Response to the call for inputs by the UN Special Rapporteur on the Rights of Persons with Disabilities.

Implementation of inclusive humanitarian assistance and safeguards for the rights of persons with disabilities in the context of current humanitarian reform processes.

Introduction

The International Federation for Spina Bifida and Hydrocephalus (IF) welcomes the opportunity to contribute to the Special Rapporteur on the rights of persons with disabilities' report on inclusive humanitarian assistance. IF represents persons with spina bifida and hydrocephalus (SBH) and their families worldwide through its 110 Member Associations in 88 countries. Persons living with SBH experience lifelong, complex medical, mobility, cognitive, and psychosocial needs, underscoring the critical importance of inclusive, accessible, and rights-based humanitarian action.

Persons with disabilities, particularly those with SBH and other complex and lifelong health conditions, face disproportionate risks during emergencies, including armed conflict, natural disasters, pandemics, and forced displacement. Ensuring an independent and healthy life for persons with SBH requires not only access to healthcare, but continuous multidisciplinary care across neurosurgery, urology, rehabilitation, nursing, psychosocial support, and assistive technology services, in line with the Convention on the Rights of Persons with Disabilities (CRPD). Experiences from past crises demonstrate that the failure to ensure accessibility, inclusion, and participation in humanitarian responses leads to avoidable harm, increased mortality, neglect, and prolonged exclusion from essential services.

This submission draws on IF's global experience, evidence from its Member Associations, and lessons learned from humanitarian crises. It highlights key challenges, good practices, and recommendations to support the implementation of inclusive humanitarian assistance in line with the CRPD and Security Council Resolution 2475.

Implementation of CRPD Obligations

Article 11 of the CRPD requires States to take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk. Related obligations, under Articles 4(3), 5, 9, 10, 15, 19, 25, 31, 32, and 33, reinforce obligations concerning participation, accessibility, the right to life and health, data collection, and international cooperation. These commitments are further supported by UN Security Council Resolution 2475 and the Inter-Agency Standing Committee Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action.

In practice, implementation remains uneven. Persons with complex conditions like SBH require continuous access to healthcare, rehabilitation, assistive devices and accessible environments, in line with CRPD's Articles 9, 25 and 26. However, humanitarian planning and response frequently fail to address these needs, particularly in displacement settings and rapid-onset emergencies, reflecting gaps in the application of Articles 5 and 11.

Access to early identification, intervention and early childhood services for children with SBH, aligned with Articles 7 and 25, remains highly inconsistent and dependent on socio-economic and geographic factors, raising concerns under Article 5 on equality and non-discrimination. Essential supplies, including catheters, continence products, mobility aids and neurosurgical follow-up, are often unavailable or unaffordable, undermining the right to health and dignity of the SBH community.

These challenges are exacerbated in humanitarian contexts, where disrupted supply chains and weakened health systems limit continuity of care, contrary to Articles 25 and 26, including rehabilitation services, urological management and life-saving bladder and bowel management, access to clean intermittent catheterisation, shunt monitoring for hydrocephalus, and essential post-surgical follow-up for persons with SBH. Weak infrastructure, shortages of trained staff and lack of follow-up care contribute to higher infant and post-surgical mortality rates, raising concerns under Article 10 on the right to life. Ensuring continuity of care is therefore essential, particularly during the transition from pediatric to adult services and in community-based support, consistent with Article 19.

Furthermore, preventive measures remain insufficiently integrated into humanitarian responses. Strengthening maternal and newborn health systems, including access to folic acid supplementation, food fortification, and quality prenatal care, is essential to reduce preventable neural tube defects such as SBH, in line with Article 25. Ensuring continuity of these preventive services during crises is critical, as disruptions in humanitarian settings increase the risk of avoidable disabilities and long-term health inequalities.

Access to information, as required under Article 9, remains a critical gap. Information on evacuation, services and protection is often not provided in accessible formats, increasing risks for persons with disabilities.

In conflict situations, damage to health systems and forced displacement severely disrupt lifelong multidisciplinary care pathways for persons with SBH, including access to continence supplies, hydrocephalus monitoring, mobility support, and rehabilitation services, thereby undermining continuity of care and increasing health risks.

Humanitarian assistance has often failed to include essential disability-related supplies, contrary to Articles 11 and 25. Barriers to shelters and evacuation routes further demonstrate persistent shortcomings in accessibility and inclusion, demonstrating the persistent gaps in inclusive humanitarian planning.

Diversity of Disability Experiences and Intersectionality

Inclusive humanitarian action must recognise the diversity of disability experiences, in line with Articles 5 and 9 of the CRPD. Preparedness and response measures must address physical, sensory, cognitive and psychosocial needs, as failure to do so results in systemic discrimination, inequity and unequal access to essential services, contrary to CRPD Articles like Articles 11 and 25.

Children with SBH face heightened risks when specialised paediatric, neurosurgical, and rehabilitation care services are disrupted, raising concerns under Articles 7 and 25. This includes interruptions to essential bladder and bowel management, hydrocephalus follow-up care (including shunt monitoring), and rehabilitation services, placing children at high risk of vulnerability in the absence of continuity of specialized services and of medical neglect.

Children are also disproportionately excluded from education in emergencies. Disruptions to schooling, combined with inaccessible temporary learning spaces, lack of accessible sanitation facilities, absence of continence-support measures, and non-availability of adapted learning and communication materials (such as easy-to-read formats, visual supports, and assistive communication tools), result in long-term educational gaps, contrary to Article 24 of the CRPD and other international frameworks. Inclusive responses must ensure access to education and strengthen collaboration with OPDs and education actors, including through resilience-based and multi-year programming.

Also, an intersectional approach is essential, consistent with Article 6. Women and girls with disabilities face additional, multiple and compounding forms of discrimination, particularly in humanitarian settings. Evidence from Ukraine highlights increased risks of gender-based violence and exclusion, reinforcing the need to integrate in humanitarian responses gender and disability perspectives, in line with the Women, Peace and Security Agenda.

**“*In Ukraine people experience double discrimination.*
First on the basis of gender and next on the basis of disability”.**
Woman with SB, Ukraine

Challenges and Barriers in Inclusive Humanitarian Action

Significant structural barriers continue to hinder inclusive humanitarian action. Critical issues present in ordinary systems are reflected and amplified in crisis contexts, especially regarding the difficulties in accessing highly specialized healthcare services for SBH needs. Also, physical inaccessibility of shelters, sanitation facilities, including those required for catheterisation and hygiene management, and multidisciplinary SBH healthcare services, persist while being contrary to Article 9 of the CRPD. Infrastructure disruptions, including electricity outages, further exacerbate exclusion, limiting mobility, access to assistive devices and safety.

Specialised medical needs are frequently unmet, reflecting gaps in Articles 25 and 26. Disruptions to supply chains affect access to essential items such as the necessary catheters and other medical devices for the SBH community. Furthermore, the shortages of trained personnel hinder the management of complex conditions, resulting in preventable health deterioration, including urinary tract infections, kidney damage, and complications related to untreated or poorly monitored hydrocephalus.

Persons with disabilities are also at risk of being left behind during evacuations and relief efforts, highlighting shortcomings in implementing Article 11 and UN Security Council Resolution 2475.

Data gaps remain a critical barrier. The lack of disability-disaggregated data limits inclusive planning and resource allocation, contrary to Article 31 of the CRPD and commitments under the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action.

Participation and Role of persons with disabilities and OPDs

Article 4(3) of the CRPD requires the active involvement of persons with disabilities and their representative organisations (OPDs). However, participation in humanitarian action remains limited and often occurs too late to influence decision-making, undermining effectiveness and accountability.

Barriers include insufficient funding, lack of accessible communication, and limited political will. In conflict-affected contexts, OPDs may also face security risks, restricting safe participation, which raises concerns under Articles 16 and 29 of the CRPD. These risks often persist in post-conflict settings, limiting engagement in recovery and reconstruction processes.

Despite these challenges, OPDs play a critical role in bridging policy and practice by identifying the real needs of persons with disabilities, supporting families, and facilitating dialogue with institutions. It is also important to recognise and support the role of family caregivers as essential support systems that enable persons with disabilities to access healthcare, essential services, and community participation, including in humanitarian settings. IF's experience demonstrates that strengthening local SBH associations, caregiver networks, and peer support systems contributes to more responsive, inclusive, and community-based humanitarian action, in line with Articles 19 and 32 of the CRPD.

Data, Funding, and Capacity

The absence of disability-disaggregated data remains a major barrier to inclusion, limiting needs assessments and monitoring, contrary to Article 31 of the CRPD. For persons with SBH, this includes a lack of data on functional needs such as continence management, access to catheters and hygiene supplies, and availability of neurosurgical and rehabilitation services, obscuring critical gaps in humanitarian response. Strengthening data systems in collaboration with OPDs is essential to ensure visibility and informed planning.

Funding constraints further undermine inclusion. Disability is often not prioritised in humanitarian budgets, and OPDs rely on short-term funding, limiting their sustainability and engagement contrary to Article 32 on international cooperation. For SBH, this results in insufficient support for essential supplies and continuity of specialised care, while increased and sustained funding would also contribute to strengthening SBH capacity, supporting preparedness measures adapted to SBH needs, and ensuring more resilient and inclusive humanitarian responses.

Capacity gaps among humanitarian actors also persist, particularly in addressing SBH-specific needs including bladder and bowel management, hydrocephalus follow-up, and post-surgical care, underscoring the need for targeted training and implementation of the IASC Guidelines.

Humanitarian Reform and Peacebuilding

Current humanitarian reform processes, including the Humanitarian Reset, present both risks and opportunities. While efficiency gains are important, cost-reduction approaches risk undermining inclusion and specialised services, particularly as the specialised and continuous care required by persons with SBH cannot be addressed through short-term or standardised interventions, contrary to CRPD obligations.

Reform processes should instead institutionalise disability inclusion as a core principle, so as it becomes a structural, rather than a residual, element in reform and reconstruction policies, with clear accountability mechanisms, aligned with Articles 11 and 33 of the CRPD. Inclusion must be reflected in funding criteria, performance indicators and monitoring frameworks.

In peacebuilding contexts, stronger safeguards are needed to ensure inclusion, consistent with Article 29 of the CRPD. The United Nations peacebuilding architecture should integrate measures to protect and support OPDs, ensuring their safe and meaningful participation in reconstruction processes.

Conclusion

Persons with SBH, as part of the broader disability community, remain disproportionately affected in humanitarian crises. Persistent barriers to multidisciplinary SBH care services, education, protection and participation continue to undermine their rights under the CRPD.

Inclusive humanitarian assistance requires a proactive, rights-based approach across all stages of the humanitarian cycle, in line with Articles 11 and 5. Current reform processes provide a critical opportunity to strengthen inclusion.

IF calls on States, UN entities, donors and humanitarian actors to fully implement CRPD obligations, ensure meaningful participation of OPDs, invest in inclusive systems and embed disability inclusion as a core component of humanitarian action, ensuring that no one is left behind.

Recommendations

To strengthen inclusive humanitarian action and align with CRPD obligations, IF calls for:

- Disability inclusion must be systematically embedded across all humanitarian action and reform processes, including the Humanitarian Reset, with clear accountability frameworks and dedicated funding, in line with article 5 and 33 of the CRPD.
- Integrate SBH-specific needs and risks into humanitarian planning, including evacuation protocols, accessible shelter design, and sanitation facilities suitable for continence management, as well as continuity of neurosurgical and rehabilitation care, in line with Articles 9, 11, 25 and 26.
- Ensure continuity of care through life course via a continuous access to healthcare, assistive products and early intervention services, including in emergency and displacement settings, particularly for persons with complex conditions like SBH, consistent with Articles 25 and 26.
- Ensure continuity of SBH essential care in emergencies by establishing pre-positioned and uninterrupted supply chains for catheters, continence products, mobility aids and shunt-related medical follow-up materials, including in displacement and conflict settings.
- Establish continuity-of-care protocols for persons with SBH across crises, ensuring uninterrupted access to rehabilitation, paediatric and adult follow-up care, psychosocial support and essential health services during conflicts, pandemics and climate-related disasters.
- Ensure meaningful participation of OPDs at all stages of the humanitarian cycle, with adequate resources and safe environments.
- Strengthened the capacity of humanitarian and health actors through disability and SBH-specific training, including continence care support, mobility assistance, hydrocephalus-related cognitive needs, safeguarding and dignified care, in line with Articles 4(3), 25, 26 and 29 of the CRPD.
- Strengthen disability-disaggregated data collection and use it for planning and monitoring, in accordance with Article 31.
- Ensure intersectional approaches, in line with Articles 6, 7 and 24, and strengthen structured participations and partnerships of OPDs and humanitarian actors.
- Strengthen prevention of SBH within maternal and newborn health systems across development and humanitarian preparedness and response settings, including through folic acid supplementation, mandatory food fortification, and awareness-raising, ensuring continuity of these preventive health services in fragile and crisis-affected contexts to reduce neural tube defects such as SBH, in line with Article 25.

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About the International Federation for Spina Bifida and Hydrocephalus

The International Federation for Spina Bifida and Hydrocephalus is the global organisation representing people with Spina Bifida and Hydrocephalus and their families. IF brings together Member Associations from Africa, the Americas, Asia-Pacific, and Europe, each contributing unique expertise on SBH.

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 through a comprehensive approach that includes improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education.

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