**Submission in Response to the Questionnaire of the Special Rapporteur on the rights of persons with disabilities concerning the right of persons with disabilities to the highest attainable standard of health**

Christian Action Research & Education (CARE) is a well-established Christian social policy charity providing resources and helping to bring Christian insight and experience to matters of public policy and practical caring initiatives.

CARE welcomes the Special Rapporteur’s inquiry into the right of persons with disabilities to the highest attainable standard of health.

CARE is concerned that despite the Convention on the Rights of Persons with Disabilities (the Convention) being ratified or acceded to by 174 countries worldwide, the rights of disabled persons are not fully recognized or adequately implemented leading to the exclusion and segregation of persons with disabilities. Article 25 of the Convention, which requires state parties to ‘recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability,’ is not always taken seriously.

Furthermore, as emphasized in the Preamble of the Convention, States must recognize the ‘inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world.’ CARE believes that a failure to recognize this inherent dignity, worth, and equality prevents persons with disabilities from enjoying their human rights fully or at all, including the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

Unfortunately, laws denying or adversely affecting the right to health of persons with disabilities are still in existence and continue to be introduced, even in countries that have a reputation for protecting human rights.

CARE’s submission focuses on the existing law in the United Kingdom, a new law that is being considered by the Isle of Man, and comments upon the international developments that will adversely affect the right of persons with disabilities.

Some of the challenges faced by persons with disabilities in the UK will be familiar to the Special Rapporteur. The Committee on the Rights of Persons with Disabilities identified in its concluding observations on the initial report on the United Kingdom, (CRPD/C/GBR/CO/1, 3 October 2017) several failings and insufficiencies in the UK’s implementation of the Convention and in applying the human rights model of disability. The Committee directly referred to the disability selective abortion provision enshrined in the Abortion Act 1967.

***Abortion Act 1967***

According to the Abortion Act 1967, abortion is generally allowed until 24th week of pregnancy and in certain cases after the 24 weeks limit, for example, when there is a threat to the life or health of the pregnant woman or when the unborn child suffers from ‘such physical or mental abnormalities as to be seriously handicapped.’ While allowing abortion when the life or health of the pregnant woman is threatened is not discriminatory, allowing abortion on the basis of the disabilities of the unborn child is clearly discriminatory. According to the current law, after the 24th week, an unborn disabled child can be aborted because of their disability, while an unborn child without a disability will be protected by the law such that any attempt to abort them would trigger a criminal sanction.

It must be emphasized that at the time it was debated and adopted the case for law allowing disability-selective late-term abortion was supported by discriminatory arguments that cannot exist in the 21st century. More importantly, the Abortion Act 1967 pre-dates the Equality Act 2010 prohibiting discrimination on grounds of disability. With the Equality Act 2010, the Abortion Act 1967 should have been amended to ensure that the disability-selective late-term abortion provision was removed. However, years after the introduction of the Equality Act 2010 the provision for the disability-selective late-term abortion is still in place.

In the Committee on the Rights of Persons with Disabilities’ ‘List of issues in relation to the initial report of the United Kingdom of Great Britain and Northern Ireland’ dated 20 April 2017, the Committee requested information from the UK government on the ‘measures taken to prevent discrimination on the basis of potential impairment as regards termination of pregnancy’ in accordance with Article 5 obligations.

In a document dated 21 July 2017, the UK responded to the list of issues stating that: ‘the UKG’s abortion policy, in relation to disability, only differs from standard practice where “serious” foetal impairment is identified to allow abortion without time-limit. Serious impairment is not defined in law; these decisions are made using the expert judgement of two doctors in consultation with the parents, who receive information and support from a properly trained multidisciplinary team.’ The UK government failed to address the discriminatory nature of the provision and only provided a clarification on when it is applied. However, even this explanation of the scope of the provision is misleading as it does not show the extent of the problem of targeting persons with disabilities.

In the Committee’s concluding observations, document dated 3 October 2017, the Committee recommended the UK to:

‘amend its abortion law accordingly. Women’s rights to reproductive and sexual autonomy should be respected without legalizing selective abortion on the ground of fetal deficiency.’

The Committee said that it was ‘concerned about perceptions in society that stigmatize persons with disabilities as living a life of less value than that of others and about the termination of pregnancy at any stage on the basis of fetal impairment.’ CARE fully supports the Committee’s conclusion and recommendation and hopes that the UK Government will be willing to engage in a dialogue on the issue.

To address this discriminatory provision, Lord Shinkwin proposed a bill to remove it from the Abortion Act 1967. His Abortion (Disability Equality) Bill [HL] aims to accommodate the provision for disability equality and for the provision of balanced information in respect of abortions. The bill had its first reading on 11 July 2017 and currently awaits its second reading.

While it is commendable that an individual parliamentarian, a life-long disability campaigner, should have introduced such a Bill, two things must be acknowledged:

First, as a non-government, ‘Private Members Bill’ it is unlikely to progress very far and may indeed never be debated.

Second, while Lord Shinkwin is doing the right thing, the Government is moving in the diametrically opposite direction:

In the first instance, the Government is currently considering the introduction of NIPT (non-invasive prenatal testing) into the NHS Fetal Anomaly Screening Program. If implemented, the testing would affect the process of identifying disabilities prenatally, mainstreaming discrimination against persons with disabilities, especially persons with Down’s syndrome.[[1]](#footnote-2)

In the second instance, the UK government has recently intervened in relation to the draft General Comment No. 36, supporting the content of a draft that discriminates against persons with disabilities. The UK government supported the very broad interpretation of the provision of abortion and indicated no concerns about the provision of disability-selective late-term abortion that is accommodated in the Abortion Act 1967.

CARE is very concerned that the discriminatory provision enshrined in the Abortion Act 1967 has a wider impact than unborn disabled children. In affording able bodied unborn foetuses stronger legal protections than disabled foetuses, this arrangement sends out the clear message that the able bodied are of greater importance, and thus worthy of greater protection, than the disabled. This cannot but impact the way society views the able bodied and disabled after birth. In a society where such a provision is law, there is little hope that persons with disabilities can enjoy full and equal rights with others.

As emphasized by the Committee in its response to the draft General Comment on Article 5, any such laws (customs or practices) must be modified or abolished. Apart from ensuring that the law does not contain any provisions accommodating discrimination of persons with disabilities, states must also take steps to ensure *de facto* equality of persons with disabilities. This may include introducing provisions and policies that would help to combat stereotypes, stigmatization or discrimination of persons with disabilities.

CARE fully supports the Committee’s recommendations for the UK to ‘amend its abortion law accordingly. Women’s rights to reproductive and sexual autonomy should be respected without legalizing selective abortion on the ground of fetal deficiency.’

***Abortion Reform Bill 2018 in the Isle of Man***

The lower house of the Isle of Man Parliament, the House of Keys, is currently considering the Abortion Reform Bill 2018, a bill that aims to liberalise the provision of abortion on the Isle of Man. The bill has passed its Second Reading and proceeded to its Clauses Stage where it is now being scrutinized.

As it stands, the bill contains provisions that discriminate against persons with disability as it proposes a very significant extension of the basis for abortion after 24 weeks in cases of disability when this does not apply to able bodied babies from 24 weeks.

The current law allows for abortions with disabilities which are not life-limiting (e.g. Down’s Syndrome) up to 24 weeks and up to birth for circumstances where there is ‘substantial risk’ that the child is unlikely to survive birth or die shortly after. CARE has been campaigning for there to be an ‘equal’ time limit for abortions regardless of whether an unborn child has a disability or not (i.e. neither the current situation in the 1995 Act nor that proposed in the new Bill as published).

As it stands, the bill proposes to legalize disability selective abortion on a far wider basis than is currently permitted. If it is allowed to become law, the bill will not only facilitate much wider discrimination against unborn, disabled babies. It will further normalise the wider message that the disabled are worthy of less protection which cannot but have an adverse effect on the perception of disabled persons in general.

***International Law***

CARE is very concerned that some discriminatory provisions directed against disabled persons seem likely to be incorporated into international law by way of the recent draft of the Human Rights Committee’s General Comment No. 36. Paragraphs 9 and 10 of the draft General Comment No. 36 contain an interpretation of the right to life that is discriminatory against persons with disabilities, ultimately denying the right to life of persons with disabilities on grounds of their disabilities. Such a selective reading of the right is highly controversial as it accommodates and normalizes discrimination against persons with disabilities. Such interpretation is further contrary to Article 5 of the CRPD.

**Paragraph 9 of the draft General Comment No. 36**

‘States parties must provide safe access to abortion to protect the life and health of pregnant women, and in situations in which carrying a pregnancy to term would cause the woman substantial pain or suffering, most notably where the pregnancy is the result of rape or incest or when the foetus suffers from fatal impairment.’

CARE is very concerned that this recommendation neglects the States’ obligation to care for persons with disabilities and imposes an obligation to provide abortion instead. This interpretation opens the door to discriminatory provisions, allowing abortion on grounds of disability (while abortion of persons without disabilities continues to be prohibited, apart from a limited number of scenarios, for example, when the mother’s life is in danger).

CARE stresses the need for States to protect the rights of disabled children and protect them from discrimination, especially, from discriminatory legal provisions.

**Paragraph 10 of the** **draft General Comment No. 36**

‘States parties [may allow] [should not prevent] medical professionals to provide medical treatment or the medical means in order to facilitate the termination of life of [catastrophically] afflicted adults, such as the mortally wounded or terminally ill, who experience severe physical or mental pain and suffering and wish to die with dignity.’

CARE is deeply concerned that the draft General Comment No. 36 recommends the provision of assisted suicide and euthanasia in that this may be discriminatorily used against persons with disabilities resulting from being terminally ill or mortally wounded. Assisted suicide and euthanasia differentiate between life worthy of protection and life unworthy of protection based on physical or mental characteristics accommodating discrimination based on this differentiation. The life that is designated as unworthy of protection by way of such differentiation includes the lives of disabled people.

Similarly, the recommendation accommodating the termination of the life of disabled persons is discriminatory in that it devalues the life of disabled persons and presents the protection of the right to life as conditional upon the well-being of persons which can be understood as not including those with disabilities. Again, such understanding of the right to life discriminates against persons with disabilities and prevents persons with disabilities from ever gaining equality in society.

CARE stresses the need to amend the recommendation to focus on assisting persons with disabilities to live, not to die. CARE further emphasizes the need to respect state sovereignty. For example, the UK recently debated the issue at length and voted overwhelmingly against assisted suicide. Their decision must be respected.

Paragraph 10 of the draft General Comment No. 36 continues:

'In such [i.e. assisted suicide] cases, States parties must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and, unambiguous decision of their patients, with a view to protecting patients from pressure and abuse.’

The recommendation for the introduction of safeguards in the provision of assisted suicide and euthanasia is detached from empirical reality. The empirical data indicates that once assisted suicide or euthanasia are legalised, any safeguards introduced to protect individuals, or limit the use of assisted suicide, tend to become redundant or irrelevant.[[2]](#footnote-3) In both the Netherlands and Belgium, despite the fact that the law aimed to regulate the practice of euthanasia to prevent abuse of the procedure, this aim has not been achieved.[[3]](#footnote-4) Despite the fact that the use of assisted suicide or euthanasia was meant for cases of incurable illnesses or excruciating pain and suffering, deaths under the law have included individuals who do not fit these criteria, and which include those with disabilities.[[4]](#footnote-5)

**Paragraph 64 of the draft General Comment No. 36**

‘The right to life must be respected and ensured without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or any other status, including caste, sexual orientation and gender identity, disability albinism and age. Legal protections for the right to life must apply equally to all individuals and provide them with effective guarantees against all forms of discrimination. Any deprivation of life based on discrimination in law or fact is ipso facto arbitrary in nature. Femicide, which constitutes an extreme form of gender-based violence that is directed against girls and women, is a particularly grave form of assault on the right to life.’

CARE commends the explicit prohibition of discrimination concerning the right to life. CARE agrees that the right to life of all, irrespective of disability, must be protected by States and the protection must be applied equally. However, CARE notes that this provision is contradicted in the body of the draft General Comment No. 36 in paragraphs 9 and 10.

***Conclusions***

This submission comments upon some domestic and international provisions that have an adverse effect on the rights of persons with disabilities, including the right of persons with disabilities to access the highest attainable standard of health. Such provisions must be repealed and replaced by provisions ensuring the rights of persons with disabilities in equality with able bodies persons.

CARE calls upon the Special Rapporteur on the rights of persons with disabilities to engage in a constructive dialogue with the UK Government to scrutinise the above discussed laws that are discriminatory against persons with disabilities. Persons with disabilities will never be able to enjoy the highest attainable standard of health if there are laws that target their right to life in the first place. The right to life of persons with disabilities must be adequately protected and guaranteed before any other rights are considered. The denial of the right to life of persons with disabilities denies all their other rights.

1. Reliable Accurate Prenatal Non-Invasive Diagnosis, Available at: http://www.rapid.nhs.uk. [↑](#footnote-ref-2)
2. Lewis Penney and Isra Black, *The Effectiveness of Legal Safeguards in Jurisdictions that Allow Assisted Dying. The Commission on Assisted Dying: Briefing Paper* (London: Demos, 2012) 23. [↑](#footnote-ref-3)
3. Ibid. [↑](#footnote-ref-4)
4. Ibid. [↑](#footnote-ref-5)