



UPR Submission: Disability Discrimination in Abortion

Introduction

1. We are a group of over 17,000 people with Down's syndrome, their families and supporters who are actively working to build a United Kingdom (UK) where people with Down's syndrome are equally valued and have an equal chance of being born. Currently around 90% of babies found to have Down's syndrome in the UK are aborted. This alarmingly high percentage is as a result of discriminatory legislation, policies and practice – as well as wider cultural attitudes towards life with Down's syndrome.
2. This report draws attention to the United Kingdom's (UK) shortcomings in protecting the right to life and affirming the dignity of persons with disabilities.

(a) Disability Discrimination

3. In the UK, the Equality Act 2010 explicitly protects the rights of persons with disabilities against direct and indirect discrimination, harassment, or victimisation. Under the law, it is unlawful to treat a person with disabilities differently to another person on the basis of this characteristic.¹ Employers and organisations are moreover under a legal duty to make reasonable adjustments so that persons with disabilities can access jobs, education and services to the same degree as non-disabled persons. A failure to comply with this duty amounts to discrimination under the law.²
4. In 2021, Dr Liam Fox MP introduced a Private Members' Bill to Parliament to introduce guidance for local authorities to better meet the needs³ of persons with Down's syndrome in the exercise of their relevant functions. This Bill raises attention to the specific and additional needs of persons with this category of disability across the UK.⁴
5. Article 10 of the Convention on Persons with Disabilities (CRPD), to which the United Kingdom is also a State Party, safeguards persons against discrimination on the basis

¹ Section 6 of the Equality Act 2010

² Id. section 20-21

³ Section 6 of the Equality Act 2010

⁴ Down Syndrome Bill 17 2021-22



of disability by stating, “States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.”⁵ Article 5(2) says, “States Parties shall prohibit all discrimination on the basis of disability.”⁶

6. Article 25 of the CRPD specifies that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.” Article 17 provides the right to respect for physical and mental integrity. Article 26 requires that those with disabilities be provided “comprehensive habilitation and rehabilitation services and programmes, particularly in the [area] of health....”. They are to be afforded “full inclusion and participation in all aspects of life.”⁷

(b) The Right to Life

Background

7. In England and Wales, abortion is a criminal offence carrying a maximum sentence of life imprisonment,⁸ unless two registered medical practitioners, in good faith, are of the opinion that an abortion can be legally performed for the reasons set out in the Abortion Act 1967. This includes 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. ...”⁹

8. The upper time limit for abortions is set at 24 weeks except in certain health-related risk situations for the mother and where the child would have a ‘severe disability’, where abortions are permitted in law up to birth (40 weeks).¹⁰ In 2020, 236 abortions were performed in England and Wales over 24 weeks’ gestation.¹¹
9. Abortions performed after 24 weeks involve a potassium chloride injection to the unborn baby’s heart to stop the heartbeat and then a medical induction after 48 hours to deliver

⁵ Convention on the Rights of Persons with Disabilities (CRPD), opened for signature on Dec. 13, 2006, 2515 U.N.T.S. 3, art. 10.

⁶ Id. art. 5(2).

⁷ Id., art 25, 17, 26.

⁸ Sections 58 and 59 of the Offences Against the Person Act 1861

⁹ Section 1(1)(d) of the Abortion Act 1967

¹⁰ Section 37 of the Human Fertilisation and Embryology Act 1990

¹¹ Table 5, National Abortion statistics, England and Wales: 2020, Department of Health and Social Care, Updated 1 October 2021



the baby. Live births have been reported following 2.2% of late term abortions.¹²

10. There is no definition of 'substantial risk' in law, so medical guidance rests the decision upon the professional judgement of the clinicians made in 'good faith'; this includes but is not limited to the nature and severity of the unborn child's condition, the timing of the diagnosis, and the likelihood of the event. 'Serious handicap' is also not defined by law, and the guidance defines it as a "physical or mental disability which would cause significant suffering or long-term impairment of their ability to function in society".
11. In practice, the interpretation of the law of permitting abortions after 24 weeks' gestation by the Crown Prosecution Service has allowed the definitions to include unborn children with bilateral cleft lips and palates. In Jepson (2003), the Chief Crown Prosecutor said the doctors believed, in good faith, that there was a substantial risk that the child would be 'seriously handicapped' due to these conditions, and therefore that abortion was permissible under the law.¹³
12. As part of the National Health Service (NHS) screening pathway for Down's syndrome, Edwards syndrome and Patau syndrome, most maternity providers across England offer noninvasive prenatal testing (NIPT) as an option in pregnancy following the existing pregnancy screening tests. A prenatal diagnosis will be required if a woman wishes to receive a definitive diagnosis of an anomaly following the NIPT result.
13. In 2020, the total number of abortions due to 'severe disability' was reported as 3,083.¹⁴ Prenatal testing has reduced the number of babies born with Down syndrome in Europe by half¹⁵. It is estimated that approximately 90% of pregnancies where a mother is expecting a child with Down's syndrome are aborted.¹⁶
14. Doctors have to submit data on the number and categories of abortions¹⁷ and the Department of Health annually publishes data on all abortions. However, concerns have

¹² Draper E, Alfirevic Z, Stacey F, Hennessy E, Costeloe K, for the EPICure Study Group. An investigation into the reporting and management of late terminations of pregnancy (between 22+0 and 26+6 weeks of gestation) within NHS Hospitals in England in 2006: the EPICure preterm cohort study. BJOG 2012;119:710–715.

¹³ Jepson v Chief Constable of West Mercia Police [2003] EWHC 3318 (Admin)

¹⁴ Table 9a, National Abortion statistics, England and Wales: 2020, Department of Health and Social Care, Updated 1 October 2021

¹⁵ <https://www.massgeneral.org/news/press-release/Prenatal-testing-has-reduced-the-number-of-babies-born-with-down-syndrome-in-europe-by-half>

¹⁶ The National Down Syndrome Cytogenetic Register for England and Wales 2010 Annual Report. Queen Mary University of London, Barts and The London School of Medicine and Dentistry 2011 and Professor Joan Morris, Oral Evidence Session 4, pages 82-3, Parliamentary Inquiry into Abortion on the Grounds of Disability (2013)

¹⁷ Form HSA4



been raised in Parliament in previous years about the reporting and transparency of decision-making related to abortions on the grounds of disability after 24 weeks' gestation. During the Parliamentary Inquiry on Disability Abortion in 2013, witnesses claimed that there were discrepancies between the statistics on late term abortions and the numbers of reported abortions that remained unaccounted for.¹⁸ This was confirmed by the Government in 2014.¹⁹ This could mean that the number of abortions on the grounds of "serious handicap" could be much higher than reported.

15. According to a Parliamentary report from 2013, the vast majority of people who provided written evidence believed that allowing abortion up to birth on the grounds of disability was discriminatory.²⁰

The Right to Life in International Law

16. Article 6 of the International Covenant on Civil and Political Rights (ICCPR), to which the UK is a State Party, provides, "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life."²¹ The protection of unborn life is also found through an ordinary reading of the language in the preamble of the Convention on the Rights of the Child (CRC), to which the UK has ratified. The CRC explicitly recognises the child before birth as a rights-bearing person entitled to special needs and protection. The preamble states, "[T]he child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth."²²
17. Article 1 of the CRC defines a child as "every human being below the age of eighteen years." This provides an upper limit as to who is a child, but does not provide a lower limit on when the status of "child" attaches. Moreover, Article 6 of the CRC holds, "States Parties recognize that every child has the inherent right to life. States Parties shall ensure to the maximum extent possible the survival and development of the child." Viewed in the context of the preamble, both Articles 1 and 6 of the CRC indicate recognition and protection of unborn life.

¹⁸ One witness stated "approximately 53% of TOPs recorded by EPICure2 are presented in DH abortion statistics for NHS hospitals" and that "substantial differences in the numbers of reported [abortions] remain unaccounted for." Para.40 of the Parliamentary Inquiry into Abortion on the Grounds of Disability (2013)

¹⁹ <https://www.gov.uk/government/publications/under-reporting-of-abortions-for-fetal-abnormalities>

²⁰ Summary of findings

²¹ ICCPR, art. 6.

²² Convention on the Rights of the Child (CRC), opened for signature Nov. 20, 1989, 1577 U.N.T.S. 3, art. 1 & 6.



18. The UN Committee on the Rights of Persons with Disabilities has criticized countries which distinguish abortion on the basis of disability²³ and has recommended that Great Britain and Northern Ireland amend abortion legislation to affirm that abortion should not be legal on the ground of foetal deficiency.²⁴
19. As supplemental information, Article 2 of the European Convention on Human Rights (ECHR) states, “everyone’s right to life shall be protected by law”. As to the question of when life begins, the European Court of Human Rights has ruled that the matter is to be left within a Member States’ margin of appreciation;²⁵ this is particularly the case in light of the “acute sensitivity of the moral and ethical issues raised by the question of abortion” and the “public interest at stake.”²⁶

(c) UK legal challenges

20. In *Re Northern Ireland Human Rights Commission’s Application for Judicial Review* [2018],²⁷ the Supreme Court considered whether sections 58 and 59 of the Offences Against the Person Act 1861 and section 25(1) of the Criminal Justice Act (NI) 1945, which criminalised abortion in Northern Ireland apart from to preserve the life of the mother or some limited exceptions²⁸, were compatible with the ECHR. The Commissioner cited the reason of serious malformation of the foetus as one of three reasons for incompatibility. The majority of judges held that the Commission did not have standing to bring the judicial review proceedings; a procedural issue. Nonetheless, the court also engaged in non-binding observations on the scope of protections for unborn life.
21. While the justices held an array of viewpoints between them, a non-binding majority of the judges noted that they would have found the law in Northern Ireland to be disproportionate and incompatible with Article 8 of the ECHR in so far as it criminalized abortion in the case of fatal foetal abnormality if the Commission had standing. However, all seven justices unanimously decided that there would be no incompatibility

²³ Convention on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities, Consideration of reports submitted by States parties under article 35 of the Convention, sixth session, 19-23 September 2011, CRPD/C/ESP/CO/1

²⁴ Convention on the Rights of Persons with Disabilities, Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, 3 October 2017, CRPD/C/GBR/CO/1

²⁵ *Vo v France* (2005) 40 EHRR 12

²⁶ *A, B and C v Ireland* (2011) 53 EHRR 13, para.233

²⁷ *Re Northern Ireland Human Rights Commission’s Application for Judicial Review* [2018] UKSC 27; [2019] 1 All ER 173

²⁸ *R v Bourne* [1939] 1 KB 687, where the continuance of the pregnancy will make the woman a physical or mental wreck



with the ECHR where abortion was prohibited for the reason of ‘serious foetal abnormality’ or ‘serious malformation’ of the foetus. The justices concluded that a child with a disability should be treated as having equal worth in human terms as a child who does not have a disability.²⁹

22. In the case, Lord Kerr provided some important obiter comments regarding ‘serious malformation of the foetus’ and abortion:

“many children born with disabilities, even grave disabilities, lead happy, fulfilled lives. In many instances they enrich and bring joy to their families and those who come into contact with them... the difficulty in devising a confident and reliable definition of serious malformation is a potent factor against the finding of incompatibility. For these and the other reasons given by the judge, I would refuse to make a declaration of incompatibility [with the ECHR]...”³⁰

23. In September 2021, the High Court handed down a ruling in *Crowter & Ors* on whether section 1(1)(d) of the Abortion Act 1967 was incompatible with section 4 of the Human Rights Act (HRA). The Claimants had contended that law on disability abortion was incompatible with Articles 2, 3, 8 and 14 of the ECHR and that it was impermissible to differentiate between pregnancies with a substantial risk of the child being “seriously handicapped” when born, and those where it would not. The specific focus of the case was Down’s syndrome, and the lawyers for the Claimants highlighted the reality that the foetus’ life is considered viable outside the womb after week 24 of gestation. This is particularly pertinent in light of medical advancements since the assent of the Abortion Act (1967).³¹

24. The judges, Lord Justice Singh and Mrs Justice Lieven, acknowledged that the Royal College of Obstetricians and Gynecologists’ guidance noted that the timing of the disability was an issue unresolved by the law. Namely, whether the two situations of a disability that could be resolved by surgical treatment and a disability that was only likely to develop later on in life.³²

25. The judges rejected the claim and concluded that it needed to be for Parliament to change the law and for the courts to provide a safeguard against unjustifiable

²⁹ Re Northern Ireland Human Rights Commission’s Application for Judicial Review [2018] UKSC 27; [2019] 1 All ER 173, paras. 31, 133, and 331

³⁰ Id. para.332

³¹ R (*Crowter and Ors*) v Secretary of State for Health and Social Care [2021] EWHC 2536 (Admin) para. 119

³² Id. para.19



discrimination.³³ It rejected the grounds of the challenge and decided not to rely on the comments of the Committee on the Rights of Persons with Disabilities.³⁴ As regards to Article 14 of the ECHR, the court ruled that no other Convention rights were breached. Regardless, and following on from the Supreme Court's precedent in another case,³⁵ Justices Singh and Lieven ruled that the difference of treatment in law between the interests of the foetus and mother in section 1(1)(d) of the Abortion Act fell within the margin of discretion afforded to Parliament.³⁶

26. The judgment in *Crowter* made it clear that without Parliament taking steps to define “serious handicap”, judicial intervention to protect foetuses with Down’s syndrome against abortion up to term was not likely to be forthcoming.

(d) Recommendations

27. In light of the aforementioned, the signatories suggest the following recommendations be made to the United Kingdom:
- a. Recognize and honour the international obligations to protect the right to life from for all persons, regardless of disability or other status;
 - b. Affirm the dignity of all persons, including those with disabilities, by raising awareness on the need to reverse the trend of near eradication of persons born with Down’s syndrome, Patau Syndrome, and Edwards Syndrome;
 - c. Review the Abortion Act 1967 and reduce the elements which are discriminatory to ensure non-discrimination against persons with disabilities in accordance with international obligations, specifically removal of Section (1)(d) which allows for abortion to take place through to birth specifically on the grounds that a baby has a disability.
 - d.
 - e. Increase transparency and accountability of medical decision-making and reporting in cases of fetal disability;
 - f. Take immediate and effective steps to combat discrimination against persons with disabilities, particularly those with disabilities, and strengthen public awareness campaigns to uphold their rights and provide comprehensive support

³³ Id. para.64

³⁴ Id. para. 106

³⁵ R (SC) v Secretary of State for Work and Pensions [2021] UKSC 26; [2021] 3 WLR 428

³⁶ Id.19, para.144



and assistance to concerned persons and their families.