

MAPPING OPPORTUNITIES FOR DEAFBLIND PEOPLE ACROSS EUROPE: Executive Summary

As more people across Europe experience deafblindness it is vital that their support needs are met. This project is the first to explore the differences between states in their approach to disability rights, social care and legislative responses for deafblind people. It calls for improved recognition of deafblindness as a specific and distinct condition, and underlines a need to develop a common framework in order to systematically assess the situations of deafblind people now and in the future.

Recommendations

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

Background

The specific needs of deafblind people are not routinely considered in disability policy. 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 (UNCRPD) but there is little discussion about how these commitments could be extended to those facing problems with communication, mobility and access to information.

This is a summary of findings and recommendations from a two year project financed by the European Commission under its Lifelong Learning Programme: the Grundtvig Learning Partnership. The aim of the project was to explore the rights and opportunities for deafblind people across Europe, providing the first overview of opportunities and services for deafblind people across Europe.

What is deafblindness?

The condition of deafblindness is not well recognised although it is becoming more common in line with the ageing demographic of Europe. Deafblindness refers to any degree of dual-sensory impairment and is different to the separate conditions of blindness and deafness. It is *the combination* of both impairments that creates the most significant issues for individuals; hence deafblindness should be recognised as a distinct and unique disability.

How was the project undertaken?

The Project Group comprised nine deafblind organisations (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.

The survey was developed from the IDEE (Indicators of Disability Equality in Europe) document and from direct feedback and consultation with deafblind people and their families at a number of forums.

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.¹ 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.

What did we find?

A number of key findings in each domain were identified.

Domain One – Deafblindness rates and demographics

Domain one considers the number or prevalence of deafblind people within each of the 27 states. Organisations were asked if and how information about the number of deafblind people is recorded.

A lack of official data: *only 3 out of 27 states collect official data (i.e. census data) on the number of deafblind people in their population. This is largely due to a lack of official recognition of deafblindness as a distinct condition. Due to the lack of official data an estimated prevalence rate had to*

¹ A copy of the survey can be found at <http://deafblindindicators.eu/>

be used to calculate figures for each state. Based on these estimates, there is an indication that the population of deafblind people across the 27 states could be nearly 3 million.

Domain Two – Participation in Social and Family Life

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.

Disparities in opportunities to participate in social and private life: *Whilst the majority of states have some support services in place to enable social participation, services tend to be focused on enabling participation in leisure activities. Fewer have support in place for deafblind people to participate in family activities. This, along with limited access to technical assistance equipment aids and a lack of training to use them adversely impacts the deafblind person's capacity to sustain family relationships.*

Domain Three – Choice and Control

This domain 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.

Inadequate accommodation options: *Few states provide deafblind people with the legal right to support for living in a place of their choice. In states that do offer this legal right (10 states) choice is constrained*

by the type of accommodation that is available. More accommodation options are required to enable independent living and greater choice.

Restricted access to support to vote: *While the majority of states have at least one form of support available to enable deafblind people to exercise their right to vote, access to this support is often patchy and only obtained at the request of the deafblind person or their family. The voting system needs to become more accessible both physically and in terms of ensuring that deafblind people are informed about elections.*

Little consistency in mechanisms for organisations representing deafblind people to feed into disability consultation processes: *Mechanisms are in place in 17 states, but there is little consistency in how this works in practice, with some regularly consulted and others consulted on an ad hoc basis. A move towards coordinated consultation mechanisms that are both transparent and routine would increase the likelihood that the specific needs of deafblind people would be routinely considered.*

Domain Four – Access to Goods and Services

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.

A lack of comprehensively accessible services: *Most states do not offer comprehensively accessible services for deafblind people. Even where accessible*

services exist, the emphasis is predominantly on physical accessibility rather than sensory accessibility, which is key for many deafblind people.

Limited access to public transport: Legal rights in relation to public accessibility exist to some degree in 21 states. However, accessible transport is limited in most cases to cities and urban areas, leaving deafblind people residing in rural areas unable to travel or visit certain places (for work, education, health and leisure activities etc.)

Patchy access to special aids and equipment: Legal rights to special aids and equipment are present in the majority of states, in practice however, aids and equipment are not always available, and eligibility mechanisms can restrict access.

A lack of medical services specific to the needs of deafblind people: 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.

Domain Five – Education and Lifelong Learning

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.

Limited educational options for children: There is a lack of specialist deafblind education options for children, with only 10 states providing specialist early education

programmes and 11 states providing specialist secondary education options.

Reduced options for the elderly: Specialist rehabilitation programmes for adults are available in just over half of states, but many cater only for the 20-65 age group. There is a dearth of provision for those aged 65 and above, despite deafblindness being more common in this age group.

Only half of states have options for deafblind adults to attend special rehabilitation options and rehabilitation provision is even less common for those aged 65 or over.

Domain Six – Work and Employment

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.

A lack of information about employment: 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.

Support in the workplace is lacking or difficult to access: In states that could provide some information, it would appear that support for deafblind people in the workplace is largely unavailable, resulting in a reliance on colleagues to provide support. The lack of support acts as a barrier for deafblind people to take up employment.

Domain Seven – Income and Poverty

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

Inconsistent eligibility criteria for financial support: *Whilst financial support, minimum income guarantees and lifetime awards are available in all or most states, eligibility criterion and processes are not consistent and may result in some deafblind people falling short of thresholds.*

Limited state funds restricts access to equipment and aids: *Financial support for essential devices, such as basic equipment and aids, is available in most states, but organisations reported that due to limited state funds, deafblind people frequently have to pay for most items themselves in practice. A high proportion of income therefore, may be spent on support resulting in a lower standard of living and increased risk of poverty.*

Inadequate funding exists for organisation to provide services: *Financial assistance for specific Personal Professional Assistance (PA) is available in only 8 states and even where financial assistance exists, organisations are often dependent on external funding in order to actually provide the service. This results in financial assistance for services that are not available in practice.*

Application processes restrict access to financial support: *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.

Conclusion

What is evident from this project is that the lack of recognition that deafblindness is a specific and distinct condition has a significant and often detrimental impact on the lives of deafblind people across Europe.

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 specific needs.

Specific deafblind service provision is 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.

Whilst the UNCRPD 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.

Many more people will experience deafblindness in the future and this report calls for the development of common framework under which we assess

provision for deafblindness systematically across each state.

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.

For more information see the project website www.deafblindindicators.eu or email info@deafblindindicators.eu

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