

IF response to the roadmap for the Green Paper on Ageing (published 2020/11/16).

Spina Bifida and Hydrocephalus (SBH) are complex health conditions which develop during the first four weeks of pregnancy as a result of the neural tube and spine not developing correctly. The International Federation for Spina Bifida and Hydrocephalus (IF) has represented people with SBH and their families since 1979. With global coverage, IF's mission 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.

Europe is currently going through a demographic transition as the ageing population continues to make up a larger proportion of our society. Individuals with SBH are, thankfully, witnessing the same transition. Improvements in medical science and advancement of technology has led to a significant increase in the life expectancy of babies born today with SBH. With current research suggesting that 75% of newborns with SBH will reach adulthood.

This is a welcomed development but nevertheless presents individuals with SBH, their families and the communities which they live in with a challenge to take into consideration the additional needs of individuals experiencing ageing with SBH. How to safeguard their independence and wellbeing and ensure that they have access to the services which they require is an important issue for IF and it's ageing members.

IF welcomes the roadmap for the Green Paper on Ageing. In particular the importance of looking beyond the purely economic side of demographic change and the emphasis on health care, long-term care and the need for adequate pensions. However, IF considers it to be vitally important that the Green Paper on Ageing takes into account the needs of individuals who experience accelerated ageing due to SBH or other conditions. The difference in how individuals with SBH experience ageing can have a tremendous impact on their quality of life and mental health, access to adequate pensions, health care, rehabilitation, employment and so much more.

The topic of ageing for individuals with SBH is of high importance for IF. The federation facilitates activities together with the Working Group on Ageing with Spina Bifida and Hydrocephalus and in 2020 IF published a report on Ageing with SBH which outlines the results of those activities. The report includes recommendations for European social policy and in the context of the European Commission's Roadmap for the Green Paper on Ageing, IF would like to highlight the following recommendations:

- Identify areas of best practice for transitional model of care for (older) people with neurological conditions such as SBH;
- Produce a detailed atlas of variation that collate maps with a narrative to identify and address unwarranted transitional care variation and support improvement in outcome across Europe;
- Advocate for a person-centred provision of services that include coordinated and integrated health and social care input;
- Consider introduction of legislation to enshrine the right for employment and meaningful occupation of those experiencing accelerated ageing;

You can read more about this in IF report "Ageing with spina bifida and hydrocephalus"