**Bioethics and Disabilities**

IF response to the questionnaire launched by

the UN Special Rapporteur on the Rights of Persons with Disabilities

September 2019

**Introduction**

The [**International Federation for Spina Bifida and Hydrocephalus (IF)**](http://www.ifglobal.org) is a global organisation of persons with disabilities governed by adults with spina bifida and/or hydrocephalus (SBH), or parents of children with SBH. IF’s mission 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. Universal respect of the rights reaffirmed in the UN Convention on the Rights of Persons with Disabilities (UNCRPD)for all children and adults with SBH is IF’s underlying philosophical base, and we support the call to leave no one behind through the implementation of the Sustainable Development Goals (SDGs).

IF is a member of International Disability Alliance, the European Disability Forum and the International Disability and Development Consortium, as well as the European Patients’ Forum, EURORDIS and Rare Diseases International. IF has held consultative status to ECOSOC since 1991.

**Spina bifida** is one of the most complex neural tube birth defects compatible with life, characterised by various degrees of damage to the spinal cord and consequent life-long health conditions necessitating care and support related to reduced mobility, urological and bowel management issues, orthopaedic needs, and weight management. Many people with spina bifida also develop **hydrocephalus**, which is an accumulation of excess cerebrospinal fluid in the brain. If untreated, hydrocephalus can cause blindness, intellectual disabilities, and premature death. Although those affected are usually born with hydrocephalus, a person can also develop the condition from neonatal infection, tumours, haemorrhage, etc.

We will be answering this questionnaire with a specific focus on spina bifida (SB) and hydrocephalus (H), congenital disabilities that can be prenatally diagnosed, provided that adequate knowledge and medical equipment are available and prenatal services are acceptable and accessible. There is also ongoing research into innovative procedures to try and improve the outcome for children with these lifelong disabilities.

**Prenatal diagnosis**

**The science**

In 1968, the World Health Organization (WHO) published a “Public Health Paper” by Wilson & Jungner: “Principle and practice of screening for disease”. The authors stated that **screening is not intended to be diagnostic** and that referral is needed to a physician for diagnosis and necessary treatment. They also described the various types of screening, including “selective screening”, “early disease detection” and “case finding”. According to Wilson and Jungner: “**Early detection (case-finding) aims at discovering and curing conditions** which have already produced pathological change...”[[1]](#footnote-1)

In 1974 it was discovered that raised serum amniotic fluid alphafetoprotein (AFP) was associated with open spina bifida. Similar to information stated by Wilson and Jungner, this type of maternal blood screening did not result in a diagnosis, it only indicated the likelihood of spina bifida being present in the foetus.

However, ultrasound advances moved in parallel with those made in the laboratory, and this made it possible – when indeed present – to positively diagnose spina bifida and hydrocephalus in a foetus while still in the womb, at around 20 weeks of gestation.[[2]](#footnote-2) In countries with adequate resources, the 20-week ultrasound to detect foetal structural congenital disabilities started to become standard practice.[[3]](#footnote-3),[[4]](#footnote-4) The WHO listed “(early) ultrasound” as part of pregnancy care for “fetal anomaly scanning” and “prenatal diagnosis” in its 2010 “Birth Defects Report by the Secretariat”[[5]](#footnote-5), which was accompanied by the WHO Birth Defects Resolution WHA63.17.[[6]](#footnote-6)

In 2016, the WHO published its **recommendation on early ultrasound in pregnancy**, meaning before 24 weeks of gestation, to improve a woman’s pregnancy experience, but also to **improve the detection of fetal anomalies**.[[7]](#footnote-7)

Currently, researchers have been looking at the effectiveness of a 12-13-week ultrasound for the diagnosis of foetal congenital disabilities.[[8]](#footnote-8) (See also “Disability-related abortion”.)

**The ethics**

As Wilson and Jungner pointed out, screening – and diagnosis – should be aimed at discovering and **curing** conditions. While the prenatal screening field was still in development in 1968, Wilson and Jungner already referred to the use of antenatal – selective – screening, where “congenital conditions are sought by the application of simple tests.”

What we would like to point out here is that while the mother-to-be will be the one undergoing the medical screening and diagnostic procedures, it is – also – the health of the foetus that is being assessed, including possible congenital disabilities. With the development of maternal-foetal medicine from the 1970’s onwards, this eventually led to the concept of “**the foetus as the patient**”.[[9]](#footnote-9) Regardless of this, it will always be the mother, and where applicable the parents, who will have to give informed consent to any follow-up procedures that will have an impact on the foetus, their unborn child.

When prenatal screening and diagnosis were first introduced for SBH no cure was available, only treatment, similar to the situation we face today. With the difference that in the 1970’s and 1980’s, there was a debate taking place about selective treatment for children diagnosed with SBH. Those that were deemed to have a “poor prognosis” were not treated and only given palliative care[[10]](#footnote-10).

In the Netherlands, in 2005, the notions of an extremely poor prognosis and a poor quality of life led to the development of the so-called “Groningen Protocol”, which established a framework that allows for the termination of life of “severely ill newborns” - up until one year of age - without legal consequences.[[11]](#footnote-11),[[12]](#footnote-12) (See also “Euthanasia and assisted suicide”.)

**The issue**

When following the Wilson and Jungner criteria, prenatal screening should lead to an accepted treatment for the patient, facilities for diagnosis and treatment should be made available, and there should be an agreed policy on whom to treat as patients. Yet, as mentioned before, for SBH **treatment will not result in a cure**; it is aimed at preventing further damage to the spinal cord, preventing infection of the wound, managing hydrocephalus, and addressing other physical conditions (e.g. clubfoot, scoliosis).

As a result, the medical world started to see prenatal screening and diagnosis as “**preventive medicine**”. Termination of pregnancy was offered as “the only means available for reducing the number of live infants born with these congenital defects”.[[13]](#footnote-13)

Yet not all parents were willing to take part in prenatal screening, and not all parents wanted a termination of pregnancy. As stated by Gagen in “Ethics, justification and the prevention of spina bifida” (2007), “the reluctance of parents to go through the full process was seen as a **hindrance to efficacy of the prevention programme**, rather than a point at which genuine ethical discussion could take place. Moreover, parental concerns were interpreted as affecting the success of prevention of spina bifida, materially and negatively”.

Unfortunately, up to this day, parents who refuse to undergo prenatal screening and/or refuse termination of pregnancy when they receive the diagnosis spina bifida for their unborn child, can be met with disbelief, disrespect, continued requests to change their mind, and even hostility at the workplace when needing time off to care for their child.

Contemporary philosophers such as the Australian Peter Singer, who link disability with “suffering”[[14]](#footnote-14) and openly advocate for the abortion of children with disabilities, contribute to this persisting negative and stigmatising point of view.

In 2005, IF launched its “**Policy Statement on Prenatal Diagnosis and the Right to be Different**”, which was also adopted by the European Disability Forum (EDF), stating that the existence of spina bifida in a foetus is not a sufficient reason for termination and that parents must feel free to make a choice.[[15]](#footnote-15)

**Disability-related abortion**

As mentioned with prenatal diagnosis, screening followed by termination of pregnancy (or “averting the birth”) of a wanted child was embraced by the medical world as a way to reduce the prevalence of certain types of birth defects, in particular when a child had Down syndrome or spina bifida. Detecting a disability in a foetus and then terminating the pregnancy was primarily seen as cost saving in a period of financial difficulties. The overall – financial – benefit of the prenatal screening programme was estimated to be greater than its costs.

In the 1970’s, when these medical practices were introduced, persons with disabilities were still mainly perceived as “costly and unproductive citizens”. They were often described as a **burden**, to their families and to society, and faced a lot of stigma, discrimination and an inaccessible and uninviting environment. The disability rights movement was only just starting at this time, and the rights of the foetus or newborns with disabilities were not being discussed.

With regards to the parents, apart from the belief that they would “benefit” from not having a child with a disability (financially and psychologically), it was also thought that “termination half-way through an affected pregnancy causes less upset than a still or neonatal death, and the distress which a severely handicapped child imposes on a family”.

In reality, many parents struggle to make the irreversible decision to end the life of their unborn child, a child they wanted, or to continue their pregnancy without knowing what life will hold for their child with a disability, often only having been told all the possible medical consequences. Still, doctors do not have a “crystal ball” and they can’t say with certainty what the exact complications will be for a child with spina bifida and/or hydrocephalus at 20 weeks of pregnancy.

Even today, when in various countries there is the option of foetal surgery for spina bifida, which has to take place before the 26th week of pregnancy and which can have an impact on the health and well-being of the mother too, making a decision for their unborn child remains incredibly difficult.

This is especially true in situations where there is no access to **adequate and unbiased counselling and support**, making the right decision an even greater challenge to overcome.[[16]](#footnote-16) Even when people ultimately have made a decision on behalf of their unborn child with a disability, they may continue to have doubts as to whether they made the right decision for many years afterwards.[[17]](#footnote-17), [[18]](#footnote-18)

In the Netherlands, the government has now decided to start offering a **standard 13-week ultrasound** to all pregnant women, to offer parents more time to decide whether or not to have an abortion when the scan reveals a birth defect or disability.[[19]](#footnote-19)

In a 2017 article, Dutch researchers state: "An early scan performed at 12-13 weeks' gestation by a competent sonographer can detect about half of the prenatally detectable structural anomalies and 100% of those expected to be detected at this stage. Particularly severe anomalies, often causing parents to choose TOP [Termination Of Pregnancy], are amenable to early diagnosis. The early scan is an essential part of modern pregnancy care."[[20]](#footnote-20) They also believe that an early termination of pregnancy will be “less traumatic for the mother”.

It is important to keep in mind that congenital disabilities such as spina bifida and down syndrome are in most cases compatible with life. Yet termination of pregnancy is advised – again and again – on the basis of a perceived “poor prognosis” and an expected “poor quality of life”. While many children and adults with spina bifida continue to prove their doctors wrong and grow up similar to their peers who are without disabilities (provided they receive timely and adequate treatment and care) the medical opinion with regard to spina bifida and hydrocephalus is slow to change in various parts of the world, even in developed countries. In 2004, this led to the publication by authors Dr. Joseph P. Bruner and Dr. Noel Tulipan, of their article “Tell the truth about spina bifida”.[[21]](#footnote-21)

**Informed consent to medical treatment and scientific research**

As pointed out earlier, prenatal screening is performed on the mother, but can lead to a diagnosis for the foetus. With ongoing improvements in medical science, nowadays a prenatal diagnosis of spina bifida can be followed by in-utero surgery. Again, it will be the parents who will have to give informed consent to this type of treatment, which will still offer no cure, but will prevent further damage to the spinal cord, will significantly reduce the risk of hydrocephalus developing, and will improve mobility.

However, not every mother or foetus may be a candidate for this type of surgery. Parents who decide to continue the pregnancy will have to give informed consent for the treatment of their child with a disability after birth, and often several times during their childhood years. Accurate, up-to-date, clear and unbiased information is key for families to be able to make these highly important decisions which will have a lasting impact on their child’s life and future.

When growing up, children with lifelong disabilities such as spina bifida and hydrocephalus need to be properly prepared and empowered to be able to make these important decisions about their health themselves, ready for when they reach adulthood.

Both parents and people with disabilities should have access to appropriate information and be able to fully understand whether medical treatment is experimental or whether it is considered to be standard practice. Information should be based on science and not misleading. For example, while researchers are currently looking into the application of stem cells in the treatment of spina bifida in the womb, it is far too soon to consider this a “cure”.[[22]](#footnote-22) Even more disturbing are the commercial companies that offer stem cell treatment to children and adults with spina bifida[[23]](#footnote-23), without any scientific evidence of its effectiveness.

For people with cognitive disabilities, it is key that the information provided to give consent to medical treatment or participation in scientific research is in a suitable format, and measures should be in place to ensure that they have understood the information correctly and that they are giving their consent willingly. Adequate protection of the rights of persons with disabilities who are represented by a legal guardian should also be in place to ensure that no decisions are made against their will.

**Euthanasia and assisted suicide**

Children born with spina bifida are an extremely vulnerable group of newborns. Due to their disabilities, they are not only at risk of abandonment, neglect and non-treatment, they also are at risk of termination of life. For instance, there is anecdotal evidence of the killing of children with disabilities in Kenya[[24]](#footnote-24) and in Tanzania.[[25]](#footnote-25)

However, as mentioned before, not only in developing countries are the lives of newborns with disabilities at risk. Since 1985, in the Netherlands, euthanasia for competent persons **older than 16 years of age** has been legally accepted. Yet end of life decisions are also made in neonatal care units and paediatric wards for newborns and infants. In their 2005 paper, “[The Groningen Protocol – Euthanasia in severely ill newborn](https://www.nejm.org/doi/10.1056/NEJMp058026)”, Dr. Verhagen and Dr. Sauer stated: “Twenty-two cases of euthanasia in newborns have been reported to district attorneys' offices in the Netherlands during the past seven years”. However, a survey they held had “indicated that such procedures are performed in 15 to 20 newborns per year”, suggesting that most cases were simply not being reported.

All 22 cases that were reported earlier involved children with what is described as “severe forms of spina bifida”. The discrepancy in the numbers led the authors to develop a “protocol”, in close collaboration with a district attorney, with general guidelines and specific requirements related to the decision about euthanasia of “severely ill newborns” and its implementation.

While the authors admit that “suffering is a subjective feeling that cannot be measured objectively”, the protocol’s requirements are based on an expected extremely poor quality of life (even if this may be in the future), **presumably unbearable suffering**, and all with no hope of improvement.

Their publication was countered by Dr. T.H. de Jong in the Netherlands, who wrote “[Deliberate termination of life of newborns with spina bifida, a critical reappraisal](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2092440/)”, stating that: “...‘Unbearable and hopeless suffering’ cannot be applied to newborns with MMC [myelomeningocele; spina bifida]. They are not ‘terminally ill’ and do have ‘prospects of a future’. In these end-of-life decisions, ‘quality of life judgments’ should not be applied. ...”[[26]](#footnote-26)

Nevertheless, the Netherlands introduced the regulation of termination of life of neonates up to one year of age in 2007, which was revised in 2015[[27]](#footnote-27), together with the regulation of late termination of pregnancy[[28]](#footnote-28).

This year, in April 2019, it was published in the news that in Belgium doctors have expressed interest in a similar regulation as the ‘Groningen Protocol’. More than 60% of respondents to a survey among neonatologists and nurses were in favour of being able to “end the suffering of sick babies”.[[29]](#footnote-29)

In 2011, IF published its “Position Paper on the Groningen Protocol – Disability Stereotypes, International Human Rights and Infanticide” developed by public interest lawyer James E. Wilkinson to review the Groningen Protocol according to human rights principles.[[30]](#footnote-30) Our position is clear: “**Stereotypes about the lives of people with disabilities drive these recommendations. These practices are perhaps the most serious instances of disability discrimination**.”

While little information is available about euthanasia for people with disabilities, the prevailing negative assumptions with regard to expected poor quality of life and unbearable suffering (without prospect of improvement) of persons with – lifelong – disabilities could influence doctors’ decisions when asked for their consent. Here too, protection needs to be in place for people with intellectual disabilities[[31]](#footnote-31).

**Summary**

Screening for disability in pregnancy was initially introduced by medical researchers and professionals in a time when people with disabilities were perceived as a burden to society and to their families and seen as “costly and unproductive citizens”.

Little to no ethical debate took place when prenatal screening and diagnosis for “foetal malformations” were introduced as a standard procedure for all pregnant women, even when there was no cure available for the conditions that were screened for. When an unborn child was diagnosed with a disability, termination of pregnancy was seen as the most logical and preferable outcome.

While the United Nations Convention on the Rights of Persons with Disabilities has brought a shift in society’s thinking with regard to people with disabilities, **stigma, prejudice, superstition and preconceived notions remain** and are difficult to remove. It could be argued that the promotion of the practice of prenatal screening followed by termination of pregnancy has contributed to the views that a life with a disability is not worth living. It is such a view that has led to non-treatment, selective treatment, and the ending of lives of newborns with disabilities.

Accurate, up-to-date, and appropriate information with regard to prenatal diagnosis and the conditions that are being screened for must be available to healthcare providers and medical students, parents(-to-be), persons with disabilities, and the general public. In addition, healthcare professionals need to be educated on the rights of persons with disabilities and trained to offer unbiased, suitable, and compassionate counselling.

Greater acknowledgement is needed of the fact that parents are asked to consent to procedures that could put them in a position to make a **life or death decision** about their unborn child with a disability, sometimes with very little information to go on, other than often very negative and agendered descriptions of the diagnosed medical condition(s).

Any information provided to parents(-to-be) and/or persons with disabilities for screening, medical treatment or participation in research needs to be accessible, understandable, and factual, and enough time should be allowed to digest the information, ask questions, and to seek input from others in order to give informed consent.

We greatly value this opportunity to express our concerns and to highlight the importance of a debate on the criteria being used in medical decision making, such as expected quality of life, presumed unbearable suffering, hopelessness, and the dignity and rights of persons with physical and intellectual disabilities.

For the board of directors and the Global Experts Panel of the International Federation for Spina Bifida and Hydrocephalus,

Warm regards,

  

Renée Jopp Lieven Bauwens Dr Margo Whiteford
Information officer Secretary General President

1. [Principles and practice of screening for disease (Wilson, Jungner; 1968)](https://apps.who.int/iris/handle/10665/37650) [↑](#footnote-ref-1)
2. [Prenatal screening for open neural tube defects and Down syndrome: three decades of progress (Wald; 2010)](https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1002/pd.2517) [↑](#footnote-ref-2)
3. [EUROCAT Special Report Prenatal Screening Policies in Europe 2010](https://www.orpha.net/actor/Orphanews/2010/doc/Special-Report-Prenatal-Screening-Policies.pdf) [↑](#footnote-ref-3)
4. [CDC, Diagnosis of birth defects](https://www.cdc.gov/ncbddd/birthdefects/diagnosis.html), visited 9 September 2019 [↑](#footnote-ref-4)
5. [WHO Birth Defects Report by the Secretariat (2010)](https://apps.who.int/gb/ebwha/pdf_files/WHA63/A63_10-en.pdf) [↑](#footnote-ref-5)
6. [WHO Birth Defects Resolution (2010)](http://apps.who.int/gb/ebwha/pdf_files/WHA63/A63_R17-en.pdf) [↑](#footnote-ref-6)
7. [WHO recommendation on early ultrasound in pregnancy (2016)](https://extranet.who.int/rhl/topics/preconception-pregnancy-childbirth-and-postpartum-care/antenatal-care/who-recommendation-early-ultrasound-pregnancy) [↑](#footnote-ref-7)
8. [Effectiveness of 12-13-week scan for early diagnosis of fetal congenital anomalies in the cell-free DNA era (Kerkhuis; 2018)](https://www.ncbi.nlm.nih.gov/pubmed/28397377) [↑](#footnote-ref-8)
9. [The fetus as a patient: an essential ethical concept for maternal-fetal medicine (Chervenak; 1996)](https://www.ncbi.nlm.nih.gov/pubmed/8796779) [↑](#footnote-ref-9)
10. [Results of selective treatment of spina bifida cystica (Lorber; 1981)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1627397/) [↑](#footnote-ref-10)
11. [The Groningen Protocol - Euthanasia in Severely Ill Newborns (Verhagen; 2005)](https://www.nejm.org/doi/10.1056/NEJMp058026) [↑](#footnote-ref-11)
12. [LZALP (Dutch website on late TOP and termination of life of newborns)](https://www.lzalp.nl/) [↑](#footnote-ref-12)
13. [Ethics, justification and the prevention of spina bifida (Gagen; 2007)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2598205/) [↑](#footnote-ref-13)
14. [Peter Singer says it’s OK to abort babies with Down’s syndrome (YouTube video; 2018)](https://youtu.be/tNn5htTKm30) [↑](#footnote-ref-14)
15. <https://www.ifglobal.org/publications/if-policy-statement-on-prenatal-diagnosis-and-the-right-to-be-different/> [↑](#footnote-ref-15)
16. [To the mother who is considering aborting her baby with spina bifida (blog article Amanda Kern, 2015)](http://www.amandakern.com/blog/2015/02/to-the-mother-who-is-considering-aborting-her-baby-with-spina-bifida/) [↑](#footnote-ref-16)
17. [Echo (Dutch book by Maarten Slagboom, 2011)](https://maartenslagboom.nl/boekecho/) [↑](#footnote-ref-17)
18. [«Baby Sighted» Conspicuous Ultrasond Findings and their Consequences (2001)](https://www.ta-swiss.ch/2001_40A_KF_ultraschall_dfe_3.pdf) [↑](#footnote-ref-18)
19. <https://nos.nl/artikel/2291827-13-weken-echo-wordt-standaard-voor-alle-zwangere-vrouwen.html> [↑](#footnote-ref-19)
20. [Effectiveness of 12–13‐week scan for early diagnosis of fetal congenital anomalies in the cell‐free DNA era (Kenkhuis, 2017)](https://obgyn.onlinelibrary.wiley.com/doi/full/10.1002/uog.17487) [↑](#footnote-ref-20)
21. [Tell the truth about spina bifida (Bruner, 2004)](https://obgyn.onlinelibrary.wiley.com/doi/full/10.1002/uog.1742) [↑](#footnote-ref-21)
22. [Researchers seeking a cure for spina bifida get a step closer to their goal](https://health.ucdavis.edu/publish/news/newsroom/13630) [↑](#footnote-ref-22)
23. [Stem Cell Therapy for Spina Bifida (Sino Stem Cells)](https://sinostemcells.com/stem-cell-treatment/spina-bifida/) [↑](#footnote-ref-23)
24. [Infanticide in Kenya: 'I was told to kill my disabled baby' (BBC, 27 September 2018)](https://www.bbc.com/news/world-africa-45670750) [↑](#footnote-ref-24)
25. [Bethany Kids 2009: Francesca's Story](https://youtu.be/8pKrOYXJ1KY?t=34) [↑](#footnote-ref-25)
26. [Deliberate termination of life of newborns with spina bifida, a critical reappraisal (de Jong, 2008)](https://www.ncbi.nlm.nih.gov/pubmed/17929034) [↑](#footnote-ref-26)
27. <https://www.government.nl/latest/news/2015/12/11/new-regulation-on-late-term-abortions-and-termination-of-life-in-neonates> [↑](#footnote-ref-27)
28. <https://www.government.nl/topics/euthanasia/euthanasia-and-newborn-infants> [↑](#footnote-ref-28)
29. [Grote bereidheid bij verplegers en artsen om zieke baby’s uit hun lijden te verlossen (Nieuwsblad, 17 April 2019)](https://www.nieuwsblad.be/cnt/dmf20190416_04334428) [↑](#footnote-ref-29)
30. [IF Position Paper on the Groningen Protocol (2009)](https://www.ifglobal.org/publications/if-position-paper-on-the-groningen-protocol/) [↑](#footnote-ref-30)
31. [Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012–2016)](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5838868/) [↑](#footnote-ref-31)