



**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**



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The International Federation for Spina Bifida and Hydrocephalus (IF) presents this document to provide results of a survey on mental health and the pandemic impact on it, conducted by the IF International Youth Group with Spina Bifida and or Hydrocephalus (SBH). It underlines the current perceptions and lived experiences among youth with SBH with respect to aspects of mental health. This document builds upon an explorative study conducted in 2019 by the IF International Youth Group with SBH.

To have better insight in the aspects related to mental health among young people living with SBH and in order to provide better support, the IF International Youth Group with SBH initiated a survey to assess mental health implications of the COVID-19 pandemic on youth with SBH. The results are presented through this report.



# 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 organization of persons with disabilities with global coverage. IF now includes over 80 SBH associations in Africa, Australia, the Americas, Asia and Europe.

The majority of IF member organizations are led and governed by adults with Spina Bifida and Hydrocephalus (SBH) 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 organizations. 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.

Communities across the world are experiencing the short-term and long-term effects of the COVID-19 pandemic, which has deepened pre-existing inequalities in our societies<sup>1</sup>. Individuals with Spina Bifida and Hydrocephalus across the world have encountered new and additional barriers during these difficult times. As the world continues to struggle with the ongoing crisis as well as moving forward to address the socio-economic consequences of the pandemic and reflecting on the lessons learned, it is vital to acknowledge that COVID-19 has affected some groups more than others.<sup>2</sup>

In 2020, the United Nations published a disability-inclusive response to COVID-19. This Policy Brief highlights the impact of COVID-19 on persons with disabilities, including for example having a greater risk of contracting COVID-19, a greater risk in developing more severe health conditions, and greater risk of discrimination in accessing healthcare services.

The impact of the COVID-19 pandemic on persons with disabilities and individuals with rare diseases was furthermore studied by the International Disability Alliance (IDA)<sup>3</sup>. A survey on the experiences among 600 persons with disabilities worldwide, it was reported that the pandemic has had a devastating impact especially on the mental health of persons with disabilities.

Consultations with IF Members revealed that many individuals with SBH experienced challenges to have access to healthcare services. Multidisciplinary care and access to timely diagnosis and treatment is essential for the management, mental health and wellbeing of individuals with SBH.

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1. United Nations (2020). Policy Brief: A Disability-Inclusive Response to COVID-19.

<https://unsdg.un.org/resources/policy-brief-disability-inclusive-response-covid-19>

2. The International Federation for Spina Bifida and Hydrocephalus. *IF Statement on COVID 19*.

<https://www.ifglobal.org/publications/if-statement-on-covid-19/>

3. The International Disability Alliance (2021). *Survey on the Experience of Persons with Disabilities Adapting to the COVID-19 Global Pandemic*. [https://www.internationaldisabilityalliance.org/sites/default/files/covid-19\\_survey\\_report\\_final.pdf](https://www.internationaldisabilityalliance.org/sites/default/files/covid-19_survey_report_final.pdf)

As highlighted in previous IF publications, serious barriers for individuals with SBH to accessing quality healthcare services and medical devices existed before the pandemic. These barriers hinder the enjoyment of the highest attainable standard of health without the discrimination on the basis of disability as outlined in article 25 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The impact of the COVID-19 pandemic on mental health has been and is widespread and complex. For individuals with SBH there are additional challenges faced during the pandemic. Increased anxiety regarding being able to access quality healthcare is only one example. Other public services, which individuals with SBH rely on, were cancelled, reduced or subjected to restrictions or changes in operation. Including for example social services, education and accessible public transport leaving some individuals with SBH unable to travel for healthcare appointments and intensifying existing social isolation.

In previous years the IF International Youth Group with SBH focused their work on issues relevant to the SBH youth community. Mental health has been one of the emergent topics during the time of the pandemic. To better understand lived experiences by youth with SBH during this crisis, several activities were organized including social media awareness actions, focus group meetings and a survey addressing mental, physical and sexual health. The current report described outcomes of an explorative survey among youth with SBH during times of a pandemic.

# METHODOLOGY & SURVEY RESULTS



youth



## *Survey Development*

The IF International Youth Group with SBH conducted a survey on the topic of mental health. An online survey, SurveyMonkey<sup>4</sup> was used to develop the survey. The survey was developed into five sections: (i) mental health in general; (ii) mental health and friendship, romantic relationship; (iii) mental health and sports, exercises; (iv) mental health and body confidence, self-esteem; and (v) mental health and physical health.

For each of these sections, survey questions were developed based on consensus among the members of the IF International Youth Group with SBH. In total, the survey consisted of 71 questions, including 30 open-ended questions and 41 closed-ended questions. All questions were available in English. Upon request, the survey was made available in Spanish with the support of the Latin American youth group with SBH.

## *Dissemination*

The survey was disseminated by the IF International Youth Group during August 2021. The youth followed a stepwise approach whereby the survey was first shared with member associations they represent; Australia, Germany, India, Ireland, Nigeria, New Zealand, Pakistan, The United Kingdom (UK), The United States of America (USA), Argentina, Chile, Colombia, Costa Rica, Ecuador, Guatemala, Paraguay and Spain.

For participating in the survey, the inclusion criteria were age (18 to 35 years) and language (English and or Spanish).

An introductory email was sent to presidents of each member association including further details of the survey and the request to actively share the survey invitation among youth within their associations.

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4. SurveyMonkey, online survey platform: [www.surveymonkey.com](http://www.surveymonkey.com)



Interested youth followed the link to the survey whereby they also received information on privacy and data handling procedures. In the survey no personal information was asked. Data resulting from this survey will be stored at the IF office and only be used for the purpose of this report and to inform follow-up actions by IF. Participants could leave the survey at any time. Moreover, the option was made available to re-enter the survey at a later moment.

### **Participants**

The participants are 63% female ( $n = 104$ ) and 37% male ( $n = 61$ ) aged between 18 to 35 years (Mean age: 26,5; Standard Deviation: 5,34).

The following diagnosis were reported: Spina Bifida and Hydrocephalus ( $n = 86$ ; 53%); Spina Bifida ( $n = 61$ ; 37%); Hydrocephalus ( $n = 9$ ; 5%); other such as bowel and bladder inconsistency; Meningomyelocele; Depression/bpd/ptsd; Medullary lesion; Spina Bifida occulta and type 3 spinal muscular atrophy; vertebral crush due to an accident ( $n = 9$ ; 5%). With respect to occupation, the majority of participants reported to be students ( $n = 52$ ; 32%), followed by employed ( $n = 49$ ; 29,7%) unemployed due to their disability ( $n = 29$ ; 18%); unemployed and looking for a job ( $n = 26$ ; 16%); or working as volunteer ( $n = 9$ ; 5%).

### **Demographic**

Participants represent 18 countries across four continents. The participants were located in Ireland ( $n = 36$ ; 21,8%); followed by Colombia ( $n = 21$ ; 12,7%), Argentina ( $n = 16$ ; 9,7%), Guatemala ( $n = 15$ ; 9,1%), Chile ( $n = 13$ ; 7,9%), India ( $n = 11$ ; 6,7%), Costa Rica ( $n = 10$ ; 6,1%), Spain ( $n = 10$ ; 6,1%), Australia ( $n = 9$ ; 5,5%), Pakistan ( $n = 7$ ; 4,2%), Nigeria ( $n = 5$ ; 3%), USA ( $n = 3$ ; 1,8%), Ecuador ( $n = 3$ ; 1,8%), Paraguay ( $n = 2$ ; 1,2%), UK ( $n = 1$ ; 0,6%), New Zealand ( $n = 1$ ; 0,6%), Germany ( $n = 1$ ; 0,6%) and an unspecified country in Asia ( $n = 1$ ; 0,6%).

A total of 165 participants participated in the survey of which a total of 54 participants completed the survey. The results will be reported per section: (i) mental health in general; (ii) mental health and friendship, romantic relationship; (iii) mental health and sports / exercises; (iv) mental health and body confidence / self-esteem; (v) mental health and physical health.

## ***Mental Health in General***

In this first section, questions were posed related to a general state of mental health. Questions included for example how youth with SBH feel on a daily basis, coping mechanisms, influencing factors, relation between mental and physical health, and support needed. Total respondents included 63% (104 from the 165). Mental health is an important topic to young persons with SBH. One of the questions was posed to ask participants if having a good mental health is important. This was confirmed by the majority (65,4%). Some respondents even shared how this is the case: *"relevant to enjoy and face life"*. Also, *"Mental health forms the basis of our mood, attitude and character towards the tasks we face each day. The healthier we are mentally, the better we can face these tasks regardless of the hurdles in front."*, Moreover, *"good Mental health is very important in order to be able to manage and live a good life with your disability and lack of motivation"*, *"I believe positive mental health helps people in their daily lives and their physical health"*, and *"if I'm mentally ill, I can't function"*.

The majority felt they do not currently suffer from mental illness (74%). However, some answers did show feelings of depression. Also, some reported to observe specific signs such as eating disorders, anxiety attacks, suicidal thoughts, no motivation, loneliness and sadness.

With respect to mental health related issues, questions were posed to assess sleep and chronic pain challenges with respect to mental health.

To the question do you have sleep problems, 56 (53,85%) of the participants responded “no” and 58 (55,77%) stated that the lack of sleep does not affect their mental health. To the question, do you suffer from chronic pain, 70 (67,31%) participants declared that they don't suffer from chronic pain and 80 (76,92%) participants stated that chronic pain does not affect their mental health. For the 34 participants who declared suffering from chronic pain, 24 of them stated that it affects their mental health. Chronic pain has a huge impact on their motivation, anxiety and their ability to be more aggressive.

Responses showed that during the pandemic, new regulations needed to be followed including social distancing. This increased social isolation of young persons with SBH from their families and friends. Some open answers highlighted these challenges: *“Made it harder as you were socially isolated from your friends and family”*; *“Made me more cautious in my day to day life and has curtailed my social life”*; *“Because of Covid-19 events that I would normally attend were not on so I was very isolated”*.

Youth find their support from informal (e.g., friends, family) and formal environments (e.g., medical support). In general, participants indicated their need for support. In total, 71,15% reported seeking support to improve their mental health. For 58,65% it was reported not to be easy to ask for support. In addition, it was stated there is a need for peer-support; *“having support from people ageing with Spina Bifida and/or Hydrocephalus”* and *“more support and awareness from the no disabled community removing barriers in society”*.

## ***Mental Health and Friendship, Romantic Relationships***

In this second section of the survey, questions addressed mental health and friendship, romantic relationships. Total respondents included 55% (90 from the 165).

Respondents answered general questions as to how they felt during the COVID-19 pandemic. The results differ from person to person. In general, the majority felt alone and isolated (52.22%), half experienced feelings of sadness (50%), less than half felt reflective and thoughtful (44.44%), depressed (35.55%), angry (30%), optimistic (23.33%),

To the question in what way COVID-19 impacted friendships, relationships and ability to go out and meet new people, respondents shared some examples: *"It has stopped me going out socializing and meeting friends and family", "I was stuck in the house a lot and because of restrictions I could not see anyone", "I haven't meet up much with people", "like everyone COVID has put a stop to my social life"*.

This pandemic situation emerged feelings among the youth community with SBH, 52,22% felt alone and isolated, 50% felt sad, 44,44% reflective and thoughtful, 35,55% depressed, 30% angry, 23,33% optimistic, 18,88% empathetic and 15,55% happy.

The support from friends cannot be underestimated. With respect to mental health, youth reported that having friendships is of great importance (64.4%). Friendship was perceived as a relationship between people with a special bond. Within friendships, the youth indicated to seek qualities in friends such as being reliable, loyal, sincere, sharing the same perspectives and interests, respect, honesty, good communication, and a general understanding to "have each other's back". In total 58.9% stated to feel more comfortable in a group of friends sharing similar interests.

Beyond these qualifications, respondents indicated that friends are often preferred above family; *"the go-to persons to discuss mental health issues as sometimes it's not easy to open up to family members"*. Some reasons as to why friends are sometimes better to talk to included: *"I spend time with friends who understand what it's like to live with Spina Bifida"*, *"I feel better with friends who I am able to talk with and spend time with"*, *"friends always help in difficult situations"*, *"friends make us forget things"*.

Making new friends was reported to be difficult. Half of the respondents mentioned it is more difficult to make friends due to having a disability. Several perceptions were shared, including: *"Sometimes people see the disability e.g. wheelchair rather than the person"*; *"as a teen yes, people do not know how to address you and you are not invited places, people a friendlier in college"*; *"able bodied people aren't always as comfortable to communicate with me"*; *"absolutely find it hard to get friends"*.

Within current relationships with friends, youth also indicated difficulties with feeling understood. Some shared their experiences as follows: *"I can't participate in some of their activities"*; *"I feel a lot of them do their own thing and a lot of public places are not accessible for socializing in so I feel isolated at times when it comes to socializing"*; *"I get jealous of family members and some family members refuse to take me places because of the difficulty in getting me around"*; *"many treat me like I can't do anything right"*.

The respondents indicated to feel lonely at times (54.5%). Some examples were shared to overcome such feelings of being alone, including listening to music, traveling, doing things which makes you happy, and *"try to forget that I have a disability"*.

When it comes to having romantic relationships, some respondents are in a romantic relationship, others not, and some never have been in a relationship. For those being in a relationship, some positive thoughts were shared on the disability not having an impact: *"it doesn't. I'm in a long term relationship with someone who doesn't have a disability"*, *"thankfully it doesn't, have a lovely husband"*.

For others, their disability was perceived as a limitation; *“never in a relationship”, “I have never been in a relationship”, “able-bodied people see my disability before my personality”, “I always had a poor body image, so I denied that aspect of my life”, “I have no experience, I just had a relationship and it’s over”, “because of my bladder and bowel incontinence no one finds me attractive. Plus I’m scared of being in a bad relationship”, “lack of confidence”, “so far I do not know why I have never had a partner, but in today’s times they focus more on the physical than on the true feeling”.*

The youth community with Spina Bifida and/or Hydrocephalus often have the feeling of not being wanted, poor body image of themselves, or again are not seen as a potential partner, *“able-bodied people see my disability before my personality”, “I feel people that do not have a disability may not want to go out with somebody that has a disability”,* and therefore don’t risk approaching people.

Interestingly, a difference was observed between men and women. In general, women (37% of women, against 17% of men), indicated more often the perception that their disability affects their relationship and therefore have difficulties in approaching other persons. This was supported by beliefs such as *“I feel people that do not have a disability may not want to go out with somebody that has a disability”,* and therefore don’t risk approaching people.

## **Mental Health and Sports, Exercises**

In this third section of the survey, questions addressed mental health in relation to physical activities. Total respondents included 52% (86 out of the 165).

In total 40.7% indicated to be physically active. In some cases, this was related to the pandemic and in other cases, this had a different reason. *"I was physically active when I swam in a local club but my activity is done since Covid-19 as well as my motivation to do exercise", "I am on my feet most of the day at work then have my poultry to look after so always in the garden pottering about. When it's safe, I will get back to swimming", "playing sports, when quarantine allows it", "I cannot be physically active since I cannot do physical activity by medical order due to my condition", "going outdoors for fresh air, a 10 min push in my chair", "I do workout dance, do housework as much as I can do or it's possible for me".*

Doing sports with other people was not common (32.56%). Some comments reflected the added value of exercising with people without a disability; *"I generally practice with abled people. This gives me a really good level of competition for myself. Also it enables me to think about myself as not being 'disabled' in any way. It motivates me to push myself further", "I prefer to exercise among the general public", "stop putting us into a labelled group".*

The majority of persons responded not to have a gym membership (87.21%). Reasons for this were related to accessibility and costs; *"not accessible and not able"; "too expensive. I'm too tired to go out anywhere. I don't feel motivated/disciplined to make the money worthwhile. I see exercise physiologist at their gym instead", "I use a free rehabilitation center", "there are no gyms in my area"; "because my financial capacity does not allow it"; "my condition of prostate by the wounds of the skin does not allow me", "the last few times I had anxiety attacks because women in their 70s have more physical capacity than me".*

There was also one question related to having personal training with a disability. Nearly 70% responded they never worked with a personal trainer and 52.32% responded they would feel more comfortable to work out with a personal trainer who also has a disability. Reasons for this varied; *“they would have a more of an understanding”, “they would understand my limitations and disability”, “to understand the disability more and understands the limitations more”, “because it would be more personalized”, “because I would have the knowledge of what exercises I can or cannot do”, “probably yes, because he has a notion from his own experience, of our real physical limitations at the time of a physical activity”.*

In addition, questions were posed as to the perception of young persons with SBH to the link between physical activities and mental health. Half of the participants believed being physically active could also improve their mental health. Some respondents gave an explanation as to how sports can improve their mindset such as: *“feel relaxed mind during exercise”, “It's made me have a positive attitude towards life”, “It has helped me realize I can still exercise even when I am at home”, “well, it helps to stimulate our ideas”, “opens my mind”; “because I stay more positive and show myself that I can do things much better”.*

The vast majority (79.17%) answered that you can train your mindset to become more positive. For this several young persons with SBH shared their advice such as: *“By speaking affirmative statements to myself and deliberately thinking things that are positive”, “by focusing on positive things”, “yes I do believe so for e.g. if you have a goal you want to meet. Set small steps for it and it will help you to stay focused and positive to achieve what you want”, “forgiving, having more patience and disposition and also working my spiritual side and concentrating my energies on the good things that God gives us”, “with good professional and family support and a lot of work”, “emotional training through mindfulness has helped me a lot to achieve this”.*



The pandemic also influences routines. Over 50 percent of respondents (55.81%) shared that the COVID-19 affected their daily routines on several occasions. Examples included:

*"I had to be careful when I go out", "no access to my physiotherapist", "I am less active", "it has had a mostly negative impact on my training routine. Swimming pools are closed down and I find it very difficult to exercise at home. Also there is lack of self motivation for doing so as there are no specific goals to achieve as of now".*

To stay active and overcome several challenges during the pandemic, respondents indicated to find new ways to maintain physically active. Examples of alternative activities included: *"brisk walking. This helped me reduce my weight by a great deal", "did yoga on and physical exercises and meditation on Zoom", "I worked out using Zoom and my physical therapist during the pandemic", "doing gymnastics at home with homemade elements", "my partner is a coach and we were lucky enough to do sessions together during lockdown", "using home tools is a good way to exercise".*

### ***Mental Health and Body Confidence, Self-esteem***

In this fourth section of the survey, questions addressed mental health in relation to mental health and body confidence as well as self-esteem. Total respondents included 52% (86 out of the 165).

On a five point scale (one being not at all, five being very high), all respondents indicated their self-esteem and body confidence to be a four, good. The vast majority also indicated self-esteem to be closely related to mental health (70.93%). Self-esteem influences a positive mindset; *"If you look good, you feel good", "I don't like looking at myself and every time I'm around people who have a different body type than me I always want it", "if I'm feeling good about myself I have good mental health and vice versa".*

Some indications were given as to which factors play an important role in one's self-esteem, including some quotes:

*"family, friends, environment", "how you look and how you feel", "upbringing, past experiences what other people say about you, especially family (parents) and people important to you beliefs and what you think you should be/look like", "health, independence and positive appearance", "my mental health is not good, neither will it be", "emotional stability".*

In addition, respondents shared three common factors related to body confidence and or self-esteem. The majority of participants indicated their own perception to be important (65.11%). This was followed by the perception of how other people see them (15.11%). Lastly, the lack of knowledge as to how to improve one's self-esteem (10.45%).

Several suggestions were shared to improve one's self-esteem and mental health. Respondents indicated that it can be done by simple things such as wearing nice clothes (41.86%), telling self-reassuring messages (36.04%), exercising (27.91%) or again getting early, doing activities they enjoy (singing, listening to the music, drawing) (22.09%).

The youth who completed this section of the survey also indicated their body confidence to be influenced by several people in their environment. In total 47.68% of respondents were influenced by their friends, 44.18% by themselves, 39.53% family members, 18.60% partner, 16.28% followers on social media, and 13.95% a mix of the before mentioned.

## ***Mental Health and Physical Health***

In this fifth section of the survey, questions addressed mental health in relation to physical health. Total respondents included 50% (83 out of the 165).

Physical health is closely linked with individuals with Spina Bifida and or Hydrocephalus.

It is therefore not surprisingly 66.26% indicated the important role of physical health. Some shared examples as to why this is the case: *"If u lose your ability to move properly u lose independence", "it's very important to have good physical health to do the simple things e.g. house work, personal care etc", "you can't take care of yourself or continue to live independently if your physical health is bad", "if I am physically well, it seems that everything is going better", "without a good physical condition, I cannot carry out any activity of daily life, so yes ... I have to take care of my physical condition, to be able to do my daily activities".*

In total 67.47% of respondents furthermore mentioned the important aspects of taking good care of their physical health. Some arguments were shared as follows: *"If I am not healthy, I can't do anything", "I had a transplant, a second chance, I need to take care of myself physically", "when I am good on this outside it helps me feel better on the inside", "you have to maintain a good physical condition for a better lifestyle".*

When it comes to taking care of their physical health, the participants stated that eating well, diet, having adequate sleep, taking their medication, following-up with their medical team, staying connected socially and staying connected with their peers was part of their routine to stay healthy physically and therefore mentally.

The relation between mental health and physical health become more clear in an open question asking about the connection between these two concepts. In general, answers reflected that these two concepts are interrelated. Some responses included: *"Happy body, happy mind"*, *"good physical health enhances your mental health"*, *"if you feel good on the outside, you feel more positive inwardly"*, *"mental health can cause disturbances that affect physical health and certain physical conditions have symptoms of mental illness"*, *"fully related"*.

To the question how these two concepts of mental and physical health are interrelated, respondents shared example situations on how they cope with physical health having an impact on their mental health, including: talking to someone they trust (53.01%), seek support from a mental health professional (26.51%), meditate (10.84%), and other things (9.64%; *"sleep"*, *"listen to idols"*, *"turn to someone who can listen"*).

Similar to the previous section, the pandemic influenced daily routines. With respect to physical health this implicated accessing physical therapists and going to the pool to exercise. When the pandemic forced restrictions on people, respondents indicated they were unable to go outside for a walk. Similar to the earlier mentioned challenges, this required alternative ways to stay active. Respondents indicated online exercises and small walks in the garden allowed for them to remain physically active.

As a final question, respondents were asked to share their recommendation to empower other youth with SBH to keep mentally and physically healthy in times of the pandemic. Their advices were as follows: *"Listen to your body"*, *"work with peers"*, *"do what you can to make you feel better and proud of yourself"*, *"don't be afraid to ask for help"*, *"don't look down on yourself even when it seems the world is against you. Seek help, seek faith"*, *"let them see the beauty in every moment of life and be grateful"*, *"be yourself without looking at what others say or what others want from you"*.

# CONCLUSIONS AND RECOMMENDATIONS

The current study explored mental health implications of the COVID-19 pandemic on youth with SBH. The results from this study reflect the importance of several mental health related topics, including the role of friendships, sports and exercises, body confidence and self-esteem, and physical health. Some major implications in times of a pandemic related to mental health related challenges included: social isolation, having good friends and being able to talk to family members, being able to be physically active, having access to healthcare professionals, rely on peer support, and strengthen one's self-esteem and confidence.

The results from this study confirm conclusions made by the International Disability Alliance in an earlier published report on experiences of persons with disabilities adapting to the COVID-19 pandemic.<sup>5</sup> The outcomes of the current study highlight the breakdown of communication, social support, and peer networks because of social distancing. It is clear the COVID-19 pandemic affected mental health related issues among youth with SBH in several ways. This has serious repercussions for the physical and mental health of those affected as well as participating in society on an equal basis with other.<sup>6</sup>

The impact of the COVID-19 pandemic on mental health has been and is widespread and complex.<sup>6</sup> The current explorative study provides a rare insight into the experiences of youth with SBH during the pandemic. The findings show a need for continued support during and after the COVID-19 pandemic.

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5. The International Disability Alliance (2021). Survey on the Experience of Persons with Disabilities Adapting to the COVID-19 Global Pandemic. [https://www.internationaldisabilityalliance.org/sites/default/files/covid-19\\_survey\\_report\\_final.pdf](https://www.internationaldisabilityalliance.org/sites/default/files/covid-19_survey_report_final.pdf)

6. The International Federation for Spina Bifida and Hydrocephalus. IF Statement on COVID-19. <https://www.ifglobal.org/publications/if-statement-on-covid-19/>

In a previous report conducted by the IF International Youth Group with SBH, the important aspects of body awareness, confidence, and mental health were reported in relation to sexual health.<sup>7</sup> The outcomes of the current explorative study highlight the intersectionality between mental, physical, and sexual health. It is therefore worthwhile to explore these concepts further.

To address these needs, the IF International Youth Group with SBH continue their awareness raising activities, collaborate with youth from different disability organizations, organize digital meetings to connect and share best practices with youth around the world, and develop advocacy materials.

For example, during international awareness days relevant to youth with SBH (e.g., International Youth Day, World Spina Bifida and Hydrocephalus Day), activities are organized to showcase strengths of youth with SBH and to improve understanding of concepts youth with SBH may experience such as mental health. Moreover, through representative positions in youth committees and collaboration with youth from other NGOs, the youth continue their advocacy and develop meaningful partnerships.

In conclusion, the results of the survey showed a variety of mental health related needs during the COVID-19 pandemic. This report moreover provided insights to the diversity of needs among youth with SBH. To provide a better understanding of the consequences of this pandemic both in the context of pre-existing barriers and the need for targeted actions in order to minimize the long-term impact of an emergency, the IF International Youth Group with SBH provides the following recommendations.

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7. 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>

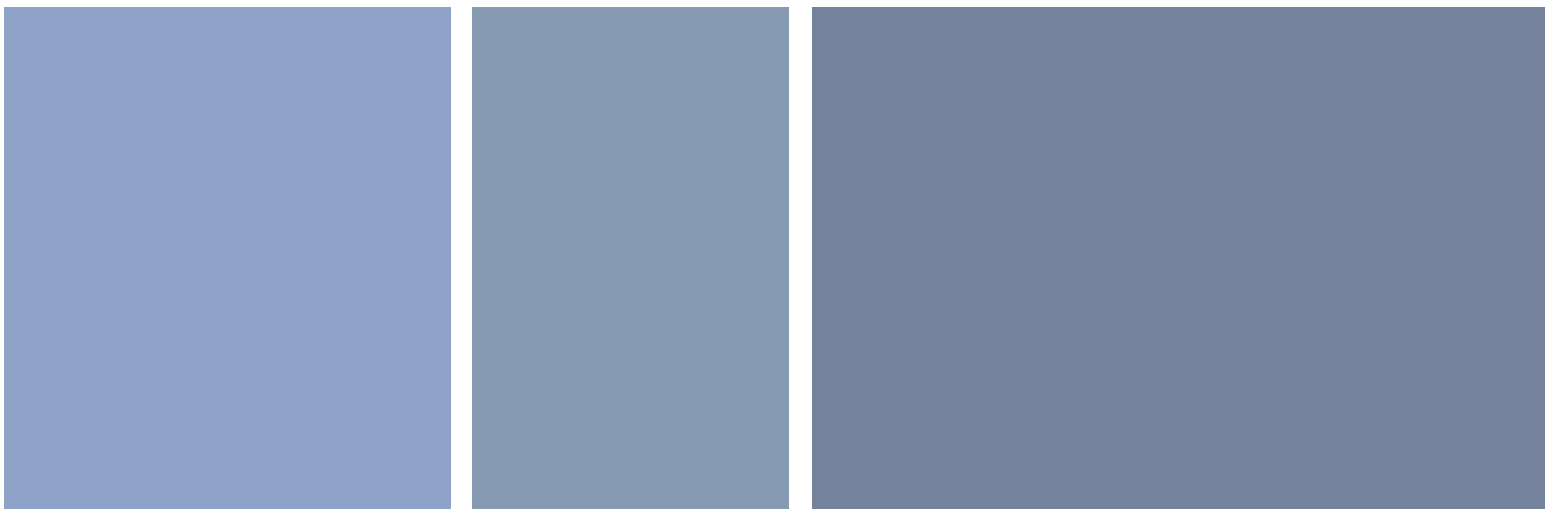
It is recommended for:

- Policy makers, healthcare service providers and professionals to explore and understand the interconnectivity between physical health and mental health for persons with SBH.
- Policy makers to ensure that the specific needs of the SBH community are addressed in the social and economic recovery from the COVID-19 pandemic. With a particular focus on the effects of social isolation, access to health and social care services and the disproportionate impact on the mental health of persons with SBH.
- Policy makers and other stakeholders to raise awareness and understanding of the effects of inaccessibility of the built environment, transport and other barriers on the mental health, social isolation, physical activity and health of persons with disabilities including SBH.
- Policy makers, healthcare service providers and professionals, IF member associations, and other relevant stakeholders to facilitate access to peer support and raise awareness of the need and benefits of peer support for youth with SBH.
- All relevant stakeholders to take action to increase awareness and actions taken to tackle the societal stigmas surrounding disability, SBH and mental health.

This report was prepared by the IF International Youth Group with SBH including the following members: Marcus Ward (Ireland), Rebecca Austin (Australia), Parth Hendre (India), Elisa Garcia de Ceca (Spain), Cillian Dunne (Ireland), Patrícia Albertová (Slovakia), Malik Armughan Ali (Pakistan), Mirela Bukovac (Croatia), Rereloluwa Jesulayomi (Nigeria), Saad Mouhdi (Morocco), Opeyemi Samuel (Nigeria).

They dedicated their time and energy to develop and disseminate the survey on mental health and discuss the outcomes, in order to investigate the needs of the community of young people living with SBH in communities across the world.

Last but not least, IF would like to acknowledge the generous support and sponsorship of the European Commission DG Employment, Social Affairs, and Inclusion who funded this report.





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