

IF Statement on Conflict and Humanitarian crisis

Introduction

The International Federation for Spina Bifida and Hydrocephalus (IF) calls for a greater awareness and urgent action towards the needs of persons with Spina Bifida and Hydrocephalus (SBH) in time of conflict and humanitarian crisis. According to the Office of the High Commissioner for Human Rights (OHCHR), a humanitarian crisis includes man-made conflict, natural disasters, or pandemics – or all of them. This raises concerns on human-rights and exacerbates pre-existing human rights vulnerabilities, especially for persons with disabilities ⁽¹⁾.

Ensuring an independent and healthy life for individuals with SBH requires a full realisation of their human rights. It is particularly important to provide us protection, and access to inclusive multidisciplinary care while supporting our families and carers. This can only be achieved through the full implementation and adherence to the United Nations Convention on the Rights of persons with disabilities (UNCRPD).

The United Nations (UN) recently released a global survey report on Persons with Disabilities and Disasters ⁽²⁾. In this report, key findings are reported such as the lack of preparedness among 84% (5,322 out of 6342 respondents) and exclusion of participation in community-level disaster risk reduction (DRR) decision-making and planning among 86%.

In this statement, attention is given to (1) the main obligations from the UNCRPD to be applied by the States Parties (countries and regional organisations that ratified the UNCRPD) during conflicts and humanitarian crises; (2) how conflicts and humanitarian crises have an impact on the lives of persons with SBH; (3) why it is necessary to adopt an effective rights-based approach for implementing plans to protect persons with SBH; and (4) IF's recommendations to respect the obligations held by Article 11 of UNCRPD.

Obligations under the UNCRPD

When a conflict or a humanitarian crisis arises, the States Parties are obligated to protect the rights of persons with disabilities as outlined by the UNCRPD. In particular, Article 11 of the UNCRPD binds the States Parties to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters ⁽³⁾.

In addition to this article, the UNCRPD establishes other obligations: equality and non-discrimination (Article 5), accessibility (Article 9), the right to life (Article 10), freedom from torture or cruelty, inhuman or degrading treatment or punishment (Article 15) and health (Article 25). Persons with SBH already face barriers to independent living in the form of access to health care services, necessary support, and education. These struggles only worsen in times of conflict or humanitarian crisis.

Areas where the rights and needs of persons with SBH must be safeguarded and applied during conflicts and humanitarian crises

For an inclusive disaster preparedness, protection, access to healthcare service, food, and safety ⁽⁴⁾, the involvement of persons with disabilities, including those with SBH, in building actions plans for reducing the risks of disasters is necessary. This lack of inclusivity leads to systemic discrimination and a lack of food, safety, and healthcare which further exacerbates our pre-existing challenges. Below, three example areas are described where our rights and needs have to be safeguarded and applied during conflicts and humanitarian crisis.

Pandemics

Communities across the world experienced short-term and long-term effects of the COVID-19 pandemic, which has deepened pre-existing inequalities in our societies ⁽⁵⁾. As described in the previous IF statement ⁽⁶⁾, our members across the world have encountered new and additional barriers during these difficult times. 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 mental health, and our wellbeing. This statement reported that access to healthcare was made even more difficult due to COVID-19, with operations and healthcare services that were determined to be 'non-urgent' often cancelled or postponed. This has serious repercussions for the physical and mental health of those affected as non-urgent care does not equate to non-essential care.

As highlighted above, serious barriers for us 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 (UNCRPD).

The impact of the COVID-19 pandemic on mental health has been and is widespread and complex. However, the additional pressures we have faced during the crisis is evident. Increased anxiety about being able to access quality healthcare is only one example. Other public services, on which we rely on were cancelled, reduced, or subjected to restrictions or changes in operation. Including for example social services, education, and accessible public transport, which left some of us unable to travel for healthcare appointments and intensified existing social isolation.

This pandemic 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 to minimise the long-term impact of an emergency. IF provided recommendations in its previous statement for a disability and SBH inclusive COVID-19 recovery.

Wars and conflicts

As stated by the United Nations ⁽⁷⁾, it is estimated that of the 235 million people who need humanitarian protection and assistance in 2021, 35 million are persons with disabilities. Of the 79.5 million people who have been forcibly displaced as a result of conflict, persecution, and human rights violations, approximately 12 million are persons with disabilities. For us who are living in, or fleeing from, conflict zones, displacement is a complicating factor that poses numerous threats to our physical, mental health

and well-being, further aggravating existing disabilities or leading to secondary ones. The (UN) recommends including persons with disabilities for monitoring any progress in their protections during conflicts and crises; to strengthen the cooperation and coordination between different stakeholders related to the humanitarian assistance; to ensure our participation, women and girls included, and our organisations for adopting a human rights-based approach to promote an inclusive protection and our safety.

A report by the United Nations Special Rapporteur on the rights of persons with disabilities ⁽⁸⁾, underlines the importance of adhering to the guidelines of the UNCRPD, and the resolution 2475 of the United Nations Security Council of 2019 for defending the rights of persons with disabilities within the context of armed conflicts. States Parties are asked to include the reference of UNCRPD and Resolution 2475 in their military manuals. In the same report, the Rapporteur insisted that any humanitarian action should ensure disability-inclusive programming in all aspects.

In addition to the rights stated by the UNCRPD, the Security Council adopted, the Resolution 2475 ⁽⁹⁾ on the protection of persons with disabilities in conflict in 2019. Article 11 of this Resolution notably urges States Parties to comply with the obligations applicable to us with the UNCRPD.

At the European level, the European Commission's 2021-2027 action plan on integration and inclusion ⁽¹⁰⁾ mentioned that migrants with disabilities may face discrimination. It stressed the special educational needs of children with disabilities and also pointed to the difficulties migrants with disabilities face in accessing the labour market. During armed conflicts, our needs, and vulnerabilities are amplified, as is the risk of discrimination towards us. The European Commission's Civil Protection and Humanitarian Aid Operations department published operational guidelines on disability inclusion ⁽¹¹⁾. Their purpose is to ensure that the needs of disabled people are taken into consideration in all projects supported by EU humanitarian aid.

The European Disability Forum (EDF) notably reported that persons with disabilities lack accessible shelters or humanitarian corridors, information, and healthcare services ⁽¹²⁾. This is often associated with discrimination, exclusion, and difficulties accessing food, clean water, sanitation, and hygiene. For us with SBH, from childhood to advanced old age, the struggle is evident as our access to healthcare, mobility, and sanitary services are not adapted for us in this context. The International Disability Alliance (IDA) also shared a report on the refugees with disabilities ⁽¹³⁾, which offering a similar overview of the challenges we face. These two organisations recommend ensuring accessible shelters and services, to provide clear and accessible communication and information while involving us and -our organisations in the establishment of humanitarian support.

Climate change

Climate change is undoubtedly a threat for persons with disabilities as a most pressing humanitarian issue ⁽¹⁴⁾. According to the OHCHR ⁽¹⁵⁾, persons with disabilities are often among those most adversely affected in an emergency, sustaining disproportionately higher rates of morbidity and mortality, and at the same time being among those least able to have access to emergency support. The impact of extreme events on us is amplified by responses that do not consider our specific needs.

Climate change has different elements that impacts our lives. Both sudden or slow natural disasters endanger our access to food and nutrition, safe drinking water and sanitation, health-care services, and medicines, education, and training, adequate housing, and access to decent work ⁽¹⁶⁾.

An article by the EDF on climate change, emphasised the lack of involvement of public authorities regarding the inclusion of persons with disabilities in their plans to face the consequences of climate change ⁽¹⁷⁾. As stated in its statement on multidisciplinary care ⁽¹⁸⁾, since persons with SBH require regular access to healthcare services, IF reminds that access to healthcare and its multidisciplinary care essential to be considered when making climate action plan for the population.

For us, the climate change can complicate the implementation of primary prevention regarding the prevalence of neural tube defects (NTDs) worldwide as it requires a safe production of the micronutrient, vitamin B9. A 15 years of impact statement by Smarter Futures ⁽¹⁹⁾ demonstrated how food fortification of staple foods with micronutrients, such as folic acid, is one of the most cost-effective, and easiest ways to ensure that most pregnant women receive sufficient micronutrients. The intake of micronutrients is especially important for facilitating human rights on primary prevention for NTDs such as Spina Bifida.

To further emphasize the importance of food fortification, a statement by IF ⁽²⁰⁾, encompassed various critical aspects related to NTDs, and how social determinants of health affected them. The document also discussed the concept of food fortification, detailing its critical role in reducing the prevalence of NTDs. Moreover, it highlighted the economic advantages associated with food fortification compared to healthcare costs incurred by us. The statement identified the essential role of global effort towards implementing mandatory fortification of staple foods with folic acid which aids primary prevention within the context of disability rights. It underscored the necessity for an effective rights-based approach in preventing NTDs and concluded by presenting recommendations from IF on achieving a worldwide reduction in NTD prevalence through food fortification.

Following the important recommendations of food fortification in facilitating human rights on primary prevention of NTDs such as Spina Bifida, on the 30 May 2023, the World health Assembly has issued a resolution, WHA76.19 resolution ⁽²¹⁾, titled, *“Accelerating efforts for preventing micronutrient deficiencies and their consequences, including spina bifida and other neural tube defects, through safe and effective food fortification”* urges member states to recognise the importance of, and promote food fortification of micronutrients, such as folic acid using staple foods. Due to the complications caused by climate change in implementing adequate food fortification, this resolution becomes increasingly important, and urges global action by member states.

The OHCHR ⁽²²⁾ recommends involving persons with disabilities and supporting organisations in climate action at all levels. In this regard, there are developed tools such as the Inter-Agency Standing Committee Guidelines on the inclusion of persons with disabilities in humanitarian action ⁽²³⁾ and the United Nations Disability Inclusion Strategy ⁽²⁴⁾.

Several publications describe different ways to reach a disability-inclusive approach to climate change. For example, in a technical brief the European Disability Forum (EDF) shared a short guidance in which some efficient activities were presented ⁽²⁵⁾. Activities include: implementing a national adaptation plan which includes specific obligations with respect to persons with disabilities and other vulnerable groups, such as: the promotion of user-friendly, climate smart technologies, and support for the development and dissemination of simplified meteorological and agrometeorological information. This encourages creating a national adaptation plan that highlights our vulnerability to risks and hazards from climate change.

In another example by the International Labour Organisation, in its Just Transition Policy Brief ⁽²⁶⁾, practices from employment were shared. Such as: conducting a human rights impact assessment in legislative reforms and amending the Climate Act to include and take into consideration the rights of persons with disabilities both in the consultation phase and in the impact assessment; different companies in the world mixed their sustainability policy with a positive social impact by recruiting persons with disabilities, who then can be active actors for the climate transition; an international project enabled women with disabilities in rural areas to have a training for doing a climate-smart agriculture.

Lastly, the OHCHR, in its analytical study on the promotion and protection of the rights of persons with disabilities in the context of climate ⁽²⁷⁾ change, shared a list of good practices as well: at the legal level, some laws were adopted on the rights of persons with disabilities which guarantees us a barrier-free legislative environment based on equal opportunity, equality and non-discrimination, including in relation to climate change protection; for concrete actions against climate change, there are plans that requires information to be provided on the measures taken to protect persons with disabilities. It further requires persons with disabilities to be prepared and instructed on disaster risk reduction and included in evacuation plans, and that shelter and assistance units be available and accessible to persons with disabilities during disasters and emergencies. The OHCHR also mentioned the fact that in some places, it is recognized that persons with disabilities are more vulnerable during emergencies, this indicates it is necessary to devise specific actions plan for us. A work programme has also been created for climate adaptation that identifies relevant action areas for working with health and climate change. Persons with disabilities are included as a group particularly at risk for health problems or death in relation to increasing temperatures. An intersectoral technical health commission has made efforts to identify the specific requirements of persons with disabilities as part of its preparations for environmental threats and disasters.

Despite these positive actions, persons with SBH are still left behind in numerous countries. The OHCHR reminds in its analytical study that persons with disabilities are at greater risk due to climate change. Risks to discrimination and a violation to the principles of the UNCRPD requires action towards the needs of persons with SBH in time of conflict and humanitarian crisis. It is necessary to use an intersectional perspective regarding the broad range of needs and backgrounds we have when supporting us within a climate-change action. Besides, the UNCRPD is a legal framework to be applied and not merely mentioned: our rights during a climate crisis remain the same and must not be neglected.

The need for global action

The International Federation for Spina Bifida and Hydrocephalus calls for a greater awareness and urgent action towards our needs to ensure our protection and safety in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters. Moreover, the climate change has a particular consequence for ensuring the implementation of food fortification. Yet, it is vital to tackle micronutrient malnutrition in a warming world. Even when there is no conflict or humanitarian crisis, we already cope with difficulties related to the lack of accessibility, access to the healthcare services and the challenges to build and maintain an independent life. These difficulties worsen when a conflict or a humanitarian crisis arise. Pandemics, armed conflicts, or climate change should not be used as an excuse or a reason for not ensuring our safety, which constitutes a discrimination and a violation to the principles of the UNCRPD. Existing frameworks such as the Sendai Framework for Disaster Risk Reduction ⁽²⁸⁾ as promoted by the UNDRR ensures a disability-inclusive disaster risk reduction. In addition, IF shares the following recommendations to ensure our rights and needs are safeguarded and applied during conflict and humanitarian crisis.

Recommendations

- IF calls on policy makers to respect the principles of the UN Convention on the Rights of Persons with Disabilities during conflicts and humanitarian crisis, as stated by Article 11.
- IF calls on public authorities to provide medical supplies and clinical support to many persons with SBH in need as soon as possible in case of risk and humanitarian emergencies.
- IF recommends public authorities and partners to organise actions and initiatives in collaboration with persons with SBH and supportive organisations. This entails aligning actions and initiatives with the obligations outlined in Article 25(b) of the Convention to safeguard and ensure the safety of individuals with disabilities during times of risk.
- IF recommends that SBH associations and our partners organise a raising-awareness campaign to ensure that local, national, European, or international decision-makers include the needs of persons with SBH when conducting plans for protecting the population in case of humanitarian emergencies and crises.
- IF calls on policy-makers to implement early preventive measures that have a comprehensive approach on the needs of individuals with SBH, including our physical, material, and psychological needs, and well-being.
- IF calls on public authorities to focus on capacity building and on strengthening participation across different demographics and through various crises such as pandemics, wars, and climate change. Sharing resources with organisations that aid persons with SBH during humanitarian crisis is vital.

- IF calls on policy makers to keep in mind that persons with disabilities, and especially those with SBH, are part of a diverse community, whose needs covers a broad range of areas. Therefore, any action planned for supporting us during a humanitarian crisis requires their involvement. With them and our representative organisations, inclusive solutions can be proposed to the benefit of everyone.
- IF calls on policy-makers, health authorities and healthcare professional to ensure a primary preventive action for the prevalence of neural tube defects and hydrocephalus while considering the challenges caused by climate change.

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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.

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