European
Deafblind
Indicators

MAPPING OPPORTUNITIES FOR DEAFBLIND PEOPLE ACROSS EUROPE

Government and voluntary sector responses to the growing issue of deafblindness in Europe

May 2014

Lifelong
Learning
Programme

EDbN
European
Deafblind
Network

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Contents

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Disclaimer

While every effort was made to check the accuracy of the report, this has not always been possible and the data may inevitably be inaccurate in some places. Data included in this report have been supplied by individual representatives of voluntary organisations in each country or region, on behalf of their country or region, and are not official or governmental responses. European Deafblind Indicators cannot be held responsible for future use of the information contained within the report.

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Abbreviations

Comms support	Support that aids a deafblind person’s communication
EU	The European Union
Hr p/w	Hours per week
IDBE	Indicators of Deafblindness in Europe
IDEE	Indicators of Disability Equality in Europe (*the basis for IDBE*)
IS	Interpreter Services
PA	Personal Assistance
SLI	Sign Language Interpreter
UN-CRPD	United Nations Convention on the Rights of Persons with Disabilities

Glossary

Accessibility	The extent to which individuals can access the physical environment, transportation, information and communication technology, and other facilities and services open or provided to the public. Physical and sensory accessibility is important for deafblind people.
Activities of Daily Living	Activities performed on a daily basis, including personal care, eating, shopping, cooking, getting dressed, bathing, etc.
Audio description	A spoken visual description or narration track i.e. of a TV programme/film intended primarily for the blind and visually impaired
Autonomy	The extent to which a disabled person is able to exercise choice over their day-to-day lives. To be autonomous is to have a voice, choice and control over any aspect of everyday life
Communal home settings	Individuals who live in shared accommodation with some form of support, e.g. settings such as residential homes
Early rehabilitation	A programme designed to equip someone with the necessary communication and practical skills for everyday living
Environmental communication method	Specialised communication methods such as tactile adaptations to sign languages and using mobility and orientation clues from the environment
Financial Assistance for Essential Devices	Financial provision for essential devices such as basic adaptive equipment for the home, ramps, mobility aids etc.
Financial Assistance for Life	Financial support for disabled individuals for life, typically available at those whose condition is unlikely to improve
Guaranteed minimum income	A system of social welfare provision that guarantees that all citizens have an income sufficient to live on
Independent Living	Adults who have a disability and live independently and do not require formal support
Intervener	A person who works consistently one-to-one with an individual who is deafblind. The combined loss often compromises the ability to access information in the environment or to communicate effectively. Interveners, through the practice of intervention, provide a vital link to the people, things and events in the world surrounding a person who is deafblind. Interveners provide services in educational settings for students, as well as in early intervention and community settings.
Occupational rehabilitation	A program designed to support individuals to return to work
Personal assistant	A role that supports disabled people with activities of daily living
Rare disease	A disease that affects less than 5 in 10,000 of the general population
Sign Language Interpreter	Someone who has been trained to use sign language: a system of conventional symbols or gestures made with the hands and the body which help individuals who are deaf, hard-of-hearing or with speech impairments to communicate
Special rehabilitation program for the elderly	A programme designed to maintain functional independence for the elderly
Specific Personal Professional Assistance	Financial assistance for the employment of a personal support/assistance (see PA, above) to help with activities of daily living
Subtitling for deaf	Written captions that translate or transcribe the dialogue or narrative i.e. of a TV programme/film
Support Worker	A person who provides care and support to a deafblind person; this includes emotional and practical forms of support
Supported accommodation	A living situation where children or adults with disabilities receive occasional assistance by support staff for activities of daily living
Tactile communication method	A form of nonverbal communication; tactile communication such as haptic communication and hand-over-hand (hands-on) signing

The key to humanity's talent

As a re-elected deaf MEP with the kind support of the national disability organisations as well as international community, I sincerely respect people with deaf blindness and consider them as a specific group with a distinct, unique and complex disability affecting sight and hearing altogether.

They indeed represent the youngest but not the least important "generation" in the field of international disability movement. What's more, they indeed can frame the development of disability rights within the activity of the United Nations because the first disabled group to be dealt with at international level during 1950s was the blind and in this respect the last group became the deaf in the 1980s. Deaf blindness therefore combines and intertwines these groups which mean greater responsibility and respect for these people. They are my heroes: despite I hardly can imagine a world without sight and sounds; I know they represent the force of will and real talent of humanity to live and adopt to new challenges.

We now have an excellent foundation to get to know their situation as well as to build on: based on a survey in 27 European States or regions this report provide us, for the first time, of an overview of the current state of services, support and legal rights for deafblind people across Europe.

Let me note that on the account of the importance of studies and analyses, as your representatives from Hungary might already informed your community, I personally conducted and commissioned disabled experts, including your Hungarian experts on the deafblind, covering all disabilities with the involvement of a member of the Convention on the rights of persons with disabilities (CRPD) and an expert from academia last year. Our joint work turned out to be entirely fruitful: the Hungarian government acknowledged this effort important and it also know more what NGOs think about their needs and suggestions.

Even though in the Hungarian focal point of CRPD and official advisory body on disability affairs for the Hungarian government the Hungarian deafblind are represented, more needed to be done.

In Europe, as we all know generic disability services are not suffice for deafblind people who need specialist support. The official recognition of the deafblind definitely supports their further opportunities to have better access to funds and financial means.

In Europe making progress in the field of identification, support and prevention of the deafblind seems to be difficult since most social related competencies and funding belongs to national level. However, the so-called and long awaited European Accessibility Act of the European Union due to be proposed since 2012 may accelerate better access to services and tools for the deafblind.

I do hope that the deafblind community at international level will be as active as the Hungarian colleagues and make sure that the EU institutions will hear about your precise needs and suggestions.

Ádám Kósa, MEP

1. Introduction

More people than ever are living with deafblindness.

Nearly 3 million people in Europe may face issues associated with combined hearing and sight problems; this report is a rare opportunity for their voices to be heard.

1.1 Scope of the study

The purpose of this report is to provide an overview of services, support and legal rights for deafblind people across Europe. Drawing together information relating to the life opportunities of deafblind citizens in 27 European states and regions (such as for housing, education and employment) this report aims to raise awareness of deafblindness so that the needs of deafblind people are considered in future developments of national and international disability policy. This report provides a snapshot of the types of provision and support available across Europe along with recommendations for how to improve opportunities for deafblind people.

1.2 Introduction

The condition of deafblindness is not well recognised although it is becoming more common in line with the ageing demographic of Europe. Although the term ‘deafblindness’ leaves little room for misunderstanding, many people are unaware of the causes of deafblindness, the variation of impairment that may be experienced and the impact of deafblindness on everyday life. The report is based on the findings of a survey regarding the rights and opportunities of deafblind people, in 27 European states or regions.

1.3 What is deafblindness?

Deafblindness is a distinct and unique disability affecting sight and hearing; it is different to the separate conditions of blindness and deafness. ‘Deafblindness’ does not refer only to profound blindness and deafness; it refers to any degree of dual-sensory impairment. It is *the combination* of both impairments that creates the most significant issues for individuals. The most widely accepted working definition of ‘deafblindness’ is found in the Nordic definition which explains commonly referred to ‘types’ of deafblindness. It is the definition used in this report:

Nordic definition of deafblindness

“Deafblindness is a distinct disability. It is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology (*Nordisk Lederforum, 2007*).

- **Congenital deafblindness**: born deaf and blind or becoming deaf and blind early in life before the development of language (pre-lingual deafblindness).
- **Acquired deafblindness**: becoming deaf and blind after the development of language (post-lingual deafblindness).
- **Older people’s deafblindness** (+65 years): Acquired deafblindness which appears in old-age. This is an emergent and little known situation”.

1.4 What causes deafblindness?

Deafblindness is caused by many conditions, some of which are rare and complex. It affects people of all ages and cultures and may be the result of prematurity or birth trauma, exposure to infections such as Rubella (Congenital Rubella Syndrome), rare conditions such as CHARGE or Usher Syndrome or due to changes in sight and hearing in older age. For many, the cause of their deafblindness is unknown or undiagnosed. A list of examples of these causes is listed in Table 5.

1.5 Why this report, now?

This is the first overview of opportunities and services for deafblind people across Europe. Deafblind people’s needs are not routinely considered in disability policy so this is an attempt to bring into focus the extent of deafblindness and the ways in which we should seek to support deafblind people. Disparities between the current levels and types of service provision across Europe make it increasingly difficult for organisations, governments and health system evaluators to assess and compare different models of support available to deafblind people. This report therefore gives focus to the differences between states in their approach to disability rights, social care and legislative responses for the first time and calls for the development of a common framework in order to systematically assess the situations of deafblind people now and in the future.

More children are surviving prematurity and childhood illness and we are living longer than ever; welcomed medical advancements that actually increase the likely presence of deafblindness. This condition therefore needs be better understood by more practitioners (particularly in the health and social care sectors) and the needs of deafblind people must feature in future policy developments. There has been some attempt at improving the life experiences and opportunities of disabled people across the EU under the United Nations-Convention for the Rights of Persons with Disabilities (UN-CRPD) but there is little discussion about how these commitments could be extended to those face problems with communication, mobility and access to information.

The report also shows that whilst we have collectively made significant progress, there is still much to do. We have a commitment to uphold the rights of deafblind people and it is not enough to rely on deafblind organisations to do all of the work without better resources. This report speaks up for deafblind people because in a world where this issue is ignored there is a world that continues to be silent and dark for more and more people.

2. The project

This report represents the culmination of a two year project financed by the European Commission under its Lifelong Learning Programme: the Grundtvig Learning Partnership. The Project Group comprised nine deafblind organisations[1] (from eight European Union Member States) working together from September 2012 to September 2014 to develop a survey tool to explore the rights and opportunities for deafblind people across Europe. All of the individual members of the project group are part of the European Deafblind Network and it is through this Network that the project was conceived and developed.

The group were responsible for the progress of the project including the development of the survey, analysis of the results and the organisation of project group meetings. The survey, based on the IDEE document, was designed to explore the context of deafblind services and the rights and opportunities of deafblind people across Europe. This was developed alongside direct feedback and consultation with deafblind people and their families at a number of forums.

Table 1: **Project Group members**

Spain	**CT (ES)**	Catalan Association Pro Deafblind People (APSOCECAT) **(Project Co-ordinator)**
UK	**UK**	Sense, The Deafblind and Rubella Association
Scotland	**S1**	Sense Scotland, The Deafblind and Rubella Association
France	**FR**	National Resource Centre for Rare Disabilities – Deafblindness (CRESAM)
Denmark	**DK**	Centre for Deafblindness and Hearing Loss (CDH)
Austria	**AT**	Austrian Relief Organization for People Who Are Deafblind and People with Significant Vision and Hearing Impairments (ÖHTB)
Netherlands	**NL**	Royal Dutch Kentalis
Slovakia	**SK**	Association of Parents and Friends of Deafblind Children (ZRaPHSD)
Hungary	**HU**	Hungarian Deafblind Association (SVOE)

2.1 Consultation with deafblind people and their families

Between November 2013 and January 2014, deafblind people and their families from 9 states were asked to contribute their views regarding the domains included in the survey, including which domain areas they considered to be most important to them, a write up of these findings can be found on the project website: http://deafblindindicators.eu/

A total of 95 questionnaires were completed and returned, 70 from deafblind people using services and 25 from family members of people using services.

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[1] The application was initially submitted by 14 organisations; however five organisations were not successful in securing funding.

2.2 Project meetings

Five project meetings took place during the course of the project in order for project team partners to discuss the development and distribution of the questionnaire.

Table 2: **Consortium meetings**

November 2012	Glasgow (S1)	Working groups created Website launched
June 2013	Aalborg (DK)	Indicators discussed and decided
August 2013	Lille (FR)	Questionnaire confirmed
February 2014	Sint-Michielsgestel (NL)	Results of questionnaire presented and discussed
June 2014	Barcelona (CT) Final congress	National models presented Official report launched

Questions about seven domains were incorporated into the survey: Deafblindness demographics, Personal and family life, Choice and control, Access to goods and services, Education and lifelong learning, Work and employment, and Incomes and poverty.[2] See *Fig. 1.* below for an overview of how the survey was developed.

The survey was sent to contacts in 29 countries and regions in October 2013 and a total of 27 responses were returned (including surveys from the project group members) from 25 separate European states.[3] ***For more information about the contributors, see the list of organisations that returned a survey on pages 4-6.***

2.3 A note on the quality of the data

The information received from the survey returns was extremely insightful and many states were careful to qualify and contextualise their answers. However, many of the questions in the survey were designed to yield 'yes' or 'no' answers rather than context. The reality is often much more complex; if a state answers 'yes' to a question about whether an example of this service exists, that does not mean that this service is universally provided, widely available or appropriate for deafblind people. Trying to synthesise such disparate contexts has been a difficult task and where possible, additional information has been included to provide more context. Further in-depth studies will be needed to investigate these situations in more detail. It is also important to note that respondents answered the survey in English and the vocabulary used across states in relation to services, learning techniques, financial payments etc. may not have been comparable, resulting in some loss of meaning and context. It was

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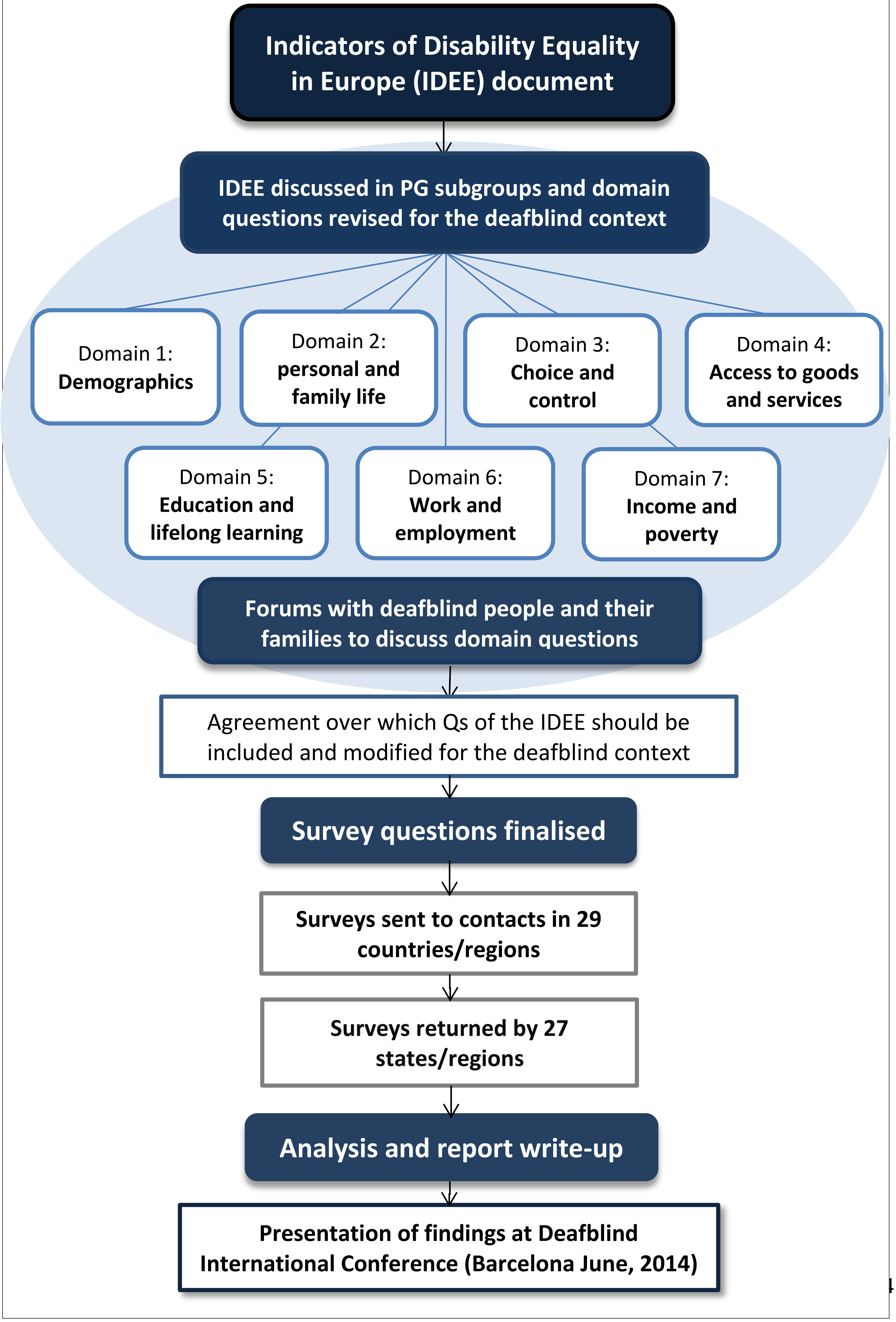
[2] A copy of the survey can be found at http://deafblindindicators.eu/

[3] Catalonia (CT) returned a survey for the region of Catalonia and Spain (ES) returned a separate survey relating to Spain excluding Catalonia. Scotland (S1) returned a survey relating to Scotland only, the UK survey relates to the UK excluding Scotland. Answers for CT and S1 are therefore described separately. CT and S1 will be referred to as 'states' for the purposes of ease and consistency in this report, unless it is necessary to distinguish differences between these states and the wider national/federal context at an ES and UK level.

not possible to cross-check every piece of information but we hope that this report reflects *as accurately as possible* the current opportunities for deafblind people across Europe.

Fig. 1 ***Flowchart of survey and project design***



2.4 The legal landscape

At the suggestion of the European Deafblind Network (EDbN), the condition of Deafblindness was officially recognised by the European Parliament, when the Written Declaration on the Rights of Deafblind Persons was approved in 2004 (Declaration 1/2004). Importantly, this declaration officially sets out the specific barriers detailed in the Nordic definition of 'deafblindness' relating to accessing information, communication and mobility; the widely adopted definition used in this project. The United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) in 2008 has further strengthened the fundamental rights of disabled people and the responsibility of governments to ensure that these rights are upheld. This legal framework provides a standard upon which to ensure disabled people's full and equal access to areas such as employment, education, health and justice. The convention has so far been signed by 154 countries worldwide and ratified by 126, including 24 EU member states. The Optional Protocol, which establishes two procedures aimed at strengthening the implementation and monitoring of the Convention, has been signed by 90 countries and ratified in 76.

Table 3: **Current ratification status of UN-CRPD in project states**[4]

State	Signed	Year ratified	Optional protocol ratified	State	Signed	Year ratified	Optional protocol ratified
ES/CT	✓	2007	✓	**LT**	✓	2010	✓
HU	✓	2007	✓	**FR**	✓	2010	✓
HR	✓	2007	✓	**SK**	✓	2010	✓
AT	✓	2008	✓	**RO**	✓	2011	×
SI	✓	2008	✓	**BG**	✓	2012	×
PT	✓	2009	✓	**EL**	✓	2012	✓
DE	✓	2009	✓	**MT**	✓	2012	✓
IT	✓	2009	✓	**EE**	✓	2012	✓
UK/S1	✓	2009	✓	**PL**	✓	2012	×
CZ	✓	2009	×	**NL**	✓	×	×
DK	✓	2009	×	**FI**	✓	×	×
TR	✓	2009	×	**IE**	✓	×	×

The subsequent implementation of the EU Charter of Fundamental Rights (which became legally binding on EU governments in 2009) goes further to preserve these rights by specifically prohibiting practices that discriminate on the basis of a person's disability (Article 21) and promoting the integration of persons with disabilities in social life (Article 26). The more recent publication of the European Disability Strategy 2010-2020, led by the Directorate General of Employment, Social Affairs and Equal Opportunities of the European Commission, keeps this issue on the table. The strategy covers eight key areas of focus including: accessibility, participation, equality,

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[4] CH has neither signed nor ratified the convention (NL, FI, IE have signed the convention but have not ratified it).

employment, education and training, social protection, health and external action. A timeline for key actions under each strand is included as well as details on the specific barriers for disabled people under each of these themes. Actions under this strategy will be monitored and updated periodically over the first five years and funds will continue to be available for support to projects related to disabled people's opportunities under the European Social Fund.

Despite moves to instate the rights of disabled people in legislation via the charter and strategy, the development of inclusive policies for disabled people has been slow. Disability has only been specifically addressed in two European Union Directives so far: The Employment Directive (2000) and the Air Passengers Directive (2008) both of which include reference to the needs of disabled people in regards to employment rights and air travel but this clearly represents a narrow focus on the lives of disabled people. A proposal for a more widely relevant policy, in the form of an Anti-Discrimination Directive, has been agreed by the European parliament but the European Council, which has been considering the proposal for the last six years (since 2008), has yet to make a decision. Other key developments for supporting inclusivity for disabled people have not yet materialised, including the idea of a European Accessibility Act which could make access to goods and services easier for deafblind people. This is currently being discussed by the European Commission but as yet, no draft has been suggested.

The work of this project then is commensurate with the aims of the European Disability Strategy. The documents generated by the Academic Network of European Disability (ANED), which was established by the European Commission in 2008, have also served as a valuable starting point for this project. ANED's development of the 'Indicators of Disability Equality in Europe' (IDEE) have offered a new framework for comparative monitoring of European-wide disability provision and it is the framework used in this project, albeit modified for the specific deafblind context. This is important since the specific barriers caused by deafblindness, described in the accepted definition, have *specific and unique* impacts on everyday life described under each domain in the IDEE. Under this framework, provision and services for deafblind people can be better understood and compared across states. This is the first step in highlighting the needs of this growing group of people and serves as an overview of the European context. More research and investigation will be required in and across the different domains to ensure that the needs of deafblind people across Europe are protected under UN-CRPD as well as under the Human Rights Act (1998).

3. Domain One
Deafblindness rates/demographics

There could be as many as 3 million deafblind people in Europe

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Table 4: **Estimated population of deafblind people across participating states**

	State	**Population total**[5]	**Calculated deafblindness in population ≤64 (~0.2%)**	**Calculated deafblindness in population ≥65 (~2%)**	**Total expected population of deafblind people**
AT	Austria	8,219,743	13,447	29,920	43,367
BG	Bulgaria	7,037,935	11,514	25,618	37,132
CH	Switzerland	8,036,917	13,341	27,326	40,667
CT	Catalonia	7,565,603	12,589	25,420	38,010
CZ	Czech Republic	10,512,419	17,976	30,486	48,462
DE	Germany	80,523,700	127,872	331,758	459,629
DK	Denmark	5,534,738	9,387	16,826	26,213
EE	Estonia	1,274,709	2,098	4,512	6,611
EL	Greece	9,903,268	16,043	37,632	53,676
ES[6]	Spain	39,493,930	65,436	135,523	200,959
FI	Finland	5,262,930	8,652	18,736	27,388
FR	France	66,000,000	110,352	216,480	326,832
HR	Croatia	4,494,749	7,479	15,102	22,582
HU	Hungary	9,981,334	16,928	30,343	47,272
IE	Ireland	4,209,000	7,442	9,765	17,206
IT	Italy	60,626,442	96,639	246,143	342,782
LT	Lithuania	3,525,761	5,888	11,635	17,523
MT	Malta	416,055	718	1,140	1,858
NL	Netherlands	16,357,992	28,070	46,457	74,527
PL	Poland	38,536,869	66,823	102,508	169,331
PT	Portugal	10,781,459	17,854	37,088	54,942
RO	Romania	21,848,504	37,230	64,672	101,901
S1	Scotland	5,295,400	8,875	17,157	26,032
SI	Slovenia	2,010,347	3,389	6,312	9,702
SK	Slovakia	5,439,448	9,573	13,055	22,628
TR	Turkey	75,627,384	141,726	95,291	237,016
UK[7]	United Kingdom	57,053,047	95,621	184,852	280,473
	Total	565,569,683	**952,964**	**1,781,757**	**2,734,721**

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[5] All data is available via individual countries demography pages at: http://fr.wikipedia.org/wiki. Accessed May 2014

[6] Excluding population of Catalonia (CT)

[7] Excluding population of Scotland (S1)

Recommendations

- Official recognition of deafblindness as a unique disability is required across every state *first and foremost* to ensure that the rights and lives of deafblind people are acknowledged
- National censuses must routinely ask people whether they have sight and/or hearing problems so that we have a better understanding of the *extent and characteristics* of deafblindness
- Health professionals should be mandated to collect data on the number of people diagnosed with, or treated for, conditions causing deafblindness: early detection would significantly improve the lives and experiences of deafblind people
- Schools and Social Services should collect and report data on the populations of deafblind people to a National Deafblind Census Agency
- Eurostat should collect and publish data on the populations of deafblind people to highlight this issue
- Disability organisations must collect data about the lives of the deafblind people they support
- Organisations working with older people must collect data about eyesight and hearing problems since the majority of deafblind people are over the age of 65

Few states collect official data on the number of deafblind people in their population; making it difficult for those campaigning for deafblind issues to demonstrate how widespread the condition is. In fact, only 3 of the 27 states collect official data, i.e. census data, regarding the number of deafblind in their population. We can reasonably infer from this that the extent of deafblindness (and potentially the needs and experiences of deafblind people) are relatively invisible to those not working in this field. At least 13 organisations provided a figure for the number of deafblind people that their organisation works with (i.e. from their internal database), which is a helpful source of information but is likely to underestimate the total figure. Other organisations provided best estimates of this number.

The three states that have a record of the number of deafblind people in the population, demonstrate that this is not an impossible task. In FI for example the mechanism for doing this seems to be via eye doctors (ophthalmologists) or hospitals who record the number of people with visual impairments *and other impairments*. Mechanisms such as a census question/s relating to deafblindness would start to cover some of the gaps in the information we have about the population of deafblind people but this needs to be implemented consistently across populations and states in order to arrive at a more precise prevalence rate.

Because of the lack of official data about deafblindness, an estimated prevalence rate had to be used to calculate the figures in *Table 4* which comes from a study undertaken in the UK in 2010 by the Centre for Disability Research (CeDR) to calculate the prevalence of deafblindness.[8] It is stressed that these figures are *estimates* for the UK and have yet to be verified by subsequent research in other states. This study (and others) indicate that the incidence of deafblindness increases significantly with age and therefore prevalence calculations were applied to separate groups of populations aged 65 and under and those 66 or over. Using the estimates in this study, an *average* rate for these two age groups[9] was applied to the population figures for each state. An average percentage calculation of 0.2% was applied to the 65 years and under group and a higher average calculation of 2% for the 66 and over group. Based on these estimates, there is an indication that the population of deafblind people across the 27 states could be nearly 3 million. It is worth noting that evidence in this study suggests a steep rise in the presence of deafblindness in very old age (13% of those aged over 90 years old are likely to be deafblind). Deafblindness is likely to be a significant issue in states such as DE and IT, which have significantly higher numbers of older people in their populations, or states where the population is older on average. Figures can be found in *Table 6*.

It should also be noted that these estimates do not take into account the differences between individual states in terms of health opportunities, such as access to health care, antenatal provision and vaccination coverage, which may affect the rate of deafblindness. However, considering that Europe’s population is ageing generally, deafblindness will become a reality for many more people in every state regardless.

3.1 Why don’t we have better data about deafblindness?

Deafblindness is a complex condition that lacks official recognition in many states. This may have contributed to the limited data about deafblind people, some of these issues and recommendations for improving data are considered below.

3.2. Deafblindness is a unique and complex condition

In order to gather better information about deafblindness, its causes and impacts need to be better understood. Deafblindness is complex and heterogeneous; there is no single cause of the condition and the combinations and degrees of impairment can occur at any stage in life and will affect individuals differently. ‘Deafblindness’ refers to a *spectrum* of impairment and includes people who have been both deaf and blind from birth (also known as ‘congenital’ deafblindness) as well as those who develop degrees of impairment in their hearing and sight at any time of life (also known as ‘acquired’ deafblindness). The range of currently known conditions causing deafblindness (*Table 5 below*) demonstrates how varied and complex the needs of

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[8] Robertson, J & Emerson, E (2010) *Estimating the number of people with co-occurring vision and hearing impairments in the UK*, Centre for Disability Research, Lancaster University, Lancaster.

[9] Note that these figures were averaged from the ‘upper estimates’ described in this study. The upper estimate is based on the estimated number of people with *any degree* of combined sight and hearing impairment.

deafblind people might be. Many of these conditions are rare syndromes or complex disabilities which are potentially difficult to identify and diagnose.

There are currently more than 80 known causes of deafblindness, including hereditary and chromosomal conditions, pre-natal congenital complications, post-natal non-congenital complications and older age. A sample of these is provided below, for the extended list please refer to http://deafblindindicators.eu/

Table 5: **Examples of causes of deafblindness**

Hereditary/Chromosomal Syndromes	*Examples include:* CHARGE, Alstrom Syndrome, Bardet-Biedl syndrome, Down syndrome, Usher I, II, III Syndrome, Cri du Chat Syndrome, Prader Willi Syndrome, Leber congenital amaurosis, Wolfram Syndrome, Refsum syndrome
Pre-natal/Congenital Implications	*Examples include:* Congenital Rubella, Cytomegalovirus, Congenital Toxoplasmosis
Post-natal/Non-Congenital Implications	*Examples include:* Asphyxia, Meningitis, severe head injury, Stroke, Tumours
Related to Prematurity	*i.e.* complications of prematurity
Undiagnosed	*i.e.* no aetiology can be determined

3.3 The condition of deafblindness lacks official legal recognition

It is important to recognise the condition of deafblindness officially; this would improve understandings of the condition and better support for deafblind people. Official recognition could lead to requirements for health and social care sectors to record this data and this would be a valuable resource of information about how best to support this growing number of people. Currently, little is known about the general characteristics of deafblind people in Europe, including their gender, ethnicity, socio-economic status and co-existing conditions, making progress in the field of identification, support and prevention extremely difficult. Without official recognition the needs of deafblind people are unlikely to be included in future service design and development.

3.4 Why is recognition and identification important?

Better recognition and identification of deafblindness is likely to improve health and wellbeing outcomes for deafblind people. Better recognition of deafblindness should lead to better identification of the condition which is important because it has health implications for deafblind people who feel uncomfortable about their care or receive inadequate healthcare. This is evident in the UK where a study found that the majority (64%) of deafblind people sampled did not feel confident about managing their own health situations and needs, which in turn led to higher levels of anxiety and depression in this group.[10]

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[10] Davies, S.C. (2014) "Annual Report of the Chief Medical Officer, Surveillance Volume, 2012: On the State of the Public's Health" London: Department of Health

The same research indicates that people who are deafblind are also likely to live with other numerous long-term health conditions. Around 69% of deafblind people also live with at least *four* other health conditions and this is especially those who have experienced higher levels of socio-economic deprivation. Where co-existing conditions are complex or chronic, deafblindness may go unnoticed, unrecorded and untreated. If primary and secondary healthcare providers could identify the presence of deafblindness more easily and readily, deafblind people would be less likely to miss out on care for other conditions. With an understanding of deafblindness, medical practitioners would be more aware of the need to give information about treatments, medicines and dosage to deafblind people in appropriate ways. Doctors would be more aware of the impact of deafblindness on someone's ability to self-care or self-medicate and would be able to apply this within the context of health planning. Importantly, better recognition of deafblindness could support deafblind people to better communicate their health needs and receive medical attention more quickly and effectively.

Recognition of age-related deafblindness is imperative, as many older people may not seek support for deteriorating eyesight and hearing if they have associated this with 'natural ageing'. This group will potentially miss out on simple, low-cost interventions such as better glasses or hearing aids. Official recognition would also boost awareness of the condition amongst health professionals who work with older people. Training would also be important, so that staff look out for the presence of deafblindness. Without awareness and training, older people will be at increased risk of isolation, depression and loneliness[11] as a result of deafblindness.

Health outcomes are compromised for deafblind people in these ways but better recognition and identification will not be effective if service designs do not cater for deafblind people. Services prominently rely on the exchange of information online, in person or in writing, as well as on accessing public buildings all of which contributes to the exclusion of deafblind people. An example of inaccessibility is illustrated below.

Example: a GP appointment that is not accessible for a deafblind person

- GP appointment must be made via phone, internet or face to face.
- Appointment details are sent to deafblind person in writing through the post.
- Use of public transport is required to attend the appointment.
- Appointment takes place in a building that is not accessible to a deafblind person (e.g. use of sound and visual displays to call up patient, poor lighting, long walks between entrance and department, lack of tactile signage etc.).
- Healthcare professional cannot communicate with deafblind person resulting in a family member (sometimes a child under the age of 18) interpreting complex/sensitive personal health information to the deafblind person.
- The deafblind person's family member is responsible for administering medication or explaining the required dosage and frequency.

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[11] Vogelpoel and Jarrold (2014) "Social prescription and the role of participatory arts programmes for older people with sensory impairments", Journal of Integrated Care, Vol. 22: 2

Official recognition of deafblindness could also lead to an increase in the number of practitioners specialising in the condition. Currently, deafblind people have to attend separate appointments for sight and hearing problems, but with better recognition of deafblindness ophthalmologists and audiologists could receive training to look for the combined presence of impairments. This would improve early diagnosis of deafblindness in many cases. Deafblind specialists could support deafblind people holistically and reduce the need to attend numerous appointments.

3.5 How do we improve data collection?

Few states collect information about deafblindness through the national census although this would be an optimum way of gathering this data, especially if census questions provide opportunities for respondents to answer 'yes' to separate questions about sight and hearing loss. This would help eliminate responses that require respondents to indicate just one answer, or the impairment they deem 'primary' or most significant. This would also avoid missing those who do not use the terminology 'deafblind' or do not see themselves as deafblind but rather 'dual sensory impaired'. There have been calls for the creation of a disability subsection in the health pages on Eurostat and the dissemination of data collected in European surveys that have included questions that are relevant to deafblindness.[12] This would significantly improve access to information about deafblindness.

Information about deafblind children could also be collected effectively via formal mechanism such as the one developed by The National Consortium on Deafblindness (NCDB) in the US. Every year, data is collected through *The National Child Count of Children and Youth who are Deafblind* for the purposes of identifying national and state technical assistant needs for children and youth who are deafblind, their families and the service providers and systems which service them.[13] Questions on gender, extent of vision loss, aetiology of deafblindness, ethnicity and early intervention setting are included. A survey similar to this across Europe would be invaluable to deafblind organisations and would also potentially improve educational outcomes for deafblind children.

Better recording is essential so that the extent of deafblindness and how to support deafblindness is properly understood.

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[12] For more information see: http://deafblindindicators.eu/images/PDF/EUROSTAT%20Disability%20Statistics.pdf

[13] For more information see: https://nationaldb.org/groups/page/11/national-child-count

4. Domain Two
Personal Life and Family Life

Recommendations

- It is essential that communication training is available for deafblind people in order to promote independence and protection under EU legislation; governments should fund voluntary sector organisations to provide this service
- Voluntary sector organisations should also receive funding from the government to provide training to deafblind people and their family members in how to use equipment and new communication methods; this will help sustain deafblind people's use of vital equipment and independence
- Every state should ensure that there are enough specially trained interpreters and interveners to meet the demand for this service from deafblind people; more training courses are needed for professionals
- There needs to be an end to the overreliance on family members to provide communication and interpreter support to deafblind people

This domain considers deafblind people's participation in social and private life. Organisations were asked if opportunities exist for deafblind people to socialise, in family life and friendships and social and leisure activities, and whether personal assistance and interpreter services are available to facilitate this.

4.1 Personal assistance and Interpreter services support

Table 6: **Is support available to deafblind people to take part in family and social life through Personal Assistance (PA) and Interpreter Services (IS)?**

Support for deafblind people:	Both PA + IS support	PA *only*	IS *only*	None
To have family relations and friendships[14]	CH, CZ, DE, DK, EE, FI, FR, HR, HU, IT, NL, RO, SK, UK	BG, EL, SI, S1	CT, ES, PL, PT	AT, IE, LT, TR
To join leisure activities[15]	BG, CH, CZ, DK, EE, FI, FR, HU, IT, NL, RO, SK, UK	EL, SI	CT, ES, HR, MT, PL, PT	AT, TR

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[14] No IS support in MT but available PA support is 'unknown'

[15] Data not provided for: DE, IE, LT and S1

Personal assistance (PA) and interpreter support (IS) services seem to be available to deafblind people for both family life *and* leisure time across 12 states. The majority of states have some services in place for private and public participation. Two states stated that support options like these are not available to support deafblind people to participate in family or leisure time. Fewer states have support in place for deafblind people to participate in *family activities* compared to *leisure activities,* highlighting a potential disparity between support available for private family life and public participation in leisure activities. As PL point out, many deafblind people will have to rely on a family member to provide this type of support. This is likely to be the case in a number of the states where there are limited services such as this or where deafblind people do not have the resources to pay for this privately.

4.2 Communication support and training

The Nordic definition emphasises that communication is a specific barrier for deafblind people, so it is clear that communication support and communication development needs to be a specific focus of deafblind service provision. Deafblind communication is varied and depends on personal preference, access to training and ability to pursue different methods. Examples of more common types of communication are detailed in Table 7. Because of the unique nature of deafblindness, communication may be a significant issue for a deafblind person who may require support to learn and develop communication. Every deafblind person has the capacity for communication so it is the lack of training in communication methods which can restrict deafblind people's opportunities for a full and active life.

Table 7: **Examples of communication methods used by deafblind people** *(taken from Sense UK website[16])*

Non-verbal	Body movement and gestures, Changes in breathing pattern Eye pointing, Vocalising, Leading others to wanted objects or activities
Symbol systems	Objects of reference, Picture symbols, pictograph symbols
Sign systems	Sign language, Sign supported language, Haptic communication, Makaton
Speech-based	Clear speech, Lip-reading, Tadoma
Alphabet based	Deafblind manual, Block, Braille, Moon

Specialised communication methods, such as tactile and environmental methods, may be appropriate for those deafblind people who are unable to communicate using verbal or visual language, but the success of these methods rely on deafblind people, families and professionals **receiving training and support to use them**. Most states support deafblind people to develop communication but there appear to be some gaps in this provision in a number of states.

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[16] Available at: http://www.sense.org.uk/content/methods-communicating-deafblind-people Accessed May 2014

Table 8: **Is training available for deafblind people to learn new communication methods**[17]

	Tactile communication methods	**Environmental communication methods**
Yes	BG, CH, CZ, DE, DK, EE, FI, FR, HU, IT, NL, PL, PT, RO, S1, SI, UK,	BG, CH, DE, DK, FI, HU, IT, MT, NL, PL, RO, S1, UK
No	AT, CT, EL, ES, IE, MT, LT, SK, TR	AT, CT, CZ, EE, EL, ES, FR, HR, IE, LT, PT, SI, SK, TR

Training in tactile communication methods appears to be more common across Europe compared to environmental communication. However, the extent to which this type of professional communication support is available, in practice, is not known.

The number of trained communicators could have a significant impact on deafblind people's opportunities for communication. **It is essential that communication training is available for deafblind people, their families and support workers** so that deafblind people can overcome common barriers and have opportunities for more interaction and autonomy.

Table 9: **Number of specially qualified communication professionals per state**

State	**No. trained sign language interpreters**	**No. trained Interveners / Support Workers**	**Comments regarding deafblind communication professionals**
AT	92	0	-
BG	350	-	Sign Language interpreters are trained at the Union of the Deaf
CH	265	30	Plus 30 comms assistants; 250 volunteers for acquired and elderly deafblindness and 2 Master courses in Congenital deafblindness
CT	600	40	The intervener qualification is not official
CZ	100	-	Only 3 trained deafblind interpreters
DE	-	43	-
EL	78	10	Estimation
ES	3000	114	The intervener qualification is not official
HR	50	2	Only 9 trained deafblind interpreters
HU	122	35	Only 8 SLIs are active in deafblind interpretation
NL	468	300	Plus 90 writing interpreters
PL	500	10	About 90 interpreter guides
RO	-	-	Deafblind organisation has trained 138 deafblind specialist teachers
SI	1	-	Only 1 SLI for deafblind interpretation
SK	45	3	0 interpreters for deafblind people
TR	250	11	-
UK	1105	374	Plus 237 trainee SLIs

Data not provided for: DK, EE, FI, FR, IE, IT, LT, MT, PT, S1, TR

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[17] Data not provided for : HR

Different states have different types of support for communication which are not all captured in this question. For example, in PL these are called interpreter guides. Some states seem to have high numbers of trained communicators but relatively low numbers working with deafblind specific techniques. It was not always possible to distinguish from answers how many of the communication professionals are training and active in deafblind communication.

Even if training is available to deafblind people and their families, it does not mean that deafblind people have the opportunity to communicate more widely, since this may depend on the availability of intervener and interpretation services. These services appear to be most widespread in ES and UK which have the highest number of communication specialists compared to states such as SL and CZ (the latter has only three deafblind communication specialists). This is likely to impact on the extent to which deafblind people can communicate for themselves in many situations.

4.3 Technical assistance support

Table 10: **Is technical support and training available for deafblind people and their families to take part in family and social life?** [18]

Support for:	**Both technical equipment/aids + training**	**Technical equipment/ aids *only***	**Training *only***	***Neither***
Deafblind people[19]	AT, BG, CH, DE, DK, EE, FI, FR, HR, IT, NL, PL, PT, S1 UK	CT, CZ, ES, RO, SK, TR	EL, HU	*SI*
Family/friends of deafblind people[20]	n/a	n/a	BG, CH, DE, EL, HU, IT, PT	n/a

Just over half of the states seem to provide deafblind people with technical equipment and training, although similar training for family and friends is only available in six states. Technical equipment appears to be the most commonly available resource but it is not clear how widespread this type of provision is and whether or not this type of support meets the needs of deafblind people.

Conclusions

4.4 A lack statutory funding reduces opportunities for deafblind people

In ES it seems that personal support is only available from NGOs and voluntary organisations and is not funded through the administration. This was cited as a reason

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[18] Family and friends were only asked about whether training was available

[19] Data not provided for: IE, LT, MT

[20] Data not provided in: AT, CT, CZ, DK, EE, ES, FI, FR, HR, IE, LT, MT, NL, PL, RO, S1, SI, SK, TR and UK

for limited and patchy provision in other states where support for socialising depends on the capacity of the organisation. In DE it was noted that although support exists for deafblind people to have family relationships, in practice this support is not available in every region because of limited state funding for deafblind services. There seems to be access to support in some states but the ways in which services and equipment are offered to deafblind people and families require further investigation. In the UK and S1, deafblind people are eligible for services (in Table 6 and 10) on the basis of a statutory social care assessment outcome but recent austerity measures may have led to a reduction in this type of support being included in assessments. In HR, deafblind people rely on donations to purchase equipment since a legal requirement for equipment only exists in respect to deafness and blindness as separate conditions. Because there is only one deafblind service provider in HR the organisation is unable to support everyone who requests or needs it, a gap they feel 'can adversely impact on the deafblind person's capacity to sustain family relationships'.

4.5 A lack of legal recognition of 'deafblindness' limits support for deafblind people

In some states, specialist support is scarce since deafblindness is not legally recognised as a disability in its own right. In EE for example, few deafblind people receive these support services because of this and deafblind people access support through services for the deaf or blind which is unlikely to be specialist deafblind support. Again, deafblind people seem to fall between the gaps of eligibility criteria available for other disabled people. In PL, the types of services described above are sometimes available through individual projects but this is not done systematically because of a lack of legal regulations. **Thus access to services relies on personal awareness, goodwill and whether or not funds can be sought to pay for services.**

Generic disability services will not suffice for deafblind people who need specialist support, especially those who require personal assistance or interpreter services for communication (for examples see Table 7). Without legal recognition of the uniqueness of deafblindness it will be increasingly difficult to provide the appropriate types of support for this group and services for deaf and blind people will come under increasing pressure to provide services that do not meet the needs of deafblind people.

4.6 Deafblind people, their family and friends need better access to training in order to improve outcomes for deafblind people

Although the majority of states provide deafblind people with some degree of access to equipment, the lack of available training for family and friends to use equipment means that they may feel ill-equipped and unprepared to use this on a daily basis; affecting the appropriate use of and the sustainability of this type of support. Examples of good practice may be found in CH, IT, DE and PT where technology and training is provided for both the deafblind person and their family. It is unclear why HU and EL provide training without the equipment.

5. Domain Three
Choice and Control

Recommendations

- Every state needs to ensure that there are adequate accommodation options for deafblind people, especially independent living options; this gives deafblind people more choice and may not mean having to move far from home
- The voting system needs to become more accessible both physically and in terms of ensuring that deafblind people are informed about elections; there should be a protocol between governments and deafblind organisations to operationalise this
- Formal and transparent consultation processes need to be formed between governments and deafblind organisations to ensure the rights and needs of deafblind people are included in national policy

Domain three concerns deafblind people's choice and control at a community and personal level i.e. political participation and housing support. This domain also covers the role of deafblind organisations in the consultation of disability legislation.

5.1 Support for deafblind people to live in a place of their choice

According to the answers of the survey, deafblind people generally do not have *legal rights* in relation to support for living in a place of their choice. In the 10 states where seems to be a right; this is usually contingent on factors discussed below.

Table 11: **Do deafblind people have a legal right for *support* to live in the place of their choice?**

Yes	No	Unsure
BG, DK, FI, HU, NL, PL, RO, SK, S1, UK	AT, CH, CT, CZ, EE, EL, ES, FR, HR, IE, IT, PT, TR	DE, LT, MT, SI

The housing choices available to deafblind people will vary depending on the type of accommodation that is available and whether this is appropriate for an individual. Accommodation choices are not standardised across Europe and vary depending on cultural and legal approaches to disability and the existing housing infrastructures in each state. Each state will also follow domestic housing legislation, which may further limit and vary the choice available across the continent. Housing options could include family homes, independent living, supported accommodation and communal home settings. The levels of support required for each setting will vary too. More needs to be known about how this support is offered in practise as this was not explored in the survey. This would be difficult without mechanisms in place for families, organisations or housing authorities to record information on choice and support.

5.2 Deafblind people’s right to vote

Organisations were asked about deafblind people’s right to vote and whether this was supported through: access to information in Braille, large print, accessible websites, interpreters, communication support or transport to polling stations.

Table 12: **What support is available for deafblind people to exercise their right to vote?**[21]

	Info in Braille	Large print	Accessible websites	Interpreter	Comms support	Transport to the polling station
DK	✓	✓	✓	✓	✓	✓
CH	✓	✓	✓	✓	✓	✓
DE	✓	✓	✓	✓	-	✓
IE	✓	✓	✓	✓	✓	-
PL	✓	✓	×	✓	✓	✓
HR	✓	✓	×	✓	✓	✓
CT	✓	-	✓	✓	×	✓
ES	✓	×	✓	✓	×	✓
FI	✓	✓	-	✓	-	✓
S1	✓	✓	✓	-	✓	×
UK	✓	✓	✓	-	✓	×
BG	×	×	–	✓	✓	✓
EL	✓	✓	×	✓	×	×
HU	✓	×	✓	✓	×	×
NL	×	×	×	✓	✓	✓
RO	✓	-	-	✓	✓	-
SK	×	×	✓	✓	-	✓
CZ	×	×	×	×	✓	×
EE	×	×	✓	×	×	×
FR	×	×	×	✓	×	×
IT	×	×	×	×	✓	×
LT	-	-	-	-	-	✓
MT	-	-	-	-	-	✓
SI	×	×	×	✓	×	×
AT	×	×	-	×	×	-
PT	×	×	×	×	×	-
TR	×	×	×	×	×	×

Just two states (DK and CH) reported having all six forms of available support for deafblind people to vote. Altogether, only 16 states in total have at least three mechanisms in place to support deafblind people to exercise their right to vote. The most common form of support is interpreter services, available in 17 states, followed

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[21] (-) = data not provided

by information available in Braille in 15 states. Communication support is available in 12 states and accessible websites and large print information in just 10. Access to political participation is likely to be restricted in AT, PT, SI and TR, where support is not available for deafblind people to vote. Sometimes support is provided by organisations or through individual political parties rather than being universally or proactively provided. States where exercise of this right is not supported are unlikely to fulfil the realisation of deafblind people's right to participate in political and public life as set out in Article 29 of the UN-CRPD.

5.3 The role of deafblind organisations in government consultation processes

Mechanisms for deafblind organisations to feed into consultation processes for disability legislation, norms and policies are in place in 17 states. Nine states answered that there were no channels for doing so and LT was unsure of this process. It was not possible to differentiate between mechanisms employed in this process for examples of good practice.

Table 13: **Are there mechanisms in place for deafblind organisations to feed into the development of disability policies by the state?**

Yes	No	Unsure
BG, CH, DE, DK, EE, FI, FR, HR, HU, IE, MT, NL, PL, RO, S1, SK, UK	AT, CT, CZ, EL, ES, IT, PT, SI, TR	LT

Organisations that have a mechanism for consulting on these issues have established these in different ways; some of which are more formal than others. States such as CH are involved formally through membership of official commissions feeding into government proposals for disability policy. Similarly, in HU and FI organisations are regularly asked to contribute to formal discussions around issues affecting deafblind people. Organisations in SK, S1, UK and IE have established links with governments, councils, policy consultations and all party parliamentary groups. Formal links with legislators would provide better consideration of the needs of deafblind people and it is important to introduce these mechanisms in states where this has not happened.

Conclusions

5.4 Legal rights do not mean that deafblind people have practical rights

The right to housing support does not mean that support is provided in practice. Deafblind people's housing choices may be constrained because of a lack of practical support. In many cases, families are looking after deafblind relatives because there is no support for them to live elsewhere through choice. Others move to residential settings far from home because there is no support for independent living. Article 19 of the UN-CRPD specifies that disabled people must have the right to *community living*, meaning that communal homes and clinical settings should not be the norm for deafblind people. In many states, there may be no right for support in the community, no suitable community housing or not enough support staff. For example, in HU deafblind people have the right to choose where to live but since specialised housing for deafblind adults is unavailable, it is likely that this choice is limited. In other states, such as NL, there appears to be support across the country for deafblind people who want to live independently but whether the same rights apply to support to live in family homes is not specified. In many states it seems that support is restricted due to funding pressures. Sometime housing support is provided on a small scale through pilot schemes such as in DE where there are a number of new projects designed to support deafblind people to live at home. Whilst this seems to be a good example, the number of people whom these projects will reach is likely to be small.

5.5 Deafblind people may be prohibited from exercising their right to vote

AT, EE and FI have measures in place to take the ballot to deafblind people; however this seems to be restricted to those people in residential accommodation and potentially excludes hundreds of thousands of deafblind people who do not live in this type of accommodation. There are variations across the types of support available, meaning that deafblind people in some countries have better access to voting. How support is provided needs more interrogation as it is unclear from the survey how often support is provided and how many deafblind people exercise this right. In states such as DE, where support is available across all six mechanisms, this does not mean that it is available universally. In FR and HU, deafblind people have access to an interpreter only, but again it is unclear how widespread this is and it may be unlikely to be provided to everyone who needs it. In the UK and S1, some accessibility support (such as accessible information and transport to the polling station) is only provided at the discretion of specific political parties.

5.6 Deafblind people must proactively request support for voting

Generally, if support is available it is only offered at the request of the deafblind person or their family who must then access and apply for this service; it is not necessarily proactively offered. This puts the responsibility for fulfilling this right onto the deafblind person or their family and it is further unclear as to what extent support is provided in the first place to make requests of this nature, as well as to navigate the bureaucracy underpinning this right.

5.7 Without formal consultation the needs of deafblind people may be ignored

There seems to be little consistency in how deafblind organisations can feedback to administrations about disability policy. In some states, deafblind organisations are consulted on an informal *ad hoc* basis and in others this is done consistently. The impact of formal mechanisms is difficult to assess in this context but it can be reasonably assumed that where these do not exist, or rely on goodwill, the views and experiences of deafblind people are unlikely to be considered routinely or at all. The potential result is that policies disadvantage deafblind people in relation to access to information, communication and mobility. A move towards coordinated consultation mechanisms that are both transparent and routine would improve this.

6. Domain Four
Access to Goods and Services

Recommendations

- A European Accessibility Act should be passed so that deafblind people have rights to receive better access to goods and services
- There should be a common European budget for technical assistance which would be made available to deafblind people to help afford the cost of technological aids which is otherwise prohibitive
- Manufacturers should engage in research that makes their products suitable for deafblind people; this could increase mobility, independence and safety as well as increase revenue for companies
- Social care sectors, technology providers and social enterprises must develop more deafblind specific goods and services; to increase deafblind access to support that is suitable
- Public bodies and organisations must meet any ‘duties’ laid down in state legislation
- Deafblind organisations need to agree on a shared vocabulary; when this is done, we will be in a better position to compare and assess goods, services and developments across Europe
- Enforcement of accessibility regulations such as accessible transport, internet, TV and public buildings to ensure deafblind people can have a full and active life

Domain four covers questions about deafblind people’s legal rights to goods and services, including rehabilitation, communication and assistance support, equipment, access to public buildings, transport, school and medical services.

6.1 Personal support services

Most states have some form of personal support service for deafblind people, although these may be called different names or have different functions, meaning that it is difficult to differentiate between the services below. Some states may have better coverage of personal support but only have one type of support service, other states may have examples of all types of services but these are limited. The most common legal right seems to exist in relation to special interpreter guides (in 14 states) and intervener/support workers (13 states respectively). The least common legal right is for special communication services and special guide services for deafblind people. In the case of personal support services, they are more likely to be available in practice (through voluntary organisations) as opposed to existing due to a legal requirement.

This of course means that the existence of these services is vulnerable to funding and personnel changes at an organisational level.

Table 14: **Do deafblind people have legal rights for equal access to support services and are there practical examples of these services in your country?**

State	**Special interpreter guide**		**Special comms service**		**Special guide service**		**Personal assistant service**		**Intervener/ support worker**	
	Legal	e.g.	Legal	e.g.	Legal	e.g.	Legal	e.g.	Legal	e.g.
DE	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
DK	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
NL	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
RO	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
UK	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
EE	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
SK	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
ES	✓	✓	×	×	✓	✓	✓	✓	✓	✓
HU	✓	✓	✓	✓	✓	✓	×	×	✓	✓
PT	×	✓	×	✓	×	✓	✓	✓	✓	✓
PL	✓	✓	✓	✓	×	✓	×	✓	×	✓
CT	✓	✓	×	×	×	×	✓	✓	✓	✓
EL	✓	×	✓	U	✓	U	✓	×	✓	×
FI	✓	✓	×	×	×	✓	✓	✓	×	×
FR	×	✓	×	✓	×	✓	×	✓	×	✓
CZ	×	✓	×	✓	×	✓	×	✓	×	✓
S1	×	✓	×	✓	×	✓	×	✓	×	✓
AT	×	×	×	×	×	✓	×	✓	×	✓
IT	×	✓	×	✓	×	✓	×	✓	×	×
CH	×	✓	×	✓	×	✓	×	×	×	×
IE	×	✓	×	✓	×	✓	×	✓	×	✓
BG	×	×	×	×	✓	✓	U	✓	×	×
MT	U	✓	U	×	U	×	U	×	U	✓
TR	×	×	×	×	×	×	×	×	×	×
HR	×	×	×	×	×	×	×	×	✓	✓
SI	×	✓	×	×	×	×	×	U	×	U
LT	U	×	U	×	U	×	U	×	U	×

6.2 Special aids and equipment

‘Aids’ and ‘equipment’ refer to any item, piece of equipment or product system that is used to increase, maintain and improve functional capabilities of individuals with disabilities. This can range from simple equipment (such as magnifiers) to integrated systems such as environmental controls (computerised systems for home automation tasks such as answering phone calls, answering door, turning lights off).

Legal rights to *special aids and equipment* are present in the majority of states and most have practical examples of this service.

Table 15: **Do deafblind people have a legal right to special aids and/or equipment for independent living and is this equipment available?**[22]

State	Legal right	Example
BG, CT, DE, DK, ES, FI, FR, IT, MT, NL, PL, PT, RO, UK	✓	✓
AT, CH, CZ, EE, IE, S1	×	✓
HU	✓	×
EL, HR, SI, TR	×	×

Technology has advanced to the point where many everyday activities can be supported with equipment such as: reading mail, answering the door and remembering to take medication and safety aides that monitor for flooding, gas leaks and extreme temperatures. The use of technology in supported living is potentially more widespread than in independent homes.

Aids and equipment are not available in every state and deafblind people must sometimes rely on taking part in small-scale projects and on technology providers to access equipment. Other disabled people must go through an eligibility assessment to receive this type of support. In MT where an 'assistive apparatus scheme' exists, an independent board decides which disabled people are most deserving of financial assistance. Individuals can currently receive subsidy for 50% of the cost, up to 1800 EUR or 3500 EUR for the 'most deserving' cases which is capped at market prices. Assistive technology has evolved rapidly and many items such as personal alarms (sometimes worn around the neck) are becoming more common, low-cost and viable options for disabled people. As technology interfaces become more tactile, it is important that it is available for deafblind people and their families with appropriate support.

6.3 Rehabilitation services

Table 16: **Do deafblind people have the right for equal access to rehabilitation services and are there examples of these services in your country?**

Early rehabilitation services			**Occupational rehabilitation services**		
State	**Legal right**	**e.g.**	**State**	**Legal right**	**e.g.**
AT, BG, CT, DE, DK, EE, EL, ES, FI, FR, HU, NL, PT, PL, RO, TR, UK	✓	✓	BG, CT, DE, DK, EL, ES, FI, FR, HU, NL, PL, PT, RO, S1, TR, UK	✓	✓
CH, CZ, IT, S1	×	✓	AT, CH, CZ, EE, IT	×	✓
MT	U	✓	MT	U	✓
HR, SI	×	×	HR, SI	×	×

Data not provided for: IE, LT, SK

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[22] Legal right to special aids/equipment but data regarding example not provided – LT; data not provided - SK

The majority of states have legal rights for, and examples of, rehabilitation services. Early rehabilitation services are slightly more common than occupational rehabilitation services. Rehabilitation services seem to be absent in at least two states (and the existence of these services was unknown in an additional three states). A lack of rehabilitation services may impact on the ability of deafblind people to return home or to work, reducing opportunities for personal choice, self-development and financial security.

Access to rehabilitation services may be contingent on an assessment of 'eligible need'. In S1, local authorities determine what constitutes an eligible need, which means that a 'right to access' in one authority may not be a right in another: 'yes' does not mean *universal access*.

6.4 Accessibility in everyday life

Physical accessibility may be a significant issue for deafblind people. Many public buildings and transport services are only accessible for people with good sight and hearing, requiring people to use stairs, read signage and use audio-visual prompts.

Table 17: **Is there a legal right to equal access for transport and public buildings?**

Yes – both	Transport only	Buildings only	Neither
CT, DK, EE, EL, FR, HR, HU, LT, NL, PL, PT, RO, S1, UK	ES, SK, TR	CZ, IE, FI, MT	AT, BG, IT

Data not provided for: CH, DE and SI

Legal rights in relation to public accessibility exist to some degree in 21 states. In the other six states, deafblind people may be unable to travel or visit certain places (for work, education, health and leisure activities etc.) restricting their rights to full and active participation in social life.

6.5 Public buildings

Seven states do not uphold legal rights for access to public buildings including libraries, places of worship and schools, which restricts deafblind people's opportunities and participation in society. Whilst some newly built environments cater for disabled people, many states included in the survey mentioned the lack of accessibility in historical city centres, buildings and infrastructures. Legislation specifying accessibility standards for new buildings would go some way to improving accessibility in the future. For historical buildings, tactile signage and guide services would improve accessibility.

6.6 Public transport

Some states such as NL, HR and ES, provide a greater degree of accessible transport, although this is more likely to be available in cities rather than rural areas. It is unlikely that deafblind people living outside of these areas will have equal access to accessible transport if the availability of transport is limited anyway. The majority of states may not collect information about accessibility (this data is unavailable in 15 states) so it is difficult to ascertain how widely available accessible transport is.

Table 18: **transport types and disability accessibility in cities of reference**
(in order of approximate highest to lowest %)

State	**Cities of reference**	**% of accessible buses**	**% of accessible taxis**	**% of accessible trains**	**% of accessible other transport (e.g. boats…)**
NL	S-Hertogenbosch, Eindhoven	100	100	100	0
CT	Barcelona	100	1	80	80
HR	Zagreb & Split	100	100	5	50
ES	Madrid & Valencia	70	1	83	97
UK	London	100	100	U	36
PT	Lisbon & Porto	100	0	100	0
SK	Bratislava, Kosice	40	50	30	30
PL	Warsaw & Krakow	50	5	0	50
IE	Dublin	100	0	0	0
EL	Athens & Thessaloniki	0	0	67	0
MT	Cirkewwa	0	0	0	0

Data not provided for: AT, BG, CH, RO, S1, SI, IT, LT, DK, EE, HU, CZ, DE, FI, FR

Buses are likely to be the most accessible transport option overall, according to Table 18 indicating that short distance travel may be more accessible than long distance travel. Spanish cities like Madrid and Valencia have very few accessible taxis meaning that deafblind people have to rely on public transport to get around compared to SK where the most accessible forms of transportation is taxi travel, which is likely to be more expensive. Trains are the only form of accessible transport in EL, despite the fact that Greece, an island nation, comprises many small islands without railway systems.

The level of accessibility in terms of transport largely depends on infrastructure within each state. For example, in the UK even if some trains are accessible (many of which are, although the percentage is unknown) most train stations that were built over 100 years ago are not.

6.7 Access to health services

Access to health services is fundamental to most people and especially to those whose disability requires regular contact with doctors or clinicians. Yet, answers indicated that a few states have limited health options for deafblind people (although it is not clear whether some states answered yes/no to ‘equal access’ or yes/no to whether these types of service exist.

Table 19: **Do deafblind people have access to the following health services?**

States	Preventative Health Checks	General Practitioner	Specialist Clinics related to condition
CH, IT, NL, PL, TR, S1, SK, UK	✓	✓	✓
AT, BG, EL, IE, HU, MT, PT	✓	✓	×
RO	×	✓	✓
FI, FR	×	×	✓
ES	×	×	×
HR	U	✓	U

Data not provided for: CT, CZ, DE, DK, EE, LT, SI

Access to some form of medical service is available to deafblind people in most states. Deafblind people may require medical services specific to their health condition, besides deafblind support, but specialist clinics appear to exist in only 11 states. In the other 16 states, clinics like this either will not exist or are not known to organisations (and presumably deafblind people). In these states it seems unlikely that deafblind people will receive adequate specialist support for their specific health conditions and experiences. Again, generic services will not necessarily take into account the specific issues facing deafblind people.

General practitioners seem to be the most common form of health service available to deafblind people and are usually the gateway to further medical support, if required. However, if the condition of deafblindness is not widely known, it is unlikely that healthcare professionals will specialise in deafblindness or in the complex conditions causing deafblindness. Evidence from an Usher Syndrome survey[23] carried out by Sense in England in 2013 indicates that deafblind people often have to explain their condition to their GP, as well as the progression of the condition and the types of issues they face in everyday life. This takes time and energy for the deafblind person, especially if they see a different doctor each visit.

Preventative health checks are important, see domain one, in order to check for the presence of co-existing conditions. If better data about deafblindness is collected, medical professionals would know more about the types of co-existing conditions and screen deafblind people accordingly. This proactive approach would likely benefit deafblind people who may otherwise be unable to communicate their health needs.

6.8 Communication and media

Forms of accessible media (i.e. TV programmes) are available to deafblind people in at least 19 states. Accessibility appears to be the mainstream for NL who broadcast the vast majority of TV in an accessible format. Other states offer this sporadically or once daily.

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[23] Tadesse, Y. (2013) *Usher Information and Research Survey, Final Report*, Sense: internal report

Table 20: **Accessible TV (% or frequency of accessible programmes, in order of approximate highest to lowest)**

State	News **subtitled**	Other programmes **subtitled**	Programmes with **audio description**	News in **sign language**	Other programmes in **sign language**
NL[24]	100%	95/50%	100%	Twice daily	0%
CH	100%	20%	5%	100%	0%
S1[25]	25-100%	25-100%	10%	5%	5%
UK[26]	25-100%	25-100%	10%	5%	5%
EL	50%	50%	-	50%	10%
PT	-	+50%	+50%	+50%	-
AT	60%	40%	5%	5%	5%
ES	45%	50%	1 hr p/w (private) 3 hrs p/w (public)	-	(same as audio description)
SK	50%	30%	10%	10%	0%
EE	0%	13 progs p/w	2 channels	daily	0%
IE[27]	23%	23%	1.25%	-	-
HR	10%	40%	0%	3%	1%
SI[28]	-	-	-	100%	-
HU	0-20%	0-20%	0%	0-1%	SL channel
FI	One channel	100%	-	Daily	-
DE	-	14/8.4%[29]	-	2 channels	-
PL	-	18.44%	1%	-	0.1%
MT	-	-	-	Daily	Occasionally
BG	0%	0%	0%	Once daily (public + private TV)	1.5 hours weekly

Data not provided for: CT, CZ, DK, FR, IT, LT, RO, TR

The table indicates that accessible TV is available in some states though potentially not in 8. This type of data is commonly published by broadcasting agencies, which may overemphasise the extent of accessible programming.

Data relating to accessible websites was too patchy to present in this report but at present only a small percentage of websites are fully accessible to people using assistive technology (such as screen readers). Voluntary agreements have so far failed

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[24] NL public/private programme percentage
[25] BBC subtitles 100%, other channels 25-100%
[26] BBC news channels subtitles 100% content plus daily lunchtime news in BSL
[27] At peak times (6.30-11pm) IE channels RTE 1 subtitles up to 90% of programmes, RTE 2 up to 60%
[28] A TV station for the deaf has been available for 4 months
[29] 14% Public programmes are subtitled: 8.4% of programmes overall

to deliver accessible websites. In February 2014, the first European Standard *EN 301 549* on accessibility requirements for Information and Communication Technologies (ICT) products and services was adopted and published. In 2013 the European Commission put forward a proposal for a *European Directive on Accessible Websites* but unfortunately, the scope was limited and the definitions were not clear. Members of European Parliament have been debating the proposal recently and hopefully a more ambitious scope and clearer definitions have been put forward in amendments.

Conclusions

6.9 Equal access is mainly an exception

Most states do not offer accessible services for deafblind people across the board. Even where accessible services exist, the emphasis is predominantly on physical accessibility rather than sensory accessibility, which is key for many deafblind people. Accessible options may be the more expensive options; such is the case for accessible taxis and accessible cable channels.

Accessibility in relation to goods and services may be improved with the introduction of a European Accessibility Act. This would ensure that manufacturers include more accessibility functions for their products. Not only would this improve independence for some deafblind people but it would open up the market for manufacturers.

6.10 Deafblind people may need support to access support

In most states, disabled people will be required to formally apply for many goods and services. For deafblind people, support for communication may be vital for navigating this process (which is largely conducted by phone, internet or letter). Fairly obviously, if communication support is not available in the first place, this will affect whether deafblind people can apply to access this service in the first place. For deafblind people, access to communication and interpretation services is vital if it provides the only opportunity for them to express their wishes about care, support and their future. Similarly, older people may be missing out on fundamental support from health care providers or social activities because they are unable to access information about how to apply or unable to arrange participation over the phone.

It must be recognised that the process for accessing goods and services will not be appropriate for many deafblind people. In states, where access to these goods and services is a legal right, it will be largely left to NGOs, voluntary organisations and families to try to ensure that these are delivered to the deafblind person. Evidently, in some states, the lack of legal recognition of deafblindness will have contributed to these issues and made access to services particularly difficult. The process of means-testing, patchy local provision, reliance on families, lack of legal recognition of deafblindness and the absence of specific services can be reasonably attributed to increasing pressure on deafblind people in everyday life.

7. Domain Five
Education and Lifelong Learning

Recommendations

- The introduction of a school census would provide better information about how many pupils are deafblind and what their educational needs and circumstances are
- More training for educators in deafblind techniques is needed; there are not enough training programmes or specialist teachers to meet the demand for education nor enough dedicated units or schools for deafblind children
- The introduction of a standardised qualification for deafblind teachers would ensure that deafblind children across Europe receive the same standard of education and facilitate shared practice
- The establishment of adequate educational and rehabilitation centres and courses for deafblind adults is essential; this will support and sustain the development of skills and competency in communication and everyday living activities
- Early identification of deafblindness is crucial so that deafblind children receive appropriate education at the earliest opportunity for better educational outcomes
- More resources are needed to provide training for deafblind people who wish to enter paid employment

This domain covers the educational provision available to deafblind children and adults in each state; including access to specialist and non-specialist educational settings. It also includes information on specialist training programmes for educators working with deafblind people of all ages.

7.1 Early education

Early education options for deafblind children are available in the majority of states, although the extent to which deafblind children can access this depends on the accessibility and availability of these types of option, which may not be widespread. Early education options are important for deafblind children to develop confidence and autonomy.

The most widely available educational option for deafblind children seems to be generic special early education programmes for 0-3 year olds. Specialist deafblind education is less common and is available in ten states. The survey did not ask about the numbers of children attending each type of education in each state, so the availability of this type of option would need further investigation.

Table 21: **Do deafblind children have access to the following early educational options?**

State	**A special early childhood programme (0-3 years)**	**A special early childhood programme only for children with deafblindness**	**Regular pre-school (0-6)**
DK, EL, IT, PL, PT, RO, S1, UK	✓	✓	✓
CH, DE	✓	✓	×
EE, FR, HU, NL	✓	×	✓
AT, CT, ES	✓	×	×
HR, IE, SI, SK, TR	×	×	×

Data not provided for: BG, CZ, FI, LT, MT

It is not clear what educational options are available to deafblind children in the 5 states where these types of programme are unavailable, further investigation is required.

7.2 Secondary education

Secondary special schools are available in most states but specialist deafblind schools are available in only 11 states. There may have been differences across what defines 'school' and some states have deafblind units within special schools or schools for deaf or blind students. In other states, deafblind children may or may not have access to specialist support from trained deafblind educators outside of a school environment (i.e. private tutors or education programmes via voluntary organisations). Educational outcomes are likely to be diverse across this group and more research is needed into the types of educational provision, and their impact, for deafblind students across Europe.

Table 22: **Do deafblind children have access to the following secondary education options?**

State	**A special school (6-20)**	**A school for children with deafblindness (6-20)**
CH, DE, DK, EL, FR, HU, IT, NL, S1, SK	✓	✓
AT, BG, CT, EE, ES, FI, PL, RO, TR, UK	✓	×
PT	×	✓
HR, SI	×	×

Data not provided for: CZ, IE, LT, MT

Of the 11 states with specialist deafblind secondary schools, these predominantly take the form of specialist units located within schools for the deaf or blind and are not independent institutions. For example in PL, there are two schools for the blind which have separate units for deafblind students. In other states, such as SI, deafblind children are educated in either a school for the deaf or blind as there are no deafblind specific schools. These types of educational option are unlikely to either cater for enough students or provide enough emphasis on deafblind communication techniques.

7.3 Adult education

Programmes for adults (20-65) are available in more states than programmes for the elderly. Just over half of states have options for deafblind adults to attend special rehabilitation programmes, and 10 have places for elderly deafblind adults.

Table 23: **Do deafblind adults have access to the following adult education programmes**

State	Special rehabilitation programmes for adults (20-65)	Special rehabilitation programmes for the elderly (>65)
BG, CH, DE, DK, IT, NL, PL, S1, UK, FI	✓	✓
EE, EL, HU, PT, RO, SK	✓	×
AT, CT, ES, FR, HR, TR, SI	×	×

Data not provided for: CZ, IE, LT, MT

Further investigation is needed into how widespread this type of provision is, how many adults are enrolled and how useful these programmes are. It is unclear from the survey what this type of service includes and whether they are designed for adults and elderly people with congenital deafblindness or age-related deafblindness.

7.4 Specialist deafblind training for educators

The majority of states have at least one type of training for educators working with deafblind people. Training for professionals working with elderly people is available in just seven states compared to 12 states which have training for acquired deafblindness and 12 that have training for educators working with people with congenital deafblindness.

Table 24: **What types of specialist deafblind training programmes are available for educators working with people with congenital and acquired deafblindness**

State	Congenital deafblindness	Acquired deafblindness	Elderly people with deafblindness
DK, IT, NL, S1, UK	✓	✓	✓
CH, HR	×	✓	✓
DE, FI, FR, IE, RO	✓	✓	×
EL, SK	✓	×	×
AT, BG, CT, EE, ES, HU, PL, PT, SI, TR	×	×	×

Data not provided for: CZ, LT, MT

The lack of specialist training available in 10 (potentially 13) states suggests that education may not be deafblind specific in some states. This would be a significant barrier for deafblind children and adults who require specialist education. It is not clear what the situation is in those states that have deafblind education but no educational training programmes for teachers, according to the survey results.

The results in the tables do not provide context as to how established and widespread this type of training is. For example, training for educators is a relatively new edition in CH, but there is little focus on acquired deafblindness. In some states where training is not available for deafblindness that does not mean that this is not happening through another mechanism. For example in PL there are no dedicated training courses but staff at the deafblind organisation informally cooperate and share knowledge with universities offering postgraduate studies in multiple disabilities. In some states there are more established training courses, including qualifications, for teachers of deafblind children and adults. Staff can attend university courses for an undergraduate certificate or diploma in deafblind studies in the UK and S1. In other states, the deafblind organisation is responsible for the training of educators such as in RO where the organisation has trained up to 138 specialists working with deafblind children, through courses and regular meetings of the Network of Special Education Teachers working with deafblind children.

Conclusions

7.5 There are inconsistent educational options for deafblind children and adults across Europe, including a lack of dedicated deafblind specific options

Dedicated deafblind educational programmes are not commonly available across all of Europe for deafblind children and adults. Information from DE seems to suggest that there would be a demand for this type of option if it was available; as 70 deafblind students (0-18 years old) attend specialist education programmes in just 1 state. Where specialist deafblind schools are not available, deafblind students tend to educated in general ‘special schools’ or specifically in schools for the deaf or blind. Education for deafblind children is inconsistent across Europe and there are a mixture of different options that require more investigation. For example in MT, programmes are available for children with ‘complex needs’ but not deafblindness specifically. In HR and SI, children are sent to schools for the hearing or sight impaired but there are no deafblind schools. In PL, there are specialist units for deafblind student in schools for the deaf or blind. In CH, education for young deafblind children is usually provided through private tuition.

For older people, the situation is similar in that rehabilitation options vary across many of the states. In DK, older people with acquired deafblindness can be offered individual training rather than specific programmes of education. Whilst this may be appropriate for some individuals, this also means that services could be inconsistent. A yes answer does not mean that these programmes are commonplace or universally available for every older person.

Sometimes places are only available through individual schemes. For example in RO, there is a pilot programme for adults to develop vocational skills in three vocational centres. Currently 20 deafblind adults are learning trades and vocational skills. There are no permanent rehabilitation programmes in PL but adults can attend two week long ‘rehab camps’ focusing on activities such as computer skills and sculpture. Whilst these schemes are very positive, there will be many deafblind adults who are unable to take part.

7.6 Education options are not widespread or easily accessible for deafblind people

If specialist education programmes are available these are often provided in few areas or settings. For example, in many states including HU, educational options are only available in the cities where deafblind organisations are based or where there are appropriate schools. Choice regarding educational options may be restricted if deafblind people and their families have to relocate to become eligible for a school place. This is likely to be the case in states such as EE and MT where there is a single specialist school that provides deafblind education, although in EE children have the option to attend mainstream schools if they have access to assistance. It is unlikely that these current options for education will meet the demand for specialised education, especially considering the high numbers in Table 4.

7.7 The lack of recognition of deafblindness affects children’s educational opportunities

Deafblindness is listed as a separate disability category in the list of education needs in LT, but since this is not a functional definition it does not describe the types of support that many deafblind people will require. As a result, deafblind students may not be receiving appropriate support within centres for blind and visually impaired students. It is suspected in EE that many deafblind children will be at home with their parents, either because their child has not been diagnosed as deafblind or because they may be unaware that specialist education exists. Clearly, recognition and earlier identification would improve educational opportunities for those students requiring specialist programmes.

7.8 Good practice example

An example of how early identification of deafblindness can benefit students comes from RO where, since 2007, Sense International has facilitated an early intervention service for sensory impaired babies in 4 major towns. Because of this level of identification, around 113 children have so far benefitted from early diagnosis, rehabilitation and intervention from 4 dedicated support centres in the country. Without this, the educational requirements of these students may have gone unnoticed. The importance of early intervention for deafblindness has been recognised at a national level and has been formally included as part of the national education system through approval of Order 307/2013. Besides this programme, a National Curriculum for deafblind and multi-sensory impaired children, developed by the organisation and endorsed by the Ministry of National Education, has been available since 2001.

8. Domain Six
Work and Employment

Recommendations

- Governments, deafblind organisations and employers must collect better data about the numbers of deafblind people (*those with sight and hearing impairments*) who work and what they do
- Deafblind organisations need to work with social enterprises, employers and voluntary organisations to increase the number of deafblind people undertaking meaningful and gainful experiences in the workplace
- Deafblind people may require assistance to enter the workplace, including PA support, and this need should be met by the government
- Development of workshops for deafblind people to gain skills for and insights to the workplace would be a positive service addition
- The development of a Human Resource toolkit (by deafblind organisations) to increase employers' awareness of deafblindness; deafblind employees needs would be better understood and supported

This domain covers issues relating to the employment opportunities for deafblind people including the proportion of deafblind people employed in the open and supported labour market and the assistance available to support them.

Table 25: **How many deafblind people are employed in the supported and open labour market with and without assistance?**[30]

State	**Supported labour market**	**Open labour market**	***Proportion with the following types of support:***				
			PA	*Special equipment*	*Workplace arrangement*	*More than one type of assistance*	*None*
CT	3	0	2	0	1	-	-
DK	28	17	16	20	10	-	-
ES	18	6	4	-	5	-	-
HU	10	17	10	-	17	-	-
PT	-	8	-	-	-	-	8
RO	-	-	-	-	-	-	25
SK	3	0	-	-	-	-	-

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[30] Data not provided for: AT, BG, CH, CZ, DE, EE, FI, FR, HR, IE, IT, LT, MT, NL, PL, S1, SI, TR, UK

Very little information about the employment situations of deafblind people exists in most states, either because there are no requirements to record this information or because very few deafblind people are employed.

The government in EE is currently preparing to reform social services with the aim of including more disabled people in the employment market. It is unclear whether this reform will include efforts to create opportunities for deafblind people and the organisation is aware of only 2 deafblind people who are currently working in the open labour market. Disability organisations have been involved in the consultation process for this reform, which is planned to come into force in 2015, so it will be important to observe whether this makes a difference to the employment opportunities for deafblind people in the future.

Conclusions

8.1 Support for deafblind people in the workplace is largely unavailable

In the UK and S1, the Access to Work scheme provides personal assistance to disabled people in the labour market, including intervener or interpreter support. This is often a vital source of support for people who wish to work but it is not available everywhere in Europe. In HU there is no organised personal assistance service for disabled workers despite the need for it; often colleagues have to provide support instead. In PL, support comes from examples of good practice by NGOs and pilot projects aimed at helping deafblind people enter the labour market. However, the availability and effectiveness of these types of scheme require further investigation as to what impact they have on deafblind people's employment opportunities.

8.2 Opportunities for deafblind people are hindered by the nature of the labour market

In PL, where 90% of the deafblind people the organisations work with are of working age, it has been observed that most of the deafblind people could work in the open labour market but that finding a job and fear of taking up a job may be hindering the employment rate of deafblind people. Even where opportunities exist, these are often uninteresting and poorly paid jobs. More needs to be done to ensure that deafblind people are not missing out on the opportunity to work and earn money if they want to. This could have a huge impact on other outcomes such as self-esteem, confidence and financial autonomy which would be important developmental and life benchmarks for many deafblind people.

9. Domain Seven
Income and Poverty

Recommendations

- A mechanism for informing deafblind people of their financial entitlements should be developed; this should be proactive and will inform deafblind people of their rights in an accessible format
- We need to develop new application and assessment processes that do not require deafblind people to fill out forms or make phone calls
- Deafblind people should not be financially disadvantaged because they require essential communication support; access to a separate budget for PA/communication support, which does not come out of their personal disability payment, could improve this situation and introduce more equality across the disability sector
- Better awareness of deafblindness amongst social care assessors would improve the application and assessment process for financial assistance and support for deafblind people
- The unavailability of lifetime disability financial awards could adversely affect deafblind people whose condition is not expected to improve; the current inaccessible application process difficult for those deafblind people who must continually reapply
- An agreement across European states for a technology budget should be sought, to ensure that deafblind people do not have to rely on goodwill or the existence of small scale projects to access inexpensive and beneficial technology

This domain covers issues relating to the financial situation of deafblind people, including minimum incomes, access to financial assistance and personal assistance.

Research indicates that disabled people and their families often incur additional costs to achieve a standard of living equivalent to non-disabled people.[31] Disabled people are also more likely to face a higher risk of poverty compared to the general population. [32] This has a significant impact on the quality of life of disabled people and the ability to pay for equipment or support that is not provided via the state. Whilst

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[31] World Health Organisation and the World Bank (2011) *World Report on Disability,* WHO. Available at: http://www.who.int/disabilities/world_report/2011/report.pdf

[32] Shima, I. and Rodrigues, R. (2009) *The implementation of EU social inclusion and social protection strategies in European countries with reference to equality for disabled people. Report prepared for the Academic Network of European Disability Experts*. Human European Consultancy and the University of Leeds

benefit entitlements exist for disabled people across Europe, the ways in which these are administered have an impact on the general equality of deafblind people. There are various social welfare ‘models’ in operation across Europe and states differ in the ways that they provide financial assistance to disabled people. Broadly speaking, this comprises different approaches to allocating payments and expenditure per capita on social welfare. Scandinavian states tend to spend more on social insurance compared to Mediterranean states, which developed social welfare systems later. States also impose different restrictions on inclusivity; meaning that financial support is available more readily in some states and not others, regardless whether the disability is the same. Some states operate a system of ‘disability pensions’, the pay-out of which is contingent on a number of eligibly criteria including: the minimum period of insurance contributions, age and degree of disability. Those that do not meet these criteria are assisted by allowances or minimum income schemes.

Table 26: **Which types of financial support are available to deafblind people?**

State	Guaranteed minimum income	Financial Assistance for Life	Financial Assistance for Essential Devices	Specific Personal Professional Assistance (PA)
CH, DE, DK, FI, FR, IT, NL, PT, UK	✓	✓	✓	✓
EE, EL, PL, RO, SK	✓	✓	✓	×
BG, IE, S1	✓	✓	×	×
HU	✓	×	✓	×
AT, HR, SI, TR	✓	×	×	×
CT, ES	×	✓	×	×
CZ	×	×	×	×

Data not provided for: LT, MT

8 states appear to provide benefit assistance in all of the forms detailed above, with the majority of states providing at least two forms of financial assistance. For the majority of time, entitlement to most of these types of financial assistance is dependent on eligibility.

9.1 Minimum incomes

In terms of minimum income states such as NL, FR, PT, IE, TR and UK (and probably others), have legislation that applies to all citizens irrespective of disability. In PL, a minimum income is guaranteed if one meets the eligibility criteria and similarly in RO, level of minimum income is based on degrees of disability. In RO there are four disability categories: ‘slight’, ‘medium’, ‘accentuated’ and ‘severe’, all of which dictate the amount of financial support received. Deafblind people are usually considered to fall into the accentuated or severe category.

9.2 Lifetime financial awards

In terms of lifetime financial awards, these are available in the majority of states but the eligibility criterion and processes are not consistent across Europe. In some states, like EE and IT, this is paid through a form of pension (although this is going to be reformed in EE within the next two years). In IT, the government decides the pension amount each year (meaning that incomes are not guaranteed year to year) and the award amount depends on the personal income of the deafblind person. A separate universal allowance is available to deaf and blind people if they require assistance, but it is unclear whether this would cover those who are deafblind. In IE, up until the age of 66, deafblind people are entitled to a domiciliary care allowance that ends at the age of retirement and is then available through the state pension. However, it is not clear whether or not this award is of the same value.

In RO, lifetime assistance is based on severity of disability. If deafblindness is not deemed ‘severe’, applicants will have to be annually assessed. Only some disabled people appear to receive lifetime awards in SL. In the UK and S1, benefit systems are changing, although the planned abolishment of lifetime awards may change once the costs involved in conducting reassessments is realised. If not, disabled people will have to reapply for disability benefit every 10 years, regardless of whether their condition is expected to improve.

9.3 Financial Assistance for Essential Devices

Financial support for essential devices, such as basic equipment and aids, is available in most states, but that does not mean that deafblind people do not have to pay for most items themselves in practice.

In EE, the state can compensate up to 90% of the cost, but in practice it is suggested that most disabled people will pay the majority of the cost. Again, pilot schemes can provide support in this way and in PL deafblind people are reliant on the presence of these to fund devices. It seems unlikely that this support will be systematic and widespread as there are special rules about when one can receive particular equipment and support and what amount is co-financed by the state. There are legal rules about providing state funded equipment in RO, but it is suggested that this law is rarely put into practice due to the low budgets for social care and the lack of funding within the health care system. In UK and S1, schemes often exist on a local commissioning level and can be provided by social services depending on a person’s assessment outcome and the availability of resources.

9.4 Financial assistance for specific Personal Professional Assistance (PA)

This type of financial assistance is available for deafblind people in 8 states. However, this assistance may be difficult for deafblind people to access. In PL and IT, funding for PA services exist only if deafblind organisations can obtain external funding. In other states this is available although it must be applied for and relies on deafblind people navigating the application process without support in the first place. In the UK, deafblind people are entitled to an assessment under the Deafblind Guidance which may recommend the provision of PA support. However, what they receive will depend on where they live and what is available.

The variation across states makes it difficult to assess and compare approaches relating to income and poverty, and some welfare systems have evolved in a way that reflects prevailing disability rhetoric as to what support is deemed suitable. More research is needed to investigate the financial outcomes and expectations of deafblind people across Europe and the impact of this on life opportunities.

Conclusions

9.5 Deafblind people may spend a high proportion of their income on support

In most states, minimum wages and social security benefits apply equally to all, regardless of disability and most states provide financial assistance for disabled people specifically. However, this universality may disadvantage some deafblind people who may require enhanced levels of communication or personal assistance support on top of other types of support or essential services they may need. On the other hand, this could mean that deafblind people have to choose whichever service they can afford to pay for rather than the service/s they most need. This clearly impacts on deafblind people’s access to goods and services described in domain four if they are required to pay for these out of their benefit entitlements. Paying for support, including technology and day services, may be out of the reach of many deafblind people and their families who receive limited financial assistance from the state.

9.6 Deafblind people may be missing out on payments because of inflexible bureaucracy

Most financial assistance is preceded by an application and assessment process that is conducted primarily in writing, over the phone or in person. This kind of process may be onerous on deafblind people and a lack of communication support to do so could delay or deprive some deafblind people’s access to financial support. In IE, the process for applying for PA support is complicated. A deafblind person could be required to apply for this funding via a government scheme and once funding has been allocated they will need to enter into negotiations with service providers in order to receive an appropriate PA service. This system appears to involve a number of hurdles which a deafblind person may be unable to navigate without the assistance of a PA in the first place.

Changes to welfare systems as a response to austerity measures in place across much of Europe could affect deafblind people in future. Certainly in the UK and S1, the abolishment of lifetime awards could impact on deafblind people’s experiences, especially if this requires deafblind people to be intermittently reassessed regardless of any improvement of their condition. Systems such as these must become more responsive to the barriers that deafblind people face in accessing them and processes need to be more flexible to ensure that deafblind people have access to financial support.

9.7 There is not enough deafblind specific provision

Even if funds for PA services exist, this is little good if there are not enough appropriately trained PAs. This seems to be the case in states such as RO and PL where these services are not deafblind specific. It is difficult to see how deafblind people would get the most out of this type of service if the support is unable to use specialist communication techniques and if that is what the deafblind person requires most.

10. Conclusion

Many questions have been raised during this project, not least ‘how do we capture information about the deafblindness across Europe in a meaningful way’? The scope of this project has been broad in its attempt to pull together an overview of deafblind rights and opportunities across Europe. It is a starting point and it sets the groundwork for more in-depth studies in the future. The first point that this report raises is the considerable variation across cultures, infrastructures and approaches to disability across Europe. This has made the task of comparability and synthesis challenging but it also demonstrates that there are clear learning opportunities to be had across all domains in relation to how we support and work with deafblind people. It is also clear that deafblind organisations valued this collaborative opportunity to provide context to the services that they deliver in their own states. A total of 27 surveys were returned and completed in English with the best information that the deafblind organisation could provide. This will have been no easy task and inevitably there are gaps: sometimes because of language and vocabulary differences but also because the survey, being a quantitative data collection tool, requires predominantly ‘yes/no’ answers rather than nuanced qualitative explanations.

What is evident from this project is that we do not collect enough data about deafblindness. Few states systematically collect this data and organisational records significantly underestimate the extent of deafblindness. An effective way of collecting data about deafblindness would be to include questions in national censuses which pick up on those who combine sight and hearing loss. Official legal recognition of deafblindness, acknowledging it as a unique condition, could also increase the identification and recording of deafblindness. As well as numerical data we need qualitative data about the needs, experiences and opportunities of deafblind people. We need to do this through health and social care records and through the records of deafblind organisations. Information and knowledge are powerful instigators of change; without these kinds of data, the issue of deafblindness will remain hidden.

It is also clear that there are not enough specific deafblind services in most states. Deafblindness is not the same as deafness or blindness but frequently deafblind people must join or apply for services via organisations that do not cater for their needs. This stretches the capacities of other organisations and does no good for deafblind people who want specialised support to communicate or be mobile. Deafblind service provision is still an emerging entity, especially in states where organisations for the deafblind are still relatively new but this should be seen as an opportunity, not a drawback. The development of a European Deafblind Resource Centre would create more opportunities to share this learning. Without adequate resources, it is unlikely that new services will be developed responsively to deafblindness. It is imperative that we do not resort to putting more pressure on families of deafblind people who are already providing communication, interpretation and technical support on top of other family and work commitments. This is not a sustainable model and older deafblind people who do not have family to care for them will be left out completely. More rehabilitation and day services for elderly deafblind people must be funded. This has the potential to lead to cost savings in the long run as more people could be supported to be more independent, socially active and to seek healthcare at appropriate times.

Health and social systems appear to be inflexible and inaccessible to many deafblind people. Not only do they face barriers to communication, access to information and mobility, they must also negotiate complex application and assessment systems with little support. Most services (such as GPs, hospitals, social work) rely on everyday competencies: talking, reading, listening, walking; activities that are taken for granted by most of us, but not for those whose sight and hearing is poor. Across most of Europe, communication support and personal assistance schemes appear to be patchy and inadequate for deafblind people despite being an essential need. Communication support should be a basic right for deafblind people; the unavailability of these services withholds the rights of deafblind people to health care, social care, family life and leisure.

Whilst the UN-CRPD has legislated for better inclusion and equality for disabled people in social life, it is clear that legal rights and practical rights are not equated for many deafblind people. In reality this means that even if a legal right exists in relation to support, a lack of resources negates this right in practice and even where resources exist generally, these may not be accessible to a deafblind person. Even in an environmental sense, accessibility is often taken to mean physical accessibility, not sensory accessibility, meaning that increased accessibility is unlikely to benefit deafblind people to a great extent. Ratification of the UN-CRPD seems to have made little practical difference to the realisation of disabled people’s rights in some states, let alone for those who are deafblind. Wider economic influences and the development of public, private and associative models of care will have a significant impact on how we achieve better outcomes for deafblind people but it is sufficient to acknowledge that we can no longer ignore the expected growth in demand for specialised services.

This project has highlighted a number of key issues and commonalities relating to deafblind service provision and practice. The domains explored in the project overlay well onto everyday life and successfully expose where there are gaps and where there are gains. Some states have made significant progress and provide high standards of deafblind services, whilst others are still starting out. However, this report is a starting point: the domains must be refined and made more specific and further interrogation of opportunities under each domain, and the impact of these on deafblind people’s lives, is required. Many more people will experience deafblindness in the future and so it is time to *make a noise* about it. This report calls for the development of common framework under which we assess provision for deafblindness systematically across each state. This is the basis on which we can appeal to European and state legislators for change.

Deafblind organisations have shown dedication to improving opportunities for deafblind people: this is the best indicator that positive change is possible, so long as there is better support from our government administrations to do so.

11. Recommendations

Every conclusion and recommendation in this report is based on evidence from the survey responses and a commitment to achieve greater equality and better opportunities for deafblind people across Europe. An overview of the main recommendations is detailed below.

At a European level:

- A *Common Framework* must be established to regularly collect standardised data relating to deafblind rights, opportunities and services in each state in order to assess and compare differences and developments
- Development of a *European Deafblind Resource Centre* – a centre of excellence that deafblind organisations can use as a resource for skill development, good practice and knowledge exchange
- *Publication of data* relating to deafblindness e.g. via Eurostat
- *A Common European Budget for technical assistance* must be established to ensure that essential technology is affordable for deafblind people in Europe

At a state government level:

- *Official legal recognition* of deafblindness as a unique condition is imperative; this is essential for deafblind people's needs and experiences to be recognised and considered in disability legislation and policy changes
- *Standardised census questions* must be established in each state to collect data on the number of people with sight *and* hearing impairments; so that the extent of deafblindness is understood and captured
- *Deafblind people should receive a specific budget for communication support;* this is an essential service, as is more *training* for deafblind people, families, teachers and support workers in communication methods
- Health professionals must focus on *early identification and recording of deafblindness;* this would improve outcomes for deafblind people (e.g. for education and employment) and would provide better prevalence rate data
- Recognition that deafblindness is *most common amongst older people*; a focus on early detection and support could prevent more serious health issues in this population
- *Formalisation of consultation mechanisms* between deafblind organisations and government policy makers

At a deafblind organisational level:

- Deafblind organisations must agree on a *shared vocabulary* for concepts important to deafblindness; shared meanings would make our message more powerful, avoid confusion in future research and increase the effectiveness of the *Common Framework* data collection tool
- Deafblind organisations must be better at *recording information* about the deafblind people we support, including gender, age and characteristics; this will enable us to focus resources, have a better understanding of the lives of those we support and strengthen our shared message