

# ABC of equality



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## Introduction

This short introduction to the international and European norms on the right to health is by no means an exhaustive reference. It has been put together to give the reader a taster of the human rights arguments that advocates at the national level should be making when they demand better quality healthcare services for people with Spina Bifida and Hydrocephalus (SB/H).

This guide should not be read alone. It accompanies IF toolkit for drafting advocacy strategies on the right to health, and should inspire the reader to set more ambitious, concrete and achievable objectives in relation to the right of health of all persons with SB/H.

It cannot be under-emphasised that the secretariat of the International Federation for Spina Bifida and Hydrocephalus remains at the disposal of its members for information, advice and support. We will remain in close contact with our members, proactively supplying relevant information and aiming to provide tailor-made support to all those who express the wish to try the research-based advocacy approach in relation to the right to health.

1. International human rights instruments that protect the rights of people with SB/H
2. SB/H and the European Union

Access to healthcare for people with SB/H is a human rights issue. The human rights argument is often lost in the debate about the availability, accessibility and cost of health services and procedures, and yet, it is very important to make it.

### **Why make the human rights argument?**

- Because people with SB/H are first and foremost persons who have inalienable and universal human rights. Only then are they clients, patients, somebody's children or service users.
- Because governments are bound by their international obligations to respect the right of men, women and children with SB/H to the highest attainable standard of health.
- Because speaking in the human rights language is likely to bring onboard many supporters of your cause who are not necessarily experts in SB/H, such as disability movement, human rights defenders, children's rights organisations and women's rights activists. Together we are stronger!

## What is the right to health?

The right to health does not mean the absence of illnesses. It means the right to the enjoyment of a variety of goods, facilities, services and conditions necessary for the person to be as healthy as possible (i.e to 'achieve the highest attainable standard of health'). People's right to health imposes three types of obligation on governments:

### 1. The obligation to respect.

This obligation means that the States must refrain from interfering with the individual's right to health. In other words, the State is not permitted to deny or limit access to healthcare services; to withhold or misrepresent health information; to impose discriminatory criteria in accessing health by some groups of population; or to market unsafe medications

### 2. The obligation to protect.

This obligation requires States to prevent third parties from interfering with the right to health. This means taking measures to control the provision of healthcare by private actors; regulate the marketing of medical equipment and medicines; ensure that third parties do not limit people's access to health-related information; and make sure that health professionals provide healthcare to people with disabilities with their free and informed consent.

### 3. The obligation to fulfil.

This obligation includes the requirement to adopt a national health policy or strategy covering the public and private actors and including mechanisms to collect data and measure progress; ensure equal access for all to the underlying determinants of health, such as pre-natal healthcare and nutrition; provide counselling on health-related issues; and ensure that doctors and rehabilitation workers are properly trained.

## What international obligations are there to protect the right to healthcare by people with SB/H?

### The multitude of international norms

International human rights law is the first starting point to start exploring the human-rights based approach to healthcare. The general obligation to respect, protect and fulfil the right to health is found in the **International Covenant on Economic, Social and Cultural Rights**<sup>1</sup> (CESCR) that requires that countries make every possible effort, using all available resources, to ensure the enjoyment of the highest attainable standard of health by all people within its jurisdiction, without any discrimination<sup>2</sup>.

The **Convention on the Elimination of All Forms of Discrimination against Women**<sup>3</sup> (CEDAW) requires States to ensure that women have appropriate services in connection with pregnancy, including healthy nutrition and information about safe pregnancy and motherhood<sup>4</sup>.

This obligation is reaffirmed in the **Convention on the Rights of the Child**<sup>5</sup>(CRC) which also makes it clear that States must take measures to diminish infant mortality, to ensure the provision of medical assistance and health care to children, and to provide necessary health information to them<sup>6</sup>.

The protection of the right to health is also enshrined in the **Convention on the Rights of Persons with Disabilities**<sup>7</sup>.

1 <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>

2 Arts 2 and 12 CESCR

3 <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CEDAW.aspx>

4 Art 12 CEDAW

5 <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

6 Art 24 CRC

7 <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

## Special focus: UN Convention on the Rights of Persons with Disabilities

A country that ratifies a Convention must take measures to make sure that the rights of people protected under this Convention are respected. It then has to report to a respective international committee of experts on the steps taken to implement the Convention. These committees (there is one per each international treaty) adopt authoritative recommendations to the country with its views on the national situation. Although non-binding, these recommendations have strong political weight, and should be used to advocate for the right to health nationally.

**IF secretariat will help you identify relevant international recommendations that apply to your country!**

### **CRPD Committee Concluding Observations to Hungary, 2012:**

*17. The Committee notes with concern that the Act on the protection of the life of the foetus makes "abortive treatment possible for a wider circle than in general for the foetuses deemed to have health damage or some disability" (CRPD/C/HUN/1), thereby discriminating on the basis of disability.*

*18. The Committee recommends that the State party abolish the distinction made in the Act on the protection of the life of the foetus in the period allowed under law within which a pregnancy can be terminated, based solely on disability.*

### **CRC Committee Concluding Observations to Romania, 2009:**

*64. The Committee recommends that inequalities in access to health services are addressed through a coordinated approach across all government departments and greater coordination between health policies and those aimed at reducing income inequality and poverty. The Committee, in particular recommends that the State party improve sanitation and quality of care in health facilities (out patient clinics, hospitals) in deprived areas.*

*65. The Committee further recommends that the State party increase efforts to improve the health of infants and young children, particularly through paying more attention to pre-natal and postnatal care, increasing the number of baby-friendly hospitals and specially trained social workers in hospitals, setting up of a home visitation service aiming to prevent abandonment, neglect and abuse...*

## Why is the CRPD important?

- It is the first international human rights treaty that addresses people with disabilities specifically;
- It moves away from treating people with disabilities as objects of charity and patients medical interventions, and affirms their role as subjects of inalienable human rights;
- It clearly states that all available resources must be used to promote full inclusion of people with disabilities in the society, and prohibits discrimination of people with disabilities;
- It is binding on the countries that have joined it;
- It gives people with disabilities tools to complain about their rights' violations to the UN committee of international disability experts.

## Who does CRPD protect?

The Convention protects the rights of all persons with disabilities. They are defined as people who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Article 1). Unavailable, inaccessible or costly healthcare, lack of information about rights or discrimination can be some of the barriers that hinder the person's participation in the society.

## What rights do people with disabilities have under the Convention?

People with disabilities have exactly the same right to healthcare as people with disabilities. They cannot be discriminated against because they have a disability.

Discrimination can mean:

- Giving identical individuals different treatment without a reasonable justification;
- Giving distinct individuals the same treatment.

Therefore, when people with disabilities have distinct health needs, these must be respected and addressed. The obligation to ensure non-discrimination requires specific health standards to be applied to all individuals who need it.



The Convention clearly states that people with disabilities have the right to access, as closely to their homes as possible:

- **Disability-specific healthcare.** These are the medical and social services needed specifically because of their disabilities, such as early identification and intervention, services designed to minimise and prevent further disabilities, and orthopaedic or rehabilitation services;
- **General healthcare.** These are healthcare services that are available to the general population, such as immunisation, eye and dental care, gynaecological and reproductive health services, or complementary and alternative medicine. It is prohibited to provide fewer or less good services to people with disabilities because of their disabilities.

## CRPD Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

## What changes does the Convention bring to SB/H advocates?

- Most European countries<sup>1</sup> have become party to the CPRD. This means that the Convention takes the central place in the national legal system and supersedes national laws. The national legislation, policy and practice that contradicts the Convention must be removed and replaced by a Convention-compliant legislation, policy and practice. It is important to remind to the government that all branches of the government, as well as the national parliament, must respect the Convention!
- Thanks to the Convention, the principles of equality, non-discrimination and right to health that it protects are increasingly receiving more international attention and generating discussions around them. This is the opportunity for the SB/H organisations to make their voice heard and demand more equality in access to healthcare by people with SB/H.
- Following the ratification of the Convention, most countries have adopted (or are in the process of doing so) a national action plan to implement it. This is your opportunity to make sure that the relevant national ministry (usually the Ministry of Social Affairs) is aware about the barriers experienced by people with SB/H and takes them into account when drafting the national action plan.
- In order to implement the Convention, based on the national action plan, the country must make dedicated budget available. This is your opportunity to put pressure on the government that this budget is used to address the SB/H issues.
- Every country that has joined the Convention must report to the UN committee of international disability experts, called the Committee on the Rights of Persons with Disabilities, about its efforts to live up to the Convention standards. The organisations of people with SB/H have the opportunity to give visibility to SB/H issues in the monitoring process, and submit their own reports to the UN, raising concerns about the right to healthcare of people with SB/H. **IF will support its members in engaging with the international processes.**

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<sup>1</sup> Except Finland, Ireland and the Netherlands (as of April 2014)

1. International human rights instruments that protect the rights of people with SB/H
- 2. SB/H and the European Union**

## Who is who in the European Union

### Why is the EU relevant to my work at the national and local level?

- A substantial proportion of rules that are applied at the national level originate from the European Union. The EU can regulate issues such as free movement of goods, services and people from one EU country to another; the transparency in pricing of medicinal products; or quality standards for the food and drinks consumed in the EU. The EU also has at its disposal impressive instruments to finance research, facilitate exchange of good practices, undertake projects and support NGOs.
- The European Union is able to exercise significant influence over its Member States even in areas where it does not have direct influence. The example is the close involvement of the EU in the national-level processes to close residential institutions for children and adults with disabilities that the EU supports politically and financially.
- The European Parliament is directly elected by its citizens every five years (next election is in May 2014). Members of the European Parliament are very well placed to promote at the EU level the issues of importance that has been brought to them by their national voters.
- The EU Agency for Fundamental Rights is able to monitor the situation of children and adults with disabilities in the EU countries. For example, in 2013 it published a report on **Inequalities and Multiple Discrimination in Access to and Quality of Healthcare**<sup>1</sup>. These are opportunities to bring visibility to the concerns of people with SB/H to the national and EU attention.

IF secretariat works to promote the rights of people with SB/H in the international and European Union policies. The best results are achieved when our work at the EU level is matched by similar activities at the national level. Therefore, basic understanding of the EU procedures and how they can benefit children and adults with SB/H is necessary.

View this **simple presentation**<sup>2</sup> to better understand how the EU works.

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1 <http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare>

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2 [http://europa.eu/abc/euslides/index\\_en.htm](http://europa.eu/abc/euslides/index_en.htm)

## Main European Union instruments that are relevant to people with SB/H

### European Disability Strategy 2010 - 2020

The **European Disability Strategy**<sup>1</sup> is the comprehensive policy instrument that the European Union adopted in 2010 to fulfil its obligations under the CRPD. **The overall aim of the Strategy is to empower people with disabilities so that they can enjoy their full rights, and benefit fully from participating in society and in the European economy.**

The Strategy focuses on eliminating barriers in eight main areas: **Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health and External Action.** In the area of Health, which is mainly under the competence of Member States, the European Union commits to support policy developments for quality health and rehabilitation services for people with disabilities, promote awareness of disabilities in medical schools and in curricula for healthcare professionals; promote the development of early intervention and needs assessment services.

### Employment Equality Directive

This **European directive**<sup>2</sup> protects against discrimination on the ground of disability in relation to employment and vocational training. The prohibition of discrimination also extends to non-disabled people who for one reason or another associated with someone who has a disability.

Sharon Coleman worked for a small law firm in London, UK. She had a disabled son Oliver for whom she was the sole carer. She was harassed by her employer and co-workers when she asked for flexible working time to enable her to care better for Oliver. She was ultimately fired, and filed a complaint against “unfair dismissal”. The European Court of Justice found that she was victim of disability discrimination, even though she was not disabled herself. This case **Coleman v Attridge Law**<sup>1</sup> is significant because it makes it clear that family members of people with disabilities must be protected against discrimination in the workplace and provided with means to care for their disabled relatives.

1 <http://bit.ly/1iHfvZf>

2 <http://bit.ly/1kruvG8>

1 <http://bit.ly/1iLGtZU>

## Directive on application of patients' rights in cross-border healthcare

The **EU Directive on application of patients' rights in cross-border healthcare 2011**<sup>1</sup> is the European law that recognises for the first time that patients have a right to receive healthcare services and be reimbursed for it in a country other than the country of their residence.

NB! This Directive is important to associations of consumers, patients, persons with disabilities, etc. Make sure to approach them when deciding what action to undertake to campaign for implementation! If you don't know what organisations are active in your country, see the following:

- Eurordis – Rare Diseases Europe<sup>2</sup>
- EPHA – European Public Health Alliance<sup>3</sup>
- EPF – European Patients' Forum<sup>4</sup>
- EDF – European Disability Forum<sup>5</sup>

## Directive “must-know’s” for SB/H associations<sup>6</sup>

### What type of care is covered in the Directive?

Care provided in the country of care (i.e abroad) can include:

- Consultation
- Examination
- Surgery
- Treatment, including medicines
- The above applies to the primary diagnosis of the person (i.e Spina Bifida), as well as other services (such as eye care or hip replacement).

1 <http://bit.ly/1kruvG8>

2 <http://www.eurordis.org/sites/default/files/members.pdf>

3 <http://www.eph.org/spip.php?rubrique14>

4 <http://www.eu-patient.eu/Members/The-EPF-Members/Full-Membership/>

5 [http://www.edf-feph.org/page\\_generale.asp?docid=28539](http://www.edf-feph.org/page_generale.asp?docid=28539)

6 Adapted from [http://www.eurordis.org/sites/default/files/Q&A\\_cross\\_border\\_care\\_final.pdf](http://www.eurordis.org/sites/default/files/Q&A_cross_border_care_final.pdf)

### Do I need to ask my Member State for prior authorisation before undergoing treatment in another country?

Each Member State must publish the list of treatments that must be authorised before the patients travels to another Member State to receive it. This list must be publicly available and include the explanation of the procedure to undergo to apply for prior authorisation. *The organisations of people with SB/H can advocate for exclusion of certain most typical SB/H treatments from the list to reduce the bureaucracy that the persons have to undergo.*

### Do patients need to pay full costs of treatment abroad in advance, and be reimbursed at a later stage?

Member States of affiliation (i.e where you live) may also decide to pay the healthcare provider directly. This is not an obligation, but an option.

### Can travel and accommodation also be reimbursed?

This is optional; Member States can decide to do so but are not obliged. *The organisations of people concerned by cross-border healthcare should advocate at national level for their Member State to use this option.*

### Can I seek healthcare abroad if the treatment is not available in my country?

If a treatment is not available in your Member States and it is NOT included in the “health benefits package”, then the authorities may refuse prior authorisation to undergo it in a different Member State. If a treatment is included in the “health benefits package” but it is not available for other reasons (such as long waiting list, unavailability of equipment or expertise), then the authorities cannot refuse. In this case, treatment provided abroad will be reimbursed. *The organisations must advocate for the most important SB/H treatments to be included in the “health benefits package”.*

## Can my Member State refuse prior authorisation for me to seek treatment in another Member State?

If the Member State refuses authorisation, it can ONLY be on one of the following grounds that must be clearly explained and justified:

- If the patient will be exposed to an unacceptable safety risk;
- If the general public will be exposed to a substantial safety hazard;
- If the healthcare is to be provided by a healthcare provider that does not comply (or may not comply) with standards and guidelines on safety and quality;
- If the healthcare can be provided on its territory within a medically justifiable time-limit.

## How can I receive detailed information about cross-border healthcare?

*National contact points*, established under the Directive, are obliged to provide patients with the most updated, accessible and complete information about medical treatment abroad. This includes information about patients' rights and entitlements, as well as practical aspects of receiving cross-border healthcare, e.g. information about healthcare providers, quality and safety, accessibility of hospitals for persons with disabilities, to enable patients to make an informed choice. *National SB/H association must cooperate with the national contact points to make sure that the information about SB/H treatment is accurate and updated.*

## If I can only receive treatment abroad, but it costs more than it would in my Member State, if it were available there, can full costs of treatment be reimbursed?

In cases where the actual cost of treatment in the country of care is higher than what would normally be reimbursed in the country of affiliation, the Member States can decide to reimburse the full cost (even if it exceeds the national ceiling). *This is not mandatory, so patients' organisations must advocate for this to happen!*

## Will the Directive also have an impact on cross-border exchange of best practices about medical treatments?

The Directive provides for reinforced cooperation between the EU and Member States in the development of diagnosis and treatment capacity, particularly for rare diseases. This includes reinforcement of the European networks of health professionals (so-called European Reference Networks), and improvement of the knowledge about funding treatments of rare diseases in different EU countries.

## To recap: advocacy opportunities for SB/H associations:

- Advocate for inclusion of the most important SB/H in the national "health benefits package";
- Advocate for the possibility to travel abroad to receive certain SB/H treatments without needing to apply for prior authorisation;
- Advocate for reimbursement of additional costs related to medical treatment abroad (such as travel, accommodation, bringing a personal assistant or a parent);
- Advocate for the reimbursement of the full cost of treatment abroad, even if it exceeds the national ceiling for comparable treatments;
- Make sure that the National Focal Points seek the most updated, complete and transparent information about SB/H treatments abroad.

## Third Health Programme 2014 – 2020

The new **EU Health Programme**<sup>1</sup> with the overall budget of € 449 394 000 aims to promote health, reduced health inequalities, encourage innovation in health and increase the sustainability of national health systems. Potential candidates for funding are national health authorities, public/private bodies, international organisations and NGOs with a general interest in health.

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1 <http://ec.europa.eu/eahc/health/index.html>



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