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| SBH_logo.jpg | IF  16 rue des Alexiens 1000 Brussels, Belgium  T: +32 (0)2 502 0413  E: [info@ifglobal.org](mailto:info@ifglobal.org) W: [www.ifglobal.org](http://www.ifglobal.org) |

**IF Comment to the Draft General Comment no. 36 on Article 6 of the International Covenant on Civil and Political Rights - Right to life**

**About us**

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with Spina Bifida and Hydrocephalus (SBH) and their families in 1979. Over the years, it has grown from a voluntary association into a professional organisation of persons with disabilities with global coverage, democratic structure and transparent processes. Its fast growing membership now includes 60 member organisations from all parts of the world. IF is a full member of the European Disability Forum and the International Disability Alliance. The mission of IF is to improve the quality of life of people with spina bifida and hydrocephalus and their families, and to reduce the incidence of neural tube defects and Hydrocephalus by primary prevention; by raising awareness and through political advocacy, research, community building and human rights education.

**General remarks**

The right to life is of particular importance to IF, as the right to life of children born with Spina Bifida and Hydrocephalus has been questioned and in many cases violated throughout the years. Up until the 1970’s[[1]](#footnote-1), doctors advised and practiced non-treatment in what they considered “severe” cases. They heavily sedated children, not providing them with food or liquid, and eventually these children died of starvation, the fatal progression of Hydrocephalus, or infections that were not treated. This non-treatment policy was based on the “expected quality of life” of children born with SBH, conditions that can lead to paralysis and incontinence issues, and in some cases developmental delays. Children with Hydrocephalus in particular would often be described as “vegetables”, under the assumption that the condition caused severe damage to the brain. This happens to this day.

However, with proper treatment soon after birth, through surgical implementation of a so-called shunt, Hydrocephalus can be managed and further damage averted. There may be specific learning challenges, but with the right support, these can be managed.

Similarly, Spina Bifida can be surgically treated, either right after birth or nowadays, in some cases, while the child is still in the womb, before 26 weeks of gestation. While this does not offer a cure, it does allow children to grow up into adulthood and the possibility to live their lives equal to others.

In the year 2000, at IF's 12th International Conference in Toulouse, France, adults with Spina Bifida and Hydrocephalus stated very clearly that their quality of life is not a reason for abortion[[2]](#footnote-2). Parents of children with Spina Bifida and Hydrocephalus and adults with these conditions stated that the impairments are not the burden. The burden is the constant struggle against inaccessible environments and inadequate systems, which should offer them support.

Yet even today, many children born with Spina Bifida and Hydrocephalus are still not treated, causing their parents great mental suffering, having to watch their child slowly deteriorate. This mostly happens in developing countries with limited resources, but non-treatment also occurs in countries that do have the resources for medical care. In these cases, children with disabilities may be seen as “not worth the investment” and a burden to society. Stigma, prejudice, lack of knowledge and superstition can also be causes for non-treatment.

In addition, many children with Spina Bifida and Hydrocephalus are never born, because they can be detected through prenatal ultrasound at around 20 weeks of gestation, and their diagnosis is often followed by - late - termination of pregnancy. Even with today’s knowledge, parents-to-be are often only told what will be medically wrong with the baby they are expecting, and offered a grim future for their child. Again, this prediction is based on the expected quality of life, with the diagnosis possibly coloured by negative assumptions of what living with a disability must be like. This policy could be viewed as deprivation of life based on discrimination, as these are “wanted pregnancies”, but it is the developing child with a non-fatal disability that is being aborted. This is even more evident in twin pregnancies, where selective abortion is performed when a congenital condition is detected, or in cases where the foetus is aborted because it is of an undesired gender. In these situations, not all developing children are equal before the law (Article 26 of the Covenant).

* We would like to emphasize that unbiased counselling, with up-to-date information and respect for the rights and capabilities of children with disabilities, should be part of adequate prenatal healthcare for pregnant women, mentioned in **§9** of the Draft General Comment, in particular for “impairments” that are not fatal when appropriately treated.

Similarly, with regard to post-abortion healthcare, it is important to recognise and address the mental stress of parents-to-be who have to make the extremely difficult decision to end the life of the child they are expecting and originally wanted. Couples who wish to do so, should have the option to name and register their child that was not born alive, as recognition of its existence.

**§27 Protection towards persons in situation of vulnerability – Children with disabilities**

As pointed out before, the lives of children (born) with disabilities and chronic health conditions are very much at risk, due to various threats. They can be abandoned, abused, end up in orphanages, left untreated, because of prejudice, superstition, out-of-date knowledge, or because their parents are too poor to pay for their treatment, or treatment is not available in the area where they live.

* We recommend that children with disabilities should be included in the list of examples of persons in situation of vulnerability in §27, and mentioned specifically in **§63**.

**§63** of the Draft General Comment states that special measures designed to protect the life of *every* child should be adopted.

We therefore recognise the importance of Article 24, paragraph 2 of the Covenant, which states that “Every child shall be registered immediately after birth and shall have a name.” This is in line with Sustainable Development Goal 16, target 9[[3]](#footnote-3), and Article 18, paragraph 2, of the Convention on the Rights of Persons with Disabilities[[4]](#footnote-4) (CRPD).

Registration at birth is a first step in ensuring a child’s survival, in particular for children with disabilities. Correct data is needed to make children with disabilities visible. Countries need to acknowledge their existence and plan for their care and support.

**§28 Persons with disabilities - Access to healthcare - Institutionalization**

We highly value §28, since not only the lives of children with disabilities are at increased risk, but all persons with disabilities and chronic conditions can face increased threats to their survival, for similar reasons (stigma, prejudice, poverty, etc.). They too can be persons in situations of vulnerability.

Lack of access to essential goods and services, in particular in the areas of health and rehabilitation, can cause additional, life-threatening, situations. For instance, in the case of persons with Spina Bifida, adequate continence care, including access to urinary catheters, is essential to prevent kidney failure, and as mentioned earlier, the non-treatment of Hydrocephalus, not having access to a shunt and neurosurgical care, will eventually become fatal. However, it can take many months of suffering, and a life without any dignity, before death occurs.

In addition, inadequate social protection and discriminatory attitudes towards adults with disabilities can lead to their placement in institutions, where they may be regarded as legally incompetent because of their disability. This could become an issue with regard to “protective custody”, with free and informed consent, as mentioned in **§27**.

According to the World Report on Disability[[5]](#footnote-5) “people with disabilities are at greater risk of violence than those without disabilities”. This applies in particular in an institutional setting. In this regard we also refer to **§58** of the Draft General Comment, which addresses torture and ill-treatment, and **§61** on arbitrary detention. It is important to take into account that - forced - institutionalization of persons with disabilities is a form of detention without criminal charges.

“Reasonable accommodation of public policies” is not enough to protect the lives of persons with disabilities. Access to appropriate healthcare and adequate social services, and living independently, are basic human rights and key to the survival of persons with disabilities.

* We recommend that special measures of protection for persons with disabilities are in line with Article 25, Health, of the CRPD, such as “ensuring access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation, and providing these services as close as possible to people’s own communities, including in rural areas”;
* as well as, “preventing discriminatory denial of healthcare or health services or food and fluids on the basis of disability”. While **§64** mentions legal protection and effective guarantees against all forms of discrimination, knowing that these life-threatening practices still exist, this measure of protection should be included.
* In line with Article 19 of the CRPD, States parties should ensure that “Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement”.

**§10 Termination of life – Persons with disabilities and non-fatal chronic conditions**

As stated above, stigma, prejudice, out-of-date knowledge and negative assumptions can influence people’s perceptions with regard to (persons) living with a disability and create discriminatory policy.

In 2007, the Netherlands adopted legislation which allows the termination of life of newborns up to 1 year of age with serious, but non-fatal, medical conditions, when they are deemed to suffer unbearably and their prognosis is “hopeless”, based on the criteria in the so-called Groningen Protocol[[6]](#footnote-6). This is yet another example where the “expected quality of life” determines the life, or death, of children (born) with disabilities and chronic conditions.

* We recommend that “Robust legal and institutional safeguards” ensure and verify that medical professionals working with persons with disabilities are trained in the rights recognized in the present CRPD (according to Article 4 of the CRPD).

**§30 Duty to protect life – Fighting stigma, prejudice and superstition & medical examinations**

Stigma, prejudice and superstition remain major threats to the life and well-being of children and adults (born) with disabilities and chronic conditions and to their entitlement to enjoy a life with dignity.

While some person with disabilities may also have a (chronic) disease, this is by no means true for all. The assumption that disability and poor health are equal is yet another prejudice.

* We therefore recommend to edit the existing phrase in §30 [“States parties should also develop action plans...”] into “strategies to fight the stigmatization associated with diseases and disabilities...”

Another strategy “to address the general conditions in society that may eventually give rise to direct threats to life...” would be raising awareness, in line with Article 8 of the CRPD.

* We recommend that States parties should adopt effective measures “to combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life” and create public awareness campaigns “designed to nurture receptiveness to the rights of persons with disabilities”.

States parties should indeed develop campaigns “for improving access to medical examinations and treatments designed to reduce maternal and infant mortality”. However, we must highlight that prenatal medical examinations do in fact contribute to infant mortality, due to the termination of life of developing children with (non-fatal) congenital conditions.

For this reason, IF advocates for primary prevention of neural tube defects (NTDs), such as Spina Bifida, through mandatory fortification of flour with Folic Acid and Folic Acid supplementation. Measures to end malnutrition also contribute to the prevention of NTDs by improving the diet of women of childbearing age. IF also advocates for the prevention of Hydrocephalus, for instance by raising awareness on the importance of reducing the risk of premature birth and neonatal infections, and by promoting a healthy lifestyle.

**§30 Duty to protect life – Pollution of the environment and §65 Environmental degradation**

We wholeheartedly agree that it is crucial for future generations that the environment should be protected against harm and pollution. In particular for pregnant women pollution of the environment, whether it is the air, water, or soil, can have a detrimental effect on their developing child. This can lead to spontaneous miscarriages, or to prenatal detection followed by termination of pregnancy.

* We do recommend that the Committee reconsiders its position with regard to the rights of developing children, as their health and well-being also determines the health and well-being of the future generation.

1. [Results of selective treatment of spina bifida cystica](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1627397/) [↑](#footnote-ref-1)
2. [IF Resolution on prenatal diagnosis and the right to be different](https://www.ifglobal.org/images/stories/pregnancy/toulouse-resolution-right-to-be-different.pdf) [↑](#footnote-ref-2)
3. [Sustainable Development Goal 16](https://sustainabledevelopment.un.org/sdg16) [↑](#footnote-ref-3)
4. [UN Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) [↑](#footnote-ref-4)
5. [World Report on Disability (2011)](http://www.who.int/disabilities/world_report/2011/en/) [↑](#footnote-ref-5)
6. [Groningen Protocol (2005)](http://www.nejm.org/doi/full/10.1056/NEJMp058026) [↑](#footnote-ref-6)