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IF Statement on the EU's Implementation of the UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) requires all States Parties to report to the Committee on the Rights of Persons with Disabilities (CRPD) on their implementation of the convention. The European Union (EU) last reported to the CRPD in 2015 and is expected to do so again soon. In this statement the International Federation for Spina Bifida and Hydrocephalus (IF) reflects on the implementation of the UNCRPD by the EU since its last report to the CRPD and puts forward IF's priorities for the assessment of the rights of persons with disabilities in the EU.

The vision of IF is a society that guarantees the human rights of children and adults with Spina Bifida and Hydrocephalus (SBH), and celebrates their contributions in all areas of life, while guaranteeing equitable access to maternal health literacy for all. The UNCRPD represents a major milestone in the continued advancement of the rights of persons with disabilities. The convention outlines the human rights and fundamental freedoms of persons with disabilities and the obligations of States Parties to the UNCRPD to advance and protect those rights. In article 25 of the UNCRPD addresses the topic of health and healthcare. Article 25 states that '*States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.*' The right to health is a high priority for IF and the global SBH community. Health is an enabler of inclusion, health enables access to education, employment, leisure, independent living and active participation in the community. Access to good quality and affordable multidisciplinary healthcare is essential for individuals with SBH and their families. Without access to healthcare preventable comorbidities develop, quality of life decreases and the risk to the individuals independence including the risk of institutionalisation increases. This risk is present across the lifespan including for individuals experiencing ageing with SBH¹. As an influential regional and international actor in the field of international human rights and the first international organisation to become a State Party to a UN Convention, the EU has a major role to play in advancing the rights of persons with disabilities globally.

¹ IF Working Group on Ageing with SBH (2020). *Ageing With Spina Bifida and Hydrocephalus – A Descriptive Analysis*. International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-report-ageing-with-spina-bifida-and-hydrocephalus-a-descriptive-analysis/>

Several concerns were raised in the 2015 CRPDs “Concluding Observations On The Initial Report Of The European Union”². While the EU has taken steps to address some of them, key issues remain. In regards to article 25 of the UNCRPD, as well as for other policy areas, the fact that the Commission proposal for a horizontal directive on implementing the principle of equal treatment outside the field of employment including disability has not yet been passed leaves EU citizens with disabilities vulnerable to discrimination, including when accessing healthcare. This is in addition to other barriers that persons with disabilities face when accessing healthcare in the EU such as affordability, availability and accessibility. In paragraph, 63 of the 2015 concluding observations the CRPD recommended that the EU take action to explicitly prohibit discrimination on the grounds of disability in healthcare and to improve accessibility.

Through explorative studies IF has investigated the diverse needs of the SBH community when it comes to achieving the highest attainable standard of health and accessing multidisciplinary care. These studies have revealed that the right to health is not guaranteed in Europe. EU Member States are not ensuring access to good quality and affordable healthcare services, reimbursement for essential medical devices are still non-existent or inadequate, and access to multidisciplinary care remains elusive for many individuals with SBH³. The EU’s uniqueness in being the only international organisation to ratify the UNCRPD presents certain challenges. Mainly that it does not have the competency to directly act on or implement the UNCRPD in its entirety. In the context of article 25 it is the EU Member States that maintain competency over matters concerning the protection and improvement of human health. With the exception of common safety concerns relating to public health⁴ the EU can only coordinate or supplement the actions of EU Member States in this area⁵. However, the EU remains active on the topic of health, a policy area that has become ever more important to EU citizens. The EU has stated that it intends to take action on disability and health. The overall aim of the European Disability Strategy 2010-2020 was to empower people with disabilities so that they could enjoy their full rights, participate in society, the economy and the single market. However, health was also identified as one of the eight main areas for action. In the 2010 European Disability Strategy, the European Commission made commitments to support policy developments for equal access to healthcare and support national measures to deliver accessible, non-discriminatory health services and facilities. Including promoting awareness of disabilities in the training and education of healthcare professionals⁶.

² Committee on the Rights of Persons with Disabilities (2015). *Concluding observations on the initial report of the European Union*. United Nations: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolNo=CRPD%2fC%2fEU%2fCO%2f1&Lang=en

³ International Federation for Spina Bifida and Hydrocephalus (2016). *Right to Health: Reality of Persons with Spina Bifida and Hydrocephalus*: <https://www.ifglobal.org/publications/if-report-right-to-health-reality-ofpersons-with-spina-bifida-and-hydrocephalus/>

⁴ European Union (2007). *Consolidated version of the Treaty on the Functioning of the European Union*, 13 December 2007, 2008/C 115/01, article 4(k): <https://www.refworld.org/docid/4b17a07e2.html>

⁵ European Union (2007). *Consolidated version of the Treaty on the Functioning of the European Union*, 13 December 2007, 2008/C 115/01, article 6(a): <https://www.refworld.org/docid/4b17a07e2.html>

⁶ European Commission (2010). *European Disability Strategy 2010-2020: A renewed Commitment to a Barrier-Free Europe*. P8-9: <https://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM%3A2010%3A0636%3AFIN%3Aen%3APDF>

It is therefore disappointing that subsequent policies and initiatives following the publication of the 2010-2020 European Disability Strategy and the 2015 concluding observations by the CRPD have not addressed the right to health in the context of disability rights. While the topic of health was included in the Strategy for the Rights of Persons with Disabilities 2021-2030⁷ as outlined by IF's Statement on the new strategy⁸ stronger actions are still needed. In the 2021-2030 strategy, the European Commission pledges to use the EU4Health Programme as well as other existing legislations and initiatives to improve access to healthcare for persons with disabilities. However, the new EU4Health Programme⁹ makes no mention of disability rights nor the UNCRPD and the areas of action do not address the comments made by the CRPD in the 2015 concluding observations. It is therefore clear that serious challenges remain for the effective mainstreaming of disability rights into EU actions on health. It is vital that in those sectors where the EU does not have competency to address the UNCRPD in its entirety and instead pledges to support actions on that topic that this promise is truly followed through on.

The active involvement of persons with disabilities and their representative organisations plays a vital role in the implementation of the UNCRPD and the reporting cycle, in light of this IF has several recommendations for incorporating the views of the SBH community into that process. IF urges both the CRPD and the European Commission to take into account the following recommendations in the evaluation of the implementation of the UNCRPD by the EU.

⁷ European Commission (2021). *Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030*. P17: <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes>

⁸ International Federation for Spina Bifida and Hydrocephalus (2021). *IF's Statement on the European Union Strategy for the Rights of Persons with Disabilities*: <https://www.ifglobal.org/publications/ifs-statement-on-the-european-union-strategy-for-the-rights-of-persons-with-disabilities/>

⁹ Regulation (EU) 2021/522 of the European Parliament and of the Council of 24 March 2021 establishing a Programme for the Union's action in the field of health ('EU4Health Programme') for the period 2021-2027. March 2021. OJ L 107/1: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32021R0522>

Recommendations:

- IF recommends that the EU take urgent action to explicitly prohibit discrimination on the grounds of disability in the field of healthcare as recommended in the 2015 concluding observations.
- IF recommends that special attention should be given to examining the implementation of article 25 by the EU in light of the expanding actions by the EU into health policy such as in the new EU4Health Programme.
- IF recommends that whether or not the new 2020-2030 Strategy for the Rights of Persons with Disabilities adequately addresses the concerns raised in the 2015 concluding observations needs to be assessed in the next reporting cycle.
- IF highlights that greater effort is needed to improve coordination between different EU institutions and ensure that the UNCRPD is mainstreamed and adhered to in all legislations, initiatives and funding programmes.

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. The organisation founded in 1979, represents Member Associations in countries all over the world 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 incidence of neural tube defects and hydrocephalus through primary prevention by improving maternal health literacy, raising awareness, political advocacy, research, community building, and human rights education. The vision of IF is a society that guarantees the human rights of children and adults with SBH, and celebrates their contribution in all areas of life, while guaranteeing equitable access to maternal health literacy for all.

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