

**RIGHT TO HEALTH:  
REALITY OF PERSONS WITH SPINA BIFIDA  
AND HYDROCEPHALUS**





## Right to Health: Reality of persons with Spina Bifida and Hydrocephalus

### Foreword by IF President Dr Margo Whiteford BSc, FRCP

The United Nations Convention on Rights of Persons with Disabilities (UN CRPD) provides a framework for our rights and enables us to demand respect of those rights. Being healthy and staying healthy enables us to be active participants in the society. To us, people with spina bifida and/or hydrocephalus, staying healthy usually requires more specialist interventions than for people without a disability. It means being able to see specialist doctors when we need to see them, having different doctors communicate with each other to have the full picture of our health, and having our health needs attended to in a 'one stop clinic' that knows and respects our needs and preferences. In other words what we want, when we speak of fulfilling our right to health, is available, affordable and accessible **multidisciplinary care**.

This type of care already exists for people with some other disabilities in many European countries. In my own experience as doctor and member of several different multidisciplinary teams, I know how much people appreciate being seen in a timely manner by a coordinated team of professionals who have an in-depth understanding of their health needs. I also know that such a coordinated approach is an important element of preventing serious health complications that may lead to surgeries, lengthy rehabilitation and prolonged loss of independence for a disabled person!

The reality on the ground is extremely uneven for people with spina bifida and/or hydrocephalus across Europe. People are often faced with medical professionals who have no idea about SBH-specific health needs, the waiting lists are lengthy, putting the person at risk of medical complications, and the procedures themselves are far from accessible.

The main message of the findings of this report is that revisiting the way people with spina bifida and/or hydrocephalus access healthcare makes both good medical and economic sense. Most important, it makes sense under the UN Convention on the Rights of Persons with disabilities that confirms our right to the 'highest attainable standard of health without discrimination on the basis of disability'. Today, we call for urgent attention to the obligation to make health services to be accessible and available to all persons with disabilities!



## DEFINITIONS

### What is Spina Bifida and Hydrocephalus?

Spina Bifida (SB) is one of the most complex birth defects compatible with life, which can result in impaired mobility, loss of sensation, continence issues, and learning disabilities. The majority of children born with SB also develop Hydrocephalus (H), resulting in additional health concerns and learning disability. Both children and adults with SBH are at high risk for the development of secondary medical conditions <sup>1</sup>.

Access to healthcare and regular medical follow up are therefore crucial for persons with SBH to promote good health and prevent the development of life threatening conditions. The healthcare needs of persons with SBH are best addressed through multidisciplinary care, which is why IF advocates for access to multidisciplinary care for people born with SBH of all ages throughout the life-course <sup>2</sup>.

### What is the International Federation for Spina Bifida and Hydrocephalus (IF)?

IF was founded by people with SBH and their families in 1979, and its mission is to improve the quality of life of people with Spina Bifida and Hydrocephalus worldwide. It is now a professional Disabled People's Organisation (DPO) with global coverage and its fast-growing membership includes 62 member organisations from all parts of the world. IF is a full member of the European Disability Forum, European Patients' Forum and the International Disability Alliance. Three main working priorities of IF are:

1. primary prevention of neural tube defects through folic acid food fortification and supplementation;
2. equitable right to health by all persons with SBH; and
3. building a strong community of people with SBH and their families.

Article 25 of the Convention on Rights of Persons with Disabilities (CRPD) is particularly relevant for the work of IF. It provides a basis on which to demand the right to health for all people with SBH whereby they enjoy timely and appropriate access to healthcare without prejudice or discrimination.

### What is multidisciplinary care?

Children and adults with SBH need different specialists who can address their multiple medical and cognitive issues and promote a healthier lifestyle. This can include urologists, neurologists, orthopaedists, psychologists and others. Simply put, individuals with SBH need an integrated system to deliver this complex multidisciplinary care <sup>3</sup>. Services need to be age-appropriate and should ensure an effective transition from paediatric to adult care <sup>4</sup>. Multidisciplinary care is ideally delivered through a one stop clinic where the patient sees all the specialists he/she has to see without the need to get various appointments for different specialists at different locations. The multidisciplinary approach also relies on good communication within the team of specialists about the patient's condition. IF sees multidisciplinary care as the right care for persons with SBH.

<sup>1</sup> IF Statement on multidisciplinary care <https://goo.gl/XZ60Uk>

<sup>2</sup> IF Position Paper "Unfold their potential – Ageing with Spina Bifida and Hydrocephalus (2012)" <https://goo.gl/3Jk6OM>

<sup>3</sup> Liptak 2010: 'Optimizing health care for children with Spina Bifida' <https://goo.gl/QbtcMn>

<sup>4</sup> Sawin 2015: 'Transitioning adolescents and young adults with spina bifida to adult healthcare: initial findings from a model program' <https://goo.gl/CYJdch>



## DEFINITIONS

### What is the right to health?

The World Health Organisation (WHO)'s Constitution on the Rights of Persons with Disabilities (CPRD) enshrines "...the highest attainable standard of health as a fundamental right of every human being<sup>5</sup>". The right to health includes access to timely, acceptable, and affordable health care of appropriate quality. According to the CRPD "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<sup>6</sup>". By signing the Convention the States Parties commit to: providing the same standard and quality of free or affordable care to persons with disabilities as to others as well as providing disability specific care, to healthcare services being as close to communities as possible, to prohibiting discrimination in insurance, and preventing denial of healthcare due to disability<sup>7</sup>. The right to health is universal and non-negotiable.

### What is the CRPD?

CPRD is an international HR treaty adopted by the UN. It entered into force in 2007, and has, as of December 2016, been ratified by all but one EU Member States. The EU concluded the Convention in 2010, making it the first ever international human rights treaty to apply to the Union. The Convention codifies human rights of persons with disabilities and sets out the obligations of governments in this respect. It is based on principles of equality and non-discrimination, accessibility and meaningful participation of persons with disabilities in all areas of life that concern them.

### What is CRPD review of the European Union (EU)?

The Convention obliges the EU to take all measures to ensure the right of people with disabilities to health, personal mobility and participation, among others. In 2015, the EU's progress to fulfil its obligations under the Convention was reviewed by the CRPD Committee, and in September 2015 the Committee published recommendations, called Concluding Observations, outlining what actions the EU should take. Two recommendations of particular relevance to IF are:

#### **Article 5 Non Discrimination:**

The Committee recommends that the European Union adopt its proposed horizontal Equal Treatment Directive extending protection from discrimination to persons with disabilities, including by the provision of reasonable accommodation, to all areas of competence. Furthermore, the Committee recommends that the European Union ensure discrimination in all aspects based on disability is prohibited, including multiple and intersectional discrimination.

#### **Article 25 Health**

The Committee recommends that the European Union explicitly prohibit disability-based discrimination in the field of health care and take measures to ensure access to quality health care for all persons with all types of disabilities. It further recommends that the European Union evaluate the impact of its Cross-Border Healthcare Directive with regard to gaps in access for persons with disabilities, including accessible information, reasonable accommodation and training of professionals.

<sup>5</sup> World Health Organisation, Right to Health <https://goo.gl/89XXS3>

<sup>6</sup> UN OHCHR, Committee on the Rights of persons with disabilities, Convention on Rights of Persons with Disabilities Art. 25 <https://goo.gl/OFXo09>

<sup>7</sup> ibidem





## DEFINITIONS

The next progress report to the Committee is to be submitted by the EU by January 2019. The years leading up to it must be used efficiently to follow the Committee's Concluding Observations and make the Convention a reality for all persons with disabilities.

### **What is the horizontal equal treatment directive?**

If adopted, this European directive would protect people against discrimination on the basis of their disability, religion/belief, age or sexual orientation in the areas such as access to goods and services, education, or healthcare. However, the proposal for the directive adopted by the Commission in 2008<sup>8</sup>, has been blocked by the EU Member States who fear – despite the numerous evidence to the contrary – that the Directive would create undue burden on the private sector and be financially prohibitive.

### **What is cross-border healthcare?**

Cross-border healthcare refers to a mechanism in which the patient from one EU member state (where he/she is insured) uses the health services in another member state. People often seek healthcare elsewhere when a specific treatment is unavailable, the specific care in the other country is considered better or on doctor's recommendation.

### **What are European Reference Networks (ERN)?**

ERNs were set up by the Directive 2011/24/EU "on the application of patients' rights in cross-border healthcare"<sup>9</sup> and are designed to improve the access to diagnosis and the provision of high-quality healthcare to patients with rare and complex conditions<sup>10</sup>. This initiative is based on European cross-border cooperation of professionals and provides for the involvement of patients in order to deliver the best possible patient focused care.

<sup>8</sup> Proposal COM/2008/0426 final - CNS 2008/0140 <https://goo.gl/1G6JGx>

<sup>9</sup> Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross border healthcare OJ L 88, 4.4.2011, p. 45–65 <https://goo.gl/sMFC7B>

<sup>10</sup> More information about ERNs <https://goo.gl/XWHUI1>

## EXECUTIVE SUMMARY

This report maps the situation of persons with SBH in relation to healthcare access and is a follow up of the CRPD Concluding Observations Art.25. Through a comprehensive survey, IF collected valuable data on the experiences, satisfaction, and perceptions of healthcare coverage of individuals with SBH across Europe. Based on our findings, the financial coverage of treatment and assistive products for patients with SBH is grossly insufficient across the EU. Europe as a whole lacks multidisciplinary care and specialised SBH teams, which translates into long waiting times and insufficient knowledge of the SBH specificities. Only 17 % of people have a multidisciplinary clinic in their area.

Persons with SBH therefore have to wait weeks, months and in some cases over a year to obtain appropriate, specialist care. Very often people living with SBH face long distances to the nearest specialist or a multidisciplinary clinic, if there even is one in their country, which also means they have to take time off from school or work. These obstacles negatively impact every facet of their health and wellbeing.

These and other barriers render the necessary care inaccessible to persons with SBH and effectively prevent them from exercising their right to health. Delays in receiving care can lead to serious, even life-threatening, complications.

The existence of multidisciplinary care, or lack thereof naturally impacts on people's satisfaction with the care they receive; satisfaction was much higher in countries that have higher availability of multidisciplinary care, such as Belgium or Germany.

Considering these findings, IF urges the EU Member States to adequately support the healthcare needs of persons with SBH, and to invest more substantially into creating multidisciplinary clinics that can help avoid preventable complications<sup>11</sup> and may reduce the overall burden<sup>12</sup> on the patient and the system. In addition, the Member States should actively support creation of the European Reference Networks as a way of improving care for persons with SBH. IF also calls on the European institutions for support in training medical professionals on rights of persons with disabilities.

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<sup>11</sup> Wilson 2011: 'Targeted preventive care may be needed for adults with congenital spine anomalies' <https://goo.gl/E2DWEY>

<sup>12</sup> Kinsman 1996: 'The Cost of Preventable Conditions in Adults with Spina Bifida' <https://goo.gl/u4So7S>

# INTRODUCTION



In 2011 the CRPD entered into force in the EU. Two years later IF published its first report ('Active and healthy EU citizens') measuring access to healthcare for persons with SBH <sup>13</sup>. In addition, a checklist <sup>14</sup> created by IF and other DPOs following the report advocated for affordable, accessible and available health services, on-going education of healthcare professionals and their training on rights of persons with disabilities. After the CRPD Concluding Observations were published in September 2015, IF wanted to build on their recommendations. This is why the data collection was anchored in the CRPD Concluding Observations (Art.5 and 25) <sup>15</sup>. Just recently, the European Economic and Social Committee (EESC) called on the European Commission (EC) to take immediate steps regarding the directive to ensure it is compliant with the CRPD Concluding Observations <sup>16</sup>.

This year, 10 years of adoption of the Convention on Rights of Persons with Disabilities by the UN are being celebrated. This is a good moment to look at the work that the EU has done in the past to implement the Convention. Even more so, this is an opportunity to assess what still needs to be done. IF proposes to focus the discussion on article 25 of the CRPD and the right to health, given how essential this is for the fulfilment of other basic rights, such as the right to independent living, work or the right to education. When in good health, persons with disabilities can actively participate in society.

The Convention creates obligations for all the State Parties that have ratified it regarding rights of persons with disabilities that have to be respected and upheld in practice. It further reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms <sup>17</sup>. This treaty impacts the lives of 80 million people with disabilities living in the EU and sets a framework for their rights.

Provision of healthcare in the EU is not under the exclusive competence of the European institutions but it is rather shared between the EU and the Member states, with the EU focusing on cross-border healthcare and Member states on the care in their respective countries. Healthcare provision, reimbursement of medical costs, and social security measures vary greatly across the EU. In Spain, a woman with SBH will lose her disability support the moment she marries, while in Poland, a mother of a child with SBH must cover all costs of care herself. In Italy, a woman with SBH in a wheelchair has no other option than go to see a private doctor due to the unrealistic waiting times in the public hospitals, which carries an additional financial burden.

The structure of this report is as follows: First, it looks at coverage of medical care, assistive devices etc. and its impact on the health of persons with SBH. Next, a section is dedicated to relationships between patients and doctors, as this is essential in the lifelong management of conditions such as SBH. The third section discusses issues related to accessing healthcare, for instance the ease of access to the right care, availability of multidisciplinary care, waiting times and the situation in different EU Member States. Following that, the chapter on treatment of patients looks at the experience, perceptions and feelings of persons with SBH when using healthcare. The fifth chapter assesses the use of care with focus on the most recent medical visit and related issues. The final chapter looks at the overall satisfaction with care received as well as satisfaction with the respondents' own health. Some questions on cross-border healthcare were also included in the survey but received very low responses and therefore are not included in this report in detail.

Questions for the survey were designed based on the Model Disability Survey (MDS) <sup>18</sup> created by WHO and the World Bank and adapted to the reality of persons with SBH by IF staff. The draft survey was also consulted with a member of the IF Global Expert Panel. The survey was made available in 8 different languages: English, Dutch, Italian, French, German, Spanish, Polish and Portuguese in order to collect more data and at the same time ensure accessibility for people who do not have a sufficient command of English. Translations were made by using the resources of IF secretariat and IF members who volunteered to translate the survey. This is why it has been made available only in certain languages.

The data collection ran from the 15 June 2016 until 15 September 2016. Social media played an important role as it helped reach out to as many people as possible in an easy and accessible manner. The survey was distributed through email, social media and IF's monthly newsletter to the IF members in Europe who were encouraged to share the survey with their networks on local and national levels. It was also included on the IF website and promotional materials have been made and shared with IF members.

<sup>13</sup> IF report 'Active and Healthy EU citizens' <https://goo.gl/seo5rj>

<sup>14</sup> IF Disability and Healthcare checklist <https://goo.gl/Yc5kj5>

<sup>15</sup> Committee on the Rights of Persons with Disabilities; Concluding observations on the initial report of the European Union, p.3 & p. 8 <https://goo.gl/dYPZ1q>

<sup>16</sup> EESC Opinion: Concluding observations of the UN CRPD Committee – A new strategy for persons with disabilities in the EU <https://goo.gl/plUgib>

<sup>17</sup> European Disability Forum [www.edf-feph.org](http://www.edf-feph.org)

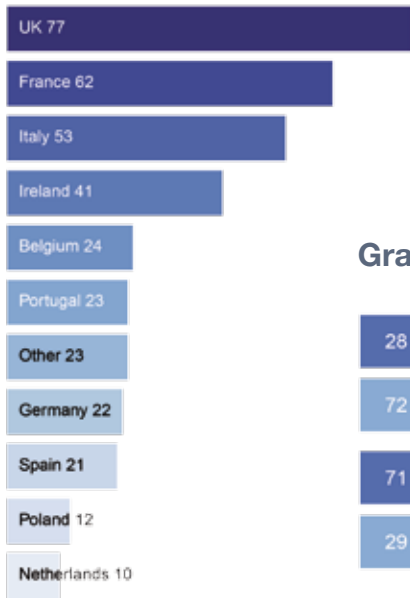
<sup>18</sup> World Health Organisation: Model Disability Survey; Providing evidence for accountability and decision-making <https://goo.gl/CRWSw1>



# GENERAL FINDINGS

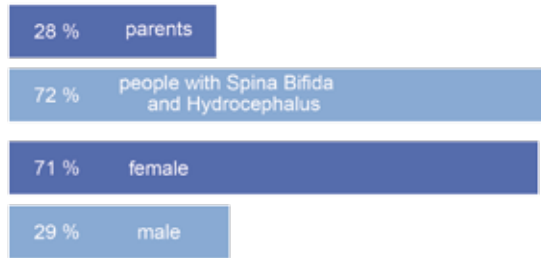


**Graph 1. Countries of respondents**

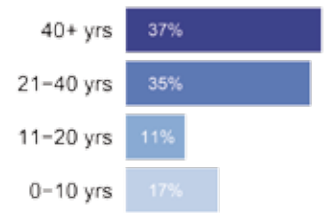


IF received responses from **368 persons**, including 100 parents and 261 persons with SBH, (7 respondents did not indicate this information). The data for age, sex, typology etc. can be found below.

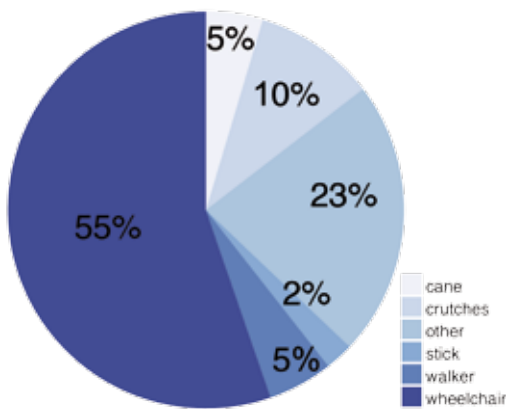
**Graph 2. Typology**



**Graph 3. Age**



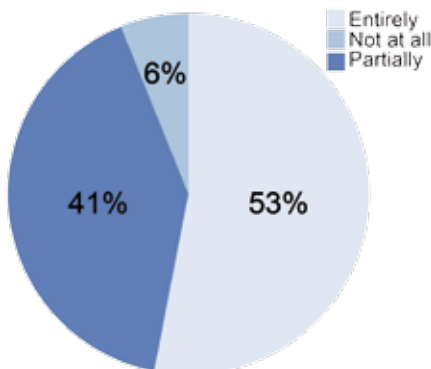
**Graph 4. Mobility devices**



The survey also assessed what kind of **mobility devices** people use; 55 % of respondents indicated they use wheelchair, which makes it the most common mobility device.

When the state does not provide full **coverage of the costs** of the SBH specific treatments that are on-going and require regular follow up, this will result in increased personal payments. This is the case for 41% of the respondents who stated that their or their child's medical expenses are only partially covered by the state, while 6% do not have any coverage at all. A full or partial contribution on the part of the patient is expected in these cases, which can pose additional financial challenges and pressures.

**Graph. 5. State covering the medical care**

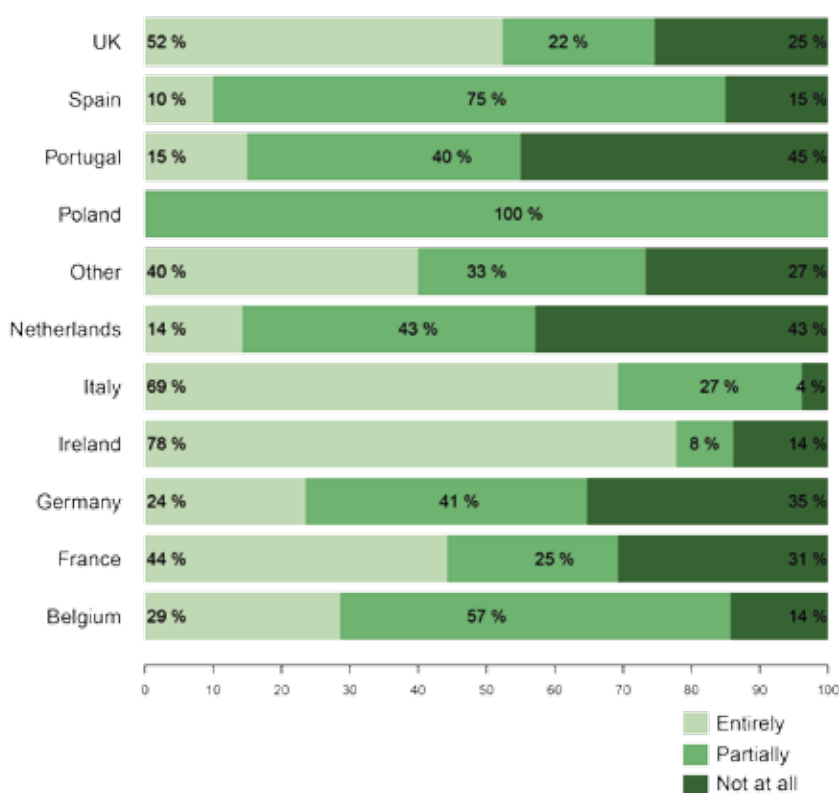


At the same time, most people (54%) rely on the state to cover their healthcare costs without having other sources of funding. Also, it is not usual to have the state fully cover the costs for mobility devices such as wheelchairs, walkers etc.

**Did you know that in many countries in Europe people with SBH still have to pay extra for treatments and supportive devices?**

The situation is similar in case of continence aids, where 29% have their costs covered partially and 18% not at all. With regard to the single Member States, the situation is best in Ireland and Italy, where 78 % and 69% respondents respectively have a full coverage of continence aids. On the other hand, states such as the Netherlands and Portugal have the highest number of cases where these aids aren't reimbursed at all.

**Graph 6. State covering the continence devices (by EU State)**



Not having their continence aids and mobility devices fully covered by the state severely impacts on the people with SBH who cannot afford to pay for them or contribute to their purchase. Not having access to sufficient catheters and other continence aids can lead to infections and other serious health complications. Both the lack of continence aids and appropriate mobility devices prevents persons with SBH to actively participate in social activities, education and work, and increases isolation. This isolation itself often results in the development of further issues affecting mental health such as depression. In addition to a gross human rights violation, this situation creates additional strain on the national healthcare system that eventually ends up having to cover costs of expensive treatments for medical complications resulting from inadequate coverage of primary health needs. These include treatments for kidney failure, urinary tract infections, pressure sores (may require surgery or even amputation in certain cases) and skin infections<sup>19</sup> as well as treatments for mental health problems that are often the result of denial of care.

“We have a two tier system. If you can afford to pay, there are many more options open to you and this puts pressure on the families that can't”  
**Ireland**

“Healthcare only covers the very basic of things that are needed or equipment etc. so I have to try to fundraise”  
**UK**

“We had to pay a sum of 2000 euro ourselves for a wheelchair and a tricycle”  
**France**

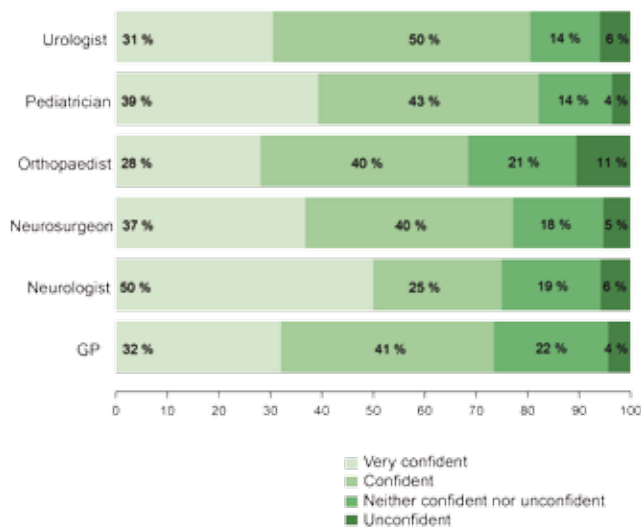
“In most of the cases we cover the costs of the treatments, rehabilitation and equipment ourselves. The state is supporting it at a very small degree or not at all.”  
**Poland**

“The financial and assistance support is very insufficient”  
**Spain**

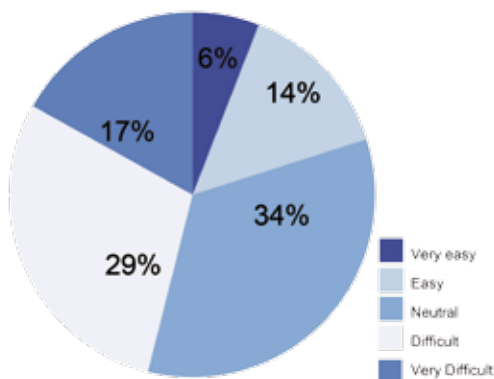
“Personal payments for chronically ill people needs to be reduced.”  
**The Netherlands**

<sup>19</sup> McDonnell 2000: 'Why do adults with spina bifida and hydrocephalus die? A clinic-based study' <https://goo.gl/sQQgul>

**Graph 7. Percentage of people confident in their doctors**



**Graph 8. Getting access to SBH-specialised healthcare**



## DOCTOR-PATIENT RELATIONSHIP

The relationship between a patient and doctor is essential in the healthcare process and should be built on mutual trust and respect, particularly when it comes to a lifelong condition such as SBH where follow up by specialists is on-going and necessary to prevent further health complications. As can be seen from the graph, the majority of people are confident in their specialists. This shows that once the necessary care is provided, people tend to trust their doctors and rate the experience largely positively.

## ACCESS TO THE RIGHT CARE = MULTIDISCIPLINARY CARE

Persons with SBH can have extensive healthcare needs (such as urinary infections, orthopaedic problems, pressure ulcers, obesity etc.)<sup>20</sup> that are best treated through multidisciplinary care involving a number of specialists.

People with SBH have problems in accessing healthcare; close to 50% of all respondents find their access to specialised healthcare difficult to very difficult. In this respect, the distance to care and lack of multidisciplinary care close to the patient's home play a significant role. Only 6% of the respondents find their access to the right care very easy. No significant outcomes have been recorded with regard to differences between child and adult care.

Persons with SBH from all over Europe have been calling for multidisciplinary care repeatedly. Unfortunately, the right to health is still not a reality for many people with SBH, with 27% of all SBH patients having to travel over 40 km to get the right care (that being specialised multidisciplinary care). This makes combining education or work with the necessary health treatments complicated and may even make the care inaccessible to them. Thirty eight percent of all respondents stated they do not have a multidisciplinary clinic in their area, compared to only 17% who do.

In order to optimise resources, SBH related services such as rehabilitation could be shared with persons with disabilities such as spinal cord injuries- this is the case in Sweden at the Spinalis<sup>21</sup> centre, which cares for persons with SBH but also for those with spinal cord injuries, head injuries, stroke and MS (Multiple Sclerosis) patients.

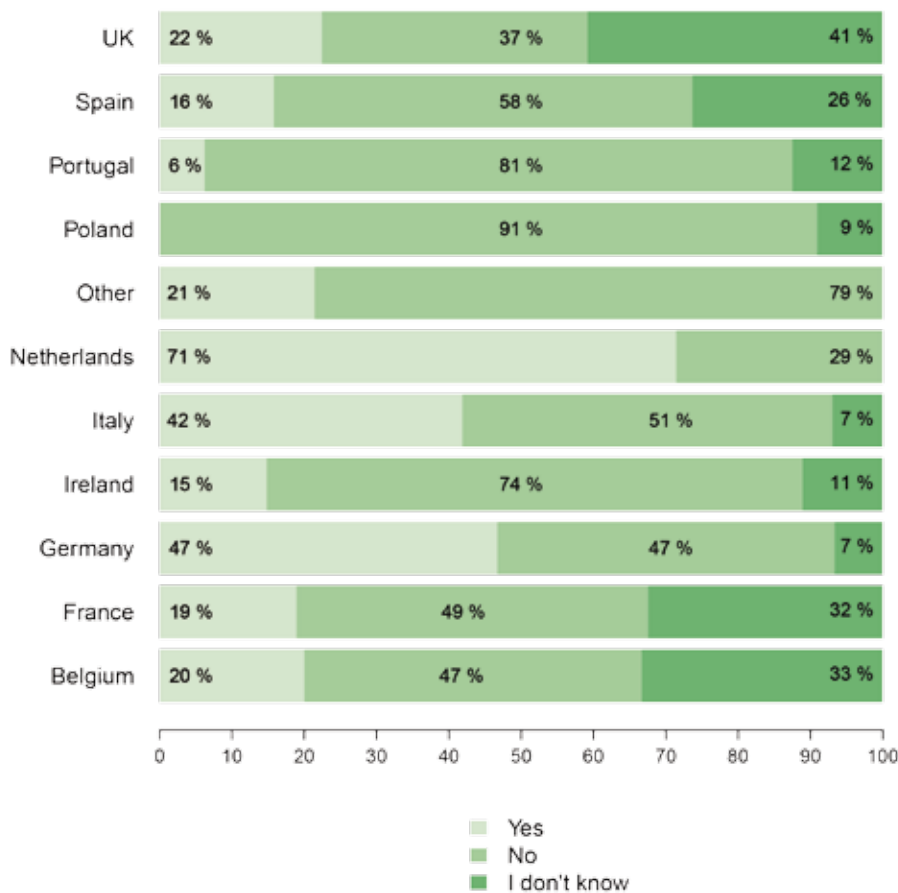
<sup>20</sup> Brei 2007: 'The Future of the Multidisciplinary Clinic' <https://goo.gl/OZ82K0>

<sup>21</sup> More information on Spinalis website: [www.spinalis.se](http://www.spinalis.se)



Some respondents have stressed that multidisciplinary care for adults is needed in their countries. It is indeed often the case that care for SBH patients only exists for children and youth until the age of 18. IF is aware of this situation for instance in Slovakia. Some European countries such as Belgium offer also adult care. Nowadays more and more people with SBH live until old age, meaning that individuals are living for a greater number of years with ever increasing health needs that are exacerbated by the aging process, and therefore there is an increased need for care throughout their lifespan; this should be reflected in the healthcare system.

**Graph 9. Multidisciplinary clinic in the area**



**What should be improved in provision of care to persons with SBH?**

“SBH centers for adults should be opened. So far only clinics for children exist.”

**Germany**

“There is no SBH center or multidisciplinary team that would bring together all the specialists from the area.”

**Austria**

“A multi-disciplinary team needs to be put together for adults in Ireland with Spina Bifida and hydrocephalus”

**Ireland**

“Having a SB clinic, having child specialists in every big town... coverage of catheters, equipment...”

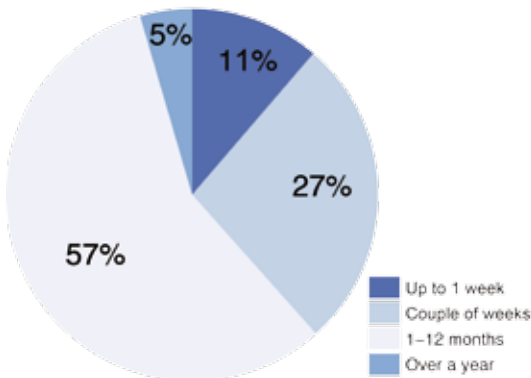
**Bulgaria**

“More sensitivity, more knowledge about SBH, more interest and a bigger number of doctors treating this condition”

**Portugal**

**Lack of multidisciplinary care in Europe is the primary obstacle for persons with SBH in fulfilling their right to health**

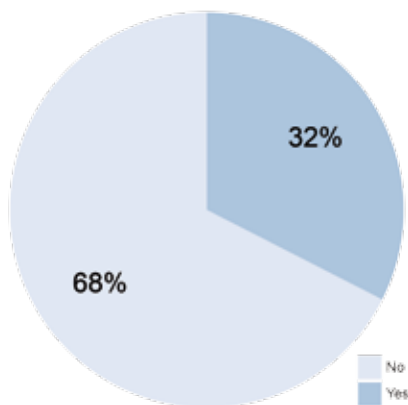
**Graph 10. Waiting time for specialist consultation**



Access to healthcare can be measured based on the availability of the appropriate care and also on the time that it takes before a patient receives the needed treatment. Very long waiting times for specialised consultations or surgeries may cause the patient with SBH to develop serious complications. The waiting times are closely connected to the availability of multidisciplinary care. In places where there is a specialised SBH team/clinic, the patient can usually see all the specialists during the same visit and therefore waiting times for different specialists (neurologist, urologist etc.) are avoided, and patients are seen by specialists that have a greater understanding of their condition as a whole.

As this graph shows it takes most often months before a person with SBH manages to see a specialist. Five percent of respondents have to even wait a year for a specialist consultation, which is likely to have a very negative impact on their health.

**Graph 11. Have you/has your child ever felt discriminated because of disability in general healthcare?**



**TREATMENT OF PATIENTS**

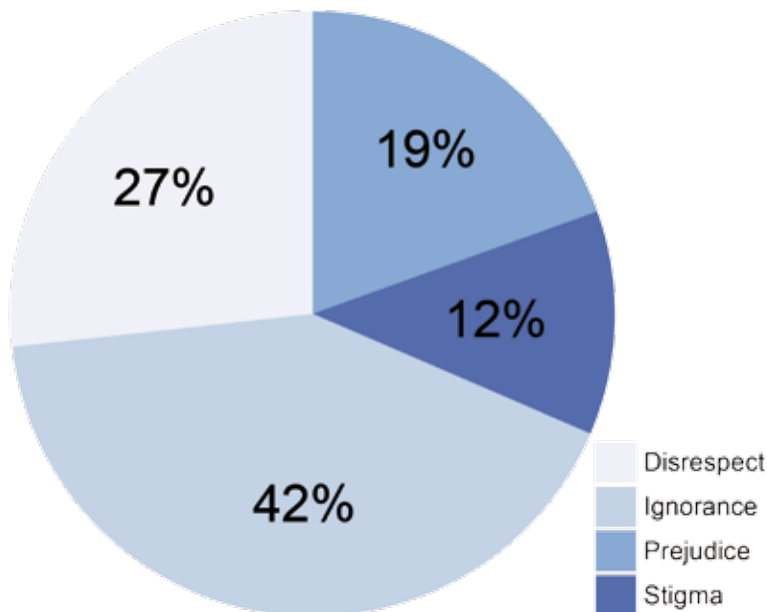
This question focused on the perception of discrimination as experienced by persons with SBH. By discrimination, we refer to a situation in which a person with SBH is being treated (or perceives that they are being treated) unfairly or not getting the changes he/she needs because of their disability. Discrimination is a critical issue that has regularly been reported by IF members over the recent years and it was therefore important to capture this in the survey. Equality and non-discrimination have been recognised as key issues by the CRPD committee where the EU must take action. The EU must ensure the absence of discrimination in all areas and provide reasonable accommodation in social services, health-care, housing etc. (Art.5 CRPD Concluding Observations) <sup>22</sup>. Discrimination in healthcare and other areas could be minimised if the EU adopted the proposed horizontal equal treatment Directive as recommended in the Concluding Observations <sup>23</sup>.

Out of the total, approximately one third (32%) of respondents felt discriminated against in general care, demonstrating a clear need for EU wide anti-discrimination legislation.

**People with SBH still experience discrimination in healthcare**

<sup>22</sup> Committee on the Rights of Persons with Disabilities; Concluding observations on the initial report of the European Union, page 3 <https://goo.gl/dYPZ1q>  
<sup>23</sup> Ibidem

**Graph 12. Have you/ has your child experienced negative societal attitudes because of disability (disrespect, ignorance, prejudice, stigma) in healthcare?**



The most common forms of discrimination reported by survey respondents were ignorance and disrespect, which can have profound implications on the self-esteem of persons with SBH. Twenty six percent of respondents indicated that they experienced discrimination at times.

Particularly, in healthcare and issues related to one's body it is essential to treat persons with lifelong conditions such as SBH with respect and inform them about their treatment options adequately. It is also necessary for the medical professionals to recognise patients with SBH (and other kinds of disabilities and conditions) as equal partners in care and value their opinions rather than dismiss their worries.

**The following kinds of discrimination when accessing healthcare were also reported:**

'Bad treatment, not being taken seriously, they didn't believe me, discrimination'  
**Germany**

'Rudeness, not taken seriously as the patient' –

'Lack of knowledge or awareness'  
**UK**

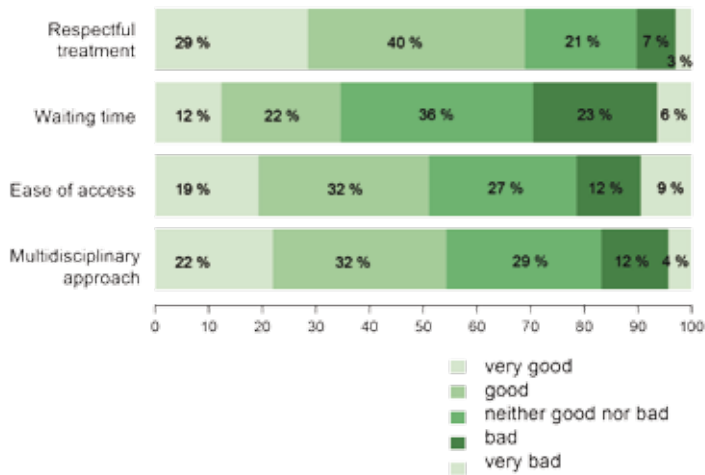
'Hurtful questions'  
**Lithuania**

'Infantilization, as if we didn't know our condition, what is good for us and what not...'  
**France**

'Lack of respect, ignorance and bullying'  
**Italy**

**Did you know that ignorance and disrespect are the most common forms of discrimination in healthcare?**

**Graph 13. When thinking about the last time you/your child accessed healthcare, how would you rate it?**



**USE OF CARE**

People felt generally positive about the treatment they received during their most recent medical visit. However, as can be seen in the graph, waiting times are still an issue that complicates access to care. Twenty nine percent of respondents rated waiting time as ‘bad’ and ‘very bad’.

Further to that, the majority of people with SBH reported having to take time off from school/work in order to access healthcare (44 % compared to 18% who do not, the remaining 38% did not indicate their answer), which means additional complications resulting from not being able to follow the school curricula or be present at work. This can severely affect the employability of persons with SBH as well as their right to work and education.

**SATISFACTION**

Only close to 29% of the respondents overall were satisfied with the care they receive. No significant difference has been recorded between child and adult care. Regarding single countries, people were most satisfied in Germany, the Netherlands and Belgium, where multidisciplinary care is widely available. It is possible that they were satisfied because those countries offer multidisciplinary care. In addition, this trend can be linked to knowledge of SBH, waiting times etc. The lowest satisfaction was recorded in Poland followed by Ireland, which were also listed as having none or very low multidisciplinary care coverage.

**Did you know that most persons with SBH often have to take time off from school or work just to stay healthy?**



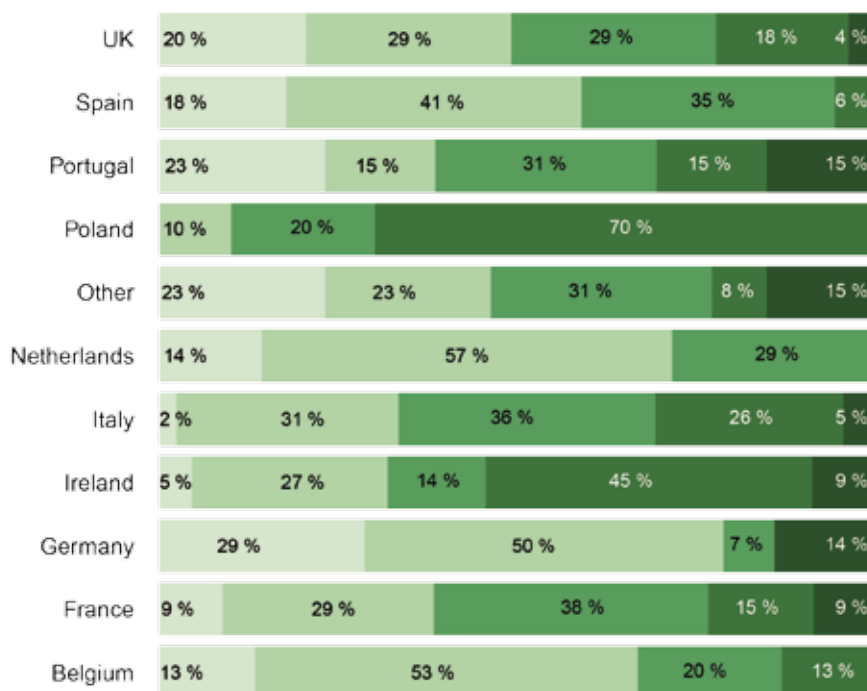
## Did you know that only very few people with SBH choose to use cross-border healthcare?

Over 85% of respondents chose to skip questions related to this topic, which shows that persons with SBH have not used this care or have never heard of it.

More thorough coverage on this is available in the report IF published in cooperation with EDF and EPF, focused more broadly on cross-border healthcare's impact on persons with disabilities and chronic conditions.

When asked about satisfaction with one's own health, only 26% of respondents viewed their health positively. Satisfaction with one's own health is a very personal matter and depends on many aspects of healthcare provision, which, as our data demonstrate, is far from perfect in most European countries.

**Graph 14. Satisfaction**



### Are persons with SBH happy with the care they receive?

'Bigger investment on behalf of the state are needed to improve medical assistance in co-relation with shorter waiting times, more staff and improving capacity of establishments. There are areas with more patients than available rooms in hospitals' **Spain**

'Doctors should be a bit more up-to date. The Spina Bifida of my son was discovered when he was already 2 years old and the angioma was being treated with cortisone' **Italy**

'The government decided to shut down the hospital close to where I live so I have to go to another one for 3 hours to have my 3 year old son with SBH treated. The journey is not reimbursed and neither is the equipment. Doctors don't know what SBH is. My son was refused the recognition of SBH as a disability because the authority doesn't know SBH.' **France**

'Doctors should specialize with SBH patients'.

**Lithuania**

'Money wastage in the HSE is a disgrace. If more money was spent on the important things we would have a better service' **Ireland**

# CONCLUSIONS



This report aimed at providing a holistic view of the right to health in practice and the challenges as experienced by persons with SBH in the EU.

The CRPD Concluding Observations Art.25 on Health called on the EU to “ensure access to quality health care for all persons with all types of disabilities”. Quality healthcare for persons with SBH is multidisciplinary care. The right to health and access to healthcare are still not a reality for everyone in the EU. Often, persons with SBH suffer from discrimination in access to healthcare through lack of multidisciplinary care, additional costs of care, negative attitudes and stigma, which prevent them from fully exercising their right to health.

In some Eastern European countries, such as Poland, there is no multidisciplinary clinic but also in Western European countries the situation is far from ideal (Portugal, Ireland). Multidisciplinary care is scarce, usually centred in the capital city which means patients have to travel long distances to see the specialists. This disproportionately affects persons with SBH who have the right to the same standards of appropriate care and a right to specific healthcare, which they need due to their disability. SBH is a lifelong condition, which requires on-going medical and management. This is particularly the case for shunts to treat Hydrocephalus, which are prone to failure, evaluation of the neurological bladder, assessment of diabetes risk, etc. Therefore, persons with SBH need to see the relevant specialists on a regular basis to stay healthy.

The main conclusion of the study is that far more **multidisciplinary care** is needed all over Europe. Without proper care, persons with SBH face additional life threatening complications. The same is true with regard to financial support for medical devices such as catheters, walkers etc. Without multidisciplinary care persons with SBH cannot fulfil their right to health. This will in turn have an impact on their other rights and other areas of life. The right to health enables persons with SBH to become active members of society.



## RECOMMENDATIONS

Considering the findings presented in this report, IF proposes the following recommendations:

By signing the CRPD, the EU Member States committed to 'provide those health services needed by persons with disabilities specifically because of their disabilities'. Therefore, Member States should invest into multidisciplinary care as a way of prevention of medical complications and costly surgeries that create an unnecessary burden on the health system and the lives of those with SBH. IF calls on the EU Member States to adequately reimburse the costs of care and assistive devices that are critical for the health and wellbeing of persons with SBH given that they made a commitment to provide "services designed to minimize and prevent further disabilities"<sup>24</sup>.

In the context of the CRPD Concluding Observations, the European Parliament must take a stand on the Right to Health of persons with disabilities supported by substantial research material i.e. its own study focusing on issues such as access to general/specialised care and the EU obligations in this field.

The European Commission should initiate and finance training modules on human rights of persons with disabilities for medical professionals, with the support of DPOs.

Member States are asked to actively support the creation of European Reference Networks (ERN) as a way of improving access to care and the care itself for persons with SBH across Europe.

In the framework of ERN, the European Commission should facilitate the creation of a list of fast access to care in another Member State for persons with SBH and other lifelong conditions.

<sup>24</sup> UN OHCHR, Committee on the Rights of persons with disabilities <https://goo.gl/Oy7Adu>





## FINAL WORD

This report is a clear call to action around access to care for people with disabilities generally, and those with spina bifida and hydrocephalus (SBH) specifically. SBH is a complex condition that requires on going monitoring and management by a multi-disciplinary team of experts. Although those with SBH are now living much longer lives than before, it is critical that they receive appropriate, specialised care in order to participate fully in life and the communities in which they live. The Convention on the Rights of Persons with Disabilities was hailed as a historic opportunity to create positive changes in healthcare provision for those with disabilities. In particular, Article 25 outlines the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. This includes early identification and intervention to minimize and prevent further disabilities and the provision of health services as close as possible to people's own communities. Although promising strides have been made in some areas, the findings in this report underline the fact that there is much more still to be done to ensure that all people can exercise their right to timely, appropriate and accessible health care. To make health dependent upon where an individual lives or their personal resources is discriminatory and unacceptable.

I therefore commend the International Federation of SBH for conducting the survey detailed in this report and strongly support the recommendations that have resulted from it.

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## ACKNOWLEDGEMENTS

IF would hereby like to thank Carolina Saskia Ballert (Dipl.-Stat, PhD, Health Scientist) who dedicated a substantial amount of her own time to provide us with the consolidated data sets and graphs.

IF would also like to thank the IF Global Expert Panel member Amy McPherson for her insightful feedback on the survey and the report.

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Funded by the  
European Union