

November 2021



## IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus

From 14 to 17 September 2021 the International Federation for Spina Bifida and Hydrocephalus (IF) held an international conference focused on multidisciplinary care. During this conference leading healthcare professionals in their fields, researchers in the fields of health and social care, persons with Spina Bifida and Hydrocephalus (SBH), their families as well as young scholars came together to discuss the need, benefits and barriers to multidisciplinary care for SBH.

Article 25 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) declares that *“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”* The conclusion from the IF Conference on Multidisciplinary Care is that the highest attainable standard of health for persons with SBH cannot be achieved without multidisciplinary care.

Persons with SBH require care from a wide range of different services and medical specialists. In the absence of (accessible) multidisciplinary care individuals with SBH and their families struggle to obtain and coordinate these different services and needs. For instance, IF member associations report that their members may even be required to travel long distances around the country for different specialised care with no assistance from healthcare providers in coordinating this process. In addition, the frequent change in healthcare professionals as well as stigmatisation of SBH and a lack of coordination and communication between specialists and services results in inconsistent and even conflicting advice, diagnosis management and care. With each healthcare professional only focusing on the symptoms most relevant to them, rather than seeing the individual as a whole. This impact on the success of management and care at home as well as on the wellbeing and mental health of persons with SBH and their families. Together this results in the increase of preventable comorbidities and even necessitating invasive procedures that may have otherwise been avoided.

Health is an enabler of inclusion. The consequences of inadequate access to multidisciplinary care has a wider impact on the lives of individuals with SBH and their families. Pain, loss of mobility, recovery from surgical procedures or management of comorbidities is also a threat to independent living of persons with SBH (article 19 UNCRPD). At the IF Conference on

Multidisciplinary Care for SBH<sup>1</sup> the role of integrated multidisciplinary services in fostering inclusion and independence was highlighted with an emphasis on how specialised integrated SBH care helps to empower both parents and individuals with SBH with management strategies at home. Multidisciplinary care must take a personalised approach and examples of services co-produced with service users and clinical teams were presented. However, the development of such services remains inconsistent as national guidelines are lacking. Too often these services exist only for children with SBH, with little to no integrated multidisciplinary services available for the transition from childhood to adulthood, for adults and those ageing with SBH.

Multidisciplinary care is also essential where access to healthcare is limited and in regions with a high infant and child mortality rate. Access to healthcare as early as possible is essential. No child should die because they cannot access essential surgical procedures for SBH. However, accessing surgical care is only one aspect of essential healthcare for individuals with SBH. Family support and aftercare post-surgery is an essential factor in lowering the mortality rate, ensuring the right to family life for children with SBH and supporting informal carers and parents who play a crucial role in the care of individuals with SBH. At the IF Conference on Multidisciplinary Care for SBH family centred support after surgical interventions was highlighted as the most important factor in lowering the mortality rate of children with SBH in low-income countries. A multidisciplinary approach to SBH in low-income countries also improved efficiency, allowing healthcare providers to increase the number of patients. Lack of support for post-surgical care as well as shortage of equipment and supplies was identified as barriers to healthcare for SBH in low-income countries.

The IF Conference on Multidisciplinary Care for SBH included inputs and speakers from all over the world, from different specialties, professions and lived experiences. The diversity of the event allowed for the discussion of many different perspectives, realities and challenges. However, the common conclusion from the four-day conference was the importance of multidisciplinary care. With respect to how integrated services and multidisciplinary care facilitates early access to care and information, improves patient outcomes and wellbeing, empowers and prepares young persons with SBH for an independent life and helps persons ageing with SBH maintain their independence. How multidisciplinary care for SBH is about more than medical services, the importance of including mental health, physiotherapy and family support in those services. The benefits to healthcare professionals and systems are also numerous, with improved communications and efficiencies. Multidisciplinary care is essential for the attainment of the highest standard of health without discrimination on the basis of disability as per article 25 of the UNCRPD.

In light of this IF hereby presents the following recommendations to healthcare professionals, providers and policy makers:

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<sup>1</sup> International Federation for Spina Bifida and Hydrocephalus (2021). *International Federation for Spina Bifida and Hydrocephalus Conference on Multidisciplinary Care: Programme Book*: <https://www.ifglobal.org/publications/if-multidisciplinary-care-conference-book-2021/>

## Recommendations:

- IF recommends that research into the development of integrated multidisciplinary care be strengthened and that policy makers, international organisations and other relevant stakeholders incentives research through actions such as increased availability of funds and resources;
- IF recommends that the crucial role of SBH associations in providing guidance and support to persons with SBH and their families be recognised and that the SBH community be involved in the development of SBH services to ensure inclusion and person centred care;
- IF recommends that policy makers, international organisations and other relevant stakeholders take an integrated multidisciplinary approach to developing healthcare services in low-income countries;
- IF recommends that policy makers on the national and regional level instigate the development of national guidelines and policies for the development of multidisciplinary care for SBH in order to tackle regional inequalities in access to care as per article 25(c) of the UNCRPD;
- IF extends to healthcare professionals and healthcare professional organisations and invitation to join IF in calling for integrated multidisciplinary care for SBH:

## 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 ivzw

International Federation for Spina Bifida and Hydrocephalus

*Consultative status special category Economic and Social Council at the United Nations*

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