
Article:
Adam-Smith, Rachel (2020) Disabled foetuses and the search for equality. York Law Review, 1. pp. 111-144.

https://doi.org/10.15124/yao-ivwpy87q

Disabled foetuses and the search for equality

Rachel Adam-Smith

Abstract
This paper questions whether and how the Abortion Act 1967 discriminates against the disabled foetus. It argues that the lack of definition and guidance on the terms 'substantial risk' and 'serious handicap' affords doctors wide discretionary powers. The broad definition and lack of guidance on these terms enables the termination of foetuses with completely treatable and manageable conditions. This paper contends that the Abortion Act has failed to keep pace with advancements in modern medicine and human rights. As a result, the existing legislative measures provide foetuses with a potential disability a lower level of protection than they would otherwise have 'but for' their diagnosis. In reflecting on the value placed on disabled lives by law and society, this paper will argue that the time limit for the abortion of disabled foetuses should be brought into line with the time limit for non-disabled foetuses.

1 Introduction

Abortion raises important questions of reproductive autonomy, and progress made in this area must be safeguarded. However, medical advances are ever-improving thus our understanding of obstetrics and neonatal care have raised new questions for the social, moral, and medical permissibility of late-term abortions. This paper interrogates the provisions of the Abortion Act 1967 (the Abortion Act) in light of these advancements by questioning its applicability to foetuses with disabilities. It examines the ongoing tension between current legislation and the disability rights movement.

In its first section, this paper will outline historic and current abortion legislation, and will address issues of ambiguity and disagreement which stem from the lack of definition to the terms 'serious handicap' and 'substantial risk' within abortion legislation.[1]

The second section of this paper sets out how the right to life enshrined in Article 2 of the European Convention of Human Rights (ECHR) applies to foetuses. It raises the question as to whether a viable foetus, regardless of disability, should be afforded the same legal protections as a premature infant. It draws on the decision of the European Court of Human Rights (ECtHR) in *Vo v France*[2] which held that the foetus was entitled to 'some protection of human dignity'.[3]

Through a comparison with the test for disability discrimination protection set out in the Equality Act 2010, this paper then moves to examine the 'serious handicap' threshold within abortion legislation, and attempts to reconcile this test with advances in medical treatment that mean many more conditions are now treatable and manageable. The fourth section of this paper also draws on the Equality Act and applies notions of direct and indirect discrimination to current abortion law.

In its fifth section, this paper articulates the need to protect a foetus from pain and suffering, by comparison with premature infants. It will be argued that there is no intrinsic difference between a premature infant and a viable foetus of the same age and level of development.[4]

---

[1] Abortion Act 1967, s 1(1)(d) Ground E; Sheelagh Mcguiness, 'Law, Reproduction, and Disability: Fatally "Handicapped"?' (2013) 21 Medical Law Review 213; Elizabeth Wicks, Michael Wyldes, and Mark Kilby, 'Late Termination of Pregnancy for Fetal Abnormality: Medical and Legal Perspectives' (2004) 12(3) Medical Law Review 285.
[2] *Vo v France* [2005] 40 EHRR 12; Rosamund Scott, 'Interpreting the Disability Ground of the Abortion Act' (2005) 64 Cambridge Law Journal 388.
[3] *Vo v France* (n 2).
[4] Jeff Mcmahan, 'Infanticide and Moral Consistency' (2013) 39(5) Journal of Medical Ethics 272.

Thus, it will be argued that there can be no difference in moral status between a viable foetus and a premature infant of the same age. This section will question the unlimited nature of section 1(1)(d) abortions in light of the need to protect a foetus from pain and suffering. Further, it will consider whether the process of late-term abortions affords a foetus dignity in line with the decision in *Vo v France*, in which the ECtHR made it clear that the foetus was entitled to 'some protection of human dignity'. It concludes by arguing that viable foetuses should be afforded the same protections as a premature infant.[5]

The penultimate section of this paper considers the value that society places on disabled lives. It examines the considerable social and economic costs of having an impairment, and the potential impact of these costs on decisions to abort by prospective parents. It argues that parents and their disabled children must be empowered to lead fulfilling lives within a society that respects and values disabled lives.[6]

In the final substantive section of this paper, the issue of genetic screening will be addressed. The consequences of advances in genetic knowledge and the huge proliferation of prenatal tests has increased concern that genetic screening signals powerful messages about disabled people's fundamental right 'to be'.[7] As most genetic testing and other screening is completed prior to the current twenty-four-week threshold enshrined within the Abortion Act, it questions the ongoing need for late-term abortions on the basis of the section 1(1)(d) criteria.

2 History of abortion legislation

Abortion is an offence under sections 58 and 59 of the Offences Against the Person Act 1861 and section 1(1) of the Infant Life (Preservation) Act 1929.[8] Section 1(1) of the Infant Life (Preservation) Act 1929

[5] Scott (n 2); *Vo v France* (n 2).
[6] Scott (n 2).
[7] Linda Ward, 'Whose right to Choose? The New "Genetics", Prenatal Testing and People with Learning Difficulties' (2002) 12(2) Critical Public Health 187.
[8] Jo Samanta and Ash Samanta, *Medical Law Concentrate: Law Revision and Study*

provides that it is an offence to destroy the life of a foetus that is 'capable of being born alive' and is punishable up to a maximum penalty of life imprisonment. The phrase 'capable of being born alive' was defined in *Rance v Mid-Downs Health Authority*[9] as 'breathing and living by reason of its breathing through its own lungs alone, without deriving any of its living or power of living by or through the connection to its mother'. It is noted that, under section 1(2) of the Infant Life (Preservation) Act, a foetus of twenty-eight weeks' gestation or older is presumed to be capable of being born alive.[10]

The Abortion Act legalised the medical process of abortion on certain grounds by registered practitioners.[11] The Abortion Act allows for the abortion up to forty weeks' gestation on a wide number of grounds.[12] In order to understand the form the Abortion Act took, it is important to realise that the legislation was not enacted in order to provide women with the right to terminate their unwanted pregnancies.[13] The principal factor behind public and parliamentary support for legalisation was concerns about high mortality rates resulting from illegal abortions, especially among the poor.[14] Coupled with this, there was inadequate contraception, as the pill only became widely available during the 1960s, meaning that unwanted pregnancies were common. Abortion was not legalised in order to enhance women's reproductive autonomy; instead, the main purpose was to enable doctors to act lawfully in assisting desperate women to end their pregnancies.[15]

Guide (3rd edn, OUP 2018) 77; Offences Against the Person Act 1861, ss 58, 59; Infant Life (Preservation) Act 1929.

[9] *Rance v Mid-Downs Health Authority* [1991] 1 All ER 1230, 1241.

[10] Jonathan Herring, 'Contraception, Abortion and Pregnancy' in *Medical Law and Ethics* (7th edn, OUP 2018) 324; Life Preservation Act, s 1(1)(2).

[11] NHS, 'Overview Abortion' (*NHS*, 17 August 2016) <https://www.nhs.uk/conditions/abortion/> accessed 20 December 2018; Abortion Act, s 1(1)(d) Ground E.

[12] NHS (n 11).

[13] Emily Jackson, *Medical Law: Text, Cases, and Materials* (4th edn, OUP 2016) 9.

[14] Ibid.

[15] ibid.

The statutory grounds for an abortion are found in section 1 of the Abortion Act, as amended by the Human Fertilisation and Embryology Act 1990, which states:

> (1) Subject to the provisions of this section, a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered medical practitioner if two registered medical practitioners are of the opinion formed in good faith
>
> (a) that the pregnancy has not exceeded its twenty fourth week and that 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 or any existing children of her family; or
>
> (b) that the termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or
>
> (c) that the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or
>
> (d) that there is a substantial risk that if the child were born it would suffer from physical or mental abnormalities as to be seriously handicapped.[16]

It is worth noting here that the Abortion Act still uses the terminology 'handicapped', a word which is now generally avoided in communicating with or about disabled people, as set out in the Government's inclusive language guidance issued in December 2018.[17]

---

[16] Abortion Act, ss 1(1)(a), (b), (c), and (d); Jonathan Herring, *Medical Law and Ethics* (7th edn, OUP 2018) 304.

[17] Gov.uk, 'Guidance Inclusive Language: Words to Use and Avoid when Writing about Disability' (*Gov.uk*, 18 December 2019) <https://www.gov.uk/government/publications/inclusive-communication/inclusive-

Having set out the statutory criteria, it is important to note that the Abortion Act does not allow a woman to decide to terminate an unwanted pregnancy. There is no right to abortion, even if the grounds in the Act are plainly satisfied. Instead the statute legitimises the doctors' decision to administer an abortion in circumstances which meet the section 1(1) criteria. [18] Therefore, the Abortion Act focuses on the opinion of the doctors. It is not necessary to show that one of the statutory grounds was actually made out; it is sufficient that the doctors were of the opinion that it was.[19] This means that the statute enshrines deference to medical opinion, and a prosecution could only be brought on the grounds that the doctors had not acted in good faith. [20] Consequently, the law empowers doctors, rather than women, to judge whether an abortion should be performed.

This paper centres on section 1(1)(d) of the Abortion Act.[21] Prior to the Abortion Act, statutory protection of foetuses was determined solely by the stage of gestation, with twenty-four weeks representing an arbitrary cut-off point.[22] The Abortion Act altered this by creating a situation whereby foetuses are differentiated on the basis of a potential disability or 'serious handicap'.[23] Section 1(1)(d) therefore, can be seen as an anomaly in the broader context of legislative measures to prevent late-term abortions, as it affords foetuses with a potential disability a lower level of protection than they would have but for their 'diagnosis.'[24]

language-words-to-use-and-avoid-when-writing-about-disability> accessed 20 November 2018.

[18] Emily Jackson, 'Abortion, Autonomy and Prenatal Diagnosis' (2000) 9(4) Social and Legal Studies 467.

[19] Herring (n 16) 303.

[20] ibid.

[21] Abortion Act, s 1(1)(d) Ground E; Mcguiness (n 1) 213–242.

[22] Mcguiness (n 1).

[23] ibid.

[24] ibid.

3 The foetus and the right to life

A foetus does not possess a legal personality, therefore, a foetus has no right to life in English Law.[25] The question as to whether the foetus, including the late-term foetus has a right to life under Article 2 of the ECHR was addressed by the ECtHR in *Vo v France*.[26] In this case, the ECtHR made it clear that the foetus was entitled to 'some protection of human dignity'.[27] However, the Court observed that 'the unborn child is not regarded as a "person" directly protected by Article 2 of the Convention. Thus, the foetal right to life is implicitly limited by the mother's rights and interests.'[28] As a result, the only point of agreement is that the embryo or foetus is human. The Court observed that since the foetus has the capacity to become a person, it requires 'protection in the name of human dignity, without making it a "person" with the "right to life" for the purposes of Article 2'. However, if prenatal life is given some legal protection by the criminal law, then it could be argued that Article 2 should apply to the foetus at the point when the foetus becomes viable.[29] Otherwise, the protections afforded to the foetus by the criminal law would appear to be redundant and insignificant.

4 Abortion and the disabled foetus

The analysis above has shown how the Abortion Act section 1(1)(d) provides for a ground of abortion where there is a 'substantial risk' that the child born would suffer a 'serious handicap',[30] known as the disability ground for abortion.[31] Yet, how 'serious handicap' should be defined has remained subject to ambiguity and disagreement. Some have suggested that the legislation is deliberately vague to avoid

[25] Rosamund Scott, 'The English Fetus and the Right to Life' (2004) 11(4) European Journal of Health 355.
[26] *Vo v France* (n 2).
[27] ibid [84].
[28] Scott (n 2), *Vo v France* (n 2).
[29] Scott (n 2).
[30] Abortion Act, s 1(1)(d) Ground E.
[31] ibid.

fettering the discretion of the two certifying doctors.[32] This is grounded in the fact that the Abortion Act is silent on the definition of serious handicap. As a result, this broad definition allows the termination of foetuses with medical conditions such as cleft lip and/or palate (cl/p), which are deemed as treatable, as the NHS guidance states: 'Most of these problems will improve after surgery and with treatments such as speech and language therapy.'[33]

Despite the fact that conditions such as cl/p can be treated, they still fall under the umbrella of 'serious handicap'. The issue as to what constitutes a level of disability which might amount to 'serious handicap' was considered in *Jepson v Chief Constable of West Mercia Police Constabulary*.[34] Jepson asked West Mercia Police to investigate the circumstances of an abortion carried out on a twenty-eight-week foetus with bilateral cl/p.[35] The police concluded that the abortion was in line with the legislation, whereas Jepson argued that late abortions could only be justified for more serious conditions. Leave was granted to apply for judicial review and the court concluded that since the doctors had formed their opinion in good faith (that the child would be seriously disabled), there was insufficient evidence for a conviction, and therefore the decision of the police was sound.[36]

The case of Jepson reinforces the difficulties that arise due to the lack of clear definition as to what constitutes 'serious handicap' in the 1967 Act.[37] As a consequence of this case, the Disability Rights Commission stated:

[32] Mcguiness (n 1), Wicks, Wyldes, and Kilby (n 1).
[33] NHS, 'Overview cleft lip and palate' (*NHS*, 29 July 2016) <https://www.nhs.uk/conditions/Cleft-lip-and-palate/> accessed 28 January 2019.
[34] *Jepson v Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318.
[35] ibid.
[36] ibid. Samanta and Samanta (n 8) 75.
[37] Mcguiness (n 1).

> Section 1(1)(d) is offensive to many people; it reinforces negative stereotypes of disability, to permit terminations at any point during a pregnancy on the grounds of disability, while time limits apply to other grounds set out in the Abortion Act, is incompatible with valuing disability and non-disability equally.[38]

Disability is the loss or limitation of opportunities to take part in the life of the community on an equal level with others.[39] By comparing the Equality Act with section 1(1)(d) of the Abortion Act, it can be seen that the lack of definition afforded to the terms 'substantial risk' and 'serious handicap' in section 1(1)(d) illustrates how the Abortion Act is at odds with the Equality Act 2010, which specifically defines disability as having a physical or mental impairment that has a 'substantial' and 'long term' negative effect on your ability to carry out normal daily activities.[40] The term 'substantial' in the Equality Act is defined as more than minor or trivial - for example, it takes much longer than it usually would to complete a daily task such as getting dressed.[41] Therefore, if 'substantial' was assessed in line with the Equality Act, then, the question that needs to be asked is whether the condition in question would have more than a minor or trivial impact on the daily activities of the child. A lack of definition in the Abortion Act as to the terms 'substantial risk' and 'serious handicap' illustrates there is a lack of coherence between the definition of disability under the Equality Act and the understandings of foetal disability contained in abortion legislation. As a result, the lack of definitional coherence affords the

---

[38] Celia Hall, 'Disabled Group in Abortion Law Attack*', The Telegraph* (London, 22 August 2001) <https://www.telegraph.co.uk/news/uknews/1338130/Disabled-group-in-abortion-law-attack.html> accessed 16 February 2019.

[39] Tania Burchardt, 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability' (2014) 19(7) Disability & Society 735.

[40] Equality Act 2010, section 6(1)(b). Gov.uk, 'Your Rights under the Law, Definition of Disability under the Equality Act 2010' (*Gov.uk*, 13 December 2018) <https://www.gov.uk/definition-of-disability-under-equality-act-2010> accessed 10 November 2019.

[41] ibid.

medical profession wide discretionary powers.[42] However, this definitional failure potentially removes protection for foetuses that may well have enjoyed a good quality of life.

The lack of definition discussed above potentially enables society to select against some traits. This could exacerbate the discrimination and stigmatisation of those with similar traits; so much so that selection cannot comfortably coexist with society's professed goals of promoting inclusion and equality for people with disabilities.[43] Consequently, the impaired foetus is in a much weaker legal position than the unimpaired one, as highlighted by the case of Jepson.[44] Further, in looking to define the terms 'substantial risk' and 'serious handicap' we must reflect on the varying degrees of disability, advancements in medicine, and, most importantly, the equality agenda and the social need to respect and value disabled lives.

5 The disabled foetus and discrimination

Tom Shakespeare defines disability equality as the political principle that people should be treated equally, should be included rather than excluded from society, and should have the right to be heard, regardless of physical or intellectual endowment.[45] This implies not only a negative obligation not to discriminate, but also a duty to recognise differences between people and to take positive action to achieve real equality.[46] However, the United Nations (UN) Committee's recommendations illustrate that disability equality in the UK is not

[42] Chris Cowland, 'Selective Abortion: Selecting the Right Response' (2010) 2 King's Student Law Review 55.
[43] Adrienne Asch, 'Genes and Disability: Defining Health and the Goals of Medicine: Disability Equality and Prenatal Testing: Contradictory or Compatible?' (2003) 30 Florida State University Law Review 315.
[44] Scott (n 2); *Jepson* (n 34).
[45] Tom Shakespeare, 'Choices and Rights: Eugenics, genetics and disability equality' (1998) 13(5) Disability & Society 665.
[46] Daniel Moeckli and others, *International Human Rights Law* (3rd edn, OUP 2017) 148.

currently being realised.[47] The UN were concerned that some people think that disabled people's lives are less valuable than the lives of non-disabled people. According to the UK committee, the UK should 'change its abortion laws so that they do not allow selective abortion at any stage of pregnancy because the foetus has an impairment, while respecting women's rights to reproductive and sexual freedom'.[48] Furthermore, they recommended that an action plan should be produced to stop disabled people being perceived as not having a 'good and decent life', and to recognise that disabled people are equal to non-disabled people.[49]

Unlawful discrimination means treating someone less favourably than others on the basis of certain personal attributes that are protected by law.[50] The Equality Act states that you must not be discriminated against because you have a disability, someone thinks you have a disability (this is known as discrimination by perception), or you are connected to someone with a disability (this is known as discrimination by association).[51] Within the Equality Act, a disability is defined as a physical or a mental condition which has a substantial and long-term impact on your ability to do normal day-to-day activities (section 6

[47] European and Human Rights Commission (EHRC), 'How is the UK Performing on Disability Rights, the UN Recommendations for the UK' (EHRC 18 January 2018) <https://equalityhumanrights.com/en/publication-download/how-well-uk-performing-disability-rights> accessed 10 November 2018.
[48] Ibid 9.
[49] Ibid 14.
[50] Equality Act 2010 Guidance, 'Guidance on Matters to be Taken into Account in Determining Questions Relating to the Definition of Disability. Introduction' (Equality Act 2010 May 2011) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/570382/Equality_Act_2010-disability_definition.pdf> accessed 20 April 2019; Equality Act.
[51] Equality Act, s 6; EHRC, 'Disability Discrimination' (*EHRC*, 11 April 2019) <https://equalityhumanrights.com/en/advice-and-guidance/disability-discrimination> accessed 20 April 2019.

(1)).[52]

Protection from discrimination for disabled people applies in a range of circumstances.[53] Only those disabled people who meet the definition of disability in accordance with section 6 of the Equality Act and the associated schedules and regulations made under that section will be entitled to the protection that the Act provides.[54] Whether a person satisfies the definition of a disabled person for the purposes of the Abortion Act will depend upon the full circumstances of the case. That is, whether the substantial adverse effect of the impairment on normal day-to-day activities is long term. Importantly, the effects of impairments may be more difficult to ascertain in babies and young children because they are too young to be assessed against activities that are normal and day-to-day for older children and adults.[55]

Direct discrimination is treating one person less favourably than you would treat another person because of a particular protected characteristic that the former has. The definition is set out in section 13 of the Equality Act. In order to establish direct discrimination, the complainant has to show that the treatment was less favourable than the treatment of someone else in similar circumstances who did not have that characteristic.[56] In other words, they have to show (comparatively) less favourable treatment, not just unfavourable treatment.

A classic example of direct discrimination is when members of a certain group are denied access to a public facility, such as a swimming pool, which is open to everyone else. But most cases of direct discrimination are not as straightforward as this.[57] More often, direct discrimination

[52] EHRC (n 51).
[53] EHRC, 'Being Disabled in Britain, A Journey Less Equal' (*EHRC*, 3 April 2017) <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> accessed 24 April 2019.
[54] Equality Act, s 6.
[55] ibid.
[56] ibid.
[57] Moeckli and others (n 46).

occurs covertly: the 'discriminator' will not admit that the difference in treatment was based on a prohibited ground, making it difficult for the complainant to provide sufficient evidence.[58] However, it is clear from the discussions in this paper that whilst the Abortion Act does not allow the abortion of a non-disabled foetus post-twenty-four weeks, it makes an exception for the disabled foetus. Therefore, the discrimination that this paper contends is extant within the Act does not occur covertly, it is openly acknowledged that a foetus can be aborted at any stage in the pregnancy based upon disability.

Indirect discrimination is defined by Section 19 of the Equality Act as when:

> A person (A) discriminates against another (B) if A applies to B a provision, criterion or practice which is discriminatory in relation to a relevant protected characteristic of B's.[59]

Unlike direct discrimination, indirect disability discrimination can be lawful if objectively justified as a proportionate means of achieving a legitimate aim.[60] Some of the most insidious types of discrimination do not operate overtly, but instead come in the form of neutral measures that disproportionately affect those with protected characteristics.[61] Though this paper maintains the distinction made under section 1(1)(d) of the Abortion Act, it would also be captured by the indirect discrimination measures of the Equality Act if it was deemed a neutral measure, as under section 19(2)(b) it puts foetuses with a disability at a significant disadvantage as compared with their non-disabled counterparts.

Though a discussion of discrimination legislation is important to indicate the misalignment between equality policies and abortion

---

[58] ibid.
[59] Equality Act, s 19.
[60] EHRC (n 53).
[61] Ruth Costigan and Richard Stone, *Civil Liberties and Human Rights, Freedom from Discrimination* (Article 14) (11th edn, OUP 2017) 495.

legislation, it is important to note that sections 13 (direct discrimination) and 19 (indirect discrimination) are both limited in their applicability to 'persons'. As noted above, foetuses lack legal personality and thus would not be eligible for protection under the Act.

6 Pain and legal personality: why disabled foetuses require protection

Some foetuses will have a significant and life-limiting disability. If born they would exist without any realistic expectation of a reasonable lifespan and/or would suffer immeasurable pain, up to the point of their death. Consequently, aborting a disabled foetus with no expectation of a long-term life could be considered legitimate, as ultimately you are preventing future harm in the form of pain and suffering that could be experienced by the child. By way of example, conditions such as Tay-Sachs disease (a genetic life-limiting condition which destroys nerve cells in the brain and spinal cord) or anencephaly (a severe life-limiting developmental disorder involving the absence of major portions of the brain, skull, and scalp) would fall within this category.[62] However, where birth is compatible with a good or reasonable quality of life, as in the case of Down's syndrome, then, arguably, it will most likely be in the foetus's interests to be born.[63] This argument is supported by Kate Greasley, who states that:

> only with respect to extremely debilitating and rare diseases could the suffering involved in life be so acute that it is plausible to suggest that an individual would be better off having that life ended before birth.[64]

---

[62] NHS, 'Tay-Sachs Disease' (*NHS*, 7 February 2018) <https://www.nhs.uk/conditions/tay-sachs-disease/> accessed 14 March 2019; NHS, 'Fetal Anomaly Screening Programme' (*NHS*, 2019*).* <https://www.gov.uk/guidance/fetal-anomaly-screening-programme-overview> accessed 14 March 2019; Shakespeare (n 45).

[63] Scott (n 2).

[64] Kate Greasley, *Arguments about Abortion: Personhood, Morality, and Law* (OUP 2017) 229.

Having addressed the pain and suffering that a future child may feel, further consideration must also be given to the pain a disabled foetus may feel during the late-term abortion process. As discussed above, if further research determines that a foetus does feel pain at the point of viability (twenty-four weeks), then it could be argued that the disabled foetus should, during the process of late-term abortions, be afforded the right to freedom from 'inhuman or degrading treatment' under Article 3 of the ECHR. Arguably, this could establish a further reason as to why the Abortion Act provide equality in terms of time limits for non-disabled foetuses, as proposed by Lord Shinkwin in his private members' bill.[65] Despite this, there is of course an issue as to whose rights should take priority – the mother's or the foetus's. This paper has established that the Abortion Act was not enacted in order to provide women with the right to terminate their unwanted pregnancies.[66] However, section 1(1)(d) seemingly prioritises the mother's rights over those of the foetus. The effect of raising a disabled child and the potential rationale underpinning the prioritisation of material rights, will be discussed later in this paper.

Conversely, Chris Cowland argues that the abortion of a foetus with disabilities seeks to allow only the birth of children with desirable characteristics and essentially murders those who lack such attributes or more accurately, who possess undesirable traits.[67] Further, Cowland asserts that a foetus can be murdered and that selective abortion is the same as infanticide.[68] McMahan also argues that there is no intrinsic difference between a premature infant and a viable foetus of the same age and level of development.[69] Thus, if moral status is a function of intrinsic properties only, there can be no difference in moral status

[65] HL Deb 21 October 2016, vol 774 col 2545.
[66] Jackson (n 13) 698.
[67] Cowland (n 42).
[68] ibid.
[69] Mcmahan (n 4) 273.

between a viable foetus and a premature infant of the same age.[70] Disabled and non-disabled foetuses must therefore be afforded the same levels of protection *vis-à-vis* infliction of pain.

The International Association for the Study of Pain defines pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage'.[71] To feel something is defined as having 'the emotions excited, to experience a sensation'.[72] These definitions imply that the brain must achieve a certain level of neural functioning, as well as having prior experience, before pain can be understood.[73] Currently, there is no direct way of assessing pain in foetuses.[74] The most rational approach is to make an informed guess based on the knowledge of the development and function of the nervous system at different gestational ages. Pain is a complex phenomenon, however, and even if the nature of the experience changes with development, this does not prove that immature humans cannot be distressed by pain.

Ferschl and others argue that invasive foetal procedures clearly elicit a stress response, but it is unclear if this response correlates with conscious perception of pain.[75] Furthermore, they state that by nineteen weeks' gestation, a foetus can reflexively withdraw from a noxious stimulus without involvement of the cerebral cortex. They state, even if pain fibres reach the cortex at twenty-four weeks' gestation, the signals may not translate into what we perceive as pain.[76] However, Lloyd-Thomas and Fitzgerald state that even at twenty-six weeks very low

[70] ibid.
[71] International Association for the Study of Pain (IASP), 'Pain' (IASP, 2018) > https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698> accessed 12 February 2019.
[72] Stuart Derbyshire and others, 'Do Foetuses Feel Pain?' (1996) 313 British Medical Journal 795; IASP (n 72).
[73] Derbyshire (n 73).
[74] ibid.
[75] Marla Ferschl and others, 'Anesthesia for *in Utero* Repair of Myelomeningocele' (2013) 118(5) Anesthesiology 1211.
[76] ibid.

birthweight infants show a clear and measurable flexion withdrawal reflex to noxious stimulation, suggesting that nociceptive afferent (perception to pain) input to the spinal cord is present.[77] Whilst these studies were carried out after birth, it is reasonable to infer that such responses would also occur *in utero*.[78] As there have been considerable advances in prenatal diagnostic technologies, especially ultrasonography, an increasing number of foetal anomalies are being diagnosed early in gestation.[79]

The issue of pain perception is discussed further in the following paragraphs. Koul and others state that available scientific evidence show that possible foetal pain perception occurs well before late gestation, during the second trimester. [80] However, the British Pregnancy Advisory Service states that current research shows the senses of the foetus are not developed enough to feel pain before twenty-eight weeks' gestation.[81] Despite suggestions from the Royal College of Obstetricians and Gynaecologists (RCOG) that foetuses are certainly unable to experience pain until at least the end of the second trimester (twenty-six weeks), Koul and others state that adequate pain relief should be provided to a foetus from mid-gestation onwards during any surgical procedure. [82]

The issue of pain that a foetus may feel needs further attention, so that

---

[77] Derbyshire (n 73).
[78] ibid. Katharine Andrews and Maria Fitzgerald 'The Cutaneous Withdrawal Reflex in Human Neonates: Sensitization, Receptive Fields, and the Effects of Contralateral Stimulation' (1994) 56 Science Direct 95.
[79] Archna Koul, Raminder Sehgal, and Jayashree Sood, 'Anaesthesia for Foetal Surgery' (2015) 5 Current Medicine Research and Practice 22.
[80] ibid.
[81] British Pregnancy Advisory Service, 'Abortion: Frequently Asked Questions' (*BPAS*, 2015) <https://www.bpas.org/abortion-care/considering-abortion/abortion-faqs/> accessed April 2019.
[82] Royal College of Obstetricians and Gynaecologists, 'Fetal Awareness Review of Research and Recommendations for Practice' (*RCOG*, March 2010) <https://www.rcog.org.uk/globalassets/documents/guidelines/rcogfetalawarenesswpr0610.pdf > accessed 19 April 2019, 19; Koul (n 80).

pain management for all foetuses is consistent. Particularly, as the RCOG states, 'the case for administering analgesia after twenty-four weeks when the neuroanatomical connections are in place, needs to be considered.'[83] Vivette Glover suggests that foetuses over seventeen weeks old may feel pain and states, 'given there is a possibility (that a foetus can feel pain) we should give the foetus the benefit of the doubt'.[84]

The evidence set out above indicates there is a difference in the administration of pain dependent on whether the foetus is to be aborted or operated on *in utero*. On that basis, it is questionable whether the late-term abortive foetus is afforded the same level of dignity in line with the decision in *Vo v France* (discussed above),[85] in which the ECHR made it clear that the foetus was entitled to 'some protection of human dignity'.[86] This is particularly important when reflecting on the process of abortion carried out in the third trimester. Whether the process of abortion subjects a foetus to inhuman or degrading treatment and what should amount to 'human dignity' needs further consideration but goes beyond the remit of this paper. However, it is clear from the findings set out above that further guidance is required as to what is meant by 'some protection of human dignity'. [87] Further, there is a need for further research to establish whether a foetus feels pain, particularly, as at twenty-six weeks, very low birthweight infants show a clear and measurable flexion withdrawal reflex to noxious stimulation, suggesting that nociceptive perception to pain input to the spinal cord is present. [88] Consequently, it is reasonable to assume that such responses to pain would also occur in utero and as such, the issue as to whether a foetus feels pain needs addressing further.[89]

---

[83] ibid.
[84] BBC News, 'Abortion Causes Foetal Pain', *The BBC* (London, 29 August 2000) <http://news.bbc.co.uk/1/hi/health/900848.stm> accessed 19 April 2019.
[85] Scott (n 2).
[86] *Vo v France* (n 2).
[87] ibid.
[88] Derbyshire (n 73).
[89] ibid; Andrews and Fitzgerald (n 79).

7 Disabled children and social exclusion

One measure of social development is how society chooses to support and enhance the opportunities for all members of society, not just for those who are considered able-bodied.[90] It is reported by the Equality and Human Rights Commission that more disabled people than non-disabled are living in poverty or are materially deprived.[91] As a result, parents are often unable to buy specialist equipment, whether sensory, medical or educational.[92] Families with disabled children are often more socially isolated than other families, and a lack of money is one of the main causes.[93] Thus, parents are faced with many barriers including affordability and inaccessible facilities. Furthermore, Zaidi and Burchardt argue that the extra costs of a disability are substantial, with costs rising in line with the severity of the disability.[94] For families with children who have disabilities, the decision of one parent not to work may be more of a necessity than a choice.[95] It is evident that the monetary expenses associated with raising disabled children in terms of both out-of-pocket outlays and opportunity costs are significantly higher than those associated with raising non-disabled children.[96] Consequently, a disabled person's family will achieve a lower standard of living than a non-disabled person's family on the same level of income.[97]

---

[90] Shirley Porterfield, 'Work Choices of Mothers in Families with Children with Disabilities' (2002) 64(4) Journal of Marriage and Family 972.
[91] EHRC (n 53).
[92] Contact a Family, 'Counting the Costs 2012. The Financial Reality for Families with Disabled Children Across the UK' (*Contact a Family*, 2012) <https://contact.org.uk/media/381221/counting_the_costs_2012_full_report.pdf> accessed 23 March 2019.
[93] ibid.
[94] Asghar Zaidi and Tania Burchardt, 'Comparing Incomes when Needs Differ: Equivalization for the Extra Costs of Disability in the UK' (2005) 51(1) Review of Income and Wealth 89.
[95] Porterfield (n 91).
[96] ibid.
[97] Zaidi and Burchardt (n 95).

The prevalence of poverty and social exclusion experienced by disabled families can have consequent impacts on the decision of prospective mothers considering termination.[98] On this reasoning, prospective parents would be making a decision based on the society that they live in, not necessarily the intrinsic effects of impairment.[99] Arguably, society should be morally obliged to do more to remove discrimination and social barriers, thus supporting all members of society equally.[100] It is accepted that a woman should have the reproductive autonomy to terminate a pregnancy whatever her reasons, but she must also feel empowered *not* to terminate the foetus, and confident that society will do what it can to enable her and her child to live fulfilling lives.[101] However, Meakin argues that the interests of all parties concerned – not only those of 'the person the child may become', but also those of the parents, the family, the 'next child', and the community – are often considered.[102] Thus, it is argued that the decision to terminate a pregnancy often rests upon a utilitarian calculation taking all of these parties' interests into account.

There is also a consequential concern that discrimination against disabled people can be aggravated by this practice. Kate Greasley argues that the routine termination of disabled foetuses diminishes the quality of life of disabled persons by depleting their numbers.[103] Furthermore, she argues that with fewer disabled people in the world, the motivation to adapt the environment so as to counter the disadvantage experienced by disabled persons who do exist may be weaker.[104] For example, when the number of wheelchair-users is high,

[98] Porterfield (n 91).
[99] Shakespeare (n 45).
[100] ibid.
[101] ibid.
[102] Derek Meakin, 'Should the Baby Live? The Problem of Handicapped Infants – Book Review' (1986) 1(2) Disability, Handicap & Society 211; Helga Kuhse and Peter Singer, *Should the Baby Live? The Problem of Handicapped Infants* (OUP 1985) 3.
[103] Greasley (n 65).
[104] Meakin (n 103).

there is a greater incentive for the state, and others, to invest in the infrastructure that allows wheelchair access, such as ramps or disabled bathrooms, but less incentive when there are fewer wheelchair-users requiring such facilities.

Social barriers and financial implications, often result in prospective parents making a decision based on the society that they live in, rather than the intrinsic effects of impairment.[105] As Shakespeare argues, the fewer disabled people there are, the less need there is to adapt, or understand how society could be more inclusive.[106] Moreover, it is argued that by screening and terminating those with disabilities one may in fact be selecting against impairments that could be successfully alleviated with greater public support.[107]

8 Proposals for reform: advancements in genetic screening and the value of disabled life

For the disabled community, prenatal diagnosis followed by abortion is a social, moral, and political issue, not simply a health or medical one, as traditionally perceived.[108] The very existence of a test for foetal abnormality can create pressures to use the technology in order to reach an early diagnosis. Therefore, it is naïve to say that technology is neutral, because the possibility of obtaining prenatal genetic information inevitably creates new problems and dilemmas which did not previously exist. The implication is that testing, and subsequent selection are desirable advances.[109] Ward argues that:

> the 'effectiveness' of prenatal diagnosis is determined by health economists, via cost-benefit analysis which set the resources invested in screening against the savings that result, that is the

[105] Shakespeare (n 45).
[106] ibid.
[107] Rosamund Scott, 'Prenatal Testing, Reproductive Autonomy, and Disability Interests' (2005) 14(1) Cambridge Quarterly of Healthcare Ethics 65.
[108] Ward (n 7).
[109] Shakespeare (n 45).

savings to the State of the costs of supporting a disabled child.[110]

Thus, it is argued, that the State's interest in prenatal testing is not about women making an informed choice but about making a particular choice, namely to abort foetuses with severe impairments.[111] Scott supports this argument, and states that 'the routine nature of screening, can be interpreted as an overzealous attempt to eliminate disability'.[112] As a result, it is argued that the approach of science fails to distinguish between impairment (biological) and disability (social).

On this point, Shakespeare goes on to argue that 'far from valuing disabled people, our society currently views disabled people as an unnecessary social cost'.[113] Further, he states that 'foetuses with genetic abnormalities are terminated because society places no value on disabled lives, and because the social and economic costs of having an impairment in a disabling society are considerable'.[114] However, he concludes, 'the decisions underlying selective termination may often be about the social implications of bringing up a disabled child, not a eugenic unwillingness to bring disabled people into the world'.[115] Thus, advances in genetic knowledge and the huge proliferation of prenatal tests adds to concerns that genetic testing raises fundamental question about disabled people's right 'to be'.[116]

By way of example, if we consider individuals with Down's syndrome, it is argued that most of these individuals lead healthy lives.[117] However, Down's syndrome is one of the two most common conditions

---

[110] Ward (n 7).
[111] ibid.
[112] Scott (n 108).
[113] ibid; Shakespeare (n 45).
[114] Shakespeare (n 45) 679.
[115] ibid 672.
[116] Ward (n 7).
[117] Rebecca Reingold and Lawrence Gostin, 'Banning Abortion in Cases of Down Syndrome, Important Lessons for Advances in Genetic Diagnosis' (2018) Journal of the American Medical Association 319(23), 2375.

for which prenatal testing is offered. Given that people with Down's syndrome rarely suffer physical pain or distress as a direct result of their primary impairment (though they may have other conditions in addition), it is questionable as to whether the impairment should be described as 'serious'.[118] Thus, Ward argues that prenatal testing for Down's syndrome is more about preventing the 'suffering' (social or psychological) of others (e.g. parents), than of the individual directly affected.[119] Moreover, Marteau and Drake found that where women gave birth to children with Down's syndrome, having declined the opportunity to have prenatal screening, they were consequently more likely to be blamed for their situation.[120] Thus, the routine gestational screening for Down's syndrome is indicative of social expectations that a positive diagnosis should at least provoke a serious consideration about termination.[121]

We turn now to the screening for Down's syndrome and other syndromes. According to the NHS website, screening for Down's syndrome and other syndromes is offered between ten and fourteen weeks.[122] Amniocentesis is usually carried out between fifteen and twenty weeks of pregnancy, but may be later if necessary (though there is a lack of guidance on the meaning of necessity here).[123] An alternative to amniocentesis is a test called chorionic villus sampling, which may be carried out between the eleventh and fourteenth week of

---

[118] Ward (n 7).
[119] ibid.
[120] Theresa Marteau and Harriet Drake, 'Attributions for Disability: the Influence of Genetic Screening' (1995) 40 Social Science and Medicine 1127; Shakespeare (n 45).
[121] Greasley (n 65) 229.
[122] NHS, 'Your Pregnancy and Baby Guide, Screening Tests in Pregnancy' (*NHS*, 8 February 2018) <https://www.nhs.uk/conditions/pregnancy-and-baby/screening-tests-abnormality-pregnant/> accessed 13 March 2019. NHS, 'Screening For Down's Syndrome, Edwards' Syndrome And Patau's Syndrome' (*NHS*, 22 February 2018) <https://www.nhs.uk/conditions/pregnancy-and-baby/screening-amniocentesis-downs-syndrome/> accessed 10 May 2020.
[123] Amniocentesis is a screening test involving the removal of a small amount of amniotic fluid. NHS, 'Overview – Amniocentesis' (*NHS*, 21 April 2016) <https://www.nhs.uk/conditions/Amniocentesis/> accessed 13 March 2019.

pregnancy if there is an increased risk of genetic or chromosomal disorders.[124] A further detailed ultrasound scan, sometimes called the mid-pregnancy scan, is usually carried out between eighteen and twenty-one weeks and looks at the baby's bones, heart, brain, spinal cord, face, kidneys, and abdomen.[125] None of the timeframes set out by the NHS are post-twenty-four weeks. This raises the question as to why abortion on the grounds of disability are possible up to the point of birth if genetic testing appears to be complete by twenty-four weeks.

The question of time limit for the abortion of disabled foetuses was central to the proposals that were put forward by Lord Shinkwin in his Abortion (Disability Equality) Bill. Lord Shinkwin proposed that the time limit for the abortion of foetuses where there is a 'substantial risk' of 'serious handicap' should be brought into line with the time limit for non-disabled foetuses.[126] He justified this by stating that section 1(1)(d) of the Act creates a 'search and destroy' approach to screening, and questioned how this can be consistent with principles of equality.[127] Further, he argued, 'there is an inconsistency within the law, whereby discrimination on the grounds of disability is prohibited in law after birth, yet is enshrined in law at the very point at which the discrimination begins, before birth'.[128] Thus, he stated, 'laws governing disability discrimination and abortion are moving in conflicting and contradictory directions'. [129] Lord Shinkwin suggested that any abortions by reason of disability need to be carried out within the first

[124] Chorionic villus sampling is a screening test which requires a small sample of placental tissue cells. NHS, 'Chorionic Villus Sampling' (*NHS*, 20 July 2018) <https://www.nhs.uk/conditions/chorionic-villus-sampling-cvs/> accessed 10 May 2020.
[125] NHS, 'Your Pregnancy and Baby Guide, 20-week Anomaly Scan' (*NHS*, 6 March 2018) <https://www.nhs.uk/Conditions/pregnancy-and-baby/anomaly-scan-18-19-20-21-weeks-pregnant/> accessed 13 March 2019.
[126] Abortion Act, s 1(1)(d) Ground E; Abortion (Disability Equality) Bill [HL], 2016–17.
[127] HL (n 66).
[128] ibid.
[129] ibid.

twenty-four weeks, except when there is a risk of serious permanent damage to the mother or her life is at risk, in which case they will remain legally permissible until birth, and governed by section 1(1)(a) of the Abortion Act.[130] As set out above, genetic screening according to the NHS guidance seems to be complete by twenty-four weeks. Therefore, there appears to be no reason why abortion based on the grounds of disability should be allowed or is necessary over the twenty-four-week time limit.[131]

9 Conclusion

One of the main issues discussed in this paper is the lack of definition for the terms 'serious handicap' and 'substantial risk'.[132] This lack of guidance affords doctors wide discretionary powers, and potentially gives disproportionate weight to subjective medical notions of 'serious' and 'substantial'. Importantly, this broad definition allows the termination of foetuses with medical conditions such as cl/p, which are considered to be treatable.[133] This paper has determined that the lack of definition to the above-mentioned terms illustrates that the Abortion Act, section 1(1)(d) fails to reflect the changes in the law and medical advancements.[134] The terms 'substantial risk' and 'serious handicap' should be clearly defined, so as not to lead to the abortion of foetuses with conditions which in reality are not 'serious or substantial'.

The Equality Act fails to prohibit discrimination against the disabled foetus, despite protecting other characteristics such as race and sex, and despite the fact disability is a protected characteristic.[135] Therefore, this paper agrees with Lord Shinkwin's contention that the ability to abort a disabled foetus at any point in a pregnancy puts section 1(1)(d) at odds

[130] Abortion Act, s 1(1)(a)
[131] NHS (n 125).
[132] Abortion Act, s 1(1)(d).
[133] NHS (n 33).
[134] Abortion Act, s 1(1)(d); Equality Act; Human Rights Act 1998.
[135] Equality Act.

with more general developments in the equality agenda.[136] Furthermore, the lack of time limitations on section 1(1)(d) abortions seems at odds with with the fact that NHS genetic screening appears to be completed before twenty-four weeks' gestation. This paper concludes that, in line with the proposals put forward by Lord Shinkwin, the disabled foetus should be afforded the same legal protections as the non-disabled foetus. This can be achieved by bringing the twenty-four-week time limit for disabled foetuses in line with non-disabled foetuses, except when there is a risk of serious permanent damage to the mother or her life is at risk, in which case they will remain legally permissible until birth.[137] This would mean that the ability to abort over twenty-four weeks would be allowed only when there is risk of serious permanent damage to the mother or her life is at risk.

[136] HL (n 66).
[137] Abortion Act, s 1(1)(a).