

IF Statement on Mental, Physical and Sexual Health for Youth with SBH

Mental, physical and sexual health and disability rights are irretrievably interconnected topics of which the International Federation for Spina Bifida and Hydrocephalus (IF) has been advocating on. IF represents the persons with Spina Bifida and Hydrocephalus (SBH) and their families worldwide. The vision of IF is of a society that guarantees the human rights of persons with SBH and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy for all. Mental, physical and sexual health was identified as high priority topics by the SBH youth community. In this statement IF presents the main conclusions of this work by the SBH youth community and the IF International Youth Group, the challenges that persons with SBH encounter in regards to mental, physical and sexual health and IF's recommendations for advancing the rights and wellbeing of persons with SBH in regards to mental, physical and sexual health.

The SBH community, including youth with SBH, experience strong taboos surrounding physical, mental and sexual health in relation to disability. While sexual health, physical health and mental health are very often associated with strong societal taboos on their own, these taboos create specific challenges for persons with disabilities such as SBH when they combine with the prevailing stigma, social exclusion and discriminations surrounding disability and SBH. For example, for sexual health the stigmatising misperception that persons with disabilities are asexual is still all too commonly held. This perception can have a highly damaging effect on a young person's self-image, mental health and social exclusion and may result in challenges of accessibility and quality of care. It can also have serious consequences if educators, healthcare providers and professionals share this view resulting in lack of access to comprehensive sexuality and sexual health education or reproductive and sexual healthcare. Indeed, although the topic of mental, physical and sexual health can be more complex and patient-specific for persons with disabilities such as SBH. Standardised sex education often fails to address these concerns. The perceived stigma prevents them from talking about these issues with healthcare professionals, friends or family and even when they are prepared to do so youth with SBH are given few private opportunities to talk about them with healthcare professionals.¹

Access to physical health, mental health, sexual and reproductive services is essential for the wellbeing and full realisation of their human rights by persons with SBH. However, access to such

¹ International Federation for Spina Bifida and Hydrocephalus (2019). *Survey on Sexuality and Body Awareness of People with Spina Bifida and Hydrocephalus*: <https://www.ifglobal.org/wp-content/uploads/2019/12/report-survey-sexuality.pdf>

services, including education and information in addition to healthcare services is not guaranteed for many in the SBH community². The challenges in accessing these services come in different forms. Stigmatisation of SBH, disability, mental and sexual health are a significant barrier. Perceived stigmas by persons with SBH from friends, family and healthcare professionals prevents persons with SBH from seeking out support and services in the first place. In particular, when persons with SBH experience that they are being treated only for one aspect of their body, instead of as a complete human being, it discourages people from discussing sensitive topics such as mental or sexual health, which in turns impacts their physical health. Lack of access to quality and affordable multidisciplinary care for SBH is a significant factor. It is also important to note that mental, physical and sexual health are not always incorporated into multidisciplinary care for SBH when such services are available.³ In addition, too often when multidisciplinary care for SBH is available it is only for children, with little or no support for the transition to adulthood, mental and sexual health,⁴ parenthood or ageing with SBH.⁵ The physical, mental and sexual health of persons with SBH, as well as sexuality and mental health for persons with disabilities, is often viewed to be highly specialised topic for educators, social and healthcare professionals. This means that persons and especially young persons, with SBH experience that they have few opportunities to talk about their concerns, as the specialised healthcare professional who is prepared to talk about sexual or mental health is not prepared to discuss their disability. Or that the healthcare professional who looks after their physical health is unwilling or unprepared to talk about mental or sexual health. This means that not all mainstream mental health and sexual health services are truly accessible to persons with SBH. In addition, often when youth with SBH do visit healthcare professionals specialised in SBH they are often accompanied by a parent or family member and are not always given a private opportunity to discuss matters they do not wish to share with their family. The SBH youth community would like to highlight that insufficient funding for mental health, sexual health and SBH healthcare services makes these challenges even more difficult.

Persons with SBH report that they do want to have physical and romantic relationships but that they encounter difficulties in pursuing them. Persons with SBH also report low self-confidence and embarrassment of physical appearance and disability for example concerns regarding incontinence. However, it is the embarrassment surrounding incontinence, rather than the severity of the incontinence which has the biggest impact. In addition, mental health is another issue which persons with SBH have identified as being essential for living a good life. While access

² International Federation for Spina Bifida and Hydrocephalus (2016). *Right to Health: Reality of Persons with Spina Bifida and Hydrocephalus*: <https://www.ifglobal.org/publications/if-report-right-to-health-reality-of-persons-with-spina-bifida-and-hydrocephalus/>

³ International Federation for Spina Bifida and Hydrocephalus (2021). *IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus*: <https://www.ifglobal.org/publications/if-statement-on-multidisciplinary-care-for-spina-bifida-and-hydrocephalus/>

⁴ International Federation for Spina Bifida and Hydrocephalus (2021). *IF Statement on Ageing with Spina Bifida and Hydrocephalus*: <https://www.ifglobal.org/publications/if-statement-on-ageing-with-spina-bifida-and-hydrocephalus/>

⁵ IF Working Group on Ageing with SBH (2020). *Ageing with Spina Bifida and Hydrocephalus – A Descriptive Analysis*. International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-report-ageing-withspina-bifida-and-hydrocephalus-a-descriptive-analysis/>

to services is essential, relationships including friendships, form an irreplaceable foundation for wellbeing for all persons. Youth with SBH have described that they find it more difficult to make friends due to their disability. But the challenges described are not due to the disability itself but rather people's reactions and perceptions of disability. That people see the disability before or even without seeing them as an individual. People may feel uncomfortable, don't know how to address a person who has visible disabilities or do not understand or accommodate their limitations. Accessibility plays a role here as well, with people with SBH reporting that they are excluded from outings and events planned by family or friends because the venues are inaccessible. Friendships in particular are very important, it is essential to have a safe space and safe people to discuss sensitive topics such as their physical, mental and sexual health.⁶ Having fewer opportunities to form friendships further reduces opportunities to have an open discussion, coupled with the challenges in accessing and discussing their mental, physical and sexual health with healthcare professionals, persons with SBH may have very few opportunities to talk about their concerns. A situation which has been made worse by the Covid-19 pandemic.⁷ All these concerns, experiences and barriers compound to foster feelings of isolation, social exclusion and low self-esteem which has a significant impact on the mental, physical and sexual health of persons with SBH.

State parties to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) have an obligation to implement legislation and policies to advance and safeguard the rights of persons with disabilities. In the context of mental, physical and sexual health article 25 states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. In article 25(a) access to the same range, quality and standard of free or affordable health care specifically includes the area of sexual and reproductive health. As has been outlined above this is not always the case for persons with SBH. In light of the stigma and social isolation experienced by persons with SBH it is also important to highlight article 8 which outlines the duties of state parties to raise awareness of the rights of persons with disabilities, to combat stereotypes and promote awareness of the capabilities and contributions of persons with disabilities.

In light of the challenges outlined above for persons with SBH in pursuing their right to physical, mental and sexual health IF presents the following recommendations to policy makers, healthcare professionals and other relevant stakeholders.

⁶ IF International Youth Group (2021). *Mental Health Implications of COVID-19 on Youth with Spina Bifida and Hydrocephalus— an explorative survey conducted by the if international youth group with SBH*. International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-report-mental-health-implications-of-covid-19-on-youth-with-spina-bifida-and-hydrocephalus-an-explorative-survey-conducted-by-the-if-international-youth-group-with-sbh/>

⁷ International Federation for Spina Bifida and Hydrocephalus (2021). *IF Statement on COVID-19*: <https://www.ifglobal.org/publications/if-statement-on-covid-19/>

Recommendations:

- IF calls on policy makers to increase investment in mental and sexual health services which are inclusive and accessible to persons with disabilities;
- IF calls on increased actions on the international, European, national and local levels to raise awareness of the rights of persons with disabilities in accordance with article 8 of the UNCRPD to combat harmful stereotypes and stigma especially in the context of mental and sexual health;
- IF recommends that healthcare professionals take part in facilitating open discussions regarding mental and sexual health in the context of disability;
- IF calls on policy makers, donors, healthcare professionals and their professional organisations and other stakeholders on the local, national, European and international level to address the stigmatisation of disability in the context of mental, physical and sexual health through public awareness campaigns, trainings and information materials.

ABOUT IF

Spina Bifida and Hydrocephalus (SBH) are complex health conditions which develop during the first four weeks of pregnancy as a result of the neural tube and spine not developing correctly. 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 organisation founded in 1979, represents Member Associations in countries all over the world with unique and expert knowledge on SBH. With global coverage, IF's mission is to improve the quality of life of people with SBH and their families, and to reduce the prevalence of neural tube defects and hydrocephalus.

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