INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

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Provision of support to persons with disabilities

Response to the consultation launched by
the UN Special Rapporteur on the Rights of Persons with Disabilities

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About us

International Federation for Spina Bifida and Hydrocephalus (IF) is a global organisation of persons with disabilities governed by adults with spina bifida or 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 member of International Disability Alliance, the European Disability Forum and the International Disability and Development Consortium.

What is spina bifida and hydrocephalus

Spina bifida, one of the most complex neural tube birth defects compatible with life, is characterised by various degrees of damage to the spinal cord and consequent life-long health conditions necessitating care and support related to reduced mobility, urological and bowel management issues, orthotic needs and weight management. Many people with spina bifida also develop **hydrocephalus**, which is an abnormal accumulation of cerebrospinal fluid in the brain. If untreated, it causes blindness, intellectual disabilities and premature death.

Although persons with SBH may experience the same support needs as persons with other disabilities (such as personal assistance, daily support in the community, support in decision-making and communication), they also experience **distinct needs that stem specifically from the complex nature of the disabilities in question**. Since it is these support needs that most often remain unmet, making the person vulnerable to abuse of their human rights, they are be focus of the present submission.

Underlying obstacles to availability of support

Lack of data

Widespread failure to collect data on prevalence of spina bifida and hydrocephalus in the society is the underlying reason for the inadequacy of support services for persons with SBH in both the developed world and the developing countries. The little data that is being collected is rarely disaggregated by the person's support needs, focusing instead on her medical history, such as the presence of a shunt, or past surgeries, making it impossible to identify the extent of support the person needs, and plan and budget accordingly. This is especially detrimental to young children with SBH who need timely and adequate support and care to maximise their chances of survival and quality of life.

Misunderstanding of SBH and consequent lack of expertise

As the result of lack of reliable data, the profile of spina bifida and hydrocephalus remains low, and misconceptions about the disabilities - widespread. This, in its turn, leads to stigma that is routinely experienced by people with SBH and their families who are shunned from their communities, denied access to information and support and excluded from the society. Inaccurate and often dangerous speculations are made about the future quality of life of children with SBH, often leading to denial of essential care that would help children to survive and thrive. Scarcity of data also leads to the wrongful presumptions that spina bifida is rare in the society, and as such, not worthy of investment in medical research or care, or development of support services.

Lack of attention to the person's mental health and well-being

The often overwhelming and continuous physical needs of a person living with SBH throughout the life cycle[1] commonly leaves little space to address the mental health and wellbeing of persons with SBH. Indeed, even when specialised SBH support services exist, their focus is often on the person's physical health, while the mental and emotional health comes secondary.

This is a dangerous pattern. IF members universally report the mental health problems that people with disabilities experience due to repeated medical complications, painful surgery recoveries, chronic pain, but also isolation and social exclusion that is often a reality for people with SBH. Misconceptions about the abilities of person with SBH and the phenomenon of **learned helplessness**[2] add to the invisibility of challenges faced by persons with SBH, further increasing their isolation and pressure on mental health.

Support needs throughout the life cycle

Many distinct support needs experienced by persons with SBH are related to their health and vary throughout the life cycle.

Infancy and childhood

The first and, possibly, the most crucial need for informed and appropriate support demonstrates itself immediately after the birth when parents of the newborn with SBH are presented with **medical choices that will inform the life of their child for the future**. The cases of parents receiving biased information from the medical professionals, traditional healers and wider community about their child's chances of survival and future quality of life are sadly widespread. Despite medical advances enabling to ensure high quality of life for persons with spina bifida, the disability is still frequently portrayed as a 'near death sentence' to new parents. Very often, counselling is conducted by medical

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[1] Such as shunt maintenance, orthopaedic challenges (incl scoliosis and joint contractures), urological problems, pressure ulcers or obesity, as well as potential complications from the chronic effects of surgeries and other medical interventions.

[2] Learned helplessness is a phenomenon where the extent and content of support provided to persons with congenital disabilities has not been adapted to their growing maturity (from infancy to childhood to adolescence to adulthood), resulting in disempowerment of the person, their complete reliance on the carer (usually a parent) and lack of self-advocacy skills.

professionals only, without the participation of DPOs or parent support groups, and the emphasis is made on challenges that the person with SBH will encounter in life, instead of abilities and opportunities the person will have. Lack of **unbiased, positive support to parents of newborn children with SBH** often results in poor care received by the children, abandonment and institutionalisation, or even active termination of life.

Discrimination of children with SBH in educational settings due to refusal to provide reasonable accommodation and support is often identified as the most serious and persistent violation of human rights of children with SBH. IF frequently receives accounts of children with SBH being excluded from mainstream education due to the absence of **support in bladder and bowel management at school**. Lack of **accessible facilities** and **trained assistants** available on school premises, over-medicalisation of continence management ("only a trained nurse can help the child catheterise, and we don't have one") and misconceptions about living with SBH (including the mobility limitations that often come with it) usually result in one of two scenarios: either one parent of the child with a disability provides unpaid support (usually forcing the parent out of formal employment and putting the family in financial dire straits) or the child ends up in a segregated schooling system (or, without access to education at all).

Lack of understanding of the learning needs of children with hydrocephalus, such as difficulties in processing and organising information, or keeping up with the pace in the classroom, often results in failure to **make the learning methods and environments accessible**, including through **provision of support teachers and adapted curricula**. This, in its turn, may lead to segregation in education and underachievement of their potential by children with hydrocephalus.

Adolescence

As young people with SBH mature into adulthood, new challenges, such as **self-management of multidisciplinary health needs**, **learning about sexuality and family planning**, or **self-advocating for the best health options**, emerge.

For young persons with SBH, 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. Indeed, adolescence is a weak link in provision of both formal and informal support, as young people are gradually being released from the care of their parents who have supervised their health needs from birth into the care of trained professionals whose role is to support and guide young people through the array of decisions to be made. 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 housing.

Among good examples helping transition for people with disabilities from childhood and youth into adulthood is the **"**Growing up ready**" programme** developed by Holland Bloorview Kids Rehabilitation hospital, developed in close consultation with families with members with disabilities, and aimed at parents, teachers and medical professionals working with children and young people with disabilities. The programme includes practical support tools (including a timetable and checklists) to guide them through the delicate stage of transition from childhood into adulthood and facilitate the increasing independence and self-agency of a young person with a disability. The programme was adapted for specific needs of children and young people with spina bifida and hydrocephalus in Norway, where it is being successfully piloted by the **Norwegian association for spina bifida and hydrocephalus**[3].

Adulthood and ageing with SBH

People with SBH born in the Western world in the 1950s are the first generation to survive the childhood and live through adulthood. Thanks to improved medical research and care, **the numbers of people living and ageing with SBH are on the increase** and will continue to rise over the next few decades. Due to lack of precedents, little is known about progression of SBH throughout adulthood and ageing, making the availability of care and support scarce and, often, non-existent.

In addition to SBH-specific conditions (such as tethered cord syndrome, kidney failure or pressure sores), people with SBH often experience an early onset of secondary conditions usually associated with old age (such as arthritis, osteoporosis, obesity or diabetes) and necessitate **timely and continuous interventions and support to preserve their independence and quality of life**. Physical challenges faced by many people with SBH, especially as they age, greatly increase the difficulty of finding and maintaining a full-time, office-based job with traditional working hours. Having to attend multiple medical appointments can be time-consuming, physically enduring, financially burdensome and may even provoke incomprehension and stigma at work.

One of the most efficient ways of addressing these challenges is providing adults with SBH with a **multidisciplinary model of care and support**, where the person's medical, rehabilitation, but also social and civic support needs are coordinated in a seamless fashion (usually at a hospital or a SBH-specific clinic). The **one stop shop approach** helps avoid gaps in care, minimise the time spent commuting to receive it, and equips the person with the necessary tools (such as support in hiring a personal assistant, information about rights and remedies, and emotional counselling) to increase their independence.

However, even in Europe the availability of multidisciplinary care is low. Research conducted by IF in 2016 shows that 38 % of respondents do not have a multidisciplinary clinic in their area, compared to only 17 % who do. The numbers are even lower in the developing world, contradicting the principle that in order to be adequate, care should be both available and accessible.

The Peer Support Service of the Spina Bifida Hydrocephalus Ireland was established in 2013, following an explicit request from SBHI members, and has since helped many people, some in very severe crises. The issues dealt with have ranged from those regarding personal care, personal and sexual relationships and difficulties with self-confidence and self-esteem. The service is run by trained volunteers and was rolled out thanks to financial support of a private company that shared the values of empowerment and independence of persons with SBH.

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[3] http://www.ifgoodpractices.org/norway

Partnerships between different actors

The availability of the above-mentioned **seamless multidisciplinary model of care and support is essential for realisation of human rights and dignity** of persons with spina bifida and hydrocephalus at all ages. In addition to providing preventative annual check-ups and timely expertise interventions for medical emergencies, multidisciplinary clinics are able to counsel individuals and provide them with support concerning social security entitlements, employment, or peer support.

IF and its partners in developing countries have developed the S.H.I.P. model – Spina Bifida and Hydrocephalus Interdisciplinary Program – that emphasise a coordinated approach between the different partners in care and support the neurosurgical hospital, the CBR (community-based rehabilitation) centre, ambulant clinics, parent groups and local authorities. The purpose of S.H.I.P. is to help partners communicate better and understand each other's role in the process of supporting the individual with SBH. The model has successfully been implemented in Uganda, Kenya and Tanzania.

IF strongly supports the collaborative model where medical professionals cooperate closely with local SBH associations in running the SBH clinics. Close involvement of DPOs helps gain trust of persons with SBH seeking support and give value to the expertise of DPO self-advocates.

In Flanders (Belgium), the SBH association participates in monthly multidisciplinary clinic at the University Hospital Leuven, where it counsels participants and informs them of the support available from the association. This valuable collaboration allows people with SBH find peer support in their local community, and to the association – to reach out to people it wouldn't have otherwise identified and expand their membership.