



QUESTIONNAIRE ON THE EUROPEAN DEAFBLIND INDICATORS

Presentation

This questionnaire forms part of a project launched by the European Deafblind Network (EDbN) in the framework of a Grundtvig Learning Partnership in Deafblindness (GLP-Db). This partnership was established by the Lifelong Learning Programme of the European Commission and officially brings together nine organizations active in the field of deafblindness in Europe.

The partners involved in the project have developed the European Deafblind Indicators. This list of indicators has been specifically adapted to deafblindness from the existing Indicators on Disability Equality in Europe (IDEE), as defined by the Academic Network of European Disability experts (ANED).

The data collected using these indicators should help to define best practices on a European level and to recommend models of care in this field.

In this current phase, this questionnaire based on a selection of these European Deafblind Indicators has been distributed to national deafblind organizations in each of the European States.

More information about the partners and the activities of the project can be found on the website: www.deafblindindicators.eu.

Instructions

- Please read this page before completing the questionnaire.
- Please note that all the information in the form should be referenced to your geographic reporting.
- Please complete the questionnaire in English.
- The questionnaire is a snapshot and should reflect the most recent and most accurate information available to your organization.
- Please note that some questions may require some consultation with other agencies, like your national administrations or any existing statistics in your country. In some questions you are asked to make clear if the source of your answer recognised statistical information from a reliable source, whether it is an estimate or whether the figure is unknown in your country. For example, you may not have a survey of deafblind people in your country, but you may have a rough idea based on statistical information collated over the years. In this case, you should record an estimated figure.
- The project assumes that in many countries there may be little information available. Please leave questions unanswered where you do not have the relevant information. Please answer only what you know.
- The language and reporting elements used in this questionnaire are consistent with those standards generally accepted in deafblind publications.
- It is recommended that the questionnaire is completed using Word 2007 or 2010. Using Word 2003, it may be more difficult to tick the boxes.
- Should you require any further information regarding the completion of the questionnaire, please e-mail rlopez@edbn.org (copy to jfreixes@edbn.org).
- Any other information which you feel may be relevant can also be included on the separate sheet at the end of the questionnaire.

Definition of Deafblindness

Although each State has its own criteria, the Nordic definition of deafblindness is widely accepted as the common working standard definition: “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 become deaf and blind early in life before the development of language (pre-lingual deafblindness).
- Acquired deafblindness. Become deaf and blind after the development of language (post-lingual deafblindness).
- Older people¹ deafblindness. Acquired deafblindness which appears in old-age. This is an emergent and little known situation”.

¹ Older people: >65 years.



CONTACT INFORMATION

Please note that the deadline to send back the questionnaire is Friday 8 November 2013.

The results from the questionnaire will be included in a comparative study for the Book on Deafblindness in Europe, to be published in 2014.

Please e-mail your completed questionnaire to Ricard Lopez, President of the European Deafblind Network (EDbN), with a copy to Javier Freixes jfreixes@edbn.org.

Ricard Lopez

President

European Deafblind Network (EDbN)

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Geographic reporting	
Name of the State: Spain	Name of the region (if needed):

People responsible for completing questionnaire (add more rows if needed)				
Name	E-mail	Phone	Position	Organization

Date on which the questionnaire was finished:
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Domain 1: Deafblindness Rates / Demographics

1. Total population of the country (Population according to EUROSTAT for 2013 or the last available year: <http://bit.ly/30n9wE>):
2. Is there a specific (official) census figure for deafblind people? (Some countries and regions have a census, others not. This questionnaire should show this difference).
 - Yes (please specify how many people are identified as deafblind in this census):
 - No
 - UnknownAdd comments, if necessary:
3. Ratio of total deafblind people per 100.000 population believed to be in your country (some ratios usually considered are 5, 15, 20, 40 or 400 depending on the definition and other internal reasons):
Source of information: Recognised statistic Estimate Unknown
Add comments, if necessary:
4. Total number of identified deafblind people.
 - a. Total number:
 - b. Older deafblind people:Source of information: Recognised statistic Estimate Unknown
Add comments, if necessary:
5. Number of identified deafblind people receiving specific services (Services which are 'as required' should not be included, only those on daily or weekly programs).
 - a. Total number:
 - b. Older deafblind people:Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

6. Number of identified deafblind people classified by gender.

a. Male:

b. Female:

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

7. a. Are deafblind people prioritized as candidates for cochlear implant?

Yes No Unknown

b. If yes are they a priority for bilateral implants?

Yes No Unknown

Add comments, if necessary:

8. How many deafblind people have additional impairments or conditions (orthopaedic/physical, conditions-cognitive, conditions-behavioural, complex health care needs, communication, speech/language):

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

9. Identified deafblind people classified by Residential Setting.

a. Number of identified deafblind people living at home (with parents, relatives, foster):

b. Specifically for deafblind people:

Living situation	Number of deafblind people living there	Number of available places
Residential facility		
Supported living		
Independent (alone or unsheltered)		

c. Others (please specify):

Source of information: Recognised statistic Estimate Unknown



Add comments, if necessary:

Number of identified deafblind people using as communication method:

- a. Sign Language:
- b. Symbolic Communication:
- c. Speech:

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

Domain 2: Personal and Family Life

1. Do deafblind people have opportunities to socialise, so they can have family relations and friendships?

Yes No Unknown

To this end, is there support provided in form of:

a) Assistance: Yes No Unknown

b) Interpreter: Yes No Unknown

c) Technical equipment: Yes No Unknown

d) Training to use technical equipment: Yes No Unknown

e) Training for family members and friends to use technical equipment:

Yes No Unknown

f) Training in new communication methods for deafblind people (e.g. tactile communication):

Yes No Unknown

g) Training in new communication methods for deafblind people for “the environment”:

Yes No Unknown

Add comments, if necessary:

2. Do deafblind people have the support they need in order to join social/leisure time activities (e.g. sports, public discussions, official celebrations, art/theatre/cultural activities)?

a) Personal Assistance: Yes No Unknown

b) Interpreter: Yes No Unknown

c) Transport: Yes No Unknown

d) Technical aids, light, loop...: Yes No Unknown

Add comments, if necessary:

Domain 3: Choice and Control

1. Is there a legal right for deafblind people to receive support to enable them to live in the place of their choice? (If a person lacks capacity to choose where they would wish to live, then there is a legal right for the person to receive support to live in the place that is considered by the person legally nominated to make that choice on their behalf to be the most suitable for their best interests).

Yes No Unknown

Add comments, if necessary:

2. How many deafblind people require support to enable them to live in the place of their choice?

a. Number of deafblind people requiring this support:

b. Number of deafblind people receiving this support:

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

3. Is there support provided to deafblind people to make use of their right to vote by means of:

a. Information material in Braille: Yes No Unknown

b. Large prints: Yes No Unknown

c. Accessible websites: Yes No Unknown

d. Interpreter: Yes No Unknown

e. Communication support to get all the information needed:

Yes No Unknown

f. Transport to the polling station: Yes No Unknown

Add comments, if necessary:

4. Are there mechanisms in place to ensure that deafblind organizations are consulted



and involved by the administration in the development of norms and policies in disability?

- Yes No Unknown

If yes, please specify:

Domain 4: Access to Goods and Services

1. Do deafblind people have legal rights for equal access to Goods and Services?

(Indicate if there is a legal right to the good or service).

1.1. In relation to Support Services:

Special Interpreter Guide. Yes No Unknown

Special communication services. Yes No Unknown

Special guide services. Yes No Unknown

Personal assistant services. Yes No Unknown

Intervener / Support Worker. Yes No Unknown

1.2. In relation to Rehabilitation / Intervention:

Early rehabilitation services Yes No Unknown

Occupational rehabilitation services Yes No Unknown

1.3. In relation to Accessibility:

a. Is there legal right to have special aids and/or equipment (Assistive Technology) available for independent living? (Assistive Technology: any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities).

Yes No Unknown

b. Is there a legal right to equal access to:

Buildings Yes No Unknown

Public transportation Yes No Unknown

Medical facilities Yes No Unknown

Schools Yes No Unknown

Work places Yes No Unknown

Information & communication media Yes No Unknown

Add comments, if necessary:

2. Whether or not it is a legal requirement, are there examples of these services in your country? (Indicate if there are examples).

In relation to Support Services:

- | | | | |
|---------------------------------|------------------------------|-----------------------------|----------------------------------|
| Special Interpreter Guides. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Special communication services. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Special guide services. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Personal assistant services. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Intervener / Support Worker. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |

In relation to Rehabilitation / Intervention:

- | | | | |
|---------------------------------------|------------------------------|-----------------------------|----------------------------------|
| Early rehabilitation services. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
| Occupational rehabilitation services. | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |

In relation to Accessibility:

a. Is there special aids and/or equipments (Assistive Technology) available for independent living?

- Yes No Unknown

1. Number of deafblind people requiring this support:

2. Number of deafblind people receiving this support:

Source of information: Recognised statistic Estimate Unknown

b. Is there equal access to:

Buildings. Yes No Unknown

Public transportation. Yes No Unknown

a. If yes, please answer how easy is it for deafblind people to use public transportation (please consider two cities as basic models) In order to be considered accessible for deafblind people, the public transport must have:

- A step-free gangway from the front to the back, allowing ease of access for people with mobility impairments.
- A large wheelchair bay near the access door.

- Alert system next stop by audio and visual announcements. Including a T-Loop system which transmits announcements for passengers with hearing aids.
- a. Cities of reference:
- b. % of accessible buses:
- c. % of accessible taxis:
- d. % of accessible trains:
- e. % of accessible others (e.g. boats...):

3. Medical services.

Preventative Health Checks	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
General Practitioner	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
Specialist Clinics related to condition	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
Schools	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown
Work places	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown

Information, communication, media.

- a. Accessibility to TV (public and private).
 - a. % of news subtitled:
 - b. % of other programs subtitled:
 - c. % of programs with audio description:
 - d. % of news in sign language:
 - e. % of other programs in sign language:

Add comments, if necessary:

- b. Do commercial and public websites meet accessibility standards?
(For a web page to be accessible all important semantics about the page's functionality must be available so that assistive technology can understand and process the content and adapt it for the user. Modern Web applications often apply scripts to elements to control their functionality and to enable them to act as a control or other dynamic component. WAI-ARIA (Accessible Rich Internet Applications) is a specification published by the World Wide Web Consortium that specifies how to increase the accessibility

of dynamic content and user interface components developed with Ajax, HTML, JavaScript and related technologies)

Yes No Unknown

a. How many deafblind people use government websites for their management with the administration?

b. How many deafblind people use commercial websites for shopping?

Source of information: Recognised statistic Estimate Unknown

Number of specifically qualified professionals.

Sign Language Interpreters:

Interveners / Support Workers (or similar):

Add comments, if necessary:

Domain 5: Education and Lifelong Learning

1. Do people with deafblindness have access to:

a. A special early childhood programme (0-3 years)?

Yes No Unknown

If yes, give the number of people accessing this programme:

b. A special early childhood programme only for children with deafblindness?

Yes No Unknown

If yes, give the number of people accessing this programme:

c. Regular pre-school (0-6)?

Yes No Unknown

If yes, give the number of people accessing this programme:

d. A special school (6-20)?

Yes No Unknown

If yes, give the number of people accessing this programme:

e. A school for children with deafblindness?

Yes No Unknown

If yes, give the number of people accessing this programme:

f. Special rehabilitation programmes for adults (20-65)?

Yes No Unknown

If yes, give the number of people accessing this programme:

g. Special rehabilitation programmes for elderly (>65)?

Yes No Unknown

If yes, give the number of people accessing this programme:

Add comments, if necessary:

2. Do you have specialized training programmes for educators, working with:

a. People with congenital deafblindness?

Yes No Unknown



b. People with acquired deafblindness?
 Yes No Unknown

c. Elderly with deafblindness?
 Yes No Unknown

Add comments, if necessary:

3. How many deafblind children (0-20) are at home, not having education or day care?

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

4. Is there specific legislation referring system/assessment for deafblind children?

Yes No Unknown

Add comments, if necessary:

5. What is the teacher/child ratio for teaching deafblind children in your country?

Add comments, if necessary:

Domain 6: Work and Employment

1. Employment rate.

- a. Number of deafblind people able to work in supported labour market?
- b. Number of deafblind people able to work in open labour market?

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

2. Breakdown by employment support. Number of deafblind people working in supported labour market?

- a. With personal assistance:
- b. With special equipment:
- c. With arrangements at the workplace:
- d. More than one of the above:
- e. Without any need:

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

3. Breakdown by employment support. Number of deafblind people working in open labour market?

- a. With personal assistance:
- b. With special equipment:
- c. With arrangements at the workplace:
- d. More than one of the above:
- e. Without any need:

Source of information: Recognised statistic Estimate Unknown

Add comments, if necessary:

Domain 7: Incomes and Poverty

1. Is there minimum income guaranteed for deafblind people?

- Yes No Unknown

Add any comments, if necessary:

2. Do deafblind people receive Financial Assistance for Life (FAL)?

- Yes No Unknown

Add any comments, if necessary:

3. Do deafblind people receive Financial Assistance for Essential Devices (FAD)?

- Yes No Unknown

Add any comments, if necessary:

4. Is there Specific Personal Professional Assistance (PA) available for deafblind people?

- Yes No Unknown

Add any comments, if necessary:

Domain 1. Complementary information. Primary Identified Aetiology

According to your expertise please indicate the number of deafblind people on each aetiology from the list that best describes the primary aetiology.

We recognize that this part is extremely complex so we do not expect this information to be fully detailed, however we would request that you complete those parts which you do know. (e.g. Usher syndrome).

A second reason for this extensive list of aetiologies included here is to publicise professionally known possible causes of deafblindness.

# cases	Aetiology	# cases	Aetiology
Hereditary/Chromosomal Syndromes and Disorders			
	101 Aicardi syndrome		132 Moebius syndrome
	102 Alport syndrome		133 Monosomy 10p
	103 Alstrom syndrome		134 Morquio syndrome (MPS IV-B)
	104 Apert syndrome (Acrocephalosyndactyly, Type 1)		135 NF1 - Neurofibromatosis (von Recklinghausen disease)
	105 Bardet-Biedl syndrome (Laurence Moon-Biedl)		136 NF2 - Bilateral Acoustic Neurofibromatosis
	106 Batten disease		137 Norrie disease
	107 CHARGE Syndrome		138 Optico-Cochleo-Dentate Degeneration
	108 Chromosome 18, Ring 18		139 Pfeiffer syndrome
	109 Cockayne syndrome		140 Prader-Willi
	110 Cogan Syndrome		141 Pierre-Robin syndrome
	111 Cornelia de Lange		142 Refsum syndrome
	112 Cri du chat syndrome (Chromosome 5p- syndrome)		143 Scheie syndrome (MPS I-S)
	113 Crigler-Najjar syndrome		144 Smith-Lemli-Opitz (SLO) syndrome
	114 Crouzon syndrome (Craniofacial Dysostosis)		145 Stickler syndrome
	115 Dandy Walker syndrome		146 Sturge-Weber syndrome
	116 Down syndrome (Trisomy 21 syndrome)		147 Treacher Collins syndrome
	117 Goldenhar syndrome		148 Trisomy 13 (Trisomy 13-15, Patau syndrome)
	118 Hand-Schuller-Christian (Histiocytosis X)		149 Trisomy 18 (Edwards syndrome)
	119 Hallgren syndrome		150 Turner syndrome
	120 Herpes-Zoster (or Hunt)		151 Usher I syndrome
	121 Hunter Syndrome (MPS II)		152 Usher II syndrome
	122 Hurler syndrome (MPS I-H)		153 Usher III syndrome
	123 Kearns-Sayre syndrome		154 Vogt-Koyanagi-Harada syndrome
	124 Klippel-Feil sequence		155 Waardenburg syndrome
	125 Klippel-Trenaunay-Weber syndrome		156 Wildervanck syndrome

126 Kniest Dysplasia	157 Wolf-Hirschhorn syndrome (Trisomy 4p)
127 Leber congenital amaurosis	158 Rosenberg Chutorian Syndrome
128 Leigh Disease	159 Wolfram Syndrome (DIDMOAD)
129 Marfan syndrome	160 Zelweger Syndrome (Cerebrohepatorenal Syndrome)
130 Marshall syndrome	199 Other
131 Maroteaux-Lamy syndrome (MPS VI)	
Pre-Natal/Congenital Complications	Post-Natal/Non-Congenital Complications
201 Congenital Rubella	301 Asphyxia
202 Congenital Syphilis	302 Direct Trauma to the eye and/or ear
203 Congenital Toxoplasmosis	303 Encephalitis
204 Cytomegalovirus (CMV)	304 Infections
205 Foetal Alcohol syndrome	305 Meningitis
206 Hydrocephaly	306 Severe Head Injury
207 Maternal Drug Use	307 Stroke
208 Microcephaly	308 Tumours
209 Neonatal Herpes Simplex (HSV)	309 Chemically Induced
299 Other	399 Other
Related to Prematurity	Undiagnosed
401 Complications of Prematurity	501 No Determination of Aetiology



Please feel free to add any additional information which you feel may be relevant:

Thank you very much for your time and cooperation in completing this questionnaire.

Please return to the following addresses before next Friday 8 November 2013:

rlopez@edbn.org; jfreixes@edbn.org