



# Recognition

a survey of deafblindness in the European Union



European Deafblind Network

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**In the European Union there are at least 150,000 deafblind people who represent one of the most socially excluded groups of European citizens. Deafblind people are often isolated, unable to get a job or even go to the shops without support.**

On 1st April 2004, Written Declaration 1/2004 (Appendix 3) was adopted by the European Parliament. The Written Declaration, which was signed by 323 MEPs, called for the recognition of deafblindness as a separate disability across the European Union.

This report is based on a European Union wide survey of the recognition of deafblindness that has been carried out by the European Deafblind Network (EDbN). Members of EDbN filled in a questionnaire, answering questions about the situation in their country. Organisations in twenty one of the twenty five Member States sent replies to the survey.

This survey was done to find out the actual situation of recognition of deafblindness in the Member States of the European Union, in order to highlight the changes that needs to take place in response to the Written Declaration. It shows that there is a wide variation in the situation of deafblind people in the different Member States and recognition of deafblindness at the national level is vital to even out that variation.

### Organisations who contributed to the EDbN survey

Sense UK	Záblesk – The association of Parents and Friends of Deafblind Children, Czech Republic	Lithuanian Training Centre for the Blind
Sense Scotland	The Association of Parents and Friends of Deafblind Children in Slovakia	The Netherlands Knowledge Centre for Deafblindness (LED)
Lega del Filo D'Oro, Italy	Centre for the Deafblind, Denmark	Directorate of education, Norway
CRESAM, France	Estonian Support Union of Deafblind	Polish Association for Welfare of the Deafblind (PAWDB)
ÖHTB (The Austrian Relief Organization for People Who Are Deafblind and People with Significant Vision and Hearing Impairments)	The Finnish Deafblind Association	School of Health – Polytechnics Institute – Setúbal, Portugal
K.I.Spermalie, Belgium	German Deafblind Consortium	Babes-Bolyai University, Faculty of Psychology and Educational Sciences, Romania
Apascide – Spanish association of parents of deafblind people	Greek Association for Deafblind people	Mogard, Sweden
Apsocecat – Catalan association for helping deafblind people	Hungarian Deafblind Association	SZB Swiss National Association for the Blind
St Barnabus School for the Blind, Cyprus	Fighting Blindness, Ireland	

## The key findings

Organisations in twenty one of the twenty five Member States of the European Union responded to the survey, so all the statistics quoted are based on the situation in those twenty one countries.

- In 76% of the Member States there is no recognition of deafblindness as a distinct disability.
- In 62% of the Member States there is no specific programme for identifying newly diagnosed deafblind people.
- In 38% of the Member States there is no specific training for interpreters and communicators.
- In 48% of the Member States deafblind people do not have the right to the support they need to be able to work.

## The key recommendations

- Deafblindness needs to be recognised as a separate disability throughout the European Union. Individual countries should decide on the best way to recognise deafblindness to make sure that specialist services are provided.
- Deafblind people should have the right to receive the support they need to be able to work and take part in training at work throughout the European Union.
- Deafblind adults and children in all the Member States of the European Union should be entitled to receive early intervention services (early intervention services are explained on pages 10 and 11).
- Deafblind children and young people in all the Member States of the European Union should have the right to receive an education in either a mainstream school or a specialist school, depending on what is appropriate for the individual. Teachers working with deafblind children need specialist training.

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## 1.1 Understanding deafblindness

Deafblindness is a unique disability that is more than simply vision loss and hearing loss. The combined effects of not seeing or hearing clearly are experienced uniquely by each deafblind person. Their lives are profoundly affected, particularly by difficulties in communication, mobility, and access to information. Many deafblind people are effectively prisoners in their own homes, with little support to enable them to take part in everyday activities.

Individuals experience deafblindness in different ways. Some people are completely deaf and blind; many others will have some sight and/or hearing that they can make use of. There are people who are born deafblind, other people are born either deaf or blind and then lose the other sense and there are others who lose some hearing and sight later in life. Many will have other difficulties to cope with, such as physical disabilities, learning difficulties, experience delays in learning, or have challenging behaviour.

It is vital that deafblindness is recognised as a separate disability because services that are designed for people who are either deaf or blind are not suitable for people who are deafblind because they rely on the use of the remaining sense to compensate.

## 1.2 What is EDbN?

EDbN is a European level organisation supporting deafblind people, parents and professionals with a website and an email network and the aim of campaigning to achieve recognition of deafblindness at a European level. It is part of Deafblind International (DbI), which is a worldwide network of people aiming to share information and good practice across international boundaries, to stimulate the growth of information about deafblindness.

### 1.3 Why this survey?

In 2002, members of EDbN took part in a European Commission funded Social Inclusion project which produced a Charter for the Deafblind Citizens of Europe (Appendix 1). At a seminar in Brussels where this Charter was launched, Richard Howitt MEP, Chair of the Disability Intergroup in the European Parliament, expressed his support for the Charter. In 2004 he showed this support by submitting Written Declaration 1/2004 on the rights of deafblind people to the European Parliament with four other MEPs, on behalf of EDbN.

326 MEPs signed Written Declaration 1/2004 (Appendix 2) and on 1st April 2004 it was adopted by the European Parliament. This Written Declaration called for the recognition of deafblindness across the European Union. A survey was carried out to find out the actual situation of recognition of deafblindness across the European Union, so that it is possible to see what needs to happen in order for the aims of the Written Declaration to be achieved.

Organisations in 84% of the Member States of the European Union replied to the questionnaire. We have no contacts in Luxembourg and Slovenia; however we are trying to make contacts with people and organisations in these countries. In addition we received a response from Romania, which is soon to be a Member State of the EU, and Norway and Switzerland, which are connected to the EU but are not Member States.

## 2. What did we find out?

The percentages presented in these findings are based on the answers from organisations in 21 of the 25 Member States. The answers from Romania, Norway and Switzerland which are outside the EU at the moment are presented separately. All the percentages are rounded up or down to the nearest whole figure.

### 2.1 Is deafblindness recognised as a specific disability?

Yes	24%
No	76%

Yes	Romania and Norway
No	Switzerland

The majority of the countries in the European Union do not recognise deafblindness as a separate disability.

In one or two cases this is because they have general disability law which does not mention specific disabilities. However, in the majority of cases it is because there is no or very limited disability law in place. It is vital that deafblindness is recognised as a separate disability, to ensure that specific services are developed, that are not for deaf or blind people, but are for deafblind people. Recognition also facilitates the inclusion of the needs of deafblind people in other areas of legislation.

### 2.2 Do deafblind people have the right to the support they need in order to be able to work and take part in training at work?

Yes	57%
No	38%
No answer	5%

Yes	Norway and Switzerland
No answer	Romania

Employment is a significant way in which deafblind people can break down the isolation they experience. Earning money and taking part in work enables people to be independent, make friends and be part of something. With the right support many deafblind people can do a job and take part in

training at work alongside and equal to their colleagues. However, without the right support this is not possible. It is vital that deafblind people have the right to receive the support they need to work in all the Member States of the European Union.

### 2.3 Do deafblind people have the right to receive specialist social care? ( For example, assessments and one to one support)

Yes	76%
No	24%

Yes                      Romania, Norway and Switzerland

People who are deafblind have very specific needs and services that are developed must suit those specific requirements. Without the right to receive specialist social care, deafblind people will remain isolated and unable to carry out everyday tasks.

### 2.4 Do deafblind children have the right to receive an education?

Yes	90%
No	5%
No answer	5%

Yes                      Romania and Norway

Spain is the only country where deafblind children do not have the right to receive an education.

It is vital that deafblind children have the right to receive an education which takes into account their very specialist needs. Children need to be able to receive an education to enable them to develop their communication and interactive skills.

2.5 Is there a specific programme for identifying newly diagnosed deafblind people?

Yes	38%
No	62%

Yes	Romania and Switzerland
No	Norway

A programme for identifying newly diagnosed deafblind people is vital to find out how many deafblind people there are in each country. National or local government departments or health departments need to know how many people are deafblind in order to be able to plan services and make sure there is funding available to pay for those services. Without a programme for identifying newly diagnosed deafblind people many will not be identified and will not receive the services they need.

2.6 Is there specific training in deafblindness for professionals assessing the needs of deafblind people?

Yes	43%
No	52%
No answer	5%

Yes	Norway and Switzerland
No	Romania

Specific training is vital for professionals who are assessing the needs of deafblind people because deafblindness is a unique disability which is not just the sum of deafness and blindness. Proper assessments need to be carried out by people who really understand the effects of deafblindness to make sure that people receive the services they need. In many cases the training that is provided is not a recognised qualification, but instead individualised courses are provided by voluntary organisations.

2.7 Is there specific training for interpreters and communicators supporting deafblind people?

Yes 52%  
No 48%

Yes Norway  
No Romania and Switzerland

Deafblind people are often isolated and unable to communicate with the people around them. Interpreters and communicators can be their link to the world. This training leads to a recognised qualification in many of the countries where it is provided. In the countries where no training is available, many deafblind people rely on friends or family to provide them with a link to the world. This can be unreliable and place an enormous strain on relationships.

2.8 Is there specific information about deafblindness for families?

Yes 86%  
No 14%

Yes Romania, Switzerland and Norway

When families receive a diagnosis of deafblindness for their son or daughter they need information and support to help them cope. In the majority of cases this information is provided by the organisations who responded to the survey. However, in some countries local government is providing this information for families.

2.9 Are there Early Intervention (EI) services for deafblind people?

Yes 67%  
No 33%

No Romania and Switzerland  
Yes Norway

'Early intervention for children who are deafblind' (Murdoch PhD 2002) describes the importance of early intervention.

“Early intervention has been recognised for several decades as a means of ameliorating the developmental constraints associated with disability. The developmental consequences of deafblindness indicate a need for early intervention which involves families, a need for specialist intervention and a need for co-ordinated services.”

“For children with deafblindness, intervention must include the provision of information normally available through sight and hearing. This role may be undertaken by trained intervenors or by parents or others in contact with the child.”

Early intervention is also important for adults who are in the process of losing their hearing and/or vision. It is much easier to learn new methods of communication and new ways of getting around before you lose your hearing and/or vision than it is once a person is deafblind.

It is vital for both deafblind children and adults that early intervention services are provided.

## 2.10 Do specific programmes exist for?

### 2.10.1 Children – birth to school age

Yes	62%
No	33%
No answer	5%

Yes                      Romania, Switzerland and Norway

### 2.10.2 Young people – school/college age

Yes	71%
No	19%
No answer	10%

Yes                      Romania, Switzerland and Norway

### 2.10.3 Adults

Yes	57%
No	38%
No answer	5%

Yes Romania, Switzerland and Norway

### 2.10.4 Older people

Yes	38%
No	47%
No answer	15%

Yes Romania, Switzerland and Norway

Specific programmes for people of different age groups are very important, as they can help to ensure that people receive the services that are appropriate to them. For example, the needs of a child who was born deafblind are very different from the needs of a person who acquires deafblindness later in life.

## 2.11 What places do deafblind people live in in your country?

As with any other group of people deafblind people live with their parents, with friends, alone or in supported living accommodation.

In some of the countries, including Spain and Slovakia, there are deafblind people living in institutions, such as long stay hospitals, that are not appropriate for their needs.

## 3. Recommendations

- Deafblindness needs to be recognised as a separate disability throughout the European Union. Individual countries should decide on the best way to recognise deafblindness to make sure that specialist services are provided.
- Programmes to identify newly diagnosed deafblind people need to be set up across the European Union. Once people are identified they can then be linked with specific services for deafblind people.
- Deafblind people should have the right to receive the support they need in order to be able to work and take part in training at work throughout the European Union. Individual countries need to decide on the best way to ensure that deafblind people have the right to receive this support to enable them to work.
- Deafblind adults and children in all the Member States of the European Union should be entitled to receive early intervention services.
- Deafblind children and young people in all the Member States of the European Union should have the right to receive an education in either a mainstream school or a specialist school, depending on what is appropriate for the individual. Teachers working with deafblind children need specialist training.
- In some of the Member States, training programmes need to be established to train interpreters and communicators to support deafblind people.
- In some of the Member States, deafblind people are living in inappropriate residential situations, such as long stay hospitals. They need to be moved out of these inappropriate places into more suitable living arrangements with the appropriate support.

## 4. Conclusions

Many deafblind people across the European Union are isolated and unable to take part in everyday activities because they are not receiving the support and services they need.

This survey has shown that there are countries in the European Union where deafblindness is recognised as a separate disability, deafblind people are receiving specific services and are able to get the support they need to work. However there are other countries where deafblind people who do not have any of these rights and the only support they receive is provided by voluntary organisations that have been set up by the parents of deafblind children.

It is vital that there is widespread recognition of deafblindness as a separate disability across the European Union, so that deafblind people have the same life chances as other European citizens.

## 5. Appendices

### Appendix 1

#### What is the situation in specific countries?

##### Austria

In Austria there is no specific recognition of deafblindness, no programme for the specific identification of newly diagnosed deafblind people and no training for professionals or interpreters. However, OHTB (the Austrian Relief Organisation for people who are deafblind and people with significant vision and hearing impairments) is involved in providing specific information about deafblindness for families and provides early intervention services as well as specific programmes for deafblind people of all ages, at times jointly with other organisations. Deafblind people have the same rights to work as other people with disabilities, but in reality OHTB say that does not mean they receive the support they need. They have the right to receive specialist social care but the funding is not sufficient, so people have to finance some of the care they receive themselves.

##### Belgium

In Belgium deafblindness is not recognised as a specific disability, and people receive services that relate to their hearing or visual loss. There is no programme to identify newly diagnosed deafblind people and no training for professionals in assessing the needs of deafblind people. There is a programme for interpreters for deaf people, that includes a section on how to communicate with deafblind people who may want to use their service. There is information about deafblindness available to families, there are Early Intervention services and there are specific programmes for children, young people and adults. There is, however, only limited early intervention with people who have acquired deafblindness in adulthood and no specific programmes for older people. The benefits provided to deafblind people who are not in work are very generous, unfortunately they are often they are so good that working is not an option. The right to specialist social care is available to deafblind people, including interpreter time, free use of public transport, lower prices for telephone and electricity and some funding towards the costs of equipment.

## Cyprus

In Cyprus deafblindness is not recognised as a separate disability. There is no programme for the identification of newly diagnosed deafblind people and no training for professionals assessing the needs of deafblind people or for interpreters. There is no specific information about deafblindness for families or Early Intervention services for deafblind children or adults. There are services for children, young people, adults and older people who have either a visual or hearing impairment, but there are no services for children or adults who are deafblind. There is legislation giving disabled people the right to the support they need to work and the right to social care, and this includes deafblind people. Deafblind children have the right to an education but there is a lack of expertise and appropriate educational programmes. Deafblind people, parents and friends are in the process of trying to form an association in Cyprus so that they support one another and work together to get recognition of deafblindness.

## Czech Republic

Deafblindness is not recognised as a specific disability in the Czech Republic. There is no specific programme for the identification of newly diagnosed deafblind people and there is no training for professionals assessing the needs of deafblind people or for interpreters. LORM, the society for the deafblind in the Czech Republic that responded to the questionnaire, produce information about deafblindness for families. They are also working on a course to train interpreters and personal assistants. There are Early Intervention services for children who have hearing or visual impairments, but no specific services for deafblind children. Deafblind people do not have the right to the support they need to work or the right to receive specialist social care, but children do have a right to receive an education.

## Denmark

Deafblindness is recognised as a specific disability in Denmark. There is a specific programme for identifying newly diagnosed deafblind people and training for professionals assessing the needs of deafblind people and also for interpreters. The counselling service of the Centre for the Deafblind provides information about deafblindness for families and Early Intervention services. Deafblind people have the right to receive specialist social care and there are specific programmes for children, young people and adults.

## Estonia

Deafblindness is not recognised as a specific disability in Estonia and there is no specific programme for identifying newly diagnosed deafblind people. The Estonian Support Union of Deafblind collects information on the numbers of deafblind people, but there is no government programme for detecting people. The Estonian Support Union of Deafblind provides some training for professionals assessing the needs of deafblind people and for interpreters and communicators. There are no specific programmes for children, young people, adults or older people and deafblind people do not have a right to receive specialist social care. Deafblind children have the right to receive an education in special schools for deaf or blind children.

## Finland

Deafblindness is not recognised as a separate disability in Finland and there is no specific programme for identifying newly diagnosed deafblind people. There is no specific training for professionals assessing the needs of deafblind people but there is training for interpreters and communicators supporting deafblind people. There are several schools for interpreters in Finland and the training takes place there. Information for families is provided by the Finnish Deafblind Association. Ten regional counsellors provide Early Intervention services. There are no specific services for children, young people, adults or older people. There is a law enabling all disabled people to get the support they need to work, which includes deafblind people but makes no special mention of them. Deafblind people have the right to receive specialist social care and all children have the right to an education.

## France

Deafblindness is recognised as a separate disability in France. There is no comprehensive system to identify newly diagnosed deafblind people, but there is a register of deafblind people. Training for professionals and interpreters is organised by a voluntary organisation, CRESAM. Early Intervention services are provided, as are specific programmes for children, young people, adults and older people. There is a system which enables all disabled people to get the support they need to work, that includes deafblind people. Deafblind people do have the right to receive specialist social care, but whether they get it depends on where they live. Deafblind children have a right to receive an education, either in mainstream schools or special schools.

## Germany

There is no official recognition of deafblindness in Germany. There is a specific programme for identifying newly diagnosed deafblind people which is carried out by organisations of/for deafblind people. There is training provided for professionals assessing the needs of deafblind people and for interpreters supporting deafblind people. Early Intervention services are provided for deafblind people and there are specific programmes for children, young people, adults and older people. Deafblind have the right to receive the support they need to be able to work and to receive specialist social care. Children who are deafblind have the right to receive an education.

## Greece

Deafblindness is not officially recognised in Greece as a separate disability. A programme for the identification of newly diagnosed deafblind people is carried out by one of the voluntary organisations. There is no training provided for interpreters and communicators supporting deafblind people but there is a teacher who provides training for professionals who are assessing the needs of deafblind people. The Greek Association for deafblind people provide specific information about deafblindness for families. There are no Early Intervention services or specific programmes for children, young people, adults or older people. Deafblind people do not have the right to the support they need to be able to work, but they do have the right to receive specialist social care. Deafblind children have a right to receive an education and a school for deafblind children has been set up by the Ministry of Education.

## Hungary

Deafblindness is not recognised as a separate disability in Hungary. The Hungarian Deafblind Association is in the process of trying to identify deafblind people. There is training provided for professionals assessing the needs of deafblind people but at the moment there is no specific training for interpreters and communicators working with deafblind people. The Hungarian Deafblind Association provides information for families and they are beginning to work on Early Intervention services. There are specific programmes for children, young people and adults but not for older people. Deafblind people do not have the right to the support they need to work or to receive specialist social care. Deafblind children do have a right to receive an education and there is a deafblind unit in the state school for the blind.

## Ireland

Deafblindness is not recognised as a specific disability in Ireland and there is no national programme for identifying newly diagnosed deafblind people. There is no formal training for professionals assessing the needs of deafblind people or for interpreters and communicators, but training is provided in-house by the Anne Sullivan Foundation, a voluntary organisation. There are no Early Intervention Services or specific services for children. The Anne Sullivan Foundation provides services specifically for young people and adults. The St Josephs Residential Centre provides services for older people. The legislation that covers all disabled people gives deafblind people the right to receive the support they need to work and take part in training at work and the right to receive specialist social care. The legislation that gives all children a right to an education includes deafblind children but the specialist provision does depend on where a child lives.

## Italy

There is no official recognition of deafblindness as a separate disability in Italy. The only law that mentions deafblindness is the Drivers Code in which drivers are required to recognise the red and white cane, to indicate that a pedestrian is deafblind. There is no specific programme for identifying deafblind people but Lega del Filo D'Oro is notified when a person needs to be assessed. There is no specific training for professionals who are assessing the needs of deafblind people, but there is training for interpreters and communicators. This training is not state-recognised yet, but there is work taking place to try and make this happen. Lega del Filo D'Oro provides information to families and assessments for Early Intervention services. Specific programmes are available for children, young people, adults and older people. Deafblind people do not have a right to the support they need to take part in work and training but Lega del Filo D'Oro do talk to employers and provide information. Deafblind do have a right to receive specialist social care, but not all of the care they receive is funded by social services, some is paid for by Lega del Filo D'Oro. Deafblind children do have a right to receive an education with extra support as appropriate.

## Lithuania

In Lithuania there is no official recognition of deafblindness or programme for identifying newly diagnosed deafblind people. There is no training for professionals assessing the needs of deafblind people or for interpreters and communicators who support deafblind people. There is some

information available for families in hospitals. There are some services for children. Deafblind people do not have the right to receive the support they need to work or to receive specialist social care. Deafblind children do have the right to receive an education and a department for deafblind education has been founded in the training centre for the blind.

## The Netherlands

In the Netherlands deafblindness is not recognised as a specific disability. There is a programme for identifying new cases. There is training for professionals assessing the needs of deafblind people and for interpreters and communicators supporting deafblind people. Early Intervention services are being developed and information is available for families. Specific programmes are available for children, young people, adults, and older people and people who also learning disabilities. Deafblind people have a right to receive the support they need to work and they have a right to receive specialist social care. Deafblind children have the right to receive an education in various different schools including some mainstream schools.

## Poland

In Poland deafblindness is not recognised as a specific disability and there is no programme for identifying newly deafblind people. There is training for professionals in assessing the needs of deafblind people provided by the Polish Association for the Welfare of Deafblind People but it is not formally recognised. There is training for interpreters and communicators supporting deafblind people. There is no specific information for families about deafblindness and no Early Intervention Services. There are no specific programmes for children, adults or older people but young people can receive education services. Along with all other disabled people deafblind people have the right to receive the support they need to work and receive specialist social care. Deafblind children have the right to receive an education and there is a unit in the school for the blind.

## Portugal

There is no official recognition of deafblindness in Portugal and there is no programme for identifying newly diagnosed deafblind people. The Ministry of Education has a register of deafblind students but there is no other register of deafblind people. There is no training for professionals assessing the needs of deafblind people or for interpreters and communicators. There is no information about deafblindness for families, but there are Early

Intervention Services which are not deafblind specific. There is no specific programme of services for children or older people but there are specific programmes for young people and adults. Deafblind people do not have the right to the support they need to work and though they do have the right to social care the services will not be deafblind specific. Deafblind children have a right to receive an education and there is a special school at Casa Pia.

## Slovakia

There is no official recognition of deafblindness in Slovakia. The parents' organisation is planning to fight for this recognition. There is no programme for identifying newly diagnosed deafblind people and no training for professionals assessing deafblind people or for interpreters or communicators. Information for parents is provided by one of the organisations for deafblind people. There are no Early Intervention Services, but there are services for children, young people and adults provided by voluntary organisations. There are no specific services for older people. There is no legislation giving deafblind people the right to the support they need to work or to receive specialist social care, but the government does provide some funding to the parents association to provide services. Deafblind children have the right to receive an education and the government has accepted that they need one to one teaching, but the funding has not been provided to ensure that happens. There are deafblind people in Slovakia who are living in long stay hospitals which are not the most appropriate places in most cases.

## Spain

There is no official recognition of deafblindness in Spain and there is no specific programme for identifying newly diagnosed deafblind people. There is training for professionals assessing the needs of deafblind people and for interpreters and communicators but the representative from the organisation APASCIDE who replied did not feel the courses were really adequate. Information for families is available from voluntary organisations APASCIDE and APSOCECAT. There are Early Intervention Services and specific services for children and young people but apparently they only reach a small number of people. There are no specific services for adults or older people. Deafblind people do not have the right to receive the support they need to be able to work or to receive specialist social care. Deafblind children do not have the right to receive an education. There are some deafblind people living in long stay hospitals which are not the most appropriate places in most cases.

## Sweden

Deafblindness is officially recognised in education and healthcare legislation. In other areas deafblindness is not specifically mentioned but there are laws for all disabled people that include deafblind people. There is a programme for identifying newly diagnosed deafblind people and Early Intervention Services. Voluntary organisations provide training for professionals in assessing the needs of deafblind people but it does not lead to a formal qualification. Training leading to formal qualifications is available for interpreters and communicators. Regional authorities are required to provide interpreter services for deafblind people. Training in using objects of reference is also available from voluntary organisations. Information and services are available at rehabilitation centres based in the major regions of the country. Legislation for all disabled people gives deafblind people the right to the support they need to work and to receive specialist social care. Deafblind children have a right to an education and there is a school for deaf children with additional disabilities.

## UK

In the UK there is official recognition of deafblindness in England and Wales but not in Scotland or Northern Ireland. This recognition is in the guidance that the government issued to local authorities on the services they should be providing to deafblind people. The guidance includes the requirement for local authorities to identify deafblind people in their area. Training for professionals on assessing the needs of deafblind people is provided by Sense and Deafblind UK but it does not lead to any formal qualifications. Training for interpreters and communicators is provided and leads to formal qualifications. Specific information for families is provided by Sense and Deafblind UK. Early Intervention Services are in the process of being developed. There are specific services for children, young people, adults and older people depending on where you live. Legislation for all disabled people gives deafblind people the right to the support they need to work and take part in training at work. The guidance to local authorities includes a requirement that deafblind people should be able to receive specialist social care. Legislation covering education for all disabled children gives deafblind children the right to receive an education.

## Romania

In Romania there is now recognition of deafblindness as a distinct disability, it is mentioned in various government laws. There is some work taking place identifying newly diagnosed deafblind people but it is not

organised by local authorities at the moment. Multi-disciplinary teams from local authorities assess people's needs but not all of them know about deafblindness. There is currently no specific training for professionals who are assessing the needs of deafblind people or for interpreters and communicators. The Parents' Association provides information on deafblindness for families. Work on establishing Early Intervention Services is beginning to take place. There are specific services for children, young people, adults and older people. There is legislation which gives Deafblind people the right to specialist social care. Deafblind children have the right to receive an education and there are now deafblind units in a few schools around the country.

## Norway

Deafblindness is recognised as a specific disability in Norway. There is no programme for the identification of newly deafblind people. There is a national register of deafblind people, which includes the cause of deafblindness. Specific training is available for professionals in assessing the needs of deafblind people and for interpreters and communicators. Specific information for families is available from regional support centres and the parents' association. Early Intervention Services are provided from regional support centres. There are specific services for children, young people, adults and older people. Deafblind people have the right to the support they need to work and to receive specialist social care. Deafblind children have the right to receive an education. The majority of children go to mainstream schools, but there are also two state funded deafblind schools.

## Switzerland

Deafblindness is not recognised as a specific disability in Switzerland. There is no programme for the identification of newly deafblind people. There is specific training in deafblindness for professionals assessing the needs of deafblind people, but there is no training for interpreters and communicators. A new brochure was issued in September 2004 about services for deafblind children. Early Intervention Services are provided. There are specific services for children, young people, adults and older people. Deafblind people have the same rights as all other disabled people in Switzerland to receive the support they need to work and take part in training at work and to receive specialist social care, paid for by the Swiss social insurance system. Deafblind children have the right to receive an education in either special school or mainstream schools.

## Appendix 2

# WRITTEN DECLARATION

for entry in the register

pursuant to Rule 51 of the Rules of Procedure

by Richard Howitt, Mario Mantovani, Elizabeth Lynne, Patricia McKenna and Ilda Figueiredo

on the rights of deafblind people

Adopted by European Parliament 1 April 2004

### **The European Parliament,**

- having regard to Rule 51 of its Rules of Procedure,

- having regard to Article 13 of the Treaty on European Union and the principle of human dignity,

- A. whereas deafblindness is a distinct disability that is a combination of both sight and hearing impairments, which results in difficulties having access to information, communication and mobility,
- B. whereas there are about 150,000 people in the European Union who are deafblind,
- C. whereas some of these people are completely deaf and blind, but most have some remaining use of one or both senses,
- D. whereas, having a distinct disability, deafblind people need specific support provided by people with specialist knowledge,
  - 1. Calls on the institutions of the European Union and the Member States to recognise and implement the rights of people who are deafblind;

2. Declares that deafblind people should have the same rights as are enjoyed by all EU citizens; these should be enforced by appropriate legislation in each Member State and should include:
  - the right to participate in the democratic life of the European Union;
  - the right to work and access training, with appropriate lighting, contrast and adaptations;
  - the right to person-centred health and social care;
  - the right to lifelong learning;
  - the right to receive one-to-one support where appropriate from communicator-guides, deafblind interpreters and/or intervenors;
3. Instructs its President to forward this declaration to the Commission, the Council, and the governments of the Member States.

## Appendix 3

This was the Charter produced by the 2002 Social Inclusion project.

# **A charter for the deafblind citizens of Europe**

## **Deafblindness**

Deafblind people face unique disadvantages in a world that is organised for the hearing and sighted. There are at least 150,000 deafblind citizens living in the European Union; together they represent one of the most socially excluded groups of European citizens. Fundamental human rights are the basis of the European Union, and yet they continue to be denied to deafblind people.

## **Deafblind people have the right to participate –**

Deafblind people have the right to take their place as active citizens of the European Union, participating fully in the democratic life of the Union and its Member States and contributing to the development of policy. The goal of participation by deafblind people should be self-advocacy. This can only take place if

- deafblind people are provided with one-to-one support where appropriate, in the form of Communicator-Guides, Deafblind Interpreters and/or Intervenors
- institutions in Europe and Member States become fully accessible by providing information in formats which can be understood by deafblind people such as large print, moon, audio tape, braille.

## **Deafblind people have the right to work –**

Deafblind people have a right to access training and employment alongside their non-disabled peers.

- Member States and Accession Candidate countries must legislate to ensure that this right is enshrined in employment practice
- work environments are adapted where necessary to include appropriate lighting, contrast and adaptations.

## **Deafblind people have the right to person-centred care –**

Deafblind people have the right to high standards of person-centred health and social care. This can only be achieved if

- medical procedures are properly explained to deafblind people
- care and health staff are appropriately trained in deafblind issues.

## **Deafblind people have the right to life-long learning –**

For deafblind people, learning is a critical right that must be offered from early intervention through to vocational training. This right must be

- specialist education support that recognises their needs as a deafblind person enshrined in the education policies of Member States and the European Union.

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