



Deafblindness in the UK: National Benchmark for Action

A Post-Roundtable Briefing Following the House of Commons Event Facilitated by Deafblind UK

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Purpose of This Briefing

The **Deafblind UK House of Commons Roundtable** brought together parliamentarians, sector leaders, and individuals with lived experience to discuss practical ways to improve the lives of those affected by deafblindness. The event highlighted the urgent need for joined-up policy, early intervention, and greater awareness across health and social care, education, and employment systems.

Themes included the importance of cross-sector collaboration, inclusive education and opportunities for young people, representation in government decision-making, and stronger recognition of deafblindness as a distinct condition. The roundtable reinforced the need to move from discussion to tangible action.

The meeting concluded with a shared commitment to create a national framework for deafblind inclusion, advocate for representation in policymaking, and continue the House of Commons event annually as a platform for monitoring progress.

Why a National Benchmark Is Needed

This document sets out a **clear national benchmark** for what good support for deafblind people should look like across health, social care, education, and employment. It distils the priorities raised at the **Deafblind UK House of Commons Roundtable** and provides a unified framework for policymakers, commissioners, and sector leaders.

The goal is simple:

Ensure that every deafblind person in the UK receives consistent, specialist, timely and equitable support - wherever they live.

More than 450,000 people in the UK live with deafblindness - a distinct disability that requires specialist support. Yet the roundtable made clear that:

- Provision varies dramatically between local areas across the country

- Deafblindness/dual sensory loss is often not recognised in health, social care, and education pathways
- Families experience systemic fragmentation and “advocacy fatigue”
- Professionals lack training and confidence
- Data about deafblind people is inconsistent and incomplete
- Government advisory bodies rarely include deafblind representatives

A national benchmark offers a single, shared standard to hold systems to account and guide improvement.

National Benchmark for Deafblind Inclusion

Below is the proposed outward-facing benchmark, co-designed from roundtable priorities and best practice.

This can be used as:

- A policy checklist
- A commissioning standard
- An accountability tool
- An advocacy platform

Benchmark 1 - National Recognition & Definition

- Deafblindness is formally recognised as a distinct disability.

A consistent UK-wide definition is adopted across health, social care, education, and employment. This should be a functional definition such as the Nordic definition, Dutch functional definition, or that currently found in English Social Care Law (Care and Support [Assessment] Regulations 2014).

Recognition of deafblindness as a distinct disability is evident in the European Parliament written declaration formally adopted by the European Parliament on 1st April 2004 (*Declaration on the Rights of Deafblind People* 03A_DN(2004) 04-01 PAR002) and in England, a motion by the sub-committee on sensory impairment to recognise deafblindness as a third discrete sensory impairment was endorsed by the Association of Directors of Social Services (Alley and Keeler 2009). The United Nations has also officially recognised deafblindness as a distinct disability and designated 27th June as International Deafblindness Day.

- All public bodies recognise that deafblindness / dual sensory loss requires specialised pathways, not generic ones nor those designed for single sensory impairment

Success looks like:

All four UK nations adopt a shared definition and commissioners fund services based on dual sensory need.

Benchmark 2 - Early Identification & Clear Pathways

- Routine screening for deafblindness/dual sensory loss in key settings (audiology, ophthalmology, schools, care homes)
- Early referral routes to sensory services, communication support, and specialist assessment
- Family navigation support from first diagnosis

Success looks like:

Every person with hearing or sight loss is screened for the other and referred into a joined-up pathway if dual sensory loss is detected.

Benchmark 3 - Specialist Deafblind Assessment (Social Care Needs)

- Assessment carried out only by trained deafblind specialists (not generic professionals) as currently mandated in English law (The Care and Support [Assessment] Regulations 2014)
- Assessment must include the need for communication, one-to-one human contact, mobility, social interaction and emotional wellbeing, independent living skills, habilitation/rehabilitation, safeguarding, and assistive technology
- Nationally recognised assessment tools used and informed by domains highlighted in the WHO ICF (the International Classification of Functioning, Disability and Health) Core Set for Deafblindness

Success looks like:

Every local authority provides timely specialist assessment within set national timeframes.

Benchmark 4 - Access to Specialist Services

All deafblind people should be able to access:

- Communicator guides/intervenors (this applies to deafblind people of any age who have been assessed to be in need of such services))
- Interpreters with qualification and competence in language/communication modalities used by all deafblind/dual sensory impaired people
- Tailored habilitation/rehabilitation, mobility and orientation training
- Accessible information in preferred formats
- Peer and community connection programmes
- Support (psychosocial/physical/practical/educational) for families and carers

Success looks like:

Zero postcode lottery: consistent offer across every local authority and ICS.

Benchmark 5 - Communication Accessibility

- Deafblind/dual sensory impaired individuals' communication preferences and needs should be met in line with the steps described in the Accessible Information Standard: identify, record, flag, share, meet, and review.
- NHS, social care, and education should follow clear accessibility standards.

It is noted that the government is currently working on a 'mandatory' version of the NHS AIS (accessible information standards) with plans to enact Section 95 Health and Care Act 2022, to further strengthen its underpinning legal framework.

Success looks like:

No deafblind person is unable to access healthcare, social care or education due to communication barriers.

Benchmark 6 - Technology Access & Funding

- Consistent access to assistive technology, including hearing technology, visual aids, tactile/haptic devices, screen readers, braille displays, and smart-home safety technology
- Nationally equitable funding model
- Dedicated training on technology use

Success looks like:

Technology is not dependent on local budgets; every deafblind person can access and use the tools they need.

Benchmark 7 - Workforce Competence

- National professional standards for everyone supporting deafblind people
- Mandatory deafblind awareness training for frontline staff
- Professional qualification routes for interpreters, intervenors, and communicator guides

Success looks like:

Public sector staff report confidence and competence in working with deafblind individuals/those with dual sensory loss, and individuals with dual sensory loss experience fewer barriers in accessing services and reporting improved health and wellbeing.

Benchmark 8 - Safeguarding & Rights Protection

- Safeguarding protocols explicitly account for communication barriers, isolation and other risks specifically associated with deafblindness/dual sensory loss
- Rights-based approach across all services, aligned with the Human Rights Act 1998, Care Act 2014 (England), Social Services and Well-being (Wales) Act 2014 (Wales), Adult Support and Protection (Scotland) Act 2014 (Scotland), Equality Act 2010, and Accessible Information Standard
- Supported decision-making embedded in practice

Success looks like:

Safeguarding enquiries, assessments, support planning and reviews routinely consider the unique needs associated with deafblindness/dual sensory loss.

Benchmark 9 - Data, Research & Accountability

- Improved data capture of deafblindness in NHS records, local authorities' records, and education settings
- National reporting on waiting times, assessments, and outcomes.
- Regulators include deafblind provision in inspections
- Research co-produced with people with lived experience of deafblindness/dual sensory loss, including those in underrepresented groups

Success looks like:

Reliable national statistics and published annual progress.

Benchmark 10 - Co-production & Representation

- Deafblind people and families included in decision-making at all levels
- Government advisory panels include deafblind members, representative of the spectrum of dual sensory loss
- Charities collaborate through a unified advocacy alliance

Success looks like:

Policy is shaped *with*, not *for*, deafblind people.

Cross-Sector Calls to Action**Government & Parliament**

- Adopt a UK-wide definition of deafblindness
- Ensure deafblind representation on advisory panels
- Support development of a national framework

NHS & Integrated Care Systems

- Embed dual sensory screening in clinical pathways
- Commission specialist support services

Local Authorities

- Identify and contact deafblind people in their areas
- Provide specialist deafblind assessments
- Implement benchmarked service standards

It is of note that Local Authorities in England are already mandated to do these.

Education

- Recognise and increase the number of teachers of deafblind learners (Qualified Teacher of Multi-Sensory Impairment - QTMSI). A QTMSI is a specialist teacher with postgraduate qualification and expertise in supporting children and young people with combined vision and hearing loss. They assess needs, advise on communication and access, and help ensure appropriate, inclusive educational provision.
- Ensure inclusive learning environments from early years to adulthood.

Regulators

- Include deafblind provision in inspection frameworks.

Charities & Sector Organisations

- Act together through a shared advocacy agenda.
- Share evidence and amplify lived experience.

Conclusion

The Deafblind UK House of Commons Roundtable demonstrated a unified desire for progress. The benchmarks in this document offer a national standard for excellence - one that ensures every deafblind child, adult, and family receives the support, dignity, and opportunities to which they are entitled.

Deafblind UK invites policymakers, commissioners and partners to adopt these standards and work with us to build a future where everyone with dual sensory loss thrives, empowered by knowledge, support and equity.

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