

IF Statement on Independent Living

For the International Federation for Spina Bifida and Hydrocephalus (IF) representation of the entire global Spina Bifida and Hydrocephalus (SBH) community is central to the work of the federation. In line with that value, IF established the IF International Youth Group to facilitate and support the involvement of youth with SBH in advocacy. Each year the IF International Youth Group chooses a topic which they deem to be of the highest priority for young people with SBH. This statement focuses on the important topic of independent living.

In this statement IF outlines how independent living is enshrined in international human rights law, its interpretation and implementation and how that relates to the main concerns of the global SBH community, as identified by the IF the International Youth Group. Concluding with recommendations to policy makers and all those involved in supporting people with SBH on how to advance the right to independent living for the SBH community worldwide.

Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) establishes the right to live independently and being included in the community. Within it, independent living is defined as not just as an absence of a large institution, but as the right and ability to make choices equal to others, to have the opportunity to choose your own place of residence and with whom you live with. To have access to a wide range of community support services and not to be obliged to live in a particular living arrangement. Misconceptions and confusions about the definition of independent living and how that relates to policy changes on the national level, in particular for the process of deinstitutionalisation of persons with disabilities, are all too common. In 2017, to aid State Parties to the UNCRPD in interpreting and implementing article 19, the Committee on the Rights of Persons with Disabilities (CRPD) published *General Comment No 5 on Article 19 - The Right to Live Independently and be Included in the Community*.⁽¹⁾

In General Comment No 5 the CRPD emphasised how article 19 of the UNCRPD must be interpreted in context of the convention as a whole. In particular, State Parties should look towards the general principles established in article 3 of the UNCRPD which include respect for the individual's inherent dignity, autonomy and independence. As well as inclusion and effective participation in society. General Comment No 5 emphasises that independent living can only be fully realised if all economic, civil, social and cultural rights enshrined in the Convention are fulfilled.

The interconnected nature of independent living for persons with Spina Bifida and/or Hydrocephalus to a plethora of other policy areas are revealed throughout IF's work on variety of issues such as access to integrated multidisciplinary health care,⁽²⁾ ageing with SBH,⁽³⁾ mental, physical and sexual health,⁽⁴⁾

reducing the prevalence of Neural Tube Defects,⁽⁵⁾ the COVID-19 pandemic⁽⁶⁾ and mental health for youth with Spina Bifida and/or Hydrocephalus.⁽⁷⁾ Through IF's activities on these issues it is revealed that barriers to independent living materialise in a lot of different settings and at every life stage. From parents being advised to put their newly diagnosed children with Spina Bifida and/or Hydrocephalus in institutions or other segregated settings to older persons with Spina Bifida and/or Hydrocephalus not receiving support for their changing needs, losing access to employment and their housing. The socio-economic factors which influence the prevalence of Neural Tube Defects including Spina Bifida resulting in higher prevalence in low and middle income countries and communities. Also means that those communities which are struggling with accessing necessary supports, health care and education have a higher prevalence of Spina Bifida and/or Hydrocephalus. All these factors influence how the global SBH community experience, define and realise the right to independent living.

The IF International Youth Group reached similar conclusions in their work on independent living where the members of the Youth Group, together with participants of IF and the IF International Youth Group's events on independent living explored what independent living means for youth with SBH. During those activities the IF International Youth Group identified numerous societal, political and economic factors as an important facilitators and/or barriers to independent living for young people with Spina Bifida and/or Hydrocephalus.

The IF International Youth Group emphasised the importance of confidence and having positive role models of people with Spina Bifida and/or Hydrocephalus living independently. To have the ability to make their own decisions and choices and have access to support act on those choices. As well as self-acceptance, access to information and resources for the transition into adulthood. Barriers to independent living may be visible or invisible, societal, political or economic such as lack of accessible and affordable housing, support services for persons with disabilities which are inaccessible, challenges in accessing healthcare, scarce or unsupportive of individual choices and therefore independent living as defined in article 19 UNCRPD and General Comment no 5 is not attained. Barriers to independent living may also materialise within the family or the community as damaging stereotypes of people with disabilities as well as stigma persist. Difficulties or inability in accessing education and employment also impacts the ability of young people with Spina Bifida and/or Hydrocephalus in attaining financial independence which in turn impacts their ability to make choices on their living arrangements in a way that is equal to others. This demonstrates how the topic of independent living transcends article 19 of the UNCRPD and requires concrete actions to implement the UNCRPD in its entirety. Young people with Spina Bifida and/or Hydrocephalus need greater recognition and understanding by policy makers on the international, national and local level. It is key to share that there are a wide range of policy challenges that can impact a young person's opportunity to act on their choices and realise their right to independent living.

Independent living is a vast and interconnected subject. However, at its core also lies the urgent matter of deinstitutionalisation. The CRPD in General Comment No 5, and in the 2022 Guidelines on Deinstitutionalisation Including in Emergencies¹ makes it clear that independent living and being

¹ Committee on the Rights of Persons with Disabilities. "CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies" (Adopted September 2022): Accessed online November 2022: <https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpd5-guidelines-deinstitutionalization-including>

included in the community is incompatible with any form of institutionalised care. It is unknown how many children and adults with SBH are confined to institutions across the world. One of the many abuses of rights and wellbeing that befall individuals confined to institutions is being disconnected from their community. Including civil society such as representative organisations of persons with disabilities and other human rights advocates. Individuals with SBH confined to institutions in addition to being deprived of their right to independent living and inclusion in the community are at high risk of neglect, abuse and human right violations. SBH are rare- and complex conditions which require immediate specialised healthcare interventions as well as lifelong support through integrated multidisciplinary healthcare. Needs which are rarely met within institutionalised settings. Institutionalisation of persons with disabilities is an international pandemic of human rights abuses which must end.

As policy makers across the world embark on structural reforms to address changing needs of communities it is essential that those reforms are rooted in the principles of the UNCRPD, General Comment no.5 and the 2022 Guidelines on Deinstitutionalisation Including in Emergencies. It is vital to consult persons with disabilities and their representative organisations, including condition specific representative organisations in order to gain an understanding of what is required to enable persons with disabilities, including those with SBH, to live in the community with choices equal to others. The activities undertaken by IF and the IF International Youth Group have highlighted that persons with lived experiences know best the nature of the challenges and barriers that they face when attempting to realise their human rights as per the UNCRPD.

The International Federation for SBH presents the following recommendations to international organisations and policy makers on the national and local level.

Recommendations:

IF calls on international organisations and other relevant stakeholders on the international and regional level including the European Union to support the following recommendations:

- Mainstream the principles of the UN Convention on the Rights of Persons with Disabilities in all work relevant to persons with disabilities and ensure that actions, initiatives, or funding do not directly nor indirectly support or contribute to the institutionalisation of persons with disabilities;
- Actively support the process of deinstitutionalisation of persons with disabilities on the national level in line with the definitions and guidelines provided by the Committee on the Rights of Persons with Disabilities;
- Consult persons with disabilities through their representative organisations in the design and implementation of actions which are relevant to and may impact persons with disabilities;
- Recognise the diversity of the disability community and seek to involve a diverse representation of persons with disabilities in these consultations, including by involving condition specific organisations and representatives of rare diseases;

To policy makers on the national and local level:

- Accelerate the process of deinstitutionalisation of persons with disabilities and ensure that national plans for deinstitutionalisation are in line with the UN Convention on the Rights of Persons with Disabilities, General Comment No 5, guidelines and other publications by the Committee on the Rights of Persons with Disabilities. Including where relevant concluding observations from the Committee on the Rights of Persons with Disabilities to the State Party;
- Provide support and resources for capacity building to representative organisations for persons with disabilities, in particular supporting organisations to provide peer support. Especially for young people with disabilities;
- Understand independent living in a wider context than institutionalisation and actively research how wider policy areas can enable or hinder the right of persons with disabilities including SBH to independent living and equal choices;
- Actively seek policy reforms that will support young people with disabilities, including young people with SBH to realise their right to independent living by ensuring access to support services, education, training, housing, leisure, transport and more;
- Consult persons with disabilities through their representative organisations in the design and implementation of actions which are relevant to and may impact persons with disabilities;
- Recognise the diversity of the disability community and seek to involve a diverse representation of persons with disabilities in these consultations, including by involving condition specific organisations and representatives of rare diseases;

References

1. Committee on the Rights of Persons with Disabilities, “General Comment No 5 on living independently and being included in the community” (28th Session, adopted 27 October 2017): Accessed online November 2022: <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no5-article-19-right-live>
2. International Federation for Spina Bifida and Hydrocephalus, “IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus” (2021): Accessed November 2022: <https://www.ifglobal.org/publications/if-statement-on-multidisciplinary-care-for-spina-bifida-and-hydrocephalus/>
3. International Federation for Spina Bifida and Hydrocephalus, “IF Statement on Ageing with Spina Bifida and Hydrocephalus” (2021): Accessed November 2022: <https://www.ifglobal.org/publications/if-statement-on-ageing-with-spina-bifida-and-hydrocephalus/>
4. International Federation for Spina Bifida and Hydrocephalus, “IF Statement on Mental, Physical and Sexual Health for Youth with SBH” (2021): Accessed November 2022: <https://www.ifglobal.org/publications/if-statement-on-mental-physical-and-sexual-health-for-youth-with-sbh/>

5. International Federation for Spina Bifida and Hydrocephalus, “IF Statement: A Call for a Global Action to Reduce the Prevalence of Neural Tube Defects Worldwide” (2022): Accessed November 2022: <https://www.ifglobal.org/publications/if-statement-a-call-for-a-global-action-to-reduce-the-prevalence-of-neural-tube-defects-worldwide/>
6. International Federation for Spina Bifida and Hydrocephalus, “IF Statement on COVID-19” (2021): Accessed November 2022: <https://www.ifglobal.org/publications/if-statement-on-covid-19/>
7. International Federation for Spina Bifida and Hydrocephalus, “IF Report: Mental health Implications of COVID-19 on Youth with Spina Bifida and Hydrocephalus – an Explorative Survey Conducted by the IF International Youth Group” (2021): Accessed November 2022: <https://www.ifglobal.org/publications/if-report-mental-health-implications-of-covid-19-on-youth-with-spina-bifida-and-hydrocephalus-an-explorative-survey-conducted-by-the-if-international-youth-group-with-sbh/>

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. 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 ivzw

International Federation for Spina Bifida and Hydrocephalus

Consultative status special category Economic and Social Council at the United Nations

Cellebroersstraat 16 - B-1000 Brussels

T: +32 (0) 471 84 41 54 | E: info@ifglobal.org

www.ifglobal.org

