“Genetic Cleansing” Under the Guise of Women’s Rights? (Part I)

ON DISABILITY-SELECTIVE ABORTION AS A MEANS TO PREVENT DISABILITY

The fight for the protection and recognition of disabled persons’ rights frequently ends before it even starts. While about 25% of fetuses are generally aborted, this percentage rises to about 90% when the fetus is diagnosed with a disability. As a result, certain disabilities are disappearing in several countries (e.g. Down Syndrome in Denmark).

This increase in disability-selective abortions roots in two distinctive (albeit inextricably linked) grounds: de jure in disability-selective abortion rules, and de facto in increasing (non-invasive) prenatal diagnostic possibilities. This piece will view these measures through the lens of international human rights law [most importantly the Convention of the Rights of Persons with Disabilities (CRPD)] and will highlight the importance of reconciling States’ human rights obligations towards women and towards persons with disabilities in this very sensitive and complex field.

The fetus under international law

The legal status of the unborn under international law remains controversial (in detail here and here). Although fetuses are not perceived as holders of the right to life themselves, there seems to be a consensus that at least in certain circumstances safeguards may be extended to the unborn child (ECtHR, Vo v. France, paras. 80, 84). However, this article does not focus on the question whether disability-selective abortions interfere with any of those safeguards, but highlights that these measures are highly problematic for the nondiscrimination (e.g. Art. 5(2) CRPD) and stigma reduction (Art. 8 CRPD) obligations of the States implementing them.

Discriminatory abortion laws

National legal systems abound in laws favoring disability-selective abortion: women often have a (temporarily) extended right to terminate their pregnancy, if a disability is diagnosed (sometimes up to the 9th month of pregnancy), whereas in several States, with more restrictive abortion regulations, a diagnosed disability is an exception to the abortion bans. The idea that disability justifies abortions seems to be backed up (at least partially) by many international human rights bodies. Inter alia, the Human Rights Committee (HRC) in its General Comment No. 36 on the right to life (para. 8) and the Committee on the Elimination of Discrimination against Women have held that absolute abortion bans are a violation of international human rights law and that abortions must be possible to protect the mother’s life and health. Notably, abortion is widely accepted in case of the diagnosis of severe abnormalities in the development of the fetus.

While the majority of human rights bodies has aimed at a quite liberal human rights approach to abortion in order to protect the pregnant women’s rights, the Committee on the Rights of Persons with Disabilities (the Committee) takes a more restrictive position in this field, deeming disability-selective abortion to be incompatible with the CRPD. Indeed, in several reports, the Committee has raised concerns over disability-selective abortion legislation: it condemned Spain in 2011 for allowing to terminate a pregnancy based solely on disability for being incompatible with Art. 1-4 CRPD (general principles and obligations) as well as the UK in 2017, Hungary in 2012 and Austria in 2013 for violating Art. 5 (Equality and non-discrimination) for the same reasons.

The disagreement among different UN treaty bodies was particularly clearly highlighted in the Committee’s concluding observations on Estonia’s initial report (Part 1).

The assessment perpetuates notions of stereotyping disability as incompatible with a good life.”

Prenatal Genetic Testing (PGT) under the CRPD

As has been noted above, PGT may also serve as a de facto promoter of disability-selective abortion. While disability rights groups have vehemently opposed such targeted testing, the Committee has hardly addressed the issue. Although considered (para. 44) the topic was not included in the Committee’s 2018 General Comment No. 6 on Art. 5, but finally, the Committee directly addressed the issue in this year’s Concluding Observations on Estonia’s initial report.

Precisely, it recognized the increased risk of the tests' CRPD-incompatibility, if they are used as a means to systematically prevent the emergence of disability. It raised concerns about PGT’s implications in the context of Art. 8 CRPD, which requires States to actively engage in awareness raising activities to combat stereotypes. Against this background, it called upon the State to “identify and combat disability stigma and stereotypes in all areas of life, including prenatal genetic testing, as a means of preventing disability, which is not in line with the Convention” (para. 18c).
The Committee’s argumentation seems to be indicating that Art. 5 CRPD grants protection against discrimination even before birth. Although, against the background of the unsettled fetus’ legal status, this interpretation may seem precarious, it does have some merit, if considered in the broader context of such abortion regulations’ impacts on the community of persons with disabilities as a whole.

The States’ general obligations to refrain from any form of discrimination based on disability (Art. 5 CRPD), to respect persons’ with disabilities inherent dignity (Art. 3 (1) CRPD) and to engage in stigma reduction (Art. 8 CRPD) are breached whenever a state officially promotes that disability is incompatible with a good life and persons with disability are living a life of less value. The same must apply if a State delivers the same message through its abortion regulations since arguably – relying on the international guidance on sex selective practices – disability-selective abortion regulations can be qualified as a “symptom of pervasive social, cultural, political and economic injustices”. As there seems to be a consensus on the fact that practicesin favor of selective abortions as a “manifestation of (…) discrimination” must be prevented, this must a fortiori apply to legal rules explicitly allowing for such differentiations. Consequently, the measure’s discriminatory and disparaging effect on persons with disabilities is indeed incompatible with the general principles and obligations of the CRPD and calls for legislative changes towards stigma reduction (such a petition has been recently submitted to the UK High Court).

However, although the Committee explicitly reaffirms the right of women to reproductive autonomy in the respective reports, it apparently fails to give due weight to the impact of an absolute prohibition of disability-selective abortion on this and other rights of women. Against the background of States’ obligation to protect women’s right to physical and mental health, the mental suffering of being forced to give birth to a non-viable child can mark the decisive difference that would justify (or even preclude) a breach of States’ CRPD obligations in the context of non-discrimination and stigma reduction (see the HRC argumentation in K.L. v Peru, para. 6.3). Contrary to the argumentation of the Committee, it is then not a matter of valuing life with disability less, but of protecting the expectant mother’s health. Consequently, although disability-selective abortion may serve as stigma promoter, it is not per se incompatible with the CRPD, as it is not necessarily based on the judgement of disabled life being inferior. It is instead required for the protection of the rights of the expectant women.

Conclusion

Nevertheless, States must be aware that the imminent danger of discriminatory stigmatization is high when having a child with disability is generally perceived as an increased burden. After all, under Art. 8 CRPD, States are not only required to refrain from any actions fostering such stigmatization, but also to actively engage in awareness raising activities to reduce and prevent it. Thus, instead of de jure differentiations in abortion legislation that can create and increase negative stigmas, liberal abortion options as a legal norm are needed to do justice to the Committees demand to respect “women’s rights to reproductive and sexual autonomy (…) without legalizing selective abortion on the ground of fetal deficiency”.

In fact, this is the only way for States to avoid complicated case-by-case considerations, which would require evaluations and uncertain predictions about the impact of certain disabilities on a (prospective) mother’s rights and would ultimately lead to additional stigmatization and discrimination. In such a scenario, where at least the lex lata would not differentiate fetuses with and without disabilities, countering the use of PGT as a de facto promoter of disability-selective abortion becomes of particular importance so that abortion will finally no longer be perceived as a “solution” to a supposed “problem” of a disability's diagnosis.