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# Towards a Scottish Declaration

# on

# Deafblindness

We hereby call for the Scottish Government to recognise deafblindness as a distinct condition and specialist disability in Scotland.

Currently, Scotland lacks a legal or formally recognised definition for deafblindness, a crucial step toward identifying and diagnosing dual sensory loss at the earliest point, and addressing the unique challenges faced by the deafblind community. This can lead to significant inequalities in relation to access to education, employment, healthcare, and public and social services and can have a negative influence on a person’s cultural and emotional wellbeing. The impact of this condition can be devastating resulting in profound levels of social isolation and resulting loneliness. Addressing this demands specialist interdisciplinary approaches and skilled intervention, with a particular focus on early identification and transitional support.

Deafblindness can be considered as a spectrum and within this context the age of onset of the condition, severity of the impairment and underlying co-morbidities will contribute to an individual’s ability to communicate, receive information, and orientate within an environment. Often, in terms of accessibility, reasonable adjustments are afforded for either hearing or visual loss, but rarely both. Without the support of skilled communication partners, people with deafblindness are at significant risk of isolation and social withdrawal, with compounding and ongoing risks to health, wellbeing, and human rights.

This declaration calls for the formal adoption of the Nordic definition of deafblindness to pave the way for a more inclusive and equitable future for deafblind people and to fortify the broader landscape of disability rights in Scotland.

Adopting this definition would bring Scotland into line with other significant health systems and countries, and in particular The World Health Organisation[[1]](#footnote-1) (WHO), who recognise that deafblindness is a distinct disability. There is currently an ICD-10[[2]](#footnote-2) code rated to dual sensory loss, recognising that this is distinct from other diagnostic classifications.

The Nordic definition of deafblindness states:

*Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.*

*To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation, and the ability to move around freely and safely. To help compensate for the combined vision and hearing impairment, the tactile sense becomes especially important.*

*(nordicwelfare.org)*

The full Nordic Definition on Deafblindness can be viewed here: <https://nordicwelfare.org/wp-content/uploads/2018/03/nordic-definition-of-deafblindness.pdf>

Current research[[3]](#footnote-3) estimates more than 30,000 people live with the condition in Scotland, and this number is set to rise in line with an aging population. Adopting this definition will enable Scotland to uphold and enshrine the human rights of people living with a dual sensory loss now and in the future.

## Recognition of Rights

People living with deafblindness possess inherent human rights. They have the right to live, learn, work, and engage in social activities in an environment that respects their unique needs and promotes their autonomy.

Current legislation that may have bearing on the lives of people living with deafblindness is as follows and is not an exhaustive list. (For further information including a summary and section of each legislation, please see appendix 1a):

* The Universal Declaration of Human Rights (United Nations) (1948)
* The Human Rights Act (1998)
* The Convention on the Rights of Persons with Disabilities (United Nations) (2006) (UNCRPD).
* The United Nations Convention on the Rights of the Child (UNCRC (United Nations Convention on the Rights of the Child))
* The Equality Act (2010)
* The British Sign Language (BSL) (Scotland) Act (2015)
* The Patient Rights (Scotland) Act (2011)
* The Social Care (Self Directed Support) (Scotland) Act (2013)
* The EU Written Declaration on Deafblindness (2004)

Through the act of countersigning this Declaration we ask you to join us in calling for the adoption of a Scottish definition of Deafblindness and protection of these existing rights through a collective effort to uphold the following six commitments.

## Article 1: Inclusive Education

Deafblind children and adults have the right to access quality, accessible and inclusive education, and opportunities to learn and develop. We shall work to create an educational environment that accommodates diverse learning styles and communication methods. We shall support specific teacher competencies for deafblind learners including haptic approaches using the bodily-tactile modality and towards the development of dynamic and person-centred approaches within the dialogical perspective[[4]](#footnote-4).

## Article 2: Access to Information and Communication

We commit to ensuring that deafblind individuals have equal access to information and communication. This includes the promotion of accessible technologies, tactile communication methods, sign language interpreters, guide communicators, competent communication partners, intervenors and other appropriate resources that enable deafblind people to express themselves and engage with the world around them and those in it.

## Article 3: Support Services, Habilitation and Rehabilitation

We pledge to provide comprehensive and specialised support services to assist deafblind individuals to achieve their full potential. This includes access to assistive devices, augmentative and alternative communication methods, orientation and mobility training, vocational rehabilitation, counselling, and other essential services that enhance independence and quality of life.

## Article 4: Participation in Decision-Making

We commit to ensuring that deafblind people are able engage in meaningful participation over decisions that affect their lives. We shall work closely with expert organisations to create inclusive platforms for consultation, representation, and collaboration, allowing deafblind people to contribute to policies, services and programmes that address their needs and aspirations.

## Article 5: Public Awareness and Advocacy

We will raise awareness and promote understanding of deafblindness across Scotland via the Scottish Government’s See Hear strategy and through education and policy initiatives. We will aim to combat stigma, dispel misconceptions, and foster an inclusive society that champions the unique contributions of deafblind individuals.

## Article 6: Partnerships and Collaboration

We recognise that addressing the challenges of deafblindness requires the collective effort of governmental bodies, non-governmental organisations, the third sector, academic institutions, businesses, and the wider community. We pledge to collaborate, share resources, and coordinate actions to ensure a comprehensive and sustainable approach to supporting the deafblind community in Scotland.

# Signatories:

We the countersigned ask the Scottish Government to undertake to formally adopt the Nordic definition of deafblindness in Scotland, creating a framework within which the Human Rights, agency and potential of deafblind people are upheld and championed.

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# Next Steps:

We ask The Scottish Government to work with expert organisations and individuals to take these first steps to creating a more equal life for deafblind people.

1. Ratify and adopt the Nordic definition of Deafblindness with distinct provision outlined within the See Hear Strategy.
2. Work with expert organisations to coproduce assessment, identification, and intervention pathways for people with congenital and acquired deafblindness, including Usher Syndrome.
3. Ensure assessment for services are undertaken by clinicians and professionals competent in deafblindness through establishment of professional development pathways on deafblindness.
4. Consequently, develop a centralised system of notification mirroring that of VINCYP (Visual Impairment Network for Children and Young People) and HINCYP (Hearing Impairment Network for Children and Young People).

# Appendix 1: Relevant acts and articles

## *\*Please note that text appearing in bold has direct relation to the Nordic Definition of Deafblindness*

**The Universal Declaration of Human Rights (United Nations) (1948)**

* Article 19 sets out that everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.

**The Human Rights Act (1998)**

* Sets out the fundamental rights and freedoms that individuals in the UK are entitled to. Of note, **Article 10 sets out the Right to Information.**

**The Convention on the Rights of Persons with Disabilities (United Nations) (2006) (UNCRPD).**

* Article 21 enshrines the communication rights of people living with disabilities:
* **Freedom of expression and opinion, and access to information.** States parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, **including the freedom to** **seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.**

**UN Convention on the Rights of the Child (UNCRC)**

* Article 12, respect for the views of the child
* Article 13, freedom of expression
* **Gives equal rights to all children to express themselves and understand information to the best of their ability.**

**Equality Act (2010)**

* The Act requires service providers to make reasonable adjustments for disabled people to avoid disadvantage and is **clear that reasonable adjustment includes provision of information in accessible formats.**

**British Sign Language (BSL) (Scotland) Act (2015)**

* Raises awareness, promotes, supports, and encourages the use of British Sign Language (BSL) in Scotland, **including ‘hands-on’ or tactile BSL.**
* **Specifically mentions provision within the Act for the condition of deafblindness.**

**The Patient Rights (Scotland) Act (2011)**

* Aims to improve patient’s experiences of using health services and to support people to become more involved in their health and health care.
* The Act enshrines the patient’s right that the healthcare they receive should consider their needs and what would be of optimum benefit to them and **encourage them to take part in decisions about their health and wellbeing and** **provide information and support for them to do so.**

**Social Care (Self Directed Support) (Scotland) Act (2013)**

* **The supported person must be provided with any** **assistance that is reasonably** **required to enable the person to express views about the options available to them and to make an informed choice about their options for support.** This is a key principle, essential to ensuring that the person can be fully involved in designing and implementing their support.
* **Statutory guidance to** **accompany the Social Care (Self Directed Support) (Scotland) Act (2013).**

**The EU written declaration on deafblindness (2004)**

* Recognises that deafblindness is a distinct disability that is a combination of both sight and hearing impairments resulting in difficulties accessing communication, information, and mobility.
* Some deafblind people may be completely deaf and blind although this is rare. Most deafblind people will have some residual use of one or both senses.
* Deafblind people require specific support provided by people with specialist knowledge.
* The Declaration states that deafblind people should have the same rights as enjoyed by all EU citizens and should be enforced by appropriate legislation in each Member State and include:

1. The right to participate in the democratic life of the European Union
2. The right to work and access training, with appropriate lighting, contrast, and adaptions.
3. The right to person centred health and social care
4. The right to lifelong learning
5. The right to receive one-to-one support where appropriate from communicator-guides, deafblind interpreters and/or intervenors.

**Public Sector Equality Duty**

Recent review of the Public Sector Equality Duty in Scotland has resulted in the prioritisation of **regulatory changes that include a new duty on public bodies to provide access to Inclusive Communication.**

# Appendix 2: Integrated Care Pathways

In 2007, Vanhaecht et al. defined the term ‘care pathway’ or ‘pathway’ as follows:

“A care pathway is a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period.”

Defining characteristics of care pathways include:

· An explicit statement of the goals and key elements of care based on evidence, best practice, and patients’ expectations and their characteristics.

· The facilitation of the communication among the team members and with patients and families.

· The coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, the patients, and their relatives.

· The documentation, monitoring, and evaluation of variances and outcomes, and

· The identification of the appropriate resources.

The aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources.”

1. Vanhaecht K, De Witte K, Sermeus W. The impact of clinical pathways on the organisation of care processes. PhD dissertation, Belgium: KU Leuven; 2007. [Google Scholar]

# Appendix 3: A Dialogical Approach within Deafblind Education

The dialogical perspective within education is an approach that emphasizes the importance of meaningful and reciprocal communication and interaction between teachers and students, as well as among students themselves. It is rooted in the philosophy that learning is a social and collaborative process, and that knowledge is constructed through active engagement, discussion, and reflection. It is of crucial importance when constructing appropriate curriculums of education for deafblind learners, promoting an environment of person-centred, experiential learning.

Key features of the dialogical perspective within education include:

* Open communication: In a dialogical classroom, communication is open and encourages two-way exchanges. Teachers and students engage in genuine conversations, where both parties actively listen, share ideas, ask questions, and supply explanations.
* Co-construction of knowledge: The dialogical approach views knowledge as something that is co-constructed. Instead of the teacher solely being the source of knowledge, both teachers and students contribute to the creation of knowledge through their interactions and discussions.
* Respect for diversity: Dialogical education respects and values the diverse backgrounds, experiences, and viewpoints of both teachers and students. This perspective encourages the exploration of multiple perspectives and the inclusion of different voices in discussions.
* Critical thinking and reflection
* Shared authority
* Scaffolding and Zone of Proximal Development: The dialogical perspective aligns with the concept of the Zone of Proximal Development (ZPD)[[5]](#footnote-5), where teachers provide the necessary support and guidance to help students move from their current level of understanding to a higher level. This scaffolding is often provided through dialogue and collaborative learning experiences. This can be enhanced by the work of Dr Paul Hart and his ‘Double-Sided Zone of Proximal Development’[[6]](#footnote-6) which considers teachers and students co-developing meaning together.
* Cultivation of social skills
* Student-centred approach: The dialogical perspective is inherently student-centred, focusing on the needs, interests, and experiences of individual students. This approach aims to create a supportive and inclusive learning environment where students feel comfortable expressing themselves.

In summary, the dialogical perspective within education prioritizes active and meaningful communication, collaborative learning, and the co-construction of knowledge. It promotes critical thinking, respects diversity, and empowers students to become active participants in their own learning journey.

1. [ICF Core Set for Deafblindness – Deafblind International](https://www.deafblindinternational.org/icf-core-set-for-deafblindness/) [↑](#footnote-ref-1)
2. https://www.icd10data.com/ICD10CM/DRG/951 [↑](#footnote-ref-2)
3. Kösters, N., McMenemy, A., and Johnson, C., 2022. Prevalence rates for those with dual sensory loss and dementia in Scotland. Datafakts Ltd., Research report.

   <https://eresearch.qmu.ac.uk/handle/20.500.12289/12653> [↑](#footnote-ref-3)
4. For further information on a dialogical perspective within education please see appendix 3. [↑](#footnote-ref-4)
5. Vygotsky, L. S. (1978). Mind and society: The development of higher psychological processes. Cambridge, MA: Harvard University Press. [↑](#footnote-ref-5)
6. https://txdeafblindproject.org/deafblind-interaction/zone-proximal-development/#:~:text=Paul%20Hart%2C%20of%20SENSE%20Scotland,the%20teacher%20becomes%20the%20student. [↑](#footnote-ref-6)