



Equality Now!

Political Brief to Government

September 2020



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INTRODUCTION

Spina Bifida Hydrocephalus Ireland (SBHI), is a national organisation that supports individuals living with spina bifida and/or hydrocephalus (SB/H) in Ireland. SBHI would like to take this opportunity to congratulate the new Government. As with all newly formed Governments, our elected representatives (TDs) now have a renewed opportunity to show that people living with disabilities matter. It is our hope that you will put issues related to disability at the top of the political agenda.

This political brief sets out what actions elected representatives can take in relation to supporting those living with spina bifida and hydrocephalus, we have detailed them under the following key themes:

1. Ensuring equal rights
2. Right to adequate health services
3. Right to a life in the community
4. Right to access
5. Right to education
6. Right to employment

1. ENSURING EQUAL RIGHTS

Ratification of UNCRPD

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is an International Agreement directed at changing attitudes and approaches to persons with disabilities. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity.

Since the ratification of the UNCRPD in 2018 in Ireland, it is important that all Governments departments should now implement the Convention.

Key ask:

Implementation of the Convention on the Rights of Persons with Disabilities (UNCRPD) by the Government across all departments.

Department with responsibility: The Department of Justice & Equality.

2. RIGHT TO ADEQUATE HEALTH SERVICES

There is a lack of essential health services across the board for individuals living with SB/H in Ireland. Essential services in the management of SB/H include urology, colorectal, neurology, orthopaedic, physiotherapy, occupational therapy, ophthalmology, and neuropsychology services¹.

Child Services

There are two paediatric multidisciplinary clinics, CHI at Temple Street and CHI at Crumlin.

All children with SB/H around the country attend these clinics resulting in extremely long waiting lists. Additionally, the services provided in the two hospitals are not of the same standard. Children born before 2009 attend CHI at Crumlin and are unable to access the same standard as those born after this date who attend a more comprehensive service in CHI at Temple Street.

According to Article 7 of the UNCRPD², Parties should take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

Unfortunately, this is not the case as children living with SB/H cannot access the same standard of healthcare despite having the same condition and needs. Unfortunately, the year they were born defines the quality of healthcare services they are able to access.

Adult Services

Despite the National Model of Care for Paediatric Healthcare services in Ireland stating that 'preparation for transition should begin by mid-adolescence, at the latest'³, currently there is no established transitioning plan.

Once individuals with SB/H reach the age of 18, there is no multi-disciplinary clinic to transition into. The individual must ensure that referrals are made to different specialists, and not all service users follow this up, many are placed on long waiting lists to see specialists and some are unable to source suitable specialists in their regions.

Consequently, most service users only see specialists when there is a significant problem. Adults living with SB/H nationwide rely on services which are predominantly offered in Dublin-based hospitals. These are inadequately resourced, difficult to access, and have long waiting lists resulting in significant health deterioration for adults living with SB/H.

Article 25 of the UNCRPD² states that States Parties should provide health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to

minimise and prevent further disabilities, including among children and older persons. To comply with Article 25, health services should be as close as possible to the person's own community, including in rural areas.

In addition to the long waiting lists and the difficulties in accessing specialists in their local regions, for adults living with SB/H, self-management can be an issue. There is so much to contend with in terms of remembering all appointments (for those with hydrocephalus, poor memory is normally a part of living with the condition) that often the individual is overwhelmed.

The consequences of having hydrocephalus are overlooked and the expectations that service users would have the capacity to organise all the necessary appointments is very unrealistic due to the level of brain injury arising from the condition. Improved access to multidisciplinary clinics will provide essential care to individuals managing SB/H.

Mental Health Services

The ratification of UNCRPD affirmed that all persons with a disability must enjoy the same fundamental human rights and basic freedoms as those without a disability.

Individuals living with SB/H tell us that they feel invisible and poorly treated by mental health services. They are struggling to access any kind of service when they experience a mental health crisis.

There is a general lack of understanding of hydrocephalus and its impact. Hydrocephalus should be looked at as a spectrum and each service user should be assessed automatically to ascertain its impact on the individual. Intellectual disability services and funding should allow hydrocephalus to come under their umbrella where needed.

There is no appropriate mental health support – most counselling services are unaware of the impact of hydrocephalus on individuals and their response to treatment.

Key asks:

- Provide multi-disciplinary clinics for adults and children living with SB/H across Ireland.
- Provide adequate mental health supports for individuals with SB/H
- Allow hydrocephalus to come under the umbrella of Intellectual Disabilities where needed.

Department with responsibility: The Department of Health.

3. RIGHT TO A LIFE IN THE COMMUNITY

Housing

Key findings of a survey carried out by SBHI in 2018⁴ revealed that most adults with SB/H live with their parents and have no plan for the future. This is due to the lack of independent accommodation and supported living for people with physical disabilities.

Article 28 of the UNCRPD² states that State Parties must ensure there is equal access by persons with disabilities to public housing programmes. However, people living with SB/H pinpoint the lack of available supports as one of the biggest barriers to accessing housing. This cohort find it difficult to access disability services unless they are in a crisis situation. A crisis could be the following:

- Where a person's care needs change drastically and cannot be managed at home.
- Where a carer becomes ill and can no longer continue in their caring role.
- Where a carer dies.

The lack of adequate housing and support has resulted in some individuals with SB/H living in nursing homes, some of whom are in their thirties. This has been exacerbated by the lack of community Occupational Therapists who can provide independent living training or an SB/H Occupational Therapist (OT) within the organisation. The services of an OT could have a significant impact for the service users of SBHI in the following areas:

- Occupational performance
- Independent living
- Vocational rehabilitation
- Mobility function
- Mental health and wellbeing

SBHI currently receives 10 hours' worth of funding for an OT to work with our service users. However, recruitment has been difficult, and the feedback is that OTs would prefer longer part-time hours or a full-time position. To date, our request for a full-time OT has been unsuccessful.

The services of a full-time OT have the potential to significantly reduce on HSE funding and services. This could be achieved through:

1. Reduced Personal Assistant hours as individuals would have increased capacity.
2. Preventing premature access into inappropriately aged nursing home facilities.

Key asks:

- Allocate the HSE with an adequate budget to address the issue of support services for people with physical disabilities.
- Ensure there is a standardised process where people with physical disabilities can apply to receive support services and ensure that these applications are recorded so that people can access housing in the community.
- Ring-fence funding of local authority to provide adequate housing for people with physical disabilities.

Department with responsibility: Department of Housing, Planning and Local Government.

Personal Assistance (PA) is a critical element of any social justice infrastructure. PA services can support individuals with SB/H to live independently and to participate in the community as equal citizens.

Article 19 in the UNCRPD² states that persons with disabilities should have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.

Many concerns have been raised about PA services by individuals living with SB/H. These include:

- Unsuitable and inadequate allocation of PA hours.
- Lack of adequate personalised care plans for PAs to follow.
- The lack of regulation and training within the sector.

Key asks:

- Sustainable funding must be dedicated to PA Services.
- Everyone with a physical disability must be assessed, and allocated PA hours based on their needs.

Department with responsibility: The Department of Health and Department of Housing, Planning and Local Government.

4. RIGHT TO ACCESS

Transport Access

Article 9 of the UNCRPD² places an obligation on States Parties to ensure persons with disabilities have access on an equal basis to transport, information, and services in both rural and urban areas. To comply with this, measures should be taken to identify and eliminate barriers to accessibility.

Access to suitable transport remains one of the biggest challenges for individuals living with SB/H. The lack of accessible transport is even more pronounced for those living in rural Ireland. This has a huge impact on independence, and we often receive reports of individuals who are living in isolation due to lack of access.

The abolishment of the mobility transport grant without a replacement has further exacerbated the problem of transport for individuals living with SB/H. This has resulted in a loss of independence and feelings of frustration, which could have easily been avoided had a replacement scheme been provided in a timely manner.

The reduction of the notification notice period for assistance at train stations from 24 hours to 4 hours has been hugely welcome. However, we have many reports of individuals arriving at train stations and assistance is not readily available and lifts are often not working.

Key Asks:

- Replace the transport mobility grant.
- Ensure all transport, buses, trains, and taxis are fully accessible for individuals with physical disabilities.
- Ensure ramps and practical assistance is available at all stations.
- Ensure lifts are working at train stations.

Department Responsible: Ministry of Transport, Tourism and Sport

Access to Infrastructure

Persons with physical disabilities have a right to access public services in a manner that is accessible to them. As well as their Public Sector Duty, public services have obligations under the Disability Act 2005 to ensure that their services are accessible to people with disabilities in line with Article 9 of the UNCRPD².

Access to various infrastructure remains a challenge for wheelchair users. To enable persons with physical disabilities to live independently and participate fully in all aspects of life, the Government must implement appropriate measures to ensure access, on an equal basis with others, to the physical environment, and to other

facilities and services open or provided to the public, both in urban and in rural areas.

Key Asks:

- Implement the National Disability Authority (NDA) 'Code of Practice on Accessibility of Public Services and Information provided by Public Bodies'⁵ and the NDA Accessibility Toolkit⁶.
- Promote access and participation by people with disabilities in the design and implementation of local services.

Departments Responsible: All Government Departments

5. RIGHT TO EDUCATION

Article 24 of the UNCRPD² states that children with disabilities should be educated in the general education system alongside their peers without disabilities. However, adequate supports are needed in schools to achieve this goal. There is still need for a clear education policy around SNAs and their role in assisting those living with a physical disability who are attending schools.

Within the education system, hydrocephalus is recognised and considered as a medical condition. However, there is no acknowledgement of its impact on executive function, mental health, and the cross over with symptoms of autism. We have received reports of children not receiving adequate supports unless they have a formal intellectual disability diagnosis.

Individuals with SB/H need individualised education plans to realise their full potential. There is a great need for the Government to implement the EPSEN Act 2004⁷. This gives a child with a disability a right to an assessment of their education needs and access to an individual education plan that addresses any identified need.

Key Asks:

- Clear Policies on the role of SNAs in physical disability in schools.
- Acknowledge the impact of hydrocephalus in education and provide necessary supports.
- Implementation of the ESPEN Act 2004.

Departments Responsible: Ministry of Education

6. RIGHT TO EMPLOYMENT

Article 27 of the UNCRPD² affirms the right of persons with disabilities to work, on an equal basis with others. Individuals with SB/H experience multiple barriers to accessing employment, including lack access to transport, infrastructures and supports, negative societal attitudes, environmental barriers, the education system, and lack of opportunity.

According to 2017 CSO figures⁸, only 36% of people with disabilities of working age are in employment and this indicates a societal problem. The Comprehensive Employment Strategy for People with Disabilities⁹ (CES) outlines strategies that the Government can employ to address this inequality.

The National Disability Inclusion Strategy includes a target to increase the public sector employment target of persons with disabilities from 3% to 6% by 2024. Recent data from the National Disability Authority annual report¹⁰ indicates that only 3.5% of employees working in the public sector are people with disabilities.

Whilst the 6% is a realistic target, a study by the Economic & Social Research Institute (ESRI) 2017¹¹ indicated that despite people with disabilities being keen to work, they face significant barriers. These include low levels of education and a lack of access to develop key skills and opportunities.

While the Employability programme has been welcomed, not all individuals with SB/H have been able to access Employability supports because they are not 'job ready'. Additionally, the Ability Programme funds aimed at supporting young people with disabilities who are not currently job ready through the provision of a range of person-centred supports is not readily accessible to all organisations supporting individuals living with physical disabilities.

Key Asks:

- Ensure people with disabilities are given the right supports to enter and maintain employment.
- Ensure that workforce planning and recruitment meets the 6% target of public sector jobs.
- Ensure employment initiatives are accessible to all support organisations.

Departments Responsible: The Department of Justice and Equality

7. ABOUT US

In 1968, a small group of parents whose children had spina bifida and/or hydrocephalus (SB/H) established a voluntary organisation which would highlight awareness of these two conditions and support families, individuals and carers who were affected. These parents were pioneers who laid the foundations for what is now a nationally recognised organisation – Spina Bifida Hydrocephalus Ireland (SBHI).

Our purpose is to be a powerful community, united by spina bifida and hydrocephalus, and moving together towards fulfilled futures.

Our actions include the following:

- We provide essential information, support, and advice to everyone living with spina bifida and/or hydrocephalus.
- We believe in, and seek to realise, a socially inclusive and equal society for all people living with spina bifida and/or hydrocephalus.
- We enable our members to get the very best from health, education, and social services.
- We lobby the Government to significantly improve services and all necessary access for people living with spina bifida and hydrocephalus.

We deliver our services through our dedicated Family Support Worker team, Recreation and Respite team, Education and Training team and the National Resource Centre, Clondalkin. We also provide week-long residential camps that facilitate independence training, peer support, and social opportunities.

The employees and volunteers involved in this work are highly dedicated and seek to ensure that every person in Ireland living with spina bifida and/or hydrocephalus receives maximum access to life-transforming services throughout their lifetime.

What is spina bifida?

Spina bifida literally means ‘split spine’. Spina bifida is a condition which affects about one in every 1,000 children born per year in Ireland. Ireland has one of the highest incidences of spina bifida births in the developed world. Spina bifida is the most common neural tube defect (NTD) which causes incomplete development of the spinal cord.

Types of spina bifida

There are different types of spina bifida:

- Spina bifida occulta
- Meningocele (pronounced men-in-jo-seal)
- Myelomeningocele (pronounced my-lo-men-in-jo-seal)

Myelomeningocele is the most common form of spina bifida. The areas affected are dependent on the location of the split. The split contains the spinal cord, and nerves are held in the sac which will also be filled with fluid. The spinal cord and nerves become exposed and the degree of damage will determine the extent of the disability. A myelomeningocele is most frequently found in the lumbar area but can occur anywhere along the spine.

What are the effects of spina bifida?

In the past, spina bifida was considered to be potentially fatal. The effects of spina bifida vary enormously, depending on the type, the location, and the severity of the condition.

The effects of spina bifida include varying degrees of paralysis and loss of sensation, lack of bladder and bowel control (incontinence), hydrocephalus, scoliosis, latex allergies, and pressure sore.

Individuals with spina bifida are also more prone to obesity and mental health issues. Yet with a greater level of medical understanding, it is now possible to treat many of the effects and create a higher quality of life.

What is hydrocephalus?

Hydrocephalus is a potentially dangerous condition involving excessive accumulation of spinal fluid within the brain caused either by over production of the fluid or, more usually, by an obstruction to its normal circulation.

While it is a complication of spina bifida occurring in approximately 65% of cases, hydrocephalus is by no means exclusive to spina bifida. It is also a standalone condition resulting from premature births, meningitis, infection, Dandy Walker cysts, tumours, genetic causes or as a result of bleeding within the brain.

How is spina bifida and hydrocephalus managed?

The management of spina bifida and hydrocephalus requires a multi-disciplinary approach which includes urology, colorectal, neurology, orthopaedic, physiotherapy, occupational therapy, ophthalmology, and neuropsychology specialist services to effectively manage the condition.

8. REFERENCES

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