Written evidence submitted by Huntington's Disease Association to the Health Public Bill Committee (HB43)

About us

We are the Huntington's Disease Association. Our aim is to help people affected by Huntington's disease in England and Wales to live a better life. We provide support for people with Huntington's disease and their families, educate health professionals, and champion people's rights.

About Huntington's disease

Huntington's disease is a rare, genetic, neurodegenerative condition and there is no cure. Around 8,000 people in the UK have the disease. It is caused by a genetic mutation that leads to widespread and irreversible brain damage, making it difficult to develop effective treatments. Despite ongoing research in areas like gene therapy, available treatments can only help to manage symptoms rather than stop or reverse the disease's progression. Every child conceived naturally to a parent who has the faulty Huntington gene has a 50% chance of inheriting it. If a person is 18 or over, they can take a genetic test to find out if they have the faulty gene.

Symptoms of Huntington's disease can include:

- Movement (movements may happen that you do not expect, while doing what you want to do becomes more difficult)
- Cognitive (difficulties in thinking and processing information)
- Mental health (changes in behaviour and personality)

Symptoms can start at any age, but they commonly appear between 30 and 50. Huntington's disease is usually fatal after a period of up to 20 years.

Summary

We are proposing two amendments to the Health Bill, focused on the following areas:

- Integration between neighbourhood health services and specialised and highly specialised services.
- Accountability for NHS Integrated Care Boards (ICBs) to deliver national service specifications.

The amendments, and the rationale for implementing them, are detailed below. Our key concern is the need to ensure there is accountability for local NHS systems to deliver the 10 Year Health Plan's vision of continuous, accessible and integrated care. This is particularly important for people with rare and complex conditions, such as Huntington's disease.

There are frequently multiple professionals involved in a person's care, often with little knowledge of the disease. Over six in 10 people (62%) we surveyed (2026) said they needed to explain Huntington's disease to a healthcare professional in the previous 12 months. Only 30% of respondents agreed or strongly agreed that the different services involved in providing Huntington's disease care worked well together[i].

The quotes below highlight the need for better care coordination for people living with Huntington's disease.

"I am doing all the coordination and arrangements for my partner. This includes all the appointments including at the hospital, GP, Speech therapist, social services, bank, occupational therapist and all other things relating to their care. It is impossible to contact some of the services directly and often replies take a long time."

Family carer (2026)

"It has been down to the person I care for or myself as a carer to attempt to coordinate any kind of communication between services. Often things go full circle and are just pushed back to the Huntington's disease clinic, which isn't really of any use when we only have annual appointments there."

Family carer (2026)

1. **Integration between neighbourhood health services and specialised and highly specialised services**

Background

The NHS 10 Year Health Plan commits to developing 250 new neighbourhood health centres by 2035. These centres will act as a 'one stop shop' for patient care and will be the place from which multidisciplinary teams operate. This model has the potential to improve care for people living with Huntington's disease. For example, people would benefit if services such as physiotherapy, speech and language therapy, occupational therapy, and mental health support, were all provided in one place, closer to home.

Local areas have flexibility to design neighbourhood health centres that reflect the specific needs of their populations. However, there needs to be accountability to ensure that local systems consider how neighbourhood services will integrate with specialised and highly specialised services. NHS England's Neighbourhood Health Guidelines 2025/26 highlight the importance of hospital-based clinicians working collaboratively with community-based teams who are in neighbourhood health centres. An example of this approach would be a person's Huntington's disease clinic providing specialist input to neighbourhood multidisciplinary teams through joint clinics.

Strengthening accountability mechanisms will help ensure the needs of people with rare, neurodegenerative conditions, such as Huntington's disease, are considered as plans are developed.

Proposed Amendment: Neighbourhood Health Plan (Clause 24)

Require Neighbourhood Health Plans to demonstrate how neighbourhood services will

integrate with:

- specialised and highly specialised services;
- regional clinical networks;

Rationale

People with rare, complex and neurological conditions rely on care that can span neighbourhood, regional and national services. The challenge lies in fragmented accountability, commissioning complexity and misaligned funding arrangements. Neighbourhood care will only succeed for people with complex conditions if it is designed as part of a wider system that includes specialist expertise and coordinated regional pathways.

2. **Accountability for NHS ICBs to deliver national service specifications.**

In August 2025, NHS England published its Specialised Neurology Services Service Specification for adult care. This sets out minimum service requirements for both specialised neurology services and core (ICB commissioned) neurology services. Since April 2026, it has been necessary for services to meet these standards of care.

The specification outlines how specialised and local NHS services should work together in joined-up networks called Integrated Neurology Systems. The aim is to make it easier for people to move between services and receive more of their care closer to home. This would reduce the need for people living with Huntington's disease to travel long distances to get the care they need. However, there is a lack of accountability for local NHS systems to implement this model of care.

Proposed amendment: Performance Assessments of Integrated Care Boards (Clause 20)

Require performance assessments of ICBs to include consideration of:

- implementation of national service specifications;
- compliance with clinical commissioning policies;
- access to specialised services;
- patient outcomes;
- variation between populations and geographies.

Rationale

Current specialised commissioning arrangements already require compliance with national service specifications, NICE guidance and clinical commissioning policies. However, decisions about how services are prioritised and funded remain a matter for local discretion, and there is no mechanism for the Department of Health and Social Care to mandate or require specific provision. Performance assessment is one of the few mechanisms available to ensure that national standards are translated into practice.

[i] Huntington's Disease Association. May 2026. *Support at every step: Improving care coordination for people living with Huntington's disease*. Available here.