**Written statement from the International Federation for Spina Bifida and Hydrocephalus to the Committee on the Rights of persons with Disabilities for the general discussion on article 27 of the UNCRPD.**

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.

Access to work and employment is essential for the societal inclusion of persons with disabilities. Individuals with SBH face barriers to the full realisation of the rights bestowed under article 27 of the UNCRPD. Examples include accessibility of built environment, access to education and training, discrimination, and exclusion. The stigma around disability and SBH can hinder an individual's access to opportunities from infancy which then has a significant impact on work and employment later in life. Having access to work and employment is only one part of the process. Having equal opportunities to career advancement, breaking the often unfounded stigma that people with disability are unable to work, lifelong learning, and remaining in employment for as long as an individual wishes is equally as important.

In addition IF wants to underline the pressing need to ensure that article 27 of the UNCRPD is fully implemented by every state party to the Convention. IF would like to highlight the importance of taking an intersectional approach to the topic of work and employment. The impact of ageing should be taken into account in the dialogues around work and employment for individuals with disabilities. In 2020 IF published a report titled ‘Ageing with Spina Bifida and Hydrocephalus’ highlighting the challenges of individuals experiencing ageing with SBH.

Individuals with SBH often experience accelerated ageing and may need additional support and accommodations in order to have equal access and opportunities in work and employment. In the IF report on ageing with SBH it was furthermore emphasised that the impact on employment is considerable with respondents highlighting the challenges of facing intersectional discrimination based on age and disability when searching for employment. Individuals with SBH also expressed the need for additional support to cope with the effects of accelerated ageing and other challenges of higher age such as care responsibilities without leaving the labour market entirely.

However, it is important to note that IF together with its members identified the important topic of employment as a potential for improvement. Employment denotes access to societal inclusion, it is a source of pride, affirmation, and self-realisation. Supporting individuals who experience ageing with SBH to remain employed ensures their inclusion, their economic prosperity, independence, and wellbeing, both mental and physical, which in turn also contributes to implementation of the UNCRPD as a whole.

Promoting additional actions, legislation, and policies to enshrine the right to and support the employment and meaningful occupation for those experiencing accelerated ageing due to disability is therefore vital in order for individuals with SBH and persons with disabilities to fully realise their rights under article 27 of the UNCRPD.