

A written submission from the International Federation for Spina Bifida and Hydrocephalus to the Committee on the Rights of Persons with Disabilities regarding the ‘Draft Guidelines on Deinstitutionalization, including in emergencies’

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. 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 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 welcomes the ‘Draft Guidelines on Deinstitutionalization, including in emergencies’ by the Committee on the Rights of Persons with Disabilities. Advancing the process of deinstitutionalization is essential for the advancement and protection of the human rights of persons with disabilities, including people with SBH. As the COVID-19 pandemic and other recent regional and national emergencies have demonstrated, it is vital that this process is not set aside but rather accelerated when faced with emergencies.

However, in this written response IF suggests several additions to the draft guidelines. Persons with disabilities is a very diverse group encompassing diverse support needs. It is vital to recognise this diversity, including the reality that for some persons with disabilities a significant portion of their support needs is concerned with health. This may include assistance with daily self-management, for example for persons with SBH this can include assistance with the use of catheters or training on how to do so oneself. Persons with SBH also require the care of multiple health care specialists and support for independent living for a person with SBH may need to include assistance with the management of multiple appointments and transport to specialists outside the community.

IF members report that barriers to independent living often come from challenges with accessing multidisciplinary health care, lack of awareness of the rights based model of disability and the UNCRPD by health care services, lack of access to specialised health care services and barriers in accessing mainstream health care services including sexual and mental health.¹ Changing needs throughout the lifespan and discomfort among other support staff including in education, mental health or other disability specific or mainstream public services in providing support for disability or health related

¹ IF International Youth Group (2021). IF Statement on Mental Physical and Sexual Health for Youth with SBH. International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-statement-on-mental-physical-and-sexual-health-for-youth-with-sbh/>

needs. These barriers vary depending on the age of the person with SBH. Spina Bifida is a congenital condition that is often detected before or soon after birth. Risks for institutionalization can begin at the moment of diagnosis if parents are given advice, including from health care professionals, which contradicts their child's rights under the UNCRPD. For example, being advised that the best place, or even the only place, where the child with SBH can receive the best health care be within an institution.

Segregation is a significant risk factor for institutionalisation. Risks of segregation continues as the child ages as access to mainstream education and leisure activities may be denied or compromised because their support needs such as assistance with incontinence, including the use of catheters, is deemed to be a 'medical need' which does not fall under the scope of disability support or accommodations and is therefore denied.² The risks of institutionalisation further evolve with age. Persons experiencing ageing with SBH find that their needs and mobility change and without the right support this poses a significant risk to their independence and independent living.³

Multidisciplinary care is often not available and when it is it is not unusual that it is only available for children with SBH.⁴ This makes transition from childhood to adulthood even more difficult as it now includes managing appointments, advice, correspondence with and transport to different specialised health care professionals and providers. Sometimes very far from their community. This is if these health care services can be accessed at all. Without access to necessary health care services persons with SBH begin to experience worsening symptoms of preventable comorbidities, putting their life, welfare and independence at risk. As demonstrated by the COVID-19 pandemic access to these vital health services is severely affected by emergencies.⁵ It is important that State Parties to the UNCRPD recognise how an individual becomes at risk for institutionalisation so policies and supports can be put in place to ensure that deinstitutionalization is successful in not only closing institutions but also in improving supports, independence and access to services which are in line with human rights standards.

² International Federation for Spina Bifida and Hydrocephalus (2016). IF Report Right to Health: Reality of Persons with Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-report-right-to-health-reality-of-persons-with-spina-bifida-and-hydrocephalus/>

³ IF Working Group on Ageing (2021). IF Report on Ageing with Spina Bifida and Hydrocephalus – Findings from Online Focus Group Discussions. International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-report-on-ageing-with-spina-bifida-and-hydrocephalus-findings-from-online-focus-group-discussions/>

⁴ International Federation for Spina Bifida and Hydrocephalus (2021). IF Statement on Multidisciplinary Care for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org/publications/if-statement-on-multidisciplinary-care-for-spina-bifida-and-hydrocephalus/>

⁵ International Federation for Spina Bifida and Hydrocephalus (2021). IF Statement on COVID-19: <https://www.ifglobal.org/publications/if-statement-on-covid-19/>

IF presents the following recommended amendments to the ‘Draft Guidelines on Deinstitutionalization, including in emergencies’ by the Committee on the Rights of Persons with Disabilities. The suggested changes by IF are written in red.

Paragraph (9), States Parties should not use lack of supports, **health care** and services in the community, poverty, or stigma to justify ongoing maintenance of institutions, or delay their closure.

An addition to the section ‘Deinstitutionalisation processes’

The process of deinstitutionalization should include training and awareness campaigns on the rights based model of disability, the UN Convention on the Rights of Persons with Disabilities and independent living. In particular for professionals who are instrumental in the care and support of persons with disabilities of all ages such as healthcare professionals, social care professionals and educators.

Paragraph (23), In order to be aligned with the Convention, support services for living independently should be available, accessible, acceptable, affordable, and adaptable **for the entire lifespan of the person including childhood and old age.**

Paragraph (24). Support services for living independently and being included in the community include personal assistance, peer support, crisis support, support for communication, mobility, securing housing and household help, and other community-based services. Support should also be available so that persons with disabilities can access and use mainstream services such as education, employment, **health care**, and the justice system.

Paragraph (37), Where a person chooses to receive support from their family, States Parties should ensure that the family has access to adequate **health care**, financial, social, and other assistance to fulfil their support role.

Paragraph (39), Discrimination on the basis of disability may occur whether or not persons are institutionalized explicitly on the basis of disability. Multiple discrimination and de jure or de facto discrimination may also occur in the community through a lack of support services, which may drive persons with disabilities into institutions. For example, stigma against single parents, **congenital disabilities**, sex workers, the imposition of psychiatric diagnoses, and denial of parental rights may lead to institutionalization of a parent and/or child with disabilities.

Paragraph (49). States Parties should develop and ensure access to support services in the community, including personal assistance and peer support, for children and adolescents with disabilities, as necessary. Educational systems should be inclusive and **health care should be multidisciplinary and integrative to social and education systems to enable accessible and appropriate support.** States Parties should include children with disabilities in mainstream schools, and prevent and avoid placement in segregated education, which undermines community inclusion and leads to increased pressure to place children in institutional settings.

Paragraph (97). Persons leaving institutions require to experience a more robust vista of possibilities of daily living, life experiences and opportunities to thrive in the community. States Parties’ general obligations on accessibility, personal mobility, privacy, bodily and mental integrity, legal capacity, liberty, freedom from violence, abuse, and exploitation and from torture and other ill-treatment, access to

culture and recreation, **health care** and the right to political participation, should be ensured on an equal basis with others.

Paragraph (101). States Parties should ensure comprehensive health care, including primary health care, for persons leaving institutions, on an equal basis with others. Health care services should must respect the choice, will and preferences of persons with disabilities leaving institutions, and provide additional health care support as needed, for example, to withdraw from psychiatric medication or assistance and **training for the persons leaving institutions and their support network on the management of health needs and accessing health care including specialised health care if needed**, and to access nutritional and fitness programs, with a view to retrieving their overall health and wellbeing, and always on the basis of their free and informed consent.

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