

IF Statement on Ageing with Spina Bifida and Hydrocephalus

The International Federation for Spina Bifida and Hydrocephalus (IF) calls for greater awareness of and actions to meet the needs of individuals ageing with Spina Bifida and Hydrocephalus (SBH). The challenges faced by people ageing with SBH are, in a sense, a story of success. In the whole of human history, there has never been a significant population of older people with SBH – until now. The surgical advances of the early 1960s and subsequent improvements in care mean that there is now a growing population of SBH adults in their 50s and 60s – and that population will grow over the next few decades. Work carried out by the IF Working Group on Ageing with Spina Bifida and Hydrocephalus has identified emerging concerns with physical and mental health and with the provision of associated care. 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.

The IF report ‘Ageing with Spina Bifida and Hydrocephalus a Descriptive Analysis’¹ 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. These changes could be characterised as “accelerated ageing”. All of these things can contribute to a decline in the quality of life. This has implications on a range of aspects including housing, employment, financial stability and ability to enjoy a full social life. SBH is a complex condition and given the range of health issues it gives rise to benefits from a multidisciplinary approach. While SBH clinics are sometimes available for children, this is not usually the case for adults. This means that an older person with SBH may be seen by a variety of different specialists – none of whom see the full SBH picture. This also results in SBH adults having to repeat their case history to different people involved in the various aspects of their care, which can be frustrating. There is a need for a multidisciplinary approach, to ensure holistic care of the growing adult SBH population.

Related – perhaps inseparable – from the physical health challenges faced by SBH adults and increased reports of mental health challenges. The lived experiences of many SBH adults involves increased isolation – in large part due to the changes in physical health described above, that can

¹IF Working Group on Ageing with SBH (2020). *Ageing With Spina Bifida and Hydrocephalus – A Descriptive Analysis*. International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-report-ageing-withspina-bifida-and-hydrocephalus-a-descriptive-analysis/>

make it more difficult to enjoy a full social life. It is not surprising then that many people report an increase in anxiety and depression. This can result in a negative cycle, as people are less likely to make the effort to see others, which further increases the sense of isolation. It is necessary for healthcare providers, policy makers, and other relevant actors to understand the link between mental and physical health and for mental health services to be part of the package of care available to SBH adults.

As noted above, this is an unfolding story. Further detailed research is required, in order to better understand the lived experiences by individuals ageing with SBH and improve the quality of care. It is clear that some people show greater resilience to changes they face than others, maintaining good mental health, in the face of physical changes. We need to learn from such examples and apply those lessons to improve the resilience of the community as a whole. There is also a need to identify successful approaches adopted in different places, to draw together and publicise examples of best practice, so that it becomes more widespread. In this way, we can ensure that the transition of people with SBH to older age can be well managed.

Recommendations:

IF calls on policy makers to:

- 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.

ABOUT IF

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. The organisation founded in 1979, represents Member Associations in countries all over the world with unique and expert knowledge on SBH. The mission of IF is to improve the quality of life of people with SBH and their families, and to reduce the incidence of neural tube defects and hydrocephalus through primary prevention by improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education. The vision of IF is a society that guarantees the human rights of children and adults with SBH, and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy for all.

IF Working Group on Ageing with Spina Bifida and Hydrocephalus

The IF Working Group on Ageing with Spina Bifida and Hydrocephalus is composed of adults with SBH and people who act as formal and informal carers for adults with SBH. Its key objective is to improve the understanding of the lived experience of individuals ageing with SBH. To that end it has organised a continuing programme of work, including an international survey and focus group discussions, aimed at giving adults with SBH the opportunity to describe and share their experiences. The results are promoted through publications and presentations.

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International Federation for Spina Bifida and Hydrocephalus

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Cellebroersstraat 16 - 1000 Brussels

T: +32 (0) 471 84 41 54 | E: info@ifglobal.org

www.ifglobal.org

