



IF position paper on the 2021-2027 Multiannual Financial Framework and its implementation

Spina Bifida and Hydrocephalus (SBH) is a serious health problem affecting communities worldwide. It is a type of neural tube defect and among the most complex disabilities. Individuals with SBH often experience lifelong cognitive and physical challenges. Urgent actions aimed at primary prevention (e.g., improved nutrition by adding folic acid) and management of care are urgently needed. The protection and full realisation of the human rights of individuals with SBH, support for their families and access to multidisciplinary care is vital for the quality of life of individuals with SBH and their families. ***This can only be achieved through full implementation and adherence to the UN Convention on the Rights of Persons with Disabilities (UNCRPD).***

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded, and continues to be led by individuals with SBH and their families, and represents SBH associations across the world. The primary mission of IF is the promotion and protection of the human rights of individuals with SBH and their families. Together with important stakeholders IF strives to: raise awareness of SBH and the rights of persons with disabilities; to call for change where necessary; build inclusive communities; reduce the incidence of SBH in the world through primary prevention; and improve management and care for individuals with SBH and their families. The European Union has a strong influence on the policies and actions of states within and beyond its membership. IF therefore, together with other stakeholders, actively monitors and engages with policy developments on the EU level.

The Multiannual Financial Framework (MFF) of the European Union has the potential to significantly impact the lives of individuals with SBH and their families, both in Europe and internationally. The MFF plays a key role in setting the long-term policy priorities of the EU including in areas such as health, education, social inclusion and development aid. Most crucially, the MFF can influence the implementation of the UNCRPD, which is extremely important for individuals with SBH and their families, as the full implementation of the UNCRPD is the cornerstone of inclusion of persons with disabilities. The MFF is also a significant tool for the EU to implement the European Pillar of Social Rights and the new European Disability Rights Strategy 2020-2030 (EDS). The MFF is the EU's long-term budget and sets the EU's budget limits and priorities for the next seven years. Negotiations for the new



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2021-2027 MFF and the Next Generation EU (NGEU), which will be used to mitigate the effects of the COVID-19 crisis, took place throughout 2020. IF would like to highlight the federation's key concerns regarding the implementation of the 2021-2027 MFF and NGEU.

The EU and its Member States have a duty to adhere to and implement the UNCRPD. The EU also has an opportunity to demonstrate to the international community the advantages of regional collaboration on the subject and to create and share good practices on the implementation of the UNCRPD in both internal and external policies. MFF can play a key part in that process if implemented correctly. The new MFF will come into force at the same time that the new EDS will be presented. Supporting the new EDS with funding will be essential in order for it to be effective. However, the implementation of the UNCRPD and the new EDS includes not only discussions on the budget itself, but the conditionalities on which the funding is distributed. Projects and initiatives which do not foster inclusion but rather further entrench the segregation of persons with disabilities, especially children with disabilities, **must not be supported by EU funds**. EU funds, whether being used within or outside the EU, **must foster inclusion** and support rights-based, and evidence-led services and projects. Disability rights as laid out in **the UNCRPD, must be mainstreamed** throughout the MFF and within the conditionalities of any EU funds, instruments or programmes including NGEU.

The COVID-19 pandemic has caused a great deal of uncertainty, requiring swift and often difficult actions on both the national and European level. However, despite the unprecedented nature of this crisis it should be noted that the past two decades have shown that resilience comes from investing in people. This is especially true for people with disabilities, including individuals with SBH and their families. Investing in their health, their education, access to employment and welfare is crucial to foster inclusion in our communities. IF welcomes the increased focus on public health services in the discussions regarding the 2021-2027 MFF and NGEU, and would like to use this opportunity to highlight the need to incorporate article 25 of the UNCRPD into actions taken on health on both the European and national level.

Furthermore, in some instances where the EU and its Member States have implemented very successful programmes and policies aimed at education, employment, access to health services and combating poverty and social exclusion, these policies have not always been accessible or effective to persons with disabilities. Barriers such as inaccessible application processes, burdensome regulations (which disadvantage organisations or applicants with lower funds), and



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delayed or insufficient compensation for accessibility and disability-related expenses (such as personal assistants or accessible transport), often render these programmes inaccessible for persons with disabilities and their representative organisations. ***This is an omission which the EU must address in the implementation of the 2021-2027 MFF and NGEU.***

Instruments such as the European Social Fund+ and the EU Health Programme have served as an important tool to foster inclusion, but more work is needed to translate the European Pillar of Social Rights into policies. The European Semester has gone through a great deal of transformation in the past years, in particular, the social and health dimension has been strengthened considerably. It is important that the MFF supports the implementation of the European Pillar of Social Rights and the UN Sustainable Development Goals, in order to strengthen the social dimension and ensure that this progress is not lost either within the European Semester or in any new monitoring instruments introduced by the NGEU.

In light of this, IF has the following recommendations for the EU and its Member States for the adoption and implementation of the 2021-2027 MFF and NGEU.

IF asks that

- The EU mainstream disability rights throughout the implementation of the MFF and the Recovery Package, in all projects, funds, programmes or instruments, including external actions and aid;
- Adherence to the UNCRPD be set as a conditionality for all projects that receive EU funds;
- Article 25 be considered and incorporated into any EU actions regarding health;
- The new MFF and NGEU be used as an opportunity to improve the accessibility of EU programmes;
- The new MFF and the subsequent budgets be used to implement the new European Disability Strategy and support the implementation of the UNCRPD;
- The social dimension be reinforced in the new MFF, in the European Semester and in any new instruments or monitoring systems introduced by NGEU;



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