

## **IF Statement on Multidisciplinary Care for the treatment of children and adults born with Spina Bifida and Hydrocephalus**

Spina Bifida (SB) is one of the most complex birth defects compatible with life, which can result in impaired mobility, loss of sensation, continence issues, and learning disabilities. The majority of children born with SB may also develop Hydrocephalus (H). Both children and adults with SBH are at high risk for the development of secondary medical conditions, including ventricular shunt malfunction or infection, orthopaedic problems like scoliosis and joint contractures, tethered spinal cord, urinary tract infections and other urologic problems, pressure ulcers, and obesity.<sup>1</sup>

In addition, adults may face potential complications from the chronic effects of childhood procedures such as ventricular shunting, urinary diversions, continence procedures, and orthopaedic surgeries on spines, hips, and lower extremities<sup>2</sup>. The need for repeated medical interventions can result in depression and anxiety. Children and adults with SBH need specialists who can address their medical and cognitive issues and promote a more healthy lifestyle, including nutrition and exercise. Simply put, individuals with SBH need an integrated system to deliver this complex care and to align and inform all the providers.<sup>3</sup> Services need to be age-appropriate and should include measures to ensure a proper transition from paediatric to adult multidisciplinary care for SBH<sup>4</sup>.

Without multidisciplinary care, children and adults with SBH will have to make multiple appointments, often in different hospitals at separate locations. When scheduling the appointments, they can be faced with long waiting times, and getting to each appointment may involve extensive and expensive travel. For those born with SBH, a delay in access to healthcare services can be life-threatening. Even without any incidental problems or urgency, annual neurological, urological, and orthopaedic check-ups are a necessity to prevent additional future health issues.

It is often the case that communication between the medical specialist dealing with one aspect of SBH and the other (health)care providers involved in the well being of individuals with SBH will often be lacking. This non-holistic approach increases the risk that a potential health complication may be overlooked, such as forgetting to pay attention to the person's mental health that is overshadowed by physical health issues.

In order for children, youngsters and adults with Spina Bifida and Hydrocephalus to reach their full potential, age actively and healthily, and enjoy a good quality of life, the International Federation for Spina Bifida and Hydrocephalus strongly recommends access to multidisciplinary care for people

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<sup>1</sup> [The Future of the Multidisciplinary Clinic](#) (Brei; 2007)

<sup>2</sup> [Optimizing health care for adults with spina bifida](#) (Webb; 2010)

<sup>3</sup> [Optimizing health care for children with spina bifida](#) (Liptak; 2010)

<sup>4</sup> [Transitioning adolescents and young adults with spina bifida to adult healthcare: initial findings from a model program](#) (Sawin 2015)

born with Spina Bifida and Hydrocephalus of all ages.<sup>5</sup> Furthermore, we call for integration of the medical care of persons with disabilities and other indivisible elements of the person's life cycle, such as rehabilitation, education, employment, and access to social services. Only with systematic provision of such an integrated care approach will it be possible to guarantee to people living with SBH the enjoyment of all their human rights and fundamental freedoms in line with the UN Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals.

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<sup>5</sup> [IF Position Paper Unfold their potential – Ageing with Spina Bifida and Hydrocephalus](#) (2012)