

**REPORT**  
**AGEING WITH SPINA BIFIDA AND HYDROCEPHALUS**

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**AN OVERVIEW OF  
BEST PRACTICES AROUND  
THE WORLD**



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# PREAMBLE

The International Federation for Spina Bifida and Hydrocephalus (IF) presents this document to provide outcomes of the study with different IF Member Associations.

This document builds upon the IF reports 'Ageing with Spina Bifida and Hydrocephalus – a Descriptive Analysis' and 'Ageing with Spina Bifida and Hydrocephalus – Findings from Online Focus Group Discussions'<sup>1</sup> both produced by the IF Working Group on Ageing with SBH. They underline the need for multidisciplinary care, especially with respect to mental and physical issues experienced by adults with Spina Bifida and Hydrocephalus.

To support IF Members' efforts to bring the most appropriate care and support to persons with SBH in their countries, the IF Working Group on Ageing with SBH conducted a study among IF members, to map best practices around the world. The results are presented within this report.

# INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with Spina Bifida and Hydrocephalus (SBH) and their families in 1979.

It has grown from a voluntary association into a professional organisation of persons with disabilities with global coverage. IF now includes over 80 SBH associations in Africa, Australia, the Americas, Asia-Pacific and Europe.

The majority of IF Member Associations are led and governed by adults with Spina Bifida and Hydrocephalus or parents of children with SBH. Nowadays, many young people with SBH have taken over the leadership of their organisations.

In most cases, IF Members choose close cooperation with medical and education professionals and researchers, given the importance of these professions to children and adults with SBH for their survival and development.

The mission of IF is to improve the quality of life of people with Spina Bifida and Hydrocephalus and their families, and to reduce the prevalence of neural tube defects and Hydrocephalus by primary prevention; by raising awareness and through political advocacy, research, community building and human rights education.

# INTRODUCTION

Spina Bifida and Hydrocephalus (SBH) are complex health conditions leading in many cases to disabilities involving cognition, behavior, and neurological dysfunctions. These are the most common Neural Tube Defects (NTDs), which affect over a quarter of a million annual birth outcomes worldwide<sup>2</sup>. However, rapid developments in medical science, advancement of technology and improvement in healthcare practices have seen a significant increase in the life expectancy of babies born today with these conditions.

For persons with SBH life expectancy is on the rise. Data from the last three decades suggest that more than 75% of newborns will reach adulthood. For the first time in history, there is an older SBH community in their late 50s and early 60s, which is predicted to rise dramatically over the next few decades.<sup>3</sup> Since it is the first time that this has happened, the investigation into adults with SBH, especially the ageing SBH community is lacking.<sup>4</sup> There is a need to explore and expand our knowledge and gain insights into the current situation of older people with SBH.

The topic of healthy ageing is therefore a high priority, not only for the national organisations but also for the International Federation. For instance, in 2019, the International Federation for Spina Bifida and Hydrocephalus (IF) supported the United Nations Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas Aguilar, in drafting a report emphasising the rights of older persons with disabilities.<sup>5,6</sup>

Also, other initiatives show the support of ageing communities worldwide. To give an example, the United Nations together with World Health Organisation (WHO) lead an international initiative called 'Decade to Healthy Ageing' to improve lives of older people, their families, and communities worldwide between 2021 to 2030. Emphasis is given to multi stakeholder engagement whereby older people play a central role in collaborations.

The topic of ageing for persons with SBH has a special focus for the International Federation for Spina Bifida and Hydrocephalus. The International Federation represents persons with SBH and their families worldwide. Together with IF Members during the IF International Conference in 2010, the message was shared that there is no time to lose when it comes to optimising care for adults with SBH. For example in 2012, IF looked into the issue of ageing and published a position paper 'Unfold their potential, (y)our return on investment. Ageing with Spina Bifida and Hydrocephalus, no time to lose'<sup>8</sup>. With this position paper, IF called for coordinated actions to support what was described as an 'urgent need' for older people with SBH to receive the services persons with SBH require and deserve.

# INTRODUCTION

Since then, the IF has focused on this important topic and emphasised the importance of raising awareness about ageing with Spina Bifida and Hydrocephalus (SBH). One of the IF's key objectives is to improve our understanding of the lived experience of older persons with SBH. Therefore, the IF Working Group on Ageing with SBH, formed by IF member representatives, was created. Several actions have been undertaken to advocate for the rights of persons with disabilities also on behalf of IF members. For example, in 2019 the IF Working Group on Ageing with SBH conducted a Europe-wide explorative study using an online survey<sup>9</sup>. The report described results from 650 persons with SBH and their lived experiences. Not surprisingly, the results from the survey revealed a range of lived experiences which clearly shows there is no one single lived experience for adults with SBH. Nevertheless, it did reveal clear trends, including a decline in both physical and mental health for many people. Following the report in 2019 and activities, there was a need for qualitative investigations to adopt a more in-depth approach to data collection and affirm overall findings from the previously conducted survey. In subsequent meetings, in 2020 and during the IF International Conference on Multidisciplinary Care for SBH in 2021, the IF Working Group on Ageing with SBH continued to actively raise awareness. Continuing the work in 2021, the IF report 'Ageing with Spina Bifida and Hydrocephalus - Findings from Online Focus Group Discussion'<sup>1</sup> described outcomes of focus groups discussions to better understand lived experiences for persons with SBH with respect to mental and physical health.

Having described the problems associated with ageing with SBH in these reports, the IF Working Group on Ageing turned its attention to solutions. It was decided to survey IF Member Associations to identify best practices with respect to the needs and support for ageing with SBH from IF Member Associations, so that these could be explored and shared. Therefore, this study aims to gain deeper insights into what is happening on a country level, what are needs from older individuals with SBH and identify best practices by IF Member Associations around the world to support their ageing SBH community. The intention is to describe the examples of best practice in sufficient detail to allow national associations to decide whether it is something that they could adapt for their own needs.

# METHODOLOGY

## *Data collection*

Since the beginning of February, the survey questions were developed based on consensus among the members of the IF Working Group on Ageing with SBH.

The survey consisted of 10 questions and was developed into 2 main sections (i) background information and (ii) best practice information.

- The first section consisted of questions about the members association, contact person and email address.
- The second section consisted of all open-ended questions with the main aims of identifying the target audiences, objectives, components, outcomes and lessons learned of the best practices.

Between February 16 and May 2022, all IF Members Associations were invited to participate in this study via invitation emails and verbal invitations during IF meetings. Members of IF Working Group on Ageing with SBH also reached out to their association to disseminate the survey.

A variety of different survey responses were received, with varying levels of detail. In order to ensure a uniform level of content for the report, it was decided to follow up the survey with interviews. From May to the end of June, follow-up interviews were conducted with IF Member Associations who had participated in the survey.

Semi-structured interviews were developed based on consensus among the members of the IF Working Group on Ageing with SBH. The interviews were divided into four main sections: (i) background, (ii) target audience, (iii) components, and (iv) result. Answers were recorded by note-taking, and seven interviews were also filmed with consent. The interviews took place in a digital meeting room using Zoom. The duration of each interview was 45 to 60 minutes.

## ***Data management***

The results from the survey and the interviews were conducted by the IF Project Officer and chairperson of the IF Working Group on Ageing with SBH. However, the responses were analysed by the IF Project Officer only. All were stored on Google Drive, a file storage service developed by Google. The IF Project Officer made transcripts of all recorded meetings. Recordings were captured for internal purposes only and are automatically deleted after six months. Results of the study are described below.

# **RESULTS**

## ***Overview***

Seven IF Member Associations joined the study including Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (Spina Bifida and Hydrocephalus Association in Flanders, Belgium), Spina Bifida Hydrocephalus Scotland, SBH Nederland (Spina Bifida and Hydrocephalus Association in the Netherlands), Spina Bifida Association Malaysia, the Central Uganda Spina Bifida and Hydrocephalus Network, Association for Spina Bifida and Hydrocephalus South Africa, and the Spina Bifida Association in the USA. There were one from Asia, three from Europe, two from Africa, one from the Americas.

Results showed there were a variety of best practices for adults with SBH in the different countries which are summarised in the table below.

**Table 1. An overview of best practices**

Countries	Challenges experienced by ageing SBH community	Best practices	Objectives
Belgium	<ul style="list-style-type: none"> <li>Lack of opportunities for social interaction</li> <li>Feelings of loneliness and social isolation</li> </ul>	Road trip	<ul style="list-style-type: none"> <li>Bring people ageing with SBH together</li> <li>Provide an enjoyable reasonable-priced road trip</li> <li>Educate older people with SBH about different aspects of ageing with SBH</li> </ul>
Malaysia	<ul style="list-style-type: none"> <li>Insufficiency of knowledge related to living with SBH at older ages</li> <li>Lack of connection with other persons ageing with SBH and specialists</li> </ul>	Regional Workshop	<ul style="list-style-type: none"> <li>Raise awareness of persons with SB about their ageing issues in different areas</li> <li>Strengthen the relationship within the SB community</li> <li>Connect SB ageing community with their healthcare professionals on more personal levels</li> </ul>
Scotland	Resources and information related to ageing with SBH are not accessible	Online Ageing Hub	Launch a holistic self-management platform for people ageing with SBH
The Netherlands	<ul style="list-style-type: none"> <li>Lack of platform for sharing and discussion</li> <li>Feelings of loneliness and social isolation</li> </ul>	Online Workshop	<ul style="list-style-type: none"> <li>Decrease social isolation of persons ageing with SBH</li> <li>Provide people ageing with SBH opportunities to freely share their questions and concerns within their community</li> </ul>

**Table 1. An overview of best practices**

<b>Countries</b>	<b>Challenges experienced by ageing SBH community</b>	<b>Best practices</b>	<b>Objectives</b>
<b>Uganda</b>	<ul style="list-style-type: none"> <li>Absence of job training and job opportunities for adults with SBH</li> </ul>	Rehabilitation Centre	<ul style="list-style-type: none"> <li>Offer training and employment assistance to people with SBH</li> <li>Create jobs for people ageing with SBH</li> <li>Empower adults with SBH to become self-reliant and self-worth in the society</li> </ul>
<b>The USA</b>	<ul style="list-style-type: none"> <li>Lack of platform for sharing and discussion</li> <li>Feelings of loneliness and social isolation</li> </ul>	Virtual gathering	<ul style="list-style-type: none"> <li>Create a positive, safe and educational space for sharing and discussion</li> <li>Strengthen the relationship within ageing SB community</li> </ul>
<b>South Africa</b>	<ul style="list-style-type: none"> <li>Absence of medical history of adults with SBH</li> <li>Insufficient knowledge and understanding of novice medical staff about SBH and ageing with SBH</li> </ul>	Record card	<ul style="list-style-type: none"> <li>Record the medical history of the persons ageing with SBH</li> <li>Ensure that potentially serious complications are evaluated by medical staff appropriately with undue delays in treatment</li> <li>Educate novice medical staff who may be unfamiliar with SBH</li> </ul>

# Road trip in Belgium

## Background

Every year, the Spina Bifida and Hydrocephalus Association in Flanders, Belgium sees an increase in the number of people becoming older with SBH, along with an increase in several ageing related challenges such as loneliness, depression and social isolation. The older people with SBH become, the fewer opportunities for social interaction. The COVID-19 pandemic since the beginning of 2020 has made the situation worse, since there has been restrictions on people to gather and meet one another. Some members ageing with SBH of the Spina Bifida and Hydrocephalus Association in Flanders, Belgium are reported to have not seen anyone for two years and a half. Moreover, despite a rising number of older people with SBH, there is a lack of support for this community nationwide. Once people reach adulthood, there are no working groups that specifically provide assistance for them in Belgium.

According to the IF report 'Ageing with Spina Bifida and Hydrocephalus- Finding from Online Focus Group Discussions'<sup>1</sup>, absence of social connections can have profound effects on the overall health of ageing SBH community. More specifically, loneliness is one of the factors with the greatest impact on people's mental health. It was emphasised that staying active while also meeting other people could enhance mental health and decrease feelings of social isolation. Therefore, this problem can be addressed by providing an ageing SBH community more social activities in order to interact with others.

## Best practice description

The Spina Bifida and Hydrocephalus Association in Flanders, Belgium organised several road trips once a year in Belgium and/or abroad for their adult members.

The primary objective of a road trip was to bring all adults with SBH together and strengthen the ageing SBH community. Furthermore, the association aimed to provide the road trip at a reasonable price. Most importantly, this road trip was seen as an opportunity for people to discuss important issues related to the topic of ageing with SBH, such as incontinence, sexuality, housing, and setting goals in life. To the association, education is considered one of the key things during the road trips, aiming to increase members' knowledge about the topics directly related to them.

There are two main groups who participate in the road trips; groups aged from 19 to 30 and groups aged beyond 30. The reason for splitting the groups lay in the different needs and interests of these two specific groups. In every road trip, the average number recorded was around 20 members and 12 volunteers. Volunteers were those who supported preparation and organisation of every road trip.

Specifically, volunteers sought for the location, checked facilities, raised funds for the road trip through service clubs, and supported the participants throughout the road trip. These volunteers also played a key role in connecting all the participants since many of them have known each other before and kept in touch throughout the year. The volunteers together with the adult participants created a tight community. For educational purposes, some trainers, and experts on different topics related to ageing with SBH were also invited to the road trip to discuss with the participants and increase their knowledge about the different topics.

There were multiple activities organised during the day which vary depending on the location and duration of each trip. For some road trips, these could be museum visits and city trips. Other trips consisted of walking in the park and discovering nature. The evening focused on networking and discussion. All participants gathered to talk about different topics related to ageing with SBH. This could be a formal workshop with the invitation of guest speakers; but it could also be an informal talk in the bar. To decide on the topics and the format of the gathering events during each road trip, the association gained inputs from their members in advance by (1) having a conversation with the members, (2) posting and asking members in the close Facebook group (3) organising polls and voting system for members to choose their interested topics. By attentively listening to members, the organiser brought the topics that majority are concerned about and mostly interested in.



## Outcomes

The first road trip of the adult members at the Spina Bifida and Hydrocephalus Association in Flanders, Belgium was to London. Since receiving lots of positive feedback from participants, the association continued organising more road trips for their members. In the beginning, the associations organised a road trip for one weekend per year.

Given its success, options were explored to organise it more frequently, with up to four road trips a year. There were around 30 participants including 20 members and 12 volunteers per trip, with a huge number of participants that re-registered frequently. This confirmed the beneficial impact the trip for participants and positive experiences the participants had. For those who did not participate in the trip, the association also tried to reach out to them to listen and understand what barriers prevented them from participation.

## Lessons learned

The Spina Bifida and Hydrocephalus Association in Flanders, Belgium always reflected and evaluated every single trip to provide the best support for their ageing community. Below are several lessons learned that were shared by the Spina Bifida and Hydrocephalus Association in Flanders, Belgium from the study so that other associations can learn from.

Before planning activities and choosing destinations to visit, there was a team of four to six people who were in charge of checking all the accessibilities in advance. Some possible questions could be asked such as 'Is the hotel accessible? Is there a lift in the museum? Are there toilets available?'. Transportation must be also taken into consideration as persons with SBH require certain special needs. For example, the association always prepared an accessible bus for overseas trips. For weekend trips within Belgium, members were advised to go to the location via shared vehicles. When planning activities, it is advised not to design a heavy schedule for a big group trip. A flexible programme allowed people to relax and enjoy the trip.

The day trip organised by the Spina Bifida and Hydrocephalus Association in Flanders, Belgium is a creative initiative that not only strengthens the ageing SBH community and, tackles the social isolation issue but also increases their understanding and knowledge about topics of ageing with SBH. This best practice of the Spina Bifida and Hydrocephalus Association in Flanders, Belgium has enriched the lives of persons living with SBH.

# ***Regional workshop in Malaysia***

## **Background**

The lived experiences of older people living with spina bifida (SB) in Malaysia varies depending on-, for example, whether they live in urban or rural areas. In rural areas, the ageing SBH community encounter more challenges compared to urban areas, due to the average lower education level of adults living there, and lack of knowledge and understanding about ageing with SB. For example, persons with SB are often unaware of what it means to have SB, and how to live with SB at older age.

Furthermore, in many rural areas in Malaysia, many individuals with SB and their parents possess a wrong assumption that persons living with SB can neither grow up nor have a long lifespan. It was reported that several parents of children with SB born in the 60s thought their children had polio and believed that their children could not survive. Consequently, persons with SB did not have appropriate specialists to follow up their treatment, and the children lived with this misdiagnosis for a while until persons with SB grew up and showed other complications.

Moreover, the Spina Bifida Association Malaysia (SIBIAM) itself encounters difficulty in disseminating information to people with SB and their families in these areas. As a result, persons with SBH cannot get access to the information which directly affects their lives.

Awareness of their disability is very essential in terms of prevention, early detection, and treatment. Being aware of SBH, its symptoms and how it influences lives at older ages means persons with SBH and their families are more likely to take preventative action, go for check-ups, and take multidisciplinary care into consideration. Therefore, it is important to educate people about topics related to SBH and ageing with SBH as well as making the information available and accessible to everyone.

## **Best practice description**

To tackle the aforementioned situation in Malaysia, SIBIAM organised regional workshops in different states including both urban and rural areas. The idea of organising workshops officially began in 2008, when SIBIAM first had an annual general meeting. SIBIAM recognised a need from its members for knowledge and information acquisition about different topics of SB, especially new topics such as ageing with SB. Since then, education and awareness raising have become the key values that SIBIAM wished to bring to its members. With the support and sponsorship of its partners, SIBIAM started to organise more workshops for all their members with several main sessions on the topic of ageing with SB.

The key goal of these sessions is to raise awareness of persons with SB and their families about ageing with SB since there is lots of changing and evolving when SB persons become older. This change is not only seen in their physical problems but also their mental health, relationship within the community, work, finance and caregiving issues. It is necessary for ageing people to be well educated and so can themselves seek information, assistance and advice if needed.

These workshops not only serve as an educational opportunity, but also aim to strengthen the relationships within the SB community in Malaysia and-, encourage the social inclusiveness of the older members in SIBIAM-related activities. Also, these workshops help people ageing with SB connect with their healthcare professionals on a more personal level and make medical advice more accessible.

Moreover, by organising regional workshops in different states, including both urban and rural areas, SIBIAM wishes to reach a wider population of participants, not limited to persons ageing with SB, but also young persons with SB, parents of children with SB, healthcare professionals, education teachers and anyone who is interested in this topic. SIBIAM believes that supporting ageing with SB is the role of the whole community, in which experts and parents are the key actors. It is imperative for them to have in-depth understanding of the conditions of persons with SB and-, common challenges that adults with SB are facing, in order to help them remove barriers, bring accessibility and equal opportunities for ageing people with SB.

SIBIAM has actively promoted the workshops on their social media channels, especially their Facebook group and group chat on Telegram, where most of their communications with the members are maintained.

To decide on what was discussed during the workshops, SIBIAM gathered information from different resources. Firstly, SIBIAM used their members' group to talk with and ask ageing people with SB for their concerns. There were a variety of issues listed, such as transition care, medical complications, decline in independence due to multiple factors, loss of parental/caregiver support, mental health issues, financial support, difficulties in accessibility, and so on. Taking these issues into consideration, SIBIAM has engaged healthcare professionals from different states to identify the interested topics in their communities in order to make the workshops tailored to the specific population.



## Outcomes

The regional workshops are now being carried out and are expected to finish in the next year and a half. More results will be updated accordingly.

## Lessons learned

During the preparation stage, SIBIAM already gained several lessons learned, one of which is the importance of partnership and collaboration. SIBIAM is conducting the regional workshops together with the local team, including medical professionals and doctors in specific regions. SIBIAM highlights the importance of collaboration with the local team, in which they act as the linking point to connect SIBIAM with the audiences. These medical professionals and doctors who have a database and good communication with SB people and their families in those areas, can easily disseminate the information of the workshops within their network. In addition, with the support and the global grants of their sponsor, the workshops can also be spread more widely and reach a wider population. Without collaboration with different stakeholders, the workshops cannot reach their goals.

The regional workshops served as a nationwide awareness raising and educational campaign. These workshops provide accessible and valuable resources, educate people about different topics related to ageing with SB, connect ageing people with their peers and healthcare professionals to give them timely assistance. They have tackled the challenges in several areas where people lack access to resources and knowledge about different topics related to SB and ageing with SB, leading to wrong assumptions as well as delayed or/and insufficient treatment and care.

# Online hub in Scotland

## Background

There is a distinct lack of resources and services on an organisational, local and national level for ageing people with SBH in Scotland. Lack of accessible resources and healthcare may lead to inappropriate diagnosis, preventive actions and treatment, as well as wrong decisions and choices affecting lives of older individuals with SBH. The survey conducted by SBH Scotland to people over 35 in Scotland and the IF report 'Ageing with Spina Bifida and Hydrocephalus: A descriptive analysis'<sup>3</sup> shared the same findings and highlighted the need for accessible 'ageing' resources for people with SBH. However, solving this challenge with traditional approaches seems to not generate desirable outcomes. A more innovative strategy is needed. Persons ageing with SBH should be seen as the consumers of healthcare in which persons with SBH need to be engaged and take ownership of their own health.

The Spina Bifida Hydrocephalus Scotland (SBH Scotland) wants to further this aim by providing an inclusive platform that touches upon different issues around being an ageing person with SBH (e.g. self-management, wellness, mental health); and more specific areas relating to the age group (e.g. housing, benefits, employment and physical health deterioration). Moreover, the association prioritises personalised experience, in which persons with SBH can navigate all resources and services themselves to choose what are really needed.

## Best practice description

The online 'Healthy Ageing Hub' is a space solely created for persons ageing with SBH who are seen as service users - owners of their own health.

The project is aimed at people with SBH aged 35+ and aims to deliver a series of self-management guides which can be accessed through SBH Scotland's new online hub. It is an interactive place for users to access resources, be part of forums/discussion spaces with peers and access information on the groups SBH Scotland run at their centre and online. The resources will cover a range of topics from self-management of a long-term condition, to employment, to using the SBH Scotland wellness app, MyCarepod. There will also be information on the SBH Scotland Health and Wellbeing Clinic and Counselling service.

In order to satisfy the needs of the service users with this project, Scotland SBH sent out a survey to all those aged 35+ years. SBH Scotland used this as a priority setting exercise and it was useful in highlighting a variety of topics for them to focus on. Overall, SBH Scotland received 79 responses, which was a sufficient number to gain a robust sense of what to prioritise. In addition to learning what topics people would like to see represented, SBH Scotland also learned that the majority would be keen to have access to an online hub space and would prefer to access the workshops online, as it removed restrictions that travelling creates for some people. The quantitative data displayed a desire for a focus on mental health, self-management and physical health, therefore these became the primary focus. Other topics were sexual health, finances/benefits and legal issues. The qualitative data brought forward a few topics not included in the options available to vote for; these included medical advocacy, weight management, nutrition and exercise for wheelchair users.

SBH Scotland received funding from private, public or other types of funding sources to deliver this project. As the ageing online hub is a multi-sectorial program with a variety of objectives, the association have taken a multi-faceted approach to this project, drawing knowledge from source; contacts across health and social care; and using existing SBH Scotland services to strengthen their objectives. They set up a steering group at the beginning of this project to help guide their way towards best practice and have so far held two meetings with this group. In this group they have representatives from SBH Ireland, the University of Dundee and the University of Edinburgh, as well as their Mental Health Counsellor and Specialist Health and Wellbeing Nurse. In addition, to increase their capacity for delivery they have brought on a Research and Innovation Intern and two Occupational Therapy placement students. Each of these have brought their own knowledge, expertise and interests which have driven the project forward and made it all the more interesting and insightful.

## Outcomes

The ageing hub is still in the piloting process, though the initial workshops have taken place and the Wellbeing Counselling service is now in its second year. The SBH Scotland hope to achieve these following outcomes throughout the project:

- Improved self-management and independence of service users above the age of 35 who interact with project;
- Improved mental health and wellbeing in those who use the clinic and counselling service;
- Increased health literacy in service users who interact with the project;
- Increased feelings of dignity, self-compassion and self-esteem amongst citizens with SBH;
- Reduced feelings of social isolation for individuals with SB/H and their carers;
- Increased understanding of the legal and financial system and the support available for people with complex conditions in SB/H population;
- Increased understanding within the organisation of the issues facing the SBH population in terms of ageing.

## Lessons learned

There is still a lot of work to be done with the ageing hub, however, throughout the process, SBH Scotland have collected lessons that could be shared. The ageing online hub is quite a large-scale project that requires many resources, including finance and human resources. It is important to have a clear and concrete plan to seek sustainable funding and relevant partnership. Also, it is interesting to note that the team supporting the ageing online hub also comprised student interns. SBH Scotland have collaborated with universities to provide internships for students. It is seen as a win-win situation, as students have the chance to gain real working experience. At the same time, the association has a cost-effective way of gaining new staff, with lots of fresh perspectives to bring to the project.

The ageing hub with SBH is a great solution for the country's lack of access to resources and quality and affordable healthcare. It provides older individuals with SBH with the ability to get access to multiple resources related to different aspects of ageing with SBH, communicate with their health providers, participate in remote consultations and workshops, connect with their peers all over Scotland. This online platform can be an example for not only organisations working for people with SBH but any organisation working in the healthcare sector to learn from to deliver holistic, seamless and individualised experiences for every single user.



Welcome!

Spina Bifida  
Hydrocephalus  
Scotland

Support Helpline: 03455 211 300  
General Enquiries: 03455 211 811  
Fundraising: 03455 211 600

Facebook Twitter Instagram

Spina Bifida Hydrocephalus Scotland  
Online Hub

## Wellness Workshop

Occupational Therapy Students  
Meghan & Nicole

**Ageing and Spina Bifida/Hydrocephalus**

People with spina bifida and hydrocephalus (SBH) are living longer lives. This is good news but may come with some new challenges

As people with SBH age, they can struggle with things that they were able to do before.

### 8 Dimensions of Wellness

- Emotional
- Physical
- Social
- Occupational
- Financial
- Environmental
- Spiritual
- Intellectual

(Swarbrick & Yudof, 2015)

Intellectual Emotional Physical Social Environmental Financial Occupational

# Online workshop in the Netherlands

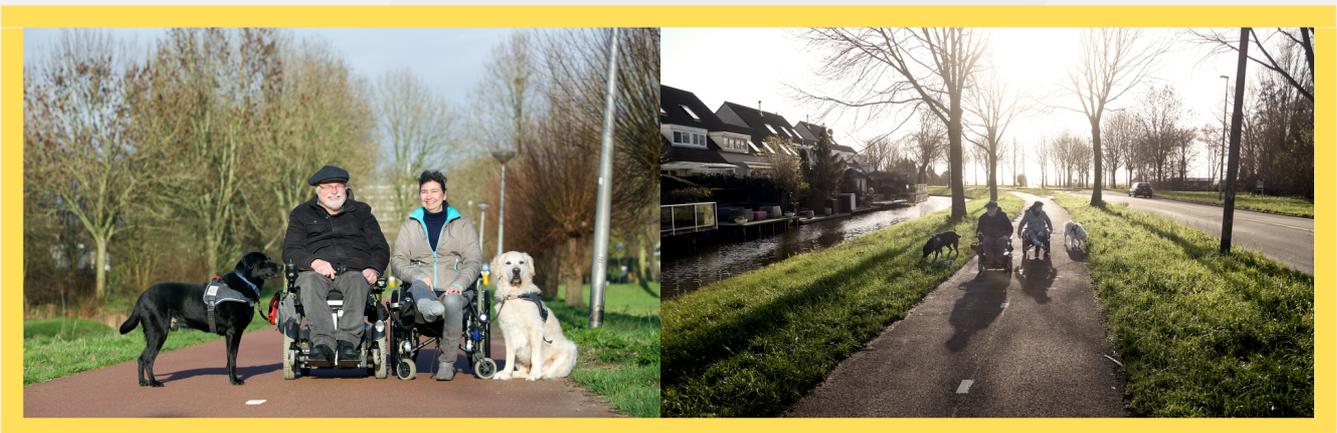
## Background

Over the past few years, the Netherlands has witnessed a fast increasing number of adults with SBH, due to advances of medical progress. More specifically, two thirds of the members of the SBH association in the Netherlands are in their 50s+. The more people get older, the more difficulties persons with SBH experience, such as limited access to healthcare services and employment. Since the outbreak of Covid-19 pandemic, ageing people with disabilities in the Netherlands have encountered additional challenges, such as lacking the opportunities to meet friends and family, resulting in social isolation.

There is a need to provide more support for ageing people with SBH, especially focusing on providing a platform where persons with SBH can join and feel the sense of community, as well as exchange ideas and experiences. Considering the current situation, ageing with SBH is one of the target groups for SBH association in the Netherlands. Also, the theme of ageing with SBH becomes an important element of its policy and vision. The SBH association in the Netherlands acknowledges their role to offer support and encourage social inclusiveness for persons with disabilities.

## Best practice description

An online workshop on the topic of ageing with SBH 'Ageing with Spina Bifida and Hydrocephalus' was developed. The main objectives of this workshop were to decrease social isolation of older individuals with SBH and give them the opportunity to freely share their questions and concerns within their community. Most importantly, the online workshop ensured the safety and convenience of ageing people with SBH. The participants did not need to travel, but only needed a device connecting to the internet to participate in the workshop with their peers.



The target audience of the workshop was adults with SBH who were aged 45 years and beyond. This age group was chosen based on the response from the association's members and followers on social media. It was reported that persons ageing with SBH, especially after the age of 40, encounter increasing medical and mental health problems, particularly during the past few years. Interestingly, the workshop on the topic of ageing with SBH was also appealing to younger generations and parents of children with SBH. The association said that mothers and young people with SBH found information about ageing with SBH helpful as the older people can act as role models to inspire and create hope for the younger generation to believe in their future life.

Topics discussed during the workshop were decided based on the requests of members. Some example questions were 'How do older people manage their lives during the Covid pandemic, what are the problems individuals ageing with SBH encounter in their life, how to find help, how can people connect with other people'. Loneliness and the impact of the pandemic on mental and physical health were the most common concerns of participants during the workshop.

During the workshop, there were guest speakers such as healthcare professionals, who joined the workshop to answer the questions from participants and give them medical advice.

The SBH association disseminated the workshops through different channels, including a- website, Facebook group, Instagram, LinkedIn, and Twitter. The association also promoted the website through their online newsletter and sending emails to members. It was noted that email is the most effective method of communication when it comes to promoting the ageing workshops for members because members find it more personal.

## Outcomes

The online workshop 'Ageing with Spina Bifida and Hydrocephalus' was organised twice per year. A total of eight adults participated and shared their experiences during the latest workshop. Their experience after the online workshop was very positive. Participants expressed their interest in the workshop as persons with SBH could share personal problems with other people, and do not need to spend time and money for travelling, since it was online. It was suggested that the online workshops should be repeated and carried out more regularly.



## Lessons learned

After organising each workshop, the SBH association in the Netherlands kept reflecting with the aims of improving their workshops and increasing the satisfaction of participants. There are several key takeaways as below.

Firstly, it is advisable to invite an expert to join the workshop to share their knowledge with the participants. It is very helpful for the participants as persons with SBH join the workshop not only to network with their peers, but also enhance their knowledge and understanding about difficult issues related to ageing with SBH requiring answers from professionals.

Secondly, the moderator of the workshop plays a key role in connecting participants and guiding the conversation. It is recommended that this person should be an adult with SBH who can share their lived experience and open the discussion. The moderator should be the one to create a comfortable and safe environment, where participants find it easy to talk and share. This helps facilitate an effective discussion and makes a huge difference.

Thirdly, follow-up activities are suggested to maintain the communications since once the workshop ended, the association realised that many participants were back to their loneliness.

The online workshop organised by the SBH associations in the Netherland has brought many benefits for the ageing SBH community. It connected older people with SBH and gathered them to get involved in discussion and conversation on different topics related to them. It ensured a safe and healthy environment for all participants taking into account the COVID-19 pandemic. It also allowed participants to join wherever they were, which was convenient, saving time and money. The COVID-19 pandemic created many challenges but also opened opportunities for different SBH organisations to bring changes and improvements, innovations and creative solutions. The SBH association in the Netherlands is an example of this.

# ***Rehabilitation centre in Uganda***

## **Background**

In Uganda, there are rehabilitation centres and more support for children with SBH up to 18 years; however, after this period, there is an absence of assistance for persons with SBH. Sadly, persons ageing with SBH are left alone and ignored by the community.

It was reported by the Central Uganda Spina Bifida and Hydrocephalus Network that persons with SBH have less opportunity for employment, and there is a large number of people with SBH unemployed or outside the workforce in Uganda. Some persons with SBH did not go to school in the past, making their chance of finding employment slimmer. More seriously, persons with SBH do not receive sufficient support from the government. Without jobs and money, many individuals ageing with SBH are struggling with their lives. Some adults in Uganda still have to live with their families, leading to burnout and strained relationships.

There is a need for ageing SBH community to have access to work and employment. It is essential for the societal inclusion of people with disabilities.

This urgent situation inspired the Central Uganda Spina Bifida and Hydrocephalus Network to bring job training and job opportunities for adults with SBH, by creating a rehabilitation centre.

## **Best practice description**

The rehabilitation centre organised by the Central Uganda Spina Bifida and Hydrocephalus Network welcomes adults beyond 18 who are left alone and need support and care. The association focuses on this group because they have realised there is a huge lack of continuity for persons with SBH life and sustainability when persons with SBH get older.

The objective of the rehabilitation centre is to offer training and employment assistance to people with SBH. By doing this, people with SBH are empowered to become self-reliant and self-worth in the society. It is noteworthy that the location of the rehabilitation centre is the house of the chairperson of the association. She offers persons with SBH this place, not only for job training but also for residence. This is a safe home for some people who are abandoned. Persons with SBH live together with the chairperson and receive lots of assistance from her.

The idea started very naturally when the association was thinking about how to create jobs for adults with SBH. One day, the chairperson talked with one of the parents of children with SBH, who is a tailor. Without much thinking, they started the job training programme with only one tailor, one sewing machine and the training place as the chairperson's house. Day by day, more and more people began to come and join the training sessions. The project became bigger and bigger. Afterwards, the Central Uganda Spina Bifida and Hydrocephalus Network received funding, which enabled a huge step to expand the project. With sponsorships, they could buy new machines, necessary equipment and catering for people.

During the day at the rehabilitation centre, individuals ageing with SBH received hands-on training on weaving and tailoring by a professional trainer. During these training sessions, participants can also share their knowledge and experience, discuss and plan together their future.

## **Outcomes**

At this moment, the rehabilitation centre has 42 people including youths and adults with SBH. The training takes place every working day. All of the participants have positive experiences in which persons with SBH feel satisfied and grateful for the rehabilitation centre.

Participants joining the centre have acquired necessary skills to make their living, look after not only themselves but also their families. Once the products are made, persons with SBH sell their products in the local areas and earn money to cater for their needs. In the near future, the association is planning to expand the business and sell the products to a bigger market by collaborating with the Ministry of Industry and Trade.

## **Lessons learned**

To ensure the quality of the training, the association has tools for storing all the information of the participants, monitoring their attendance and evaluating participants' satisfaction. During the training sessions, the team frequently ask individuals for their feedback and concerns on the spot. By doing this, the team can provide immediate support if needed.

Since the job training is open to all adults with SBH living in Uganda, many participants come to join the training from afar, leading to issues with transportation and accommodation. Commuting everyday to the training place is costly, time consuming and risky, therefore, the Central Uganda Spina Bifida and Hydrocephalus Network also need to provide accommodation for the trainees. This was not planned in the beginning, so the association encountered several difficulties. It is suggested that if there are offline training sessions, the organisers should take the travelling aspect of the participants into consideration.

The story of the rehabilitation centre by the Central Uganda Spina Bifida and Hydrocephalus Network is truly an inspiration. The association started the project initially with only an old sewing machine and a tailor, but with strong willingness and resilience from the organisers, it has now delivered a job training centre for numerous older persons with SBH in Uganda. The centre helps them to get skills and find work, overcome obstacles of being unemployed and financially dependent. More importantly, the rehabilitation centre makes ageing SBH community feel valued, confident and believe in themselves. It is also a real home for all SBH people, where persons with SBH feel happy, belonging and connected.



# *Virtual gathering in the USA*

## **Background**

The Spina Bifida Associations in the USA covers a large group of persons ageing with SB who are scattered across the country. Many live in remote areas where there is a lack social interaction, leading to feelings of isolation and loneliness. Moreover, as getting older, persons with SBH are less likely to reach out for support and connect with others.

What needed to tackle this challenge is finding an innovative way to gather a large and widespread population of ageing SBH groups with SB. Persons with SBH also need a safe and comfortable platform where persons with SBH can attend, meet and talk. To tackle this challenge, the Spina Bifida Association in the USA (SBA) delivers virtual gatherings called 'Join the Conversation'.

## **Best practice description**

The 'Join the Conversation' is a bi-monthly virtual group for adults with spina bifida, about adults with spina bifida and run by adults with spina bifida. This project follows the SBA philosophy 'Nothing about us without us' in the sense that everything SBA plans or considers with this project includes adults with SB.

The 'Join the Conversation' aims to create a positive, uplifting, entertaining, and educational space which welcomes individuals ageing with spina bifida to gather for providing valuable resources and insights, telling their personal stories and experiences, empowering others and strengthening the relationship.

To decide the topics discussed for the conversation, participants are always asked to fill in a form, with a question about the topics related to spina bifida that persons with SBH are mostly interested in. This pre-survey has helped the organisers to be aware of the most common concerns from the majority and better deliver the conversation that is needed. The interesting thing about these virtual meetings is that there is no agenda imposed. This flexible way of organisation makes the participants feel more comfortable to join. Persons with SBH just come and just talk, making it more accessible to everyone.

To disseminate the 'Join the Conversation' group, SBA promotes it on their Facebook group for adults and its official website. The association also encourages people to share it within their own network.

## Outcomes

The meeting is held twice a week online via Zoom. There are two groups with different time zones. One group is held on the first and third Tuesday evening monthly and another group is held on the 1st and 3rd Thursday evening monthly. By having a fixed schedule in the evening, it is easier for registrants to arrange their time after work and join the meeting as a routine. Moreover, this bi-monthly meeting allows the continuity of the conversation and maintains the social interaction with peers.

The number of participants varies across the meetings, but the average number is around 10 per meeting. This number is good enough for a fruitful talk. There were participants who keep joining the meetings many times. Sometimes there were people coming from other parts of the world to join the meeting. The National Resource Centre manager is the person who monitors and manages the group and all the meetings, by staying in close contact and keeping updates from the meeting facilitator.



## Lessons learned

The 'Join the Conversation' brings individuals ageing with SB closer to each other. It reduces feelings of loneliness and social isolation for them and their carers. More importantly, ageing individuals with SB are allowed to take full ownership of their meeting in which the idea of these virtual gatherings originated from the ageing community, the topics discussed are decided by the ageing SBH community, and the discussion was also delivered and facilitated by the individuals ageing with SBH. This is a key component contributing to its success.

# ***Record card in South Africa***

## **Background**

Transition of care is essential to ensure people with SBH receive the required support in the right place and at the right time. When reaching adulthood, persons with SBH should be transferred to adult care experts who have sufficient capacity to provide appropriate care and treatment to guarantee high-quality care. Professional care for persons born with SBH across the life span is necessary.

However, in South Africa, there is no record regarding how transitional care has been provided and how the transfer was managed. The transfer to adult care is often interrupted with no follow-up. Consequently, many individuals ageing with SBH receive insufficient care and treatment. Taking this challenge into account, there is a need to record their medical history to inform healthcare providers, resulting in the idea of introducing paper record cards for older individuals with SBH, created by the association for Spina Bifida and Hydrocephalus South Africa (ASBAH-SA).

## **Description**

The paper record card is personalised for each member of ASBAH-SA. It is used as a quick information tool, when individuals ageing with SBH present at a local clinic or emergency room for assistance. It is intended that the card will ensure that people are evaluated appropriately, avoiding potentially serious complications and undue delays in treatment. Another objective of this record card is to educate novice medical staff at some local clinics and emergency rooms who may be unfamiliar with SBH, for example, the required bladder and bowel regime of a person with SBH.

On the card, there are four main sections to inform the doctor of the situation of the patient and signal them what to do in the further steps:

- The first section provides basic information of spina bifida and hydrocephalus;
- The second section is personal details of the persons with SBH;
- In the next section are the medical details about shunt, surgery, clean intermittent catheterization, spinal shock and so on;
- The last section indicates some symptoms of the patient and directs them to consider some possible diagnosis such as wound infection or blocked shunt and to take appropriate follow-up actions. There are also contact details of ASBAH-SA and some hotlines.

The record card was developed, printed and disseminated to older members of ASBAH-SA. The association guides members to fill in the record card. This card is kept by the members and used whenever persons with SBH go to any clinics or emergency rooms where their information is not stored. Also, this project goes hand in hand with the SBH Helpline, in which the ASBAH-SA team will contact parents of children with SBH and adults who have SBH for guidance and direction with a handheld personal record card.

This project receives donations from paediatric professionals and persons with SBH. All persons with SBH receiving the record card were documented. And this information is monitored by the ASBAH-SA team. By doing this, they can keep track of the number and offer support for their members who have not received the card.



## Outcomes

All persons with SBH who received and used these cards reported that these cards were very helpful in helping doctors understand their situation and diagnose promptly. In necessary situations, persons with SBH were sent immediately to the hospital for treatment instead of being kept in a waiting line or sent back home like previously. The record card has saved lots of time and effort.

## Lessons learned

The record card is a part of transitional care by informing the medical situation of persons with SBH to the healthcare providers, ensuring that any potentially serious issues are appropriately identified and treated without unnecessary delays. With the record card, ASBAH-SA also has the database of all the adults with SBH since their birth by keeping records of all persons receiving the record cards. Along with their Helpline run by the associations to provide support and help for persons with SBH, ASBAH-SA has improved the the ageing management care in South Africa.

# CONCLUSION AND RECOMMENDATION

The increased longevity of individuals with SBH across the world is the result of medical and technological advances; it is a success story. Yet, the IF is aware that growing older is often associated with physiological changes, a decline in mental health, challenges with social interaction, and for some, increased frailty-, and ill health. Since the COVID-19 pandemic, individuals with SBH have encountered new and additional barriers, such as loneliness, isolation, loss of job, inaccessibility to multidisciplinary healthcare.

The aim of the current study was to identify examples of best practice from IF Member Associations around the world aimed at meeting the needs of the ageing SBH community. In this report, examples of best practice were driven by common identified needs for:

- programmes aimed at social interaction to combat isolation and loneliness;
- platforms to share experiences and meet other persons with SBH;
- platforms to meet with healthcare professionals to discuss sensitive topics including mental health;
- inclusive and holistic healthcare services and provision for persons with SBH;
- education programmes to enhance knowledge and skills on for example employment.

In other words, the needs identified in the previous IF Working Group reports. The seven member associations addressed these needs in different ways. The Spina Bifida and Hydrocephalus Association in Flanders, Belgium organised several road trips in Belgium and overseas per year for adult members with the aim of connecting persons ageing with SBH, decreasing the social isolation and loneliness that its members may encounter, and educating participants of the road trips about different topics related to ageing with SBH. Both the Spina Bifida Association Malaysia and the Spina Bifida and Hydrocephalus Association in the Netherlands held workshops; however, the way workshops in these two countries were developed and organised was different due to the unique needs of ageing community in these countries. While the Spina Bifida Association Malaysia focused on regional in-person workshops due to diverse challenges in different areas of the country; the Spina Bifida and Hydrocephalus Association in the Netherlands organized online workshops to combat the loneliness and isolation of ageing SBH community during COVID-19 pandemic. These workshops were also the platforms for persons ageing with SBH to share experiences, meet their peers and healthcare professionals to discuss different topics. These needs were also addressed by the best practice shared by the Spina Bifida Association in the USA. The bi-monthly virtual group for adults with spina bifida, about adults with spina bifida and run by adults with spina bifida was a positive, safe and educational space for older persons with SB in the USA to share and discuss. To provide an accessible holistic self-management platform for individuals ageing with SBH in Scotland, SBH Scotland developed an online 'Health Ageing Hub' where all information and resources were integrated. Not only persons ageing with SBH have difficulties to access information, but healthcare professionals also encounter this challenge.

To provide medical staff with information about the persons ageing with SBH including their health history, the Association for Spina Bifida and Hydrocephalus South Africa initiated paper personalized record card to all their members. In Uganda, the Central Uganda Spina Bifida and Hydrocephalus Network organised rehabilitation centre to offer training and employment programmes to persons ageing with SBH. Moreover, this educational programmes also brought job opportunities for adult members.

The problems described in the interviews reinforced the results described in the report IF report 'Ageing with Spina Bifida and Hydrocephalus – A descriptive analysis'<sup>3</sup> and IF report 'Ageing with Spina Bifida and Hydrocephalus - Findings from Online Focus Group Discussions'<sup>1</sup>. The interviews gave greater emphasis to a lack of employment for many adult persons with SBH. Persons with disabilities are indeed reported to have higher rate of unemployment. In developing countries, 80% to 90% of persons of working age with disabilities are jobless, while the percentage recorded in industrialized countries is between 50% and 70%<sup>10</sup>. Moreover, this report found the challenge with medical records of individuals ageing with SBH leading to insufficient and delayed care and treatment.

These best practices shared a commonality in combating loneliness and social isolation, creating a space for persons ageing with SBH to freely share their experience and exchange ideas with their peers and younger generations. Parents of children with SBH and young persons with SBH, at the same time, also wanted to hear their lived experiences as ageing people are the role models inspiring them to move forward with their lives. The report also emphasised the fact that the more informal and intimate the conversations are, the more effective they can be. Other best practices focused on providing holistic healthcare services, improving the transition of care by informing and educating healthcare professionals about SBH and ageing with SBH, and delivering job training programmes and creating employment for ageing individuals.

These best practices strengthened the IF report 'Ageing with Spina Bifida and Hydrocephalus - Findings from Online Focus Group Discussions'<sup>1</sup> on 'IF Statement on Ageing with Spina Bifida and Hydrocephalus'<sup>11</sup> where those actions to improve the quality of life of individuals ageing with SBH, give support to the individuals, and build a community and network were mentioned.

The key to the success of all best practices was a clear understanding of the ageing SBH community 'Nothing-about us without us'. Individuals ageing with SBH know what is best for them and their community therefore it's essential to listen to them to explore their challenges, identify their needs, and know what persons with SBH expect from the support. It would be meaningless to provide a service to the ageing group, no matter how good it is if it is not what persons with SBH want and need. More importantly, listening did not only occur in the beginning stage but constantly during and after the project. Associations need to gather feedback from their participants to evaluate their work and have prompt changes if necessary. It is also suggested that ageing people with SBH should be the ones to make decisions and take ownership of the events.

Another principal element leading to the success of best practices was partnership and collaboration with different stakeholders. Partnership and collaboration have helped the associations to push their projects forward, obtain stability and finally achieve the shared goals. More specially, the partnership and collaboration has supported them to maximise cost savings, strengthen the quality of the projects, and increased credibility. For example, to secure the funding of the regional workshops, several IF Member Associations partnered with different organisations who shared the same vision of supporting persons with disabilities.

To sum up, this report demonstrates that there is a need to support the SBH community and strengthen specifically aspects important for the population of people ageing with SBH, across the world. It also demonstrates that these needs are being met in innovative and creative ways by different SBH associations around the world. The seven diverse examples of best practice from IF Member Associations described in this report can inspire other SBH associations to:

- Facilitate more engagement and educational events to involve the ageing SBH community;
- Listen to the ageing SBH community to identify their needs and wants to provide the relevant services. Allow them to take ownership of services which addressed to them.
- Encourage experience exchange activities which bring all older person with SBH together for sharing and discussion;
- Offer supplementary services to address the needs of adults when becoming older;
- Develop training content for professionals, carers and service users on ageing with SBH and building resilience skills;
- Building partnership and collaboration nationally and globally to ensure the success of any programmes working to support ageing SBH community.

Moreover, this report indicated that to address the challenge of becoming older for persons with SBH, it is not only the responsibility of SBH associations but also healthcare providers, researchers, policy makers, and other relevant actors who were recommended to

- Develop more 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.

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