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Knowledge is key: understanding mental health and wellbeing of people with spina bifida and hydrocephalus and their families

The right to health for people with Spina Bifida and Hydrocephalus (SBH) has been at the heart of IF's work since its establishment in 1979. Traditionally, IF has been focused on access to physical health, recognising the unique healthcare needs of persons with SBH. In the recent years, however, the need to pay attention to a more global view on health, including mental health of people living with these disabilities has become obvious and urgent. In 2017, IF is beginning a new chapter in its history by exploring the mental health and wellbeing[1] of persons with SBH and their families. This **reflection paper** is the first building block in this process, aiming to kick off the debate and invite opinions.

Lack of understanding of mental health needs of persons living with complex physical disabilities, such as Spina Bifida and Hydrocephalus, failure to address them in a systemic manner by healthcare professionals and lack of accessible mental health services have led to an ever increasing **stigmatisation** of the mental health issue. It is rarely acknowledged or spoken about both within the disability community and in the wider society. Yet, mental health problems are more common than we may think, and research suggests that their prevalence among persons with disabilities may be higher than among persons without disabilities.

The first step in addressing the stigma is to start talking about it and understanding the possible causes of mental health problems of people living with disabilities. IF has identified four large **groups of disability-specific factors that may impact the mental wellbeing of someone living with SBH**. This list is not meant to be exhaustive, and we welcome further discussion on it.

1. Clinical factors – how living with a complex physical disability may affect your wellbeing

The medical aspects of living with spina bifida and/or hydrocephalus must be understood when exploring mental health of the SBH community. The jury is still out on the relationship between physical disabilities affecting executive functions (such as SBH) and predisposition of a mental health problem. However, most experts agree that **memory problems, difficulties in planning and organising** – common problems for many people living with hydrocephalus or spina bifida – may have negative impact on people's **self-confidence and a sense of security**.

In addition, SBH are medical conditions that will, depending on severity, necessitate some degree of lifelong follow-up care. People with SBH will invariably spend more time seeking, undergoing and recovering from medical interventions than those living without a disability. The onset, duration and impact of health challenges on life quality are unpredictable, and many of them bring about physical discomfort, surgical interventions, and a need for adjustments. The impact of living with SBH and **coping with recurrent pain and associated medical conditions** varies and is not yet fully understood. Nevertheless, it is agreed that it can affect the person's quality of life and emotional wellbeing. This is particularly acute in low and middle income countries, where having a disability may make it more

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[1] When we talk about good mental health, it is important to remember that it involves more than being free from distress or serious mental health illnesses. Mental wellbeing encompass positive perception of self, nurturing relationships with others, a sense of purpose and meaning in life, and feeling of continued self-development.

difficult for the person to participate in the household tasks, care for younger siblings and participate in traditional livelihood activities.

The psychological toll of SBH on parents and carers can also be significant when they struggle to come to terms with the unpredictable nature of the condition and make difficult decisions for their child (such as high risk surgery, painful therapy and even an amputation). Assuming the role of the child's personal assistant (usually without any compensation or recognition), often at the expense of other roles and responsibilities, does not go unnoticed.

2. Self-perception of disability – how you and your family perceive capacities, preferences and needs

The available research and personal accounts of IF members show correlation between the **attitude** of the person with SBH towards their disability and their mental health. The protective influence of a positive attitude on **self-esteem, social interactions and quality of relationships** is contrasted with the negative impact of **perceptions of beauty standards and body-consciousness**. In other words, people who feel comfortable about their body, disability and self-image fare better in life than those who are insecure, doubtful and self-critical. **Lack of people with disabilities in the media**, mainstream culture and sports contribute to feelings of self-doubt and isolation.

It is also important to understand the effect of **family dynamics** on the mental health of a person, especially a young one, with a disability. Raising a child with a complex disability, such as SBH, in the world that still does not fully understand or accepts the human diversity, is a challenge. Sudden health complications, lengthy rehabilitation processes, exclusion of the child from the mainstream school system or discrimination by the peers has a lasting impact on the family. In a humanly understandable move to shield their children from unnecessary risks that the society may hold, families may become the hubs of **overprotection**, while preventing their children from acquiring the important skills of independence and self-agency. The phenomenon of '*learnt helplessness*' has been reported by young people with SBH as a significant contributing factor to their feeling of inadequacy, isolation and dependency and consequent emotional ill-health.

3. Systemic factors – how your disability is seen and regulated in the legal and social protection system of your country

Professionals and activists agree that **the way the society treats disabled citizens** has the most direct impact on their mental health and wellbeing. Failure to effectively recognise persons with disabilities as rights holders entitled to equitable access to education, healthcare, employment, political participation or family life belittles disabled people. Ill-designed social protection systems that don't provide them with seamless support or force to choose between disability benefits (provided that such benefits even exist!) and employment, deny their citizenship. Inaccessibly construed infrastructures, transport and education systems make the performance of daily tasks a difficult feat and often result in **isolation and invisibility** of people with disabilities.

For persons living with SBH, the issue of **access to affordable multidisciplinary healthcare** deserves special attention. Most IF members report deep dissatisfaction with the care people with SBH receive. Their grievances include lack of medical knowledge about SBH treatments, long waiting times, uncoordinated nature of care and lack of availability of specialist medical devices. At the same time, general healthcare needs of people with SBH (incl their mental health) is often overlooked because of the overwhelming focus on SBH-specific care. The almost universal failure to provide persons with SBH with tailored multidisciplinary care of both their physical and mental health needs, leads to declining overall health, including **anxiety and depression**.

Insufficient attention to and respect for the role of informal carers by many countries (especially so in the developing world) leads to devaluation of the carer’s role, financial difficulties and emotional hardship. In the absence of remuneration, support and respite services for parents and carers, they are at high risk of **anxiety and burnout**.

4. Attitudinal factors - how the wider society sees people with disabilities

Abusive behaviour against persons with disabilities, or ***‘disablism’***, is characterised by holding persons with disabilities (and their parents, in case of children born with disabilities) responsible for their condition and blaming them for making additional demands on state budgets for disability benefits, healthcare costs, mobility devices, personal assistance or reasonable accommodation. Due to the global wave of recession in the last decade and the rising populist attitudes in many **Western countries**, disablism has been on the rise, affecting more and more people with disabilities and their families who are often stigmatised for their association with a disabled person. Negative portrayal of persons with disabilities in the media, presenting them as ‘needing help or sympathy’ continuously feeds disablism.

In addition to this dangerous tendency that may affect people with any disability, those living with SBH also experience **stigma** due to the nature of their disability, particularly acute in the **developing world**. Bladder and bowel management are taboo topics in many societies, and the person’s need for frequent catheterisation is not always easily accepted, making them feel like pariah. In some traditional cultures, the enlarged head associated with untreated hydrocephalus is considered to be the sign of ‘evil spirit’ and the children with hydrocephalus are maimed or even killed as the result. Families and, especially, mothers of children with SBH are also sometimes blamed for their child’s disability and shunned by the communities.

IF preliminary research confirms the shortage of investigations into workable solutions to **break down the stigma accompanying mental health problems of persons with disabilities** and to improve their mental wellbeing. IF is keen to start addressing this gap with utmost urgency and invites for collaboration organisations of persons with disabilities, healthcare professionals, policy makers and all interested and concerned parties.

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