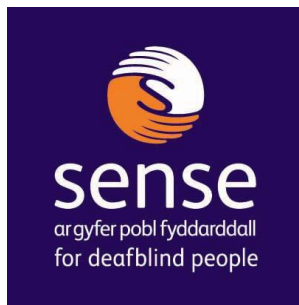


**Submission to Health and Social Services Committee from Sense and Deafblind Cymru - Human Transplantation (Wales) Bill and Explanatory Memorandum**

**Organisations responding**



Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have a single sensory impairment with additional needs.



**DEAFBLIND  
·CYMRU·**

Deafblind Cymru's vision is that people who are deafblind or have a combined sight and hearing loss should have equal rights, access and opportunities as all other citizens within society. Deafblind Cymru is an organisation of and for people who are deafblind or have a combined sight and hearing loss. We champion the rights and interests of all people who are deafblind or have a combined sight and hearing loss and deliver quality services to support individuals to have autonomy and control over their lives.

[Type text]

## **Comments on the Bill**

Sense and Deafblind Cymru's response relates to the Health Committee's invitation for evidence about "Any potential barriers to the implementation of these provisions and whether the Bill takes account of them".

### **1. Communication plan**

The current draft of the Equality Impact Assessment highlights different groups that will be targeted in the communication plan, including deaf and hard of hearing people; blind and partially sighted people; and people with learning disabilities.

We welcome the draft Explanatory Memorandum's references to people with single sensory loss. However, we are not reassured that the communication plan has addressed deafblind people and believe it might not have paid due regard to them. Therefore, we would recommend that people with dual sensory loss are treated as a unique group as well as blind and partially sighted people and people who are deaf or hard of hearing.

### **2. Why deafblind should be considered separately**

Deafblind people have combined sight and hearing difficulties. A range of congenital or acquired conditions can cause deafblindness. The issues faced by deafblind people are not simply a combination of the separate issues faced by blind and deaf people.

The Welsh Government has issued statutory guidance to local authorities on deafblindness (issued by the then National Assembly for Wales in 2001). The statutory guidance said:

"They are a unique group, who cannot always benefit from mainstream services or services for people who are either blind or deaf (but able to compensate partially for the loss of one sense by using the other)."

The statutory guidance also said:

"It is the way in which one sensory impairment impacts upon or compounds the second impairment which causes the difficulties even if, taken separately, each single sensory impairment appears relatively mild."

Deafblind people are generally more isolated from society because of the difficulties they face with communication, mobility and access to information. They may access media infrequently or not at all and can have small social networks.

The statutory Deafblind Guidance (2001) requires local authorities in Wales to identify and contact deafblind people and maintain a record of them. These local

[Type text]

authority registers can be used as a starting point to find deafblind people and ensure communication to them is in the most accessible form. However, not all registers will be up to date.

Research estimates commissioned by Sense reveal a higher prevalence rate of deafblindness than the rates found by local authorities in Wales (see Robertson J and Emerson E, Estimating the Number of People with Co-Occurring Vision and Hearing Impairments in the UK, 2010). The Welsh Local Government Association said the registers “vastly underestimated” the number of deafblind adults in Wales (WLGA, Sensory loss in the adult population in Wales, May 2012).

Sense Cymru and Deafblind Cymru can use our networks, newsletters etc to help raise awareness of the changes the Bill will enact. However, this does not replace the need for public agencies to be aware of deafblindness, to consult with local authorities to ensure deafblind people are identified and to carry out their responsibilities to give due regard to deafblind people in Wales in the communication plan.

### 3. Accessible ways to register wishes

Deafblind people will need a range of accessible methods to find out about the changes the Bill will introduce and to opt-out or register their wishes. Deafblind people come from a range of backgrounds and have different circumstances. They include people who are hearing and sight impaired from birth or early childhood; those blind from birth or early childhood who subsequently acquire a hearing loss that has a significant functional impact; those who are profoundly deaf from birth or early childhood who subsequently acquire a significant visual loss; and those who acquire a hearing and sight impairment later in life that has a significant functional impact. Some within this group may not even call themselves ‘deafblind’.

Depending on the severity of their dual sensory loss people make use of residual or useful vision or hearing; use tactile means; or alternative formats:

a) Tactile communication, such as Deafblind Manual, block or finger spelling. For the small number of people who communicate solely using these methods the public information would have to be delivered in person.

b) Alternative languages, such as British Sign Language (including adapted methods of signing such as Visual Frame for those who are also partially sighted or hands-on signing for those who are also blind). This would also include videos in BSL that could be featured on the Welsh Government, NHSBT etc websites.

c) Alternative formats, such as large print, braille and audio.

If the current methods of opting into the organ donation system were used for the opt-out system we believe there would be a number of practical issues. For example, the NHS Blood and Transplant Service website lacks a textphone number, which is used by deafblind people who have some useful sight or in conjunction with a braille

[Type text]

reader (and by deaf people). The Text Relay service ([www.textrelay.org](http://www.textrelay.org)) can be used to connect a person using a telephone with a person using a textphone.

There is also an option listed to send a text message at present to join the organ donation register but if text messaging were possible for registering wishes in the new system there would need to be an explanation about what would happen next. That is, whether a text message would be a valid way to register wishes (and how a deafblind person would know their wishes had been registered) or whether it is treated as a request for further information or contact (and whether further contact would use accessible communication).

#### 4. Congenitally deafblind people

The Welsh Government and its agencies may also encounter extra difficulties communicating the changes to congenitally deafblind people, who were deafblind from birth or before they acquired language. This means their formal language may be limited. Some congenitally deafblind people have co-occurring or connected cognitive disabilities but if their sole condition is deafblindness they can usually make decisions about concepts that are familiar to them. However, explaining abstract or novel concepts about mortality, their own organs and the consent system could be very difficult or impossible. People in this situation therefore not have the capacity to make a decision.

We believe the legal framework set out in the Bill will deal with this. However, we recommend that the Welsh Government produces a code of practice to explain these concepts to healthcare professionals. The Welsh Health Minister is currently implementing changes in response to a report, *Accessible Healthcare for People with Sensory Loss in Wales* (2012), which described examples of poor sensory loss awareness among a range of healthcare professionals. Before the Bill's provisions are enacted we would like consent to be explained clearly and concisely to health professionals and any others who will be involved in implementing them. The code of practice for the Mental Capacity Act 2005 provides a good model in this respect. It includes a series of scenarios throughout to explain the Act's provisions in practical terms. A similar document for the Human Transplantation Bill would be valuable and should include scenarios about consent and dual sensory loss.

#### **Contact details**

Nick Morris  
Sense Cymru  
Tŷ Penderyn  
26 High Street  
Merthyr Tydfil  
CF47 8DP

Email: [cymruenquiries@sense.org.uk](mailto:cymruenquiries@sense.org.uk)  
Tel: 0845 127 0090

[Type text]

Textphone: 0845 127 0092

Fax: 0845 127 0091