

April 2023

Response by the International Federation for Spina Bifida and Hydrocephalus to the call for input: *Rebuilding Inclusive Societies in Post-Conflict Situations - the active involvement of persons with Disabilities.*

issued by the Special Rapporteur on the Rights of Persons with Disabilities in 2023

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 and its Member Associations are increasingly concerned about the number of children with SBH residing in institutions worldwide. Lack of access to necessary healthcare services, support services for families as well as stigma and misinformation in society result in infants and children being placed away from their families to grow up in institutions where they are at great risk of medical neglect and all forms of abuse.

In light of the priorities of the federation and its members, IF is providing feedback on the following priority areas identified by the UN Special Rapporteur on the Rights of Persons with Disabilities.

8. Please share any suggestions on how the United Nations peacebuilding architecture can be improved to ensure the inclusion of persons with disabilities?

IF recommends that the United Nations look towards the foundational principle of disability rights, nothing about us, without us. Peacebuilding and reconstruction in post-conflict situations can only rebuild inclusive societies if the processes are designed from the very beginning to not only consult persons with disabilities, but involve them in the design and implementation of all policies relevant to them.

IF would like to highlight that the specific circumstances that are often unique to each post-conflict society must be taken into consideration in order to ensure that persons with disabilities and their representative organisations are able to fully participate in the peacebuilding and reconstructive processes. In practice, the active participation and input from persons with disabilities and their representative organisations post-conflict is often hindered by the effects and causes of the conflict itself.

Many conflicts whether they be civil, inter- or intrastate in nature result in attacks or threats against civil society organisations, prior, during or even post-conflict. This is a serious safety consideration that IF members and partners in regions affected by conflict have alerted to federation to in its work to support SBH communities facing crisis. This is a particularly important factor to be mindful of in the peacebuilding and reconstructive efforts after intrastate conflicts and/or civil wars. This is because in intrastate and civil conflicts the societal cleavages that ignited the conflict in the first place originate within the country, and in many cases within local communities as well. These social cleavages regardless of their precise origin do not simply dissipate when political or community leaders are able to reach an agreement to end the armed conflict. Even when attacks have stopped it can take a long time for persons to feel safe and empowered again to contribute to the design and implementation of policies on the local, national or international level.

In intrastate conflicts this can be a particularly persistent threat. The very nature of intrastate conflict lends itself to intolerance against any perceived dissent or critique against the states and its representatives, including that of persons with disabilities and their representative organisations expressing need for policy

changes. Such state level repression and rights violations usually began long before the conflict itself and created an environment where civil society was actively targeted, repressed and villainised.

While interstate conflicts are less likely to result in the repression of civil society in the same manner as intrastate and civil conflicts often do. This does not necessarily mean that civil society organisations including SBH associations and other representative organisations of persons with disabilities emerge unscathed from the conflict and ready with the capacity to participate in the activities of the UN. International organisations, donors and providers of humanitarian aid must fully assess the disproportionate impact that a conflict has on persons with disabilities, including persons with SBH and their families in order to effectively support them to participate in the peacebuilding processes.

The ongoing war in Ukraine has demonstrated the challenges that persons with SBH and their families in regions struck by armed conflict face. For example, the impact of collapsed state infrastructure, such as the healthcare system, on persons with disabilities and especially persons with rare conditions such as SBH is severe. This crisis is further compounded as international aid routinely fails to meet the needs of persons with disabilities and of persons with rare conditions. Supplies and supports essential to the health and survival of the SBH community is often not included in the humanitarian aid delivered into affected areas. Furthermore, persons with disabilities encounter accessibility barriers when seeking shelter or when they become forcibly displaced.

When put into context of disability rights, the correlation between disability and poverty, as well as the societal exclusion that many in the disability community, including persons with SBH, encountered prior to the conflict. The implementation of the principle 'nothing about us without us' requires more from actors within the UN peacebuilding architecture than simple openness to consultation. There needs to be conscious effort built within all stages and aspects of UN peacebuilding, reconciliation and post-conflict reconstruction activities to reach out to, support and build the capacity of persons with disabilities and their representative organisations, including the SBH community, to participate and contribute to the design and implementation of policies for peacebuilding and reconstruction. As well as to understand the potential risks and safety concerns that persons in post-conflict areas may be fearful of in relation to participating with organised civil society including representative organisations for persons with disabilities or being associated with international organisations such as the United Nations.

International and regional representative organisations of persons with disabilities play a crucial role in achieving inclusive post-conflict reconstruction and reconciliation. Representative organisations of persons with disabilities on the international level are able to provide the UN peacebuilding architecture with information about the needs of persons with disabilities. Enabling greater understanding of how to apply the UN Convention on the Rights of Persons with Disabilities in its entirety to the post-conflict peace processes.

The broad international perspective and membership of international and regional representative organisations of persons with disabilities provides these organisations with understanding of how policies have affected persons with disabilities and their human rights. For example, the barriers that persons with disabilities encounter when accessing healthcare¹, the consequences of not actively consulting persons with disabilities in any type of crisis response², or the various threats against independent living of

¹ International Federation for Spina Bifida and Hydrocephalus, "IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus" (2021): <https://www.ifglobal.org/publications/if-statement-on-multidisciplinary-care-for-spina-bifida-and-hydrocephalus/>

² International Federation for Spina Bifida and Hydrocephalus, "IF Statement on COVID-19" (2021): <https://www.ifglobal.org/publications/if-statement-on-covid-19/>



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persons with disabilities that exist on the societal and policy level.³ This expertise is essential in order to ensure that inclusion of persons with disabilities and the protection of their human rights is ensured in the work of The Peacebuilding Commission. This is vital because when inclusion is not factored in and valued at the very start of policy processes then the result of their implementation will inevitably be the strengthening of exclusion. Furthermore, international representative organisations of persons with disabilities are also essential actors in linking local groups of persons with disabilities with UN activities, are able to liaise with communities, understanding their needs and any potential safety concerns and even help build the capacity of national and local representative organisations of persons with disabilities to take part in peacebuilding initiatives. By doing so, contributing to making the work of the Peacebuilding Support Offices inclusive of the rights and needs of a diverse community of persons with disabilities.

The International Federation for Spina Bifida and Hydrocephalus presents the following recommendations to the Un Special Rapporteur on the Rights of Persons with Disabilities:

- That every level of the UN peacebuilding architecture is assessed with the view on how to facilitate the active consultation of persons with disabilities and their representative organisations including condition specific organisations on the national and international level in their decision making processes. Whether those processes are regarding specific post-conflict communities or the general policies on UN peacebuilding.
- That the risk of international relief and peacebuilding funds eroding the rights of persons with disabilities be acknowledged and that processes be put in place within the UN peacebuilding architecture, in particular the Peacebuilding Fund, to ensure that no UN funds directly or inadvertently fund any form of segregation of persons with disabilities.
- That the United Nations identify the inclusion and rights of persons with disabilities as an essential feature of peacebuilding.
- That the United Nations peacebuilding architecture incorporates the principles of article 33 of the UN Convention on the Rights of Persons with Disabilities when supporting national governments in post-conflict situations in building institutions, public administration and political processes.
- That the United Nations peacebuilding architecture put in specific processes at every level of decision making and implementation to ensure that the UN Convention on the Rights of Persons with Disabilities is respected and advanced when assisting with the reestablishment of basic services. In particular, with respect to article 25 (health), article 24 (education) and article 19 (independent living).
- For actions be taken to help build the capacity of civil society, especially representative organisations of persons with disabilities as a part of post conflict peacebuilding.

³ International Federation for Spina Bifida and Hydrocephalus, “IF Statement on Independent Living” (2022): <https://www.ifglobal.org/wp-content/uploads/2023/04/2022-IF-Statement-on-Independent-living.pdf>



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