

3 June 2020

Position Statement on:

Abortion on the Grounds of Disability

Abortion (medical termination of pregnancy) is not a criminal offence in the UK when continuance of the pregnancy is considered to involve greater risk of injury to the physical or mental health of the pregnant woman than if she did not have a pregnancy, and the pregnancy has not reached 24 weeks.¹ However, since the *Human Fertilisation and Embryology Act 1990*, it is permitted at any time up to birth 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.”²

The SCHB supports the significant drive in recent years to prevent discrimination against those with disabilities and finds that the present abortion law is discriminatory on two counts: First that disability is permitted as a reason for abortion. Second that the usual 24-week time limit for an abortion can be postponed until birth in the presence of disability.

1. Abortion on grounds of disability only is discriminatory.

Selection in abortion is not selection against a disability in a future person; it is selection between different persons. Most parents long to ensure the health of their children as far as possible. However, when parents select between children, they make a public, definite discriminatory choice. It is the possibility of ‘choosing’ between possible future children that is at the core of the problem. The act of discrimination betrays a person’s willingness to weigh the value and worth of one child’s life over another - a decision which reflects the moral values of the individual.

In other words, the determination of difference is crucial to the delivery of appropriate health care; some patients require escalation to intensive care environments with individualised nursing care, others will remain on the ward. Discrimination between patients seems important on clinical grounds but forbidden on individual or reserved characteristics such as race, sex or disability which are unfair. The resolution of this ethical dilemma hinges on whether termination of a pregnancy is determined on clinical grounds; that is in best interests of the mother or the child, or based on a reserved characteristic, in this instance disability.

Many would have legitimate concern if selection based on sex or race of the child took place. They believe that society should not abuse scientific procedures to promote prejudice on such grounds. Thus, persons with disability should be considered with the same respect as those who are non-disabled in a similar fashion to those of different gender or race.

In other words, the SCHB believes that any abortion decision based simply on the disability of the child is discriminatory on the grounds that a differential treatment has been given and the reason is unfair and unjustified.

2. It is impossible to eliminate a disability in abortion without also eliminating a person.

Advocates of selective abortion distinguish between the disability and the person with that disability. They suggest that a disability may be valued negatively, but the person with the disability may be valued positively. As a result, they believe there is no conflict of interest between attempts to eradicate a disability while helping those

¹ For a more developed discussion relating to abortion in general, see the Scottish Council on Human Bioethics Position Statement on Abortion in Scotland presented on its website.

² The *Human Fertilisation and Embryology Act 1990* amended the *Abortion Act 1967*. This stated in Section 1 (1)(d) is ‘that 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’.

who are affected by the same disability. However, the disability resides in the new life they wish to eradicate, so the separation is only imaginary/conceptual.

Observing the connection between disability and identity is essential, since many disabled people intuitively understand that children without disabilities are generally more desirable than children with disabilities.³ This may lead disabled individuals to perceive themselves as different not merely in their capabilities but also on the basis of who they are as persons.⁴

3. Disabled people may be distressed by de-selection abortion procedures.

The possibility of choosing reflects an individual's right to autonomy, but it also reflects this individual's moral value system. In turn, both the disabled and other people may wrongly assume that a certain amount of discrimination against the very existence of some disabled persons is acceptable. Thus, an important objection to reproductive selection relates to how people with disabilities may be indirectly affected by a societal acceptance of widespread selection.

Those with disabilities may sometimes consider themselves as less capable or even less valued than others because they may be unable to achieve an expected or desired performance or successful accomplishment in various fields.⁵ However, as disability rights advocates recognise, considerations such as these are inappropriate because they may reflect an unstated assumption that disability is unacceptable or that disabled people may be seen as inferior in some way.⁶

Selective abortion may exacerbate any feelings of inferiority that persons with disability experience.⁷ Since society already struggles to affirm the equal value and worth of people with disability, how much more difficult will it be when society grows accustomed to making sure persons with a disability are not allowed to be born?⁸

Societal pressure towards selective abortion may inadvertently reduce the impact of inherent and equal rights. Over time, as congenital disability becomes less common, economic factors may undermine the equality that disabled people should experience. The cost of caring for disabilities may increase as the demand for services decreases and a corresponding lack of attention to the needs for resources may arise. As selection procedures reduce the number of persons born with additional support needs may become increasingly marginalised. Selection may then undermine equality since the procedures may reinforce the view that the lives of those with a disability are undesirable and to be avoided.⁹

³ A. Fletcher. 2002. 'Making it Better: Disability and Genetic Choice', in *Designer Babies*, 21.

⁴ Over a generation ago P. Hunt edited a collection of essays that explored this very issue, 1966. *Stigma: The Experience of Disability*, London: G. Chapman. Although society is now far more positive towards disabled individuals, the basic insights of this book remain relevant today.

⁵ This is by no means a universal, and much of the literature in disability studies, as well as disability legislation, aims to counteract this. However, a strong case may be made that, on a personal level and uninformed by more academic perspectives, people with disability do indeed wrestle with feelings of inferiority and marginalisation.

⁶ This concern can be seen as arising from the eugenic programs in which people without desirable traits were degraded. For example, it is sometimes stated that a fetus *without* Down's syndrome is 'healthy', thus implying that a fetus with Down's syndrome would be unhealthy, R. Smith. 2010. 'Blood Test for Down's Syndrome', *The Telegraph*, 30 June. Retrieved 10 August 2011 from <http://tinyurl.com/telegraph-Down's-test>. Many fetuses and people living with Down's are healthy, even if they carry an extra 21st chromosome.

⁷ Individuals with Down syndrome who were consulted on the new NIPT test were 'saddened and expressed disappointment' when the decision was to terminate a pregnancy after a positive test result: https://www.nuffieldbioethics.org/wp-content/uploads/Barter_report_on_NIPT.pdf

⁸ One of the Change Champions (an ambassador against bullying) of Enable Scotland which is one of the country's main disability charities comments: *People at school have told me in the past that I shouldn't have been born, and of course that hurts. But, you can let it get to you and make you feel bad, or you can choose to stand up to it. It's not easy, but it's worth it.*⁸

⁹ German National Ethics Council. 2003. 'Position in favour of the retention and more precise specification of the ban on PGD' in *Opinion: Genetic diagnosis before and during pregnancy*, Berlin: Nationaler Ethikrat. 86.

4. De-selection of children on grounds of disability is eugenic.

Eugenic policies, intending to improve the human gene pool, were responsible for terrible atrocities in the 20th century. Using interventions such as forced sterilisation, Western countries sought to eliminate those who were perceived as having less value and worth. People with intellectual disability were often targeted which eventually led to the killing of tens of thousands of persons with disability by Nazi Germany.¹⁰ The SCHB agrees that prenatal screening for disability can be considered a form of contemporary eugenics, in that it devalues and prevents the births of people with a congenital condition.¹¹

5. Termination for seriously ill fetuses is foetal euthanasia.

Some may argue that in the face of very serious pathology, profound or painful disability it is in the best interests of the child not to be born. Thence late termination is justified to spare the child further distress or suffering. This is echoed in the legal cases where parents have claimed for 'wrongful life' which is an action brought on behalf of a severely disabled child, alleging that if they had been advised of the likely congenital disability ahead, they would have acted to terminate the pregnancy. They are stating that the child would have been better off not being born. This is clearly a form of discrimination based on disability since it suggests making sure the human life with a problem disappears in order to get rid of the problem. However, the SCHB believes that this would equate with intra uterine euthanasia, which is unacceptable since it is the deliberate taking of life with the intention of ending suffering.

6. Despite the difficulties, families may love and value a disabled child.

Most parents who have a disabled child with complex needs, who may be affected by a considerable amount of challenges or even a very short life, do not regret the very existence of the child.¹² Instead it is the possible suffering, not the child's very existence, that the parents wish to remove. Though devastated by any eventual suffering their child endures (and their own suffering in this regard) most parents remain grateful for the existence of their child who is extremely important to them. They would never choose to exchange this child for another, healthier child.¹³ Though perhaps obvious, the parents' desire to eliminate suffering in a child is grounded in an assumption that his or her life is inherently valuable and worthy.¹⁴ This is not to say that the parents welcome the child's suffering. However, as already emphasized, in philosophy and medicine it is important to differentiate between disabilities and the very existence of persons with those disabilities.

7. One child cannot be replaced by another since each is of inestimable and equal value and worth.

A utilitarian ethicist who wishes to bring the greatest happiness to the greatest number of people may argue that it is permissible to abort a child with a congenital condition in order that it may be replaced by one who is perceived as healthy.¹⁵ However, the SCHB would strongly challenge that one life can be taken in favour of another or the assumption that any life has less value and worth than another since such a perspective undermines the intrinsic value and worth of all persons. This is reflected in Article 1 of the UN Universal Declaration on Human Rights which states that: '*All human beings are born free and equal in dignity and rights.*'

¹⁰ <https://www.britannica.com/event/T4-Program>

¹¹ <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/stas1-1604.pdf>

¹² I. Knight. 2008. 'You Forgot about Love When It Comes to Down's Syndrome, Minette Marrin', *The Sunday Times*, 7 December. Retrieved 11 August 2011 from <http://tinyurl.com/SundayTimes-Down'ss-parents>.

¹³ C. MacKellar. 2011. 'Is Preconception Genetic Testing and Screening Eugenic?' *BioNews*, 18 April. Retrieved 2 June 2011, from http://www.bionews.org.uk/page_93163.asp.

¹⁴ Cases of euthanasia with children, however, do exist. A recent case involved an Australian couple suspected of euthanizing their daughter because they were reportedly unable to handle the condition. A. Dale. 2011. 'Rett Syndrome Girl's Dad "Asked about Euthanasia" before She Drowned', *Herald Sun*, 10 January. Retrieved 11 August 2011 from <http://tinyurl.com/MelbourneHeraldSun>.

¹⁵ Glover J *Causing Death and Saving Lives* (Penguin 1977) n23 at 146

Regardless of the complexity of a disability in a person and how much suffering he or she may experience, this person is of equal inherent worth and value to any other person without a disability.¹⁶ Any deviance from this axiom would be the demise of the principles enacted in the UN Declaration and, in turn, of contemporary civilized societies.

In other words, the value and worth of a human person (whether disabled or not) cannot be associated, in any way, to their perceived suffering or contentment. It also means that their inherent dignity is in an altogether different ethical dimension or category to how they feel or their experience of life.

8. Society should improve support for those with disability and their families.

The impact of a disability may be mitigated by a caring society. Everyone is embedded within a community which influences the wellbeing of its members. A more supportive approach to disability may decrease an individual's desire to pursue abortion.¹⁷ Physical conditions may be more bearable if supportive relationships undergird the disability.

The SCHB understands that disadvantages can exist related to disability which may not be the result of social discrimination; the disability itself may cause a limited function that a community cannot fully overturn but should endeavour to accommodate.

But it is possible to support families with children who have disabilities, including:

- An expansion of the role of Learning Disability liaison nurses;
- The availability of palliative (hospice) care which should be well funded and discussed with all parents whose children are facing imminent death;
- The availability of other solutions, such as adoption, for parents who have a disable child requiring long-term care (when they believe they can no longer cope).¹⁸

9. Abortion Law should be amended to take account of equality legislation with no distinction being made for disability.

The consideration of the welfare of the parents is often taken to be an indication for abortions for disability, as caring for a severely disabled infant would have significant impact on their lives. Indeed, there may be physical, social, emotional and psychological costs in bringing up a disabled child.

Many would see this as the best understanding of the disability clause in the original 1967 Abortion Act. This states that a person shall not be guilty of an offence under the law relating to abortion when a pregnancy is terminated by a registered practitioner if two registered medical practitioners are of the opinion, formed in good faith:

“(a) that the continuance of the pregnancy would involve risk to the life of the pregnant woman, or of injury to the physical or mental health of the pregnant woman or any existing children of her family, greater than if the pregnancy were terminated; or

(b) that 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.”

Therefore the special clause on disability of the child which exists in the 1967 Abortion Act seems unnecessary since, if the reason for termination is the burden it would place on the mother's mental health, then this would already be covered by section (a) of the Act. However, it seems Parliament was determined to frame the original 1967 Abortion Act with a particular provision on disability in mind, making the fact of disability in itself, a sole criterion for termination. This provision has been extended (by the *Human Fertilisation and Embryology Act 1990*) to allow termination up to term, for foetal disability.

¹⁶ It is interesting to note here that the aim of many a utilitarian commentator is the demise of the capacity to suffer in individuals. However, this would also imply the demise of any meaningful free will since all human beings would then be reduced to 'happy' automatons.

¹⁷ Human Genetics Commission, *Choosing the Future*, 23.

¹⁸ Parliamentary Inquiry into Abortion on Grounds of Disability <https://dontscreenusout.org/wp-content/uploads/2016/02/Abortion-and-Disability-Report-17-7-13.pdf>

Many cases of abortion for Down's Syndrome are not recorded on grounds of disability, but on grounds of maternal distress. This would seem to reflect an ethical difficulty for both doctors and families to record the reason for the abortion as the disability itself.

'Serious handicap' – the term used in the 1967 Abortion Act – is broad and open to interpretation ranging from cleft lip and palate (which can be corrected by surgery after birth) to anencephaly (failure of the brain to form at all, causing babies to be stillborn or die within a few hours or days).

There is therefore, in law, provision to abort an unborn baby solely on account of disability, rather than anything related to the distress to the pregnant woman. In one sense this is euthanasia (for conditions that are very serious such as anencephaly) which is unacceptable or discrimination against the right to life of disabled persons (for instance in the case of Down's Syndrome).

However, the SCHB would uphold the child as a person with full individual value and worth, meaning that euthanasia of a child, even for a fatal pathology, should not be acceptable.

Because abortions on the grounds of a disability have been shown by the above arguments to have clear discriminatory elements towards those affected by disability, these practices should not be taking place. Otherwise, equality protection becomes meaningless as society slowly eradicates the disabled by actively screening them out. It is difficult to understand the justification in maintaining such procedures when the *Equality Act 2010* prohibits discrimination on the grounds of disability.

Abortion on the Grounds of Disability

1. Definitions and general information

Abortion is the medical process of ending a pregnancy, so that it does not result in the birth of a baby. It is sometimes known as a termination of pregnancy. The pregnancy is ended either by taking medications which results in a miscarriage or having a surgical procedure to remove the unborn child.¹⁹

Disability: Defined by the *Equality Act 2010* as a physical or mental impairment that has a substantial and long-term negative effect on the ability of a person to do normal daily activities.^{20,21} Includes a wide range of conditions, such as long-term intellectual disability (for example: Down's Syndrome) and conditions such as anencephaly (failure to form the brain) which cause the baby to be stillborn or survive only a few hours or days after birth.

Discrimination on the basis of disability according to the 2006 *UN Convention on the Rights of Persons with Disabilities* means:

*[A]ny distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.*²²

Down's Syndrome a common cause of mild to moderate learning difficulties in the UK, caused by an extra copy of chromosome 21. It is associated with short stature and characteristic facial features. Some babies have other medical conditions such as heart defects.

Eugenics: strategies or decisions aimed at affecting, in a manner that is considered to be positive, the genetic heritage of a child, a community or humanity in general. This includes:

- Positive (or progressive) eugenics which reflect strategies or decisions aimed at promoting what is considered to be a desired genetic heritage in a child, a community or humanity in general.
- Negative (or preventive) eugenics which reflect strategies or decisions with the aim of avoiding or reducing what is considered to be an undesired genetic heritage in a child, a community or humanity in general.

Conception: The fertilization of an oocyte (egg) by a sperm to form a zygote which then develops for eight weeks as an embryo, in human beings, after which it is referred to as a foetus until birth.

¹⁹ <https://www.nhs.uk/conditions/abortion/>

²⁰ <http://www.legislation.gov.uk/ukpga/2010/15/contents>

²¹ Rights Campaign (ARC)²¹ suggested in Written Evidence to the Bruce Enquiry that: "It is more accurate to talk about abortion on grounds of foetal anomaly as the disability would not exist until the child were born." ²¹ But this can be contested.

²² United Nations. 2006. *Convention on the Rights of Persons with Disabilities*, Article 2. Retrieved 20 December 2011 from <http://www.un.org/disabilities/default.asp?id=150>.

Selection: In the context of reproduction can be defined as differentiating between those who are allowed to carry on their growth and development and those whose lives are terminated prematurely, due to certain characteristics. In other words, the attempt to choose one possible future child rather than a different possible future child.²³ Any selective action in abortion is not just a selection against a disability in a future person; rather, it is a choice between different persons.

Viability: Describes the earliest point at which the baby can continue to live outside the womb (born alive). Originally it was stated to be 28 weeks of pregnancy under the *Infant Life (Preservation) Act 1929* but with improvements of care of premature babies it was reduced to 24 weeks under the *Human Fertilisation and Embryology Act 1990*.

It has semantic and philosophical weaknesses since the foetus is certainly alive inside the womb. Moreover, whether the foetus can continue to live outside the womb varies depending on local technical expertise and the availability of resuscitation equipment. In addition, it may be the pregnancy itself that can be termed as viable, and not the foetus outside the womb.

Preimplantation genetic screening: For women with a higher chance of conceiving embryos with heritable anomalies, preimplantation genetic screening allows embryos created by IVF to be screened for a chromosomal anomaly before implantation into the mother's womb.

Pre-implantation genetic diagnosis allows embryos to be tested for a genetic disease usually because the parents are known to be carriers of a genetic disorder. This is usually possible only for single gene disabilities such as cystic fibrosis. Embryos without the specific genotype are then implanted. Pre-implantation genetic diagnosis offers an alternative for people who object to terminations on moral grounds but who may accept the destruction of embryos.

Non-invasive prenatal test (NIPT)

Current screening tests to determine the chance of conditions such as Down's Syndrome carry a risk of miscarriage. A new non-invasive pre-natal test (NIPT) has been developed which is perceived to be more reliable than existing prenatal tests with no risk of miscarriage (though an invasive preimplantation confirmatory diagnosis may still be necessary afterwards). NIPT is a maternal blood test that examines DNA that has crossed the placenta (the organ that is attached to the lining of the womb during pregnancy and provides a link between the baby and the mother).

2. Principles and Purpose

Abortion law under the amended *Abortion Act 1967* seems discriminatory on two counts: First that disability is permitted as a reason for abortion. Second that the usual 24-week time limit for an abortion can be postponed until birth in the presence of disability.

The principles can be expressed in the following two statements:

- Any discrimination on grounds of disability is wrong.
- Thus, abortion on grounds of disability is wrong.

However, differential treatment need not always be wrong. For example, a person may not be successful at a job interview as there is another candidate who is more qualified for the post. Discrimination is when the reason for the choice is wrong, such as to eliminate a candidate on basis of race or sex or disability.

The Disability Rights Commission (DRC) expressed it in this way relating to the *Abortion Act 1967*:

"The (Disability) Section is offensive to many people; it reinforces negative stereotypes of disability and there is substantial support for the view that to permit terminations at any point during a pregnancy on the ground of risk of disability, while time limits apply to other grounds set out in the Abortion Act, is incompatible with valuing disability and non-disability equally."

²³ Wilkinson, *Choosing Tomorrow's Children*, 2.

In common with a wide range of disability and other organisations, the DRC believes the context in which parents choose whether to have a child should be one in which disability and non-disability are valued equally.”²⁴

In this regard, Hans Reinders, who is Professor of Intellectual Disabilities in the Netherlands has described the rise of a ‘new eugenics’, which asserts that society can justify terminating the lives of those with disability. This is different from the ‘old eugenics’ as not generally motivated by aspirations of moral superiority but rather of minimising hardship. He also draws the distinction that the decisions around abortion are being made by families and not the state.

Elizabeth Schiltz, a mother of a child with Down’s Syndrome and an associate Professor of Law, grew up near Mönchberg village hospital, one of the six Nazi hospitals where children with disabilities were killed. She found that other people still questioned her decision to have her child with Down’s syndrome:

Though they do not ask aloud, you can see the question in their eyes: ‘If you knew, why did you have the baby?’ What’s buried in that question, what’s buried deep in their eyes as they ask it, is the perception of my son as ‘a choice’ – specifically, my choice – rather than as a unique human being, rather than as a fully-fledged member of the human race.

What I see in their eyes is the lingering shadow of Mönchberg. ... I worry that the joint availability of tests and abortion seems to be eroding societal consensus about our collective responsibility for vulnerable people – people with disabilities whose conditions were or could have been diagnosed prenatally...

The assumption seems to be that if you ‘choose’ to impose that cost on society by having a baby you could so easily have aborted, you should pay the price.²⁵

The English peer, Lord Shinkwin, has suggested that, because no time-limits are present relating to abortions for disabilities, this represents a form of legal discrimination towards persons with disability.²⁶ This is in line with the UN Committee on the Rights of Persons with Disabilities concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland:²⁷

- 1. The Committee is concerned about perceptions in society stigmatizing persons with disabilities as living a life of less value and the termination of pregnancy at any stage on the basis of foetal impairment.*
- 2. The Committee recommends that the State party changes abortion law accordingly. Women’s rights to reproductive and sexual autonomy should be respected without legalizing selective abortions on ground of child deficiency.*

Some foetal disabilities can cause stillbirth or may severely shorten life, but pre-natal children with congenital disabilities should be treated with the same respect as everyone else. Delivery should be timed, as far as possible, to optimise the survival of both mother and baby. Good palliative care as well as medical and surgical treatment, where appropriate, should always be provided.

This means that society should not only give disabled babies the same respect as those without disabilities, (whether inside or outside the womb), but should also help the mother find more compassionate and better alternatives to abortion. This should include the best medical and palliative care, the best social and emotional support as well as (where appropriate) assistance in letting the child be adopted.

²⁴ <http://www.bbc.co.uk/ethics/abortion/philosophical/disability.shtml>

²⁵ www.dailylife.com.au/life-and-love/parenting-and-families/why-i-kept-my-baby-after-finding-out-he-had-Down’s-syndrome-20140828-3ehgx.htm

²⁶ Because of this, he presented an *Abortion (Disability Equality Bill)*, 2016-2017 to the UK House of Lords but this has not been accepted.

²⁷ <https://mhj.org.uk/wp-content/uploads/sites/192/2017/09/Concluding-Observations-CRPD-Committee-UK.pdf>

3.History

Selective breeding in the human species was suggested as early as the Greek Philosopher Plato who thought that reproduction should be controlled by the state. But even before Plato, the ancient city of Sparta allegedly practiced a type of selection, leaving babies outside the city border to test them, with the weakest dying of exposure. However, under the growth of the main monotheistic faiths, practices such as infanticide and selection were generally rejected although many other injustices remained. But with the decline of these faiths and the discoveries in biology, the perception of 'biological quality' of human beings is now slowly re-emerging.

Eugenics was formed as a discipline in the 1860s where it was argued that society's intentions to protect the sick and weak was contravening Darwin's theory of natural selection and leading to social mediocrity. By the early 20th century, most European countries, the US, and Canada had considered or adopted eugenic policies. At the beginning of the 1920s, certain countries developed programs for the forced sterilisation of those deemed unfit to procreate.

Thus, even before the German dictator Adolf Hitler came to power, the ground had been prepared for eugenic ideas. From 1934-39 the Nazi regime sterilised up to 350,000 they thought mentally and physically 'unfit'. The regime also granted powers to euthanise 'those unworthy of life' including some 70,000 patients in psychiatric hospitals.²⁸

The breadth and power of these atrocities was notorious and revealed in the Nuremberg trials, a series of military tribunals which held Nazi war criminals accountable for their actions. The response of post-war politicians was to denounce any notion of inequality between human beings. Thus, the legislative bodies throughout the world sought to construct an ethical bulwark seeking to prevent any return of such abuse with the most noticeable contribution being the 1948 United Nations Declaration of Human Rights.²⁹

4. England and Wales Legislation and Case Law

4.1 Developments

The Infant Life (Preservation) Act 1929 in England and Wales and the original *Abortion Act 1967* did not include different time-limits between the termination of foetuses with a disability and any other foetuses. This only appeared in the *Human Fertilisation and Embryology Act 1990 (HFE Act 1990)* which enabled an abortion to take place until 24 weeks in all cases - but if the foetus was disabled an abortion could take place up to birth.

Medical termination of pregnancy is permitted by the *Abortion Act of 1967* as amended by the *HFE Act 1990*

(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 such physical or mental abnormalities as to be seriously handicapped.³⁰*

²⁸ Calum Mackellar and Christopher Bechtel (eds.), *The Ethics of the New Eugenics*, New York: Berghahn Books, 2014.

²⁹ Calum Mackellar and Christopher Bechtel (eds.), *The Ethics of the New Eugenics*, New York: Berghahn Books, 2014.

³⁰ http://www.legislation.gov.uk/ukpga/1967/87/pdfs/ukpga_19670087_en.pdf

Therefore, abortions are currently permitted at any time up to and including birth if there is a 'substantial risk' that the child might be born 'seriously handicapped'. The law does not define these criteria and they are broadly interpreted. There were 3,269 disability-selective abortions in 2018 in the UK.³¹

Personhood

In the UK, the child has no rights under current law and is not a legal person.³² In *Paton v the Trustees of the BPAS*, Sir George Baker stated: *'The child cannot, in English law, in my view, have any right of its own, at least until it is born and has a separate existence from the mother.'*³³ This, however, is a legal and not a philosophical definition.

Equality legislation (England and Wales)

The *Equality Act 2010* replaced most of the *Disability Discrimination Act 1995*, in seeking to streamline and strengthen anti-discrimination legislation in the UK. It includes the legal framework that protects disabled people from discrimination. The *Equality Act 2010* prohibits discrimination arising from a disability by preventing one person from treating another less favourably because of their disability.

In Section 15 (Direct Discrimination) of the *Equality Act 2010*, it is indicated that:

- (1) A person (A) discriminates against a disabled person (B) if—
 - (a) A treats B unfavourably because of something arising in consequence of B's disability, and
 - (b) A cannot show that the treatment is a proportionate means of achieving a legitimate aim.
- (2) Subsection (1) does not apply if A shows that A did not know, and could not reasonably have been expected to know, that B had the disability.

In Section 19 (Indirect Discrimination) it is indicated that:

- (1) A person (A) discriminates against a disabled person (B) if A applies to B a provision, criterion or practice which is discriminatory in relation to a disability of B's.
- (2) For the purposes of subsection (1), a provision, criterion or practice is discriminatory in relation to a disability of B's if—
 - (a) A applies, or would apply, it to persons with whom B does not share the disability,
 - (b) it puts, or would put, persons with whom B shares the disability at a particular disadvantage when compared with persons with whom B does not share it,
 - (c) it puts, or would put, B at that disadvantage, and
 - (d) A cannot show it to be a proportionate means of achieving a legitimate aim.

With regard to Section 19, the Explanatory Report of the *Equality Act 2010* indicates that indirect discrimination occurs when a policy which is applied in the same way for everybody has an affect which particularly disadvantages people with disability. Where a particular group is disadvantaged in this way, a person in that group is indirectly discriminated against, if he or she is put at that disadvantage, unless the person applying the policy can justify it.

³¹https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/808560/2018_Abortion_Statistics_-_Data_tables__1_.ods

³² Though a foetus does have the right to inherit. A foetus could even inherit the right to rule the UK as King or Queen.

³³ *Paton v the Trustees of the BPAS*[1979] QB276

Medical case law

In the case of *Re B (A minor) (Wardship: Medical Treatment)*³⁴ the courts held that it would be unlawful to withhold treatment to remove an obstruction in the gut from a child with Down's syndrome as there was no evidence that it was in the best interests of the child to die.

In the case of *McKay and another v Essex Health Authority* maternal rubella was not diagnosed by the doctor in Ms McKay and the resulting (disabled) child brought an action against a doctor. The claim was that the doctor should have detected the virus and given Ms McKay the option of terminating the pregnancy. The Court of Appeal held that there was no claim of wrongful life such that it could never be in someone's interests not to exist.³⁵

4.2 Present situation

Abortion (Disability) Bill 2015

Lord Shinkwin, himself disabled by brittle bone disease, introduced a private member's *Abortion (Disability) Bill* to the House of Lords in 2015 to ensure the 24-week time limit for abortion applied to all pregnancies, even those at high chance of disability. He noted that two babies with brittle bone disease had been aborted in the previous year after 24 weeks of pregnancy. To allow abortion up to full term purely on the grounds of disability establishes in law a pernicious threat to the lives of disabled people.³⁶ This was debated but did not pass through the House of Lords. The charity 'Disability Right UK' said:

*"Whatever time limit is set after which abortion should not happen, no distinction should be made between a child where the child will be born disabled and where the child will be born non-disabled. All lives are equal. We are deeply disappointed that this important Bill has not had the time it needs to be debated. We urge Government to rectify this."*³⁷

Abortion (Cleft Lip, Cleft Palate and Clubfoot) Bill 2020

In 2020, a proposed Bill to amend the *Abortion Act 1967* to exclude cleft lip, cleft palate and clubfoot as qualifying physical abnormalities for the purposes of medical termination of pregnancy was submitted to parliament by Fiona Bruce MP.³⁸

Abortion Survey

A 2017 *Abortion Survey ONLINE Fieldwork* asked the following question:³⁹

At present an unborn child with a disability can be aborted at any time during pregnancy, up to birth, whereas in most cases a healthy unborn child can only be aborted through to 24 weeks. Disability campaigners have described this differential in time limit as discriminatory. Would you support or oppose a change in law that would introduce an equal time limit for disability abortions of 24 weeks?

43% adults supported across UK (53% in Scotland)

30% adults opposed across UK (28% in Scotland)

25% adults did not know across UK (19% in Scotland)

³⁴ *Re B (A minor) (Wardship: Medical Treatment)* [1981] WLR 1421 (CA)

³⁵ <https://jme.bmj.com/content/medethics/13/2/69.full.pdf>

³⁶ www.throughtheroof.org Summary of Briefing statement Lord Shinkwin's Abortion Disability Bill

³⁷ <https://www.disabilityrightsuk.org/news/2017/january/dr-uk-welcomes-debate-abortion-and-disability>

³⁸ <https://services.parliament.uk/bills/2019-21/abortioncleftlipcleftpalateandclubfoot.html>

³⁹ <https://www.comresglobal.com/wp-content/uploads/2017/05/Where-Do-They-Stand-Abortion-Survey-Data-Tables.pdf>, Table 29 Q8.

5. Scotland Legislation and Case Law

5.1 Developments

The *Abortion Act 1967* indicated that without the permission of two doctors, abortion is illegal in Scotland and both the women and doctors may be prosecuted. (See above for England and Wales)

The *Human Fertilisation and Embryology Act 1990*⁴⁰ amended the *Abortion Act 1967* which applied to Scotland reducing the limit for abortion to 24 weeks but removed any time limit on abortion for foetal disability.

Therefore, abortions are currently permitted at any time up to and including birth if there is a 'substantial risk' that the child might be born 'seriously handicapped'. The law does not define these criteria and they are broadly interpreted.

Abortion was devolved to the Scottish Parliament as part of the *Scotland Act 2016* and campaigners have been calling for abortion to be regulated like any other healthcare procedure.

Equality legislation

As in England and Wales, the *Equality Act 2010* was enacted seeking to streamline and strengthen anti-discrimination legislation in the UK. It includes the legal framework that protects disabled people from discrimination. The *Equality Act 2010* prohibits discrimination arising from a disability by preventing one person from treating another less favourably because of their disability. This legislation is outlined in the above England and Wales Section.

5.2 Present situation

In 2018 there were 13,286 terminations in Scotland with 159 taking place because in the words of the *Human Fertilisation and Embryology Act 1990*, there was a "*substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped*".⁴¹

Abortions are not generally provided after 18 weeks in Scotland even though it is legal to do so. The report from Engender (Scotland's feminist policy and advocacy organization) noted: '*Scotland lags behind in provision of late term abortions. In 2013, 182 women had to travel to England to access safe, legal abortions.*'⁴²

It is interesting to ask why health care providers in Scotland are not prepared to terminate pregnancies after 18 weeks even when they are deemed legal. Is this really a case of 'lagging behind' but rather a clear decision by medical teams not to provide abortion after 18 weeks.

6. International

6.1 World Medical Association

The 2017 Declaration of Geneva⁴³ (modern Hippocratic Oath) states: "*I will maintain the utmost respect for human life.*" This has been amended from the 1948 version: "*I will maintain the utmost respect for human life from the time of conception.*"

The World Medical Association statement on termination of pregnancy⁴⁴ indicated in 2018 that: "*Any circumstance where the patient may be harmed by carrying the pregnancy to term presents a conflict between the life of the child and the health of the pregnant woman. Diverse responses to resolve this dilemma reflect the diverse cultural, legal, traditional, and regional standards of medical care throughout the world.*"

6.2 United Nations

⁴⁰ <http://www.legislation.gov.uk/ukpga/1990/37/section/37>

⁴¹ <https://www.isdscotland.org/Health-Topics/Sexual-Health/Publications/2019-05-28/2019-05-28-Terminations-2018-Report.pdf>

⁴² <https://www.engender.org.uk/content/publications/Our-bodies-our-choice---the-case-for-a-Scottish-approach-to-abortion.pdf>

⁴³ https://en.wikipedia.org/wiki/Declaration_of_Geneva

⁴⁴ <https://www.wma.net/policies-post/wma-declaration-on-therapeutic-abortion/>

UN Convention on the Rights of Persons with Disabilities

Guiding Principles of the Convention:⁴⁵

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Universal Declaration on the Human Genome and Human Rights (Adopted in 1997)

This stated in *Article 6* that:

"No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity."

6.3 Council of Europe (47 countries)

Conventions for the Protection of Human Rights and Fundamental Freedoms (CETS No 005 Entered into force in 1953)

This indicated in *Article 14-Prohibition of Discrimination* that:

"The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status."

Convention for the protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (CETS- No 164, entered into force in 1999)

This stated in *Article 11 Non-discrimination* that:

"Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited."

6.4 European Union (28 countries)

Charter of Fundamental Rights of the European Union (Proclaimed in Nice in 2000)

This explained in *Article 3- Right to Integrity of the person* that:

"In the fields of medicine and biology, the following must be respected in particular ... the prohibition of eugenic practices, in particular those aiming at the selection of persons".

6.5 Other countries

⁴⁵ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

United States

In the case of *Box v. Planned Parenthood of Indiana and Kentucky Inc.*, (2019), a United States Supreme Court case dealt with the constitutionality of a 2016 anti-abortion law passed in the state of Indiana. Indeed, Indiana's law sought to ban abortions performed solely on the basis of the fetus' gender, race, ethnicity, or disabilities. Judge Clarence Thomas turned down the appeal by planned parenthood. In his judgement he stated that: *This law ... promote a state's compelling interest in preventing abortion from becoming a tool of modern-day eugenics*⁴⁶

Iceland

With a population of around 330,000, Iceland has on average between 2 and 3 children born with Down syndrome per year, sometimes after their parents received inaccurate test results.

⁴⁶ <https://edition.cnn.com/2019/05/28/politics/clarence-thomas-eugenics-abortion/index.html>