

Medical education and health workforce strengthening

IF Response to the consultation launched by the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

May 2019

This submission will focus on the key role of medical education in two aspects central to the global community of people with spina bifida and hydrocephalus (SBH): primary prevention of neural tube defects (NTDs) and ending stigma surrounding these disabilities. In doing so, we will predominantly focus on questions 4 (balancing biomedical paradigms with human rights) and 5 (mismatch of competencies to patient and population needs).

I. Medical education for effective strategies to promote primary prevention of NTDs

Since 1991, it has been scientifically proven that folic acid has a protective effect with regard to the prevention of NTDs¹. However, even today, this crucial information is not common knowledge², in particular among vulnerable groups of the population, such as women of low socio-economic status, women with low levels of education or women with disabilities. As a result, these women are at greater risk of having a pregnancy affected by NTDs.³

Primary prevention of NTDs through folic acid necessitates taking measures to educate healthcare professionals and ensuring that the general public will be reached. Each new generation needs to know about the essential role of folic acid in improving pregnancy outcomes, as well as the necessity to implement lifestyle and diet changes, including taking the recommended dose of folic acid in the *preconception* and early prenatal periods⁴.

Low awareness about primary prevention of NTDs puts the woman before painful choices and often results in pregnancy termination that can be associated with medical complications, lasting emotional hardship and ethical considerations.

Key messages:

1. Misconceptions about folic acid, such as the now disproved statement that high dose of folic acid is toxic and may provoke certain cancers, must be addressed by the medical community.⁵
2. Medical protocols, including those for primary care, need to include advise on folic acid supplementation for *all* sexually active women of reproductive age regardless of whether or not they are planning a pregnancy.⁶

¹ [https://www.thelancet.com/journals/lancet/article/PII0140-6736\(91\)90133-A/fulltext](https://www.thelancet.com/journals/lancet/article/PII0140-6736(91)90133-A/fulltext)

² <https://www.ncbi.nlm.nih.gov/pubmed/23658501>; <https://www.ncbi.nlm.nih.gov/pubmed/18185493>

³ Primary prevention with folic acid is effective up to 72%. There is a number of pregnancies that are affected despite good prevention protocols due to genetic or other reasons.

⁴ https://www.who.int/reproductivehealth/publications/maternal_perinatal_health/neural_tube_defects.pdf

⁵ Prof Stein Emil Vollest et al, "[Effects of folic acid supplementation on overall and site-specific cancer incidence during the randomised trials: meta-analyses of data on 50 000 individuals](#)", the Lancet 2013.

"[Towards an optimal intake of folic acid](#)" by the Dutch Health Council, 2014 (on file with IF in English).

⁶ A good example is [Argentinian Law 5988](#) from 2018 that guarantees free distribution of folic acid to all women of reproductive age in Buenos Aires.

3. Medical professionals must be trained to reach out to marginalised populations such as women with low levels of education, women with disabilities or those from poorer socioeconomic backgrounds. They should be able to deliver information in accessible formats and alternative methods of communication.
4. Medical professionals must be trained to deliver reproductive care of the same quality and volume to women with disabilities as to women without disabilities. Often today, women with disabilities are seen as sexless human beings who cannot or should not become mothers, preventing them from accessing information.

II. Medical education to promote the human rights based approach to disability and fight against stigma surrounding SBH

Spina bifida (SB) is one of the most complex birth defects compatible with life. Up to 80% of people born with spina bifida develop hydrocephalus (H). Both children and adults with SBH are at high risk of developing secondary medical conditions and may require repeated medical interventions throughout the lifespan. A multidisciplinary approach to SBH care is necessary to deliver the optimal range of personalised services to people and support their right to the highest attainable standard of health.⁷ Medical professionals are key actors in the lives of persons born with SBH and their families from the initial diagnosis through the lifetime of medical decisions and interventions.

Over the past 50 years, medical advances have resulted in increased survival of children with SBH. Nevertheless, the familiarity of the medical profession with this condition varies greatly. Too often is spina bifida automatically associated with “incompatibility with life”, “unbearable suffering” and low quality of life of the individuals concerned, affecting the choices made by the families of children diagnosed with the conditions. The most extreme cases include termination of pregnancy based on the disability of the foetus (up to 90% of all pregnancies are terminated in, for example, the Netherlands and the Nordic countries),⁸ active termination of life of newborn babies⁹ and separation of babies with SBH from their biological families in favour of institutional care.¹⁰

Although there are a number of relevant factors influencing the negative perceptions surrounding congenital disabilities such as spina bifida and hydrocephalus, the key role of medical professionals cannot be overestimated. In most countries with well-developed prenatal testing procedures, the diagnosis of spina bifida more often than not results in the parents’ decision to terminate the pregnancy. According to the accounts of IF members in these countries, peer counselling at this stage is uncommon, and the future parents form their understanding of the expected impact of spina bifida on their lives solely based on medical opinions of what the future child will not be able to do (e.g walk, run, stay continent, learn), disregarding the fact that children born with SBH can now survive and thrive and live their lives equal to others.¹¹

⁷ [IF Statement on Multidisciplinary Care for the treatment of children and adults born with spina bifida and hydrocephalus, October 2018.](#)

⁸ IF does not have a position on termination of pregnancy but advocates for the right of future parents to access objective information about the disability and receive appropriate counselling, including by associations representing persons living with spina bifida and hydrocephalus.

⁹ Cf [Groningen Protocol](#) in the Netherlands. [IF position on Groningen Protocol](#) was adopted in 2009.

¹⁰ <https://www.wearelumos.org/stories/2017/12/12/x/>.

¹¹ J.P. Bruner, N. Tulipan [“Tell the truth about spina bifida”](#), 2004.

Discriminatory legislation minimising the value of being born and living with a disability contributes to the stigma surrounding congenital disabilities and affects the manner in which they are presented to the families:

“The doctor is responsible for causing harm to parents born with a genetic illness due to the failure to properly inform the parents of the health condition of the child, so that they can take an informed decision to either seek treatment or terminate the pregnancy.... The harm includes mental suffering due to the child’s unexpected and unwanted disability due to lack of testing and genetic information. The parents are entitled to compensation for damages.

Article 33 of the 2015 Serbian Law on Prevention and Diagnosis of Genetic Conditions and Anomalies, and Rare Diseases”¹²

When SBH are diagnosed at birth, parents in some parts of the world are automatically offered to abandon the child into state care or may feel pressured by cultural beliefs and superstitions to leave their baby behind to die¹³.

“In general, doctors press parents of a newborn to put the baby to an institution for medical care, sometimes hundreds of kilometers away from the parents. The argument is that in the institution there are medical specialists who will provide the best care for the child... The paradox is that children are left without adequate medical care in the institutions - some are left without a shunt or a back closing, or these procedures are made very late. Not to mention urological care and catheterization. After all, doctors were right and the children die. More often because of the “great care” in the institutions. The sad thing is that some of these children are exceptional fighters. They manage to survive without a shunt and without a back closing for over a year. And parents during this period are like in a trance.”

Slaveya Kostadinova, Spina Bifida and Hydrocephalus Bulgaria

Key messages:

1. (Future) healthcare professionals have access to the most up-to-date information about surviving and living with congenital disabilities, which should be based on the latest research and reflect the advances in medical technologies.
2. Continuous collaboration between the medical profession and associations representing persons with disabilities and medical conditions is necessary for lifelong learning of the medical sector. Persons facing irreversible medical decisions should be offered counselling not only with professionals but also with experts by experience.¹⁴
3. Medical professionals should be trained in SBH protocols, such as the USA [Guidelines for the Care of People with Spina Bifida](#) 2018 or [SHIP \(Spina Bifida Interdisciplinary Programme\)](#) developed by the International Federation for Spina Bifida and Hydrocephalus that is widely used in the Global South.

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¹² [Zakon o prevenciji i dijagnostici genetičkih bolesti, genetički uslovljenih anomalija i retkih bolesti.](#)

¹³ <https://www.bbc.com/news/world-africa-45670750>;
<https://www.monitor.co.ug/SpecialReports/Untold-story-mercy-killing-disabled-children/688342-4320562-7p6gsdz/index.html>

¹⁴ [“Involvement of VSH vzw in Spina Bifida clinics in Flanders \(Belgium\).](#)