



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

IF's Position on Enhancing the EU Strategy for the Rights of Persons with Disabilities 2030

Spina Bifida and Hydrocephalus (SBH) are complex, lifelong conditions that originate in early pregnancy and require continuous and lifelong access to health care, rehabilitation, assistive technologies, education, social protection, and inclusive environments. The International Federation for Spina Bifida and Hydrocephalus (IF) has represented persons with SBH and their families since 1979 and works globally to improve quality of life and prevent neural tube defects.

IF welcomes the opportunity to contribute to the public consultation on *enhancing the EU Strategy for the Rights of Persons with Disabilities 2021–2030 and strongly supports its strengthening for the period up to 2030.*

Background and General Assessment

The EU Strategy for the Rights of Persons with Disabilities 2021–2030 represents the European Union's key framework for implementing the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which both the EU and all its Member States are parties. Compared to previous strategies, it adopts a more comprehensive and rights-based approach, aiming to mainstream disability across EU policies and actions.

As an international federation representing persons with complex and lifelong disabilities, IF strongly supports the objectives of the Strategy and shares the view that its success depends on effective implementation, meaningful participation of persons with disabilities, and strong coordination across policy areas and governance levels. The second phase of the Strategy offers a crucial opportunity to consolidate progress, address remaining gaps, and ensure that commitments translate into tangible improvements in people's lives.

What the Current Strategy has Addressed Well

IF recognises that the current Strategy has laid an important foundation for advancing disability rights at EU level. The introduction of flagship initiatives has provided concrete and visible tools to support implementation, including initiatives on accessibility, employment, and mobility,

such as the Accessible EU Resource Centre, the Disability Employment Package, and the European Disability Card. These initiatives have helped operationalise UNCRPD principles and increased coherence across EU action. The effectiveness of these flagship initiatives will ultimately depend on their consistent and rights-based implementation. While important tools are now in place, sustained follow-up, adequate resourcing, and systematic monitoring are required to ensure that these initiatives translate into tangible improvements in the daily lives of persons with disabilities across all Member States.

IF particularly welcomes the establishment of the European Commission Disability Platform as a structured mechanism for dialogue between EU institutions, Member States, and organisations of persons with disabilities. As a member of the Platform, IF values its role in fostering exchange of practices, improving transparency, and strengthening engagement between policymakers and the disability community.

The Strategy has also made progress in mainstreaming disability across EU policies, including through stronger links with the European Pillar of Social Rights, the EU Gender Equality Strategy, the EU Child Guarantee, and the EU's external action. The explicit recognition of intersectionality, particularly regarding women and children with disabilities, reflects a more nuanced understanding of discrimination, exclusion, and the diverse needs of persons with disabilities.

Furthermore, IF welcomes the Commission's commitment to lead by example, including through more accessible communication, inclusive employment practices, and increased attention to disability in EU-funded programmes, humanitarian aid, and development cooperation. The enhanced focus on data collection and monitoring also represents a positive step towards more evidence-based policymaking.

These achievements provide a solid basis for the remainder of the Strategy period. However, to realise its full transformative potential by 2030, the Strategy must now move decisively from framework-setting to effective, measurable implementation, addressing persistent gaps and inequalities.

Key priorities for Enhancing the Strategy up to 2030

Health as an Enabler for the Enjoyment of Rights

For persons with spina bifida and hydrocephalus, the enjoyment of rights is inseparable from access to quality, timely and lifelong health care. These conditions require coordinated, multidisciplinary support throughout borders and life course, including specialised medical care, rehabilitation, mental health support, assistive technologies, and effective transition from paediatric to adult services. While IF welcomes the increased attention to health within the current Strategy, health remains insufficiently prioritised and is not treated as a flagship area. This weakens the effective implementation of Article 25 UNCRPD. In the second phase, health must be recognised as an enabler of inclusion, autonomy and full participation, in line with the UNCRPD. To this end, health should be treated as a cross-cutting priority and systematically

integrated across EU health initiatives and funding instruments, ensuring the disability-inclusive implementation of EU health policies.

Addressing Lifelong and Intersectional Barriers

Persons with SBH experience disability across the life course and often face multiple and intersecting forms of discrimination. Children require early intervention and inclusive education; adults frequently encounter barriers in employment, independent living and access to services; and older persons with SBH face compounded challenges related to ageing with a disability. Women and girls with SBH are particularly exposed to gender-based discrimination, including in health care. The enhanced Strategy must explicitly address these realities through targeted actions and indicators.

Independent Living Supported by Community-Based Services

Independent living for persons with SBH depends on access to personal assistance, accessible housing, assistive technologies and community-based health and social services. IF strongly supports the shift away from institutional models of care and calls for stronger alignment between disability policy, health systems and social protection. EU funding instruments should actively support deinstitutionalisation and integrated, person-centred support models that respect individual choice and autonomy.

Evidence-Based Policy through Improved Data Collection

The lack of disaggregated, comparable data on persons with disabilities remains a significant barrier to effective policymaking leading to invisibility in policy design. This is particularly problematic for persons with rare and complex conditions such as spina bifida and hydrocephalus, whose needs are often overlooked. IF stresses the importance of strengthening disability data collection disaggregated by age, gender and type of impairment, and of ensuring the involvement of organisations of persons with disabilities in data design and interpretation.

Meaningful Participation of Organisations of Persons with Disabilities

The principle of “nothing about us without us” must be fully realised in the enhanced Strategy. IF underlines that condition-specific organisations provide essential expertise, particularly in health, prevention and service design. Participation must be early, continuous, accessible and adequately resourced, and must extend to EU external action where persons with disabilities outside the EU are concerned.

Stronger Implementation, Funding and Accountability

Despite its ambition, the Strategy lacks a dedicated budget and clear implementation mechanisms. Responsibilities are spread across multiple policy areas and governance levels, increasing the risk of fragmentation. The second phase of the Strategy must prioritise delivery, with clear roadmaps, measurable indicators, transparent reporting, and structured involvement

of organisations of persons with disabilities. EU funding conditionality should be used more effectively to ensure compliance with the UNCRPD.

In conclusion, the EU Strategy for the Rights of Persons with Disabilities 2021–2030 provides a strong framework for advancing disability rights in Europe. Its flagship initiatives and participatory mechanisms, including the European Commission Disability Platform, offer valuable tools for progress. To fulfil its promise by 2030, the Strategy must now focus on effective implementation and enforcement, stronger prioritisation of health measurable impact and accountability for results.. IF stands ready to continue working with the European Commission, Member States and other stakeholders to ensure that persons with spina bifida and hydrocephalus are fully included and supported in the realisation of their rights.

Below are IF's recommendations for the implementation of the European Union Strategy for the Rights of Persons with Disabilities.

Recommendations:

The International Federation for Spina Bifida and Hydrocephalus calls on the European Commission to:

- Elevate health to a flagship priority of the EU Strategy and fully operationalise Article 25 UNCRPD across all EU health initiatives;
- Systematically mainstream disability across all EU policies and legislation, including areas not explicitly covered by the Strategy;
- Promote lifelong, coordinated healthcare pathways, including the transition from paediatric to adult care;
- Address intersectional needs through targeted actions for children, women and older persons with disabilities;
- Strengthen independent living by prioritising community-based, person-centred services and supporting deinstitutionalisation through EU funding;
- Improve disability data collection through harmonised, disaggregated indicators developed with organisations of persons with disabilities;
- Ensure meaningful participation of organisations of persons with disabilities, including condition-specific organisations, at all stages of policymaking;
- Enhance implementation, monitoring and accountability through clear roadmaps, indicators, reporting mechanisms and adequate resources.

The International Federation for Spina Bifida and Hydrocephalus calls on the Member States and the Council of the European Union to:

- Fully implement the UNCRPD, including Article 25, by ensuring equitable access to specialised and lifelong health care for persons with disabilities;
- Integrate disability rights into national health, social and education policies, recognising health as a prerequisite for inclusion;
- Invest in community-based support and independent living, including personal assistance, accessible housing and integrated care services;
- Address intersectional discrimination faced by women, children and older persons with disabilities through targeted national measures;
- Improve national disability data collection in cooperation with organisations of persons with disabilities;
- Ensure meaningful consultation with organisations of persons with disabilities, including condition-specific organisations, in all relevant policymaking processes.

The International Federation for Spina Bifida and Hydrocephalus calls on its EU Member Associations to:

- Disseminate the EU Strategy to members, families, professionals, and other stakeholders;
- Advocate at national and local level, using the Strategy as a framework to influence policy, funding, and service provision, particularly in health, independent living, and education;
- Engage with national disability platforms and cross-disability organisations, ensuring the needs of persons with spina bifida and hydrocephalus are visible;
- Share experiences, challenges, and good practices with IF and across EU forums, including the European Commission Disability Platform, to support collective advocacy and peer learning.

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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