

## IF Statement on Mental Health in Focus

As declared by WHO, mental health is a state of mental well-being that allows people to cope with life's challenges, realise their abilities, learn and work effectively and contribute to their community. Mental health has both intrinsic and instrumental value and is essential for our overall well-being. At any given time, a series of individual, family, community and structural factors can combine to protect or compromise mental health and people exposed to adverse conditions, such as poverty, violence, inequalities or disabilities, are at greater risk of developing mental health conditions, which frequently entail stigma, discrimination and human rights violations. Mental health conditions include mental disorders, psychological disabilities, and other mental states associated with significant distress, impaired functioning or risk of self-harm. Therefore, these conditions can lead to challenges in all aspects of life, including relationships with families, friends, and the community<sup>1</sup>. For this reason, it is important to put mental health in focus.

The International Federation for Spina Bifida and Hydrocephalus (IF) recognises mental health as a fundamental right for all, including those living with disabilities such as spina bifida and/or hydrocephalus (SBH). The SBH community, at every stage of life, often faces not only physical barriers but also social prejudices that can severely impact self-esteem, self-acceptance and acceptance of one's disability, thus compromising mental health. Indeed, the SBH community experiences strong taboos surrounding mental health in relation to disability. While mental health is very often associated with strong societal taboos on its own, these taboos create specific challenges for persons with disabilities such as SBH when combine with the prevailing stigma, social exclusion and discrimination surrounding disability and SBH<sup>2</sup>. This situation is in contrast with Article 8(b) of the United Nations Convention on the Rights of Persons with Disabilities

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<sup>1</sup> World Health Organization. (2021). *Comprehensive mental health action plan 2013–2030*. World Health Organization, <https://iris.who.int/bitstream/handle/10665/345301/9789240031029-eng.pdf?sequence=1>

<sup>2</sup> International Federation for Spina Bifida and Hydrocephalus. (2021). *IF Statement on Mental, Physical and Sexual Health for Youth with SBH*, <https://ifglobal.org/publications/if-statement-on-mental-physical-and-sexual-health-for-youth-with-sbh/>

(UNCRPD), which calls for combating stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on gender and age, in all spheres of life<sup>3</sup>.

Hence, mental health and its protection are of fundamental importance for the SBH community, at all ages and during every transition between different life stages. For this reason, the IF advisory groups included mental health on top of their agenda. For instance, both the International Youth Group SBH and the IF working group on Ageing with SBH developed campaigns during several awareness raising days (e.g. World Mental Health Day, World Spina Bifida and Hydrocephalus Day). Another key activity included a meet and greet between both groups to better understand how mental health can and should be addressed. This resulted in knowledge gathering activities among the broader community to prioritise key priority areas in the subject on mental health. Moreover, to foster knowledge exchange, online and in person meetings facilitated discussions and twinning opportunities to learn from one and another. These activities informed key areas important to our young and older community members as follow:

1. Intergenerational learning. Meaningful exchanges of experiences between intergenerational groups can help in providing valuable insight for young people with SBH about life experiences by learning from older persons with SBH as a role model;
2. Disability Acceptance. Experiences of living with a disability and overcoming challenges;
3. Family Support. How parents and family members can help with mental health;
4. Empathy and Bullying at School and at Work. Lack of empathy and risk of bullying in regular schools and offices where disability is underrepresented;
5. Mental Support Within the Public Healthcare Systems. Access to mental health programs and assistance in public healthcare systems;
6. Personal Relationships, Sexuality, and Family Planning. Develop and maintain relationships, explore and express sexuality, access to sexual health information and services, and family planning.

For example, the United Nation recognised international Youth Day provided an opportunity for the IF International Youth Group SBH to address a specific key area important to youth, namely disability acceptance. International days like these facilitated open discussions for our community on the topics of resilience, mindfulness, disability acceptance and psychological support. This event confirmed the importance of mental health and disability acceptance for the entire community represented by IF, as an essential pillar for leading a fulfilling, productive and

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<sup>3</sup> United Nations, *United Nations Convention on Rights of Persons with Disabilities*, adopted 13 December 2006, entry into force 3 May 2008, <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

independent life, as set out in Article 19 of the UNCRPD. This pillar must be supported through an inclusive, multidisciplinary and specific support system<sup>4</sup>.

In this regard, one of the core topics raised during the discussion was the importance of addressing taboos surrounding disability and mental health. Discrimination often leads to social isolation, preventing children, youth and adults from expressing their needs and accessing adequate support services, creating emotional and social barriers that hinder psychological well-being and inclusion. Promoting a culture that respects and values diversity is essential for improving disability acceptance at both personal and social levels, with a resulting positive impact on mental health. In fact, exposure to adversities such as social isolation is a preventable risk factor for mental disorders<sup>5</sup>.

Overcoming these barriers therefore requires a strong commitment to improving access to healthcare that addresses mental health needs. Indeed, the lack of access to quality, affordable multidisciplinary care for SBH is a significant factor. Furthermore, even when such multidisciplinary approaches are available, they often do not include mental health support or are only accessible to children, with insufficient or non-existent support for transitioning into adolescence and adulthood<sup>6</sup>. This results in limited opportunities to discuss one's mental health conditions, express concerns and address the process of acceptance with healthcare professionals who are specifically trained in both mental health and disability care<sup>7</sup>.

The importance of a multidisciplinary care approach is also reflected in the recent Kuala Lumpur Declaration, as a result of our 30<sup>th</sup> International Conference on Spina Bifida and Hydrocephalus<sup>8</sup>. The Declaration highlights that health constitutes an important form of social inclusion, understood as both physical and mental wellbeing, enabling full participation in social and economic life. Equitable access to quality and multidisciplinary healthcare and psychological

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<sup>4</sup> International Federation for Spina Bifida and Hydrocephalus. (2021). *IF Statement on Mental, Physical and Sexual Health for Youth with SBH*, <https://ifglobal.org/publications/if-statement-on-mental-physical-and-sexual-health-for-youth-with-sbh/>

<sup>5</sup> World Health Organization. (2022). *World mental health report: Transforming mental health for all*. World Health Organization. <https://iris.who.int/bitstream/handle/10665/356119/9789240049338-eng.pdf?sequence=1>

<sup>6</sup> International Federation for Spina Bifida and Hydrocephalus. (2021). *IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus*, <https://ifglobal.org/wp-content/uploads/2021/11/IF-statement-on-MDC-November-2021.pdf>

<sup>7</sup> International Federation for Spina Bifida and Hydrocephalus. (2024). *The Kuala Lumpur Declaration*, [https://ifglobal.org/wp-content/uploads/2024/11/Final-Kuala\\_Lumpur\\_Declaration\\_signed.pdf](https://ifglobal.org/wp-content/uploads/2024/11/Final-Kuala_Lumpur_Declaration_signed.pdf)

<sup>8</sup> The 30<sup>th</sup> International Conference on Spina Bifida and Hydrocephalus, *Conference Programme Book*, <https://ifglobal.org/wp-content/uploads/2024/11/ICSBH-Souv-Programme-151124.pdf>

support<sup>9</sup> is essential to ensuring that every individual, regardless of health conditions or disabilities, can lead an active, inclusive and dignified life.

Therefore, it is essential that the healthcare system begins to adequately address the burden of mental health challenges, bridging the gap between the need for care and its provision worldwide. According to WHO's Comprehensive Mental Health Action Plan 2013-2030, between 76% and 85% of people with severe mental disorders in low and middle-income countries do not receive any treatment for their condition; even in high-income countries, the percentage remains high, ranging from 35% to 50%. An additional issue is the poor quality of care for those who do receive treatment, caused by the scarcity of resources within countries to meet mental health needs and the inequitable distribution and inefficient use of these resources. Redirecting funding towards the integration of mental health into general healthcare settings and into healthcare systems specifically targeting patients with disabilities would, according to the WHO, allow for better and more cost-effective interventions for many more people.

From this perspective, WHO emphasises the importance of continuous training for healthcare providers on mental health and disability issues, which would contribute to building a comprehensive and accessible support system. This is crucial in addressing the lack of qualified medical personnel capable of providing such support. In fact, the number of specialised and general healthcare workers dealing with mental health in low and middle-income countries is severely insufficient, leading to a situation where half of the world's population lives in countries where, on average, there is one psychiatrist for every 200 000 or more people<sup>10</sup>.

The protection of mental health is also closely connected to the existence of social support networks, such as friends, family, representative organisations such as SBH associations, and peer support groups, such as youth groups and ageing groups. Actively participating in local networks or working groups, both national and international, can facilitate the exchange of experiences, provide increased psychological support and, most importantly, offer opportunities to engage in advocacy activities aimed at influencing political decisions and promoting the respect of the United Nation's principle of "Nothing About Us Without Us". As emphasised by the European Commission in its official communication on a comprehensive approach to mental health<sup>11</sup>, the responsibility for effective action on mental health does not fall solely on public authorities. Full awareness of shared responsibility, broad cooperation, and strong commitment by stakeholders

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<sup>9</sup> World Health Organization. (2024). *Health equity for persons with disabilities: guide for action*. World Health Organization. <https://iris.who.int/bitstream/handle/10665/379479/9789240101517-eng.pdf?sequence=1>

<sup>10</sup> World Health Organization. (2022). *World mental health report: Transforming mental health for all*. World Health Organization. <https://iris.who.int/bitstream/handle/10665/356119/9789240049338-eng.pdf?sequence=1>

<sup>11</sup> European Commission. (2024). *Tracking framework for the implementation of the Commission Communication on a comprehensive approach to mental health*, [https://health.ec.europa.eu/document/download/6317c605-5f5d-4d4f-9c8a-d5c93e869814\\_en?filename=ncd\\_tracking-framework-mh\\_en.pdf](https://health.ec.europa.eu/document/download/6317c605-5f5d-4d4f-9c8a-d5c93e869814_en?filename=ncd_tracking-framework-mh_en.pdf)

is necessary to intensify actions to promote good mental health and combat mental health issues. For this, the involvement of stakeholders, particularly NGOs such as representative organisations of healthcare professionals, persons with disabilities and their families, is crucial to the success of these efforts.

In light of the above challenges faced by individuals with SBH in pursuing their right to mental health, IF presents the following recommendations for policymakers, healthcare professionals and other relevant stakeholders.

## Recommendations:

- To ensure the availability, accessibility, and variety of mental health services so that all individuals with SBH have access to inclusive psychological support services through the integration of psychologists, general medicine, and social support system, at affordable costs or for free, by implementing coordinated and holistic interventions encompassing prevention, care, and support.
- To formulate, update, and enforce national policies, programs, and legislation on mental health, including codes of conduct to monitor the protection of human rights, in alignment with the United Nations Convention on Right of Persons with Disabilities (UNCRPD), scientific evidence, and best practices.
- To provide and finance specialised training programs for healthcare professionals to effectively address the specific mental health needs of individuals with disabilities through person-centred and rights-based approaches.
- To promote awareness of mental health through campaigns aimed at combating stigma related to disability and mental health and encourage participation in support groups and online platforms that offer dedicated spaces for mutual assistance, dialogue, and the exchange of experiences.
- To safeguard and promote, at multiple levels, the inclusion and active involvement of the SBH community, organisations of persons with disabilities, and users and ex-users of mental health services. Provide leadership programs and skill development opportunities to enable SBH community members to actively influence social and political decisions, in adherence to the United Nation principle “Nothing About Us Without Us”.
- To integrate mental health into routine health information systems by collecting, analysing, and reporting disaggregated data to improve service delivery, prevention strategies, and contributions to the Global Mental Health Observatory.

## ABOUT IF

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. IF has country members in Africa, Americas, Asia-Pacific, and Europe with unique and expert knowledge on SBH. The mission of IF is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of Neural Tube Defects (NTDs) through improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

### **IF ivzw**

**International Federation for Spina Bifida and Hydrocephalus**

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