

# Executive Summary

## *For the Report Ageing With Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World*

This publication builds on those previously issued by the IF Working Group on Ageing of The International Federation for Spina Bifida and Hydrocephalus (IF) - 'Ageing with Spina Bifida and Hydrocephalus – a Descriptive Analysis' and 'Ageing with Spina Bifida and Hydrocephalus – Findings from Online Focus Group Discussions'. Those publications described the problems faced by the ageing Spina Bifida and Hydrocephalus (SBH) community and put forward a series of recommendations as to how these could be addressed, directed at policy-makers, SBH associations and individuals.

Ageing With Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World provides examples of how seven different SBH associations have responded to the challenges faced by the ageing SBH community in different countries. These include social isolation, mental health, employment and more holistic healthcare. It is truly international. It truly highlights international practices, with contributions from Africa, Asia and North America, as well as Europe. The chapters on each example not only describe what was done but also the outcomes and the lessons learned. The objective is to provide enough information for any interested SBH association to adapt an example for their own situation and then successfully implement it.

While diverse, the examples in the report share some common factors that helped ensure their success: an understanding of, and involvement by, the ageing SBH community and collaboration with relevant stakeholders.

This publication is not intended to be the final word on meeting the challenges of ageing with SBH. It is recommended that SBH associations use this publication to stimulate discussion with their own SBH communities on what actions they could take. There may well be existing initiatives different from those described here within this publication. All of that will form part of the IF's continuing engagement with the challenges of ageing with SBH and IF will provide further opportunities for national associations to share and discuss best practices.

In describing what people with SBH have done for themselves, the report also makes clear what needs to be done by policy-makers.

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