

**Submission to the Ad Hoc Committee on a Bill of Rights for Northern Ireland
Huntington's Disease Association Northern Ireland, 1st December 2020**

About HDANI

HDANI works throughout Northern Ireland providing support, information, advice and social connections to those living with the impact of Huntington's Disease. Prevalent estimates for Northern Ireland would indicate that at any one time approx. 230 individuals are symptomatic with HD with as many as 5-9 people for every one affected, at risk of inheritance.

HDANI run regional support groups, provide telephone/online and face to face advice, practical and emotional support as well opportunities for families to connect through our events and befriending services. We develop HD specific resources, run a website and social media channels.

We also work closely with medical professionals to advocate for the most effective care for our clients and lobby the Executive for improved and efficient services. We provide training and awareness raising events and keep our members informed of the latest research and medical advances in the quest for effective treatments and ultimately a cure.

The Huntington's Disease Association Northern Ireland's mission is to secure the best quality of life for sufferers and their families and to work with others towards the effective management and eventual eradication of the disease.

Our vision is for those affected by HD to be empowered and supported to live as normal a life as possible.

What is Huntington's Disease?

HD is an inherited neurological disorder: if either parent has it, his or her child has a 50-50 chance of getting it. Huntington's disease is caused by an overproduction of a certain proteins in the brain as the result of a faulty gene. Symptoms, which usually appear after age 30, generally include dementia, chorea (jerky, random movements of the body), poor coordination, cognitive issues, depression, memory loss and behavioural issues. People with adult onset HD usually live for 15-20 years once the symptoms begin to appear. There is a rarer, more aggressive, form of HD which affects children known as Juvenile HD and those with JHD rarely live beyond their late teens. Although there are a number of clinical trials underway there is currently no cure for HD. HD is a highly complex condition, that although shares some features with other neurodegenerative conditions is unique, both in terms of the mix of symptoms and the profound impact it has on the entire family, generation after generation.

Why a Bill of Rights is important to us;

HDANI and its service users lend their unequivocal support to the vast majority of organisations and individuals from every corner of Northern Ireland who have repeatedly called for a Bill of Rights. We know that people within Northern Ireland do not enjoy equal rights, opportunities, access to services or quality of life. A Bill of Rights, as provided for initially in the Belfast (Good Friday) Agreement, provides the best opportunity to address these issues. We understand that a Bill of Rights is not a panacea, rather it provides a solid legal framework against which all legislation, public policy and

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practice must adhere to ensuring that everyone in Northern Ireland have the same rights and protections under the law.

We work with people who experience a range of social and economic disadvantages by virtue of their status, experience or circumstance as a carer, person with a genetic condition, someone with a physical, cognitive and/or psychiatric disability/illness, or a person living with a terminal illness. This is of course unacceptable and yet most unacceptable of all is the people who experience inequality on the basis of where they live.

Approx. 12 years ago the Health and Social Care Board commissioned a consultant neurologist to conduct a needs assessment of the HD community in Northern Ireland. There was a multidisciplinary working group established including patients and a range of allied health professionals which drawing on best practice and evidence from other jurisdictions made a number of recommendations for a HD care pathway. In essence this included multidisciplinary teams in each of our five Trusts under the lead of a HD Specialist nurse with a regional HD co-ordinator managing the pathway and providing expert assistance in more complex cases. To date this plan has not manifested.

People living with Huntington's disease in Northern Ireland, and their families, have limited access to expert health and social care services compared to those in other jurisdictions in the United Kingdom. Patients and families in Scotland, England and Wales will be seen and supported throughout their HD journey by multidisciplinary teams (MDTs) of professionals including genetics, neurology, psychiatry, occupational therapy, physiotherapy, speech and language, dietitians as well as community care teams and GPs. There is a network of EnrolHD research sites across the mainland which provide opportunities to engage in research and access clinical trials of disease modifying therapies. There are none in Northern Ireland.

In Northern Ireland, no Huntington's MDTs exist. There is one HD nurse specialist who can only see people who live within either the Belfast or South Eastern Trust. This in itself is a disproportionate caseload for one person, and unsurprisingly the service has fallen on a number of occasion. It also means that the majority of patients and families have no specialist medical help. GPs, social workers, physios, occupational therapists, counsellors, mental health nurses, dietitians, speech and language therapists, palliative care, domiciliary care and nursing home staff, psychiatrists are all likely to encounter HD patients at some time or other but without any specialist knowledge or support to help deal with the condition. HDANI, as a small charity dependent on public donations and philanthropic grants, often receive calls from health professionals who have googled the condition for information and sought our advice. We provide non-medical training about the disease and its impact on the individual/carer/family etc., which helps but is not sufficient. Other than that there is one neurology clinic in Belfast which has HD patient clinics four times per year. Waiting times for new patients can be lengthy and opportunities for meaningful reviews few. In essence the services are limited, fragmented and fraught with geographical inequities.

People living with HD in Northern Ireland are being denied *the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. The lack of co-ordinated, accessible and person centred health and social care is causing an avoidable deterioration in the mental and physical wellbeing of patients and their families, (due to the burden of care) and interfering with their right to family life. Public resources are not being effectively spent and health and social care staff

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are left unsupported while they try to provide the highest standard of care they can, in isolation, with no specialist training or network of peer or professional support. The existing legislation, policy and systems which exist is not sufficient to drive any meaningful change but perhaps the Bill of Rights provides such a vehicle.

Conclusion

We support the creation of a strong and inclusive Bill of Rights for Northern Ireland. As a first world country, we expect to see the highest possible standards of social, economic, cultural, civil and political rights, with no reduction in the protection afforded by the various UN conventions. The Bill of Rights should provide the baseline against which all legislation, public policy and practice is developed and aligned. With a Bill of Rights in place we should see an end to the postcode lottery of care and access to services experienced for so long by our Huntington's disease family members.

HDANI would be happy to engage further in the consultation process to ensure that the needs of our service users are adequately reflected in a future Bill of Rights for Northern Ireland.