



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS



REPORT

2021

**AGEING WITH SPINA BIFIDA AND
HYDROCEPHALUS**

**FINDINGS FROM ONLINE FOCUS GROUP
DISCUSSIONS**



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PREAMBLE

The International Federation for Spina Bifida and Hydrocephalus (IF) presents this document to provide outcomes of focus group discussions among adults with Spina Bifida and or Hydrocephalus. It underlines the need for multidisciplinary care especially with respect to mental and physical issues experienced by adults with Spina Bifida and Hydrocephalus (SBH). This document builds upon a Europe-wide explorative study conducted in 2019 by the IF Working Group on Ageing with SBH.

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 has conducted focus group discussions among adults with SBH. The results are presented through this report.

THE 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 70 SBH associations in Africa, Australia, the Americas, Asia and Europe.

The majority of IF member organisations are led and governed by adults with Spina Bifida and Hydrocephalus or parents of children with SBH. Children are active participants in our members' activities: they are involved in child-led activities, training workshops on independence and holiday camps. 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 incidence 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, behaviour, and neurological dysfunctions. These are the most common Neural Tube Defects (NTDs), which affect over a quarter of a million annual birth outcomes worldwide.¹ 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 and it is predicted that the numbers of older people with SBH will rise dramatically over the next few decades.² Yet, whilst the knowledge base concerning neonatal and paediatric care is growing, there is little known about the impact living with SBH has on transitioning to old age.³ There is a need to explore and expand our knowledge and gain insights into current health and wellbeing status of older people with SBH. There is a need to understand the challenges people with SBH experience, their way of developing resilience and coping mechanisms, and the impact ageing has on their occupation and independence. And finally, for a successful transition from childhood to adulthood and therefore allowing individuals with SBH to age well, there is a need for multidisciplinary care.

The topic of healthy ageing is also a high priority not only for the national organisation but also for the International Federation. For example 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 emphasizing on the rights of older persons with disabilities.^{4,5}

Also other initiatives show the support of ageing communities worldwide. For example, the United Nations together with WHO lead an international initiative called 'Decade to Healthy Ageing' to improve lives of older people, their families, and communities worldwide between 2021 to 2030.⁶ Emphasis is given to multi stakeholder engagement whereby older people play a central role in collaborations.

1. Blencowe, H., Kancherla, V., Moorthie, S., Darlison, M. W., & Modell, B. (2018). Estimates of global and regional prevalence of neural tube defects for 2015: a systematic analysis. *Annals of the New York Academy of Sciences*, 1414(1), 31–46.

Prevalence charts and tables, 2021 May 28th, European Commission, https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-data/prevalence_en

2. The IF Working Group on Ageing with SBH, 2020 October 1st, Ageing with Spina Bifida and Hydrocephalus. <https://www.ifglobal.org/wp-content/uploads/2020/09/IF-report-Ageing-SBH-2020-final.pdf>

3. Choi E.K, Bae E., Jang . *Transition programs for adolescents and young adults with spina bifida: A mixed-methods systematic review*. 22 November 2020. Website consulted on 18 November 2021 <https://onlinelibrary.wiley.com/doi/abs/10.1111/jan.14651>

4. Quinn G., Report on the rights of older persons with disabilities . United Nations Human Rights. Website consulted on August 4th 2021: <https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/SupportingTheAutonomyOlderPersons.aspx>

5. The International Federation for Spina Bifida and Hydrocephalus. IF Submission on the Rights of Older Persons with Disabilities. Website consulted on August 4th 2021: <https://www.ifglobal.org/news/if-submission-on-the-rights-of-older-persons-with-disabilities/>

6. UN Decade of Healthy Ageing 2021 - 2030. Website consulted on August 4th 2021: <https://www.who.int/initiatives/decade-of-healthy-ageing>

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 optimizing 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”*⁷. 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 they require and deserve.

Since then, it is the focus for IF into this important topic relevant to IF Members 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.⁸ The report described results from 650 persons with SBH and their lived experiences. Not unexpected, the results from the survey revealed different lived experiences which clearly shows there is no one true lived experience that we unearthed. Following the report in 2019 and activities there is 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.

Following these recommendations, the current report describes outcomes of focus groups discussions to better understand lived experiences for persons with SBH with respect to mental and physical health.

7. IF Position Paper “Unfold Their Potential (Y)our Return on Investment, (2012), <https://www.ifglobal.org/publications/if-position-paper-on-healthy-ageing/>

8. IF Survey Ageing with Spina Bifida and Hydrocephalus, October 2019: <https://www.ifglobal.org/wp-content/uploads/2020/04/Slides-Ageing-Survey-October-2019-SL.pdf>

METHODOLOGY

Procedure

Participants

All individuals with SBH aged 18 or older were invited to register for the online focus group discussion. No exclusion criteria were applied.

IF social media channels and emails to members were used to disseminate the event. All interested participants received information for the focus group discussion and the registration link. In the registration form, participants were asked to indicate their preference for different topics for the focus group discussions. Options included: “Mental Health & Physical Health and ageing characteristics”; “Social Life” and “Socio-economic changes”. The topic of mental and physical health was selected by the majority of interested participants (99%).

Upon registration, participants received a zoom meeting link and a reminder on the day to attend the meeting.

Discussion leaders

Discussion leaders included 5 persons with SBH and or with direct family members who take part in the IF Working Group on Ageing and SBH. Instructions were sent to the discussion leaders providing information on the structure of the meeting, what to do when there is silence, technical aspects of the online meeting room, and questions to pose during the meeting. These questions included:

- What does Mental Health and Physical Health mean to you?
- In what ways do you experience Mental Health and/or Physical Health challenges?
- In what way do you experience differences in your Mental and/or physical Health while becoming older?
- What can IF do to support the needs of Mental and Physical Health for persons with SBH?

An additional technical training was provided for hands-on practice of the zoom platform.

Focus group discussions

The meeting took place in a digital meeting room using Zoom. After a general instruction, participants were allocated in different meeting rooms (In total five). These five groups were formed based on region and divided as such: three groups from Europe, one group from Africa/Asia and the last one from America/Asia . For each group there was a maximum of nine participants to allow for good discussions. The discussions were led by two discussion leaders to guide discussions, take notes, and record the session. The duration of each focus group discussion was 45 minutes.

After the focus group discussions, all participants joined the main discussion room. Discussion leaders of each group shared a summary of what was discussed.

Data capturing and management

The focus group discussions were recorded. All recordings of the meeting were solely received and analyzed by the project manager. Recordings were stored in G-Drive using an encrypted folder. The project manager made anonymized transcripts of all recorded meetings. Recordings were captured for internal purposes only and are automatically deleted after six months. Outcomes of the focus group discussions are described below.

RESULTS

Characteristics of the participants

In total, 29 persons with Spina Bifida and or Hydrocephalus from around the world registered to take part in the online focus group discussions (19 females and 10 males; age range from 24 to 57 years). No cancellation was received prior to the meeting, but participants didn't show-up without any reason on the day of the event. One participant participated in the focus group discussion via chat, as she had a poor internet connection.

Focus Groups Discussions

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Focus Group I

This group included a total number of four participants, including the discussion leader. The participants were from Luxembourg, Belgium and France. Represented by one woman and two males. The youngest participant was 24 and the others were between the ages of 45 and 55.

Results from the focus group discussion are described below per question.

Question A: What does Mental Health and Physical Health mean to you?

Participants shared that mental health is how you manage and deal with a situation. It was mentioned that mental health can be linked to physical health. "When you are good in both it results in well-being". A need to take care of their Mental Health while taking care of their Physical Health is pointed out in order to not let Mental Health issues build up otherwise the consequences can be terrible.

Furthermore the need for support from family, friends was described as necessary to stay mentally healthy. Their encouragement and their accessibility to listen about anything are helping in difficult situations. Especially since the topic of mental health for persons with disabilities was still perceived as a taboo.

Question B: In what ways do you experience Mental Health and/or Physical Health challenges?

Participants shared the experience of doctors being focussed on physical aspects only “I was in a psychological hospital, they only looked after my body and didn’t check my mental health”. They mentioned that a relationship between the body and mind needs to be considered.

The need for multidisciplinary healthcare systems was raised. It was mentioned that individuals with SBH need to repeat themselves when going to different appointments. Especially there is a wish for coordinated care to increase communication between doctors whereby individuals with SBH can be viewed as a person and not only the focus of one part of the body at a time.

Question C: In what way do you experience differences in your Mental and/or Physical Health while becoming older?

While becoming older, participants indicated to become more aware of their mental and physical capabilities: “I am more and more conscious about my problems”. “I am more and more resilient”. Also aspects of social isolation and exhaustion were mentioned: “It’s hard to follow an able body when I am with them”.

Despite the awareness, becoming older also comes with other health challenges requiring other specialists. The transition phase from childhood to adulthood was in particular mentioned as a lack in the healthcare system.

Question D: What can IF do to support the needs of Mental and Physical Health for persons with SBH?

Participants shared the need for more actions on the topic of mental health. Suggestions were made to allow for more opportunities to share best practices among members. For this, the work by the IF working groups are setting good examples.

Focus Group II

This group included a total number of eight participants including the discussion leader of which one was male and others females from the UK and Ireland. The younger participants of the group are in the ages between 35 to 40, while the older were between the age range of 45 to 55 years old.

Results from the focus group discussion are described below per question. Question B was not addressed in this group.

Question A: What does Mental Health and Physical Health mean to you?

Also in this group, participants mentioned the interaction of mental and physical health. For example, it was mentioned that physical pain can lead to a mental state of depression.

Both are seen as equally important: "Physical Health and Mental Health are the most important factors in quality of life overall".

Question C: In what way do you experience differences in your Mental and/or physical Health while becoming older?

Several aspects of health were mentioned to become worse when ageing. For example, urological challenges, neurology and malfunction of limbs (legs, arms, shoulder), and latex allergy.

It was also mentioned there is less contact with other people when becoming older, leading to social isolation.

Question D: What can IF do to support the needs of Mental and Physical Health for persons with SBH?

The need for a multidisciplinary approach in healthcare systems was also mentioned in this group. Participants shared that there is no coordinated care present and they want to be seen as a person, as a whole. Not everywhere there is support for adults with SBH, specialized clinics to coordinate care are needed.

Participants shared the need for social activities and workshops to interact with other adults with SBH. It was emphasized that staying active while also meeting other people could enhance mental health and decrease feelings of social isolation.

Recommendations were shared for IF and IF member associations to pay close attention to the needs of the ageing community with SBH. For example by promoting the implementation of specialized SBH clinics for adults, or organising social activities and workshops for adults.

Focus Group III

This group included a total number of six participants including the discussion leader, all females from Norway and Sweden. The youngest participant being 36 years and the two oldest being older than 60 years. In between, the women are in their forties.

Results from the focus group discussion are described below per question, except for question D which was not addressed in this group.

Question A: What does Mental Health and Physical Health mean to you?

Mental health was described as a tool to cope with physical challenges, therefore being inseparable. Someone mentioned: "mental health is needed to be able to cope with life and to live the way I want".

Question B: In what ways do you experience Mental Health and/or Physical Health challenges?

Participants describe that getting older also impacts mobility: "It came to the point where taking the stairs at home is challenging". This was also described with respect to mental health: "it's like dealing with a loss".

Moreover participants highlighted tiredness, mostly mentally. Participants mentioned this tiredness to be a result from "little things in life", whereby "there is a direct need to lay down and try to rest".

The lack of adequate medical support by healthcare providers was also mentioned as a reason for feeling tired. Participants explained they often need to repeat their medical issues to different healthcare providers. The lack of SBH clinics was recognized by all. Also, the lack of integrated and coordinated care has given participants feelings of stress. In addition, they don't feel listened to or seen as a person.

Also with respect to other types of support was mentioned. Some participants emphasized on the lack of support or support groups in their country when they need it the most.

Lastly, the recovery process was discussed, indeed it takes more time when getting older. This is in particular a challenge since more frequent hospitalisations take place when ageing.

Question C: In what way do you experience differences in your Mental and/or physical Health while becoming older?

Loneliness was mentioned as the most important subject while becoming older: “the more you get older, the more lonely you get”. It was mentioned this is especially the case, when persons with SBH do not have a structure in life consisting of having an occupation, going to school, etc. Also with respect in making new friends. Participants mentioned it to be more difficult to make friends. Therefore they rely more on their relationship with their family. This in turn is also a concern for parents whereby a participant phrased a sentence by a parent: “What will happen to my child once I am no longer there”.

Focus Group IV

This group included a total number of four participants including the discussion leader, including one woman and two men from Turkey, Portugal and Estonia. The youngest of the participants is in their thirties while the oldest is in their fifties. And in the middle, they were in their forties.

Results from the focus group discussion are described below per question, except for question D which was not addressed in this group.

Question A: What does Mental Health and Physical Health mean to you?

Balance was mentioned to be the connection between mental and physical health. Having a good balance in life was described as having good friends, families, and relationships, “we need to establish a balance to have a happy and healthy life”, “we need companionship, friendship, healthy relationships to go through life together.

Participants mentioned physical health to be controlled by mental health. In other words, when becoming older thoughts such as feeling a burden to others can give feelings of stress, leading to a negative mindset. Therefore having a strong mental health and attitude is crucial: especially, the need for independence was highlighted “It’s important for me to be independent”,

“We should not identify ourselves through the illness, we are also human!”

Question B: In what ways do you experience Mental Health and/or Physical Health challenges?

It was highlighted that individuals with SBH cannot make plans in advance because physical challenges can affect everyday life: "My incontinence issue upset my plans".

Question C: In what way do you experience differences in your Mental and/or physical Health while becoming older?

As a first remark, participants highlighted that when ageing, new challenges arise requiring new coping strategies.

Also, the issue of anxiety was mentioned, mainly anxiety about what will happen in the future. When ageing, they said to become more conscious about the future and the impact it will have on the body. Especially with respect to several physical health issues which become more difficult to manage when older, such as increase of infection, bone, bladder, incontinence.

Also feelings of anxiety were shared about becoming a (financial) liability: "Our support is mostly our family". It was shared that when becoming older, and when there is no family around, there is a need for a personal assistant or a carer which is costly.

Focus Group V

This group included a total number of eight participants including the discussion leader. With five women and three men from Australia, Canada, Nigeria, Norway, Uganda and USA. The youngest participant of the group was 24, the others were between 45 and 56 years old.

Results from the focus group discussion are described below per question. Questions A and B were not addressed in this group.

Question C: In what way do you experience differences in your Mental and/or physical Health while becoming older?

During the discussion participants shared several challenging experiences with respect to physical activities. For example, participants mentioned they lost the ability to walk, having more spasms, osteoporosis and permanent neurological challenges. One participant shared in own words: "to have osteoporosis and osteoarthritis at such a young age was a shock to me, I didn't expect it".

With respect to mental health, the following challenges were mentioned. The ability to concentrate is more difficult, also the feeling of anxiety and depression (some participants even shared suicidal thoughts) is becoming more and more repetitive. A clear need for support from groups or psychiatrists were expressed. Not only for individuals with SBH but also their parents. One participant shared that they have to deal with perceived stigma and feelings of being discriminated against.:

“In our country we don’t have a lot of grown ups but mostly children with SBH and we have observed that parents also need some psychiatric support in order to help their children with SBH to better manage their condition”.

Question D: What can IF do to support the needs of Mental and Physical Health for persons with SBH?

Participants appreciated the focus group discussions with different individuals with SBH. A follow-up on these online meetings on the international level was suggested.

In addition, the suggestion was made to create a toolkit to provide examples on how other people cope with ageing and mental and or physical health challenges.

CONCLUSIONS & RECOMMENDATIONS

The focus group discussions highlighted the important aspects of mental and physical health for individuals ageing with SBH. As illustrated in this report, ageing with SBH, there is ample room for improvement. Discussions from five focus groups reflect the importance of ageing with a specific attention for mental and physical health. Members emphasized on several ageing related challenges such as loneliness, social isolation, physical pain, mental constraints and feeling of depression (suicidal thoughts), perceived stigma, the need for support groups and the importance of coordinated multidisciplinary care. It is important to take into consideration all aspects of ageing with SBH and not only advocate but also raise awareness, give recommendations on how to improve the quality of life, give support to the individuals, build a community and network. Those are the main actions to help people ageing with SBH.

Isolation, loneliness, mental health, stigmatisation and the need to access multidisciplinary healthcare were already mentioned in the 2020 report. Those results were also confirmed during the focus group discussions but new fears and challenges were brought to light such as the fear of the future. Becoming a burden, losing independence over time was one of the biggest concerns that generates stress and has a negative impact on mental health. The concern of parents of an individual with SBH regarding the future of their child was also raised during the focus group discussion which leads to worry - medication management, independence, being able to take care of their physical and mental health were the main concerns of the parents. The lack of country support was another finding from the focus group discussion that wasn't mentioned in the previous report.

To move forward and go further into the work related to ageing characteristics of persons with Spina Bifida and Hydrocephalus (SBH), best practices with the respect to needs and support among members associations need to be shared. Answering important questions and sharing recommendations on the lived experiences, what is happening on a country level, what is the need of individuals with SBH and what are the best practices around the world in order to take example from could be a big help for a person living and ageing with SBH.

On an international level, several actions have been organized to improve our understanding of the ageing community and provide opportunities to develop partnerships and infrastructures for people to meet each other. Conferences, meetings and webinars, give the IF Working Group on Ageing the opportunity to share best practices, and bring the issues that people ageing with SBH face. For example, during the IF International Conference on Multidisciplinary Care for SBH where a session with a specific attention for ageing was held or again the “Ageing well with Spina Bifida and Hydrocephalus” side-event where life experiences, advice without any taboo were given. The opportunity also to raise awareness arises during the international awareness days, where toolkit, key messages are shared. Advocacy is done through IF statements, which outline the challenges that the SBH community are facing regarding ageing and where the federation recommends policy makers what to do to address those issues.

Showing results of the work undertaken by the IF Working Group on Ageing with SBH in those events, having the opportunities to write on the topic of ageing allow to advocate, raise awareness and bring the issue of ageing with SBH into light. By making toolkits, surveys, reports, statements and being part of working groups allow IF to go further and have a deeper insight of the needs that individuals ageing with SBH have.

In this way, better support and guidance can be provided to individuals with SBH, identifying issues, needs and helping to advocate for the rights of individuals with SBH. Twinning opportunities, support, discussions with peers but also sharing best practices and toolkit in order to improve life and cope with ageing with SBH as requested during the focus group discussions and were even mentioned as essential.

In conclusion, the results from both the previous descriptive analysis and the outcomes of the focus group discussions described in this report, demonstrate that there is a need to support and enhance the lived experience of people ageing with SBH. We suggest considering an integrated approach, on three levels, to address the challenges that a transition to old age herald:

Social policy and Research:

- Identify areas of best practice for transitional model of care for (older) people with SBH;
- Produce a detailed atlas of variation that collate maps with a narrative to identify and address unwarranted transitional care variation and support improvement;
- Encourage the development of personalised and holistic model of care for the older adult with SBH and sustainable and well informed workforce;
- Promote systems that can deliver information about transition to people with neurological conditions such as SBH;
- 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;
- Develop a wide campaign 'OK to ask' about sex aimed at the older person including those with SBH;
- Support further research including further qualitative research on the impact of ageing and identification of outcome measures that are meaningful to people who are part of the SBH community

National - some activities may be channelled through national organisations:

- Facilitate engagement events to involve the community and co-produce education and information resources as part of a transition toolkit;
- Consider ways to enhance continence, pain management and sexual health issues for people with SBH as they age;
- Offer supplementary services to address the needs of adults as they transition to old age. Focus on emotional and mental health services where demand outstrips supply;
- Develop training content for professionals, carers and service users on transition to old age and building resilience skills;
- Support the needs of carers for and partners of those with SBH who transition to old age.

Individual:

- Engage in activities that enhance knowledge and skills of transitioning to old age;
- Hone resilience skills through enrolment in appropriate training, perhaps provided by national organisations, and through the use of self-directed resources;
- Consider ways to modify activities over time to address anticipated changes due to ageing.

ACKNOWLEDGMENT

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