**The rights of older persons with disabilities**

IF Response to the consultation launched by

the UN Special Rapporteur on the Rights of Persons with Disabilities

April 2019

**Introduction**

The [**International Federation for Spina Bifida and Hydrocephalus (IF)**](http://www.ifglobal.org) is a global organisation of persons with disabilities governed by adults with spina bifida and/or hydrocephalus (SBH), or parents of children with SBH. IF’s mission 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. Universal respect of the rights reaffirmed in the UN Convention on the Rights of Persons with Disabilities (UNCRPD)for all children and adults with SBH is IF’s underlying philosophical base, and we support the call to leave no one behind through the implementation of the Sustainable Development Goals (SDGs).

IF is a member of International Disability Alliance, the European Disability Forum and the International Disability and Development Consortium, as well as the European Patients’ Forum, EURORDIS and Rare Diseases International. IF has held consultative status to ECOSOC since 1991.

**Spina bifida** is one of the most complex neural tube birth defects compatible with life, 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, orthopaedic needs, and weight management. Many people with spina bifida also develop **hydrocephalus**, which is an accumulation of excess cerebrospinal fluid in the brain. If untreated, hydrocephalus can cause blindness, intellectual disabilities, and premature death. Although those affected are usually born with hydrocephalus, a person can also develop the condition from neonatal infection, tumours, haemorrhage, etc.

**Ageing with spina bifida and hydrocephalus**

It wasn’t until the discovery of antibiotics, the invention of the shunt, and the advances in surgical procedures, that children born with SBH began to survive and thrive, when this type of care was made available to them.[[1]](#footnote-1) Nowadays, people born with SBH who did receive timely treatment and care in the 1950s and 1960s are among the first to reach their senior years. The number of people ageing with Spina Bifida and Hydrocephalus is expected to increase in the years to come.

In 2012, in its Position Paper “Unfold their potential – (Y)our return on investment”, IF called for urgent action to address the issues faced by people ageing with SBH in the areas of health, employment and social inclusion.[[2]](#footnote-2) Adults with SBH have the right to work, to live independently and to participate in all aspects of life. However, lack of mobility, lack of adaptive equipment, lack of education and support, lack of accessibility, and discrimination and lack of social acceptance create serious barriers to exercising these rights. Currently they fear for their future and their lives, because knowledge about their conditions in advanced age is lacking and coordinated care and support is unavailable.

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). However, in countries where this type of care is available, it is often only targeting children and youth with SBH. There exist only very few clinics that offer an integrated approach to treatment, care and support for adults with SBH.

An in-depth description of the needs of persons with SBH throughout the life cycle, including in adulthood and with regard to ageing, can be found in our response to the consultation launched by the UN Special Rapporteur on the Rights of Persons with Disabilities in 2016, on the provision of support to persons with disabilities.[[3]](#footnote-3)

Last but not least, just as at the beginning of life, people ageing with SBH may be faced with preconceived notions with regard to their quality of life and their value to society. This could put them at risk of denial of treatment and negative assumptions when end-of-life decisions need to be made.

**Invisible disabilities**

People with SBH can also be experiencing cognitive issues, chronic pain, and fatigue, and they can be at risk of mental health issues, such as depression and anxiety. However, all too often, when visiting a family doctor or a medical specialist, the focus will be on their physical condition. A recent survey from Norway, among 30 adults with SBH aged between 51 and 76, showed that 40% of participants reported “severe fatigue”, 20% reported depression and 30% anxiety, and pain was mentioned as a main health issue.

In addition, authors of a 2015 study from the United States write that “Persons with spina bifida (SB) are also subject to less visible executive function impairments.” They noticed that people with SB were likely to answer “No” to the question “Do you have any problems”, even if they were known to have foot lesions. This suggested to the researchers that general questions do not elicit accurate information. Using simple and concrete language to minimise misunderstanding is essential when trying to identify secondary conditions in persons with spina bifida.[[4]](#footnote-4) Their survey also showed that pain was commonly reported (90% of respondents reported the presence of pain), as well as depression (over 50% of respondents replied ‘‘yes’’ to the question ‘‘Do you have problems with depression?’’). Participants also indicated limited social and community participation. Since an association between disability and depression has been established, identifying **mental health secondary conditions** is a priority for persons with spina bifida

It is also important to point out that older people with severe cognitive disabilities may have lost their right to exercise their legal capacity or decision making at a younger age already. They should be protected against institutionalisation and abuse, once their legal guardians pass away.

**Accelerated ageing**

Recalling the 2011 World Report on Disability, we would also like to point out that the ageing process for some groups of people with disabilities begins earlier than usual. The ageing process and associated changes also may have a greater impact on people with lifelong disabilities.[[5]](#footnote-5) It places adults born with SBH at risk of premature death, before even reaching retirement age. More research in adults with SBH is needed to better understand the **late-onset secondary conditions** associated with SBH and the longitudinal effects of childhood procedures.[[6]](#footnote-6),[[7]](#footnote-7)

The process of accelerated ageing also puts people with disabilities at risk of being placed in a nursing home for the elderly or in an institution at a younger age[[8]](#footnote-8). E.g., in Ireland, in 2017, the Health Service Executive has said that there are **more than 1,200 people, most with disabilities, who are under the age of 65 and yet living in nursing homes for the elderly**.[[9]](#footnote-9)

A similar situation has recently been reported from Canada, where a support group called No More Warehousing has been founded to fight the institutionalisation of people with severe physical disabilities in places like nursing homes.[[10]](#footnote-10)

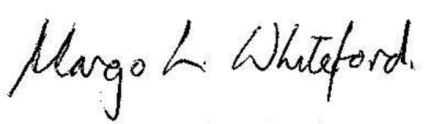
National legislation can be another barrier to the living conditions of older people with disabilities, such as the so-called “Bedroom Tax” in the United Kingdom, where subsidies were removed for social housing tenants who were deemed to have "spare" rooms in their homes[[11]](#footnote-11), and where it is now no longer possible to challenge the UK government under the Human Rights Act[[12]](#footnote-12).

**Summary**

Older people with spina bifida and hydrocephalus have the same rights as every other person. However, to exercise these rights, they have to overcome many barriers. To overcome these barriers, they need access to multidisciplinary clinics, where professionals have up-to-date in-depth knowledge on SBH treatment and care, including mental health care. They need access to assistive devices, access to inclusive education, employment with reasonable accommodations, such as flexible working hours. They need social protection against financial hardship and the risk of institutionalisation. More research is needed into the effects of ageing with SBH and the impact on daily life of secondary conditions. The health and the lives of people ageing with SBH should not be at risk due to stigma, prejudice, and the combined discrimination based on age and disability.

For the board of directors and the Global Experts Panel of the International Federation for Spina Bifida and Hydrocephalus,

Warm regards,

Renée Jopp Lieven Bauwens Dr Margo Whiteford  
Information officer Secretary General President

1. [Tell the truth about spina bifida](https://obgyn.onlinelibrary.wiley.com/doi/full/10.1002/uog.1742) (2004) [↑](#footnote-ref-1)
2. [Position Paper "Unfold their potential - (Y)our return on investment"](https://www.ifglobal.org/download/1656/) (2012) [↑](#footnote-ref-2)
3. [IF submission on support to persons with disabilities](http://www.ohchr.org/Documents/Issues/Disability/ProvisionSupport/NGOs/International%20Federation%20for%20Spina%20Bifida%20and%20Hydrocephalus.docx) (2016) [↑](#footnote-ref-3)
4. [Perception of secondary conditions in adults with spina bifida and impact on daily life](https://www.ncbi.nlm.nih.gov/pubmed/25958105) (2015) [↑](#footnote-ref-4)
5. [WHO World Report on Disability](http://www.who.int/disabilities/world_report/2011/en/) (2011) [↑](#footnote-ref-5)
6. [Optimizing Health Care for Adults with Spina Bifida](https://www.ncbi.nlm.nih.gov/pubmed/20419774) (2010) [↑](#footnote-ref-6)
7. [IF submission on the rights of PwD to the highest attainable standard of health](https://www.ohchr.org/Documents/Issues/Disability/StandardHealth/InternationalFederationSpinaBifida_Hydrocephalus.docx) [↑](#footnote-ref-7)
8. <https://www.thesun.ie/news/2852866/man-32-who-suffers-from-spina-bifida-blasts-hse-for-moving-him-into-nursing-home-for-elderly-people/> [↑](#footnote-ref-8)
9. <https://www.rte.ie/news/2017/0808/895907-disabilities-nursing-homes/> [↑](#footnote-ref-9)
10. <https://www.thestar.com/halifax/2019/04/04/disability-advocates-want-ns-government-to-fix-to-broken-housing-system.html> [↑](#footnote-ref-10)
11. <https://www.bbc.com/news/uk-37921766> [↑](#footnote-ref-11)
12. <https://www.dailypost.co.uk/news/north-wales-news/bedroom-tax-government-conservative-tories-14446315> [↑](#footnote-ref-12)