Is Disability a Justification to Undermine the Right to Life?

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Introduction

Is disability a justification to undermine the right to life? The answer to this chapter's title might look self-evident but it brings up a profound unsolved question: Why do so many legislators, prospective parents and health practitioners consider that the presence of an impairment makes the life of an unborn child less desirable? Why do we affirm there is such an assumption?

This chapter aims to provide some detail about the existing discrimination towards foetuses with disabilities precisely on grounds of their disability. It will focus on 2 countries, Spain and the UK, which are both signatories of the UN Convention on the Rights of the Child (1989) (CRC) and the UN Convention on the Rights of Persons with Disabilities (2006) (CRPD) and whose legislation allow wider conditions for termination of pregnancy when a foetal anomaly is detected. As the CRPD clearly states the prohibition of all discrimination on the basis of disability and the right to life 'on an equal basis with others', the objective of this chapter will be to consider how (if at all) it is possible to fully comply with this international commitment while simultaneously maintaining at a national level selective abortion legislation and practice which constitute discrimination on the basis of disability.

The structure of this chapter reflects the experience of my own awareness process. Being a mum of a child with Down syndrome (DS) and personally experiencing the prejudice towards my child being born, I progressively discovered how far the discrimination towards unborn children with disabilities had reached into the legal system, the healthcare practice and society as such. As a scholar, I questioned myself about its eventual contradiction with the CRPD.

Hence, in the first part of this chapter I present the context, pointing out discriminatory abortion legislation on grounds of disability, discriminatory healthcare practice and presenting some figures regarding disability-selective terminations. These figures are essential to gain awareness of the importance of our topic.

Secondly, this chapter assumes a legal approach to establish whether the domestic legal system and practice in Spain and the UK fully comply with the CRPD. For that purpose, I apply the treaty interpretation rules set out in the 1969 Vienna Convention on the Law of Treaties (herein after VCLT) to interpret art. 10 CRPD about the right to life, in the context of the whole CRPD and other international treaties on human rights, mainly the CRC.

Disability as Justification to Undermine the Right to Life

The Legal State

Spain

The adoption of Act 2/2010 of 3 March 2010 on sexual and reproductive health and voluntary interruption of pregnancy was a turning point regarding abortion legislation in Spain. Before that, according to the Criminal Law from 1985, abortion was considered a crime unless there were special circumstances, one of them being the risk of 'serious mental or physical disabilities' in the foetus, where termination prior to the 22nd pregnancy week would not be considered punishable (Rodríguez Díaz 2019, p. 179). Since 2010, abortion is no longer considered a crime but a fundamental right within the fundamental rights concerning sexual and reproductive health (art. 1 Act 2/2010) if performed within the first 14 weeks. In the case of a 'risk of serious anomalies in the foetus', the deadline to legally perform the abortion is extended up to 22 weeks while

there is no time-limit when ‘an extremely serious and incurable illness is detected in the foetus’ (art. 15).

Act 2/2010 was contested before the Constitutional Court in June 2010 (appeal on the grounds of unconstitutionality 4523-2010). More than ten years later, no ruling has yet been reached.

United Kingdom

The Abortion Act 1967 applies in Great Britain (England, Wales and Scotland) from 1968. In Great Britain, a pregnancy may only be terminated if 2 registered medical practitioners have certified that they are of the opinion, formed in good faith, that at least one and the same ground for abortion in section 1(1) of the Act exists, being one of them ‘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’.

The Human Fertilisation and Embryology Act 1990 amended the 1967 Abortion Act. It introduced a time limit on most abortions of 24 weeks of gestation but permitted termination at any gestation on grounds of serious foetal anomaly (. This discrimination was recently challenged before the courts by a young woman with DS, Heidi Crowter (Sky News, 18 October 2020). The High Court of England and Wales dismissed her claim in September 2021 (Case No: CO/2066/2020). Leaving aside some arguments made by the claimants about the contradiction with the European Convention on Human Rights (which has made clear that unborn children are not bearers of the ECHR rights), the Court barely analyses the contradiction with the CRPD and, in particular, with the prohibition to ‘all discrimination on the basis of disability’ (art. 5.2) as ‘the UNCRPD has not been incorporated by Parliament into domestic law’ (paragraph 44). Let us recall that international law prevails over domestic legislation (art. 27 VCLT) hence, ‘the UK’s internal principle of parliamentary sovereignty has no bearing on the international legal effect of the UK’s international obligations’. (Butchard 2020, p.4).

Regarding Northern Ireland, the adoption of the Abortion (Northern Ireland) Regulations 2020 made abortion lawful unconditionally if performed within the first 12 weeks of the pregnancy. Beyond this limit, it is only lawful under certain circumstances such as 'severe foetal impairment and fatal foetal abnormalities without any gestational time limit'. Throughout this chapter, I use GB and UK indistinctly, as the international liability in case of an eventual breach of the CRPD falls on the UK regardless of the said breach taking place in all or part of its territory.

The Healthcare Practice

For more than a decade, scholars have pointed out the influence of the medical professionals (Dixon 2008, p. 3) in the decision to terminate pregnancies of foetuses where impairments have been detected. However, healthcare professionals are not well trained on how to counsel under such circumstances (Jotkowitz and Zivotofsky 2010, p. 150). These authors highlight that one of the factors explaining the pressure experienced by expectant women towards termination in such cases is the concern for legal liability existing among physicians. This concern is understandable as the judiciary tends to award damages in cases of 'wrongful birth' (Martínez-Pujalte 2016, p. 160).

Spain

The routine pregnancy care system in Spain includes screening tests in the early weeks of the pregnancy. In some cases, a more invasive technique such as amniocentesis is required to get an accurate diagnosis. Also, non-invasive prenatal testing might be available as a less risky alternative whenever the foetus impairment is related to some chromosomal abnormalities.

When the screening test for chromosomal abnormalities is offered, an informed consent form is provided, stating: 'the final goal of this test is to find out about the chromosomal integrity of my child and eventually to allow me to take up the Law of Voluntary

Pregnancy Interruption.' (Informed Consent Protocol, 'Programa de Cribado de Cromosomopatías', Autonomous Community of Madrid, Hospital Puerta de Hierro, Madrid, p. 17, author translation).

Although terminating the pregnancy in such cases is presented as a choice, the previous statement reveals that a life with a genetic disorder is considered more likely to be terminated as the presence of the foetus abnormality very often switches a wanted pregnancy into an unwanted one. Furthermore, the role of healthcare professionals in the said 'switch' is noteworthy: studies about women perceptions throughout their pregnancy reveal that medical professionals in Spain encourage termination of foetuses diagnosed with DS in half of the cases and even try to actively persuade expecting mothers towards an abortion in a minority of cases (Vargas Aldecoa 2016, p. 238). Hence, I argue that disability is used a justification to undermine the right to life.

United Kingdom

Screening tests in pregnancy in Great Britain are not compulsory. If they are performed and their results show a high likelihood of a certain condition, diagnostic tests will be offered to confirm the condition. The same assumption about the close relationship between the finding of a 'condition' and the decision to end the pregnancy can be found within the NHS's practice: 'If diagnostic tests show your baby has a condition, this can lead to a decision about whether you want to continue or end the pregnancy' (NHS, 2021).

Furthermore, better implementation of screening tests is expected to result in an increase in diagnosis of different abnormalities 'which will lead to more women *being offered* an earlier surgical termination of pregnancy'. (Royal College of Obstetricians and Gynaecologists -RCOG- 2010, p. 21, my emphasis). Evidence submitted to an independent parliamentary inquiry in 2013 confirmed the bias towards termination of pregnancies if a child is likely to be disabled (Inquiry on Abortion on the Grounds of Foetal Abnormality in England and Wales, March 2013, pp. 30-31). Abortion is routinely offered even in the case of minor defects, far from what legislation requires about a

substantial risk of serious disability (House of Common Debates, UK Parliament, Hansard Volume 174, column 1190, 21 June 1990).

How Big an Issue is this?

Abortion based on foetal conditions is legal in over 80 countries (WHO, Global Abortion Policy Database). While some of them 'provide a limited list of conditions or specify a single foetal condition for which abortion is lawful' the majority of them (51%) present no restriction as to the type of foetal condition (Lavelanet et al. 2018).

In Europe 'there are between 16 and 18 States which provide for differential gestational limits on the grounds of serious foetal abnormality. There are 31 States which legislate in some way for abortion to be permitted on grounds of foetal abnormality' (UK, High Court of Justice, Case No: CO/2066/2020, 23 September 2021, paragraph 30)

Reliable figures about terminations of pregnancy for foetal anomaly (TOPFA) following prenatal diagnosis are not easily available. In Europe, although EUROCAT provides the rate of TOPFA per 1000 births, some States recognize real figures are higher than official ones. Aware of these difficulties, I analyse some figures regarding the countries where our study is focused on and also an insight in one of the most common ones: TOP following a diagnose of trisomy 21. A study carried out in 12 European countries analysing data from 2000 to 2005 showed that the rate of TOPFA before 24 weeks was 3.4 per 1000 births while there was a significant variation in the prevalence of TOPFA at 24 or more weeks between countries (Garne et al. 2010, p.660).

In the UK, the total prevalence of TOPFA per 1000 births was 5.28 in 2008-12 (Eurocat 2008-2012), rising to 5.846 in 2018 (Eurocat 2011-2018). According to Lafarge et al. (2017, p. 2) the increase in the number of TFAs (a total of '3213 in 2015 compared to 2085 in 2009') is largely due to new screening technologies that enable earlier fetal abnormality detection.

The British Pregnant Advisory Service (2022) in England and Wales recognised that the real figure of abortions for foetal anomaly is higher than the official one. There are about 2,700 TOPFA recorded each year under Ground E. However, this is an undercount, as very often there are other primary indications 'such as concerns for a pregnant woman's health, which means that abortion is recorded under Ground C' In Spain, total prevalence of TOPFA per 1000 births was 2.464 in 2011, rising steeply to 8.216 in 2017 (Eurocat 2011-2017). However, official data from the Health Ministry (Ministerio de Sanidad, Consumo y Bienestar Social, 2021), show that TOPFA in 2011-2019 represent percentages fluctuating between 3 and 4% of the overall TOP rate (3200 to 3800 TOPFA yearly).

Perhaps one of the most paradigmatic cases regarding TOP for a foetal anomaly is trisomy 21 (Down syndrome). Globally, abortion rates are 60-90 percent after a DS diagnose While in the US the rate is around 65-75%, it reaches 90% in England and France, 95% in Spain and almost 100% in Iceland. (Rodríguez Díaz 2019). These figures should help us to gain awareness of the importance of our study: why is disability being used to undermine the right to life?

Is There any Infringement of the CRPD?

In order to establish whether Spain and/or the United Kingdom are breaching the CRPD, and its art. 10 in particular, we need to analyse the wording and scope of this article. Interpreting international treaties 'is known to be one of the most difficult and contradictory issues on the applier's agenda' (Linderfalk 2007, p.1), even if the 1969 VCLT provides three articles on the interpretation of treaties. Following Rodrigo and Abegón (2017), I support a holistic interpretation of the CRPD together with other international treaties protecting general interests of the international community.

My aim is to apply the general rule of interpretation (art. 31.1 VCLT), that is, the literal interpretation, completed with the context of the treaty, its object and purpose. Secondly, I consider (as required by art. 31.3) any subsequent agreement between the parties regarding the interpretation of the treaty or the application of its provisions; any subsequent practice in the application of the treaty which establishes the agreement of the parties regarding its interpretation; any relevant rules of international law applicable in the relations between the parties. Finally, I look up the supplementary means of interpretation set out in art. 32 VCLT.

The literal interpretation

> 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 (art. 10 CRPD).

The use of the term 'Reaffirm' is consistent with core human right treaties although, as Schulze points out, 'this verb is usually used in preambular language rather than body text' (Schulze, 2009, p. 57).

'Every human being has the inherent right to life': This statement, as it is drafted, makes no distinction between a human being before or after birth. To deny the human condition to an unborn child or an embryo has no scientific consistency, as J. Lejeune testified at a US Congressional hearing in April 1981: 'The human nature of the human being from conception to old age is not a metaphysical contention. It is plain, experimental evidence.'

I explore the scope of the right to life as interpreted by the different human right treaty bodies further down.

'Shall take all necessary measures to ensure its effective enjoyment': In the case of the CRPD, the obligation to adopt positive measures is fully described in art. 4 of the Convention, including protecting and promoting the human rights of persons with disabilities in all policies and programmes. According to Schulze (2009 p. 57):

> the term 'ensure its effective enjoyment' deviates from the standard clauses on the right to life. This may be interpreted broadly, the main cause for the formulation is the fact that regularly the lives of persons with disabilities are under threat because others think their lives are not 'worth living'.

'By persons with disabilities on an equal basis with others': the term 'person with disabilities' is defined in art. 1 CRPD, that emphasizes the interaction between the impairments and the existing barriers, and so assumes the social model of disability. Following A. Palacios (2010), we consider irrelevant the fact that a foetus might not be considered a 'person' under domestic law (as it happens in Spain and the UK). The CRPD not only forbids discrimination towards persons with disabilities but also 'any discrimination on the basis of disability', which considerably enlarges its scope (Palacios 2010, p. 55). Finally, the expression 'on an equal basis with others' is consistent with the purpose of the CRPD art. 1), and with the principle of 'non-discrimination' that must permeate the whole Convention (Allain 2009, p. 21).

Consequently, 'in every stage of the life of the human being, also prenatal life, equal treatment concerning its protection should be granted' (Rodríguez Díaz 2019, p. 185): the conditions to legally terminate a pregnancy must be the same whether the foetus has or has not got an impairment (Palacios 2010, pp. 56-57). This is consistent with the CRPD Committee (CRPD/C/GBR/CO/1, 3 October 2017, paragraph 13) stating that: '**Women's rights to reproductive and sexual autonomy should be respected without legalizing selective abortion on the ground of fetal deficiency'** (author's emphasis).

In conclusion, the literal interpretation of art. 10 CRPD confirms the CRPD Committee understanding: 'Laws which explicitly allow for abortion on grounds of impairment violate the CRPD ' (CRPD Committee 'Comments on the draft GC 36 of the Human Rights Committee on article 6 of the International Covenant on Civil and Political Rights').

Furthermore, healthcare programmes or practices instilling any prejudice on the basis of impairments noticeable before birth also violate the CRPD as States must ensure the removal of any discriminatory practice (art.4b) whether it comes from public authorities (art.4d) or private organizations (art.4e).

The Context

Art. 31.2 of the VCLT clarifies what the 'context' for the purpose of a treaty shall comprise. As Allain (2009, p. 6) highlights: 'Interpreting "in context" requires that one read the specific provision in light of the overall treaty'. He further explains (p. 21-22):

> The CRPD requires that via the context which points to the object and purpose that those interpreting the Convention not lose sight of the overarching obligations of States and the rights of persons with disabilities.

Reading art. 10 CRPD in light of the overall Treaty means having in mind art. 3b, where non-discrimination is one of the General Principles; art. 5.2, which prohibits 'all discrimination on the basis of disability' and art. 4, establishing the obligations of the State Parties in ensuring persons with disabilities enjoy all human rights without 'discrimination of any kind on the basis of disability'. Thus, the text of the treaty (as part of its context) confirms the interpretation resulting from the ordinary meaning of its terms.

The 1969 VCLT (art. 31.2) mentions the Preamble of a treaty as part of its context regarding interpretation. 'I argue that the Preamble of the CRPD confirms our literal interpretation: not only it refers to 'the inherent dignity and worth and the equal and inalienable rights of all members of the human family' (paragraph 1) but it also mentions 'birth' within the grounds leading to multiple or aggravated forms of discrimination. Unborn children presenting impairments noticeable before birth are subject to discrimination on the basis of their disability.

The 'context' of a treaty includes 'any agreement relating to the treaty which was made between all the parties in connection with the conclusion of the treaty'. Therefore, we should mention the Optional Protocol, which has been ratified both by Spain and the United Kingdom, giving the Committee competence to examine individual complaints regarding alleged violations of the Convention by States parties to the Protocol. This Protocol neither confirms nor contradicts our literal interpretation but its ratification by Spain and the UK shows their commitment towards the obligations assumed under the CRPD and regarding the role of its Committee..

Lastly, the context includes any instrument 'which was made by one or more parties in connection with the conclusion of the treaty and accepted by the other parties as an instrument related to the treaty'. There were no reservations or interpreting observations concerning art. 10 CRPD, only one declaration coming from the Netherlands, not objected by any State, claiming that the term 'human being' is a matter of national legislation, as interpreted by the ECHR. This does not contradict our interpretation as we are arguing that once national legislation protects the life of unborn children, it should offer the same conditions to 'human beings' whether they have disabilities or not.

The Object and Purpose of the Treaty

Although some scholars have underlined the uncertainty resulting from the application of the 'concept of "object and purpose" in the law of treaties' (Gardiner 2008, p. 19), we consider with Allain (2009, p .7) that the teleological approach has been privileged in the case of the CRPD:

> the negotiating States sought to give voice to a reading of the Convention which gives more emphasis to the teleological approach to treaty interpretation by requiring a reader of the Convention to, after having taken into consideration the ordinary meaning of the a word or phrase, to move directly to consider via Articles 1, 3, and 4, the 'object and purpose' as contextualising one's interpretation, that is as reading the text 'in context'.

Following Allain and having in mind the object and purpose of the CRPD (art. 1, 3 and 4) as explained *supra* (the context of the treaty), we conclude that the object and purpose of the CRPD confirm the interpretation resulting from the ordinary meaning of its terms.

Further Criteria Within the General Rule of Interpretation (art. 31.3 VCLT)

Art. 31.3 refers to the 'authentic interpretation', that is, the interpretation made by the treaty authors, whether it is expressed in a subsequent agreement or in 'any subsequent

practice in the application of the treaty which establishes the agreement of the parties regarding its interpretation'. There is no subsequent agreement between the parties.

Regarding the practice and being all appliers of a treaty 'potential creators of practice' (Linderfalk 2007, p. 167) including the state parties and the non-state organ entrusted with its application, we'll focus on the practice of the CRPD Committee, which is the body of independent experts which monitors implementation of the Convention by the States Parties. It examines the reports submitted by the State parties and forwards recommendations, in the form of concluding observations, to the State Party concerned. The CRPD Committee has adopted concluding observations relevant to our study precisely addressed to the 2 countries I am focusing on.

In the case of Spain, the CRPD Committee (CRPD/C/ESP/CO/1, 19 October 2001, paragraph 17) noticed that 'time limits for abortion are extended if the foetus has a disability' and so recommended that '**the State party abolish the distinction made in Act 2/2010 in the period allowed under law within which a pregnancy can be terminated based solely on disability**. (author's emphasis).

A few years later, the CRPD Committee (CRPD/C(ESP/CO2-3, 13 May 2019), addressing itself to Spain recommended again to:

> **(b) Abolish any distinction made in law to the period within which a pregnancy can be terminated based on a potential fetal impairment… as such provisions contribute to the stigmatization of disability, which can lead to discrimination;** (author's emphasis).

Regarding the United Kingdom, the CPRD Committee (CRPD/C/GBR/CO/1, 3 October 2017, paragraph 12 and 13) expressed its concerns about societal prejudices considering lives of persons with disabilities less worthy and about TOPFA been available at any stage of the pregnacy and so recommended that '**the State party amend its abortion law accordingly. Women's right to reproductive and sexual autonomy should be**

respected without legalizing selective abortion on the ground of fetal deficiency' (author's emphasis).:

Similar recommendations have been made to other State parties of the CRPD, such as Hungary (CRPD/C/HUN/1, 22 October 2012).

'A "practice' can consist of any number of applications, one or two or many – just as long as they 'establish the agreement of the parties regarding its interpretation' (Linderfalk 2007, p. 166). Consequently, the 'subsequent practice' in the application of the CRPD confirms our literal interpretation.

Finally, art. 31.3 refers to 'any relevant rules of international law applicable in the relations between the parties'. Pauwelyn and Elsig (2012, p. 457) underscore that the systemic interpretation is not uncommon. It is considered especially necessary in case of treaties protecting general interests of the international community (Rodrigo and Abegón 2017, p. 179). Therefore, we consider appropriate to compare the interpretation of the right to life, the right to non-discrimination and the rights of children with disabilities made by the different bodies in charge of the implementation of the relevant treaties (CRPD, CRC, CCPR) and to analyse any eventual contradictions.

On one hand, the Human Rights Committee (HRC) adopted in 2018 the General Comment (GC) 36 about art. 6: right to life (ICCPR), replacing GC n. 6 and n.14:

> The right to life … is most precious for its own sake as a right that inheres *in every human being*, but it also constitutes a fundamental right, the effective protection of which is the *prerequisite for the enjoyment of all other human rights* (my emphasis).
>
> 3.*The right to life is a right that should not be interpreted narrowly*. It concerns the entitlement of individuals to be free from acts and omissions that are intended or may be expected to cause their unnatural or premature death, as well as to enjoy a life with dignity. *Article 6 of the Covenant guarantees this right for all human beings, without distinction of any kind* (my emphasis).

These paragraphs seem to interpret art. 6 CCPR in line with the very terms of art. 6.1 CCPR (‘every human being has the inherent right to life), being art. 6 CRC consistent with it (‘every child has the inherent right to life’). Furthermore, , art. 6.5 CCPR prohibits to carry out sentences of death on pregnant women: this protection of the unborn child is consistent with the Preamble of CRC, that points out the need of special protection of the child, ‘before as well as after birth’. However, the wording of the HRC is somehow conflicting as it allows domestic measures regulating termination of pregnancy and encourages State parties to provide legal and safe abortion (paragraph 8), while at the same time considers that: ‘Article 6 of the Covenant guarantees this right for all human beings, without distinction of any kind’ (paragraph 3), and thus, not differentiating between born or unborn human beings. This contradiction surpasses our object of study as we are only focusing on the eventual discrimination towards unborn children with disabilities.

In this regard, I underline that the term discrimination as used in the CCPR (art. 2.1) has been defined by the HCR (GC n.18, non-discrimination) as it:

> any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms.

Although it does not mention disability within the discriminatory grounds, it is not an exhaustive list Also, GC 18 simply clarified that ‘when legislation is adopted by a State party, it must comply with the requirement of article 26 that its content should not be discriminatory’ (paragraph 12).

The CRC Committee (GC9, the rights of children with disabilities, paragraph 31) gives particular attention to the inherent right to life of children with disabilities since in many countries there are practices that compromise this right: the prejudice existing against them make them more vulnerable to infanticide.

The CRC Committee noted the existing prejudice towards children with disabilities. Surprisingly, the HRC assumed this same prejudice in its draft version of GC 36, where it established that safe and legal abortion should be provided 'most notably where the pregnancy is the result of rape or incest or *when the foetus suffers from fatal impairment'* (paragraph 9, my emphasis). The CRPD Committee reacted proposing to delete these examples.

> Laws which explicitly allow for abortion on grounds of impairment violate the CRPD (Art,. 4,5,8). Even if the condition is considered fatal, there is still a decision made on the basis of impairment. Often it cannot be said if an impairment is fatal. Experience shows that assessments on impairment conditions are often false. Even if it is not false, *the assessment perpetuates notions of stereotyping disability as incompatible with a good life* (my emphasis). CRPD Committee 'Comments on the draft GC No36 of the HRC on article 6 of the International Covenant on Civil and Political Rights'.

In its final version, HRC GC 36 removed the term 'when the foetus suffers from fatal impairment' and redrafted paragraph 9 encouraging safe and legal abortion 'where the pregnancy is not viable'.

We can observe colliding views within UN bodies in charge of monitoring the implementation of international treaties of human rights. On one hand, the Committee Against Torture (in line with the HRC) has considered situations where 'continuation of the pregnancy is likely to cause severe physical and mental anguish and distress, namely, in cases of fatal fetal abnormality' and consequently, has recommended to ensure access to abortion 'in cases of fatal foetal impairment' (CAT/C/GBR/CO/6, Northern Ireland, para 46. 7 June 2019), which is similar to HRC view 'where the pregnancy is not viable'.

On the other hand, the Committee on the Elimination of Discrimination Against Women (CEDAW) has an intermediate position. While it recommends abortion laws to include legal abortion on grounds of 'severe foetal impairment, including FFA', it highlights the need of not 'perpetuating stereotypes towards persons with disabilities and ensuring appropriate and ongoing support, social and financial, for women who decide to carry such pregnancies to term' (CEDAW/C/OP.8/GBR/1, 23 February 2018, p. 19). Hence, the CEDAW supports the CRPD view and both consider that: 'Health policies and abortion laws that perpetuate deep-rooted stereotypes and stigma undermine women's reproductive autonomy and choice, and they should be repealed because they are discriminatory' (CEDAW and CRPD Joint Statement, Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities, 29 August 2018), which confirm the literal interpretation made *supra*.

Supplementary Means of Interpretation (art. 32 VCLT)

Art. 32 VCLT allows recourse to supplementary means of interpretation (preparatory work of the treaty and circumstances of its conclusion) either to confirm the literal interpretation of art. 31 or when it has led to ambiguous or absurd results. As the result of applying art. 31 (the literal interpretation) is consistent and reasonable, we'll refer to supplementary means of interpretation to confirm the said interpretation.

Preparatory Works

General Assembly Resolution 56/168 of 19 December 2001 established an Ad Hoc Committee 'to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities (…)'. The Ad Hoc Committee decided to establish a Working Group (Report of the Ad Hoc Committee, A/58/118) which should prepare a draft text of a convention to be negotiated by Member States. If existing, it should present textual options reflecting alternative approaches.

The Working Group draft made the following provision regarding the (then) art. 8: ‘States Parties reaffirm the inherent right to life of all persons with disabilities and shall take all necessary measures to ensure its effective enjoyment by them’. As a footnote it included: ‘There were different views expressed within the Working Group as to whether the Convention should include an article on the right to life, and if so, its content.’

> The polemic question was if the Convention could cover or not the rights of an unborn disabled child. Some delegations, such as the EU and China, did not support this inclusion, because of the lack of international consensus regarding the protection of prenatal life. Other delegations, mainly led by Colombia, considered that abortion on grounds of disability should be expressly prohibited to prevent eugenic legislation and practice. Regarding the NGOs participating in the Working Group, they widely supported the later view. (…).

Within them, Inclusion International highlighted the risk that prenatal testing for disability presents for persons with disabilities.

> Society might soon be making a distinction between lives worth living and those not worth living. This is not an argument about a women’s right to choice, it is about “our right” to be born and to be to be different. *The presence of a disability must not be allowed to become a justification for the termination of life*, nor must a disability justify changing the genetic make-up of a person. (my emphasis). (Daily Summary related to Draft Article 8 RIGHT TO LIFE, prepared by Landmine Survivors Network, January 2004)

Eventually, the Ad Hoc Committee (7th period of sessions, A/AC.265/2006/2), included an article on the right to life, recounting that: ‘There was general agreement to add, at the end of the draft article, the words “on an equal basis with others”’. Consequently, we consider that the preparatory works of the CRPD reinforce the interpretation done *supra*, in the sense that a child with disabilities should enjoy their right to life on the same terms as any other child, including prenatal life.

Circumstances of the Conclusion of the CRPD

The circumstances of the conclusion of an international treaty cover both contemporary circumstances and historic precedents (Moyano Bonilla 1985). Historically, the promotion of the rights of the persons with disabilities under different international treaties has been linked to initiatives from the global disability movement pushing to achieve the 'equalization of opportunities' (UN World Programme of Action concerning Disabled Persons, 1982) and some attempts to transform the disability issue from a 'social welfare' issue to that of 'integrating the human rights of persons with disabilities in all aspects of development processes'.

Regarding the preparation of the CRPD, 2 circumstances must be underlined because of their great influence: the participation of persons with disabilities in the negotiating process and the shift from the medical model to the social model of disability that permeates the whole CRPD.

On one hand, the involvement of representative organisations of persons with disabilities in the drafting phase was one of the most vigorous demands of the disability movement, under the motto 'nothing about us without us'. We have already pointed out the great concern existing among the persons with disabilities towards the consideration of a life with a disability as less worth living. They consequently widely stood up for their 'right to be born and to be different'.

On the other hand, the CRPD left out the medical model approach and adopted the social relational model of disability, which is made evident in the definition of 'persons with disabilities' (art. 1 CRPD), highlighting the barriers over the impairments (the neglection of which has been regretted by Shakespeare and Watson, 2001, among others). Barriers, faced by unborn children with impairments noticeable before birth, consist of discriminatory laws and discriminatory practice (laid on stigma on the basis of their impairment) that prevent them enjoying their right to life 'on an equal basis with others'.

We should keep in mind the human rights approach. Lawson and Becket (2021)

underscore the complementarity of the social and human rights models. They argue that they both are valuable tools with different purposes. For the purpose of this chapter, the prescriptive nature of the human rights model seems most appropriate since 'it provides a detailed road map for the development of human-rights-consistent law and policy' (Lawson and Becket 2021, p. 371). Any law reform must be compliant with human rights and principles and obligations, as set out in the CRPD. The CRPD not only forbids any discrimination 'on the basis of disability' but compels the signatory States to 'take all appropriate measures to eliminate discrimination on the basis of disability' (art. 4)..

Providing an extended deadline to perform an abortion in cases where the foetus carries an impairment can no longer be justified on the economic burden associated with raising a child with a disability (as the Spanish Constitutional Court did when it first decriminalised abortion on grounds of foetal impairment, Constitutional Court 153/1985) because economic considerations do not suffice to limit a fundamental right (De Asís 2016) under the human rights paradigm.

Therefore, having analysed the supplementary means of interpretation (art. 32 VCLT), we conclude that they confirm our literal interpretation.

Conclusion

Following the VCLT, the CRPD must be interpreted as forbidding domestic abortion law containing discriminatory provisions on grounds of a foetus anomaly. Disability should never be a justification to undermine the right to life. However, to prevent the aforementioned discrimination, it will not suffice to remove discrimination on the legal field. Why?

First, it is reasonable to presume that many such pregnancies would still be terminated under other existing provisions (UK Department of Health, commentary on 2015 abortion statistics), as it is already happening in the UK, where many TOPFA were conducted on other grounds, mainly that of injury to the mental health of the pregnant woman (UK

Parliamentary Debates, Abortion Disability (Equality) Bill, volume 774, 21 October 2016, column 2253). Besides, prenatal testing vastly allows to confirm the presence of a foetal disability within the general deadline to legally terminate.

States parties of the CRPD such as Spain and the UK are not only bound ‘to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities’ (art. 4.1b) but ‘to take all appropriate measures to eliminate discrimination on the basis of disability’.

Regarding the object of this study, there is a wide area of improvement to fully comply with the CRPD. , Specifically, Women Enabled International (2020, p. 8) pointed at the need to re-educate the public, including prospective parents, about disabled people’s lives.

Regarding DS, studies have shown that the main reasons prospective parents hold when terminating a pregnancy after a DS diagnose (Korenromp et al. 2007) clash with the actual experience of people with DS and their families (Skoto et al. 2011a, 2011b, 2011c). How et al. (2018) underscore the huge contrast between expectations and reality.

Therefore, a balanced communication of the diagnosis plays a vital role (Flórez 2018). Disabled scholars argue that when a woman decides to abort a disabled foetus, she is not so much choosing as being constrained to take such a decision (Morris 1991, p.66) as the ‘context in which reproductive decisions are made, undermines the capacity for free choice and promotes eugenic outcomes’ (Shakespeare 1998, p. 666). Health professionals should be educated on providing unbiased info about a foetus condition ensuring their life is as valued as any other one.

Regarding the so-called ‘burden’ of parenting children with disabilities, it refers to the excessive burden in terms of additional time, financial and emotional resources needed to support the child (Barnes, Mercer, and Shakespeare 2003, p. 222). This argument can be found in court rulings awarding damages for ‘wrongful birth’. Such ‘burden’ is the effect

of disability-related stigma and of the lack of enough affordable and locally available support for people with disabilities and their families (Women Enabled International, 2020, p. 13). This is what prevents their full inclusion in society and the full enjoyment of their rights, on an equal basis with others.

Financial support should be granted to parents of children with disabilities not because they failed to terminate their pregnancy because of a late or wrong prenatal diagnosis but so they are able to care for their child without barriers and to ensure their full inclusion in society.

Lastly, as States parties of the CRPD are bound to combat stereotypes about persons with disabilities by promoting 'positive perceptions and greater social awareness', we consider that they should play a role in preventing and even penalizing stigma.

Much has been done for children with disabilities in the last 15 years. Although they still face considerable challenges to fully participate in society, we argue that the main one is the protection of their right to life on an equal basis with others. Without it, they might achieve great success in the coming years but only the 'lucky few' allowed to be born will enjoy them.

As a conclusion, I argue that disability is being used a justification to undermine the right to life. Nevertheless, removing disability-related discriminatory provisions from abortion laws shall not suffice. A well-rounded strategy is required, including fighting against stereotypes, training health care professionals, reviewing the communication of a diagnosis process and raising awareness about how every life is equally worthy regardless of the presence of an impairment. Persons with disabilities are expected to play a role in monitoring the implementation of the CRPD. Unborn children with disabilities need a voice though. This chapter aims to give them one.

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