**15** **February 2023**

**IF Response to the Committee on the Rights of Persons with Disabilities call for written submissions for the preparation of a general comment on persons with disabilities in situations of risk and humanitarian emergencies**

The International Federation for Spina Bifida and Hydrocephalus (IF) welcomes the proposal by the Committee on the Rights of Persons with Disabilities to draft and adopt a general comment on persons with disabilities in situations of risk and humanitarian emergencies (article 11 of the Convention on the Rights of Persons with Disabilities). Spina Bifida and/or Hydrocephalus (SBH) are conditions which require life-long access to multidisciplinary[[1]](#footnote-1) specialised health care and support services. In addition, there are very strong linkages between the prevalence of SBH and social determinants of health. With low income communities and countries experiencing much higher prevalence of Neural Tube Defects (NTDs) including Spina Bifida. This is due to the fact that maternal deficiency of vitamin B9 (also referred to as folic acid or folate) contributes to a higher risk of an NTD developing during the early stages of a pregnancy.[[2]](#footnote-2) Consequently, the very communities which are at higher likelihood of experiencing situations of risk and humanitarian emergencies are also more likely to have a high prevalence of SBH. Subsequently, the provision and implementation of article 11 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) is vital for the protection of the SBH community. This is especially the case for new-borns and children with SBH as they require immediate specialist medical care to ensure survival and long-term prosperity.

IF would like to comment on section four in the provisional outline for a draft General Comment on persons with disabilities in situations of risk and humanitarian emergencies “Interactions with other articles of the Convention”.

Article 25 of the UNCRPD establishes that State Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. IF recommends that the General Comment on article 11 makes a very strong connection with article 25 as access to health care forms one of the most urgent and basic needs all persons require for survival and wellbeing. Persons with disabilities, including persons with SBH, are more vulnerable when access to health care is severed due to a crisis.

IF, in its work with members of the SBH community who are in situations of risk and humanitarian emergencies has identified serious and life-threatening challenges in accessing health care services needed by the SBH community specifically because of their disabilities, including services designed to minimize and prevent further disabilities (Article 25(b)).

Disability should never be considered synonymous with high or complex health care needs. However, it is vital that in the implementation of article 11 of the UNCRPD that State Parties, and other relevant actors who provide assistance and humanitarian aid in situations of risk and humanitarian emergencies, understand and account for the fact that persons with disabilities are more likely to have complex health care needs or be a person with a rare condition. Subsequently, they may require assistance, supplies and services which are not as common among the general population and therefore not always included in standard humanitarian relief supplies and efforts. For example, access to catheters, mobility aids or urgent specialised neurosurgical care.

An example of the SBH community in a situation of risk and humanitarian emergency which demonstrates these challenges concretely is the impact on the SBH community in Ukraine following the invasion by Russia. Since the conflict began IF has been in strong contact with IF Members and partners (representing a network of approximately 20 children hospitals) in Ukraine. IF has monitored and continuously identified the needs and priorities of the SBH community and taken measures to provide support. Despite many admirable international humanitarian actions there is still a strong need for an expansion of existing programs for medical supplies and clinical support to reach as many children in need as possible.

There is an opportunity to strengthen clinical practices for children with SBH on urological matters as well as surgical matters related to hydrocephalus. For example, with respect to paediatric urology there is a need to strengthen knowledge and expertise around different treatment options rather than only sending catheters. Access to expertise, especially for rare conditions, is an important component to healthcare and support necessary to meet the objectives of article 25(b) of the UNCPRD. A component which is often severed or reduced when a crisis begins. IF has supported the SBH community by setting steps towards the development of training modules with hybrid possibilities for priorities for the short and longer-term.

These experiences of the SBH community reflect how persons with disabilities, in particular those with rare conditions, often experience a crisis within a crisis. The initial humanitarian crisis cuts off access to specialised health care, knowledge and supplies. The response to the crisis, be it evacuation to safer areas or the distribution of aid and supplies, then frequently do not account for the medical needs of persons with disabilities, in particular persons with rare conditions. This is particularly dangerous for new-borns and children with SBH as both conditions require urgent specialised surgical interventions as soon as they are identified, without which the new-born or child is unlikely to survive. The failure to account for the principles of article 25(b) in the implementation of article 11 creates imminent risks to the safety and lives of persons with SBH.

IF therefore urges the Committee on the Rights of Persons with Disabilities to connect in its General Comment on persons with disabilities in situations of risk and humanitarian emergencies (article 11 of the UN Convention on the Rights of Persons with Disabilities) the duty of State Parties to take necessary measures ensure the protection and safety of persons with disabilities in situations of risk with the obligations set out in article 25(b) of the convention.



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

*Consultative status special category Economic and Social Council at the United Nations*

Cellebroersstraat 16 - B-1000 Brussels

T: +32 (0) 471 84 41 54 | E: info@ifglobal.org

www.ifglobal.org



1. International Federation for Spina Bifida and Hydrocephalus, “IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus” (2021): Accessed February 2023: <https://www.ifglobal.org/publications/if-statement-on-multidisciplinary-care-for-spina-bifida-and-hydrocephalus/> [↑](#footnote-ref-1)
2. International Federation for Spina Bifida and Hydrocephalus, “IF Statement A call for a global action to reduce the prevalence of Neural Tube Defects worldwide” (2022): Accessed February 2023: <https://www.ifglobal.org/publications/if-statement-a-call-for-a-global-action-to-reduce-the-prevalence-of-neural-tube-defects-worldwide/> [↑](#footnote-ref-2)