

## IF Statement on COVID-19

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 (SBH) 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. In this statement, the International Federation for Spina Bifida and Hydrocephalus (IF) outlines how the COVID-19 pandemic has affected the global SBH community. Furthermore, recommendations are formulated for greater disability and SBH inclusion in the actions aimed to tackle this ongoing crisis and its recovery.

One of the key essential services disrupted by the pandemic were healthcare services. Multidisciplinary care and access to timely diagnosis and treatment is essential for the management, mental health and wellbeing of individuals with SBH. As highlighted in previous IF publications<sup>2</sup>, 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 discrimination on the basis of disability as outlined in article 25 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD). IF Members have reported to IF that access to healthcare was made even more difficult due to COVID-19, with operations and healthcare services that were determined to be 'non-emergent' often cancelled and/or postponed. This has serious repercussions for the physical and mental health of those affected as non-emergent care does not equate to non-essential care. The consequences of not being able to access treatment in a timely manner, or not having access to any treatment at all, include worsening symptoms of SBH and comorbidities, development of preventable comorbidities and symptoms, higher risk of needing more invasive treatments later on and increased social isolation due to worsening health. These consequences cannot be addressed without targeted actions to compensate for the period of reduced and cancelled services.

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<sup>1</sup> Policy Brief: A Disability-Inclusive Response to COVID-19. *United Nations*. May 2020: <https://unsdg.un.org/resources/policy-brief-disability-inclusive-response-covid-19>

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

IF would also like to emphasise that it is not only those individuals who are directly affected by these disruptions in services which feel the impact. Consultations with IF Members also revealed that many individuals with SBH experienced anxieties about having to access healthcare services during the COVID-19 pandemic. Fearing that the healthcare system would be unable to provide the services that they needed or even deny them care on the basis of disability. This fear of discrimination was in part fuelled by a lack of information from governments, uncertainties whether individuals with SBH were more vulnerable to COVID-19 and stigmatising narratives that downplayed the severity of the pandemic with the false justification that COVID-19 is only dangerous to older persons and persons with disabilities. It cannot be accepted, regardless of circumstances, that persons with disabilities and rare diseases are discriminated against when accessing healthcare. This is not only a grave injustice but also a violation of article 25 of the UNCRPD. Nor is it acceptable that during a crisis where citizens need to rely on accessible and reliable communications from governments, healthcare professionals and political leaders that the rhetoric and lack of disability specific information create an environment where individuals with SBH and their families begin to fear that they are likely to be denied medical treatment.

The impact of the COVID-19 pandemic on mental health has been and is widespread and complex. However, the example provided above highlights the additional pressures individuals with SBH have faced during the crisis. 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. For some individuals with SBH the increase in remote learning and working has improved accessibility and eased access to reasonable accommodations. For others this has compounded the social isolation experienced by many in the SBH community especially when coupled with prolonged self-shielding. For parents of children with SBH closure of schools and other forms of healthcare and education came with additional challenges. Finding alternative childcare that is accessible and able to meet the needs of children with SBH to replace childcare professionals or extended family who had to self-shield, quarantine or shut down operations due to COVID-19 can be extremely difficult if not impossible. This in turn has a disproportionate impact on the parents' employment, financial stability, mental health and wellbeing of the family. The economic impact on communities has been extensive, with many experiencing loss of employment and income. Those individuals who were already facing difficulties in finding and remaining in employment, such as individuals experiencing ageing with SBH<sup>3</sup>, are now facing the dual challenge of navigating discrimination, including intersectional discrimination, in a labour market which is struggling. This highlights how important it is to understand the impact of the COVID-19 pandemic in the context of pre-existing inequalities in our communities.

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<sup>3</sup> Ageing with Spina Bifida and Hydrocephalus a Descriptive Analysis. *International Federation for Spina Bifida and Hydrocephalus*. October 2020: <https://www.ifglobal.org/publications/if-report-ageing-with-spina-bifida-and-hydrocephalus-a-descriptive-analysis/>

Considering the impact of such policies, IF strongly recommends that governments fully take into account the wide-reaching consequences of these actions before resorting to them. However, IF Members report that the impact on the rare diseases and disability communities including on individuals with SBH was not adequately accounted for in the policies. That restrictions in local healthcare services were at times even taken as a pre-emptive preparation for a wave of COVID-19 cases which did not always come to fruition in that particular area. In addition, IF Members have also brought to the attention of IF that these sacrifices were not distributed equally in their communities. In some cases, it was only the public health system which was utilised to combat the COVID-19 pandemic. Those individuals who could afford private healthcare and hospitals were still able to seek treatment.

IF Member Associations, in particular national SBH organisations, played an integral part supporting their community during this crisis. Providing a wide range of services including psychosocial support to combat social isolation and information and educational materials to help with remote learning. Condition-specific organisations such as IF's Member Associations possess expert knowledge, not only of the conditions themselves, but also of the local services and solutions available to individuals with SBH and their families. In addition, uncertainties in the early months of the crisis regarding vulnerability towards the effects of COVID-19 left some individuals with SBH in a legal grey area regarding employment. This is because only those individuals with conditions identified as being high-risk were eligible for financial assistance for temporarily leaving employment to self-shield. As SBH is a complex rare condition which requires multidisciplinary care, there was very little information on whether SBH or its common comorbidities necessitated self-shielding. In those instances, many local and national SBH associations played an enormous role in liaising with medical professionals specialised in SBH to communicate to individuals with SBH and their families of the latest medical opinion regarding COVID-19 and SBH.

The COVID-19 pandemic revealed the invaluable public service that patient, rare disease and disability organisations provide. IF Member Associations liaised with specialist medical professionals in the field of SBH to provide individuals with SBH and their families with information on the impact of COVID-19 on SBH. In addition, IF Member Associations were active on the local and national level in monitoring the actions taken by their government to address the COVID-19 crisis and taking action, advocating and raising awareness where governments failed to adhere to the UNCRPD. By doing so IF and its Member Associations have contributed to the implementation and adherence of the UNCRPD worldwide. It is therefore regrettable that these valuable contributions and public services provided by IF Member Associations have gone unheeded and unsupported.

Moving forward, COVID-19 has revealed the urgency for transforming policy and decision making on the local, regional, national and international level. To understand the consequences of crises such as the COVID-19 pandemic both in the context of pre-existing barriers and the need for targeted actions in order to minimise the long-term impact of an emergency. IF presents here its recommendations for a disability and SBH inclusive COVID-19 recovery.

## Recommendations:

- IF calls on policy makers to investigate the impact of the COVID-19 pandemic on persons with disabilities and individuals with rare diseases. Including impact on access to essential services, employment, education as well as the effect of the pandemic on existing socio-economic inequalities, social exclusion, isolation and mental health. In order to identify the targeted actions needed to address the effects of the pandemic on these groups.
- IF calls on policy makers to consult with persons with disabilities, their representative organisations and patient organisations on all policies relevant to them as per the UNCRPD. This is especially important for the COVID-19 recovery.
- IF calls on policy makers to put processes in place to consult persons with disabilities, their representative organisations as well as patient organisations when taking action and putting policies in place to address an acute crisis such as COVID-19.
- IF calls on policy makers to investigate to what extent Article 25 and Article 11 of the UNCRPD were adhered to during the COVID-19 pandemic and put in place actions to ensure the full implementation of the UNCRPD.
- IF calls on policy makers and healthcare service providers to heed the lessons of the COVID-19 pandemic and work to strengthen healthcare systems including by developing and strengthening multidisciplinary care and mental health and to work towards eradicating the barriers to access which existed before the COVID-19 pandemic.
- IF calls on policy makers to actively work to address stigma against persons with disabilities as per article 8 of the UNCRPD.
- IF calls on policy makers to take steps to improve the communications and public information made available during a time of crisis with a focus on ensuring that marginalised groups and individuals with additional needs such as disabilities and rare conditions are able to easily access information relevant to their situation.
- IF calls on policy makers to support national and regional disability and patient organisations, providing them with the resources needed to maintain and build their capacities in recognition of the vital public services they provide to their communities during the COVID-19 pandemic. Public services which authorities often struggled to provide to specific patient groups especially those with rare conditions such as SBH.

## 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.

### **IF ivzw**

**International Federation for Spina Bifida and Hydrocephalus**

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