

INTERNATIONAL DAY OF OLDER PERSONS October 1, 2024





Introduction

On October 1, the world will celebrate the International Day of Older Persons.

This day was designated by the United Nations General Assembly (by resolution 45/106) on 14 December 1990.

IF takes this opportunity to raise awareness on ageing with Spina Bifida and Hydrocephalus. According to the survey carried out by the IF Working Group on Ageing, 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. 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. There is a need to explore and expand our knowledge and gain insights into current health and wellbeing status of older people with SBH. We need to understand the challenges they face, their way of developing resilience and coping mechanisms and the impact ageing has on their occupation and independence.





IF International Day of Older Persons 2024

On this day, the goal is to raise awareness on ageing with SBH, the barriers older persons with SBH can face and the need for lifting these barriers.

IF aims to emphasise the importance of integrated care for persons ageing with SBH and the fact that individuals with SBH are subject to "accelerated ageing" which means the ageing process for some groups of people with disabilities begins earlier than usual, such as for individuals with SBH.

To overcome these barriers, they need access to multidisciplinary clinics, where professionals have up-to-date in-depth knowledge on SBH treatment and care, including mental health care. They need access to assistive devices, access to inclusive education, employment with reasonable accommodations, such as flexible working hours. They need social protection against financial hardship and the risk of institutionalisation. More research is needed into the effects of ageing with SBH and the impact on daily life of secondary conditions. The health and the lives of people ageing with SBH should not be at risk due to stigma, prejudice, and the combined discrimination based on age and disability.

Another important aspect to highlight on this day is the risk of institutionalisation and abuse for older persons with SBH is a serious violation of human rights.

It is vital to protect older persons with SBH from experiencing preventable loss of independence and to develop community based services to prevent institutionalisation and abuse in old age. Individuals with SBH and intellectual disabilities may have already been subjected to loss of legal capacity or institutionalisation at a younger age.

Their right to transition to community based living regardless of age or perception of quality of life must be addressed by policy makers and service providers.



NATIONAL FEDERATION SPINA BIFIDA

REPORT AGEING WITH SPINA BIFIDA AND HYDROCEPHALUS

AN OVERVIEW OF BEST PRACTICES AROUND THE WORLD



Leaving No One **Behind In** An Ageing

United Department of Economic and Social Affairs

World

World Social Report 2023

The United Nations Department of Economic and Social Affairs (UN DESA) published their "World Social Report 2023: Leaving No One Behind In An Ageing World". This report highlights the challenges older persons in different countries encounter as well as how the ageing community can best be supported socially and economically in the years to come.

Similarly, the IF Working Group on Ageing with SBH published their report responding to the challenges faced by the ageing SBH community.

This report by the ageing group spotlights multiple initiatives of different SBH associations that aimed to bring the best care and support for the ageing SBH population through several international best practices. These best practices embody concrete examples of support necessary in an ageing society as indicated in the UN DESA report.



INTERNATIONAL

Happy

DAYOF







IF Working Group on Ageing with SBH

IF represents the global SBH community and aims to advance and protect the rights of individuals with SBH and their families. IF achieves this through its policy and advocacy work as well as through awareness raising. IF actively works to increase its presence and visibility on the regional and international level, including in the EU's implementation of the UNCRPD and in relevant activities on the UN level.

In the past years, our members have emphasised the importance of raising awareness about ageing with spina bifida and hydrocephalus (SBH). Due to improved treatment and care, many children born with SBH have grown up, become adults, and are reaching their senior years. At the same time, we know very little about ageing with SBH and its impact on physiology, mental abilities and independence.

There is a need to improve our understanding of **the lived experience of older persons with SBH**, which is why it has become a key objective for our organisation.

IF Working Group on Ageing conducts several activities such as reports, webinars, monitors policies and consultations relevant to older persons with disabilities, SBH in particular.





What does this toolkit contain?

- Within this toolkit, you will find key messages, posters, hashtags, logos and banners as well as key links to download
- Come and join the challenge by sharing this toolkit with your organisation, colleagues, partners and friends!
- Participate in the IF challenge and send us your recorded video or a picture to express yourself about Ageing with SBH and what it means to you

Help us to spread awareness!

IF is looking forward to seeing your materials and share them during the #InternationalOlderPersonsDay #ElderlySBH #AgeingWithSBH



- Multidisciplinary care for all life stages. The needs of individuals with #SBH changes with age and healthcare services need to be able to meet them. The needs may change but the rights stay the same. #MultidisciplinaryCareForSBHElders #OlderPersonsDay #AgeingWithSBH
- Health and social care professionals, individuals with SBH and their families need support to adjust to the change in demographics. Develop training content for professionals, carers and service users on transition to old age and building resilience skills. #OlderPersonsDay #AgeingWithSBH
- Support the needs of carers and partners of individuals with SBH who are transitioning into old age. **#OlderPersonsDay #AgeingWithSBH #ElderlySBH**
- New ways and greater support is needed to address incontinence, pain management and sexual health issues for people with SBH as they age. #OlderPersonsDay #AgeingWithSBH #ElderlySBH







- Support needs to not end after childhood. Older people with Spina Bifida and Hydrocephalus have the same rights as every other person. To overcome the barriers, they need access to multidisciplinary clinics. #MultidisciplinaryCareForSBHElders #OlderPersonsDay #AgeingWithSBH
- More research is needed into the effects of ageing with SBH and the impact on daily life of secondary conditions. #OlderPersonsDay #AgeingWithSBH #ElderlySBH
- The health and the lives of people ageing with SBH should not be at risk due to stigma, prejudice, and the combined discrimination based on age and disability. #OlderPersonsDay #AgeingWithSBH #ElderlySBH
- It is vitally important that policy makers take into account the needs of individuals who experience accelerated ageing due to SBH or other conditions. #OlderPersonsDay #AgeingWithSBH
- A multidisciplinary care model of care and support is essential as it is one of the most efficient ways of addressing the challenges brought on by ageing with SBH. #MultidisciplinaryCareForSBHElders #OlderPersonsDay

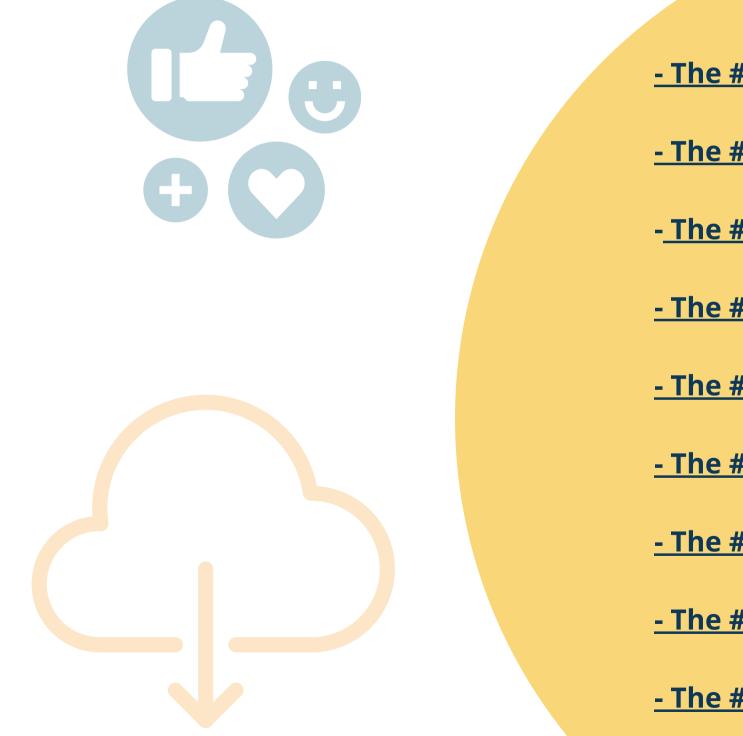


- Multidisciplinary care for SBH must not omit older people with SBH. Integrated approach to treatment, care and support for adults with SBH is as essential as for children and youth with SBH. #MultidisciplinaryCareForSBHElders #OlderPersonsDay
- Older people with SBH can be at risk of mental health issues, such as depression and anxiety, in part due to. Inaccessibility, lack of support and stigma. An association between disability and depression has been established, identifying mental health concerns as a secondary conditions is a priority for persons with SBH. #OlderPersonsDay #ElderlySBH #AgeingWithSBH
- Encouraging the development of personalised and holistic model of care for the older adult with SBH and a sustainable and well informed workforce is of utmost importance. #MultidisciplinaryCareForSBHElders #OlderPersonsDay
- It is necessary to support further neurological 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. #OlderPersonsDay #ElderlySBH #AgeingWithSBH





Materials to download and share:



- The #OlderPersons Poster - The #OlderPersons Banner - The #OlderPersons Save the date - The #OlderPersons Frame - The #OlderPersons Frame picture - The #OlderPersons Frame message - The #OlderPersons Frame picture with quote 1 - The #OlderPersons Frame picture with quote 2

- The #OlderPersons Frame picture with quote 3





Testimonial Challenge

In preparation for the International Day of Older Persons, IF invites YOU to send a short video OR story message.



- Format testimonial challenge
 - (max. 300 words)
 - b. Language in English

- Content
 - a. Introduce yourself (name, age, country)

 - awareness

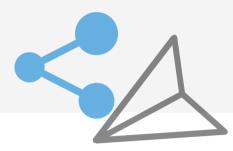
Please email your materials to info@ifglobal.org before September 29.

a. Create a **video** (mp4 file, max. 2 minutes) OR write a **short story**

b. A comment to what barriers you encounter as an older person with SBH c. What actions would you like to be taken to remove these barriers d. A call to support and invitation to join the movement to help raising



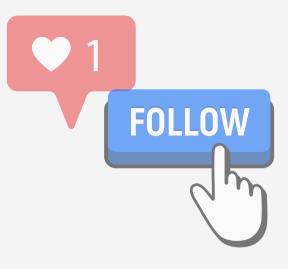
Tagg @IFSBH, Share & Follow



Share, use the hashtags: **#IFSBH** #AgeingWithSBH #ElderlySBH #OlderPersonsDay #InternationalOlderPersonsDay #MultidisciplinaryCareForSBHElders







And Follow @IFSBH



Useful Links

IF Website Working Group on Ageing: <u>https://www.ifglobal.org/our-work/working-group-on-ageing-</u> with-sbh/

IF News on Ageing: <u>https://www.ifglobal.org/news/if-report-ageing-with-spina-bifida-and-</u> <u>hydrocephalus-an-overview-of-best-practices-around-the-world/</u>

IF Working Group on Ageing Report: "Ageing With Spina Bifida and Hydrocephalus: An Overview of Best Practices Around the World": <u>https://www.ifglobal.org/wp-content/uploads/2022/12/Report-of-Best-</u> Practices-on-Ageing-with-SBH..pdf

IF Submission on the Rights of Older Persons with Disabilities: <u>https://www.ifglobal.org/news/if-</u> submission-on-the-rights-of-older-persons-with-disabilities/

United Nations DESA: <u>https://www.un.org/development/desa/ageing/international-day-of-older-</u> persons-homepage.html

United Nations DESA "World Social Report 2023: Leaving No One Behind In An Ageing World": https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2023/01/2023wsr-<u>fullreport.pdf</u>

United Nations 2023 UNIDOP theme: <u>https://social.desa.un.org/issues/ageing/events/2023unidop</u>



THANK YOU FOR YOUR PARTICIPATION IF TEAM



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