GP, or if there is a family history of a particular disorder that may include previous experience of affected children or pregnancies. Other risk factors, such as the age of the woman, were also cited as appropriate selection criteria, where they may be relevant.[216] Indeed, some respondents warned that a battery of tests should not be presented as 'routine' in the same way as, for example, an ultrasound or monitoring the mother's blood pressure. This is illustrated by the following quote:

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[214] *Ibid.*

[215] National Institute for Clinical Excellence *Antenatal Care: routine care for the healthy pregnant woman* (London, RCOG Press, 2003).

[216] Human Genetics Commission *n.67* above, at p5.

> "Some concern was expressed about the 'medical culture' which surrounds screening making it seem a 'routine' which some women may regard as reassuring without being sufficiently aware that it may lead to the diagnosis of a genetic condition." (Royal College of Nursing)[217]

Evidence presented by the ESRC Innovative Health Technologies Project Team on the social implications of one-stop first trimester prenatal screening suggests that the more screening is made routine, the greater the uptake. This is supported by other studies.[218] There is some evidence to suggest that uptake following the offer of a test as part of a routine visit is based on poorer knowledge than when it requires a separate visit.[219] Women informed that they are 'at-risk' may find it hard to refuse prenatal diagnosis or other measures that are advertised to be risk-reducing.[220] As the number of factors or people labelled as risks or at-risk increases, so, too, will offers of intervention.[221]

I have now offered evidence that demonstrates the routine nature of PND. Many of the studies referred to in this section highlight that many women do not understand the tests they are having, or what they are testing for. It is clear that for such women they are not making an informed choice. I will now explore the information provided by doctors. This will demonstrate further the lack of informed choice in the areas of PNS and PND.

4.4.4 Information provided by professionals

This section aims to address some of the issues associated with the information provided by health professionals to prospective parents.

Initially, it is important to recognise that individual needs for information vary, as do the decision making processes individuals adopt. A key argument in this thesis is that

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[217] Human Genetics Commission *n.67* above, at p22.

[218] Lorenz, R.P., Botti, J.J., Schmidt, C.M., Ladda, R.L. 'Encouraging patients to undergo prenatal genetic counselling before the day of amniocentesis' (1985) 30 *J Reprod Med* 933-935; Bekker, H. *et al n.5* above; Dormandy, E., *et al.* n.126 above; Tambor, E.S., Bernhardt, B.A., Chase, G.A., Faden, R.R., Geller, G., Hofman, K.J., Holtzman, N.A. 'Offering cystic fibrosis carrier screening to an HMO population: factors associated with utilization' (1994) 55 *Am J Hum Genet* 626-637.

[219] Tambor, E.S., *et al. Ibid.*

[220] Lippman, A. n.78 above.

[221] *Ibid.*

decisions are generally not made in a social vacuum; rather, many social factors can influence decision making.[222] There is evidence for this argument in psychology texts.[223] For instance, even if an individual is making a decision, she may feel accountable to others such as family members.[224] Simonson,[225] for example, has shown that the need to justify a decision to others causes the choice to be more sensitive to certain aspects of the decision task.[226]

When no information is processed about the characteristics of the alternatives being considered, the answer is simply based on prior evaluations of the alternatives.[227] In this way, automatic or 'gut reactions' can be important, prevalent and may be efficient and effective in the decision making process.[228] In the context of prenatal decisions, this could mean that for some women/ couples who prefer not to confront difficult decisions by analysing the available information, they instead rely on any previous attitudes, experiences, knowledge, preconceptions to the problem they previously had. In the case of disability, many people make negative assumptions about disability and so it could well be that in this situation when relying on such assumptions, people are more willing to prevent disabled lives.

As a result of the literature review conducted for this research, it is possible to identify several problems relating to the information provided by professionals, which will now be explained and considered:

1. health professionals are very influential over decisions, yet their knowledge varies;
2. the amount of information provided;
3. the way in which the information is displayed;
4. the timing of the information;

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[222] See fig. 7. Introduction to the expressivist argument (chapter 3).

[223] For example, see Tetlock, P.E. 'Accountability: The neglected social context of judgement and choice' (1985) 7 *Research in Organizational Behavior* 297-332.

[224] Payne, J.W., Bettman, J.R., Johnston, E.J. *The Adaptive Decision Maker* (Cambridge: Cambridge University Press, 1993) at p3.

[225] Simonson, I. 'Choice based on reasons: The case of attraction and compromise effects' (1989) 16 *Journal of Consumer Research* 158-174.

[226] Payne, J.W., *et al.* n.224 above, at p3.

[227] *Ibid,* at p11.

[228] Klein, G. *Sources of Power: How people make decisions* (Cambridge, MA, The MIT Press, 1999).

5. the way in which parents are informed of the results;
6. doctors often presume a certain level of existing knowledge in women;
7. the balance of the information provided;
8. the information provided about the disabilities being tested for.

For information, parents will turn to the health professionals informing them of the diagnosis. However these health professionals may vary both in their knowledge of the conditions and their perception of the quality of life in those affected by the conditions.[229] Furthermore, there is evidence to suggest that decision makers may be vulnerable to strategic manipulation by others[230] and that outcomes can depend on how the questions are asked.[231] It is therefore clear that the way information is delivered can affect the decision made. Tversky and Kahneman have shown how subtle differences in the way information is presented, or framed, will affect decisions made.[232]

Since most parents are unprepared for a diagnosis following PND and very few are familiar with these conditions,[233] the information given by health professionals is likely to be of critical importance in guiding their decisions about the pregnancy.[234] Each individual seeking information will have individual needs: for example, their personal characteristics such as style, language, social background, ethnicity, age and gender will have an impact on their decision. This may influence how individual patients respond to the information that is being conveyed, and hence how they asses its sufficiency. Individuals vary in their need for and interest in information when facing a decision.[235] Furthermore, factors intrinsic to the individual such as their mood, their past experience and knowledge, their expectations, their perception of time pressure, and their perception of outcome can also influence decision making. In addition, other factors extrinsic to the individual may also have a role such as the pressure of time, more than one individual being involved in the decision and the extremely high stakes, can all be affected by minor

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[229] Hall, S., Abramsky.L, Marteau, T. n.122 above. This point is discussed in more detail in the QL chapter (chapter 5).

[230] Payne, J.W., n.224 above, at p6.

[231] *Ibid,* at p8.

[232] Tversky, A., Kahneman, D. n.181 above.

[233] Robinson, A., Bender, B.G., Linden, M.G. 'Prognosis of prenatally diagnosed children with sex chromosome aneuploidy' (1992) 44 *Am J Med Genet* 365-368.

[234] Hall. S., Abramsky, L., Marteau, T.M. n.122 above, at p535.

[235] Miller, S.M., Mangan, C.E. n.8 above.

changes in the task environment.[236] Individuals with different outcomes of screening will recommend the provision of differing amounts and types of information.[237]

PND can be a stressful experience and although information is necessary in order to ensure informed decision making, it has been suggested that prospective parents may have to contend with perhaps the most unforeseen consequence of all: too much information; that is, information they never realized the testing might yield and information they are not emotionally equipped to handle.[238] This can lead to excess anxiety and confusion for patients.[239] It has been said that too much information may be viewed as a burden by some patients and this raises the question of how much information is considered necessary for an individual to be able to make an informed choice.[240] However, exactly what constitutes 'too much' has never been quantified, and the view that leaving out information reduces anxiety lacks empirical support.[241] In fact, there is support that including information actually facilitates informed decision making.[242] Many studies show that increasing the amount of information about alternatives increases both subjects' confidence in their judgements and the variability of responses.[243] This has implications for the information-giving process both prior to and after screening. Many of those in favour of prenatal screening programmes emphasise the importance of high quality and appropriate counselling of patients, especially those who go on to have diagnostic testing. This requires additional training for existing medical staff – doctors, nurses and counsellors – as well as the potential for additional staff resources.

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[236] Payne, J.W., n.224 above, at p1.

[237] Michie, S., Dormandy, E., Marteau, T.M. 'Informed choice: understanding knowledge in the context of screening uptake' (2003) 50 *Patient Education and Counseling* 247-253.

[238] Kolker, A., Burke, B.M. n.86 above, at p164; Payne, J.W., *et al.* n.224 above, at p36.

[239] Brunger, F., Lippman, A. 'Resistance and adherence to the norms of genetic counselling' (1995) 4 *J Genet Counsel* 151-167; Oliver, S., Rajan, L., Turner, H. *et al* 'Informed choice for users of health services: views on ultrasonography leaflets of women in early pregnancy, midwives, and ultrasonographers' (1996) 313 *BMJ* 1251-1255.

[240] Human Genetics Commission *n.67* above, at p20.

[241] Bryant, L.D., Murray, J., Green, J.M. Hewison, J., Sehmi, I., Ellis, A. 'Descriptive information and Down Syndrome: a content analysis of serum screening leaflets' (2001) 21 *Prenatal Diagnosis* 1057-1063 at p1061.

[242] *Ibid.*

[243] Slovic, P., Lichtenstein, S. 'Comparison of Bayesian and regression approaches to the study of information processing in judgement' (1971) 6 *Organizational Behaviour and Human Performance* 649-744.

Conversely, there is a belief that prospective parents receive too little, or inadequate information. In Abramsky *et al*'s study, a father wrote:

> "The consultant appeared to know little about the condition but seemed to expect us to make a judgement based on the fact that an abnormal result had occurred. I am glad that we insisted on finding out more about the condition before we were willing to make our decision, otherwise we could have decided to terminate through ignorance alone – instead we now have a lovely son."[244]

Factors such as how information is displayed, can affect how much cognitive effort is needed to implement various strategies (processability).[245] Slovic says that decision makers will tend to use only the information that is explicitly displayed in the stimulus object and will use it only in the form in which it is displayed.[246] Russo argued that making information available is not sufficient; information must be easily processable.[247] Furthermore, Fischhoff *et al* showed how the apparent completeness of the display can fail to alert a decision maker to the possibility of information that is missing from a problem description. So it seems that if a leaflet looks complete, then people will not question that any information is missing. Also if doctors do not paint a complete picture, patients rarely question doctors' portrayal of events. This is very important in relation to information provided about disability and even more so when the status of doctors and their influence is considered.[248]

Information on screening is often reported as having been vague[249] and insufficient for informed decision making, providing too little information, which is occasionally misleading or inaccurate.[250] Several factors could explain this. First, health professionals themselves sometimes do not have sufficient knowledge about the tests.[251]

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[244] Abramsky, L., *et al.* n.188 above, at p465.

[245] Payne, J.W., *et al.* n.224 above, at p4.

[246] Slovic, P. 'From Shakespeare to Simon: Speculation – and some evidence – about man's ability to process information' (1972) 12(3) *Oregon Research Institute Bulletin.*

[247] Russo, J. E. 'The value of unit price information' (1977) 14 *Journal of Marketing Research* 193-201

[248] Discussed earlier in this chapter.

[249] Bryant, L.D., *et al.* n.241 above, at p1060.

[250] Marteau, , T.M., Slack, J., Kidd, J., Shaw, R.W. 'Presenting a routine screening test in antenatal care: practice observed' (1992) 106 *Public Health* 131-141; Bernhardt, B.A., *et al.* n.119 above.

[251] Smith, D.K., *et al.* n.188 above; Sadler, M. 'Serum screening for Down's Syndrome: how much do health professionals know?' (1997) 104 *Br J Obstet Gynaecol* 176-179.

Second, they can lack even basic counselling skills.[252] Third, they may lack the time to present the information.[253] More generally, the lack of high-quality information provided at many centres may reflect negative attitudes towards providing such information.[254]

The problems with the timing of the information presented were identified in the HGC consultation.[255] At present, the majority of information is felt to be too heavily concentrated on the booking stage, that is, the first appointment in the antenatal clinic. This is believed by many to be inadequate because of the considerable number of other issues that must also be addressed in this appointment.[256] Many respondents felt that there was a need for more information before the booking stage, e.g. at referral, in order to fully inform patients of what to expect before they enter the clinic and are presented with the decision about screening. There were also concerns about the extent of counselling at later stages of the process, particularly where the patient is found through screening to be at higher risk and is offered confirmatory or diagnostic testing. However if there is a positive result on the amniocentesis, then a further, post-test session should occur – a third opportunity for counselling. There is not yet consensus on the feasibility of providing disability-relevant information in the post-test genetic counselling.[257] Antenatal Results and Choices summarise the position well in their response to the HGC consultation when they say:

> "If the bulk is given at booking, it is vital that this information is checked, consolidated and expanded if necessary as women move through the testing process, so they know the possible outcomes and implications of each step of the process. It is important to bear in mind that women's information needs vary and each individual woman will also have varying needs depending on where she is in the process and what happens to her."[258]

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[252] Smith, D.K., Shaw, R.W., Marteau, T.M., Slack, J., 'Training obstetricians and midwives to present screening tests: evaluation of two brief interventions' (1995) 15 *Prenatal Diagnosis* 317-324

[253] Green, J.M. n.113 above.

[254] *Ibid;* Khalid, L., Price, S.M., Barrow, M. 'The attitudes of midwives to maternal serum screening for Down's Syndrome' (1994) 108 *Public Health* 131-136.

[255] Human Genetics Commission n.67 above, at p18.

[256] Human Genetics Commission n.67 above, at p18.

[257] Parens, E., Asch. A. n.203 above, at p35.

[258] Human Genetics Commission *n.67* above, at p19.

The problems relating to the way parents are informed was highlighted by Abramsky *et al* who state that:

> "It is disturbing to note the haphazard nature of how parents were informed of the diagnosis, what information was given, and what was implied. Some maternity units in the study reported that they had a set protocol for giving results whereas in others the reporting seemed to be done on an ad hoc basis. Many health professionals said that it was a matter of chance that they had been the one to inform the parents of the results. What and how parents were told depended to a large extent on where they had their pregnancy care and who informed them of the results. Although there were some examples of excellent counselling, there were other examples of grossly inadequate or frankly misleading information being given."[259]

There is sometimes an assumption that by the time couples reach the clinician they are adequately informed. This was proven not to be the case in studies conducted by Smith *et al.*[260] There is substantial evidence which highlights that the information women/ couples are given about the conditions tested for is particularly problematic. Bryant *et al* argue that information provided about Down Syndrome is inadequate as it is often considered unnecessary because women already have sufficient knowledge of Down Syndrome.[261] The information provided is intended to *remind* women about Down Syndrome, rather than to inform them.[262] However, the assumption of existing knowledge about Down Syndrome may be misconceived, as research shows that many women feel that they have little real knowledge of either its effects or of affected persons.[263] Any knowledge they do have may be based on inaccurate information, myth or stereotypes.

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[259] Abramsky, L., *et al.* n.188 above, at p466.

[260] Smith, D.K., *et al.* n.188 above.

[261] Bryant, L.D., *et al.* n.241 above, at p1061.

[262] Bryant, L.D., *et al.* n.241 above, at p1061.

[263] Gekas, J., *et al.* n.126 above; Moyer, A., Brown, B., Gates, E., Daniels, M., Brown, H.D., Kupperman, M. 'Decisions about prenatal testing for chromosomal disorders: perceptions of a diverse group of pregnant women' (1999) 8 *J Womens Health Gend Based Med* 521-531; Carroll, J.C., Brown, J.B., Reid, A.J., Pugh, P. 'Women's experience of maternal serum screening' (2000) 46 *Can Fam Physician* 614-620

Williams *et al* discovered that although women were seen to vary in their knowledge about Down's Syndrome, practitioners felt that many did not understand the basic features of the condition. Practitioners themselves rarely had any practical experience or knowledge of people with a disability. This led to a reliance on 'medical textbook' information, which tends to focus primarily on the potential problems of the condition. Due to lack of time, practitioners also relied on the use of information leaflets. Education about conditions set within a broader context of disability could help to avoid the 'checklist' type approach used by many respondents.[264] The first, crucial step in helping parents achieve truly informed consent and make truly informed decisions is to give providers access to good information about what disability is really like for children with disabilities and their families.[265] Having explained that there is often a presumption of knowledge made by the doctors, it is now necessary to focus in detail on the balance of the information provided.

4.4.4.1. The Balance of Information provided

The GMC[266] deems it is necessary to explain five points to patients in the PND context: the purpose of screening; the likelihood of positive and negative findings, alongside the possibility of false positives and false negative findings; the uncertainties and risks attached to the screening process; any significant medical, social or financial implications of screening; and follow-up plans including the availability of counselling and support services. This advice does not include any discussion of the conditions tested for or the nature of life with that disability, nor does it mention describing any conditions or disabilities. Instead the focus is on the tests, the implications of the results and the reliability of the results.

Alternatively, in their guidance, the Down Syndrome Congress suggested that prospective parents who learn that their foetus has a disabling trait need to receive information on the following:

> "(a) information that seeks to dispel common misconceptions about disability and present disability from the perspective of a person with a disability;

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[264] Williams, C., Alderson, P., Farsides, B. n.114 above, at p230.

[265] Parens, E., Asch. A. n.203 above, at p34.

[266] General Medical Council n.3 above.

(b) information on community-based services for children with disabilities and their families as well as on financial assistance programs;

(c) materials on special needs adoption; and

(d) a summary of major laws protecting civil rights of persons with disabilities. [Also], people with disabilities and parents of people with disabilities should be available to talk with future parents."[267]

The information provided at present differs from this guidance, as there is a focus on the science behind the tests and conditions rather than on the effects of the conditions themselves.[268] This is a result of the medical rather than the social model of disability being dominant: the condition is seen as a medical one without social context. For example, the ESRC Innovative Health Technologies Project Team on the social implications of one-stop first trimester prenatal screening responded to the HGC Consultation[269] saying that "84% of women also reported that discussions of what it is like to have a child with Down's Syndrome never happened."[270] In Abramsky *et al*'s study, one mother wrote: "In retrospect, I feel rather shocked that parents in our situation should have so routinely be offered the option of termination – particularly without first being offered appropriate counselling… [I] felt that research papers we were shown at the hospital were both outdated and one sided."[271]

It has been recommended that prior to prenatal screening for foetal abnormality, parents should be provided with information about the condition being tested for, and about the tests and testing procedure. Such information is considered necessary to facilitate autonomous and informed decision making.[272] To date, however, research in the area of informed consent has focused mainly on the information provide about the procedures, and little attention has been given to information about the condition or conditions being tested for. This is surprising, as a major factor in the decision to terminate for

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[267] National Down Syndrome Congress *Position Statement on Prenatal Testing and Eugenics: Families' Rights and Needs* (London, NDSC).

[268] This will be demonstrated further in leaflet analysis section.

[269] Human Genetics Commission *n.67* above.

[270] *Ibid,* at p16.

[271] Abramsky, L., *et al.* n.188 above.

[272] Royal College of Physicians n.87 above; Marteau, T. 'Towards Informed Decisions about Prenatal Testing: A Review' (1995) 15 *Prenatal Diagnosis* 1215-18.

abnormality is known to be the perceived severity of the condition identified.[273] Great play is made of neutral and objective counselling. The first aim of genetic counselling is to comprehend the medical facts, including the diagnosis, the probable course of the disorder and the available management.[274] Again, this could explain the scientific slant to information provided.

In both diagnostic and screening settings many prospective parents feel that there is a lack of detail on the genetic conditions themselves and the realities of living with a genetic disorder (both for the parent and the child) currently given during the testing and counselling process. Bryant *et al* believe that the bias towards medico-clinical information in the leaflets may well be a better reflection of the knowledge and perspectives of the professionals writing them than of the needs of the women receiving them.[275]

Loeben *et al* found through their research that the majority of information presented about Down Syndrome (89%) was of medico-clinical nature, with only 11% addressing social, educational or psychosocial issues.[276] Down Syndrome is as much an educational and social concern as a medical one,[277] yet 33% of the leaflets contained no descriptive information. More description usually equated to more medico-clinical detail.[278] Overall a negative imagine of Down Syndrome was conveyed by the leaflets. Many items of information were rather vague.[279] Williams *et al* found that practitioners felt more time was often spent describing and explaining the complexities of the actual screening process than the condition(s) being screened.[280] Yet previous studies of information recalled after genetic counselling found that patients judged information about family

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[273] Verp, M.S., Bombard, A.T., Simpson, J.L., Elias, S. 'Parental decision following prenatal diagnosis of fetal chromosome anomalies' (1988) 29 *Am J Med Genetics* 613-22; Drugan, A., Greb, A., Johnson, M.P., Krivchenia, E.L., Uhlmann, W.R., Moghissi, K.S.*et al* 'Determinants of parental decisions to abort for chromosome abnormalities' (1990) 10 *Prenatal Diagnosis* 483-90; Evans, M.I., Sobiecki, M.A., Krivchenia, E.L. *et al* 'Parental decisions to terminate/continue following abnormal cytogenic prenatal diagnosis: "what" is still more important than "when"' (1996) 61 *Am J Med Genet* 353-355

[274] Michie, S., Marteau, T.M. 'Genetic counselling: some issues of theory and practice' in Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996) at p104.

[275] Bryant, L.D., *et al*. n.241 above, at 1062.

[276] Bryant, L.D., *et al*. n.241 above, at p1060.

[277] Bryant, L.D., *et al*. n.241 above, at p1062.

[278] Bryant, L.D., *et al*. n.241 above, at 1061.

[279] Bryant, L.D., *et al*. n.241 above, at 1060.

[280] Williams, C., Alderson, P., Farsides, B. n.114 above, at p232.

implications to be important more frequently than did genetic counsellors.[281] While genetic counsellors apparently consider diagnostic and prognostic information about a condition as most important, their clients rate knowledge about how a child with the condition may affect the family functioning more highly.[282] As such, the information provided about the conditions for which testing is provided tends to be brief.[283] Information is less often given about the impact of living with a child with a disability, including the educational and medical support that is available, and the likely impact of such a choice upon family life.[284]

It is really important to provide information about life with disability. Although this is not because it will convince prospective parents to raise disabled children, it may well convince them that that path is not one they wish to travel.[285] The typical woman or couple discussing prenatal testing and possible pregnancy termination knows very little about the conditions for which testing is available, much less what these conditions might mean for the daily life of the child and the family. People who do not already have a child with a disability and who are contemplating prenatal testing must learn considerably more than the names of some typical impairments and the odds of their child having one.[286] Providing more accurate information about an individual's life with disabilities and assuring that people in general have more contact with such individuals in the course of their daily lives[287] may help prevent some couples from being coerced into testing or abortion. Personal knowledge of a particular disorder can diminish the tendency of people to unthinkingly seek a 'genetic fix.' In a study of parents of children with cystic fibrosis; only 29% said they would abort for that disorder.[288] Sociologist Kitty Felker interviewed twenty mothers of children with Down Syndrome. These mothers reported that before their babies were born, "clinicians had stressed the horrors of life with disabilities," while their families themselves described instead the

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[281] Michie, S., McDonald, V., Marteau, T.M. 'Genetic Counselling: information given, recall and satisfaction' (1997) 32 *Patient Educ Couns* 101-6.

[282] Michie, S ., Marteau, T.M., Bobrow, M. 'Genetic counselling: the psychological impact of meeting patients' expectations' (1997) 34 *J Med Genet* 237-241; Michie, S., Smith, D., McClennan, A., Marteau, T.M. 'Patient decision making: an evaluation of two different methods of presenting information about a screening test' (1997) 20 *Br J Health Psychol* 317-326.

[283] Murray, J., *et al.* n.69 above; Marteau, T.M., *et al.* n.250 above.

[284] Marteau, T. Dormandy, E. n.200 above.

[285] Parens, E., Asch. A. n.203 above, at p37.

[286] Asch, A. n.206 above, at p1654.

[287] This could result from better discrimination laws and removing social barriers to disability.

[288] Wertz, D.C., Rosenfield, J.M., Janes, S.R. Erbe, R.W. 'Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis' (1991) 81 *Am J Pub. Health* 992.

satisfactions of parenting children with disabilities.[289] Health professionals may have been reluctant to provide positive information to parents who had already indicated that they would terminate the pregnancy prior to being given any information about the condition.[290]

An earlier commentary on this matter observed that information about CF and Down Syndrome differed in tone on whether the material was intended for prospective parents or for parents who had already given birth to an affected child. The prenatal material was mostly negative in tone and focused on medical problems and limitations imposed by the condition, whereas the postnatal material was more positive emphasising medical and social advances and compensating aspects of the condition.[291]

At this stage, it has been established that the information presented by professionals focuses on the medical and scientific basis of the conditions and is based on the medical model of disability. It has also been shown how the information provided can influence decisions. This study will now focus on the information provided by professionals about the effects of disability.

4.4.4.2. Information provided about the effects of disability

Williams *et al* quote one midwife who said that when describing Down's Syndrome she would include things like "an increased risk of heart defects, they are incontinent [N.B. inaccurate information], usually they have a low IQ, but that can be a spectrum from one extreme to another, some are severely disabled and some are relatively 'normal', so you have to go through the whole of that with them."[292] To a pregnant woman being offered a test for Down Syndrome, the information that 40% of affected children will have a heart defect is likely to be viewed negatively.[293] The potential of information to generate an emotional response should be taken into consideration before providing parents with a

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[289] Fore more discussion see QL chapter (chapter 5). Felker, K.S. 'Controlling the Population: Views of Medicine and Mothers' (1994) 11 *Research in Sociology in Health Care* 25-38.

[290] Hall, S., Abramsky.L, Marteau, T. n.122 above.

[291] Asch, A. n.206 above; Lippman, A., Wilfond, B.S. 'Twice-told tales: stories about genetic disorders' (1992) 51 *Am J Hum Genet* 936-937; Loeben, H.L., Marteau, T.M., Wilfond, B.S. 'Mixed messages: presentation of information in cystic fibrosis screening pamphlets' (1998) 62 *Am J Hum Genet* 1181-1189

[292] Williams, C., Alderson, P., Farsides, B. n.114 above, at p233.

[293] Bryant, L.D., *et al.* n.241 above,at p1062.

long list of the medical probabilities associated with Down Syndrome.[294] The point here is not to deny that this is important information, rather that there should be a balanced description. Bryant *et al* continue to suggest the following as an alternative description: "40% of children with Down's Syndrome are born with heart defects, which can be serious and require surgery. However, treatment for these conditions continues to advance and the degree to which they are life-threatening or limit achievement and well-being is reducing."[295] Loeben and colleagues proposed that descriptive information should include "sufficient positive statements to achieve balance with the neutral and negative ones."[296] Williams *et al* quote one paediatrician who thinks that some people "are not necessarily given a realistic picture of what the outlook will be for their unborn child, that too black a picture may be painted, and maybe by people who don't actually know themselves."[297]

It is argued that information about predictable difficulties, supports, and life events associated with a disabling condition need to be provided to enable prospective parents to consider how a child's disability would fit into their own hopes for parenthood is critical to helping parents come to terms with having a baby who may be affected by a genetic disorder, and to making this a real and viable alternative to termination. Asch believes that such information for all prospective parents should include, at a minimum, a detailed description of the biological, cognitive or psychological impairments associated with specific disabilities, what those impairments imply for day-to-day functioning; a discussion of the laws governing education, entitlements to family support services, access to buildings and transportation, and financial assistance to disabled children and their families; and literature by family members of disabled children and by disabled people themselves.[298] If prenatal testing indicates a disabling condition in the foetus, she then argues that the following disability-specific information should be given to the prospective parents: information about services to benefit children with specific disabilities in a particular area, and about which of these a child and family are likely to need immediately after birth; contact information for a parent-group representative; and contact information for a member of a disability rights group or independent living

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[294] Bryant, L.D., *et al.* n.241 above,at p1062.

[295] Down's Syndrome Association *Prenatal Testing for Down's Syndrome* (London, Down's Syndrome Association, 1996).

[296] Loeben, H.L., *et al.* n.291 above, at p1187.

[297] Williams, C., Alderson, P., Farsides, B. n.114 above, at 234.

[298] Asch, A. n.206 above, at p1655.

centre. In addition, the parents should be offered a visit with both a child and family and an adult living with the diagnosed disability.[299]

Although Asch recognises that some prospective parents will reject some or all of this information and these contacts, responsible practice that is concerned with genuine informed decision making and true reproductive choice must include access to this information, timed so the prospective parents can "assimilate general ideas about life with disability before testing and obtain particular disability-relevant information if they discover that their foetus carries a disabling trait."[300]

In order to make testing and selecting for or against disability consonant with improving life for those who will inevitably be born with or acquire disabilities, our clinical and policy establishments must communicate that it is as acceptable to live with a disability as it is to live without one and that society will support and appreciate everyone with the inevitable variety of traits.[301] Such information could be provided within the counselling context through contact, either with those who already live with the condition in question, or with the support networks that surround them. As Disability Awareness in Action wrote for the HGC Consultation:

> "Parents need to know about the realities of a particular impairment/condition, but they also need to know about the lived experience from disabled people themselves. They also need to be aware of the resources and services available to disabled children and adults with regard to independent living, education etc. This is not something doctors have expertise in."[302]

There has, however, been some resistance to this idea. For example, Williams *et al* quote one midwife recalling a consultant who thought "the Down's Syndrome Society were quite unfair because they always seemed to bring the children with Down's Syndrome who were doing the best, like going to mainstream schools[303] and he thought that was

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[299] *Ibid.*

[300] *Ibid.*

[301] *Ibid,* at p1656.

[302] Human Genetics Commission *n.67* above, at p16.

[303] N.B. attendance at mainstream schools tend to depend less on IQ than on local education policies according to Alderson, P., Goodey, C. *Enabling education: Experiences in special and ordinary schools* (London, Tufnell Press, 1998).

quite bad really, and we should be more realistic showing children who are more disabled, so that parents can make a choice knowing what they could be confronted with at the end of the pregnancy."[304]

It has been suggested elsewhere that parent support groups or Down Syndrome associations are more appropriate sources of information.[305] Nevertheless, they too have a particular viewpoint that cannot be considered completely impartial. As Lippman and Wilfond[306] point out, the 'storyteller' inevitably shapes summary information of this kind, as he or she must decide what to include and what to exclude from the vast amount of material available.[307]

The literature review completed for this project has highlighted that truly informed consent is rarely obtained and that the information provided to inform patients is inadequate. If these conclusions are accurate, it should be possible to identify these themes in the literature provided by the NHS to women/ couples considering PND/ PNS.

4.4.4.3. Leaflet analysis

A number of studies have identified specific problems with oral information given by health professionals, including inadequate knowledge, negative and paternalistic attitudes and limited time.[308] For the purposes of this study it was not possible to gain access to counselling sessions in order to observe oral information, instead, the focus of the remaining section will be on analysis of leaflets provided to inform prospective couples about amniocentesis, Thalassaemia and Down's Syndrome.[309] There are several regional genetics centres which offer these techniques. By using the 'Google' search engine[310] it was possible to locate a list of these on the 'contact a family' website.[311] The 'contact a

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[304] Williams, C., Alderson, P., Farsides, B. n.114 above, at p234.

[305] Birke,L., Himmelweit, S., Vines, G. *Tomorrow's Child: Reproductive Technologies in the 90s* (London, Virago, 1990).

[306] Lippman, A., Wilfond, B.S. n.291 above.

[307] Bryant, L.D., *et al.* n.241 above, at p1062.

[308] For example, see Green, J.M. n.113 above; Khalid, L., *et al.* n.241 above; Smith, D.K., Shaw, R.W., Marteau, T.M. 'Informed consent to undergo serum screening for Down's Syndrome: the gap between policy and practice' (1994) *BMJ* 309.

[309] Methodology for the leaflets study is in Appendices.

[310] www.google.co.uk.

[311] www.cafamily.org.uk/gencentr.html.

family' list thus became a sampling frame.[312] These centres were contacted by letter[313] and the leaflets were requested. Tversky[314] argued that the evidence of contingent decision processes shows that people may greatly benefit from various decision aids,[315] so the information provided by leaflets can influence decisions.

Services and systems

Some of the leaflets reviewed illustrated a couple of points about the prenatal services their hospital offered. Several referred to the urgency of the situation. For example, Southampton Trust and Sheffield Trust explained that the woman would be "sent an urgent appointment."[316] Some leaflets explained how there would be no time pressure in which to make decisions after a positive screening result.[317] A couple emphasised the support and information available from doctors and midwives.[318] Only the leaflet from Antenatal Screening Wales mentioned support from partners, family or friends.[319]

Routinisation

Several of the comments included in leaflets could be seen to emphasise the routine nature of prenatal diagnosis. For example St George's Healthcare Trust state: "There are a number of tests available which all women booked for delivery at St George's have full access to as part of their care."[320]

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[312] The list of regional genetics centres is included in Appendix B.
[313] A copy of the letter sent is included in Appendix B.
[314] Tversky, A. 'Discussion' in Bell, D.E., Raiffa, H., Tversky, A. (Eds) *Decisions making: Descriptive, normative and prescriptive interactions* (Cambridge, Cambridge University Press, 1988) p599-612
[315] Payne, J.W., *et al.* n.224 above, at p7.
[316] Southampton City Primary Care Trust *Antenatal Screening for Sickle Cell and Thalassaemia* (Southampton, 2001); Sheffield Teaching Hospitals NHS Foundation Trust *Testing for sickle cell and thalassaemia* (Sheffield, 2004).
[317] For examples see Department of Health *Testing for Down's Syndrome in pregnancy* (Oxford: National Screening Committee, 2004).
[318] For example see Antenatal Screening Wales *Amniocentesis* (Wales, 2004) available at www.antenatalscreening.org.
[319] *Ibid.*
[320] St George's Healthcare Trust *Antenatal Fetal Screening* (London, unknown date).

'Choice'

Many leaflets are keen to emphasise that prospective parents do have a choice as to whether or not to undergo tests, and that what happens in the event of a positive result is also up to the prospective parents. For example phrases like "You choose whether or not to have these tests,"[321] "It is your choice whether or not to have that test,"[322] and "You have a difficult decision to make"[323] are common. However, leaflets often comment that there is a choice, but then do not explain what the options are. For example, a leaflet from Leicester states that "These couples will be offered specialist information and counselling, so that they can make informed choices about their pregnancy."[324]

In particular, many leaflets may not explain that for most conditions that can be diagnosed prenatally, there is no cure. The only options are to continue to term and then either keep the baby, or have it adopted, or to have a termination. Only the leaflet from the Department of Health specifically mentioned adoption as a possibility. Others even failed to use the words 'termination' or 'abortion.' Phrases such as enabling couples to "make informed choices about their pregnancy"[325] are often used. It could be that doctors prefer to explain about terminations in the consultation rather than in a leaflet. However, this makes it less likely that women across the country receive standardised care, counselling and advice. This is supported by other research projects which argue that the options following the diagnosis of foetal abnormality include termination of the affected pregnancy as well as continuing with the pregnancy, while preparing for the birth of a child with special needs. Information on the first option as opposed to the second is more often given, although it is not always provided either in writing or orally.[326] Lippman goes as far as to say "not unlike the approach used to justify caesarean sections, prenatal diagnosis is constructed as a way of avoiding 'disaster.'"[327]

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[321] Antenatal Screening Wales n.318 above.

[322] Department of Health n.317 above.

[323] *Ibid.*

[324] University Hospitals of Leicester NHS Trust *Tests for you and your baby during pregnancy* (Leicester, 2005).

[325] For example, see *Ibid.*

[326] Loeben, H.L., *et al.* n.291 above; Marteau, T., Drake, H., Bobrow, M. n.97 above; Bernhardt, B.A., *et al.* n.119 above.

[327] Lippman, A. n.78 above.

The leaflets seemed more directive with regards to having the test in the first place than in deciding what to do afterwards. For example, in the Department of Health leaflet it explains that "You can decide not to have a diagnostic test. This means spending the rest of your pregnancy knowing the screening result, which might be stressful...The only other option is to have the diagnostic test, knowing that this will slightly increase the risk of miscarriage."[328] This could be seen to pressurise prospective parents to have the tests as they are being told to balance stress for up to nine months, or a *slight* risk of miscarriage. All medical interventions carry with them *slight* risks so many prospective parents may not consider the risks, assuming that 'it won't happen to us.'

The Department of Health leaflet also explains "Once you know the result of the screening test, you can't put the clock back"[329] so if termination or adoption are not options "you need to consider very carefully whether it would be better for you not to have the screening tests in the first place."[330] This comes close to the anecdotal evidence often described of doctors refusing to carry out PND unless couples agree to have an abortion on event of a positive result. Similarly, a leaflet from Newcastle states that "For Down's Syndrome and other major chromosome abnormalities there is no corrective treatment and the purpose of making the diagnosis is to give you a choice about continuing with your pregnancy. If for any reason you would not consider ending your pregnancy you might want to reconsider having any test performed and discuss it with us again."[331]

A leaflet from Nottingham provides an example of good practice, as it describes the requirements for consenting to the tests:

> "Before you have any tests or treatment, you have a right to be informed of the expected risks and benefits. This means that you can say 'no' to any test if you like. Staff must have your agreement before they can proceed. For most of the tests offered in pregnancy, it will be enough for you to say that you agree to go ahead. For some procedures, you will be asked to sign to say that you wish to

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[328] Department of Health n.317 above.

[329] *Ibid.*

[330] *Ibid.*

[331] Newcastle Upon Tyne Hospitals NHS Trust *Prenatal diagnosis by amniocentesis or chorion villus biopsy* (Newcastle, 2004) n.b. This leaflet is given out in conjunction with National Screening Committee Leaflet.

> have the test. You should be given more time to decide if you feel unsure about any test, unless it is an emergency."[332]

A number of the leaflets are directive in suggesting that parents should have the tests to ensure they receive the right kind of care during pregnancy.[333] For example, a leaflet from Sheffield states that "Both disorders are very serious, which is why we feel that it is important that you know whether or not you are a carrier for sickle cell or thalassaemia, as knowing this will help us to give you the pregnancy care that is right for you."[334]

Descriptions of disability

A sentence could be classed as negative either because it contained information about a negative aspect of Down's Syndrome such as the prevalence of heart defects, or because it framed information about the condition in a negative way, such as emphasising infant mortality rates rather than survival rates,[335] or if they only emphasised the severe/ serious end of the condition spectrum rather than explaining the variation. Statements classified as 'negative' focused on the following:

1) the clinical complications associated with the condition,
2) the developmental problems
3) the reduced life expectancy
4) the reduced quality of life of the affected person
5) that there is no treatment
6) stigmatising descriptions

Thalassaemia and Sickle cell anaemia were described by one leaflet as "...Serious inherited blood disorders... severe pain or sudden life-threatening infections... need transfusions every month for life."[336] This is problematic because there is no mention of the fact that many people with the conditions can live normal lives with treatment.[337]

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[332] Nottingham Antenatal Screening Steering Group *Tests for you and your baby during pregnancy* (Nottingham, 2004).

[333] For example, Antenatal Screening Wales n.318 above; St George's Healthcare NHS Trust *Antenatal Fetal Screening* (London, unknown date); Southampton City Primary Care Trust NHS n.316 above.

[334] Sheffield Teaching Hospitals NHS Foundation Trust n.316 above.

[335] Bryant, L.D., *et al.* n.241 above, at p1058.

[336] Southampton City Primary Care Trust NHS *n.316 above.* Descriptions like this were prevalent amongst all the leaflets on these conditions.

[337] *Ibid.*

The same leaflet does go on to explain that "In families who care and which support each other, those with Sickle Cell Disorders and Thalassaemia Major are likely to have fewer complications and difficulties."[338] This partly adopts the social model of disability in which attitudinal barriers are one of the main causes of discrimination for disabled people.[339]

The descriptions for Down's Syndrome seemed balanced and inoffensive. Sentences classified as 'positive' were those that focused on:

1) the fact that treatments for the clinical complications are improving
2) educational support and outcomes are improving
3) people with Down Syndrome have the ability to participate in important life activities
4) life expectancy is improving

For example, a leaflet from Nottingham says that

> "People with Down's Syndrome inherit many of their family's distinctive characteristics, but will also have features shared by others with Down's Syndrome. They also have greater difficulty learning than the majority of people the same age. The average lifespan is 40-60 years. Certain medical conditions are more common."[340]

This demonstrates that a child with Down's Syndrome will a) be part of the family and that b) will have many other characteristics and qualities other than just having Downs Syndrome. The leaflet by the Department of Health also contained a good description of Down's Syndrome:

> "There is no such thing as a typical person with Down's Syndrome. Like all people, they vary a lot in appearance and ability. People with Down's Syndrome have learning difficulties. Some have more serious difficulties than others….[341]It

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[338] *Ibid.*

[339] See models of disability chapter (chapter 2).

[340] Nottingham Antenatal Screening Steering Group n.332 above.

[341] Department of Health 'Testing for Down's Syndrome in pregnancy' (Oxford: National Screening Committee, 2004).

> is hard to tell in babies how much they will be affected as children, or when they are grown up…[342]Some adults with Down's Syndrome are able to get jobs and live fairly independent lives. However, most people with Down's Syndrome need long-term help and support."[343]

One way this description could have been improved is that whilst recognising that it is true that most people with Down's Syndrome need 'long-term help and support,' there is no mention of the help and support that is available – emotionally, practically and financially.

Antenatal Screening in Wales frequently referred to 'problems' that could be diagnosed prenatally:

> "Some women will want to prepare themselves for the birth knowing that their baby has a *problem*. Other women may decide to end the pregnancy. Some women decide to continue with the pregnancy and consider giving their baby up for adoption…Learning about a *problem* is distressing and deciding what to do is hard. Most women want and need some support. This might come from your partner, family or friends or from the health professionals who are caring for you…It can be difficult to decide what tests to have. Some women do not want to know if there are *problems*. Others want to know so they can prepare themselves for their baby's birth or think about terminating the pregnancy.'"[344]

This description adopts the medical model by equating disability with a 'problem,' thereby seeing the problem in the diagnoses rather than in the social context. This is especially the case in the context of prenatal screening where the only 'solution' would be to terminate the baby with the 'problem.'

It has been explained in this chapter that the information provided to prospective parents can influence their decisions. The leaflet analysis conducted as part of this study, sought to provide some evidence for the arguments within this chapter. In particular this small

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[342] *Ibid.*
[343] *Ibid.*
[344] Antenatal Screening Wales *Introduction to antenatal screening tests* (Wales, 2004).

scale study provided examples of the way that the 'choice' of testing is offered, yet the choices available were often not made explicit. The leaflets analysed demonstrate that examples of good and bad practice, and so it is important not to generalise criticisms made. However, it is imperative that attention is drawn to bad practice, and the expression of negative values in relation to disability.

There is evidence that inadequate resources for counselling are responsible for the lack of knowledge given and the routine nature by which many prenatal tests are presented. For example, in Jo Green's study, nearly half the sample of obstetricians said that they did not have adequate resources for counselling all the women to whom screening was offered.[345] Over 80% said that women not understanding the test was a problem.[346]

Women may turn to their general practitioners and community midwives for information and support but find that knowledge is lacking.[347] Clarification of terminology (for example, being able to distinguish between screening and diagnosis)[348] and of the relative roles of obstetricians and the primary care team may help to ensure that women receive the counselling that they require.[349] Pregnant women and their partners also have unrealistic expectations about prenatal screening for foetal abnormalities. For example, many expect that a negative result means no problem, as opposed to low risk of a problem and that a positive result means there really is a problem, as opposed to there being an increased chance of a problem.[350]

Finally, patients who are offered screening are said to be less likely to have a family history or previous experience of genetic disorders, and are therefore less prepared for the test and to have a steeper learning curve in coming to terms with its implications. This is further conflated by the reported expectation among patients that tests conducted in antenatal clinics are "routine" and are just to check that the baby is "OK". [351]

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[345] Green, J.M. n.113 above.
[346] *Ibid.*
[347] *Ibid.*
[348] *Ibid.*
[349] Statham, H., Green, J. n.189 above Marteau, T.M., *et al.* n.250 above.
[350]Smith, D.K., *et al.* n.186 above.
[351] Human Genetics Commission *n.67* above, at p15.

4.5. Conclusions

I began this chapter by exploring the power structures that exist between doctors and their patients, and between health professionals and disabled people. Using a Foucauldian analysis, I noted that the medical discourse is grounded in specific power relations and ideological interests, and in turn contributes to them. In this way the power structures are self-perpetuating. I argued that doctors enjoy power and status as a result of their perceived expertise. I also examined the role of doctors as gate-keepers – to services, treatment and benefits relating to disabled people. As a result of this study, it is possible to identify that doctors have influential power over their patients, over disabled people, and over establishing the framework within which discussion of disability in relation to RGTs occurs.

I moved on to consider the way in which RGTs are justified by providing 'choices' to prospective parents. I identified several ways in which this 'choice' is undermined by the failure of practitioners to adopt nondirective counselling styles. I suggested that this was due to time pressures, health professionals' training, variation in approaches between doctors of different disciplines, that the 'set up' of PND and PNS undermined nondirective counselling, and finally that nondirective counselling sometimes does not satisfy the patients' needs. I highlighted the reasons why the offer of PND technology is not value neutral. These included the biased framework within which the technology is offered; doctors and scientists decide the technologies to be developed so the technologies offered reflect their values. This is problematic because women assume the technologies to be positive, and interpret the offer of PND as a recommendation from a doctor. I discussed the difficulties women face in refusing the technologies, suggesting that the power, knowledge and status in which doctors are held makes their opinions influential and that the 'choices' offered make women responsible for the kinds of children they have.

I argued that informed consent is often not obtained in PNS or PND. This is partly because the tests are offered as 'routine', and partly because doctors provide inadequate information to prospective parents. In particular, the leaflet analysis I conducted highlighted that the information provided to parents focused on medical and scientific rather than social aspects of disability, concentrated on the nature of tests rather than what conditions are being tested for, explained that there was a ‘choice’ but often fail to explain the options available, and that the language used was sometimes disablist. For example, disability was often equated to a ‘problem.’

In this chapter I have shown some of the ways that reproductive decision making can be influenced. When all sections of this chapter are considered collectively, it be comes persuasive that women are not being offered reproductive ‘choices.’ They are influenced both directly and indirectly by doctors. As a result, the decisions made by women/ couples can be seen to be reflecting the values of the health profession. When considered in relation to the models of disability chapter, it can be seen that medics have power and influence over patients’ decisions and that this influence is based in a medical model of disability. The sum of this equals another layer of the concentric circles diagram (fig. 7.) where it can be demonstrated that the values which influence attitudes towards the prevention of disabled lives through the use of reproductive genetic technologies are disablist. Situating this line of thought within the expressivist argument, the models of disability chapter has already shown that disability is a complex social construct and the way society constructs disability communicates signals regarding the value society places on its disabled members.

This chapter considered some of the reasons why prenatal testing and the selective abortion of foetuses with detected impairments have become accepted practice. The remaining strand of the expressivist argument is that there are implicit assumptions involved in the accepted practice of PND. This will be the focus of the next chapter which concentrates on quality of life judgements made by doctors and lawmakers.

Chapter 5: Quality of Life

5.1. Introduction

This thesis has examined the dominant ways of thinking about disability and has related this to the context of reproductive genetic technologies. I have also explored the ways in which the current law and the current practical regimes relating to PND and selective abortion can be seen to express negative values about disability. I have highlighted that the continued reluctance to acknowledge the social effects of disability stems, in part, from the power and status of doctors. I have demonstrated that the information given to women is disablist and that nondirective counselling is impossible. This chapter aims to explore the ways in which key decision makers think about disability in order to explain the continued dominance of a flawed model of disability.

Many terms are used by the media, health professionals, courts and Parliament to describe the judgements and assumptions made about disability and disabled people. Phrases such as 'lives not worth living,' 'best interests,' 'intolerability,' 'welfare' and 'quality of life' are often used. All of these terms involve judgements being made about the quality of life of individuals and as a result are important when discussing disability; furthermore such quality of life (QL) judgements affect the law in the field of health care for disabled people. In areas of reproductive decision making, criteria are often based on 'severe' or 'life threatening' conditions. This chapter argues that such judgements are subjective, based on cultural norms and values, and on the approach taken to considering disability by the people making the decisions. QL judgments play a role in this. It is therefore important for this thesis to explore the basis of QL judgements, the ways they are used in practice, and the implications they have for disabled people.

It has been argued throughout this thesis that people make negative assumptions about impairment and disability. These assumptions can invoke 'quality of life' judgements and are often based on the medical model of disability. It has also been demonstrated that attitudes towards disability can influence policies.[1] Health professionals frequently

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[1] This was shown in both the models of disability chapter and the decision making chapter.

make QL judgements when making decisions about the care of disabled patients,[2] and the professionals' view on expected quality of life is often the key factor in determining whether effective treatment for a life threatening condition will be given or withdrawn.[3] Furthermore, professionals' perceptions may be at odds with those held by their patients.[4] Many views of disability are based on misconceptions rather than data and are not made by disabled people themselves. The more general point which can be made is that the debate about whether a life is considered to be 'worth living' should be understood in the context of social and cultural value accorded to certain people.[5] As a result of the assumptions made about disability, disabled people are seen as deserving sympathy; that they are emotional, practical and financial burdens who cause family strain and marriages to break up. Such negative views of disability are perpetuated further by law makers, health professionals, even some charities and parents of disabled people. This chapter aims to explore these ideas and demonstrate the way in which many disabled people do not see their disabilities as something wholly negative. Disability can be part of someone's identity and their culture and no one can judge the QL of a disabled person, other than the individual disabled person concerned. Discrimination and the relative ignorance of those conducting quality of life assessments raise fundamental questions when physicians are involved in decisions about access to health care.[6] There can be complications in deciding what conditions are 'serious handicaps,' or in advising Parliament and the courts on what the law should be. Decisions about health services affecting disabled people are made at a number of levels. At the highest level, the values, structure, and functions of the health care system may enable or disable disabled people.[7] What is not clear is the ethical framework and assumptions about the quality of life of disabled people that inform those decisions,[8] this will be explored in this chapter. It is

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[2] Manara, A.R., Pittman, J.A., Braddon, F.E. 'Reasons for withdrawing treatment in patients receiving intensive care' (1998) 53 *Anaesthesia* 523-528.

[3] Pellegrino, E.D. 'Decisions to withdraw life-sustaining treatment: a moral algorithm' (2000) 283 *JAMA* 1065-1067.

[4] For example see Hallan, S., Asbery, A., Indredavik, B., Wideroe, T.E. 'Quality of life after cerbrovascular stroke: a systematic study of patients' preferences for different functional outcomes' (1999) 246 *J Intern Med* 309-316. This point will be highlighted later in this chapter.

[5] Marks, D *Disability: controversial debates and psychosocial perspectives* (London, Routledge, 1999) at p40.

[6] Basnett, I. 'Health Care Professionals and Their Attitudes toward and Decisions Affecting Disabled People' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p454.

[7] *Ibid.*

[8] *Ibid*, at p455.

argued that the value-laden QL judgements made about disabled lives in the PND context influence the decisions individuals make.

Disability can be seen as part of a spectrum of different abilities (this is universalism, as described in previous chapter).[9] There is a lot of variation when discussing 'disability,' as the term encompasses many impairments caused by numerous conditions and each of the conditions will vary in the effects they cause. Disability is also socially constructed, so the extent to which a person is disabled by an impairment depends on their environment and systems of support they receive.[10] There is no precision to the class the term constructs. It includes as equal (and equally disadvantaged), members who have moderate impairments (vision and mobility) and a person who might be wholly blind, completely deaf, and quadriplegic. As Koch asks, "What does that matter? We're all… disabled."[11] It will be demonstrated that many QL judgements are based on stereotypes failing to take into account the variation of disability.

QL judgements have played a crucial role in determining some current controversial health care law cases. *Re MB*[12] involved a 17-month-old boy who has spinal muscular atrophy (SMA) type 1, an incurable progressive genetic condition. He cannot chew, swallow or breathe unaided (he receives endotracheal ventilation at hospital) and can only move his eyebrows, feet and fingers slightly. MB's parents said that he is not mentally disabled, and that he recognises and responds to them when they visit him in hospital. They wanted him to undergo a tracheostomy to allow him to breathe which will enable him to go home. The NHS trust made an application to turn off the ventilator and to let him die peacefully,[13] arguing that his life is 'intolerable.'[14] Mr Justice Holman said

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[9] See the models of disability chapter (chapter 2).

[10] This is another example of the social model, already described in detail in the models of disability chapter (chapter 2).

[11] Koch, T. 'The illusion of paradox: commentary on Albrecht, G.L. and Devlieger, P.J. (1998). The disability paradox: high quality of life against all odds. Social Science & Medicine 48, 977-988' (2000) 50 *Social Science & Medicine* 757-759.

[12] *Re MB* [2006] EWHC 507.

[13] Details of case from *Re MB* n.12 above, and media reports. Including, Sanderson, D. 'Parents' court pleas to keep baby alive' *The Times*, 04 March 2006; Frith, M. 'Court to rule on allowing severely disabled boy to die' *The Independent*, 05 March 2006;BBC News '"Right to life" baby case goes on' on www.bbc.co.uk 06 March 2006; As well as information from the solicitor acting on behalf of MB's parents, Alexander Harris Solicitors, at www.alexanderharris.co.uk.

[14] For example, see Booth, J. 'Toddler has "intolerable life," High Court told' *The Times*, 06 March 2006; Frith, M. 'Right-to-life boy "has an intolerable existence"' *The Independent*, 07 March 2006.

that "this is potentially a landmark case, as it is the first time that a court has been asked to make a life-or death ruling on a child who has near-full or full cognitive function."[15]

The case of *Re MB* is very similar to the case of Abbie Tinkley, a 19-month-old girl who also has SMA and who, after a three month legal battle with the hospital, had a tracheostomy to help her breathe. Her doctors had wanted to reduce her ventilation and to provide morphine to reduce the pain while she died. There are now plans to allow her home, and surgeons are considering fitting a voice box so Abbie can talk and laugh.[16] These cases demonstrate how controversial the issue of quality of life judgements is and how they can be the basis for life and death decisions. Recent media coverage[17] has suggested that parents in these cases are too emotionally involved to see the case objectively, and whilst everyone has sympathy with the parents they believe that doctors are trained to view cases objectively. Yet it will be argued that the medical training that doctors receive (rooted in the medical model) does not qualify them to make QL decisions. Equally problematic is leaving the power to decide such cases to the courts where there is an over-reliance on doctors as experts. Comparisons have been made between the case of MB and the Charlotte Wyatt case.[18] Both these cases will be discussed later in this chapter. Whilst they can both be described as 'right to life' cases they involve different conditions and treatments. As will be explained in more detail later, the courts have framed the Wyatt case so as not to decide whether or not her life is worth living, but as to whether resuscitation would harm her for no clinical benefit.

Another controversial issue at the moment is the decision to allow euthanasia for children in the Netherlands.[19] A committee has been set up to regulate the practice and the 'Groningen protocol'[20] has been adopted as the standard to be upheld by the regulatory committee. It was reported that each year in Holland at least 15 seriously ill babies, most

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[15] Reported in Sanderson, D. n.13 above.

[16] Information from www.alexanderharris.co.uk. As this information comes from the parents' solicitors, it could be that this interpretation is controversial.

[17] For example GMTV, 07 March 2006; Channel 4 news, 06 march 2006. This was also the view of the judge (as will be seen later in this chapter).

[18] For example, see Frith, M. n.13 above.

[19] As reported in the Sunday Times: Campbell, M. 'Holland to allow "baby euthanasia"' *The Sunday Times*, 05 March 2006. For the relevant Parliamentary document see http://www.minvws.nl/en/kamerstukken/ibe/2005/termination-of-life-neonates.asp.

[20] For more information of the Groningen Protocol, the text of the protocol is contained within the following article (written by the doctors the developed the protocol): Verhagen, E., Sauer, P.J.J. 'The Groningen Protocol – Euthanasia in Severely Ill Newborns' (2005) 352 (10) N Engl J Med 969.

of them with severe spina bifida or chromosomal abnormalities, are helped to die by doctors acting with the parents' consent.[21] Such decisions revolve around whether or not to prolong treatment and are arguably a form of 'passive euthanasia' that is practised in countries all over the world. There are concerns that this practice will lead to abuses by doctors and parents, who will be making decisions for individuals incapable of expressing a will.[22] The validity of this concern will become apparent when the attitudes of health professionals to disability are discussed later in this chapter. Others welcome the move arguing that it brings more "openness about a practice that, according to doctors, goes on secretly anyway – even in Britain – regardless of the law."[23] Whilst there are rightly concerns about this law, it does state that the parents have to want their child to die; which contrasts directly with the current 'right-to-life' cases of MB and baby Charlotte which see parents fighting to keep their children alive against the doctors' wishes. Yet as already explained in this thesis, parents' decisions are informed by the world they live in, and can be influenced considerably by doctors' opinions.[24]

This thesis does not aim to discuss these latest developments in the Netherlands in detail. The recent developments are included here only to demonstrate the importance of highlighting the way in which QL decisions are made and the implications these decisions have in the 'real world.' They are also further evidence of the expression of disablist attitudes in contexts that impact on people's lives (or their prevention). This thesis aims to explore the underlying assumptions that influence QL decisions and as such, that contribute to policies that aim to prevent disabled lives through the use of reproductive genetic technologies.

In order to analyse the ways that key decision makers assess the quality of life of disabled people, this study will begin with a discussion of the conceptual ideas behind QL judgements. This will examine the reasons behind QL assessments and a WHO model will be used as an example to analyse its appropriateness when assessing the QL of disabled lives. I will highlight that there is an underlying but consistent presumption of suffering in QL assessments of disabled lives. Whilst QL models are used on existing

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[21] Campbell, M. n.19 above.

[22] *Ibid.*

[23] *Ibid.*

[24] This was explained in the Introduction to Expressivist Argument (chapter 3) and the IDM chapter (chapter 4).

people, it is argued that the presumption of suffering is one of many negative assumptions made about disability that also influence prenatal decision making. It will be demonstrated that many of the negative assumptions stem from the dominant medical hegemony.

This chapter will develop from considering the conceptual arguments of QL to examining specific examples of QL judgements made by doctors and law makers. It has already been suggested earlier in this thesis that the views of doctors and lawmakers set the climate in which prenatal decisions are made by women/ couples. Furthermore it has been demonstrated that doctors and lawmakers can influence and constrain these decisions. It is therefore essential for this thesis to now analyse the way these key decision makers assess the quality of life of disabled lives. To this end, research will be highlighted that shows the stark contrast between the way doctors view the QL of disabled people and the way in which disabled people assess their own QL. Recent case law will then be examined to explore the approach of the courts to assessing QL, and then Hansard debates will be examined in order to demonstrate the approach of Parliament to this issue. Finally, the various ways that doctors and lawmakers assess QL will be situated within the debate about the models of disability used, in order to re-emphasise the dominance of the medical model.

5.1.1. The nature of QL judgements

Traditionally 'sanctity of life' (SL) was the dominant value in health care and health decision making.[25] However 'quality of life' (QL) has replaced it.[26] The SL doctrine asserted that human life is sacred in some unique and special sense. Axiomatically, therefore, life was not to be merely maintained but, wherever possible, to be nurtured. A fundamentally communal value, the SL doctrine argued for the inclusion of all members of the human community irrespective of a person's deviation from the norm. QL constructs are individualistic and specific rather than general and communal. Their concern is not with life itself but instead with a certain standard of life typically defined

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[25] Along with autonomy and best interests. See Montgomery, J. 'Health Care Law for a multi-faith society.' in Murphy, J (eds) *Ethnic Minorities, their Families and the Law* (Oxford, Hart Publishing, 2000) pp161-179.

[26] Koch, T. *The limits of principle: Deciding who lives and what dies* (Westport CT, Praeger Books, 1998).

as an individual or class's adherence to, or deviation from, a 'normal' physical (or cognitive) standard. Where quality of life is perceived by one or another standard as deviant, treatment may be either withheld or limited.[27] Where it is deemed at least potentially acceptable, aggressive treatment will be applied.[28]

Shakespeare points out that physical impairments are often separated from social concerns in 'disability' theories.[29] Koch demonstrates that prospective tests make a number of assumptions about the 'disease burden' attending to physical and cognitive 'disabilities.' And yet, decisions resulting from prospective QL instruments define treatment parameters and thus the lives and life qualities of persons with diagnosed limits. Physical realities and the prognosis of this or that condition are supposedly the basis of proscriptive instruments that in turn define those parameters.[30] QL instruments are used in relation to both individual decisions as well as to strategic health planning. Drawing upon the concentric circles diagram introduced earlier,[31] it can be seen that QL judgements are made at many different levels. This is problematic when (as will be shown in this chapter) these QL judgements are essentially disablist.

Koch traces the history of QL from the eugenics movement, to prospective, quantitative and utilitarian instruments. [32] He argues that the acceptance of this development has paved the way for the contemporary class of QL instruments that permit little attention to the complex social contributors to the life quality of persons with chronic and physically limiting conditions.[33] In this way he agrees with Shakespeare's analysis. The result has been an increasing reliance in health care planning, and medical decision making generally, on quantitative and prospective, health-related QL instruments.[34] To this end

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[27] This will be demonstrated later in this chapter in relation to case analysis.

[28] Koch, T. 'Life quality vs the 'quality of life' assumptions underlying prospective quality of life instruments in health care planning' (2000) 51 *Soc Sci & Med* 419-427.

[29] Shakespeare, T. 'Choice and Rights: Eugenics, Genetics and Disability Equality' (1998) 13 *Disability and Society* 665. For more detail on this see the discussion in the models of disability chapter (chapter 2) on 'bring the impairment back in'.

[30] Koch, T. n.28 above, at p420.

[31] See fig. 7., introduction to the expressivist argument chapter (chapter 3).

[32] Koch, T. n.28 above, at p421. This point is supported by Benson, T. 'How should different life expectancies be valued?' (1998) 317 *BMJ* 1155.

[33] Koch, T. n.28 above, at p421.

[34] Frisch, M.B. *Quality of Life Inventory* (Minneapolis, MN: National Computer systems, 1994); Testa, M.A., Nackley, J.F. 'Methods for quality of life studies' (1994) 59 *Annual Review of Public Health* 535-559.

these instruments attempt to measure potential life quality in the face of disability.[35] For example, the WHO model (the WHOQOL-100) measures QL by examining the following domains and facets:[36]

Fig. 11. The WHOQOL-100

Domain	Facets within that Domain
1. Physical Health	Energy and fatigue Pain and discomfort Sleep and rest
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self esteem Thinking, learning memory and concentration
3. Level of independence	Mobility Activities of daily living Dependence on medical substances and medical aids Work capacity
4. Social relations	Personal relationships Social support Sexual activity
5. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/ leisure Physical environment (pollution/ traffic/ climate) Transport
6. Spirituality/ Religion/ Personal beliefs	Religion/ Spirituality/ Personal beliefs (single facet)

'Quality of life' is neither easily defined nor explained. The WHO defines QL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and

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[35] Koch, T. n.28 above, at p421.

[36] The domains and facets are set out in Figure 11.

concerns."[37] This recognises the influence of the cultural norms and values in QL assessments. Although most scholars stress that QL is ultimately subjective, many believe that objective indicators are at least equally important.[38] The WHOQOL-100 recognises the social model of disability, in so far as it considers the environment and social relations (i.e. domains 4-5). However little is known about how non-medical factors modify and mediate the effects of impairments, symptoms, functional limitations and disability on QL.[39] This WHO model, and their other attempt (WHOQOL-BREF) are currently being field tested,[40] so the way in which they will work in practice remains unclear at the moment.

The common understanding of a good quality of life implies being in good health and experiencing subjective well-being and life satisfaction.[41] Conversely, one can argue that if people are disabled, they cannot be considered to be in good health nor possess a high level of life satisfaction. Disabled people are assumed to be limited in function and role performance and quite possibly stigmatized and underprivileged.[42] One of the assumptions frequently made relates to the presumption of suffering, an assumption that will now be explored in more detail.

5.1.2 The presumption of suffering

Many commentators err in assuming that tragedy is inevitable for the child or for the family.[43] Disability is thought to be incompatible with life satisfaction.[44] Apparently, "seeing the bright side of being handicapped is like praising the virtues of extreme

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[37] See www.who.int.

[38] For example, see Meeberg, G.A. 'Quality of life: a concept analysis' (1993) 18 *Journal of Advanced Nursing* 32-38; Campbell, A., Converse, P.E., Rodgers, W.L. *The Quality of American Life* (New York, Sage, 1976); McCall, S. 'Quality of Life' (1975) 2 *Social Indicators Research* 229-248.

[39] Ormel, J., Lindenberg, S., Steverink, N., Vonkorff, M. 'Quality of life and social production functions: a framework for understanding health effects' (1997) 45(7) *Soc Sci Med* 1051-1063 at p1052.

[40] According to www.who.int on 08/03/06.

[41] Goode, D. 'The national quality of life for persons with disabilities project: A quality of life agenda for the United States' in Goode, D. (ed) *Quality of Life for Persons with Disabilities* (Cambridge, Brookline Press, 1994) pp139-161.

[42] Brown, R.I., Brown, P.M., Bayer, M.B. 'A quality of life model: new challenges arising from a six year study' in Goode, D. (ed) *Quality of Life for Persons with Disabilities* (Cambridge, Brookline Press, 1994) pp39-56.

[43] Asch, A. 'Prenatal diagnosis and selective abortion: a challenge to practice and policy' (1999) 89(11) *Am J Public Health* 1649-57 at p1652.

[44] *Ibid,*at p1650.

poverty."[45] All QL instruments "bear a hidden negative assumption that what is important about a person is his or her injury, disease, deficiency, problem, need, empty half" irrespective of other potentially compensatory considerations.[46] Therefore one cannot be disabled *and* healthy.[47] Nor in theory, can persons with physical conditions deviating negatively from the social norm claim a positive life quality.[48] A potentially rich life is not merely unconsidered but inconceivable.[49] It is thought that (using the WHO model as an example) disabled people will invariably score low on domain 1 (because a disabled person is not healthy); it is assumed they will score low on domain 2 (because it is inconceivable that a disabled person could have a positive self-image); that because they may need assistance with independent living, they will score low on domain 3; it is wrongly assumed that disabled people cannot have meaningful social relations or sex lives so will score low on domain 4; and because their disability prevents them from accessing society they will score low on domain 5.[50] These assumptions are misconceived, but frequently made by people looking 'objectively' at the life of a disabled person. Furthermore, this thesis argues that if someone is unable to access society, the fault is not within the individual but with society i.e. the social model. It will be shown later that disabled people score themselves and their QL differently.

The common journalistic device of portraying people as victims tends to cast women at risk of having a disabled child as victims of fate needing to be rescued by efficient health services. Exceptions to the general media enthusiasm for screening are the occasional personal story by parents about how they highly value their child who has Down's syndrome. When these 'triumph over tragedy' stories emphasize strengths in the individuals concerned, they also imply how hard it usually is to live with this condition.[51]

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[45] Watson, J.D. (1996) 'President's essay: genes and politics' (Annual Report Cold Springs Harbor) at p19 quoted in Asch, A. n.43 above, at p1653.

[46] McKnight, J. 'Two tools for well-being: Health systems and communities (1994) 10(3) *American Journal of Preventive Medicine* 23-26 at p25.

[47] Albrecht, G.L., Devlieger, P.J. 'The disability paradox: high quality of life against all odds' (1999) 48 *Social Science & Medicine* 977-988.

[48] Koch, T. n.28 above, at p422.

[49] *Ibid.*

[50] General analysis of domain 6 is outside the scope of this discussion. Whilst there are good reasons to be concerned about stereotypes in the religious context, I do not intend to undertake any analysis of different religious attitudes to disability.

[51] Alderson, P. 'Prenatal Screening, Ethics and Down's syndrome : A Literature Review' (2001) 8 *Nursing Ethics* 4.

Some disabilities, such as Down's syndrome do not appear to cause suffering. So why is Down's syndrome one of the two most common conditions for which prenatal testing is offered? People with Down's syndrome rarely suffer physical pain or distress as a direct result of their primary condition (though they may well suffer from other conditions in addition). Indeed, it is arguable whether the impairment could properly be described as 'serious' (as defined by s1(1)(d) the Abortion Act 167 as amended by the HFE Act 1990). And yet Down's syndrome is the biggest single recorded diagnosis used to justify termination for foetal abnormality under s1(1)(d). Out of 1,894 abortions carried out for foetal abnormality 419 were due to a diagnosis of Down's syndrome (22%).[52] One response by Harris to this evidence is to redefine suffering "as shorthand for a whole range of disadvantageous conditions. I do not literally mean being in pain or being in discomfort."[53] Another response is to speak of the relatives' suffering: women regard a baby with Down's syndrome as an infinitely worse outcome than losing a baby from a prenatal diagnostic procedure.[54] So, is prenatal testing for Down's syndrome more about preventing the 'suffering' (social or psychological) of others (for example, parents) than of the individual affected?[55] In fact the 'quality of life' arguments, in the context of preventing disabled children being born or surviving, have been perceived as something of a 'smokescreen' for the more important motivations involved; that is, when neither society nor individuals as parents are prepared to take on what are perceived to be the social, economic and personal costs involved in having a disabled child.[56]

As already commented upon in the IDM chapter, much of the literature on the effects of prenatal diagnosis on attitudes towards disabled people considers all disabilities as a generic class and treats them as if they were equal.[57] This is not an accurate approach. Most physical and some mental disabilities can be overcome with social support and

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[52] Information from http://www.dh.gov.uk/assetRoot/04/11/75/74/04117574.pdf (table 10).

[53] Harris, J. 'Wongful birth' In Bromham, D., Dalton, M., Jackson, J. (ed*) Philosophical ethics in reproductive medicine* (Manchester, Manchester University Press, 1990) pp156-70.

[54] Lilford, R. 'What is informed consent?' in Bromham, D., Dalton, M., Jackson, J. (ed*) Philosophical ethics in reproductive medicine* (Manchester, Manchester University Press, 1990) p211-27; Alderson, P. n.51 above.

[55] Ward, L. 'Whose right to choose? The 'new' genetics, prenatal testing and people with learning difficulties' (2002) 12 *Critical Public Health* 190. For a detailed discussion about in whose interest is s1(1)(d) see Sheldon, S., Wilkinson, S. 'Termination of Pregnancy for Reason of Foetal Disability: Are there Grounds for a Special Exception in Law?' (2001) 9 *MLR* 89.

[56] Morris, J. *Pride against prejudice: transforming attitudes to disability* (London, Women's Press, 1991) at p72.

[57] Wertz, D.C., Fletcher, J.C. 'Feminist criticism of prenatal diagnosis: a response' (1993) 36(3) *Clin Obstet Gynecol* 541-67 at p545.

changes in the physical environment.[58] Some mental and neurological disabilities, however, require lifetime care and overwhelm the parents' lives. Such disabilities may never be overcome, even with massive economic and social support. Although increased support is necessary in the interests of social justice, it may not present an alternative to prenatal diagnosis and selective abortion in all cases.[59]

Perceptions of disabled lives in our society are determined by the prospect of diminishing expectations and disappointments, both for one's family and oneself. Given these perceptions, the presumption that disabled people and their families suffer from hardship is very influential in our society. Consequently, once the results of prenatal testing indicate the presence of a genetic defect, nothing seems more obvious than to avoid the birth of a disabled child. As Wood-Harper and Harris explain it, genetic testing can thereby enable the avoidance of damaging psychological effects to the parent due to having a seriously disabled child, which can be manifested as feelings of guilt and misplaced responsibility, as well as the considerable burdens associated with caring for such a child, especially when life expectancy is very limited and of negligible quality. The savings to society can be immense in terms of financial costs and the depletion of scarce resources relating to the education, health care and community support of the disabled.[60] Disabled People and their families are believed to face a life that is filled with disappointment and distress, if not suffering and grief.[61] Given this perception, using genetic testing procedures for reasons of prevention appears to be morally quite appropriate.[62]

"The view of disability is so negative and knowledge of the capacities and abilities of people with disabilities so limited that the presence of a disability is seen to overpower any positive qualities there might be in living with a disability."[63] From the view point of disability advocates, the issue is to resist the growing impact of genetics on social and

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[58] *Ibid.*

[59] *Ibid.*

[60] Wood-Harper, J., Harris, J. 'Ethics' in Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996) at p281.

[61] Scorgie, K.I. *From Devastation to Transformation: Managing Life when a Child is Disabled* (Diss., University of Alberta, 1996).

[62] Reinders, H.S. *The Future of the Disabled in Liberal Society: An Ethical Analysis* (University of Notre Dame Press, 2000) at p51.

[63] International League of Societies for Persons with Mental Handicaps *Just Technology? From Principles to Practice in Bioethical Issues* (North York, Ontario: L'Institut Roeher, 1994) pp14-15.

political barriers against full participation in society. Inasmuch as the genetic approach to disability is based on negative evaluations, it will not help to eliminate these barriers. Instead, it may well threaten the gains of normalization that have been made in recent decades in their public appeal.[64] Certainly, until far more research is conducted which takes proper account of social contexts, generalisations cannot be formed about the costs of unavoidable dependence, or the value and quality which disabled people experience in the everyday details of their lives.[65]

There is a problem regarding the possibility of mistaken expectations. For example, a child with the condition of spina bifida (a neural tube defect) may or may not develop hydrocephalus, but one cannot always be sure about whether or not they will. Nor can one be sure of how such a complication may develop. Neural tube defects are subject to a range of possible complications, some of which are dependent on where the defect is located on the spine. Consequently, there is a range of uncertainty that cannot possibly be eliminated at the moment of deciding about the child's future. This is why estimations of the quality of life for children with spina bifida remain a matter of controversy among neonatologists.[66] There is, of course, the possibility of follow-up studies which show how children with a given disorder actually develop. These studies can be used to obtain indications as to what can be expected with a reasonable degree of certainty. But the information that can be obtained from these studies is statistical, which implies that with regard to individual cases one cannot be certain as to what to expect,[67] because of the significant range of variation. Furthermore, the sample used in the statistical studies will be influenced by the assumptions being tested, given that presumably some lives with neural tube defects are prevented.

When confronted by the fact, or the risk, that one's child will be disabled, people will want to know what their future is going to be like if they decide to accept the child or the risk. In this they are dependent upon medical information.[68] This creates the further possibility that the expectations of the medical experts may be biased by their own views

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[64] Reinders, H.S. n.62 above, at p75.

[65] Alderson, P. 'Down's syndrome: cost, quality and value of life' (2001) 53 *Soc Sci Med* 627-38 at p636

[66] Weir, R.F. *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine* (Oxford, OUP, 1984); Hunt, G.M., Oakeshott, P. 'Outcome in people with open spina bifida at age 35: prospective community based cohort study' *BMJ* 326 (2003)1365-1366.

[67] Reinders, H.S. n.62 above, at p163.

[68] The problems associated with this have been explained in the decision making chapter (chapter 4)

on the quality of life.[69] This will now be discussed in more detail as we explore the views of doctors in relation to disability.

5.2 The views of doctors

Throughout this thesis much emphasis has been placed on the status, power and knowledge of doctors.[70] It is also relevant here because the medical training doctors receive ensures they are deemed expert to make QL judgements. However these judgements are usually based on the limited perspective of medical diagnosis and prognosis rather than a fuller exploration of the patients' lives. Professional power has played a crucial role in the maintenance and justification of the individual tragedy model of disability and the enforced dependency of disabled people.[71] The notion of enforced dependency is a recurring theme in the accounts of disabled people's experiences with health and welfare services.[72] Oliver argues that the creation of dependency is two-way: professionals are also dependent on disabled people for their jobs, salaries, status, quality of life, and so on. Furthermore, the construction of disability within the medical model has been contingent on the expanding production of medical and rehabilitative services.[73] Doctors are not usually expert at living with a disability and are not informed by the perspective of disabled people. If a doctor does have a disability, this alone does not make them an expert at living with all disabilities. Furthermore doctors' judgements are often rooted in the medical model reflecting how they were trained. However, as previously explored, much of disability is socially constructed.

Doctors only see disabled people as 'patients' in a consulting room, usually during a health crisis. Contact as caregivers leads to more negative attitudes towards disabled people. For example, in a review, French concludes that the attitudes of health professionals are similar to the attitudes of the general public and may become more negative as professional education proceeds.[74] This is supported by Begum's research

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[69] Reinders, H.S. n.62 above, at p163.
[70] This was discussed in both the MD chapter (chapter 2) and the IDM chapter (chapter 4).
[71] French, S., Swain, J. 'The Relationship between Disabled People and Health and Welfare Professionals' in Albrecht, G., Seelman, K., Bury, M. (eds) *Handbook of disability studies* (Thousand Oaks, Calif, Sage, 2001) at p737.
[72] *Ibid.*
[73] *Ibid,* at p738.
[74] French, S. 'Attitudes pf Health Professionals towards Disabled People: A Discussion and Review of the Literature' (1994) 80 *Physiotherapy* 687-93.

that demonstrates that doctors are not immune from general social prejudices or prejudiced attitudes towards disabled people in general and disabled women in particular.[75] Asch describes the substitution of an ill-formed social judgement about disability for a medical one.[76] Doctors do not usually have contact with disabled people as equals, and many point out the power imbalance in this relationship.[77] For many physicians, the medical, individual, and tragic view of disability[78] is reinforced at the end of their training. It could be argued that, given that this approach dominates most Western societies, it would be unreasonable to expect the medical profession to be any different.[79] Yet Basnett argues that "Health professionals have no right to be simply a mirror of society and should be more enlightened."[80] The attitudes of health professionals are very influential in society, and as a result, this perpetuates the dominance of the medical model. Particularly important for the purposes of this discussion is that health professionals directly influence the lives of disabled people through their influence in the courts and Parliament.[81] An individualistic model clearly suits the medical profession. It emphasizes the importance of their skill and assists in their professional dominance.[82] Thus it can be seen that health professionals are not just passive mirrors of society, taking an individualistic interpretation and accentuating it, but are also active promoters of a paradigm that strengthens their own role.[83]

Only a small minority of practitioners have experience of growing up with or working with disabled people.[84] One midwife thought a lack of experience and knowledge might influence the information given by practitioners.[85] Even those physicians who treat disabled people may have inaccurate impressions of the lives of such people if their

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[75] Begum, N. '"General Practitioners' Role" in Shaping Disabled Women's Lives' in Barnes, C., Mercer, G., Shakespeare, T. *Exploring Disability: A Sociological Introduction* (Cambridge, Polity Press, 1999).

[76] Asch, A. 'Distracted by disability' (1988) 7(1) *Cambridge Quarterly of Healthcare Ethics* 77-87.

[77] For example, see Eberhardt, K., Mayberry, W. 'Factors Influencing Entry-level Occupational Therapists' Attitudes towards Persons with Disabilities' (1994) 49 *American Journal of Occupational Therapy* 629-35; Roush, S.E. 'Health Professionals as Contributors towards Attitudes to Persons with Disability: A Special Communication' (1986) 66 *Physical Therapy* 151-4.

[78] Oliver, M. *The politics of disablement* (Basingstoke, Macmillan, 1990).

[79] Basnett, I. n.6 above, at p452.

[80] *Ibid.*

[81] This will be demonstrated later in this chapter.

[82] The way QL judgements made by doctors reflect the medical model of disability will be discussed later in this chapter. Basnett, I. n.6 above, at p452.

[83] *Ibid.*

[84] Williams, C., Alderson, P., Farsides, B. 'What constitutes "balanced information" in the practitioners' portrayals of Down's syndrome ?' (2002) 18 *Midwifery* 230-237 at p233.

[85] *Ibid.*

physicians interact with them only in a medical setting.[86] Few doctors get to know the person and the way they live their lives outside of the consulting room. Doctors receive little or no education about the realities of living with a disability. Taking the WHO model as an example for assessing QL, the assessment involves factors such as the environment and social contact (social barriers to participation that following the social model, disable people). The medical training doctors receive does not qualify them to judge these aspects of someone's life. Much of the disability rights critique centres on the 'failures of imagination'[87] of bioethicists, obstetricians and genetic counsellors to imagine that disabled people might lead lives as valuable, rich and complex as their own, largely because of their lack of contact with disabled adults as equals and peers.[88]

Other health professionals such as occupational therapists and district nurses may have more expertise than doctors at knowing how impairments affect the quality of life of disabled people. Yet, because they do not go through the same amount of medical training they are not seen as the experts, and instead defer to doctors who manage 'patients'' care.[89] It is also not the doctors or health professionals who specialise in dealing with disabled people[90] who advise prospective parents about PND and disability in this context. Doctors involved in PND will not have the experience of treating disabled patients in this way. Perhaps this explains why, in the context of prenatal counselling, there is evidence that they often rely on pamphlets about conditions for their information on conditions.[91]

There is a lot of evidence that illustrates the considerable variance between the views of disabled people and physicians on quality of life.[92] Physicians tend to underestimate the quality of life of disabled people. It is now necessary to concentrate this discussion on the views doctors hold in relation to disability. As was established early on in this thesis,

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[86] Andrews, L.B. *Future Perfect: Confronting Decisions About Genetics* (Columbia University Press, 2002) at p104.

[87] Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000).

[88] Ward, L. n.55 above, at p194.

[89] The courts also do not respect the views o nurses as much as doctors. This is demonstrated later in this chapter in relation to the analysis of the *Re MB* case.

[90] For example, orthopaedics, cardiologists, neurologists.

[91] This has already been discussed in the IDM chapter.

[92] For example see Rothwell, P.M., McDowell, Z. Wong, C.K., Dorman, P.J. 'Doctors and Patients Don't Agree: Cross Sectional Study of Patients' and Doctors' Assessments of Disability in Multiple Sclerosis' (1997) 314 *BMJ* 1580-83.

in relation to disabled people, it is sometimes necessary to generalise views. This is the case here, although it is recognised that not all doctors hold these views. However, there is evidence to support the notion that *some* doctors think this way, and it is therefore important to highlight views which I perceive to be problematic.

Physicians have a different view of particular disabilities than do people with those disabilities. For example, when asked to evaluate the quality of their lives, 80% of doctors said pretty good, but 82% indicated that their quality of life would be pretty low if they had quadriplegia. In contrast, 80% of people with quadriplegia rated the quality of their lives as pretty good.[93] Only 18% of Emergency Room professionals surveyed by Gerhart *et al* believed traumatic spinal cord injury patients could achieve an acceptable life quality. This contrasted sharply with positive life valuations reported by 92% of the persons who had survived spinal chord injury (resulting in long term disability).[94] In a comparative study, the general public and rehabilitation workers had significantly less positive attitudes towards disabled people than did a group of people with spinal cord injury.[95] In other studies, disabled people had significantly more positive attitudes than did nurses or member of the nursing faculty.[96] These attitudes were expressed in terms of willingness to interact with, and feel empathy for, disabled people.[97] What to many outsiders looks like a life of bleak necessity turns out to be a possible source of enrichment as well.[98]

Alderson's research into the quality and value of lives of individuals with Down's syndrome includes some transcripts of interviews with people with Down's syndrome, some of whom have GCSEs, NVQs, enjoy acting, lectures, and who work.[99] This shows how many disabled people with the right support can achieve many things, and that their lives can be full, enriched and happy. Through specific examples (being pushed in the

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[93] Gallagher, H.G. *'Can we Afford Disabled People'* (Fourteenth Annual James C. Hemphill Lecture, September 7, 1995, Rehabilitation Institute of Chicago).

[94] Gerhart, K.A., Koziol-McLain, J., Lowenstein, S.R., Whiteneck, G. 'Quality of Life following spinal cord injury: knowledge and attitude of emergency care providers' (1994) 23(4) *Annals of Emergency Medicine* 807-812.

[95] Lys, K., Pernice, R. 'Perceptions of positive attitudes towards people with spinal cord injury' (1995) 18 *Journal of Rehabilitation Research* 35-43.

[96] Berrol, C.F. 'Trainee attitudes toward disabled persons: Effect of a special physical education program' (1984) 65 *Archives of Physical Medicine and Rehabilitation* 700-765; Brillhart, B.A., Jay, H., Wyers, M.E. 'Attitudes towards people with disabilities' (1990) 15 *Rehabilitation Nursing* 81-85.

[97] Albrecht, G.L., Devlieger, P.J. n.47 above, at p978.

[98] Reinders, H.S. n.62 above, at p160.

[99] Alderson, P. n.65 above, at p627.

street, or excluded from mainstream school) the disabled people interviewed by Alderson described the frustrations, pains and restrictions of prejudice.

In practice, the anomaly is that patients' perceptions of personal health, well-being and life satisfaction are often discordant with their objective health status and disability.[100] Weinberg elaborates on individuals who embrace disability, stating that persons in this group "are satisfied with who are they are and are able to reach their life goals despite or even because of their disabilities, despite societies tendency to view disability as a continuing tragedy." [101]

Put simply, surrogate judgments often do not accurately reflect patient preferences.[102] "The external determination of a diminished or unacceptable life is often not shared by the person whose life is being judged."[103] Quality of life assessments by 'normal', 'healthy' persons tend to reflect the prejudice, fear, or concerns of the observer, not those of the person whose lived existence is being judged. Thus, "it often happens that lives which observers consider of poor quality are lived quite satisfactorily by the one living that life. It is quite possible that disabled people and their families do not just suffer from natural conditions but also from prevailing attitudes towards disability."[104] Chronic illness and disability are not equivalent to acute illness or sudden injury, in which an active disease process or unexpected change in physical function disrupts life's routines. Most people with conditions such as spina bifida, achondroplasia, Down's syndrome, and many other mobility and sensory impairments perceive themselves as healthy, not sick, and describe their conditions as givens of their lives – the equipment with which they meet the world.[105]

Even where quality of life data is based upon surveys of disabled people, that data remains unreliable. Where surveys and questionnaires begin with the assumption of 'disease burden' and a medical model of disability, the assumptions of those positions –

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[100] Albrecht, G.L., Higgins, P. 'Rehabilitation success: The interrelationships of multiple criteria' (1977) 18 *Journal of Health and Social Behaviour* 36-45; Albrecht, G.L. 'Subjective health assessment' in Jenkinson, C. (ed) *Measuring Health and Medical Outcomes* (London, UCL Press, 1994) pp7-26.

[101] Weinberg, N. 'Another perspective: Attitudes of people with disabilities' in Yuker, H.E. (ed) *Attitudes Towards Persons With Disabilities* (New York, Springer, 1988) at p153.

[102] Addington-Hall, J., Kalra, L. 'Who should measure quality of life?' (2001) 322 *BMJ* 1417-1420.

[103] Cella, D.F. 'Quality of Life: the concept' (1992) 8(3) *Journal of Palliative Care* 8-13.

[104] Reinders, H.S. n.62 above, at p161.

[105] Asch, A. n.43 above.

not the individual's state – is often what is typically measured.[106] If the life quality of those living with physical differences is in fact far better than that which such instruments or assessments would predict, the assumption underlying those instruments must be reconsidered.

There have been writings that insist one may have a very acceptable life quality despite even the most severe physical limitation.[107] Some disabled people have written about or publicly discussed their condition. For those with communicative devices, familial support, and often work, the restrictive condition has been a "life enhancing condition,"[108] "an adventure in life" and a tool for spiritual exploration.[109] While the life style it indicates demands a way of being different from the norm, a necessarily inferior life is not the inevitable result.[110] Through reading narrative accounts it is possible to recognise that the lived reality of a physically restricted life is based upon the complex mediation of personal values and social circumstances whose reality cannot be predicted.[111] Life is complex and is as a result of social context, emotional adaptation and changing individual perspectives. These elements are typically ignored by one-dimensional instruments attempting to assess and then predict the life quality of disabled people.[112] This seems to be recognised in the WHO model discussed earlier which includes domains incorporating these elements.

There is an assumption that disabled people want to be 'normal.' However, disabled people who know themselves that disability is a major part of their identity rarely voice

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[106] Koch, T. n.28 above, at p423.

[107] See Kaufert, J., Lockert, D. 'The breadth of life: medical technology and the careers of people with post-respiratory poliomyelitis' (1988) 10(1) *Sociology of Health and Illness* 24-40; Kaufert, P., Kaufert, J. 'Methodological and conceptual issues in measuring the long-term impact of disability: the experience of poliomyelitis patients in Manitoba' (1984) 6 *Social Science & Medicine* 609-619; Koch, T. *Second chances: Stories of Crisis and Renewal in Our Everyday Lives* (Toronto, Canada, Turnerbooks, 1998); Young, J., Marshall, C., Anderson, E.A. 'Amyotrophic Lateral Sclerosis Patients' perspective on use of mechanical ventilation (1997) 23(1) *Health and Social Work* 523-60; Bauby, J. *The diving-bell and the butterfly* (London, Fourth Estate, 1997).

[108] Goldblatt, D. 'A life-enhancing condition: the Honrable Mr Justice Sam N. Filer' (1993) 13 *Seminars in Neurology* 375-379.

[109] Young, J., McNicoll, P. 'Against all the odds: postitive life experiences of people with advanced amyotrophic lateral sclerosis' (1998) 23(1) *Health and Social Work* 35-43.

[110] Koch, T. n.28 above, at p424.

[111] For examples of narrative accounts see Marteau, T., Richards, M. (eds) *The Troubled Helix: Social and Psychological Implications of the New Human Genetics* (Cambridge, Cambridge University Press, 1996); Berube, M. *Life As We Know It: A Father, A Family, and an Exceptional Child* (New York, Pantheon Books, 1996).

[112] Koch, T. n.28 above, at p424.

this. Disabled people are subject to many disabling expectations, for example, to be 'independent' and 'normal,' as well as to 'adjust' and 'accept' their situation. Swain and French argue that it is these expectations that are disabling, rather than the impairment itself.[113] Working parents of children with special medical or behavioural needs find that meeting those needs takes more time, ingenuity, and energy than they would think would be spent on the needs of nondisabled children.[114] This is not the same description of 'burden' presented by many doctors. From the personal point of view of parents whose identity has been shaped by their lives with a disabled child, the two cannot be easily separated. One cannot expect these parents to answer questions as to whether they would rather have had *their* child without a disability without alienating them from *that* child.[115] For example, one parent is reported to have said:

> "David's disability is global. It is part of him just as much as his species or his gender. It affects every aspect of his existence. It is not like a pair of shoes that he can take off. Without it, he would be a total stranger to me."[116]

Decisions may be made about terminating foetuses based on certain stereotypes about disability,[117] which makes relying on physicians' assessments of disability problematic. Research has shown that some genetics professionals hold clearly eugenicist views. A majority of genetic counsellors (63%) say they themselves would abort a foetus with Down's syndrome. In research carried out by Dormandy and Marteau, all groups of healthcare professionals had positive attitudes towards screening.[118] Wertz and Fletcher recognised that 13% of geneticists agreed that "an important goal of genetic counselling is to reduce the number of deleterious genes in the population."[119]

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[113] Swain, J., French, S. 'Towards an affirmation model of disability' (2000) 15 *Disability & Society* 569-582.

[114] Parens, E., Asch, A. 'The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations' in Parens, E., Asch, A. *Prenatal Testing and Disability Rights (Hastings Centre Studies in Ethics)* (Georgetown, Washington DC, Georgetown University Press, 2000) at p22.

[115] Berube, M. n.111 above.

[116] Sobsey, D. 'Family Transformation: From Dale Evans to Neil Young' in Friedlander, R., Sobsey, D. (ed) *Conference Proceedings: Through the Lifespan* (Kingston, USA, National Association for Persons with Developmental Disabilities and Mental Health Needs, 1996) p13-16 quoted in Reinders, H.S. n.62 above, at p51.

[117] Andrews, L.B. n.86 above, at p103.

[118] Dormandy, E., Marteau, T.M. 'Uptake of a prenatal screening test: the role of healthcare professionals' attitudes towards the test' (2004) 24 *Prenatal diagnosis* 864-868 at p866.

[119] Wertz, D., Fletcher, J.C. *Genetics and Ethics in Global Perspective* (The Netherlands, Dordrecht, Kluwer Academic Publishers, 2004) at p391.

There is considerable anecdotal evidence that negative accounts of living with impairments are presented by professionals at the ante-natal stage.[120] Marteau *et al* demonstrate that the vast majority of professionals likely to be involved in counselling women prenatally, believe that termination is desirable where foetuses have open spina bifida, anencephaly, Huntingdon's disease, Down's syndrome and Duchenne Muscular Dystrophy.[121] These beliefs underwrite a prevailing professional discourse that systematically under-values disabled lives.[122] As previously explained in the decision-making chapter, the way in which physicians describe a genetic condition may make it seem much more grim than it seems to a person with that condition. "Medical descriptions of Down's syndrome – rather than revealing the variability of the condition – selectively represent the condition in uniform, distancing, negative, ungendered, and static terms."[123]

Many disabled people find QL judgements offensive. This is because they believe that only a disabled person should judge the quality of their own life. Statements are made such as "As disabled people we know that our lives have a value equal to anyone's"[124] and "We, more than any other, know of our own life circumstances, goals and capabilities."[125] As Jenny Morris puts it:

> "As a society we cannot, and should not, make judgements about the quality of other people's lives (or of potential lives). When we react to the disability of others, or the prospect of disability in a child, we bring our own subjective experience to the situation. Any assessment of whether someone else's life is worth living can only be based on what their life means to us, not on what it

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[120] Explored in more detail in IDM chapter (chapter 4).

[121] Marteau, T., Drake, H., Bobrow, M. 'Counselling following diagnosis of a foetal abnormality: the differing approaches of obstetricians, clinical geneticists and genetic nurses' (1994) 31 *Journal of Medical Genetics* 864-7.

[122] Sharp, K., Earle, S. 'Feminism, Abortion and Disability: Irreconcilable differences?' (2002) 17 *Disability and Society* 137-145 at p141.

[123] Beeson, D. 'Social and Ethical Issues in Prenatal Diagnosis of Fetal Disorders' in Sheley, B.M., O'Rourke, K.D.(eds) *Health Care Ethics* (St Louis, Catholic Health Association, 1989) p76-86 at p81.

[124] British Council of Disabled People *The New Genetics and Disabled People* (London, BCODP, 2000)

[125] Saxton, M. 'Born and Unborn: The Implications of Reproductive Technologies for People with Disabilities' in Arditti, A., Klein, R.D., Minden, S. (eds) *Test-tube Women what future for motherhood?* (London, Pandora Press, 1989) at p309.

> means to them. Such judgements can only take place in the context of our society's prejudice against disabled people."[126]

5.3 The views of lawmakers

In order to provide an insight into the ways in which lawmakers assess the quality of life of disabled people it is necessary to consider the approaches made by both the courts and Parliament. After careful consideration of the sources available it was decided that for the analysis of the courts' approach, recent judgements would be analysed. The focus of much of the discussion will be the cases of baby Charlotte Wyatt[127] and Leslie Burke.[128] Although neither the Charlotte Wyatt nor Leslie Burke cases involve reproductive decision making, and may therefore initially seem outside of the scope of this study, it is thought that they demonstrate the ways in which courts approach quality of life judgements. There were alternative cases that could have been analysed – the Hashmi/ Whittaker/ Fletcher[129] cases concerning 'saviour siblings' and the Jepson case[130] – it was thought that *Wyatt* and *Burke* provided more opportunity to examine quality of life issues.

The Hashmi/ Whittaker/ Fletcher case was explored primarily in order to examine decision making by the Human Embryology and Fertilisation Authority (HFEA). Whilst this work did not form part of the final thesis, the legal events surrounding the Hashmi decision were analysed. However the focus of this case was not QL issues but was instead whether or not the HFEA had exceeded its regulatory powers in permitting PGD with tissue typing. Thus the judgement revolved around the issue of regulatory structure and powers and thus the types of decisions the HFEA were entitled to make. This case therefore did not allow the type of analysis required to contribute to this section on the way in which law makers assess the quality of life of disabled people.

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[126] Morris, J. *n.56 above,* at p69.

[127] *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247; *Wyatt v Portsmouth NHS Trust* [2005] EWHC 693 (Fam); [2005] EWCA Civ 1181.

[128] *R (on the application of Burke) v General Medical Council* [2004] EWHC 1879; [2005] EWCA Civ 1003.

[129] R (*Quintavalle*) v Human Fertilisation and Embryology Authority (Secretary of State for Health intervening) [2004] QB 168; *Quintavalle v Human Fertilisation and Embryology Authority* [2005] UKHL 28

[130] *Jepson v. The Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318

The Joanna Jepson case already referred to in chapter three could have been an important case relating to QL judgements, however the case never came to court. Whilst the media treatment of this case has proved useful in highlighting the way the public is informed about disability issues, the limited judgement available from the case centred around technical procedural issues which again provided no scope for the detailed textual analysis of the judgements required for this section of this thesis. Whilst the Jepson and Hashmi/Whittaker/ Fletcher cases provided limited opportunity for analysis, this could be interpreted as examples of the courts framing the issues in uncontroversial ways in order to avoid confronting central issues, a point that will be expanded on later in this section.

Because the recent 'beginning of life' cases had proven of limited use for this section, it was necessary to consider other areas of health care law that would provide opportunity for analysis of the way in which the courts have approached QL assessments. 'End of life' cases seemed a useful starting point because in *Bland,*[131] and a number of subsequent cases, the courts have reached the view that it is in the best interests of patients in a persistent vegetative state to be permitted to die notwithstanding the importance of the principle of sanctity of life.[132] The focus has therefore been on how 'meaningful' life is for the patient i.e. a quality of life approach.[133] It is therefore hoped that analysis of these cases will demonstrate how QL assessments are performed as part of legal discourse. *Wyatt* and *Bland* were selected as they are both recent cases and received substantial media interest. Through textual analysis of the judgements of these cases it was possible to demonstrate prejudicial attitudes of lawmakers when assessing the quality of life of disabled people. It will be argued that this is as a result of the dominance of the medical hegemony. This is precisely the same concern that has been raised about the distortion of decision making in relation to PND created by the dominance of the medical model of disability. It is important to note that I am not trying draw an analogy between decisions made about the withdrawal of life-sustaining treatments to an individual and selective abortion. However, the assumptions that underpin such decisions are very similar to the assumptions that underpin attitudes in the

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[131] *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

[132] *Re H* [1998] 3 FCR 174; *Re D* [1998] 1 FCR 498; *Re R* [1996] 3 FCR 473.

[133] *Re D* n.132 above.

PND context. The acceptance of the medical perspective in this context demonstrates that law makers are not inclined to counteract the influence of the medical model.

5.3.1 Courts

This section of the chapter involves analysis of some of the cases brought to court that involved a discussion of 'best interests.' As briefly explained in the chapter introduction, different areas of law use different terms to assess the quality of life of individuals, 'best interests' is one of the guises of quality of life judgements utilised by lawmakers and medical professions and will be the focus here. This section does not aim to be an exhaustive description of case law to date on these issues. Instead, cases are used that are illustrative of the general points discussed in this chapter. Rather than going through each case in turn and explaining the relevance to this thesis, this section will instead use the case law as evidence to support emergent themes identified throughout the research that contributed to this section.

Courts make value judgements and the approach they take to QL and decisions they make do affect disabled people. In terms of the expressivist argument, this means that QL judgements express the value that is placed on disabled people. Furthermore, this can affect the way people think about disability and the way that disability policies evolve, both of which can influence the lives of disabled people. The areas in which the judgements are made mean that it is not melodramatic to suggest that such decisions are often a matter of life and death. However it is also argued here that courts have a role to play in challenging the way in which quality of life judgements are made. For example, in *Re C*, the doctors' evidence to the Court in this case made value judgements about dependency.[134] Adults with SMA see things very differently to the Court. For example, Jane Campbell has SMA and has written and made speeches on this point.[135]

Medical assessment should not be left unchallenged. As Sir Thomas Bingham MR said in *Frenchay Healthcare National Health Service Trust v S*[136] "It is, I think, important that there should not be a belief that what the doctor says is in the patient's

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[134] *Re C* [1998] 1 FCR 384.

[135] For example see Campbell, J. 'Choose Life' *The Guardian,* 26 August 2003 and the DRC website for the text of her speeches (www.drc.gov.uk).

[136] *Frenchay Healthcare National Health Service Trust v S* [1994] 1 WLR 601.

best interest *is* in the patient's best interest."[137] Traditionally, the courts have merely relied on doctors' opinions on quality of life.[138] In *Re C,*[139] baby C's doctors argued that her "disability was too terrible to live a quality life." In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support." The Court ruled for the hospital having received advice from a range of doctors, who all categorically stated that no one with this diagnosis could live beyond the age of two and that if they did, life would be intolerable.[140]

As previously demonstrated in this chapter, doctors often have prejudiced views of disability so this approach is dangerous for disabled people. It is therefore imperative to change the way quality of life judgements are made. The DRC, as an interested party in the Burke case, challenged the "quality of life" assessment as it relies not only on a doctor's medical opinion of whether treatment should be given or withdrawn, but also on the social welfare of the patient.[141] Whilst doctors can claim to have medical expertise, they can claim no special expertise in non-medical matters which go to form the basis of what is in the patient's best interests. Those opinions could be based on a backdrop of negative images and poorly informed assumptions of intolerable suffering, unacceptable dependence on others or that a particular disability makes life not worth living.[142] The Court of Appeal in *Burke* suggests that a condition that causes "an extreme degree of pain, discomfort or indignity to a patient"[143] would be considered not worth living and so would absolve doctors from the positive duty to keep the patient alive. Yet all those terms are very subjective – people have different pain thresholds and what some might think is uncomfortable or undignified (such as being catheterised) does not make a life not worth living.

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[137] per Sir Thomas Bingham MR, *Frenchay Healthcare National Health Service Trust v S* n.136 above, at p609.

[138] *Airedale NHS Trust v Bland* n.129 above; *Re J* [1992] 4 All ER 514; *Re C* [1996] 2 FLR 43; *Re F* [1989] 2 FLR 376; *Re B* [1987] 2 All ER 206.

[139] *Re C* n.134 above.

[140] This is also the issue in *Re MB* discussed later in this chapter.

[141] Disability Rights Commission 'Doctors must fulfil patient's "dying wishes"' (London, DRC, 2004).

[142] Munby J quoting Mr Wolfe in *R (on the application of Burke) v General Medical Council* [2004] EWHC 1879, p439, para 35.

[143] *Burke v GMC* [2005] EWCA Civ 1003, para 33.

Ian Kennedy has argued that the best interests test protects medical power rather than the patient's welfare.[144] This view is supported by Montgomery in his article on the way health care law deals with a multi-faith society.[145] He argues that "the duty to give incompetent patients the care that is in their best interests is usually judged not against the judicial assessment of where those interests lie but that of the doctors looking after them."[146] Montgomery also demonstrates that because many cases do not go to court, "the application of the best interests principle lies in the hands of health professionals rather than lawyers."[147] And that when cases do come before the judiciary, the courts have focused on ensuring that clinical judgements made are within the parameters of responsible professional decisions. In *Re J*[148] it was said that it would be an abuse of the court's powers to instruct a doctor to treat against her or his clinical judgment.

In his article, Montgomery claims "There is significant danger that best interests decision making could become little more than a mechanism for the imposition of prejudice."[149] This is a real concern to disabled people because prejudiced QL judgements could mean the withdrawal of treatment, services, or life-saving equipment. The issue in *Burke* was that "He does not want a decision to be taken by doctors that his life is no longer worth living."[150] This was reflected in a passage in the annexe to Mr Burke's claim form, which stated: "He is concerned that doctors will determine for him whether or not he ought to continue to live."[151]

When considering the best interests test in the *Burke* case, Mr Justice Munby drew a distinction between the *Bolam*[152] test, which on his analysis focuses simply on treatment that is in the interests of the patient from a clinical viewpoint, and the test of best interests which "involves a welfare appraisal in the widest sense, taking into account where appropriate, a wide range of ethical, social, moral, emotional and welfare

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[144] I. Kennedy, 'Patients, doctors and human rights' in Kennedy, I. *Treat me right essays in medical law and ethics* (Oxford , Clarendon, 1988) pp. 385-413, esp. pp395-6.
[145] Montgomery, J. n.25 above.
[146] *Ibid,* at p164.
[147] *Ibid,* at p164.
[148] *Re J* [1992] 4 All ER 614.
[149] Montgomery, J. n.25 above, at p166.
[150] *Burke v GMC* n.143 above, at para 5.
[151] *Ibid.*
[152] [1997] 1 WLR 582.

considerations."[153] However the Court of Appeal followed the *Bland*[154] judgement more literally and argued that

> "it is best to confine the use of the phrase 'best interests' to an objective test, which is of most use when considering the duty owed to a patient who is not competent and is easiest to apply when confined to a situation where the relevant interests are medical."[155]

This is surprising because traditionally 'best interests' has been given a more generous interpretation in sterilisation cases. As the President said in *Re A (Male Sterilisation)*:[156] "...best interests encompasses medical, emotional and all other welfare issues." And in *Re S* (Adult Patient: Sterilisation),[157] it was said that:

> "In deciding what is best .... the judge must have regard to .... welfare as the paramount consideration. That embraces issues far wider than the medical. Indeed it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination."

In the *Wyatt* case, all the medical evidence submitted described how terrible Charlotte's quality of life was and how she only experienced intolerable pain. It is clear on reading the High Court judgement that the judge relied heavily on this medical evidence to make his decision and indeed the medical evidence 'trumped' any other evidence demonstrating that Charlotte could experience some quality of life. When looking at the case it is possible to code the paragraphs depending on their content. In this way, the dominating influence of medical evidence is clear: from a judgement lasting 22 paragraphs,[158] 10 of them were concerned with medical opinions. Furthermore, Justice Hedley explicitly said:

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[153] *R (on the application of Burke) v General Medical Council* n.142 above, para 90.

[154] *Airedale NHS Trust v Bland* n.129 above.

[155] *Burke v GMC* n.143 above, at para 28.

[156] *Re A (Male Sterilisation)* (2000) 1 FLR 549 at p555.

[157] *Re S (Adult Patient: Sterilisation)* (2001) Fam 15 at p30 per Thorpe LJ.

[158] *Wyatt v Portsmouth NHS Trust* n.127 above. This is the first in a series of judgements relating to this case.

> "In reaching that view [that further invasive and aggressive treatment would be intolerable for Charlotte] I have *of course* been informed by the medical evidence as to the prospects and cost to her of aggressive treatment."[159]

By including the phrase 'of course' here, the judge implies that there it was obvious to him that he should rely on the medical evidence. This supports the argument running throughout this thesis regarding the dominant hegemony of medicine. It can be seen here to be so pervasive that it is not even recognised as an issue. Interestingly, the judge continues to state that he had taken into account not just her body, but her mind, spirit and personality;[160] yet he does not describe the evidence used for such considerations or how such considerations influenced his decision. Indeed he stated that "after careful and anxious consideration, I find myself convinced by the majority of medical opinion."[161] In fact he seemed to have discounted other evidence. Mr Wolfe provided evidence from an organization called Portsmouth Portage Service, (a home visiting educational service for pre-school children run by Portsmouth City Council), which recorded Charlotte as enjoying her bath; moving her head to both sides when lying on her back; appearing to listen and respond to speech by looking at the speaker's face; smiling or turning her head and demonstrating some vision by blinking when a hand was passed over her eyes; looking at a dangling toy held above her head; following an object in a horizontal pattern with her eyes and looking "at surroundings (20 cms) when lying on her back."[162] This was supported by her guardian who said "Charlotte can show what may be 'enjoyment' of things now. She makes facial movements, opening her mouth and eyes a bit more, that might suggest she gains some pleasure, e.g. when she is being tickled."[163] However, despite these improvements, the Court constantly referred to the fact that there was 'no change in her underlying clinical condition' and so the assessment of her quality of life and best interests had therefore not changed. This seems a controversial approach to take for surely by proving that Charlotte's quality of life had improved this would lead to a re-assessment of whether or not life-saving treatment would be in her best interests.

It is clear that once the Court had decided to take this approach there was only one decision that could have been made. In taking the doctors' views of the situation as

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[159] *Portsmouth NHS Trust v Wyatt* n.127 above, at para 39 (emphasis added).
[160] *Ibid.*
[161] *Wyatt v Portsmouth NHS Trust* n.127 above, at para 16.
[162] *Wyatt v Portsmouth Hospital NHS* (2005) EWCA Civ 1181 para 33.
[163] Advice from guardian in *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 46.

comprehensive, and in finding that the doctors were not making irresponsible decisions, the Court was never going to find in favour of Mr and Mrs Wyatt. This is because of the 'trumping' nature of medical evidence (as already explained), the unwillingness of the court to indicate there is a 'right' to treatment, and a fear of undermining doctors and interfering with clinical decisions. This can be seen when the Court of Appeal stated:

> "It is not the function of the court to be used as a general advice centre... it is, in our view, not the function of the court to oversee the treatment plan for a gravely ill child. That function is for the doctors in consultation with the child's parents."[164]

They also commented that "It is nearly always a matter of regret when the debate relating to the treatment of a seriously disabled or sick child, which frequently involves issues of life and death, needs to be conducted in a courtroom, rather than a hospital or a consulting room."[165] Here, the Court of Appeal appear frustrated that the medics were being challenged and so the courts were involved. They also focused on the behaviour of the parents which the Court of Appeal interpreted as obstructive in their actions towards the Trust,[166] as if in sympathy with the doctors because the parents were making a difficult situation worse by their behaviour.

Just because a person is unable to communicate or articulate their views clearly, it does not mean that their life is not worth living: many people with very severe intellectual impairments are able to express pleasure and pain, show awareness of their surroundings and relationships, and demonstrate all the feelings associated with being a human subject.[167] Montgomery said that "Once declared incompetent, patients become vulnerable to medical and judicial paternalism. The purpose of judicial scrutiny of decisions taken in the 'best interests' of patients is to ensure that as objective a view as possible is taken." [168] Whilst in theory, the courts' views are meant to be objective, in reality this is impossible because they will always be influenced by cultural norms and values that inevitably makes their views subjective. As demonstrated in *Wyatt*, medical evidence trumps any other argument. This can be seen also in *Burke* where the Court of

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[164] *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 117.
[165] *Ibid*, para 86.
[166] *Ibid*, paras 20- 21 and 119.
[167] Shakespeare, T. n.29 above, at p675.
[168] Montgomery, J. n.25 above, at p178.

Appeal held that the test of best interests is "easiest to apply when confined to a situation where the relevant interests are medical."[169] Furthermore, as previously discussed in this chapter, medics are not experts in disability issues, and traditionally take a viewpoint based on the medical model. Reliance on medical information in this way prevents the courts from taking an objective view of QL judgements.

There is much to be said for Mr Justice Munby's approach to best interests in the *Burke* case. He suggested that

> "the Bolam test is not determinative. The doctor's duty is not merely to act in accordance with a responsible and competent body of relevant professional opinion: his duty is to act in accordance with the patient's *best* interests... The decisions as to what is in fact in the patient's best interests is not for the doctor: it is for the patient, if competent, or if the patient is incompetent and the matter comes to court, for the judge."[170]

Mr Justice Munby's verdict aims to balance the power relationship between doctor and patient. Both have a breadth of knowledge and experience not available to the other. The Court considered the knowledge base of both patient and doctor to be of equal merit and that neither should take precedence over the other as a matter of course. And that in the final analysis the patient's wishes to life prolonging treatment should be provided for unless if by doing so, it prolonged an intolerable situation. The Court seemed to understand that doctors should not be asked, or expected, to pass sole judgement on what is 'in the best interests' of a severely ill or disabled patient. After Munby J's judgement in *Burke*, the DRC said:

> "this is a very important decision, which should work in practice. It places the disabled person at the heart of the decision making process. A competent person can decide what is in their own best interests. If a person is not competent to make their own decision, their advance directive will be followed if there is one. If not, the way the court has defined best interests makes it clear that an assessment of best interests and intolerability must be from the standpoint of the

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[169] *Burke v GMC* n.143 above, at para 28.
[170] *R (on the application of Burke) v General Medical Council* n.142 above, at p156 para 30.

> disabled person. There will be practical issues to resolve, not least of which will be how to conduct an assessment this way. However the benefits of doing so are clear."[171]

The Court of Appeal disagreed with Justice Munby's approach and believed it should be for doctors to decide. This is evident when they said:

> "Where life depends upon the continued provision of ANH there can be no question of the supply of ANH not being clinically indicated *unless a clinical decision has been taken that the life in question should come to an end*."[172]

This approach clearly puts a lot of power in the hands of doctors. Furthermore, this formulation looks at whether the life is worth living. It thus does not use the construction applied in *Wyatt* to avoid the type of value judgement hinted at in the next quote. Munby J believed that the patient's wish to receive ANH must be determinative, however the Court of Appeal did not agree. They said that:

> "Clearly the doctor would need to have regard to any distress that might be caused as a result of overriding the expressed wish of the patient. Ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs."[173]

Should a quasi-legal definition test be developed – intolerability?

In relation to the process of assessing competence, it has been suggested by Montgomery that steps need to be taken to balance the prejudice. The rhetoric of the test seems neutral, but the way in which it is applied to the facts is poorly controlled by the law.[174] A way needs to be found to take the personal values of patients into account even when they are not legally competent.[175] Whilst Montgomery was focusing on personal values in relation to religion here, it is equally important to take into account the views of the

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[171] DRC (28 Jan 2005) Article for Association of District Judges Law Bulletin see www.drc.gov.uk.
[172] *Burke v GMC* n.143 above, at para 53.
[173] *Ibid,* at para 55.
[174] Montgomery, J. n.25 above, at p178.
[175] *Ibid.*

disabled person. An approach called the 'substituted judgment' has been adopted in the USA.[176] The principle here being that the court should try to place itself in the patient's shoes and then make the decision that it believes the patient would have made had they been in a position to do so.[177] This seems close to the approach advocated by Mr Justice Munby in *Burke.*[178]

As an interested party in *Burke*, the DRC argued for the adoption of an 'intolerability' test. This test is based on the premise that if treatment was given or continued and the result would be that a person's life was 'intolerable', then it would be acceptable to withdraw or not to give the treatment. The DRC argued that the 'intolerability' test is currently used when courts are making decisions about withdrawing life saving treatment[179] and is a much higher threshold for withdrawing treatment than the quality of life factors referred to in the GMC's guidelines.[180] Most importantly, the 'intolerability' has to be viewed from the patients' perspective and not the doctors' perspective. Munby J found in favour of this argument, when he said

> "I therefore agree with Mr Wolfe when on behalf of the DRC he submits that, when considering whether to withhold or withdraw ANH (artificial nutrition and hydration) from an incompetent patient, (1) the assessment of best interest has to be made from the point of view of the particular patient and (2) the touchstone of best interests in this context is intolerability."[181]

This reasoning was then followed in *W Healthcare NHS Trust v KH.*[182] However, the Court of Appeal in the *Wyatt* case not only distinguished *Re KH* on the facts because it involved an adult patient and Charlotte is a baby, but also removed the possibility that it could be relied on in later cases involving adults by saying that any observations on 'intolerability' could only be considered obiter, because the judge in that case had

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[176] This doctrine has been used since the case of *Re Hinde, ex p Whitbread* [1816] 2 Mer 99.

[177] The applicability of this doctrine in English is dubious. See Kennedy, I., Grubb, A. *Medical Law* (London, Butterworths, 2000) p832-842 for more information.

[178] *R (on the application of Burke) v General Medical Council* n.142 above, at p156 para 30.

[179] *Re B* [1981] 1 WLR 421; *Re C (A Minor)* [1989] All ER 782; *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930; *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99. Although it is questionable whether or not these authorities did use the intolerability test.

[180] General Medical Council *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-Making* (London, GMC).

[181] *R (on the application of Burke) v General Medical Council* n.142 above, at para 111.

[182] 17 September 2004, [2004] EWCA Civ 1324.

already decided the case by a careful balance of all the factors in the welfare equation.[183] In the much earlier case *of Re J (a Minor) (Wardship: Medical Treatment)* it was said:

> "I consider the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child. I say "to that child" because the test should not be whether the life would be tolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable." [184]

It should be noted that it was James Munby QC who tried to persuade the court to adopt the intolerability test in *Re J.* In the *Wyatt* case however, Justice Hedley thought that "the concept of "intolerable to that child" should not be seen as a gloss on, much less a supplementary test to, best interests. It is a valuable guide in the search for best interests in this kind of case."[185] He therefore rejected the intolerability test as a touchstone of best interests, and the Court of Appeal agreed that he was correct to do so.[186] As they said:

> "it therefore appears to us that a best interests "test" based on the intolerability of the child's quality of life has its origins in (1) extempore dicta in *Re B*[187] not approved by the majority in *Re J*[188] and (2) in only one of the three judgments in *Re J.* In our view, this supports the proposition that Hedley J was right to observe that the concept of "intolerable to the child" should not be seen as a gloss

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[183] *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 84.

[184] *Re J (a Minor) (Wardship: Medical Treatment)* [1991] Fam 33 at p55 *per* Lord Taylor.

[185] *Portsmouth NHS Trust v Wyatt* n.127 above, at para 61.

[186] *R (on the application of Burke) v General Medical Council* n.142 above.

[187] *Re B (A minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421 at p1424 Lord Templeman said " … at the end of the day it devolves on this court to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die. "

[188] *Re J* n.148 above. Lord Donaldson MR believed that they were not bound by the judgement of *Re B* because it "was probably not a borderline case and I do not think that we are bound to, or should, treat Templeman LJ's use of the words 'demonstrably so awful' or Dunn LJ's use of the word 'intolerable' as providing a quasi-statutory yardstick'.[188] Instead he preferred the reasoning of Asch J in *Re Weberlist*[188] because it gives effect, as it should, to "the fact that even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's, desire to survive." *Re Weberlist* [1974] 360 NYS 2d 783 at p787.

> on, much less a supplementary test to, best interests. It is, as the judge observed, a valuable guide in the search for best interests in this kind of case."[189]

The Court of Appeal in *Wyatt* rejected any "potentially contentious glosses on the best interests test which are likely either inappropriately to shift the focus of the debate, or to restrict the broad exercise of the judicial discretion involved in balancing the multifarious factors in the case."[190] In summarising their view they held that

> "The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient (*Re J*). There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (*Re J*). The term "best interests" encompasses medical, emotional, and all other welfare issues (*Re A*). The court must conduct a balancing exercise in which all the relevant factors are weighed (*Re J*) and a helpful way of undertaking this exercise is to draw up a balance sheet (*Re A*)."[191]

The approach of drawing up a balance sheet, as advocated here, is similar to the table the WHO produced as their QL instrument.[192] Whilst it could be argued that the balance sheet records the 'pros and cons' of courses of action, it is clear in *Re MB*[193] that the balance sheet included in the judgement, relied on medical evidence about the benefits and burdens of MB's life. That is because, in order to balance the options in any particular case, it is necessary to look at what the proposed treatment options would mean for the individual, and this seems to be done by identifying the medical evidence about that particular individual: their capabilities and inabilities. This approach is another example of the court trying to look at QL objectively, when in reality this is impossible.

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[189] *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 76.

[190] *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 86.

[191] *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 87 referring to *Re A (Male Sterilisation)* (2000) n.154 above; *Re J (a Minor) (Wardship: Medical Treatment)* n.182 above.

[192] See fig. 11. earlier in this chapter.

[193] *Re MB* n.12 above, at paras 58-60.

Judges frame the debate in uncontroversial ways

The *Wyatt* case was framed to question how harmful a particular treatment was to Charlotte, rather than in explicit quality of life terms.[194] This was to ensure they were not in the position of making any judgements as to whether or not Charlotte's life was one 'not worth living.' As a result, clarification of the law in relation to 'best interests' was restricted to whether or not it was in Charlotte's best interests to receive ventilation in the event of respiratory arrest. Despite that however, value judgements about her quality of life resonated. For example, in both courts, many references were made to the fact that her underlying condition had not changed, and this seemed pivotal to the decisions made. This seems perverse because, despite evidence that her condition had improved, and she had beaten the odds, the fact that she remained disabled, and that had not altered, meant that the doctors were entitled to refuse her ventilation in the event of respiratory distress. Implicitly then, the courts were making value judgements about life with her disability.

When discussing the *Jeanette* case[195] Montgomery found that the Court selectively analysed the evidence before them, "so that what appeared to be description was in fact an interpretation."[196] The same could be said of the *Wyatt* case: the Court of Appeal seemed to ignore the evidence indicating an improvement in her condition, and instead focused on the doctors' views of her intolerable condition. For example, the Court of Appeal stated that

> "Whilst, as the Trust acknowledges, it may be very difficult for Mr and Mrs Wyatt to accept that Charlotte's underlying condition has not altered, that was clearly the Trust's evidence before the judge, which, we have already made clear, he was entitled to accept."[197]

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[194] From the offset, the Court established what the case was and was not about. See *Wyatt v Portsmouth Hospital NHS* n.162 above, at paras 9-16.

[195] Re B n.138 above.

[196] Montgomery, J. 'Rhetoric and 'Welfare'. [1989] 9 Oxford Journal of Legal Studies 395-402 at p401

[197] *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 116.

They justified this by saying that it was for the High Court to "weigh the medical evidence and set it against Mr and Mrs Wyatt's wishes,"[198] whereas the Court of Appeal explained that "we are, of course, a court of appeal, not of trial… It was neither appropriate nor, indeed, possible for us to attempt to analyse and evaluate the nature and effect of any changes in Charlotte's condition since the judge had given his judgement."[199]

Yet, it is clear from the judgement[200] that they sought and received up to date information about her, which they then continued to ignore as they were restricted to deciding whether the approach taken by Justice Hedley was the correct application of the law. Furthermore, the Court of Appeal appeared to be swayed by the medical evidence when it stated that "On the facts of this case, which includes the history we have outlined… and the powerful medical consensus that Charlotte's underlying condition had not changed…"[201]

A similarly restrictive approach was taken when the Court of Appeal overruled Mr Justice Munby's approach to the *Burke* case and demolished his judgement. The Court of Appeal made their approach to the case clear – they were determined to limit discussion only to the facts of the case, arguing that to do anything else would be dangerous.[202] Whilst they were strictly correct as a matter of law to take this approach, it meant that many issues considered by Munby J were not considered by the Court of Appeal. This makes it difficult to compare the approach of the two courts in relation to the disability issues. It also appeared that the Court of Appeal believed the case was only brought to serve the interests of others, rather than Mr Burke himself. This was due to the involvement of the DRC; the Catholic Bishops' Conference of England and Wales; Patient Concern; Medical Ethics Alliance; the British section of the World Federation of Doctors who Respect Human Life; and the Intensive Care Society as interested parties in the case with their own intervening legal representation. The Court did not seem to appreciate the involvement of these other parties. This can be seen when referring to the submissions made by the interested parties they said that:

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[198] *Ibid,* at para 33.
[199] *Ibid,* at para 49.
[200] *Ibid,* at paras 42-48.
[201] *Ibid,* at para 114.
[202] *Burke v GMC* n.143 above, at para 21.

> "a great deal of their thoughtful and well-presented contributions falls victim to our general view that this litigation expanded inappropriately to deal with issues which, whilst important, were not appropriately justiciable on the facts of the case."[203]

Indeed it is possible that the intervening submissions made the Court of Appeal even more restrictive in their comments because they were careful not to produce a judgement that could have implications for others, instead they restricted their comments to Mr Burke.[204] They stated that:

> "Mr Francis QC, instructed by the Official Solicitor, submitted to us that Mr Burke had performed a public service by enabling these wider issues to be debated. We do not agree."[205]

Judges are more careful what they say than MPs

This point will be more easily explained following the next section which explores some of the ways in which MPs described disabled people during the HFE Act 1990 debates.[206] However a few points can be touched upon here. Considering the results of the *Wyatt* and *Burke* cases in the Court of Appeal, could it be said that any recognition of disability rights by courts is merely rhetorical commitment?

In *Re B,*[207] and referred to by Justice Hedley in the *Wyatt* case, Lord Donaldson MR quoted from Asch J in *Re Weberlist*[208] which noted that

> "the fact that even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability."

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[203] *Ibid,* at para 82.
[204] *Ibid,* at para 14.
[205] *Ibid,* at para 19.
[206] For methodology of this see appendix C.
[207] [1991] Fam 33 at 46D.
[208] *Re Weberlist* [1974] 360 NYS 2d 783 at 787.

This recognises that many people may perceive disabled people's lives as intolerable, yet the person themselves may not. This picks up the point explored earlier in this chapter that only the individual concerned should make QL judgements. The Master of the Rolls also referred to McKenzie J in the passage from his judgment in *Dawson's* case[209] which said:

> "I do not think that it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance."

Initially the sentiment of this passage is appealing, as he is arguing that no one has the right to judge anyone else's QL. Yet when analysed in more detail it is important to recognise that phrases like 'disadvantaged person' are judgemental and imply a value judgement that undermines what has just been said. McKenzie J exacerbated this when he said

> "It is not appropriate for an external decision maker to apply his standards of what constitutes a liveable life and exercise the right to impose death if that standard is not met in his estimation. The decision can only be made in the context of the disabled person viewing the worthwhileness or otherwise of his life in its own context as a disabled person—and in that context he would not compare his life with that of a person enjoying normal advantages. He would know nothing of a normal person's life having never experienced it."

This is clearly offensive to disabled people as it implies that they are not 'normal,' which can be interpreted as disablist. It then becomes clear that courts often make passing politically correct comments and then proceed to undermine them. This can be seen in the Court of Appeal decision in *Burke*, where in the footnote the court is keen to point out that

> "People in the unhappy position of Mr Burke and Mrs Campbell are entitled to have confidence that they will be treated properly and in accordance with good practice, and that they will not be ignored or patronised because of their disability."[210]

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[209] [1991] Fam 33, 42G-H.

[210] *Burke v GMC* n.143 above, at para 83.

The point they are making is undermined by the way they include a value judgement that Mr Burke is in an 'unhappy position.' That this statement is also made in a footnote rather than in the main text is also poignant. The court appears to be trying to establish that people should not be discriminated against because of their disability is interesting, even though this was not an issue they allowed themselves to consider, because it was outside the court's remit on the facts of this case (as they interpreted them).

If my analysis of these cases is correct, then the themes identified by looking at *Wyatt* and *Burke* should also be evident in the most recent case of *Re MB.*[211] Whilst some may see this judgement as recognition that the courts' approach is improving in relation to the points made above, it becomes clear, on closer analysis that many of the same problems still arose.

Re MB[212]

The parties in this case, (as briefly explained in the introduction to this chapter), were the parents of a baby with severe SMA and the healthcare trust treating him.[213] The trust sought permission to withdraw ventilation, whilst the parents sought an order to make the doctors perform a tracheotomy. The doctors considered that the quality of life for MB was so low, and that the burdens of living were so great, that it was unethical to continue artificially to keep him alive. On the other hand, the parents believed that he had some quality of life, in particular that he gained pleasure from his family, music, DVDs and television. Justice Holman decided in favour of the parents, in so far as he refused the trust permission to withdraw ventilation,[214] but he would not order the doctors to perform a tracheotomy. Initially then, because of the result of the case, it could appear that this case contradicts previous assertions in this thesis in relation to the extent to which judges defer to the medical profession when assessing quality of life. This point will now be discussed in detail.

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[211] *Re MB* n.12 above.

[212] *Ibid,* at paras 58-60.

[213] The name of the baby, the parents, the healthcare trust and the doctors involved were all kept anonymous.

[214] There were however procedures which go beyond ventilation which it would be in MB's best interests to withhold – these procedures were Cardio pulmonary resuscitation (CPR), ECG monitoring, the administration of intravenous antibiotics and blood sampling.

Several strands of the argument relating to the reliance of courts on the medical profession have become apparent throughout this chapter: firstly, they are used as 'experts' in judging the quality of life of disabled people (which it has already been demonstrated in this thesis, they are not qualified to do); secondly, the medical profession dominate proceedings in court; finally, medical assessment goes unchallenged. These strands will now be considered in relation to *Re MB*.

Doctors used as 'expert' witnesses

Many doctors provided evidence in this case, two as 'treating doctors,'[215] eight other doctors from the trust (part of the overall clinical team caring for M, referred to as the 'trust doctors'),[216] and some as expert witnesses.[217] The two 'treating doctors' provided detailed reports, and the four 'expert witnesses' agreed a Joint Expert Report[218] and the 'trust doctors' each made statements. All the evidence from the doctors agreed with the trust. The senior sister of the intensive care unit also provided a statement. In her statement she explained that there was disagreement between the nursing staff about the future treatment of MB.[219] Yet despite the fact that some nurses disagreed with withdrawing treatment for MB, the judge said "There is thus a very formidable body of medical evidence of very high quality in this case which is all, *without exception*, to the same effect."[220]

Justice Holman also recognised that "the views and opinions of both the doctors and the parents must be carefully considered."[221] This would imply that it is not just the medics that provide an insight into MB's quality of life. Yet he went on to discount the opinions of the parents as they "may, very understandably, be coloured by their own emotion or sentiment."[222] Justice Holman reiterated how the parents failed to be objective by saying

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[215] Referred to in the judgement as Dr S I (Consultant in paediatric intensive care) and Dr S N (consultant paediatric neurologist).

[216] *Re MB* n.12 above, at para 26: five consultants in paediatric intensive care, two consultant paediatric neurologists and one consultant paediatric anaesthetist.

[217] *Ibid*, at para 26: four further doctors, two consulted by the trust, two by the parents.

[218] *Ibid* at para 29.

[219] *Ibid* at para 27.

[220] *Ibid* at para 30 (emphasis added).

[221] *Ibid* at para 16 (original emphasis).

[222] *Ibid* at para 16.

that the mother was "deluding herself."[223] This is interesting as he qualifies the use of the opinions of parents, but offers no qualifications as to the use of opinions by the doctors thereby implying that the opinions of the doctors were purely objective. This point has been argued against throughout this thesis.

The medical profession dominate proceedings in court

Consideration of the medical evidence supplied by the trust and the 'expert witnesses' formed a large part of the judgement in this case. Yet, as already explained, apart from the nurse's statement (seemingly discounted by the judge), the doctors all concurred in their opinions. It was interesting to note that the 'trust doctors' (not including the 'treating doctors') all sent in identical statements, as all were in agreement with the 'treating doctors' about the right course of action in relation to MB. Furthermore, the 'expert witnesses' all met up to discuss their findings, and as all were in agreement they submitted a Joint Expert Report. In this way, it could be seen that the court was kept out of the decision making process because the experts had all agreed amongst themselves the right course of action, and the court then had to rely on that body of opinion. The extent to which the judge relied on the medical evidence and the extent to which that evidence went unchallenged will now be discussed.

Medical assessment goes unchallenged

The judge was clear to define respective roles for courts and for doctors. In this way he said:

> "I wish to stress and make clear, however, that I myself am not concerned with any ethical issues which may surround this case... The ethical decision whether actually to withdraw or withhold it must be made by the doctors concerned. Judges are neither qualified to make, nor required, nor entitled to make ethical judgments or decisions."[224]

In this statement he seems to be saying that it is for doctors to decide whether or not it is ethical to withdraw treatment from MB. Yet if this was the case, then there would be no

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[223] *Ibid* at para 42 and again at para 45.
[224] *Ibid* at para 24.

need for the case to come to court, as the ethical decision would have been made by the doctors. The judge was also keen to recognise that it was not within his power to force doctors to act against their clinical judgement,[225] so for this reason he could not insist that the trust perform a tracheostomy. This can be seen when he said:

> "… the doctors may not agree to perform a tracheostomy, in which case any declaration by me might appear to be an attempt to do what I have no right or power to do, namely to require doctors to carry out a positive medical intervention against their own judgment and will."[226]

So, to this extent, it seems as if the court failed to challenge the medical evidence. Yet this does not give a full picture of the judgement. In fact Justice Holman made some scathing comments about the medical evidence supplied. The judge made the point that all the statements from the 'trust doctors' were identical, all saying, *inter alia,* that MB "already has an intolerably poor quality of life and this will only get worse…"[227] The judge, in reference to these statements said

> "I do comment that within the common statement there is no reference to, or recognition of, any possible current pleasure or benefit to M from his life."[228]

In this way, the judge could be seen to recognise the importance of the social model of disability, and the limitations in the evidence supplied by the doctors. This was again evident when commenting on the balance sheets detailing the benefits and burdens of continuing ventilation that the interested parties[229] were asked to submit. In relation to the information provided by the trust, the judge said:

> "I record, however, that even at the end of the hearing, the list… on behalf of the Trust (and with, I believe, input from Dr S I and/or Dr S N) contains under the heading "Benefit" only one item "Preservation of life." Whilst that may be said to be all embracing, it does not recognise or identify any specific benefit that M

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[225] This point was seen earlier when the *Wyatt* case was discussed.
[226] *Re MB* n.12 above, at para 54.
[227] *Ibid* at para 26.
[228] *Ibid*
[229] the parents, the trust and the guardian.

> may be getting from his life, though the "Disbenefits" are listed with considerable specific detail."[230]

Again, in this way the judge is recognising the subjective nature of the evidence provided by the doctors, which fails to acknowledge any benefits to MB in remaining alive. By challenging the medical evidence the judge believed he was performing an objective assessment. The extent to which this was achieved will now be analysed.

The objectiveness of QL assessments

On several occasions, Justice Holman reiterated the court's role in making an objective assessment about what is in MB's best interests. For example, he said his task, "difficult enough in itself, is to decide, and only to decide, where the objective balance of the best interests of M lies."[231] He also made several other references to the need for objectivity throughout the judgement.[232] In an attempt to do this, the judge followed the Court of Appeal's guidance in Wyatt, as to how to carry out an assessment of 'best interests:'[233]

> "The test is one of best interests, and the task of the court is to balance all the factors. The Court of Appeal have suggested that the best and safest way of reliably doing this is to draw up a list on which are specifically identified, on the one hand, the benefits or advantages and, on the other hand, the burdens or disadvantages of continuing or discontinuing the treatment in question."[234]

As already alluded to, it was for this reason that the judge asked all interested parties to draw up their own balance sheets. As already explained, he was unimpressed by the information provided by the trust in this way. Yet having completed this exercise, Justice Holman recognised the limitations in this approach, when he said:

> "Whilst it is a very helpful but relatively easy task to draw a list of benefits and burdens, there are still huge difficulties in striking the balance overall appraisal of

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[230] *Re MB* n.12 above, at para 59.
[231] *Ibid*, at para 24.
[232] For example, see *Re MB* n.12 above, at para 16.
[233] Already discussed above. See *Wyatt v Portsmouth Hospital NHS* n.162 above, at para 87.
[234] *Re MB* n.12 above, at para 58.

> the weight to be attached to so many varied considerations which cannot be weighed "mathematically", and so arrive at the final balance and decision."[235]

Despite trying to remain objective, the judge did make several value judgements about life with a disability. For example he says that "at birth [MB] appeared entirely *normal*."[236] This implies that MB, now disabled, is no longer 'normal,' a comment that would be offensive to many disabled people. Whilst recognising that with regards to people with less severe SMA that "many such people live very full and active lives,"[237] he comments that MB has "indeed a helpless and sad life."[238]

In the *Burke* case, the DRC was keen for the courts to adopt the 'intolerability' test when assessing what is in the patient's best interests.[239] Justice Holman considered this approach but decided to "avoid reference to the concept of 'intolerability.' It seems to me that it all depends on what one means by "intolerable" and that use of that word really expresses a conclusion rather than provides a test."[240] Yet he criticises the *Wyatt* judgement in this respect by saying:

> "In any event the most recent word from the Court of Appeal on this concept of "intolerability" is that contained within the reserved judgment of the court in Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181 at paragraphs 76 and 91 where they say that the concept of "intolerable to the child" should not be seen as gloss on, much less a supplementary test to, best interests. Although they continue by saying that the concept is a "valuable guide in the search for best interests in this kind of case", I doubt my own intellectual capacity on the one hand to exclude it even as a "gloss on", much less supplementary test to, best interests; and yet on the other hand treat it as a "valuable guide.""[241]

This thesis has argued that it is impossible for courts or doctors to make objective assessments about someone's quality of life, or what is in their best interests. In

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[235] *Ibid,* at para 62.
[236] *Ibid,* at para 2 (emphasis added).
[237] *Ibid,* at para 3.
[238] *Ibid,* at para 100.
[239] This was described in detail earlier in this chapter.
[240] *Re MB* n.12 above, at para 17.
[241] *Ibid.*

particular, this is because most assessments made by the people in power are based on the medical model, which is inherently flawed. Yet there is recognition in this case that despite a poor medical prognosis, there can still be benefits in life. This is clear when he said:

> "It is impossible to put a mathematical or any other value on the benefits. But they are precious and real and they are the benefits, and only benefits, that M was destined to gain from his life. I do not consider that from one day to the next all the routine discomfort, distress and pain that the doctors describe (but not the ones I have now excluded) outweigh those benefits so that I can say that it is in his best interests that those benefits, and life itself, should immediately end. On the contrary, I positively consider that as his life does still have benefits, and is his life, it should be enabled to continue, subject to excluding the treatment I have identified."[242]

In this way, it could be seen that Justice Holman recognised the important of resisting negative assumptions, even though he did not quite succeed. By distinguishing *Re C*,[243] it could be interpreted that the judge tried to reject the medical model because if he had only looked at the medical facts, as was the case in *Re C*, he would have found in favour of the Trust (because the evidence was so overwhelming). While Holman did not go so far as to take a social model approach, he seemed to recognise the flaws of the medical model. In this regard he recognised that doctors do not take into account anything outside the medical assessment. This judgement provides encouragement that perhaps lawmakers are beginning to appreciate that the medical model is not good enough as a basis on which to judge best interests. Whilst the court did not quite managed to adopt a social model approach, this judgement could be seen as progress albeit limited.

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[242] *Ibid,* at para 102.

[243] *Re C (A minor) (Medical treatment)* [1998] Lloyd's Law Reports Medical 1. Already discussed briefly earlier in this chapter.

5.3.2. Parliament

In this section of the chapter, I will explore the views expressed by Members of Parliament (MPs) in the House of Commons during the debates on the Human Embryology and Fertilisation Act 1990.[244] Initially examples of some of the vocabulary chosen by MPs to describe disability have been selected to demonstrate why they are hurtful to disabled people. More detailed comments on disability will then be examined. Finally, it will be shown that MPs often defer to the opinions of the medical profession when it comes to discussing disability, rather than the opinions of disabled people themselves.

Frequently, the use of reproductive genetic technologies are framed to "alleviate human suffering," [245] or the "desperate strain,"[246]the "affliction,"[247] wretched existence,"[248] the "crippling disablement,"[249] the "excruciating pain," the "self-mutilation"[250] and the "burden"[251] that parents of children with disabilities face, as they "watch helplessly."[252] These are just small phrases chosen by MPs to describe disability, however Hansard reveals many extremely disablist comments made. Some of these passages are quoted at length so the extent of the views can be demonstrated. Importantly for this chapter, MPs found themselves discussing the quality of life of disabled people. For example, Sir David Steel says that:

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[244] For a detailed explanation of methodology used here see appendix. Suffice to say here that it would be impossible to include all comments made by MPs about disability here, so focusing on HFE Act 1990 debates, and examples chosen are illustrative rather than exhaustive.

[245]For example see House of Commons Hansard Debates for 2 April 1990, Column 921 per Mr Kenneth Clarke,; **'cruel suffering'** used by Ms Richardson House of Commons Hansard Debates for 2 April 1990, Column 927; **'sufferers'** used by Sir Brian Braine, House of Commons Hansard Debates for 2 April 1990, Column 934 and Mr Dafydd Wigley, House of Commons Hansard Debates for 2 April 1990, Column 946; **'unimaginable suffering'** used by Miss Emma Nicholson, House of Commons Hansard Debates for 24 April 1990, Column 250.

[246] For example, see House of Commons Hansard Debates for 2 April 1990, Column 927, per Ms Richardson.

[247] For example, see *Ibid,* Column 940, per Sir Charles Morrisson.

[248] For example, House of Commons Hansard Debates for 24 April 1990, Column 250, per see Miss Emma Nicholson.

[249] For example see Mr Dafydd Wigley, House of Commons Hansard Debates for 2 April 1990, Column 946.

[250] *Ibid,* Column 984.

[251] For example, see *Ibid,* Column 927, per Ms Richardson.

[252]For example see *Ibid,* Column 946, per Mr Dafydd Wigley.

> "if, for example, an unborn child were diagnosed as grossly abnormal and *unable to lead any meaningful life*, there is in the opinion of the Committee no logic in requiring the mother to carry her unborn child to full term merely because the diagnosis was too late to enable an operation for abortion to be carried out before the 28th completed week."[253]

Indeed Mrs Maria Fyfe thought that

> "Sometimes there is too much easy sentimentality in the House about everyone being in favour of helping the handicapped. That is not real life. I know many people with handicaps... who feel that they receive very little help from society and from the House when it has the opportunity to spend public money on all sorts of necessities to help handicapped people to live a fuller life. We must recognise that some handicaps are so severe that no *quality of life* can be gained and the person who is suffering has a limited and extremely painful life that is often extremely short."[254]

Many assumptions about the views of parents of disabled children were made without any evidence to support them. For example, Ms Richardson said that parents of disabled children all wish their children were healthier: "Of course we all agree about that."[255] Furthermore, disabled children were often blamed for the breakdown of marriages.[256]

The idea that reproductive genetic technologies, in particular late abortion for disability could be seen as discriminatory to disabled people was dismissed by some MPs. Mr Thurnham describes it as:

> 'The argument that this process is a matter of unfair discrimination against the handicapped is one of the cruellest I've heard. *To suggest that we should want handicapped people* or that a mother would want to give birth to a handicapped child is completely wrong. All mothers would prefer to have a healthy child; it is wrong to suggest that anyone would want to enter this world with a handicap. I

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[253] House of Commons Hansard Debates for 21 June 1990, Column 1184 (emphasis added).

[254] House of Commons Hansard Debates for 23 April 1990, Column 66 (emphasis added).

[255] House of Commons Hansard Debates for 2 April 1990, Column 927.

[256] For example see Mr Thurnham, House of Commons Hansard Debates for 23 April 1990, Column 61

> am sure that Beethoven or anyone else suffering from a handicap would have preferred to be healthy. We should do all that we can to help bring about healthy people and not revel in people's handicaps.'[257]

Mr Eddie McGrady said that "when mental and physical disability will be wiped out. We all look forward to that day and we all support that concept."[258] These comments reveal a desire to prevent disabled lives, which undermines the rhetoric of choice that is presented to parents.

As with the courts, it can be seen that Parliament bows to the judgement of the health professionals. Mr Freeman (Parliamentary under-secretary for health) only ever referred to the views of the medical profession.[259] This is not totally surprising considering his job; however other MPs also relied on doctors for advice and information. Ms Richardson said that "The House has a duty to take note – as we usually do – of the views of the RCOG because it is composed of a large number of distinguished people."[260] Sir David Steele referred to a survey of Royal College of Obstetricians and Gynaecologists to argue that 75% were in favour of time limit being 24 weeks for social abortions to support this suggestion.[261]

There is also a considerable faith placed in doctors by MPs to do the 'right thing.' Mrs Virginia Bottomley said that "the application of the test [referring to s1(1)(d) of the Abortion Act 1967] is, and will remain, a matter or clinical judgement for decision by the two doctors who are required under the Act to form their opinion in good faith."[262] Sir David Steele admitted that there have been cases "in which the doctors have taken decisions on abortion with which I or my hon, Friend would not have agreed, but the fact is that the onus was put on the medical profession to act in good faith."[263] Miss Widdecombe said, "I do not believe that a doctor would put down spina bifida if it was a hare-lip, so we shall obtain some control of what is going on if the disability is

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[257] *Ibid*, (emphasis added).
[258] House of Commons Hansard Debates for 2 April 1990, Column 958.
[259] House of Commons Hansard Debates for 21 February, 1989, Column 821; 8 June 1989, Column 465; 27 July 1989 Column 1389.
[260] House of Commons Hansard Debates for 21 June 1990, Column 1199.
[261] House of Commons Hansard Debates for 24 April 1990, Column 204.
[262] House of Commons Hansard Debates for 26 Oct 1990, Column 319.
[263] House of Commons Hansard Debates for 24 April 1990, Column 205.

specified."[264] Considering the disablist attitudes held by many health professionals, such confidence in them held by MPs is worrying.

It is clear from the above discussion that Parliamentary debate on human genetics has been largely shaped by the question of what this technology has to offer with regard to the elimination of genetic disease. The apparent assumption behind this question is that to be burdened with a genetic disease is to be burdened with a life that one would rather avoid.[265] Accordingly, the medical uses of genetic technology are perceived in the context of helping people avoid a cause of suffering in their lives and thus discussion has evolved within a medical paradigm. Given this medically inspired attitude, developing new methods for detecting genetic disorders is often presumed as a way of enhancing the quality of reproductive choice. Although it can be argued that medical practices such as clinical genetics seek to enhance the well being of patients, it is very well possible that they contribute to the disadvantages for disabled people and their families in other domains of social life by influencing the public's image of disability.

Many of the comments of MPs included in this study situate disability within the individual. This, combined with their reliance on doctors, demonstrates the dominance of the medical model in this sphere. QL judgements will now be considered in relation to the medical model before this chapter concludes.

5.4. QL and the models of disability

Many scholars, policymakers, and activists in the area of disability contend that medically orientated understandings of the impact of disability on life contain erroneous assumptions with serious adverse consequences. It is felt that they view all problems that occur to people with disabilities as attributable to the condition itself, rather than to external factors.[266] In other words, if a disabled person experiences isolation, powerlessness, unemployment, poverty, or low social status, these are inevitable consequences of biological limitation.[267] Most of the problems associated with having a disability stem from discriminatory social arrangements that are changeable, such as

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[264] *Ibid,* Column 198.

[265] As already discussed in this chapter, this is a common misconception.

[266] Asch, A. n.43 above, at p1651.

[267] *Ibid,* at p1650.

rules, laws, means of communication, characteristics of buildings and transit systems, the typical 8-hour work day – they exclude people from participating in school, work, civic or social life.[268] Social conditions are as enabling or disabling as biological conditions. For example, the medical model regards Down's syndrome as a fixed, factual, physical and mental state, and its associated pathologies as the main or sole cause of morbidity and mortality in people with the syndrome. The social model instead attributes problems that people with Down's syndrome experience social as well as to biological causes.[269] Lippman asks, "Why are biological variations that create differences between individuals seen as preventable or avoidable while social conditions that create similar distinctions are likely to be perceived as intractable givens?"[270] The forty interviewees in Alderson's research tended to attribute problems to negative attitudes and social barriers rather than to their congenital condition, and most were frustrated at not having the opportunities, employment, income and social acceptance to enable them to live their lives as fully as they thought they could.[271] Deliberately or not, the interviewees' views appeared to adhere to social rather than medical models of disability, informed by their experiences.[272]

The medical and social models thus differ in their views about the origins of suffering, as either biological/genetic, or arising socially such as through substandard lifestyles and health care. The models also differ in their views on the nature of suffering. The medical model stresses the pain and misery of physical and intellectual impairments for affected people and for their families who share some of their suffering and restrictions. The social model is less concerned with bodily limitations than with the emotional pain, loneliness and unfulfilment which follow from unjust prejudices, discrimination, barriers and exclusions that unnecessarily disable impaired people. Disability rights authors argue that disabled people can live challenging and fulfilling lives when they have adequate support.[273] Prenatal medical prevention is the logical solution to non-treatable

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[268] *Ibid*, at p1651.

[269] Alderson, P. n.51 above.

[270] Lippman, A. 'Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities' (1991) 17 *Am J Law Med* 45.

[271] Alderson, P. n.65 above, at p635.

[272] *Ibid*,at pp635-6.

[273] Bailey, R. 'Prenatal testing and the prevention of impairment' in Morris, J. (ed) *Encounters with strangers: Feminism and Disability* (London, The Women's Press, 1996); Oliver, M. *Understanding Disability: From Theory to Practice* (Basingstoke, Macmillan Press, 1996); Larson, E. 'Reframing the

genetic/biological causes of suffering, whereas social/emotional suffering is resolved and prevented by changes in social attitudes and structures towards making societies more inclusive, these are reforms which are undermined by national screening programmes.[274]

Perhaps the most intrusive, violating, and invalidating experiences for disabled people emanate from the policies, practices, and interventions that are justified and rationalized by a personal tragedy view of disability and impairment.[275] Where a diminished quality of life is reported, it may not result from the limits of a chronic condition, but, instead, stigma.[276] Simply, a self-reported inferior life quality may result not solely from the underlying physical condition considered by prospective QL instruments but from a perceived social censure of people who are presumed to be 'useless' and a drain upon communal resources.[277] The domain of disability extends far beyond health related concerns to encompass the person's well-being, definition of self and social position.[278] By equating life quality with physical normalcy, prospective QL instruments generally – and utilitarian-based instruments specifically – ignore the degree to which people successfully adapt to a life with physical restrictions.[279] Because health-related QL measurements typically focus solely upon both the individual and the physical without concern for the communal and the social, they generally ignore the potential of accommodation and adaptation.[280] The WHO model discussed earlier in this chapter, aims to encompass the social elements of disability, yet it still attempts to make an objective assessment, and is performed by someone other than the disabled person.

There is no doubt that there are disabled people who 'suffer' from their physical conditions. There are even those who may choose to end their lives rather than continue in pain or with severe limitations, but this is obviously as true for non-disabled people who suffer from emotional pain and limitation of resources. It has been argued that it is not the impairment but social isolation and lack of support which makes some lives

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meaning of disability to families: The embrace of paradox' (1998) 47(4) *Social Science and Medicine* 865-875; Asch, A. n.43 above.

[274] Alderson, P. n.65 above, at p629.

[275] French, S., Swain, J. n.71 above, at p737.

[276] Powell, T., Lowenstein, B. 'Refusing life-sustaining treatment after catastrophic injury: ethical implications' (1996) 24(1) *Journal of Law, Medicine & Ethics* 54-61.

[277] Koch, T. n.28 above, at p423.

[278] Grimby, G., Finnstram, J., Jette, A. 'On application of the WHO handicap classification in rehabilitation' (1988) 20 *Scandinavian Journal of Rehabilitation Medicine* 93-98.

[279] Koch, T. n.28 above, at p424.

[280] *Ibid.*

unbearable. The assumption that certain impairments automatically lead to an unacceptably low quality of life is not rooted in an accurate understanding of the experience of impairment.[281] As a group, disabled people do not 'suffer' any more than any other group of category of humans. As Saxton says:

> "Our limitations may be more outwardly visible, our need for help more apparent, but, like anybody else, the 'suffering' we may experience is a result of not enough human caring, acceptance and respect."[282]

As previously demonstrated in the decision-making chapter, health professionals' presentation of disability is focussed on a medicalised view of impairment and on mechanisms for coping with disabilities based on misinformation and stereotypic thinking about disability,[283] as opposed to conveying the depth of contribution that all people are able to make to society. Clinicians and bioethicists assume that health status is mostly responsible for the reduced life chances of people with a disability.[284] From a medical perspective, the lives of disabled children appear as a problem that is to be treated. Thus it is not implausible to argue that, in one way or another, the practice of clinical genetics presupposes negative evaluations of disabled lives, regardless of whether individual counsellors are making such judgements.[285]

5.4 Conclusions

Society views disability as a negative phenomenon. This is due to a historical context, one of discrimination, a tendency to view disability as in need of charity, in need of medical treatment or cure. Generally, people (in particular health professionals) make negative quality of life judgements about life with a disability. This has resulted in people with disability remaining stigmatised to this day. Because disability is perceived as wholly negative, genetic reproductive technologies have been developed aiming to prevent disabled lives.

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[281] Marks, D n.5 above, at p41.

[282] Saxton, M. n.125 above, at p308.

[283] Parens, E., Asch, E. 'Disability rights critique of prenatal genetic testing: reflections and recommendations' (2003) 9 *Mental retardation and developmental disabilities research reviews* 40-47.

[284] *Ibid.*

[285] Reinders, H.S. n.62 above, at p52.

This chapter has demonstrated some of the contexts in which QL judgements are made. I have drawn attention to the way that QL judgements are informed by the world we live in, and are therefore based on cultural norms and values. I reflected that, because our society is dominated by the medical model of disability, the resulting norms and values can therefore be seen to be disablist. QL assessments become of crucial importance when they are used to make decisions for individuals incapable of expressing a will, such as children and severely disabled people. The QL judgements made by the different professions included in this chapter express values about the worth of disabled lives. This expression of negative values contributes to a situation in which reproductive decision making cannot be neutral.

I suggested that the main source of QL assessments emanates from the medical profession. Yet the QL judgements made by the doctors are often based on negative and misconceived assumptions, in particular the presumption of suffering. In this way, the views of doctors differ from those of disabled people. I moved on to consider that the predominant influences on health professionals are the norms of society, often reinforced by training and practice, and biased predominantly by seeing disabled people when they are sick. However I argued that because of the power and status of doctors, this view of disability becomes perpetuating. The analysis of the presumption of suffering made clear that it relied more on the beliefs and attitudes that prevail in society than on evidence about the lives of disabled people. I focused on the way that health professionals have developed a view of disability that is at substantial variance from its reality for many disabled people. It is important to focus upon the QL views of doctors because they can affect vital decisions involving health professionals that affect disabled people. These range from decisions at an individual clinical level, at policy level (including rationing), and at a health system level. I contended that doctors, as a result of their training, root their opinions in the medical model. To assume that a physical condition itself is the answer to every problem a disabled person may face is to ignore the social, economic and personal context of disability.

This chapter then moved on to consider some of the ways that courts make quality of life assumptions. The QL judgements made in the courts express values about life with a disability. Furthermore, court judgements in this area influence the way that people think about disability and disability policies. I demonstrated the tendency courts have to rely on medical opinion (which I have already shown to be flawed). I suggested that courts are influenced by norms and values too, and so it is impossible to make truly objective assessments.

Despite attempts to objectify QL, it remains ultimately subjective. Any objective assessments fail to take into account the cultural norms and values, and the opinion of the individual. As QL judgements are subjective it should arguably be the individual who decides the quality of her own life. If they are unable to do so, or to communicate it, those who know them best e.g. family rather than doctors or the courts, should assess from their perspective.

Mr Justice Hedley recognised this when he said

> "I have heard doctors unanimously describe her quality of life as terrible and the enduring of further aggressive treatment as intolerable. But both the quality of life and its tolerability have strong subjective elements to them. Those who have cared for a disabled child often have different perceptions of 'quality of life' and 'intolerability' to those who have not."[286]

Occasionally, the language used by lawmakers can betray the politically correct sentiments they are expressing. Lawmakers have a role to play in challenging the way in which QL judgements are made. The current approach to QL judgements taken by them is impoverished. Alternatively they should adopt a more social model – this would involve a) looking outside the medical sphere for evidence, b) acknowledging that disability does not make life not worth living, and c) listening to the disabled community. The recent case of *Re MB* provides encouragement that the approach of the courts may be evolving in some of these respects, yet one case remains a 'drop in the ocean.'

I have demonstrated that medicine and law have deep rooted institutional disablism. This is because the people involved are just people, with the same prejudices and ignorance about what it is like to live with a disability. Doctors may have expertise in the

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[286] *Portsmouth NHS Trust v Wyatt* n.127 above, at para 30.

pathologies underlying the impairments, and lawyers may be expert in health care law, however neither of these is a substitute for the experience of living with a disability. The problem is that the public look to these professionals - medics, lawyers and MPs - for information and their actions help form the cultural norms and values that it has been demonstrated fail to value disabled people. The cultural norms and values expressed by medics and law makers infiltrate every aspect of our lives. This is true for 'end of life' cases as demonstrated in this chapter but also in the context of RGTs and in particular PND and selective abortion. As previously demonstrated by fig. 7 in chapter 3, lawmakers and medics influence the decisions prospective parents make in relation to RGTs because the decisions made are influenced by their cultural context. The cultural context is informed by doctors and lawmakers and has been shown to be based on an inaccurate set of assumptions based in the medical model of disability.

Chapter 6: Conclusions

This thesis has examined the underlying assumptions that influence attitudes towards the prevention of disabled lives through the use of reproductive genetic technologies. I will now summarise my main arguments, and focus on the conclusions that can be drawn from them. I then intend to consider some constraints of the thesis before briefly considering some prospects for future research.

In chapter two, I began by describing the models of disability and demonstrating that the way in which we think about disability is important in the 'real world.' I suggested that the debate about models of disability is relevant to law because legal provisions adopt these models. Laws tend to adopt the medical model, and therefore pay insufficient regard to the interests of disabled people because a flawed model is being used. Discussions about EU law and the DDA 2005 indicate recognition of this point but relatively little concrete progress. I noted that this may be because it is difficult to incorporate social models; I illustrated this by drawing attention to the persistence of medical models in various guises within international documents. A convergence into hybrid models can be seen in the disability literature. I suggest that while it is not possible to legislate within a purely social model, the challenge is to realise the progress away from a purely medical model through more consistent legal provisions. In this respect, the social effects of disability need to be prioritised in any definition of disability. The debate about 'bringing the body back in' demonstrates the need for the social model to include references to impairment to make a definition of disability of practical use. Failure to make this progress indicates the degree to which the current law expresses disablist values which could be avoided more effectively than they currently are, even if neutrality remains difficult to achieve.

I moved on, in chapter three, to explore the expressivist argument advocated by disability rights supporters against the use of reproductive genetic technologies on the grounds of their disablist effects. This argument holds that assumptions are implicit in the accepted practice of prenatal testing and the selective abortion of foetuses with detected impairments. Disability is a complex social construct and the way society constructs disability communicates signals regarding the value society places on its disabled members. The Abortion Act 1967 s1(1)(d) was focused upon as an example of the expressivist nature of laws arguing that it reflects societal values that construe aborting a 'disabled' foetus as more justifiable than aborting a 'normal' one. I argued that whilst parents perceive their reproductive choices as private decisions, the context of their decisions is important: their decisions are influenced by the cultural context and in turn they contribute to that cultural context. Cultures can express societal values which can be damaging to disabled people. I also examined the language used to refer to disabled people in the media. The media reports surrounding the *Jepson* case were analysed in particular. I contended that the way in which disability is portrayed can make a difference. Private decisions are also influenced by these debates. Thus, there is a circle of meaning and decision-making created that could either be vicious or virtuous. I argued that because of the disablist attitudes expressed at all stages it is a vicious circle. Critics of expressivity assume that the place to look for expressivity is in the minds of the parents. This thesis has shown that actually it is in the minds and literature and practices of the professionals who constrain parental choice by defining it within a rhetoric or a structure of meaning that expresses disablist attitudes.

The way society constructs disability demonstrates the value society places on disabled people. There is an intrinsic connection between law and societal values. The values expressed at various levels were analysed in this thesis. In this way I focused on analysing the values expressed by law makers (in chapter five), medical attitudes (in chapter four), and by examining the influences on individual decision making (in chapter four).

I drew attention to some of the many factors that affect reproductive decision making (in chapter four). Focusing on the power and knowledge of doctors in our society and their influence over patients' decision-making, I noted that this enables them to frame the issues and to dominate the way disability is perceived. Furthermore, I also established that doctors' views are based on the medical model and are disablist (chapter five). Yet because of their power, knowledge and status in our society, their opinions are often accepted unequivocally by patients, policy makers and lawmakers. I concluded with the suggestion that practitioners should reflect critically on the origins of the information they are conveying to prospective parents about what it means to live with a disability. Chapter four reflected on the way that PND is justified by offering 'choice.' Yet such choice is undermined by the failure of practitioners to adopt nondirective counselling styles, that tests are offered as 'routine,' that the offer of PND in itself is not value neutral, and inadequate information is provided by doctors. The leaflet analysis conducted as part of this research highlighted that the information provided to parents focused on medical and scientific rather than social aspects of disability; concentrated on the nature of tests rather than what conditions are being tested for; explained that there was a 'choice' but often fail to explain the options available; and that the language used was sometimes disablist.

It has been argued throughout this thesis, that people make negative assumptions about impairment and disability. These assumptions can invoke 'quality of life' judgements and are often based on the medical model of disability. Decisions about health services affecting disabled people are made at a number of levels. In particular, I noted in chapter five that health professionals frequently make QL judgements when making decisions about the care of disabled patients, and moved on to consider that the professionals' view on expected quality of life is often the key factor in determining whether effective treatment for a life threatening condition will be given or withdrawn. I highlighted the way that professionals' perceptions may be at odds with those held by their patients. Despite attempts to objectify QL, it remains ultimately subjective. Any objective assessments fail to take into account the cultural norms and values and the opinion of the individual. As QL judgements are subjective it should arguably be individuals who decide the quality of their own life. If they are unable to do so, or to communicate it, those who know them best.

Justice Hedley recognised this in the *Wyatt* case when he said:

> "I have heard doctors unanimously describe her quality of life as terrible and the enduring of further aggressive treatment as intolerable. But both the quality of life and its tolerability have strong subjective elements to them. Those who have cared for a disabled child often have different perceptions of 'quality of life' and 'intolerability' to those who have not."[1]

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[1] *Portsmouth NHS Trust v Wyatt* [2004] EWCA 2247 (Fam) para 30

The Mental Capacity Act 2005 recognises the need to encourage the person to participate in the decision making,[2] then to consider the person's past and present wishes and feelings,[3] the beliefs and values that would be likely to influence his decision if he had capacity[4] and the other factors that he would be likely to consider if he were able to do so.[5] This Act therefore recognises the importance in judging a person's quality of life as they would have done if they were able to. Furthermore, this Act could be seen to recognise the social elements of disability, by requiring professionals to work to overcome the barriers to effective communication and encouraging the person to participate and communicate in any way possible[6] rather than accepting communication difficulties as an objective and unalterable impairment. Thus, the role of social constraints in disabling people is recognised.

This thesis has demonstrated that fundamental questions are raised when physicians are involved in decision about access to health care, in deciding what conditions are 'serious handicaps,' and in advising Parliament and the courts on what the law should be. In this way it was possible to conclude that QL judgements are subjective, based on political and cultural norms and values and that the debate about whether a life is considered to be 'worth living' should be understood in the context of social and cultural values accorded to certain people.

In chapter five, I proved that QL judgments are being made by law makers and then suggested that to some extent the courts' assumptions are disablist. I reflected that the law makers' approach to QL is impoverished in this way and fails to take account of the views of disabled people. As a result, it is argued that the law is complicit in this prejudice rather than a constraint upon it.

It is evident from this research that there is a link between the way disability is perceived and the laws that result from those attitudes. Furthermore, it is also clear that when the law takes a disablist position, it encourages people to share these assumptions about the lives of disabled people. It has been possible to identify consistent expression of values

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[2] Mental Capacity Act 2005 s4(4).
[3] *Ibid* s4(6)(a).
[4] *Ibid* s4(6)(b).
[5] *Ibid* s4(6)(c).
[6] See the *Mental Capacity Act 2005 Draft Code of Practice for Consultation* available from http://www.dca.gov.uk/consult/codepractise/codeofpractice.htm pp42-58.

all based on medical model and therefore disablist because they rely on negative assumptions being made. I considered that the structure of 'knowledge' is inherently disablist. And as a result, values are disseminated through expressions in different contexts: media, leaflets, case-law, Hansard and statutes. By analysing these contexts, I have drawn attention to the way values infiltrate different spheres of life. Doctors have influential power over establishing the framework within which discussion of disability in relation to RGTs occurs. The framework that is established is rooted in the medical model which fails to take into account the social effects of disability. When the values are disablist, this means the odds are stacked against disabled people. The accumulative argument put forward in this thesis is that medicine and law have deep rooted institutional disablism. This is because the people involved are just people, with the same prejudices and ignorance about what it is like to live with a disability. Doctors may have expertise in the pathologies underlying the impairments, and lawyers may be expert in health care law, however neither of these are a substitute for the experience of living with a disability. The problem is that the public look to these professionals – medics, lawyers and MPs - for information and their actions help form the cultural norms and values that it has been demonstrated fail to value disabled people.

It is now necessary to highlight the implications this research has for policy. It has been shown that s1(1)(d) of the Abortion Act 1967 (as amended) expresses negative values – that terminating a disabled foetus is perceived to be more justifiable than aborting a 'non-disabled' foetus. My research would suggest that s1(1)(d) should be repealed. This is because it follows a totally medical model. Before 24 weeks it is already possible to provide access to terminations for women who believe that the social barriers that they (or their baby) face would be so difficult that abortion is preferable to giving birth. There is no need to provide an additional ground for terminations for cases where the only difference in the situation is an impairment. Alternatively, you could extend the s1(2) to state that you should take into account the social environment when considering whether a baby with an impairment would be significantly handicapped. Both of these options would reflect the social model better. Having no time limit for abortions due to impairment indicates that it is acceptable to abort a foetus which is viable because it is disabled, whilst the law constrains women from choosing to have a late abortion for 'social' reasons. By repealing s1(1)(d) the social effects of impairment become important so the focus changes from the impairment (and thus a disablist model) to the social context.

Chapter four drew attention to the considerable body of research that shows that nondirective counselling is impossible. This thesis also argues that not only is nondirective counselling impossible in practice, but that it is also biased in a particular direction: that it expresses disablist attitudes. I suggested that this is due to a lack of understanding on the part of medics of the lives of disabled people. This is as a result of their attitudes being built on a medical model of disability that fails to take into account the social elements of disability. There should be more emphasis that prenatal tests are on an 'opt-in' rather than an 'opt-out' basis, for this to happen the information provided to prospective parents should be changed, as well as the way clinics offering the tests are run. This should help ensure that prenatal tests are not offered as 'routine' but instead as an option. Professional bodies such as the GMC should also insist on higher levels of informed consent for patients in this context, and this could be monitored by asking patients to fill in questionnaires. This would provide an additional incentive for clinicians to ensure they adequately inform their patients. Furthermore, it should be a standard element of the information provided to discuss the help and support available to parents of disabled children, and this should include contact details for local support groups and benefits offices.

Whilst removing s1(1)(d) and improving the quality of information would be progress away from the law expressing negative, disablist values, it only solves a small part of the issues facing disabled people in our society. The need to address the social environment remains to ensure that disabled people have full access to resources and opportunities to ensure they live full and enriched lives. The QL chapter identified that the aspects of being disability that frustrate disabled people are often the attitudinal and environmental barriers that prevent them from participating in society, much work needs to be done to rectify this.

The extent of these difficulties is clear from the all pervasive impact of prejudicial attitudes. A number of different approaches were taken to finding evidence to support the arguments within this thesis, incorporating a number of methodologies. Yet everywhere I looked to explore the values expressed, I always found a set of values that are inherently disablist, predominantly because they are built on a flawed medical model of disability. Whilst I used a series of small scale projects, which are open to the criticism that they are not representative, it must be made clear that this was not the aim. This research was intended to be qualitative and planned to demonstrate the types of values expressed, not the frequency with which they were expressed.

This research is open to the criticism that my suggestions merely substitute one set of values for another. Furthermore, that my arguments seem to stem from a homogenous group of disabled people, when in reality such a homogenous group does not exist.[7] Indeed the failure to appreciate the variety of the experiences of disabled people was one of the criticisms made in chapter five. I have clearly demonstrated that the values expressed by doctors and lawmakers are disablist, and that these values are drawn from the medical hegemony. In order to breakdown the existing medical dominance, it is necessary to put something else into its place. It is this stage of the reasoning process that leaves me open to the criticism just outlined. Whilst the approach I offer does make assumptions about the generic experience of disabled people it is less restraining than that within the medical hegemony. By identifying how complex the problem of the expressivist nature of RGTs is, this leads to a more flexible, and less constraining approach. At the moment, the status quo is essentially disablist, and if the criticisms I make in this thesis are to be accepted, then it leaves a choice between the existing prejudiced approach and a more liberal, supportive approach, it seems that the disability rights approach is the more acceptable alternative.

As demonstrated in this thesis, with the inclusion of the recent *Re MB* case, the approach taken by lawmakers is gradually evolving. However many problems still remain. The professions of medicine and law are constantly developing and as a result evidence relied on in this thesis may become out-of-date. Yet this research has provided an insight into a way the laws and policy of early twenty-first century Britain can be interpreted, and the implications these have on the lives of disabled people.

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[7] Evidence of this can be seen by the formation of the Genetic Interest Group (see www.gig.org.uk) who are pro-the use of RGTs (although this is arguably because they do not approach the issue from a social model standpoint).

There are several original elements to this thesis. Firstly, I demonstrated the use of different models of disability in law in a variety of contexts highlighting the difficulties in adopting a purely social model of disability. Secondly, original research was conducted by the completion of several small scale research projects – leaflets, case analysis, media analysis, and Hansard analysis – that helped provide supporting evidence for my arguments. Whilst some of this thesis builds on writings of others, I have brought the areas of disability rights, law, and RGTs together in a way not previously examined in the literature. Furthermore, I have tested the conclusions through case studies in order to demonstrate the effects of this debate in the 'real world.'

This thesis has highlighted the way that the law consistently expresses a set of values that are inherently disablist. As I have shown throughout this thesis, the predominant reason behind this is that the assumptions and values law makers rely upon are built on a flawed medical model of disability.

This brings me to thoughts for future research. With new cases developing, it would be possible to extend the framework of analysis to these cases. I could explore other areas of health care law that involve the expression of values to establish how consistent the findings of this research are. Through comparative research I could extend my research on models of disability to an international comparative piece of research; extend the discussion of abortion laws contained in this thesis to an international comparative piece of research; or extend the approach taken in this research to other areas of discrimination law for example, race, sex, religion, and sexuality and to explore the way the approach of lawmakers differs and the possible reasons behind this. Or, instead, it would be possible to develop research on the ways in which the law could adopt a more hybrid approach, to ensure that the values expressed are no longer disablist.

Introduction to Appendices

This thesis has examined the underlying assumptions that influence attitudes towards the prevention of disabled lives through the use of reproductive genetic technologies. I have discussed the models of disability, concluding that the medical model has remained dominant despite calls to incorporate social elements of disability. I have demonstrated the disablist nature of prenatal diagnosis and explored the way in which disablist values are expressed in law making processes and professional rhetorics. Much of the main arguments were based on literature reviewed, in part, to provide a paradigm in which events would be analysed. Within the main part of the thesis, there are references to:

A. some Media analysis
B. a study of prenatal leaflets, and
C. a study of Hansard materials

These projects were all performed as part of this doctorate. The following appendices (one for each project) aim to explore the methodology behind these projects. Such explanation is situated in appendices as it was thought including such discussion in the main text would detract from the argument being presented.

Reflexivity Considerations of Analysis

There has already been some discussion about reflexivity; situating the researcher in the research process. Some of the themes previously introduced need incorporating into this introduction to the appendices, in order to focus upon the issues relevant to the research projects discussed here.

Due to my interest in disability issues and as a disabled woman, my analysis of the research materials collated will necessarily be located in discourses around 'disability,' 'impairment,' 'discrimination,' 'medicine,' and 'genetics.' The analysis of the leaflets, media and Hasard are clearly shaped by the lenses through which data are interpreted. All research is shaped by the particular orientations, and values of those involved. This is due to the historically, contextually specific construction of knowledge and interpretation, effected through the interrelationship of power/knowledge.[1] Other researchers focusing upon different issues may well identify other issues and therefore come to different conclusions from the same materials. This position of reflexivity is important in terms of the personal, interpersonal, institutional, pragmatic, emotional, theoretical, epistemological and ontological influences on our research.[2] Ontologically, it could be argued that the analysis of the research materials is as much about the researcher and her way of seeing the world as about 'what is there?'[3] These mini research projects were performed in order to test out hypotheses. Furthermore, these projects aimed to illustrate the way in which certain situations in the world are perceived, yet they could have been influenced by the researcher's perceptions.

Doucet and Mauthner explain that it was only with hindsight, once their doctoral projects were completed that they could understand and articulate how their research was the product of multiple influences.[4] They suggest that the critical assumptions affecting our knowledge production may not be readily available or known to us at the time of conducting our research, it may be that reflexivity and accountability are ultimately limited. They conclude that despite all attempts to be highly reflexive, they ultimately concur with Grosz who maintains that "the author's intentions, emotions, psyche, and interiority are not only inaccessible to readers, they are likely to be inaccessible to the author herself."[5]

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[1] Gordon, C. (ed) *Power/Knowledge: Selected Interviews and Other Writings* (Brighton, Harvester, 1980)

[2] Doucet, A., Mauthner, N. 'Knowing Responsibly: Linking ethics, research practice and epistemology' in Mauthner, M., Birch, M., Jessop, J., Miller, T. *Ethics in Qualitative Research* (London, Sage, 2002) at p125

[3] Mason, J. (2nd ed) *Qualitative Researching* (London, Sage, 2002) at p154

[4] Doucet, A., Mauthner, N. n.2 above, at p135

[5] *Ibid.* at p137

Appendix A: Times Work Analysis

Methodology

The main objective of this piece of research was to identify the changes in the way in which prenatal testing and selective abortion was reported in the popular press over time. The hypothesis was that although the subject matter would stay the same the context in which it was discussed would have changed. The analysis of the language of media texts can illuminate the different ways the world is represented.[1] It is hoped this analysis of language will be connected with fundamental concerns of social analysis: questions of knowledge, belief and ideology, questions of social relationships and power, and questions of identity.[2] Representations are a long-standing concern in debates about bias, manipulation and ideology in the media. The wider social impact of media questions how they selectively represent the world and what cultural values these representations entail.[3]

It is obvious that newspapers present facts in a way that is designed to arouse the reader's interest and curiosity. It is also possible to present facts in a way that will influence the reader's view of them.[4] By addressing themselves to a perceived readership the papers create a shared ideology that can frequently work to obscure issues rather than clarify them.[5] Reah demonstrates how it is easy to resist a particular viewpoint or ideology when you know it is being presented to you, but not so easy to resist when the viewpoint or ideology is concealed.[6] Certain groups tend to be disadvantaged within particular societies. People are defined by their race, their sex, their sexuality, their religion – these groups can be disliked, feared, discriminated against or actively persecuted. Language is one of the means by which attitudes towards groups can be constructed, maintained – or challenged.[7]

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[1] Fairclough, N. *Media Discourse* (London, Edward Arnold, 1995) at p5
[2] *Ibid,* at p17
[3] *Ibid,* at p17
[4] Reah, D. *The Language of Newspapers* (London, Routledge, 2002) at p10
[5] *Ibid,* at p35
[6] *Ibid,* at p54
[7] *Ibid,* at p54

The Times newspaper was chosen for this project. There may be no clear profile of a 'Times' reader, but the papers themselves often write as though such a person exists and that there is, in fact, a homogeneous group of people with shared beliefs and values whose defining feature is the newspaper they read.[8] *The Times* was chosen because it is renowned for its vigorous reporting, especially on legal matters. It also seems to access all issues whilst (on the whole) avoiding sensationalism. This choice was made on the quality of the paper rather than the audience. This was because without doing further research on buying practices of different groups of people, the audience is difficult to determine and it is important to avoid stereotyping or assuming that certain groups of people would read certain newspapers.

It was decided to use 5 yearly intervals as the sample because it was important to select even intervals and selecting five years meant two selections were taken per decade. 1965 was selected as the start date as it was two years prior to the Abortion Act 1967, then articles were taken from every five year gap after that. 2003 was also included as the most recent full year available, and because I was aware that there had been much discussion in the press about the 'designer baby' debate and the Joanna Jepson case which were relevant.

In order to find the relevant articles, the Times Index was searched and the following headings were found to be most relevant: 'Medicine: Ethics;' Medicine: Research;' 'Abortion;' 'Birth and Pregnancy: Congenital defects;' 'Birth and Pregnancy: Research.' So for each year chosen, all the articles under these headings were printed for analysis.

Textual analysis was then performed on the articles, as an attempt to understand how meaning is generated and conveyed. Textual analysis is a way for researchers to gather information about how other human beings makes sense of the world.[9] Different methodologies will produce different kinds of information – even if they are used for analysing similar questions.[10] When reading the newspapers I tried to answer the

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[8] *Ibid,* at p36
[9] McKee, A. *Textual Analysis: a beginners guide* (London, Sage, 2003) at p1
[10] *Ibid,* at p2

following questions, the codings attributed for the answers are also detailed. All findings were recorded using SPSS and graphs created in order to make trends more visible.[11]

1) How was disability portrayed?
   a) tragedy
   b) reward
   c) charity
   d) triumph
   e) none

2) What was the background of the author?
   a) medical
   b) political
   c) science
   d) law
   e) religion
   f) sociology
   g) personal story
   h) letters from public

3) What ethical issue was the article about?
   a) abortion
   b) embryos
   c) discrimination
   d) religion
   e) PND
   f) PGD
   g) sex selection
   h) screening
   i) prevention

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[11] These graphs are included in this appendix

4) What was the context/ framework for the article?
   a) law reform
   b) medical
   c) science
   d) political
   e) religion
   f) social
   g) legal case

These questions aimed to identify the different ways in which disability was represented (question 1), the people who were interested in writing about disability (question 2), the issue that was seen as important (question 3) and the readership at which the article was aimed i.e. people interested in medicine or religion. (Question 4).

Results – Graphs

Fig. A: A graph to demonstrate the framework of the articles per year:

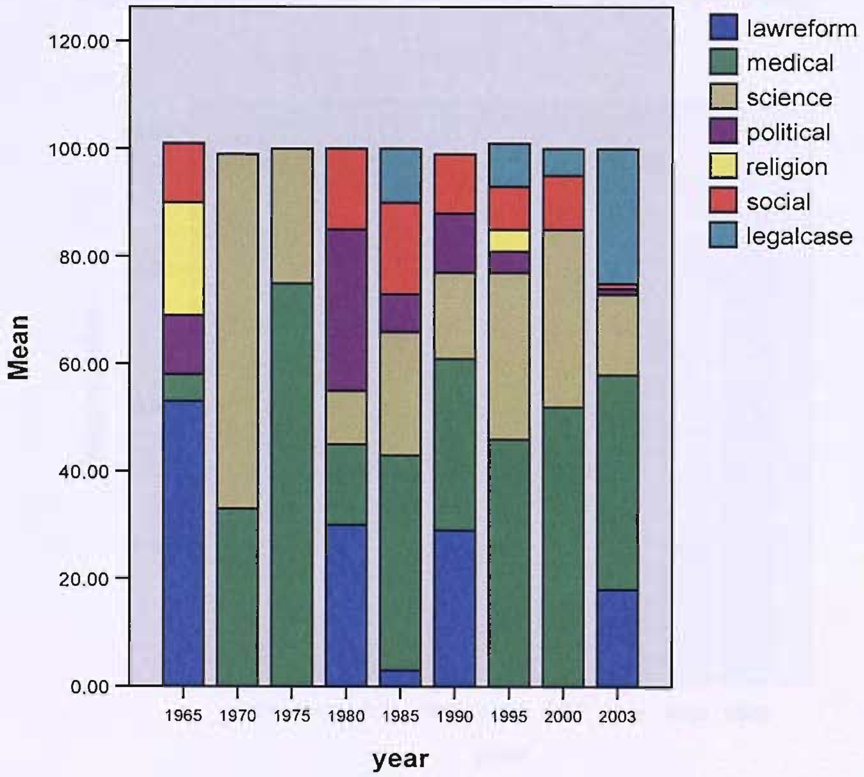


Fig. B: A graph to show the background of authors per year:

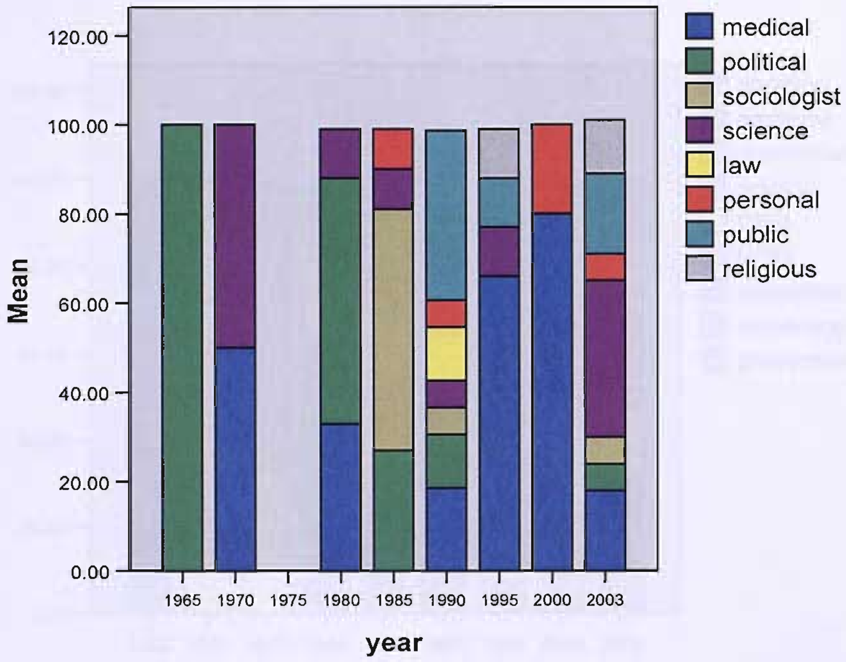


Fig. C: A graph to show the number of articles per year:

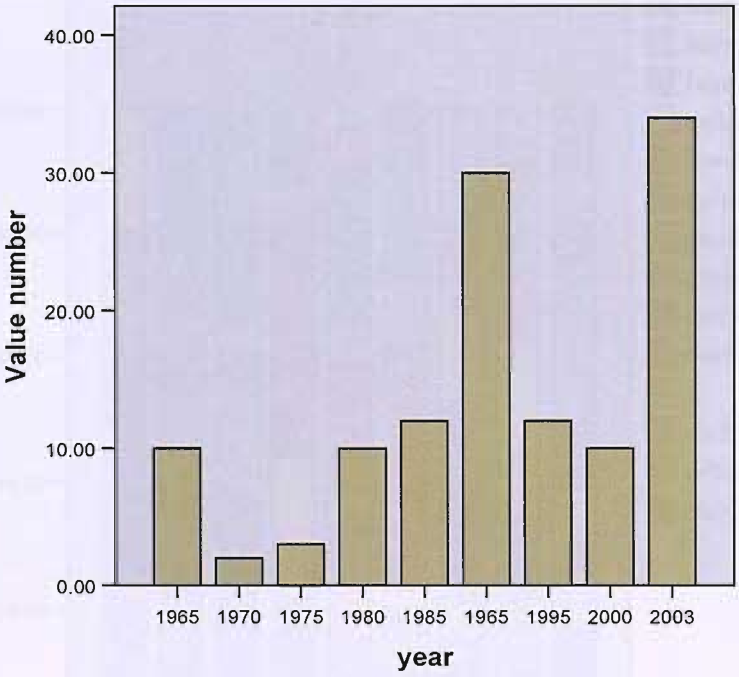


Fig. D: A graph to show % of articles in each context:

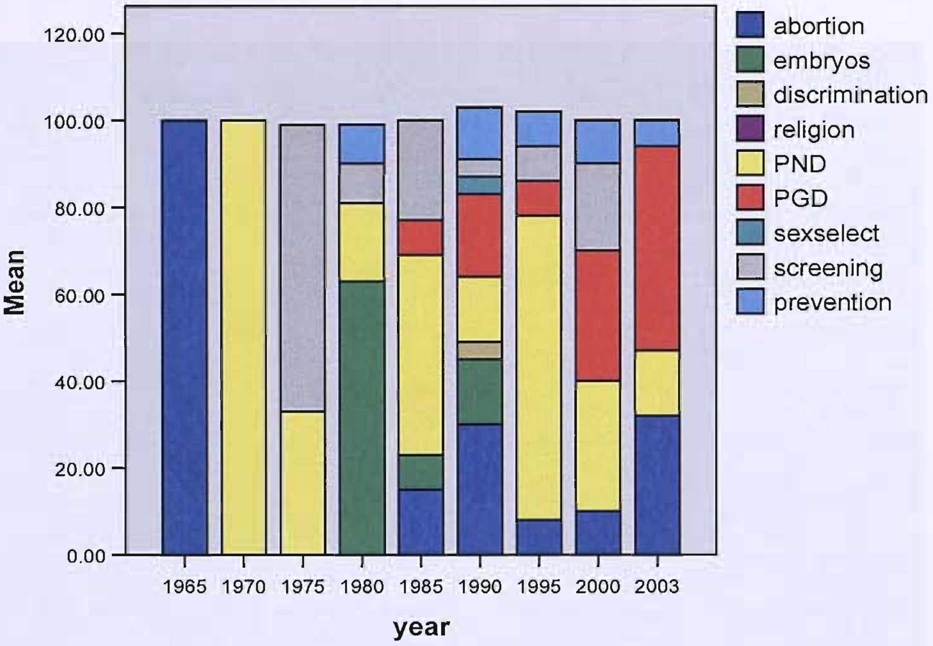
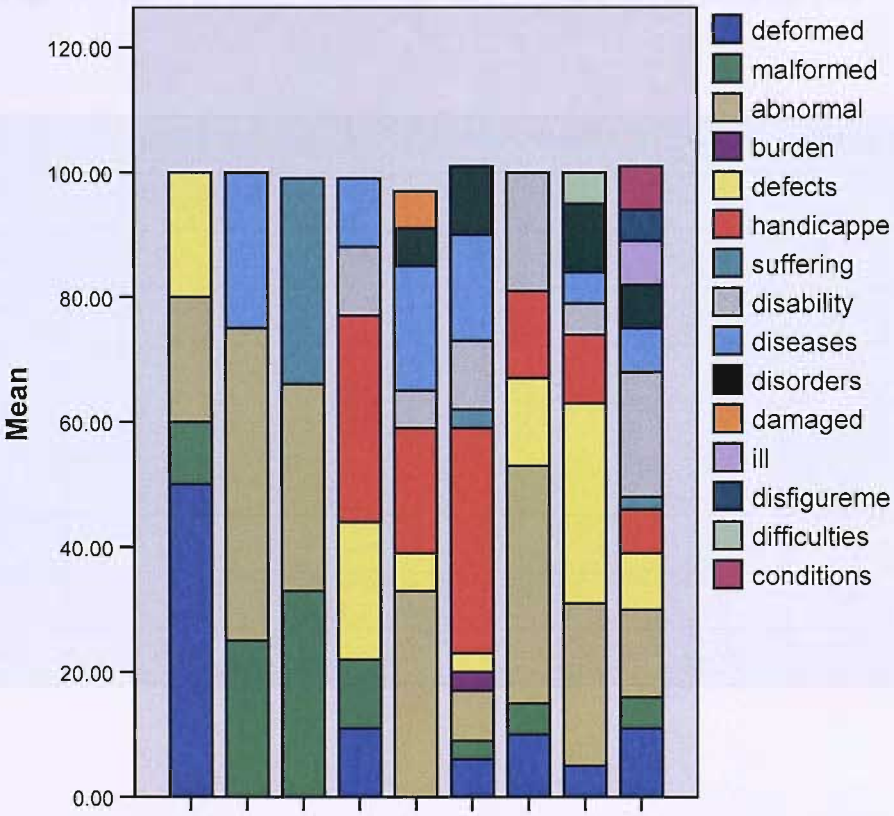


Fig. E: A graph to show the % of different descriptions per year



Results – Tables

Fig. F: Table to show the framework of the articles per year (%)

Year	Law reform	Medical	Science	Political	Religion	Social	Legal case
1965	53	5	0	11	21	11	0
1970	0	33	66	0	0	0	0
1975	0	75	25	0	0	0	0
1980	30	15	10	30	0	15	0
1985	3	40	23	7	0	17	10
1990	29	32	16	11	0	11	0
1995	0	46	31	4	4	8	8
2000	0	52	33	0	0	10	5
2003	18	40	15	1	0	1	25

Fig. G: Table to show the background of the authors per year (%)

Year	Medical	Political	Science	Religious	Sociologist	Law	Personal	Public
1965	0	100	0	0	0	0	0	0
1970	50	0	50	0	0	0	0	0
1975	0	0	0	0	0	0	0	0
1980	33	55	11	0	0	0	0	0
1985	0	27	9	0	0	0	9	0
1990	18	12	6	0	0	12	6	38
1995	66	0	11	11	11	0	0	11
2000	80	0	0	0	0	0	20	0
2003	18	6	35	35	12	0	6	18

Fig. H: Table to show the number of articles per year

Year	Number of articles
1965	10
1970	2
1975	3
1980	10
1985	12
1990	30
1995	12
2000	10
2003	34

Fig. I: Table to show the context of articles per year (%)

Year	Abortion	Embryos	Discrimination	Religion	PND	PGD	Sex select	Screening	Prevention
1965	100	0	0	0	0	0	0	0	0
1970	0	0	0	0	100	0	0	0	0
1975	0	0	0	0	33	0	0	66	0
1980	0	63	0	0	18	0	0	9	9
1985	15	8	0	0	46	8	0	23	0
1990	30	15	4	0	14	19	4	4	12
1995	8	0	0	0	70	8	0	8	8
2000	10	0	0	0	30	30	0	20	10
2003	32	0	0	0	15	47	0	0	6

Fig. J: Table to show the descriptions for disability used per year (%)

Year	Deformed	Malformed	Abnormal	Burden	Defects	Handicapped	Suffering	Disability	Diseases	Disorders	Damaged	Ill	Disfigurement	Difficulties	Conditions
1965	50	10	20	0	20	0	0	0	0	0	0	0	0	0	0
1970	0	25	50	0	0	0	0	0	25	0	0	0	0	0	0
1975	0	33	33	0	0	0	33	0	0	0	0	0	0	0	0
1980	11	11	0	0	22	33	0	11	11	0	0	0	0	0	0
1985	0	0	33	0	6	20	0	6	20	6	6	0	0	0	0
1990	6	3	8	3	3	36	3	11	17	11	0	0	0	0	0
1995	10	5	38	0	14	14	0	19	0	0	0	0	0	0	0
2000	5	0	26	0	32	11	0	5	5	11	0	0	0	5	0
2003	11	5	14	0	9	7	2	20	7	7	0	7	5	0	7

Appendix B: Leaflet analysis

Purpose of Study

As a result of the literature reviewed for this doctorate from the fields of law, medicine, psychology, sociology and disability studies, a hypothesis was developed: that there were assumptions being made as to what was relevant to women/ couples when they were making decisions. In particular the information that was relevant in relation to disability. It was thought that the medical professions who help advise women/couples believed in the 'medical model of disability' (as referred to in the main text). The way in which people think about disability is important, especially the way people with influence over these decisions think. It would have been impossible, for the purposes of this study, to sit in and observe advice being given to women/ couples, so the only way in which this could be analysed was by exploring the attitudes displayed in leaflets provided. It was thought that if the people who wrote the leaflets have disablist assumptions, there would be evidence to support this. The aim of the study was therefore to find evidence in the leaflets that provided either reassurance that such disablist attitudes were not prevalent or evidence that supported the hypothesis.

Profile of Sample

Having decided to investigate the models of disability projected in the leaflets provided to couples/ women considering PND, a method of data collection and the profile of the sample had to be established. Of particular interest were leaflets produced by the NHS for several reasons: firstly, because the majority of women in the country rely on the NHS for their prenatal care; and secondly, because researching the information provided on the NHS would link in with theories of levels of decision making. The information contained would reflect the ideas of the government, NHS, NICE and professional organisations of doctors e.g. RCOG or GMC.

The NHS website[1] provided a 'sample grid.'[2] It was hoped that this would provide the details of hospitals offering PND in England and Wales.[3] For England, all hospitals were

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[1] www.nhs.uk

[2] Mason, J. (2nd ed) *Qualitative Researching* (London, Sage, 2002)

listed under regions, for example London South East; Cheshire and Merseyside; Dorset and Somerset. In each region each hospital was listed along with its contact details. For Wales, the regions were much broader, (for example North Wales) and within each region they were then separated into the NHS Trusts controlling each area (for example Carmarthenshire NHS Trust and Conway and Denbighshire NHS Trust). There was no information provided as to which hospitals offered PND. Whether or not a hospital had an A&E department was listed. I thought that the hospitals with A&E departments were likely to be the larger hospitals in the area, and as such were more likely to provide PND. A phone call to several of these hospitals was made, but I found the main switchboards to be mainly unhelpful. This is possibly because PND sometimes comes under different departments for example gynaecology, obstetrics, or genetics services. In addition, in some areas, there is a separate hospital for pre and post natal care. It was impossible to deduce from the website which hospitals should be contacted in order to have the highest chances of a response.

As part of the research into PGD for this thesis, it was discovered that there are several regional genetics centres which offer these techniques. By using the 'Google' search link[4] it was possible to locate a list of these on the 'contact a family' website.[5] The 'contact a family' list thus became a sampling frame: "A sampling frame is a resource from which you can select your smaller sample."[6] As Mason explains "whatever frame you choose, your sampling practice will thenceforward be influenced by the parameters and characteristics of that frame."[7] The regional genetic centres are listed below:

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[3] Scotland and Northern Ireland were excluded as this thesis is only focusing on the situation in England and Wales. Scotland and Northern Ireland often have separate regulations. This is especially the case in Northern Ireland relating to abortion. Scotland has a separate legal system.

[4] www.google.co.uk

[5] www.cafamily.org.uk/gencentr.html

[6] Mason, J. n.2 above, at p140

[7] *Ibid,* at p141

Fig. K: Table to show the regional genetic centres

▪ Mothercare unit of Clinical Genetics and Fetal Medicine, Institute of Child Health, London
▪ Kennedy Galton Centre for Clinical Genetics, Northwick Park Hospital, Harrow
▪ Regional Clinical Genetics Service, Countess of Chester hospital, Chester
▪ Mersey and Cheshire Clinical Genetics Service, Alder Hey Hospital , Liverpool
▪ University Dept of Medical Genetics and Regional Genetics Service, St Mary's Hospital, Manchester
▪ Regional Dept of Clinical Genetics, Manchester Children's Hospital NHS Trust, Manchester
▪ Northern Genetics Service, International Centre for Life, Newcastle
▪ Yorkshire Regional Genetics Service, St James's University Hospital, Leeds
▪ East Anglian Medical Genetics Service, Addenbrooke's Hospital, Cambridge
▪ Dept of Clinical Genetics, John Radcliffe NHS Trust, Oxford
▪ South Thames (East) Regional Genetics Centre, Guy's Hospital, London
▪ Regional Genetics Services, St George's Hospital Medical School, Londo
▪ Regional Cytogenetics Services, Southmead Hospital, Bristol
▪ Clinical Genetics Dept, Royal Hospital for Sick Children, Bristol
▪ Clinical Genetics Dept, Royal Devon & Exeter Hospital (Heavitree), Exeter
▪ Wessex Clinical Genetics, Southampton General, Southampton
▪ Dept of Clinical Genetics, Leicester Royal Infirmary, Leicester
▪ Dept of Clinical Genetics, City Hospital, Nottingham
▪ Dept of Clinical Genetics, Sheffield Children's Hospital, Sheffield
▪ Institute of medical Genetics, University Hospital Wales, Cardiff
▪ West Midlands Regional Clinical Genetics Service, Birmingham Women's Hospital, Birmingham

Mason warned that "Theoretical or purposive sampling can be criticised for being *ad hoc* and vague if not employed systematically."[8] It should therefore be clear this far; there was a strategic purpose in selecting the sample, it was not accidental, *ad hoc* or purely opportunistic.

The sample was not intended to be representative of all hospitals offering prenatal testing. As Scott says "The intelligent use of documents involves a judgement as to whether the documents consulted are representative of the totality of relevant documents. This is not to say that good research cannot be carried out with an unrepresentative

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[8] Mason, J. n.2 above, at p137

selection; but the user must know to what extent and in what respects those documents are unrepresentative."[9] The leaflets collected by these means may represent those provided by regional genetics centres but not local hospitals. The degree to which the leaflets will be representative of regional genetics centres would depend on the response rate.

It was thought that this number (21) was a reasonable amount as this was only intended to be a small scale study, testing out a hypothesis stated in the argument of my thesis. There were also issues with time and resources available to complete this study.

A letter was sent to each of these genetic centres requesting information. It was decided that three leaflets should be requested (if routinely offered to pregnant women). These were:

1. Information given to prospective parents on **amniocentesis.** This was chosen as an example of a 'test.' By studying these leaflets it was hoped they would provide evidence of the routine nature of this test.
2. Information given to prospective parents about **Thalassaemia.** This condition was selected because it is usually targeted at Asian/ Greek families, and needs two carriers to be passed onto another generation.
3. Information given to prospective parents about **Down's syndrome.** This condition was selected because the 'risks' of carrying a baby with this condition is more related to maternal age rather than a family history. Thalassaemia and Down's syndrome would therefore be explained in different ways.

A copy of the letter sent is included at the end of this appendix.

Support groups were also located. This was done firstly by using the Genetic Interest Group (GIG) website[10] which lists all its member organisations. GIG has a membership of over 130 charities which 'support children, families and individuals affected by genetic disorders. Its primary goal is "to promote awareness and understanding of

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[9] Scott, J. *A Matter of Record* (Cambridge, Polity Press, 1990) at p24; O'Connell Davidson, J., Layder, D. *Methods, Sex and Madness* (London, Routledge, 2001)

[10] www.gig.org.uk

genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them."[11] This website again acted as a sampling frame. It is important to note that the groups who are members of GIG are generally all pro-genetic research and any medical intervention to prevent or cure the disabilities that they represent. In order to make the sample more balanced, it was therefore necessary to locate support groups who were not members of GIG.

The terms 'Down's syndrome support' and 'thalassaemia support' were also entered into the 'Google' search engine which provided some additional websites. Many of the search results were local support groups and which did not provide a web site. The focus of this study was national support groups which published information on the conditions. This was because it was more likely that prospective women/ couples wanting to find additional information may well use 'Google' and the links provided. It is this information that will be compared with the information provided on the NHS.

The response rate to the request for leaflets was 57%. This provided 24 leaflets to analyse. In future studies of this nature, a follow-up letter 'reminder letter' would be recommended as this could have potentially increased the response rate. In total, 29 leaflets were received however five were rejected for this study because they contained information on tests or conditions other than those requested. Several (5) sent the same leaflet, *Testing for Down's syndrome in pregnancy*[12] which demonstrated a move to establish national policy and a standardised leaflet across England and Wales. Several hospitals did not have a leaflet for Thalassaemia because the incidence of the condition in their area was too low to indicate a need and thus the funding required. The sample still provides enough data, with the right focus, to enable the research questions to be addressed. However as a result of the response rate this study became more illustrative or evocative rather than representative.

The list of leaflets received is below:

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[11] www.gig.org.uk/about.htm

[12] Department of Health *Testing for Down's syndrome in pregnancy* (Oxford, National Screening Committee, 2004). Provided by the UK National Screening Committee – the booklet was written by the National Down's Syndrome Screening Patient Information Group. This is a partnership between: Leeds University; University Hospital Wales, MIDIRS – Midwives Information and Resource Service, ARC – Antenatal Results and Choices, Down's Syndrome Medical Interest Group and National Screening Committee.

Fig. L. A table to show the leaflets received for this study

Title	Source	Date
Tests for you and your baby during pregnancy	Nottingham	2003
Understanding beta thalassaemia trait	South WestLondon Community NHS Trust	2001
Thalassaemia: your life, your choice, your test	unknown	unknown
A Parent's guide to newborn screening for Phenylketonuria, congenital hypotghyroidism and cystic fibrosis	NHS Scotland	2002
Amniocentesis	Liverppol Women's Hospital NHS Trust	unknown
Genetics	Cystic Fibrosis Trust	unknown
Fragile X Syndrome: fact sheet	Wessex Clinical Genetics Service, Southampton	unknown
Chorionic Villus sampling	Wessex Clinical Genetics Service, Southampton	1999
The Nenatal screening test	Trent Region Neonatal Metabolic Screening Service	2001
Is my baby alright? Screening in pregnancy	Midirs, Bristol	unknown
Information for aprents/ carers for cystic fibrosis	NSW Newborn Screening Programme, Cardiff	2000
Newborn Screening	Illinois Dept of Public Health, USA	2003
Antenatal check-ups	WHSMITH Total Guide to Pregnancy	unknown
Thalassaemia: your life, your choice, your test	Northern California Comprehensive Thalassemia Center	2003
Information for people who carry Alpha Thalassaemia	UK Thalassamia Society	1996
Hemochromatosis DNA Test	Kimball genetics, Colorado, USA	
Newborn Screening for genetic disorders	Directory of Genetics Support Groups	2003
Important Information for Parents abour the newborn screening test	Dept of Health Service, California	unknown
Newborn Screening tests	Kidshealth, The Nemours Foundation	2003
Sickle Cell Newborn Screening - FAQs	The Sickle Cell Information Center, Georgia, USA	2003
The Progress Guide to Genetics	Progress Educational Trust	1996
The Amniocentesis Test	Wessex Clinical Genetics Service, Southampton	2004
The Chorionic Villus Sampling Test	Wessex Clinical Genetics Service, Southampton	2004
The Genetic Testing of Children	Guy's and St Thomas' Hospital NHS, London	2002

Research Questions:

There have been several previous studies which purported to analyse the information given in leaflets to prospective couples. Bryant *et al* categorised sentences into the following table: [13]

Fig. M: Table to show categories used for leaflet analysis by Bryant *et al*

	Information category	**Sample statement**
1	Medical problems	30% may develop some form of thyroid disease
2	Mental retardation	The effect of this extra copy is mainly mental handicap
3	Chromosomal or genetic origins	Down syndrome is a genetic condition caused by the presence of an extra chromosome 21
4	Prevalence in population	About 1 in 700 babies are born with Down syndrome
5	Physical appearance	The eyes are upslanting and the face is rather flat
6	Variation in disability or ability	The ability of adults with Down syndrome varies considerably
7	Life expectancy	Approximately 25% of babies born with Down syndrome will not survive longer than 10 years
8	Education and development issues	Most people with Down syndrome will need special help with their education
9	Social factors (independence, employment)	Generally as they grow older they will always require supported help and accommodation
10	Inability to predict severity before birth	There is no way to predict how serious any of the disabilities will be
11	Non-availability of 'treatment' for Down syndrome	It is not a disease and cannot be treated
12	Psychosocial/emotional aspects of parenting	Some parents find their experience is not what they hoped for but it is still positive
13	Psychosocial/emotional aspects for person with Down syndrome	Many of them are nevertheless happy children

They then used a coding system to classify each sentence as positive, negative or neutral. This was based on a study by Loeben *et al.*[14] The classifications of positive and negative were used to ‘capture both the content of the sentence and the sentence’s tone or “slant”’[15] and thus the message or image it communicated about Down syndrome. For

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[13] Bryant, L.D., Murray, J., Green, J.M. Hewison, J., Sehmi, I., Ellis, A. ‘Descriptive information and Down syndrome: a content analysis of serum screening leaflets’ (2001) 21 *Prenatal Diagnosis* 1057-1063 at p1059

[14] Loeben, H.L., Marteau, T.M., Wilfond, B.S. ‘Mixed messages: presentation of information in cystic fibrosis screening pamphlets’ (1998) 62 *Am J Hum Genet* 1181-1189

[15] *Ibid,* at p1182

example, a sentence could be classed as negative either because it contained information about a negative aspect of Down syndrome such as the prevalence of heart defects, or because it framed information about the condition in a negative way, such as emphasising infant mortality rates rather than survival rates.[16]

Fig. N: Table to show the ratings of sample descriptive sentences about Down's syndrome:[17]

Neutral	**Positive**	**Negative**
Most babies will sit between 6-30 months, walk at 1-4 years and be toilet trained by 2-7 years	This means that many children with Down syndrome will accomplish more than ever before	Down syndrome is the single most common cause of severe mental handicap
Some will die very young but many will have a normal length of life	Many babies with Down syndrome will survive into old age	Some babies are affected by serious deformities which may ultimately be fatal
Each person with Down syndrome is different	If they have heart disease it can often be treated	About 40% are born with heart problems and of these 20% will require some form of heart surgery
Neutral	Positive	Negative
Most babies will sit between 6-30 months, walk at 1-4 years and be toilet trained by 2-7 years	This means that many children with Down syndrome will accomplish more than ever before	Down syndrome is the single most common cause of severe mental handicap

Another study by Murray *et al* assessed the comprehensiveness of the contents of each leaflet was broken down into individual factual statements each of which was recorded against a checklist of 54 items categorised into nine groups: medical condition; prevalence; screening terminology; biochemical markers; test interpretation; prenatal diagnosis; test performance; procedural matters; and general.[18] This approach is similar to that used by Bryant *et al.*[19]

These studies proved useful in considering the methodology for this study. However, this was only intended to be a small-scale study. The studies by Bryant *et al*, Loeben *et al*, and Murray *et al* had to use codings in order to make their conclusions representative and statistical. All that was necessary for this thesis was to find examples of leaflets to illustrate the points made in the main text.

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[16] Bryant, L.D., et al. n.13 above, at p1058

[17] *Ibid,* at p1059

[18] Murray, J., Cuckle, H., Sehmi, I., Wilson, C., Ellis, A. 'Quality of written information used in Down syndrome screening' (2001) 21 *Prenatal Diagnosis* 138-142

[19] Bryant, L.D., et al. n.13 above, at p1058

This study therefore focused on the following research questions:

- How do leaflets convey disability?
- What kind of information did the leaflet contain: scientific, medical, social, emotional, financial etc etc?
- What kind of information had prominence in the leaflets?
- What language is used?
- Does NHS leaflet refer reader to 'support groups'?
- Does leaflet include testimonies of people with condition/ parents of child with condition?
- How 'routinised' do leaflets make tests sound?

For each leaflet read, copious notes were made about the overall tone, and the answers to the research questions. This enabled this leaflets study to be used to illustrate the arguments made in the informed decision making chapter.[20]

The study by Bryant *et al* provided some guidance when considering 'how do leaflets convey disability'. Using Bryant at al's method as a guide for the leaflets on Down's syndrome, a sentence could be classed as negative either because it contained information about a negative aspect of Down's syndrome such as the prevalence of heart defects, or because it framed information about the condition in a negative way, such as emphasising infant mortality rates rather than survival rates,[21] or if they only emphasised the severe/ serious end of the condition spectrum rather than explaining the variation. Statements classified as 'negative' focused on the following:

1) the clinical complications associated with the condition,

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[20] Chapter 4

[21] Bryant, L.D., et al. n.13 above, at p1058

2) the developmental problems
3) the reduced life expectancy
4) the reduced quality of life of the affected person
5) that there is no treatment
6) stigmatising descriptions

Sentences classified as 'positive' were those that focused on:

1) the fact that treatments for the clinical complications are improving
2) educational support and outcomes are improving
3) people with Down syndrome have the ability to participate in important life activities
4) life expectancy is improving

Whereas I did not code each sentence in this way, because I did not need numerical evidence, it was useful to use the classification criteria used by Bryant *et al* in order to focus on the way in which disability was portrayed.

(Contact details)

10th January 2005

Dear Sir/ Madam

Re: Prenatal information leaflets

I am currently in the third year of my PhD (law) at the University of Southampton. My research is on 'The Prevention of Disabled Lives through the use of Reproductive Genetic Technologies.' As part of this research, I hope to analyse the information provide to patients in leaflet form about prenatal tests.

In particular I am concentrating my research to leaflets about

1. Amniocentesis
2. Thalassaemia
3. Downs syndrome

I would be extremely grateful if you could spare the time to send me a copy/ photocopy of the leaflets that your hospital uses to help patients understand the tests and the condition they test for.

Yours sincerely,

Lindsey Brown

Appendix C: Hansard Analysis

Data Collection

The initial method for identifying relevant sections of the parliamentary debate was by using searches on the Hansard website.[1] The terms entered into the search engine were: 'abortion;' 'foetal abnormality;' 'cleft palate.' The search engine seemed quite unreliable, for example when searching for 'foetal handicap' it came up with some references about abortion that had not come up when searching for 'abortion.' The paper version of the parliamentary debates in the library was then used, relying on the indexing system. This ensured no relevant sections of the debates were excluded from analysis.

All sections of debates on abortion during the passage of the Abortion Act 1967 and the HFE Act 1990 (when the time limit was removed for foetal 'handicap') were read, regardless of whether or not they were discussing disability. This was in order to understand the way in which the law had been passed. It was important to do this in order to recognise the extent of political compromises that were made in order to pass the laws, and to understand the complicated voting procedures adopted which made it difficult for MPs to know what they were actually voting for. The 2003/04 parliamentary session was also explored for debates sparked off as a result of the Joanna Jepson case study.

Having read the debates, quotes were then selected and typed up that demonstrated several themes that needed exploring:

1) the different ways of viewing disability,
2) the use of language to describe disability,
3) the sources MPs used to support their arguments.

I created a document containing all the quotes and used 'tracking changes' on the 'Reviewing' toolbar in Microsoft Word in order to make notes as to what the different quotes demonstrated. Divided quotes into themes:

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[1] http://www.parliament.uk/hansard/hansard.cfm and then click on the search engine.

1) language
2) politicians deferring to medical professions
3) views about disability
4) political compromises
5) abortion statistics
6) comments re: Joanna Jepson case

For a while I explored the possibility of 'ranking' the terms used by MPs as: favourable to disability, unfavourable to disability or neutral. This could have provided a statistical way of analysing the debates i.e. how many MPs in each category. However it proved difficult to explain how value was attributed to these comments in an objective way which seemed necessary when performing more quantitative research. It seemed as if this process would be based on personal judgements and opinions, rather than any objective criteria.

It was also thought that the context of words or images can be important when ranking, because no matter how rigorously it is done, "the same words or images can mean and convey very different things in different contexts."[2] And it would be difficult to reflect the context of these comments using such a methodology. However by selecting quotes, it was ensured that the context in which the comments were made was included in the discussion.

This project is vulnerable to the criticism that although the language MPs used was clear enough, it could be argued that too much was being read into the comments. That the choice of language used was being interpreted in a way that the MPs had never intended. The comments were made during a debate, they were possibly not reading from a script. Even if some were reading from a script, much of what was said was in response to questions from other MPs, therefore when 'adlibbing' they might not have had words prepared beforehand. It is obviously not possible to ask each MP 'did you mean x when you said y?' However, Hansard is an accurate written record of the Parliamentary debates, MPs are aware that the record is being made and will be accessible to the world and so they are potentially more careful of making declarations that will come back and

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[2] O'Connell Davidson, J., Layder, D. *Methods, Sex and Madness* (London, Routledge, 2001) at p202

haunt them. Alternatively, without political aides on hand to prompt them in their choice of language, it could be argued that the disablist language employed thus reflected a more subconscious attitude that theory could be unaware of. This would tie in with my theory (discussed throughout the main text) that the public have disablist attitudes that they may not be aware of, as a result of the historical position disabled people have been in: one of institutionalization and discrimination.

How representative are the views of MPs? They are obviously elected by society as representatives, but whose views do they represent? MPs do not have referenda in their constituencies before they decide how to cast their vote. On the abortion issue, MPs were given a 'free vote' so that should remove the idea that they are merely towing the party line or being subject to pressure from the 'whips.' The views of MPs therefore cannot be interpreted as representative of the views of society, or the views of a political party. However, they are probably indicative of the views of the MPs themselves. This is important for this thesis as the ways in which laws are passed and the values they express is a key argument. It is also important to remember that speeches made in the House are made in order to try to persuade others of a certain viewpoint – they may therefore be 'over-egging the pudding' in order to get Members to meet them just some of the way, in order to make a compromise.

Throughout the speeches, many facts and figures were cited. MPs will have chosen the facts and figures that supported their case. It could be argued that some were employing 'shock tactics.' The accuracy of the official statistics is also questionable: after all, it has been known for Governments to manipulate statistics (e.g. unemployment figures) by changing the definitions (e.g. how to define 'unemployed') in order for their policies to seem effective.

As this research was carried out in 2004/05, it is possible that an alternative framework of analysis was used other than someone in 1990 or 1967 (when the debates took place) would have done. In particular, in the analyses of the language used to describe disability. Was it as insulting and offensive to a disabled person in 1990 or 1967 as it is now? Is it just that language trends have changed and we have become more politically correct? These debates being analysed were carried out before disabled people had any legal protection against discrimination (DDA 1995). Did that change the way MPs and society viewed disabled people? It is important to consider these questions when analysing the parliamentary debates.

It is possible that the meaning of phrases could be affected by the reader's pre-existing belief about the world. "The meaning changes over time not because of what is *in* the text, but because of what the reader or researcher *brings* to the text"[3] "Or should we conclude that texts have no single, true meaning but rather a number of meanings that vary according to the subjective perceptions of the people that read an interpret them?"[4]

From a Hermeneutics perspective (i.e. the rules, interpretations and meanings through which people produce and reproduce social life)[5] do my expectations of what I will discover in Hansard affect my analysis? Would another researcher looking at the same debates come to the same conclusions? It has to be admitted that they probably would not, however this is not necessarily because of a biased perspective but because not many scholars would be trying to answer the exact same questions as me. For example, I was not interested in analysing the way the mainly male House discussed women's rights, although a feminist scholar might, just as she might not notice the way in which the MPs discussed disability. i.e. one particular theme may be more important to one researcher than another. The debates were read with 'an open mind' indeed in a way I was willing/ hoping to be proven wrong and to discover that not all MPs had disablist attitudes, and that disabled people were truly respected and treated as equal citizens.

By carrying out this project, it was surprising that abortion on grounds of disability did not seem to be very important and so was not mentioned as many times as other aspects of abortion law. This itself is important for my analysis (for it demonstrates how abortion on for this reason was rarely questioned or debated), however, how has this affected the methodology? It questions how representative the views on disability advocated by MPs were, as many MPs did not mention it. I do not think it demonstrates how MPs view disability issues as unimportant; instead it demonstrates how Members from both sides of the debate (pro-life and pro-choice) accepted the need for foetal handicap abortions.

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[3] *Ibid,* at p196
[4] *Ibid*
[5] *Ibid*

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