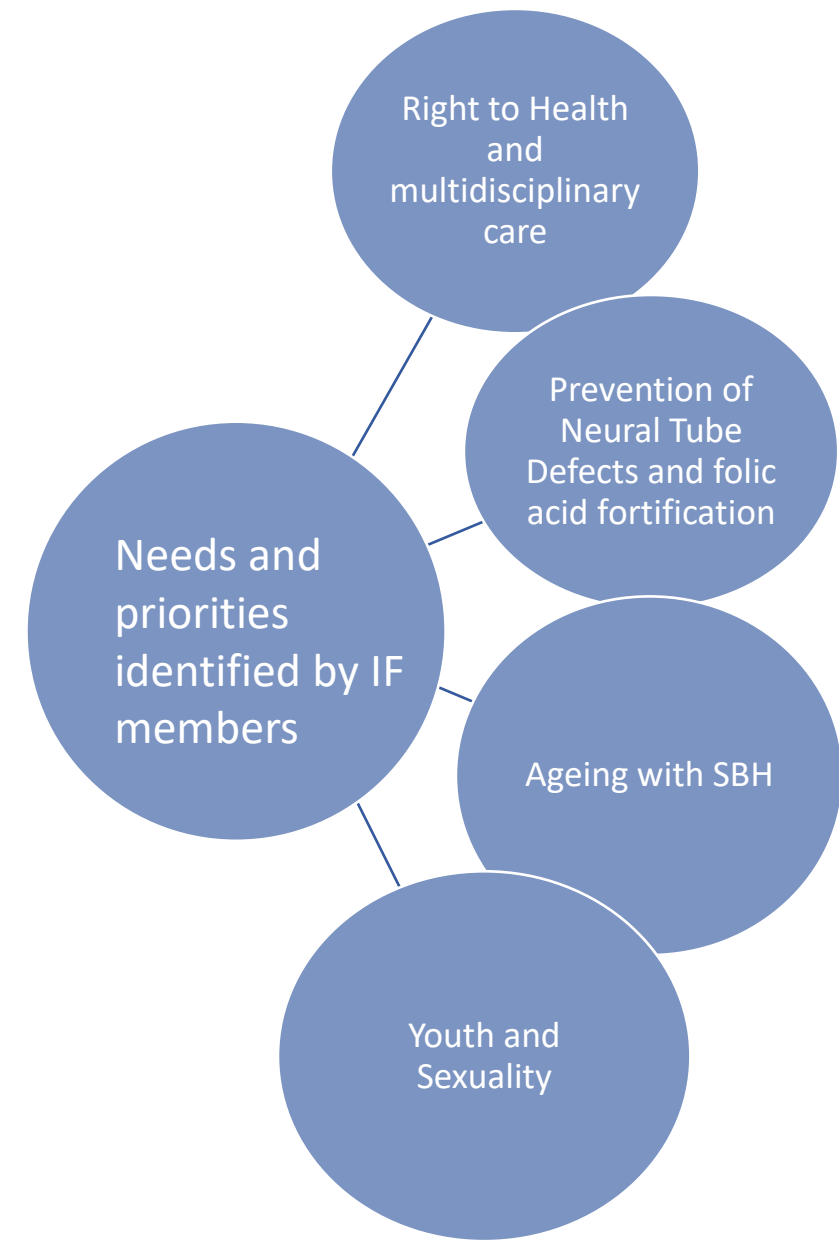




# INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

**Who we are:** The International Federation for Spina Bifida and Hydrocephalus (IF) is the international organisation representing people with Spina Bifida and Hydrocephalus (SBH) and their families worldwide. **The vision of IF is a society that guarantees the human rights of children and adults with SBH in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCPRD), and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy for all.**

Priorities for policy and advocacy work are identified by consulting the SBH community through member meetings, communications, working groups and focus group discussions.



# IF Working Group on Ageing with Spina Bifida and Hydrocephalus

The IF Working Group on Ageing with Spina Bifida and Hydrocephalus is composed of adults with SBH and people who act as formal and informal carers for adults with SBH. Its key objective is to improve the understanding of the lived experience of individuals ageing with SBH. To that end it has organised a continuing programme of work, including an international survey and focus group discussions, aimed at giving adults with SBH the opportunity to describe and share their experiences. The results are promoted through publications and presentations.

# IF Report “Ageing with Spina Bifida and Hydrocephalus – A Descriptive Analysis”

## Employment

- Ability to work and reducing work hours
- Finding employment
- Accessibility of workplaces

Encounter discrimination on the basis of disability when finding work and workplaces are often inaccessible.

## Mobility

- Changes in mobility
- Accessibility and suitable housing
- Assistive devices and personal assistance

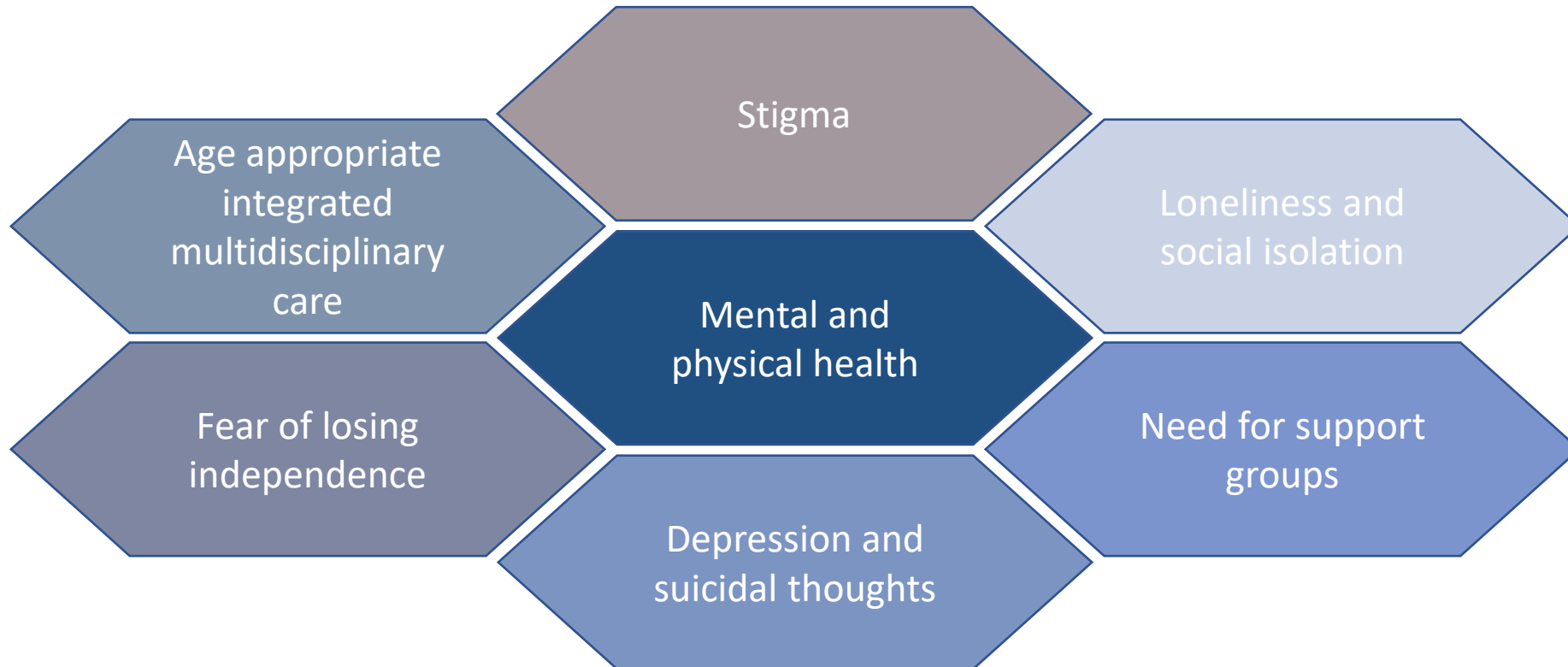
Greater physical and health related challenges with age (incontinence, pain, mobility). Access to SBH and age specific healthcare services and multidisciplinary care is often inadequate.

## Support

- Formal support (social worker, home nurse, personal assistant)
- Informal support

Formal support is not always needed but when it is there is a huge variation between countries regarding access. Complex bureaucracy is a big barrier, especially if the individual is employed.

# Key concerns identified by IF Working Group on Ageing with Spina Bifida and Hydrocephalus



# IF Statement on Ageing with Spina Bifida and Hydrocephalus

## Recommendations:

- Encourage the development of 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.