



Multidisciplinary Care for Individuals with Spina Bifida and Hydrocephalus in Europe

An explorative study
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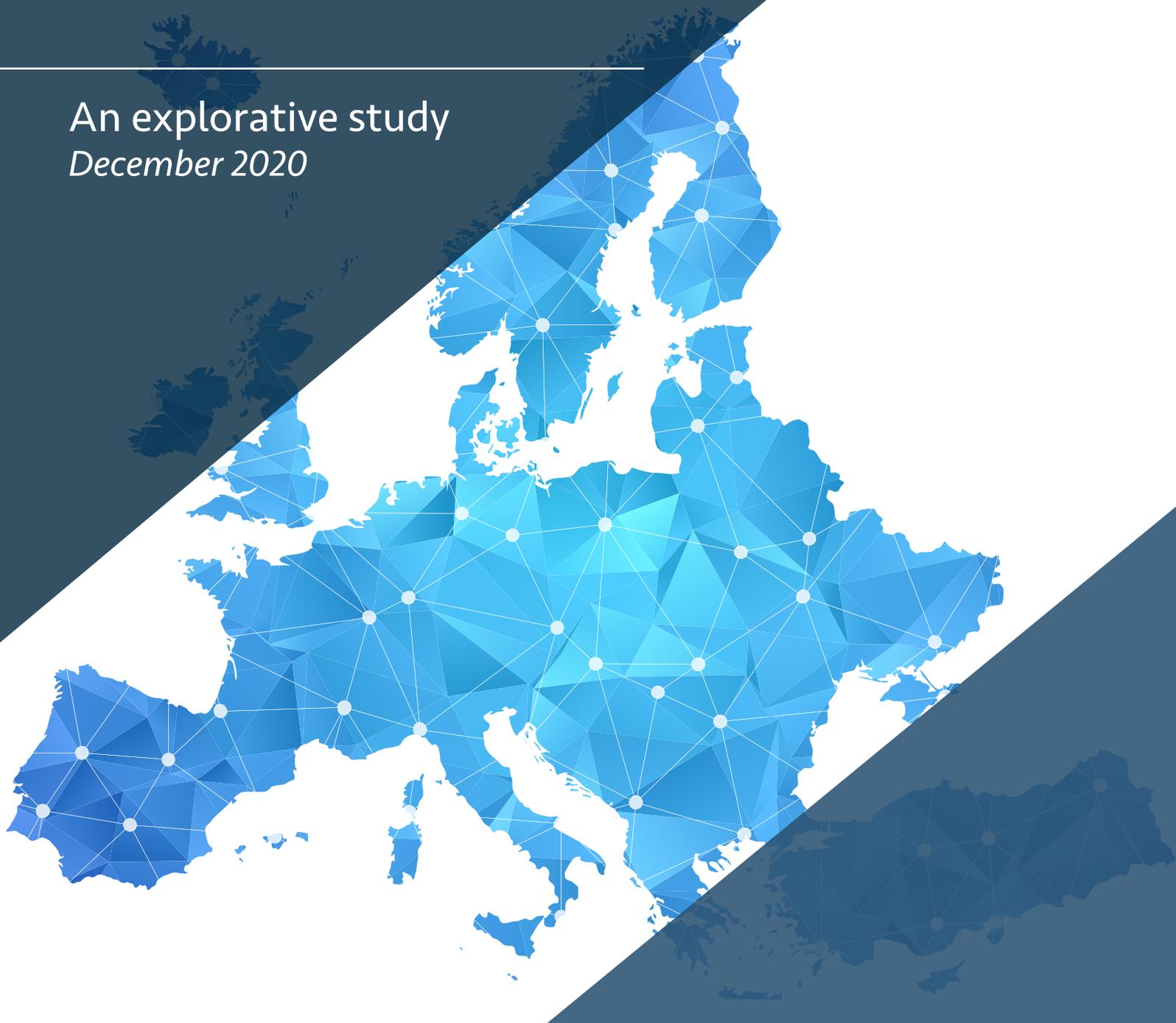




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Preamble

The International Federation for Spina Bifida and Hydrocephalus (IF) presents this document to provide an introduction to the important issue of multidisciplinary care. It underlines the need for multidisciplinary care for individuals with Spina Bifida and Hydrocephalus (SBH) and their families. In addition example practices from six member associations are presented in the Addendum. This document builds upon a scoping literature review conducted in 2018 by IF in collaboration with Ghent University. In 2019 input was obtained from six member associations to provide country examples in relation to multidisciplinary care.

To support IF members' efforts to bring the most appropriate care and support to persons with SBH in their countries, IF has conducted an exploratory study on the best practices of multidisciplinary care in Europe. The results are presented through this report.

The International Federation for Spina Bifida and Hydrocephalus

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with Spina Bifida and Hydrocephalus (SBH) and their families in 1979. It has grown from a voluntary association into a professional organisation of persons with disabilities with global coverage. IF now includes over 70 SBH associations in Africa, Australia, the Americas, Asia and Europe.

The majority of IF member organisations are led and governed by adults with spina bifida and hydrocephalus or parents of children with SBH. Children are active participants in our members' activities: they are involved in child-led activities, training workshops on independence and holiday camps. Nowadays, many young people with SBH have taken over the leadership of their organisations. In most cases, IF members choose close cooperation with medical and education professionals and researchers, given the importance of these professions to children and adults with SBH for their survival and development.

The mission of IF is to improve the quality of life of people with spina bifida and hydrocephalus and their families, and to reduce the incidence of neural tube defects and Hydrocephalus by primary prevention; by raising awareness and through political advocacy, research, community building and human rights education.

Foreword

Fifty years ago, in 1970, Dr. David W. Hide and Dr. Campbell Semple published an article in *The Lancet*¹, describing a comprehensive multidisciplinary outpatient clinic in Oxford, England, which was coordinated by an orthopaedic surgeon, a paediatrician, and a part-time secretary. A variety of additional specialists were involved in the team that provided care to children born with spina bifida and hydrocephalus.

Even then, the authors already pointed out a significant problem, which - unfortunately - for many is still true today: “Too often in the past the total child has been overlooked and very little attempt has been made to coordinate his care”. The division of care is not in the best interest of the child.

In addition, they stated that parents and children can become overwhelmed by the necessity to make multiple appointments with a variety of specialists, often at different hospitals, which could be located miles apart.

Now, half a century later, the International Federation for Spina Bifida and Hydrocephalus and its members find themselves still advocating for an integrated multidisciplinary approach across the lifespan for children and adults with spina bifida and hydrocephalus, and their families, to ensure best possible health, reaching their full potential, and to realise their right to live their lives equal to others.

In 2017, the Expert Group on Health Systems Performance Assessment published the report *BLOCKS*¹, in which the authors mention that “setting up effective integrated care systems requires solid building blocks in the form of frameworks and indicators and good practices that are transferable across Europe.”

With this report, we hope to contribute to this work with our principles of good multidisciplinary care for persons with spina bifida and hydrocephalus in Europe, which we hope will be embraced by healthcare systems and care providers in Europe.

¹ https://ec.europa.eu/health/sites/health/files/systems_performance_assessment/docs/2017_blocks_en_0.pdf

Introduction

Spina Bifida and Hydrocephalus are among the most complex congenital disabilities compatible with life. The development of spina bifida begins in the embryonic period, during the first 4 weeks of pregnancy, and affects the spine. It is a type of neural tube defect². Nowadays, it is often diagnosed during pregnancy through routine ultrasound screening. Hydrocephalus can develop during pregnancy as well, for instance as a secondary consequence of spina bifida, yet it can also occur after birth. Possible causes are amongst others a brain haemorrhage or infection of the central nervous system. Hydrocephalus occurs when there is an imbalance between the amount of cerebrospinal fluid that is produced and the rate at which it is absorbed into the bloodstream³.

The only scientifically proven method to reduce the risk of spina bifida and the associated hydrocephalus is timely and adequate intake of the B vitamin folic acid among all women of childbearing age who can conceive. Because spina bifida develops very early in pregnancy, folic acid intake needs to start at least 3 months before conception and for the first 3 months of pregnancy. The amount of folic acid is determined by the risk of experiencing NTD. Women who previously had a baby with a neural tube defect or who have diabetes or who are under anticonvulsant treatment should take 5mg folic acid daily. All other women should take a dose of 400mcg folic acid daily⁴.

Spina bifida and hydrocephalus can affect both cognitive and physical abilities, yet each person born with spina bifida and hydrocephalus will have different or specific needs, often depending on the level of the lesion⁵. The failure of the neural tube to close properly and the changes in the brain can affect motor, sensory, and cognitive functions, which may cause among others: lower-limb weakness or paralysis, lack of sensation, urinary and faecal incontinence, orthopaedic disorders, developmental delays, eye, ear and speech problems, or sexual dysfunctions.

² <https://www.cdc.gov/ncbddd/spinabifida/facts.html#types>

³ <https://www.hydroasso.org/what-is-hydrocephalus/> (visited 4 september 2020)

⁴ <https://www.ifglobal.org/wp-content/uploads/2020/02/FolicAcid-EN-1-1.pdf>

⁵ Copp, A. J., Adzick, N. S., Chittly, L. S., Fletcher, J. M., Holmbeck, G. N., & Shaw, G.M. (2015). Spina bifida. *Nature reviews Disease primers*, 1, 15007

The need for multidisciplinary care

In order to address the multiple health and rehabilitation issues that people with spina bifida and hydrocephalus may face throughout life, a sophisticated system of care, multidisciplinary care⁶, able to provide them with seamless services and support to achieve the highest attainable standard of health across the lifespan, is necessary. A holistic approach⁷, with a focus on both physical and mental health, is needed to improve the well-being and quality of life of people with spina bifida and hydrocephalus and their families, in order for them to enjoy all their human rights and fundamental freedoms. As part of a holistic approach it is of course also important to take into account social determinant of health.

Although there exist different models of multidisciplinary care teams, bringing together medical, paramedical and social care professionals, there isn't yet a clear standard on what adequate multidisciplinary care for people with spina bifida and hydrocephalus should encompass in different contexts (high/low income countries, large/small countries, socioeconomic and demographic factors, etc). Moreover, in Europe, a large divide between Northern/Western European countries and Central/Eastern countries in access to multidisciplinary care is remarkable.

Care Coordination

Multidisciplinary care for people with spina bifida and hydrocephalus can involve many different specialists and support services, therefore coordination of care is a complex task and occurs at multiple levels. Having one person in place, such as a nurse coordinator, is crucial to ensure good communication between all stakeholders. His or her role starts from the moment of prenatal counselling, by educating expectant parents, and continues throughout the lifespan of the person with spina bifida and hydrocephalus. Scheduling all necessary appointments and providing information about resources available through the hospital and community is crucial to effective care coordination⁸. The care coordinator has the primary responsibility for overseeing the overall treatment and support plan for the individual with Spina Bifida⁹.

Transition

For young persons with SBH, the importance of transition of care from paediatric to adult services cannot be underestimated. Research from the USA has shown that 37.7% of hospitalisations of young adults with spina bifida between 18 and 36 were a result of preventable conditions such as recurrent urinary tract infections, bowel issues and pressure ulcers¹⁰. Successful models of transfer of care and support must be geared to increase the young person's independence and active participation in the decisions concerning their own lives, including health, education and professional orientation, or housing¹¹. The transition process to adult care needs a specific and directed planning, starting in early adolescence. The central question is: 'when will the young person be ready to switch to adult health care?' In the transition of care, the focus needs to be more on the willingness of the young person to transfer than on physical age¹².

⁶ <https://www.ifglobal.org/publications/ifa-statement-on-multidisciplinary-care-version-2018/>

⁷ https://download2.eurodis.org/positionpapers/Position%20Paper%20Holistic%20Care%20for%20Rare%20Diseases_Final.pdf

⁸ [Care coordination in the spina bifida clinic setting: current practice and future directions \(Björstrom, 2012\)](#)

⁹ <https://www.spinabifidaassociation.org/guidelines/>

¹⁰ [Hospitalizations of Adults With Spina Bifida and Congenital Spinal Cord Anomalies \(DiCianno, 2010\)](#)

¹¹ [IF submission on Provision of Support to Persons with Disabilities \(2016\)](#)

¹² [Transition of care for adolescents from paediatric services to adult health services \(Campbell, 2016\)](#)

Challenges in multidisciplinary care

For individuals with spina bifida and hydrocephalus and their families multidisciplinary care is of utmost importance. Results from current practices show a need to provide this important patient group with comprehensive care in an effective way. To date, several barriers are present to provide individuals with such an integrated approach. This section provides examples as to what barriers individuals with spina bifida and hydrocephalus and their families can encounter in healthcare systems in France, Italy, Poland, Scotland, Slovakia and Sweden.

Healthcare systems

In the European Union (EU), the organisation and delivery of healthcare is a national responsibility. Therefore, healthcare systems, healthcare insurance, tax benefits, reimbursement schemes, and more, may differ from country to country and at national level from region to region. Within countries and regions, the quality and availability of multidisciplinary care for people with spina bifida and hydrocephalus may vary from hospital to hospital.

Information about the various health systems in the EU is available through the Health at a Glance: Europe report¹³, Country Health Profiles¹⁴, and the accompanying State of Health in the EU companion report¹⁵.

EU policy can complement national health policies, for instance through the Directive 2011/24/EU on patients' rights in cross-border healthcare¹⁶ (CBHC Directive), which enables EU citizens to seek healthcare in another EU country, and which has led to the establishment of European Reference Networks for rare and complex conditions¹⁷.

Not all countries consider spina bifida, and the associated hydrocephalus, as rare or chronic conditions associated with lifelong disabilities, which has an impact on the provision of healthcare. For instance, in France, spina bifida care is organised through its National Rare Disease Plan, first adopted under the Public Health Act of 9 August 2004, yet other EU countries do not have a legislative framework for rare and/or chronic conditions, or their National Rare Disease Plans may not include spina bifida.

As research done by a selection of our members shows, even in countries where there is a structured approach to spina bifida and hydrocephalus treatment, there can still be significant barriers to achieving the best possible multidisciplinary care. Urgent steps need to be taken to implement article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health.

¹³ https://ec.europa.eu/health/state/glance_en

¹⁴ https://ec.europa.eu/health/state/country_profiles_en

¹⁵ https://ec.europa.eu/health/state/companion_report_en

¹⁶ https://ec.europa.eu/health/cross-border_care/overview_en

¹⁷ https://ec.europa.eu/health/ern_en

Lack of funding

Multidisciplinary care for people with spina bifida and hydrocephalus requires close cooperation between many different actors in various fields. For instance, in France, reference centres for rare diseases receive funds to collaborate with competence centres for the delivery of care to patients. The competence centres ensure the care and follow-up of patients as close as possible to their homes. To do so, they manage and maintain a network of specialists in the fields of spina bifida and hydrocephalus and coordinate care across a myriad of agencies. However, to perform this highly important tasks, they receive no adequate funding.

People with spina bifida and hydrocephalus value a multidisciplinary assessment, where they are seen by and can confer with a wide range of specialists with expertise on spina bifida and hydrocephalus, yet once they return home, they have great difficulty in finding the right treatment and support locally. The complexity of arranging follow-up care near their home is creating fatigue and isolation. The lack of consistency in the way people with spina bifida and hydrocephalus are being supported, creates confusion and erodes confidence in services, which impacts on their willingness to seek help.

Waiting lists

Even when specialists and services are available at local level, patients can be faced with long waiting lists, for instance due to lack of funding for the healthcare system, or the limited availability of specialists with the required expertise.

Health issues such as a shunt malfunction in patients with hydrocephalus or urinary tract or skin infections in people with spina bifida that go undetected and untreated can cause life threatening situations. Assessments made during a multidisciplinary consultation need immediate and appropriate follow-up to prevent the development of secondary health conditions or premature mortality.

Geographical barriers

Because spina bifida is a rare condition, only a limited number of hospitals and centres will have the knowledge and resources to provide expert care. The distribution of care providers is often uneven across countries, and patients and families will need to travel long distances for consultations and treatment, when there is no multidisciplinary care for spina bifida and hydrocephalus available near their home.

The distance to locations where appropriate care and support are offered is a great concern. The need to organise and travel to multiple appointments at various hospitals or centres is challenging and time consuming. This can have an impact on education, employment, social inclusion, and mental health and wellbeing, as people repeatedly have to ask for time off and can be met with adverse responses. Missing school due to ill health or admission to hospital for treatment is a significant challenge for young children with spina bifida and/or hydrocephalus and affects their social integration with peers at school and in the local community. Transportation and accessibility issues add to the complexity and a sense of abandonment.

In France, there are 8 reference centres for spina bifida within the health sector Neurosphinx, including the coordinating reference centre C-MAVEM¹⁸ (Chiari et malformations vertébrales et médullaires rares), which all cooperate with 34 competence centres across the country.

Italy has 16 Spina Bifida Centres that provide different levels of assistance, care and treatment of Spina Bifida according to the Region in which the Centres are located, even if these Centres are neither nationally accredited structures nor officially recognized.

In Poland, 6 paediatric neurosurgical departments provide postnatal care for children with spina bifida, and two medical centres offer prenatal surgery for spina bifida, in Bytom, and in Warsaw.

Mothers from Scotland who live in remote and rural areas are transferred to the hospital where their baby is to be born and where they will be spend a few weeks post-delivery.

There are hospitals in Slovakia that are able to perform postnatal surgery for spina bifida, however, quality and skills may differ. Smaller local hospitals are recommended to refer patients to more specialised centres, such as the Children's Hospital in Bratislava, where they also teach complex continence management.

In Sweden, 7 regional university hospitals provide multidisciplinary care for spina bifida including prenatal care, neurosurgery, paediatric surgery, orthopaedics, physiotherapy, occupational therapy and general paediatrics. Regional habilitation centres are involved in the provision of this type of multidisciplinary care. For some centers (eg.: Spinalis Clinic in Stockholm) yearly checkups are offered for individuals with spina bifida but there is no consensus from a national perspective what best standards of multidisciplinary care services can be provided.

Transition of care

As reported by several of our members that took part in this research, if care for spina bifida and hydrocephalus is well organised, it is often limited to paediatric care. As a result, babies born today with these conditions - in countries which offer timely and appropriate care - have a significant increase in life expectancy. The majority will survive well into adulthood. Yet healthcare systems have not been adjusting to the continued need for a multidisciplinary approach for people with spina bifida and hydrocephalus across the lifespan, and for the transition of care.

Transition is a gradual process of planning, preparing and moving a young patient from paediatric to adult healthcare services. Ideally, planning should start early, around the age of 12, but it may depend on the maturity, pathology, and disability of the young person and not on chronological age¹⁹. Flexibility and adaptability are essential, although it is important to keep in mind that all children will eventually have to transition to adult programs and services, regardless of their level of independence.

Without proper preparation, an 18-year-old with spina bifida and hydrocephalus will not have the know-how to review and coordinate all the medical care and support services he or she may need in adult life. In addition, cognitive problems can be a significant obstacle to adequate self-care and compliance to treatment, and the ability to speak up for themselves. The transition process must address the medical, psychosocial and educational needs of young people with spina bifida and hydrocephalus, while taking into account the social, cultural, economic and environmental aspects in which adolescents and young adults live.

An example of good practice from Canada, Growing Up Ready, was introduced in Sweden around 2006. The resources of the programme were designed to help children and youth with disabilities to get ready for adult life²⁰. The Growing Up timetable was later adapted by IF for use in an African context²¹. It gives parents and young people guidance on how to develop skills in 4 different areas: medical, social, education and self-care.

¹⁸ <http://neurosphinx.fr/institution/Chiari-et-malformations-vertebrales-et-medullaires-rares>

¹⁹ Zhou H, Roberts P, Dhaliwal S, Della P. Transitioning adolescent and young adults with chronic disease and/or disabilities from paediatric to adult care services - an integrative review. *J Clin Nurs*. 2016;25(21-22):3113-3130. doi:10.1111/jocn.13326

²⁰ <http://hollandbloorvie.ca/services/programs-services/timetable-growing>

²¹ <http://www.ifglobal.org/publications/guide-for-youth-with-spina-bifida-and-hydrocephalus-in-africa/>

It is important to note that while the knowledge and tools for transition were shared in Sweden through a 3-year project funded by a government department, the implementation has been slow. Continued awareness raising is needed of the importance of transition for young people with lifelong disabilities, as well as adequate funding and resources to put theory into practice.

SBH Scotland have a dedicated transition nurse who is involved in proactive diagnostic checks to identify health and wellbeing issues and assist the young person to link into the relevant community, health and social care agencies. The role is set to facilitate multidisciplinary working across adult health care services, building trusting relationships between the young person and key stakeholders and signposting young people to appropriate advice and information regarding health, wellbeing, financial management and vocational options.

Sharing of data

Multidisciplinary care for people with spina bifida and hydrocephalus means that multiple specialists and services need to have access to a person's relevant data. This could be at local, regional or national level, but may also apply when patients seek healthcare abroad.

Legislation on the protection of personal data can create barriers to sharing a patient's files. In addition, sharing of data can be hindered when no digital records are available.

Data can also be entered in a patient registry, for research to improve treatment and support. In France, data is being collected in reference centres and competence centres for rare diseases, but there is no spina bifida specific database. In Italy, steps are taken to explore ways to collect data on birth defects in a systematic way. Feeding data into the registry is complex and time-consuming for the teams involved and there is no secretariat to support them, which has an impact on the available data.

In Europe, MMCUP²² in Sweden is collecting data of all the people with spina bifida who seek medical care and support through this national spina bifida follow-up programme.

Reimbursement of costs

The disabilities associated with spina bifida and hydrocephalus are present from birth and lifelong, which means that many children and adults with these conditions will require continence management products, anticholinergics (to treat urinary incontinence), mobility devices, possibly repeated surgeries, regular use of antibiotics, access to rehabilitation and vocational services, and/or psycho-social support throughout their lifespan.

As mentioned before, reimbursement schemes vary from country to country, from region to region, and from insurer to insurer. This can have a significant impact on the health and wellbeing of people with spina bifida and hydrocephalus, and their families.

On 22 October 2020, the Constitutional Tribunal declared the law authorising abortions for malformed fetuses to be unconstitutional, effectively banning most of official abortions carried out in Poland. Children born with spina bifida and hydrocephalus may be given a medical certificate confirming severe and irreversible impairment, which makes them eligible for reimbursement of a variety of costs related to their disability.

²² <http://mmcup.se/>

However, the maximum reimbursement amount limits the services, devices and materials people can use. In Poland, hydrophilic-coated catheters, which are associated with a lower risk of urinary tract infections²³, are on average six times more expensive than uncoated catheters. For instance, in Poland, reimbursement is currently based on the use of 180 uncoated catheters per month. The expectation is that will change with new policies being formalized by the National Health Fund in Poland. Of course, countries can differ in their financial rules regarding the quantitative limit of uncoated catheters for children (under 18) with a severe and irreversible impairment or an incurable life-threatening disease developed during the prenatal period or childbirth. For example, in Poland, currently only 70% of the calculated costs will be reimbursed and people with spina bifida and/or their families have to pay the remaining 30% plus the additional costs if they want to use hydrophilic-coated catheters instead.

A similar issue occurs in Poland with regard to orthopaedic equipment and mobility devices. Inadequate reimbursement of costs forces patients to choose cheaper and often worse equipment, which hurts instead of supports them. Ill-fitting orthopaedic shoes and equipment can be the cause of secondary conditions such as pressure sores and even broken bones. Whenever possible, orthopedic care should be rendered as part of a multidisciplinary team, working together with neurosurgery, urology, and physiatry²⁴.

By contrast, orthopaedic care in Slovakia is well-organised and equipment prescribed by experts is tailored to the individual's needs and all costs are reimbursed. In Italy the National Healthcare Service totally covers the costs for those devices that are included in the so-called "Nomenclatore"^{25,26} such as orthopaedic devices, catheters, mobility devices, diapers for incontinence and rectal devices. Any changes in the number or custom-tailoring of devices are partially covered. Besides this, Italian legislation provides the possibility of deducting the 19% of the expenses incurred, under specific limits, for the purchase of a vehicle, of medical devices, as well as personal assistance expenses and hospitalization in private health structures. There is also the possibility for people with disability to buy devices or technological equipment at a reduced VAT. Equipment is offered free of charge in Sweden, as well as orthopaedic management materials, including specially made shoes, walking sticks, rollators, and both manual and electric wheelchairs, and adaptations at home, such as lifts and height adjustable beds. In Scotland (UK) too, all equipment, medicine and professional health input is offered free.

Both Poland and Slovakia point out that only basic wheelchairs are reimbursed, heavy manual wheelchairs meant for passive use, often relying on someone else to push. Ultralight wheelchairs for more active use are very expensive and will have to be fully paid by the person or the family.

In Slovakia, a wheelchair request can be made for children of the age of 3, if this is recommended by an orthopaedic specialist. A new request can be made after 6 years of use.

In young children mobility positively impacts cognitive, physical, and social skills. Age appropriate wheelchairs can already be considered between the age of 0-11 months²⁷.

Continence management materials are only made available in Slovakia from the age of 6. This is particularly worrisome, for physical and mental health and social inclusion. The majority of children and adults with spina bifida have a neurogenic bladder, which they can't control and can't empty completely, increasing the risk of infections and kidney damage. When not having timely access to continence management materials, they are also at risk of the stigma associated with incontinence. In Slovakia, to be eligible for continence management products, requests need to be validated by a specialist every 6 months, even for people with lifelong conditions such as spina bifida. This creates an undue burden and can make people feel like their disability is not understood.

²³ Saadat SH, Shepherd S, Van Asseldonk B, Elterman DS. Clean intermittent catheterization: Single use vs. reuse. *Can Urol Assoc J*. 2019;13(2):64-69. doi:10.5489/cuaj.5357

²⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2782071/>

²⁵ Nomenclatore protesica Ministry of Health website. http://www.salute.gov.it/portale/temi/p2_6.jsp?lingua=italiano&id=1312&area=programmazioneSanitaria&menu=le

²⁶ List of devices. <https://www.trovanorme.salute.gov.it/norme/renderPdfSpring?serieq=SG&datag=18/03/2017&redaz=17A02015&artp=9&art=1&subart=1&subart1=10&vers=1&prog=001>

²⁷ Spina Bifida Association. Guidelines for the Care of People with Spina Bifida. 2018. Chapter Mobility. 121-127

In guidelines published by the European Association of Urology and the European Society for Paediatric Urology²⁸ it is stated that in newborns with spina bifida, urinary continence management should be started as soon as possible after birth. The procedure, called clean intermittent catheterisation (CIC), should also be taught to parents. It is important to introduce CIC early in life, as it will help children to accept this important type of continence management, aimed at reducing the risk of renal complications. Children with neurogenic bladder usually also have neurogenic bowel dysfunction and access to materials for bowel continence management is equally important

In the European Union, under the CBHC Directive (see Health systems), paragraph 34, patients have the right to access health services in another EU/EEA country and to enjoy assumption of costs by their home country where they are insured. However, reimbursement is up to the amount of costs when treatment would have been carried out in peoples' home country. This can create inequalities for those living in low income countries, as the same treatment may be more expensive in the country where they want to access the best possible treatment and care.

A popular centre for Polish patients is the German orthopaedic clinic in Aschau, which provides comprehensive treatment and orthopaedic equipment, including for patients with spina bifida. The costs of rehabilitation stays in Aschau are only fully reimbursed about every two years. For patients with spina bifida who require continuous stimulation and exercises, this is clearly inadequate.

Foetal surgery for spina bifida is offered in only a limited number of hospitals in the EU, which requires cross-border healthcare, yet it will depend by country whether the costs of this innovative type of treatment will be reimbursed.

Outside of the scope of the CBHC Directive, families in Slovakia are being referred for foetal surgery treatment for spina bifida in Switzerland, with full payment of costs.

According to the CBHC Directive, Member States are free, for example, to reimburse extra costs, such as accommodation and travel costs, or extra costs incurred by persons with disabilities even where those costs are not reimbursed in the case of healthcare provided in their territory. A 2015 Eurobarometer survey reported that fewer than 20 % of citizens were aware of their rights regarding cross-border healthcare²⁹. No recent data on the awareness of citizens regarding the Directive is available³⁰.

Whether the costs of medical care, including assistive and medical devices and materials, and support services are reimbursed through healthcare or social systems will vary at national, regional and/or local level.

National and regional spina bifida and hydrocephalus associations play a crucial role in providing families and people with spina bifida and hydrocephalus with information on the best options with regard to doctors, hospitals, available support services, health insurance, benefit systems, etc.

It is recommended though that this type of information should be clear and made readily available by national, regional and local key stakeholders and governments.

²⁸ Stein R, Bogaert G, Dogan HS, Hoen L, Koccyara R, Nijman RJM, Quadaackers JSLT, Rawashdeh YF, Silay MS, Tekgul S, Radmayr C. EAU/ESPU guidelines on the management of neurogenic bladder in children and adolescent part I: diagnostics and conservative treatment. *Neuro-Urol Urodyn*. 2020 Jan;39(1):45-57. doi: 10.1002/nau.24211. Epub 2019 Nov 13. PMID: 31724222.

²⁹ Special Eurobarometer 425 "Patients' rights in cross-border healthcare in the European Union"

³⁰ Special Report EU actions for cross-border healthcare, significant ambitions but improved management required (ECA; 2019)

Social systems

Similar to healthcare, in the EU the responsibility for social policy lies primarily with national governments, and the EU can support and complement Member States' efforts³¹.

As mentioned earlier, close cooperation between all actors is required to achieve appropriate and adequate multidisciplinary care for people with spina bifida and hydrocephalus, which not only focuses on physical health, but on all areas relevant for a person's wellbeing, such as education, employment, housing, social and family life, sexuality, self-image, and mental health. As stated by the World Health Organization, integrated social and medical services can be 10 times more effective than waiting for families to visit health services³².

All of the participating national researchers have pointed out that multidisciplinary care for children and adults with spina bifida and hydrocephalus in Europe should be aimed at enabling them to live independently within their community and fully participate in society, as is their right according to the UNCRPD, article 19.

In France, the mission of reference centres, composed of multidisciplinary teams, is to facilitate diagnosis and define a strategy for the therapeutic, psychological and social care of people with spina bifida. The French health sector Neurosphinx, responsible for spina bifida care, offers educational resources for families with children with rare diseases³³.

Some of the young adults and adults interviewed as part of the national research in Italy, underlined how sport activities have helped them a lot in terms of integration in society and in developing a better self-esteem and mental health. They also pointed out that would welcome information on relationships, sexuality, and reproductive health, not just with regard to medical issues, but to improve their private life, e.g. by addressing insecurities and personal questions.

With regard to social and disability benefits, these can be below the poverty line and insufficient for independent living, continuing education, appropriate housing, and more. This is in breach of article 28 of the UNCRPD, which gives persons with disabilities the right to an adequate standard of living. Moreover, if a person with a disability finds employment, he or she could be at risk of losing social or disability benefits, while the additional costs associated with having a disability remain the same. As a result, people with spina bifida and hydrocephalus would find themselves in a worse financial situation than if they did not work.

Article 27 of the UNCRPD includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. This right should not be impaired by policy measures that have a negative and unequal impact on a person's income.

³¹ https://ec.europa.eu/info/policies/employment-and-social-affairs_en

³² <https://www.who.int/social-determinants/en/>

³³ <https://neurosphinx.fr/transition/vie-scolaire>

Conclusions & Recommendations

The relevance of multidisciplinary care as an important health aspect for individuals with spina bifida and hydrocephalus and their families was highlighted. As illustrated in this report, for the multidisciplinary care for individuals with spina bifida and hydrocephalus, there is ample room for improvement. Activities by six national member associations reflect the importance of multidisciplinary care. Members have emphasized on the need for guidelines, registries, training, and involvement of people with SBH. For this, it is important to follow a systemic holistic approach also taking into account social determinants of health.

With respect to future studies into the multidisciplinary care for individuals with spina bifida and hydrocephalus, it is recommended to also investigate common neglected pediatric problems such as mental health, sexual health, and sleep problems.

Besides our current understanding on the important topic of multidisciplinary care, it is also meaningful to take into account possible factors prohibiting effective integrative approaches on national level. Analyzing interactions between science, practice, and policy is therefore of utmost importance.

On a European level, joint action plans have been carried out to develop partnerships and strengthen infrastructures to improve multidisciplinary healthcare, evidence-based management and collection of secure patient data.

For example, IF is actively involved within the patient centered network ERN-ITHACA. With this network, the ERN-ITHACA stimulates pan-European capacity building activities for management and care for individuals with spina bifida and hydrocephalus. In this way, patient representatives together with clinicians, and lay organizations aim to develop best practices and initiate guideline development where required.

Decisions about prioritizing integrated healthcare approaches to pursue in the near future are important. For individuals with spina bifida and hydrocephalus and their families, multidisciplinary care requires an improved approach, emphasizing on the reality of the complex factors between science, practice, and policy.

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Supplemental Documents

Example practices

[Multidisciplinary care for SBH in France](#)

[Multidisciplinary care for SBH in Italy](#)

[Multidisciplinary care for SBH in Poland](#)

[Multidisciplinary care for SBH in Scotland](#)

[Multidisciplinary care for SBH in Slovakia](#)

[Multidisciplinary care for SBH in Sweden](#)