

Guidelines for deafblind people, families and professionals in Europe on using Written Declaration 1/2004

- [Introduction](#)
- [What does this declaration mean?](#)
- [Campaigning at European and UN levels](#)
- [What you can do](#)
- Examples of countries where recognition of deafblindness has been achieved
 - [Romania](#)
 - [United Kingdom](#)
- [Appendix 1 Written Declaration 1/2004](#)

Introduction

These guidelines have been written to follow up on the success of Written Declaration 1/2004 (Appendix 1). EDbN (the European Deafblind Network) members worked together very effectively to achieve the adoption of the Written Declaration, now we need to make sure we really capitalise on this success.

The situation for deafblind people in individual countries varies enormously and the changes that need to take place vary so the information given is quite general and does not include too many details. If you have any questions or need any advice please do contact the Campaign team from Sense UK at campaign@sense.org.uk.

What does this declaration mean?

The Written Declaration means that the European Parliament has officially recognised that deafblindness is a separate disability and that deafblind people have the same rights as any other European citizens. This includes the right to the one to one support that deafblind people need to access information and many everyday activities.

The Written Declaration is not a law; it does not force national governments to do anything. When the European Parliament and the European Commission produce a directive they can make national governments take action as a result. However, a Written Declaration does not have this power, so they will not be forcing national governments to follow up on the declaration. It is up to individual deafblind people, families and professionals to follow up on the declaration and make sure that their governments know that deafblindness has been recognised at a European level and that they have a responsibility to recognise deafblindness at a national level and provide appropriate services.

Campaigning at the European Level

EDbN will be continuing to lobby at the European level, to make sure that the needs of deafblind people are addressed. This will be aimed at the relevant units in the European Commission; MEPs in the European Parliament; the European Disability Forum (EDF) and other European level campaigning/lobbying groups. It is important that the voice of deafblind people is included in European policy making. EDbN will be working to make sure this happens.

Campaigning at the United Nations Level

Lex Grandia, Secretary of the World Federation of the Deafblind, is taking part in the negotiations on the drafting of the potential UN Convention on the rights of disabled people. This means that

What can you do?

Assess the situation in your country

- Is deafblindness recognised by the government in your country?
- Do you feel there is an understanding of what deafblindness is and what it means to peoples' lives?
- Are deafblind people being correctly identified?
- Are deafblind people entitled to services that are specific to their communication and mobility needs?
- Are deafblind people receiving the specialist services they need?
- Do deafblind people have the right to receive the support they need to work and take part in training at work?
- Do deafblind children and young people have the right to receive an education?

What do you want to achieve?

If you feel that the answer is no to one or more of these questions then you could use the declaration to support your campaign to improve the situation.

You need to be very clear about what you want to achieve at the national or regional level.

Are you concerned about general recognition, or specific changes in education, employment, social care or provision of one to one support?

Once you know what you want to achieve you can work out how this can be done.

Who should you approach?

You need to find out who can make the change in your country.

Should you be talking to national government or regional government?

Which department is responsible?

How should you lobby them?

Once you have correctly identified the department/person you need to work out the best way to lobby them.

You could produce a report explaining what needs to happen and why.

(If you already have contacts in the right government department you could send the report to them and request a meeting.

If you do not have contacts you will need to send them the report and introduce yourself. Request a meeting.)

Keep up to date with the work of the department you are interested in. There may be existing initiatives taking place that you could input into, to make sure that the needs of deafblind people are included.

Once you have clearly explained what needs to change in your country, you can show them a copy of the Written Declaration. You can say that the European Parliament has recognised that deafblindness is a distinct disability and that deafblind people should have the same rights as other people.

Tell us about what happens

EDbN need to be able to build up a picture of what is happening in countries around the European Union following the declaration, so please could you send information to campaign@sense.org.uk. We really want to hear about the experiences people are having across Europe, both good and bad, including any problems you are having.

Examples of countries where recognition of deafblindness has been achieved

Romania

In 1999 the Director of Sense International (Romania), Cristiana Salomie launched a relationship with the Ministry of Education by signing a five year Partnership Agreement with the Head of Special Education. The relationship played to the mutual strengths of the Ministry, as the employer of teachers, and SI(R), as an agency able to access networks of expertise and education practice from overseas, particularly the European Union, as Romanian policy is geared towards membership. The partnership resulted in deafblind children accessing state education for the first time in Romania's history; the recognition of deafblindness as a distinct disability within Ministry of Education; and the development of an accredited training course for teachers working with deafblind children.

In 2000, a coalition was set up and given the job of improving the existing disability legislation. Cristiana's work with the Ministry of Education led to her being invited to be part of this coalition. During the Coalition meetings Cristiana had the chance to explain to people what deafblindness is and to emphasise the very special needs of deafblind people. The proposal was presented to the Parliament and some of the things included in the draft were accepted by the Government and included in the new law (519/12 April 2002).

"Dealing with special protection and employment of persons with handicap"(this is a quote from the law) in which there are three references to deafblind people.

1) 'Deafblindness is regarded as a separate and distinct disability that requires special methods and techniques for coping with functions of everyday life'. Deafblindness has been placed within the range of sensory impairment but it has been recognised as a unique disability.

Article 15 of the Law 519/2003

(1)"Beginning with the date when this law is enforced, signing language and the specific languages of deafblind people shall be officially recognised."

(2) "The public institutions shall provide, whenever necessary, authorised interpreters of signing language or the specific languages of the deafblind people, in order to facilitate direct relationships of the hearing impaired and with the deafblind persons. The procedures and the terms of the authorisation are to be established in a mutual agreement between the Ministry of Education and Research and the Ministry of Health and Family, with the technical support of the Deaf and Blind Associations."

The achievement cannot be overstated. In 1999 there was no word for deafblindness in Romanian. Just four years later deafblindness is taking a central place in legislative change.

UK - England and Wales

A few years ago Sense and Deafblind UK worked jointly on a campaign called 'Yes to Access'. This campaign was based on a survey of Sense and Deafblind UK members. Members were asked what one to one support they needed and what one to one support they actually received. The results showed how little support deafblind people were actually receiving in comparison to what they needed.

A lobby of parliament was organised, with the help of a member of the House of Lords, Lord Ashley. Deafblind children and adults, their families and professionals went to see their Members of Parliament, to tell them about their needs. Lord Ashley then introduced a Deafblind Persons bill in the House of Lords. The bill was supported in the House of Lords, but the government would not allow it to pass as it was.

Following negotiations, the government offered to produce statutory guidance for local authorities on the services they should be providing for deafblind people. The guidance would be attached to an existing law, meaning that local authorities had to comply. Lord Ashley accepted the government's suggestion and Sense and Deafblind UK were involved in drafting the guidance with senior civil servants. The guidance, which came into force in April 2001 includes a definition of deafblindness and emphasises the need for specialist assessment, one to one and support and services, not just services for deafness or blindness.

This guidance applies to England and Wales. Campaigners in Scotland and Northern Ireland are now trying to get the guidance or something similar introduced there using the Written Declaration. The guidance was reissued in June 2009.

