



Brussels, April 2021

IF's Statement on the European Union Strategy for the Rights of Persons with Disabilities

Spina Bifida and Hydrocephalus (SBH) are complex health conditions which develop during the first four weeks of pregnancy as a result of the neural tube and spine not developing correctly. The International Federation for Spina Bifida and Hydrocephalus (IF) has represented people with SBH and their families since 1979. 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.

Background

On the 3rd of March 2021 the European Commission published the European Union Strategy for the Rights of Persons with Disabilities 2021-2030. This strategy follows the European Disability Strategy 2010-2020. These strategies outline the European Commission's effort to implement the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which the EU and all of its Member States are party.

As a representative international organisation for individuals with SBH, IF took part, alongside other disability organisations, in the consultation process with the European Commission prior to the drafting and publication of the new strategy. IF's position for the new strategy can be found in the IF publication titled ['Towards a new European Disability Strategy for 2021 - 2030'](#).

A new and strengthened European Disability Strategy

IF welcomes the increased health dimension within the European Disability Strategy. The right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability as outlined in article 25 of the UNCRPD is a vital component of disability rights. The recent global challenges of the Covid-19 pandemic have increased the urgency for reforms on the European and national level. Disability rights and the voices



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of disability- and condition-specific organisations such as IF and its Member Associations will be vital in order to ensure the inclusivity and effectiveness of those actions. IF is therefore pleased to see the right to health in the new European Disability Strategy.

IF also welcomes that the strategy acknowledges the intersectional challenges faced by specific categories of persons with disabilities, including children and women with disabilities. Addressing barriers experienced by persons with disabilities who are at the intersection of identities is extremely important for the full implementation of UNCRPD and the genuine attainment of a 'union of equality'.

It is encouraging that several of the demands raised by IF have been incorporated into the strategy including the need to mainstream disability in all EU policies and legislations as well as connecting them with relevant European and international initiatives such as the European Pillar on Social Rights and the Sustainable Development Goals. IF has also called for the issue of disaggregated data on persons with disabilities to be included, and the strategy does lay out several initiatives to improve data collection.

IF welcomes the Commission's promise to lead by example on topics such as inclusive employment and accessibility of events and communications. In addition, the strategy's inclusion of external actions and the promise of addressing the needs of persons with disabilities in EU-funded humanitarian aid are of great importance and are commendable.

Challenges

There are, nonetheless, several challenges remaining which IF would like to highlight. The increased focus on health under chapter 5 of the strategy is encouraging. However, it is unfortunate that health is not one of the flagship initiatives of the strategy considering the increased scope of action on health policies foreseen by the EU in the coming years. Health is an enabler of inclusion and stronger actions are needed for the EU and its Member States to fully implement Article 25 of the UNCRPD.

IF would like to underline the importance of taking a multidisciplinary perspective for all ages with a strong focus on mental, sexual, and reproductive health and transition of care when discussing access to essential services, including health and social care, for persons with disabilities. The inability to access multidisciplinary care often leads to preventable



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comorbidities and worsening mental health. Persons with disabilities have not always enjoyed equal access to general health services available to all citizens due to stigma, exclusion, and inaccessibility of built environments. When care is available, they are no longer seen as people but patients with disabilities. In particular, the stigma experienced by individuals with SBH in regards to disability and sexuality prohibits good management and care. Which affects the mental health and overall wellbeing of individuals with SBH.

It is also unfortunate to see that the important topic of maternal health as a part of multidisciplinary healthcare services is not addressed within the strategy. Efforts supporting healthy lifestyles and nutrition are important aspects of prevention especially for Spina Bifida and or Hydrocephalus. Moreover, supporting women and their partners in decisions once birth defects are identified during pregnancy and postpartum are crucial.

Moreover, the strategy has not been allocated a dedicated budget and there are some uncertainties as to the specificities of the implementation of the actions envisioned in the strategy. The strategy includes initiatives which are the responsibility of many different Directorates-General (DGs), EU agencies, and institutions. It also includes policy areas where Member States retain full or shared competency in addition to promising to mainstream disability into all EU policies and actions. This is commendable and in line with IF's recommendations. However, IF recognises the organisational complexity of those goals and highlights that accountability, monitoring and follow-through will be key to ensure that these initiatives are not only implemented on paper but that they are effective in accomplishing their objectives.

Conclusion

The new strategy takes a more comprehensive approach compared to the previous one. It is encouraging to see that the recommendations of the disability community have been incorporated into the final document. However, challenges do remain, stronger actions are needed on the topic of health, and the implementation of the strategy requires a more powerful and long-lasting inter-institutional response from all of the EU institutions.

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



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IF's recommendations to the European Commission

- IF urges the Commission to pay particular attention to the importance of mainstreaming multidisciplinary care with a strong focus on mental health, ageing, and sexual and reproductive health in all healthcare related initiatives.
- IF urges the Commission to prioritise the mainstreaming of disability in all actions with a particular focus on major initiatives and reforms envisioned or taken by the EU that are not included in the strategy such as those on health policy.
- IF calls on the Commission to continue to consult persons with disabilities and their representative organisations, including condition-specific organisations, not only when embarking on initiatives included in the strategy but in all relevant EU actions.
- IF highlights the importance of making these consultation processes easily accessible and inclusive to persons with disabilities and their representative organisations on the international and national level. Including reaching out to persons with disabilities and their representative organisations from outside of the EU in those instances where they are the intended target group of the action, such as on the topic of international human rights and EU humanitarian aid.

IF's recommendations to the Member States and the Council of the European Union

- IF calls on the Council of the European Union and the Member States to proceed with the adoption of the Commission's proposal for a horizontal directive on implementing the principle of equal treatment outside the field of employment including disability.
- IF calls on the Member States to enable the mainstreaming of disability as outlined in the strategy in policy areas where they have shared or full competency, especially in the field of health policy, including multidisciplinary care with a strong focus on mental health, sexual and reproductive health, transition of care, and maternal health as well as international relations.



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IF's recommendations to the European Parliament

- IF calls on the European Parliament to mainstream disability rights, the UNCRPD and the strategy for the rights of persons with disabilities into its work with a particular focus on the initiatives listed in the strategy in order to maximise its inclusivity and effectiveness.
- IF calls on the European Parliament to consult persons with disabilities and their representative organisations, including condition-specific organisations, when working on topics relevant to disability, especially when it comes to actions related to health, multidisciplinary care with a strong focus on mental health, sexual and reproductive health and transition of care as well as maternal health and prevention.

IF's recommendations for IF's European Member Associations

- IF encourages its European Member Associations to disseminate the strategy to their members and other stakeholders.
- IF encourages its European Member Associations to advocate for the priorities of the SBH community in relation to the implementation of the strategy in their communities and to their local and national policy makers and representatives in the EU institutions.



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