

Identification of possible gaps in the protection of the human rights of older persons and how best to address them

IF response to the consultation launched by the UN Open-ended Working Group on Ageing

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Introduction

The [International Federation for Spina Bifida and Hydrocephalus \(IF\)](http://www.ifglobal.org) is the 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 prevalence 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 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 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

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 2019 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.

¹ [Tell the truth about spina bifida](#) (2004)

² [Position Paper "Unfold their potential - \(Y\)our return on investment"](#) (2012)

³ [IF submission on support to persons with disabilities](#) (2016)

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 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

Persons with disabilities is a very diverse group encompassing diverse support needs. It is vital to recognise this diversity, including the reality that for some persons with disabilities a significant portion of their support needs is concerned with health. This may include assistance with daily self-management, for example for persons with SBH this can include assistance with the use of catheters or training on how to do so oneself. Persons with SBH also require the care of multiple health care specialists and support for independent living for a person with SBH may need to include assistance with the management of multiple appointments and transport to specialists outside the community.

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 It places adults 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.^{6,7}

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 age⁸.

⁴ [Perception of secondary conditions in adults with spina bifida and impact on daily life](#) (2015)

⁵ [WHO World Report on Disability](#) (2011)

⁶ [Optimizing Health Care for Adults with Spina Bifida](#) (2010)

⁷ [IF submission on the rights of PwD to the highest attainable standard of health](#) (2018)

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<https://www.thesun.ie/news/2852866/man-32-who-suffers-from-spina-bifida-blasts-hse-for-moving-him-into-nursing-home-for-elderly-people/>

IF members report that barriers to independent living often come from challenges with accessing multidisciplinary health care, lack of awareness of the rights based model of disability and the UNCRPD by health care services, lack of access to specialised health care services and barriers in accessing mainstream health care services including sexual and mental health.⁹ Changing needs throughout the lifespan and discomfort among other support staff including in education, mental health or other disability specific or mainstream public services in providing support for disability or health related needs. These barriers vary depending on the age of the person with SBH. Spina Bifida is a congenital condition that is often detected before or soon after birth. Risks for institutionalisation can begin at the moment of diagnosis if parents are given advice, including from health care professionals, which contradicts their rights under the UNCRPD. For example, being advised that the best place, or even the only place, where persons with SBH can receive the best health care be it within an institution.

Segregation is a significant risk factor for institutionalisation. Risks of segregation continues as the child ages as access to mainstream education and leisure activities may be denied or compromised because their support needs such as assistance with incontinence, including the use of catheters, is deemed to be a ‘medical need’ which does not fall under the scope of disability support or accommodations and is therefore denied.¹⁰ The risks of institutionalisation further evolve with age. Persons experiencing ageing with SBH find that their needs and mobility change and without the right support this poses a significant risk to their independence and independent living.^{11,12}

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.⁹

⁹ IF International Youth Group (2021). [IF Statement on Mental Physical and Sexual Health for Youth with SBH. International Federation for Spina Bifida and Hydrocephalus](#)

¹⁰ International Federation for Spina Bifida and Hydrocephalus (2016). [IF Report Right to Health: Reality of Persons with Spina Bifida and Hydrocephalus](#)

¹¹ IF Working Group on Ageing (2021). [IF Report on Ageing with Spina Bifida and Hydrocephalus – Findings from Online Focus Group Discussions. International Federation for Spina Bifida and Hydrocephalus](#)

¹² IF Working Group on Ageing (2022). [Ageing With Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World. International Federation for Spina Bifida and Hydrocephalus](#)

Identification of gaps

IF recognizes that the identification of possible gaps in the protection of the human rights of older persons is essential for the advancement and protection of the human rights of older persons with disabilities, including people with SBH. Ageing persons with SBH is a very diverse group encompassing diverse support needs. It is vital to recognise this diversity, including the reality that for some persons with SBH a significant portion of their support needs is concerned with health. Below, a summary of the before mentioned points in line with the selected topics by the Open-ended Working Group on Ageing:

Social Inclusion: The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with spina bifida and hydrocephalus (SBH) and their families worldwide. IF has country members in Africa, Americas, Asia-Pacific, and Europe with unique and expert knowledge on SBH. With global coverage, IF's mission is to create a completely inclusive society to improve the quality of life of persons with SBH and their families. This is currently hindered by for example the lack of access to multidisciplinary care, healthy ageing, independent living, employment.

Equality and non-discrimination: IF recognizes that the identification of possible gaps in the protection of the human rights of older persons is essential for the advancement and protection of the human rights of older persons with disabilities, including people with SBH. Ageing persons with SBH is a very diverse group encompassing diverse support needs. It is vital to recognise this diversity, including the reality that for some persons with SBH a significant portion of their support needs is concerned with health.

Right to Health and Access to Health Services: Work carried out by the IF Working Group on Ageing with SBH has identified emerging concerns with physical and mental health and with the provision of associated care. The IF report 'Ageing with Spina Bifida and Hydrocephalus a Descriptive Analysis' shows a decline in physical health of people with SBH as they get older. This is indicated by, for example, a reduction in mobility, increased fatigue, increased pain and an increase in problems with continence. All of these things can contribute to a decline in the quality of life.

Furthermore, IF recognised that to address the challenge of becoming older for persons with SBH, it is not only the responsibility of SBH associations but also healthcare providers, researchers, policy makers, and other relevant actors. These actors are recommended to develop a more personalised and holistic model of care for the older adult with SBH. Additionally, they are pleaded to deliver person-centred provision of services that include coordinated and integrated multidisciplinary health and social care input.

Right to Work and Access to the Labour Market: The health impacts on ageing individuals has implications on a range of aspects including employment, housing, financial stability and ability to enjoy a full social life. IF members reported that persons with SBH have less opportunity for employment, and there is a large number of people with SBH unemployed or outside the workforce. Some persons with SBH did not go to school in the past, making their chance of finding employment slimmer. More seriously, persons with SBH do not receive sufficient support from the government or necessary training. Without jobs and money, many individuals ageing with SBH are struggling with their lives and cannot live independently. Therefore, access to work and employment is essential for the societal inclusion of people with disabilities.

Options on how best to address the gaps

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. For this, IF has installed a Working Group on Ageing with Spina Bifida and Hydrocephalus including members from countries around the world. Through their activities, they have identified emerging needs and concerns for the ageing population of persons with SBH. Another important activity of the working group is to make persons with SBH more resilient. As the story of ageing with SBH unfolds, urgent actions are needed to meet the needs of this emerging population and to improve our understanding of the challenges it faces.

Other options to strengthen the protection of older persons

IF recognised that to address the challenge of becoming older for persons with SBH, it is not only the responsibility of SBH associations but also healthcare providers, researchers, policy makers, and other relevant actors. These actors are recommended to develop a more personalised and holistic model of care for the older adult with SBH. Additionally, they are pleaded to deliver person-centred provision of services that include coordinated and integrated multidisciplinary health and social care input.

To strengthen the protection of older persons with SBH, IF shares the following recommendations:

- Ensure the full implementation of the UN CRPD. Protecting and ensuring the rights of persons with disabilities is vital. The European Commission and the EU Member States should ensure that the future disability policies and legislations are aligned with the CRPD;
- Ensure disaggregated data on persons with disabilities based on gender, age groups and types of disabilities. In order to fight discrimination towards people with disabilities and to design disability policies, we need accurate facts on people with disabilities and especially on SBH;
- Pay attention to specific categories of persons. The most vulnerable are always women with disabilities, children with disabilities, newborns with disabilities and ageing people with disabilities;
- Mainstream disability in all policies and legislations. Disability should not only be linked to social inclusion but also to employment, education, access to healthcare, access to digital, access to sport, transport, mental health etc;
- Enhance the health dimension. Access to affordable quality healthcare services is vital for people living with SBH. This could be improved by (1) training and informing healthcare professionals on SBH; (2) creating multidisciplinary care hospitals and/or clinics; (3) improving the cross-border healthcare directives;
 - Encourage the development of personalised and holistic model of care for the older adult with SBH and sustainable and well informed workforce;
 - Work to deliver person-centred provision of services that include coordinated and integrated multidisciplinary health and social care input;

- Consider introduction of legislation to enshrine the right for employment and meaningful occupation of those experiencing accelerated ageing;
- Support further research including qualitative and quantitative research on the impact of ageing and identification of outcome measures that are meaningful to people who are part of the SBH community;
- Support the development of services aimed at creating inclusive and accessible societies including improved mental health of persons with disabilities.
- Develop a more personalised and holistic model of care for the older adult with SBH and a sustainable and well informed workforce.

In Conclusion

The ageing SBH community has the same rights as every other person. However, to exercise these rights, they have to overcome many barriers. To overcome these barriers, the Working Group on Ageing with Spina Bifida and Hydrocephalus already works towards building resilience. In addition, there remain urgent needs to multidisciplinary care 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.

Yours Sincerely,



Dr Sylvia Roozen

Secretary General - International Federation for Spina Bifida and Hydrocephalus