INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

IFSBH
16 rue des Alexiens
1000 Brussels, Belgium
T: +32 (0)2 502 0413
E: info@ifglobal.org W: www.ifglobal.org

About us

International Federation for Spina Bifida and Hydrocephalus is a global network founded in 1979. It is governed by adults with spina bifida and hydrocephalus (SBH) or parents of children with SBH. IF's mission is to reduce the incidence of SBH by primary prevention, and to improve the quality of life of people with SBH and their families through human rights education, political advocacy, research and community-building. Universal respect of the rights reaffirmed in the UN Convention on the Rights of Persons with Disabilities for all children and adults with SBH is IF's underlining philosophical base. IF is a full member of the European Disability Forum and applicant member of the International Disability Alliance.

What is spina bifida and hydrocephalus?

Spina bifida is the most common of a group of neural tube birth defects where the spinal cord fails to properly develop at early stages of pregnancy, leading to varying degrees of damage to the spinal cord. With modern treatment, the survival rate of children with SBH has increased significantly, particularly in the Global North, and the quality of life of people with SBH increased as well both through medical advances and the shift from a charity/medical model of disability to a human rights approach. Nevertheless, most children and adults with SBH need lifelong special medical and paramedical follow-up care related to reduced mobility, urological and bowel management issues, orthotic needs and weight management.

Hydrocephalus is a medical condition characterised by abnormal accumulation of cerebrospinal fluid in the brain. If untreated, it causes blindness, intellectual disabilities and premature death. Surgical insertion of a medical device called 'shunt' relieves the pressure on the brain and significantly reduces the risks associated with hydrocephalus. The majority of infants with spina bifida develop hydrocephalus; in addition, a large proportion of hydrocephalus is non-spina bifida related and is caused by other medical conditions, injuries, or infections, particularly in the Global South.

Human rights of adolescents with SBH

Many of the human rights concerns of persons with SBH, such as physical accessibility, inclusive education, personal assistance, and respect of dignity and independence, overlap with those of people with other disabilities. In addition, children, adolescents and adults with SBH have very unique and lifelong health care needs, which will be the main focus of the present submission. It must be noted that many suggestions presented in the submission also apply to adolescents with other (congenital) cognitive and physical disabilities, such as cerebral palsy, Down Syndrome, autism, and those with brain and spinal cord injuries. Persons with SBH experience distinct and equally important health care needs throughout their life span. If in infancy and childhood, the efforts are focused on issues, such as life-saving surgeries, mobility aids or incontinence management, as they mature into adulthood, new challenges are added, such as self-management of multidisciplinary health needs, learning about sexuality and family planning, advocating for the best health options, etc.

Adolescence is a very sensitive transitional period lasting over a few years, where the importance of **transfer of care from paediatric to adult services** cannot be overestimated. 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 ulcers.[1] It has been demonstrated that the weak link in prevention is adolescence period when young people are gradually released from the care of their parents who have supervised their health since birth. It is in adolescence that the **empowerment of young people through health education and self-management techniques** is more crucial than ever, as the successful transition significantly contributes to having the best attainable standard of health later in life. In the same vein, addressing **psychosocial, vocational and interpersonal needs** of young people with disabilities in a timely and sensitive manner greatly helps them participate in their communities and reach the greatest potential in adult life. Therefore, IF advocates for multidisciplinary approach to healthcare services for young people with disabilities, as the optimal way to address the array of (para) medical concerns of youngsters.

> *"Seen my age, there were no multidisciplinary SB-teams available. So, I had to visit each specific specialist separately, i.e. a neurologist, an orthopaedist, a urologist, bowel specialist, etc. As a consequence, each specialist only treated his own branch without considering the whole body and influences on me. Besides, they did not communicate. So, I was some kind of link between all these doctors. On the other hand, it made me kind of auto-specialist. I got/get involved very closely and frequently."* ***Anonymous, Belgium***

IF's research and a questionnaire targeting adolescent members of its national member organisations distilled three essential elements that contribute to the realisation of human rights of adolescents with SBH.

1. Apply a multidisciplinary approach to transition to adulthood, which includes medical, psychosocial, vocational and social aspects of the young person's life

Transition for youth with SBH and other disabilities must encompass a wide array of components the adolescent's life, such as medical, psychosocial or educational elements, but also social life and sexuality[2].

'One size fits all' is rarely a good strategy, and it certainly does not suit young people whose support needs (in education, interpersonal communication, extracurricular activities) common to all adolescents are combined with very specific health needs (continence management, routine surgeries, etc). **Customised intervention**, taking into account the specific needs of the young person and their family is therefore a must.

The importance of **continuity of services** from childhood to adolescence to adulthood has also been stressed by young people with SBH. The support must continue and evolve together with the young person's growing independence and readiness for self-determination. If in early adolescence, the support package may include only some services (such as medical,

---

[1] Children and Youth Advisory Table – Summary Report, Detailed Recommendations, Implementation Plan and Appendices, commissioned by Toronto Central Local Health Integration Network, 2012, p 60; on file with IFsbh.

[2] Gillian A. King et al, "Planning successful transitions from school to adult roles for youth with disabilities", Children's Health Care, 34(3), pp. 193-216.

rehabilitation and psychological support), as the person matures they need to have access to counselling in questions such as (accessible) housing rights, education and professional orientation, sexuality, or social skills.

Adolescents with SBH also stress the need for a **sensitive and non-judgmental approach** to counselling and support. Young people who have been 'in the system' of support since birth (seeing doctors, scheduling surgeries, planning rehabilitation, fighting to be included in mainstream education) sometimes report emotional difficulties caused by transition. As **IF's Turkish member** witnesses:

> *"Children with SBH are monitored by paediatricians. Given the nature of SBH and the need for continual monitoring, the child forms and emotional and/or psychological bond. This bond is severely disrupted when children with SBH become adolescents/adults, and this, in return, creates both a discontinuation in the treatment/monitoring and additional emotional stress."*

Transition support services must **respect the changing priorities of adolescents with disabilities** and be designed in such a way as not to interfere with the young person's education/vocation, increasingly important in adolescence. The importance of providing young person with real-life opportunities and experiences cannot be overestimated, as it supports the adolescent's quest for independence and equip her with coping strategies.

> *"I think the main problems for teenagers are that school becomes a lot more important with pressure from teachers and parents to get certain grades and not to miss school and if you're having to go to lots of appointments in school hours it can be frustrating and stressful for everyone."* ***Anonymous, England***

Finally, transition strategies must be limited to (para) medical services, and necessarily **include social aspects** that nurture the adolescent's independence, social skills and relationships. Most adolescents with spina bifida rightfully refuse to define themselves by their disability and focus instead on social activities with their peers. In this sense, availability and accessibility of activities, such as sport, music, school trips, or art are indispensable to respect the young person's right to self-determination.

> *"I have looked for sports activities for youngsters with disabilities, but unfortunately only found hockey and swimming, which are provided by a sports club. In my opinion, these are not enough, because I would like to try other sports such as tennis. Also the accessibility of the public transport could be improved, so that we don't have to explicitly ask for accessible means of transport every time we want to move around."* ***Benedetta, Italy***

2. Ensure smooth transfer of care from paediatric to adult specialised health services

Transfer of care is an important part of the transition process for youth with SBH that often determines the quality of life of young adults. Successful models of transfer of care must be geared to increase the young person's independence and active participation in the decisions concerning their own health decisions. The parents' or other primary caretakers' role in management of complex health needs of children with SBH, so essential in early years, is gradually diminished, as the young people are provided with tailor-made support from trained professionals experienced in transfer of care.

In particular, such transfer of care models must include training in medical stability (i.e. maintaining good health and recognising early symptoms of problems), continence plan and self-management skills. In addition to SBH-specific disciplines, the models must include training in sexuality and reproductive rights for young people with SBH, as well as tailor-made psychological support and peer support.

> *"According to my life experience, access to healthcare [for children] has become better. I think it is thanks to our [national Spina Bifida] association's engagement, because we have created a network of professionals that know each other and are able to navigate parents with adolescents between them. In my opinion, a problem arises when the adolescent becomes an adult because there are no professionals specialized on spina bifida to discuss both specific and general health services with."* ***Dominik (17), Slovakia***

3. Focus on cultivating independence of adolescents with disabilities to empower and prepare them for adulthood

Many IF members report continued dependence of young people with SBH from their parents or other primary caretakers way past childhood. Turkish Spina Bifida Association (TSBA) explains:

> *"Participation rates [of adolescents with spina bifida in the activities of the association] are not as high as they should be. There are various reasons for this. One is related to the over-protective attitudes of parents. TSBA has organised a meeting in which a psychiatrist talked to the members about the ways to overcome such attitude. Another reason is related to the more general perception of the disabled as "unable". Both internalised and externally projected, such a perception undermines the self-esteem of SBH patients and makes them reluctant to voice their opinions. TSBA is working on altering this negative (self) perception, but of course such an endeavour requires a more systematic approach with the active participation of the government bodies and educators."*

Testimonies from other IF members second this: overprotection coupled with non-adapted environments and systems teach adolescents helplessness and contribute to their disempowerment. Therefore, transition processes must be revised to foster independence of young people, their reliance on themselves, ability to find support in peer community and (para-) medical circles and self-advocacy skills. The ways to do it include:

- stimulating youth-led activities ('peer exchange') to help adolescents find the safe place to talk about their interests and concerns privately and in the age-appropriate manner;
- relying on modern communication channels (social media, smartphone apps) to stimulate the exchange and cultivate independence of young people;