



Deafblindness in Ireland

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*The Anne Sullivan Centre and Deafblind Ireland
Laura English*



THE
Anne Sullivan
CENTRE FOR DEAFBLIND



**Deafblind
Ireland**

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Written by Laura English

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Abbreviations

CSO	Central Statistics Office
NCSE	National Council for Special Education
EDbN	European Deafblind Network
DBI	Deafblind International
CRS	Congenital Rubella Syndrome
CMV	Cytomegalovirus
CDBRA	Canadian Deafblind Rubella Association
NDA	National Disability Authority
AMD	Age Related Macular Degeneration

Executive Summary

In 2004, a historic Written Declaration recognising Deafblindness as a separate and unique disability was formally adopted by the European Parliament. A decade on however, significant disparities continue to exist between member states in relation to service provision and access to specialist support (EDbN, 2014). A number of member states, including Ireland have not yet adopted the declaration and evidence suggests that the needs of people who are Deafblind are not routinely considered in disability policy in Europe (*ibid*).

In Ireland, 1,749 people were recorded as Deafblind on the National Census for 2011. Based on research conducted internationally this figure is likely to underestimate the number of people affected. Furthermore, the proportion of the population who experience a combination of vision and hearing loss is expected to rise as a result of the ageing demographic in developed countries and the increased number of children surviving prematurity.

This report represents the first large-scale research ever conducted into the situation of Deafblindness in Ireland. It has uncovered a sizeable discrepancy between estimates of the number of people who are Deafblind in Ireland provided by the CSO (1,749) and the European Deafblind Network (17,206). It therefore, highlights the need for further research in the area but also outlines the importance of developing a shared vocabulary to aid the collection of standardised data relating to people who are Deafblind.

In addition, the following key findings have emerged based on the results of survey research conducted with 103 people who are Deafblind across the country.

- At least one third of the Deafblind population are over the age of 65, representing the largest diagnostic group within the Deafblind population
- Age Related Deafblindness, Usher Syndrome, CHARGE Syndrome and Congenital Rubella Syndrome are the leading causes of Deafblindness in Ireland.
- Almost 20% of the Deafblind population have a diagnosis of Usher Syndrome. Of these less than one quarter are engaged with a service provider.
- 90% of Deafblind children and young adults, have one or more additional disabilities.
- Almost two-thirds of people who are Deafblind live with family. Fewer than 15% live alone and almost 20% live in a residential care facility.
- 55% of people who are Deafblind are not in receipt of any services.

While further qualitative research is needed to fully assess the needs of people who are Deafblind in Ireland, the following recommendations are proposed to advance the rights of people with the disability, based on the findings of this report.

- A campaign for Awareness and Enabling Legislation that includes but is not limited to lobbying for Official Recognition of Deafblindness as a separate and unique disability in the Irish context
- The establishment of a strong support network of people who are Deafblind, their families and the professionals working with them to advocate for the group at local and national level
- The development of Deafblind Specific Services that meet the individual needs of the diverse population of people who are Deafblind
- Further research into the area of Deafblindness which includes greater consultation with people who are Deafblind and their families to provide the information necessary to plan and develop appropriate services for the growing Deafblind population

Chapter 1



Introduction

The following report represents the first large-scale study into Deafblindness in Ireland. It seeks to situate the diverse group of people who are Deafblind in broader discourse on the rights of people with disabilities in Ireland and provide a catalyst for further research in the area. It uses data obtained from the Central Statistics Office to estimate of the number of people who are Deafblind in Ireland in two separate age categories. Alternative estimates published recently by the European Deafblind Network (EDbN) are also outlined. In addition, the findings of survey research conducted with a sample of 103 people identifying themselves as Deafblind are examined.

Hearing and vision impairments compromise one's capacity to extract information from the environment and create barriers to communication that can isolate people and jeopardise independence and well-being (Heine & Browning as quoted in Scheider et al., 2014: 232). When vision and hearing losses combine into Deafblindness a person's ability to overcome these barriers becomes limited because one sense cannot adequately compensate for the loss of the other. Deafblindness is not therefore, deafness plus blindness; rather it is a separate and unique disability that affects overall development, socialisation and communication (McInnes 1999:9). It has no single cause and no single cure. In fact, there are over 70 different causes of Deafblindness and the causes of the condition are as diverse as the consequences of the disability (Munroe, 2011:1).

For the purpose of this research, the definition of Deafblindness used by the Department of Health in the UK and the European Union will be used. It draws upon the general though not agreed understanding of Deafblindness across Europe and states that;

"A person is regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss".

(cited in Roberts et al., 2007)

The unhyphenated version of the word 'Deafblind' will be used in favour of other terms, such as Dual Sensory Impaired and Multi-Sensory Impaired, to recognise the uniqueness of the disability and reflect common practise across international literature. The 'D' will be capitalised to acknowledge that many people who are Deafblind consider themselves as part of a distinct cultural group. Alternative terms may also appear in instances where other authors using these terms have been cited.

The following Chapter will examine the development of Deafblind specific services internationally from their inception in the United States to their subsequent emergence across Europe. It will present the reader with a brief overview of Deafblind specific services in Ireland and discuss recent developments in the area of Deafblindness on a European wide level.

A Historical Overview

As far back as the 1800s, philosophers had speculated that the mind of a child who was Deafblind had the potential to reveal what was basic and true about human beings (McGinnity, 2004). From this simple curiosity, children who were deprived of sensory input and ignorant of what the world could offer them began to be educated in schools for the blind and the Deaf

(*ibid.*). Success stories like Laura Bridgman and Helen Keller paved the way for further investment into Deafblind services and opened a new world of possibilities for people who were Deafblind.

The Rubella epidemic that started in Europe in the spring of 1963 and subsequently spread to the United States in 1964 and '65 (Witte and Karchmer cited in Poltkin, 2006:165) created a significant challenge for existing Deafblind services. It left thousands of sensory-deprived children in its wake and increased demand for services around the world. As John Varley noted in his American science fiction short story, *'The persistence of vision'*,

"In the 1970s these five thousand potential Helen Kellers were all six years old. It was quickly seen that there was a shortage of Anne Sullivans"

(Varley cited in Hodges, 2004: 3)

As a result, a number of new Deafblind organisations aimed at providing a diverse range of services and supports to people who were Deafblind and their families were established. By the late 1980's however, it was becoming evident that rapid changes were happening in the Deafblind field (DbI, 2012).

The availability of Vaccines in the 1970s had a major impact on reducing the number of children being born with Congenital Rubella Syndrome (Sense, n.d). However, while incidents of Rubella Syndrome were declining, the number of other identified aetologies was steadily increasing, as was the proportion of children with additional severe disabilities (Brown and Bates, 2005:1). Thus, while Deafblind education continued to be important, service delivery to the full spectrum of people with Deafblindness rose up on the priority lists of the growing number of Deafblind organisations worldwide (DbI, 2012). As Best pointed out in 1983, *"if this apparent change in population is a long-term one, then it has implications on the provision of placements, staffing and the development of appropriate teaching techniques and appropriate measures of assessment"* (Cited in Brown and Bates, 2005: 1)."

As this research will indicate, the change in population has, indeed, been long-term and as such, presents a myriad of challenges for relatively young, emerging Deafblind organisations. In addition, the changes highlight the need for further research into the availability and appropriateness of current service provision and the size and profile of the population in each country.

The Early Days: Perkins School for the Blind, Massachusetts, USA (Perkins, n.d)

A trip to Paris to see the world's first school for the blind in the early 1820's convinced medical student Doctor John Fisher of the dire need for such a school in America. Within 6 years of beginning classes in his father's Boston home, demand for places was so great that a larger space to accommodate more students was needed. Thomas Perkins, vice president and trustee, kindly sold his home and paid for a hotel in South Boston to be converted. The school still bears Perkins' name as a testament to his generosity.

About the same time, Samuel Gridley Howe, director at the school, began to establish a separate printing department to produce embossed books. As fate would have it, the printing shop attracted the attention of Charles Dickens, who visited in 1842 and was so impressed by the work Howe was doing with a young Deafblind girl named Laura Bridgman that he wrote about it in his book, *American Notes*. Forty years later, Kate Adams Keller read the book and was anxious to discover if her six-year-old Deafblind daughter Helen could be educated in a

similar way. In 1887, Perkins sent graduate Anne Sullivan to teach Helen in Alabama and the success of the partnership resulted in Deafblindness receiving worldwide acclaim.

The school's reputation for innovation continued with the introduction of the Braille and Talking Book Library in 1931 and the Perkins Brailler produced by David Abraham in 1951. As was the case in other Deafblind services around the world; as the school evolved, so too did the profile of its students. In 1982, Perkins changed its charter to accept children with multiple disabilities other than blindness. Today, Perkins is situated on a 38-acre site on the Charles River in Watertown, Massachusetts. A major grant from the Hilton Foundation in 1989 made it possible to expand Perkins' services throughout the U.S. and in 50 developing countries through Perkins' International Programs.

The European Experience

The Netherlands

One of the most influential, nationally recognized centres of excellence in Europe is Rafael deaf-blind Department at the Instituut voor Doven, St Michielsgestel in the Netherlands (Enerstvedt, 1996:69). It began with four children and a few dedicated teachers who had obtained knowledge from abroad and integrated it with their own methods of teaching Deaf children (Van Son, 2012:5). The reputation of the Institute is, above all, linked with the name Johannes van Dijk, a world renowned researcher and educator of Deafblind children.

After a year of working at Perkin's in the US, Van Dijk realised that the knowledge he gained there was not directly applicable to the students he taught in the Netherlands. In his own words *"we expected little Helen Kellers who could learn everything if they worked hard. But over the years, it became clear that this was not that obvious for our Rubella children (ibid.)"*. Thus, the 'Van Dijk Method' recognised the importance of focusing on each child's individual capabilities and developing communication and language through physical contact (*ibid.*). It introduced a new approach to the education of children who were Deafblind and highlighted the need for further research and international collaboration. In recent years, the number of children admitted to the Rafael department has continued to increase and now numbers 70. Similar to changes at Perkins, there has been a fall in the proportion of children with Rubella syndrome and an increase in the number of children with other more diverse syndromes (*ibid.*).

The United Kingdom

Formative influences on the education of people who were Deafblind in Britain were drawn from abroad and from the current educational practise rather than from British psychological investigation and theory (Enerstvedt, 1996: 71). The establishment of Sense in 1955 by Peggy Freeman, parent of a young girl with Rubella Syndrome and also a teacher of the Deaf, had a significant influence on the development of services (*ibid.*). It was not until the mid-1980s however, that significant professional literature began appearing in Britain and Deafblindness received widespread attention (*ibid.*). The Magpie TV Appeal in 1981 raised funds to open the UK's first centre for housing, training and education of young adults who were Deafblind. It also gave Sense the opportunity to discuss releasing people who were Deafblind from mental institutions with the British Government (Sense, 2014). By the end of the 1990's, Sense had 73 group homes, supporting 314 people who were Deafblind and had expanded their services to include people with acquired Deafblindness (*ibid.*). In 1993, Sense International was launched with the

aim of sharing expertise and developing services for people who were Deafblind in some of the poorest parts of the world (*ibid.*).

The Irish Experience

In most of Europe, the increased number of Deafblind children resulting from the Rubella epidemics of the 1960s failed to trigger national programmes, except for vaccination programmes (Brown, 2005). Individual service providers were largely left to their own devices, looking to the US for information or to one another (Brown cited in Enerstvedt, 1996: 68). In Ireland, it was not until 1989 that a group of concerned parents, whose children had been diagnosed with Congenital Rubella Syndrome, came together and formed the Anne Sullivan Foundation for people who are Deafblind in Ireland. Until then, children who were Deafblind were either educated in schools for the Deaf or were resident in institutions aimed at providing services to the mentally ill and intellectually disabled.

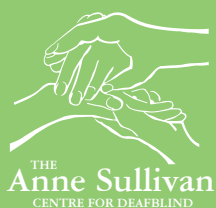
In 1996, with the generous support of Sr. Nicholas and the Catholic Institute for Deaf people (CIDP), the country's first residential centre for people who were Deafblind was opened. It aimed to offer life-long learning to its nine residents and provide opportunities for the development of communication in a safe and secure environment. By 2006, the Foundation had moved its residents from the centre's main building to four additional houses in the area. This reflected an effort to move toward a less institutional model of care and promote the independence of service users. Today, the Anne Sullivan Centre has expanded its services to include the provision of outreach services to Deafblind children and adults around the country on a limited basis. For the purpose of this research the Centre has partnered with Deafblind Ireland, a separate organisation, founded in 2010, to advocate for people who are Deafblind and their families and to provide training for professionals working in the area.

Conclusion

As illustrated above, a number of special institutions for people who are Deafblind exist in many developed countries. However, in many countries, including Ireland, people who are Deafblind are most frequently found in institutions which probably do not work with people who are Deafblind on the basis of a specific Deafblind conception. Much of the responsibility for the provision of services continues to fall to organisations for the Deaf and the Blind. This tendency to "divide people into parts for educational and developmental support" (McInnes) is strongly criticised by professionals working in the field of Deafblindness as it fails to recognise the uniqueness of the disability.

In 2004, the European Deafblind Network persuaded the European Parliament to pass 'Written Declaration - 1/2004', recognising Deafblindness as a unique disability. It has been adopted by eight member states, including the UK, Romania, Italy, Spain, Austria, Denmark, France and Sweden. In June 2014, the same organisation published the results of a European wide study into Deafblindness entitled '*Mapping Opportunities for Deafblind People Across Europe*'. It highlighted considerable differences in the provision of services for people who are Deafblind across member states and emphasised the importance of official legal recognition at a state government level. This research aims to enhance the work being done on a European level by providing data on the situation of people who are Deafblind in Ireland and by highlighting the issue of Deafblindness on a National level.

Chapter 2



Literature Review

It is intended that this research will contribute to the very limited body of material available on Deafblindness in Ireland. It is also hoped that this report will help to locate the situation of Deafblindness in Ireland in broader international discourse about the number of people who are Deafblind and the characteristics of the population. The following chapter offers an evaluation of the data, ideas and evidence that already exist on the topic being researched. It gives an indication of the literature available in three related areas; definitions and terminology, characteristics of the Deafblind population and international research on the prevalence of the disability. Endeavours are made throughout this chapter to link existing material with the potential findings of this report.

Definitions and Terminology

Despite the general consensus that Deafblindness is a unique disability, controversy around the language used to describe it rages on. According to Wittich *et al.*, communications about Deafblindness within clinical and research literature are littered with several terms that have not yet been established or defined, such as Deafblindness, dual sensory loss or combined vision and hearing impairment (Wittich *et al.*, 2013:198). Essentially, while some fear that uniform descriptions of people who are Deafblind may do damage by incorrectly homogenizing a group with dissimilar characteristics and needs (Reiman, 1993:3), others support the use of harmonized terminology to facilitate an improved exchange of ideas (Wittich *et al.*, 2013: 200). The fact that “*nobody wants to be given a label that he or she is not able to relate to or identify with*” (Gullacksen *et al.*, 2011:67), is particularly relevant in the context of this research. It indicates that potential respondents may be unwilling to participate if they feel the definition used does not adequately reflect their situation. The following notable factors are therefore, considered in relation to the research being conducted here.

Rejecting the term Deafblind

The consequence of surviving others' perceptions and presenting oneself in a particular light has led a substantial number of people with a combination of vision and hearing loss to reject the term 'Deafblind' (Schneider 2006, Gullacksen *et al.* 2011). It seems that unlike those in the deaf culture, people who are Deafblind did not see the term as a positive cultural label, rather as a negative disability label (Barnett, 2001 cited in Schneider 2006: 44). For those who acquire Deafblindness over time, an adjustment process takes place whereby in the beginning, terms such as 'Deafblind' evoke strong emotions and for most people are considered a threat to the personal identity that they are trying to maintain (Gullacksen *et al.*, 2011:61).

For Deaf people in particular, it can be difficult to leave the linguistic and cultural community in which they have grown up (Gullacksen *et al.*, 2011:45). In a CAUSE research survey of 67 people across Europe with Usher Syndrome¹, a number of participants continued to describe themselves as 'Deaf' or 'Usher' rather than Deafblind (Schneider, 2006: 44). Similarly, in a sample of 73 people in Australia, only 42% considered Deafblindness as their primary disability (Prendergast cited in

¹ Usher Syndrome is a genetically inherited disease involving congenital deafness and progressive blindness due to Retinitis Pigmentosa. Symptoms include night blindness a gradual narrowing of visual field and eventual loss of sight (Schwartz and Vernon, 1974 cited in Vernon 1979: 101).

Schneider, 2006:44). Significantly, in the Irish context, the National Council for the Blind have recorded 44 service users as 'Deafblind' with an additional 778 classifying themselves as 'blind or visually impaired with an additional hearing impairment or deafness' (NCBI, Personal Communication, 2013).

Deafblind Awareness

The extent to which the latter is a reflection of the attitudes of people who are Deafblind, as opposed to a result of poor access to information on the topic, is unclear. Certainly, respondents in a number of surveys have cited a fear of misleading others about the nature of their loss as a key reason for not describing themselves as Deafblind (Barnett 2001, Gullacksen 2011 *et al.*, Schneider 2006). As one research participant noted "*It's not about not having accepted it, but about avoiding misunderstandings* (Gullacksen *et al.*, 2011:61)". Furthermore, without understanding about disability rights, individuals may believe their deafblindness is a personal abnormality, as dominant medical discourse suggests (Schneider, 2009:174). As a result, they can become withdrawn or disengage; a passive concealing strategy used by people who become deafblind to remain uncontroversial and avoid criticism by others (Schneider, 2006:169).

Something You Become, Not Something You Are

Finally, according to Dammeyer, deafblindness should be considered as a social construction (cited in Gullacksen *et al.* 2011: 61). In this sense, there are no fixed or objective criteria for defining a person as deafblind and external factors contribute to determining whether a person belongs to the Deafblind category (*ibid.*). The concept challenges the idea that problems with communication are a consequence of the Deafblind person's impairments rather than the attitudinal and infrastructural accessibility barriers and other people's lack of knowledge about communicating with them (Hersh, 2013: 460). As such, deafblindness is not something that you are, but also something that you become. Based on this theory, a persons' decision to participate in the research being conducted here will be dependent on their experience of Deafblindness and the external factors that influence that experience, including awareness of the disability amongst the general public, accessibility to appropriate services and access to peer support.

The Changing Population of People Who are Deafblind

Congenital Rubella Syndrome and Multiple Disabilities

As has been previously noted, Congenital Rubella Syndrome is no longer the most common cause of deafblindness. In 1983, a national survey of the population of children with deafblindness in the UK confirmed this. It stated that, between 1971-79, 461 children were diagnosed with Congenital Rubella Syndrome while between 1991-96 fewer than 33 were diagnosed (Sense *n.d.*). In the UK, vaccination programmes have also resulted in fewer than 3% of women of child-bearing age being susceptible to rubella ("Congenital Rubella, 50 years on", 1991). It should however be noted that data from many other developing countries suggest that they have a risk of CRS at least as high as that in industrialized countries during the pre-vaccination era (Cutts *et al.*, 1997:64). In Ireland, the number of reported cases of Rubella has fallen from 3304 in 1961 to 4 in 2011 (HPSC, Personal Communication).

Increasingly, as well as sensory impairment, children have other complex and medical disabilities (Sense *nd.*). Advances in medicine have increased survival rates for infants with severe disabilities and for premature infants. There has also been a growing awareness of the prevalence of sensory impairments and sensory processing difficulties in the population of children with multiple and profound disabilities. Two decades ago, many of these children would probably have been perceived simply as having “severe brain damage” or “mental retardation” without any consideration of their sensory status (*ibid.*). This is supported by data from the 2003 National Deaf-blind Child Count [in the USA], which lists more than 70 possible causes of Deaf-blindness and identifies characteristics that underscore the complexity of these children (Brown and Bates, 2005:1). Of the approximately 10,000 children on the census, 60% also have physical impairments, 68% have cognitive impairments and 40% have complex health care needs (*ibid.*).

Age- Related Deafblindness

Increased longevity and drops in the birth rates generate a large population of older people with severe age-related loss of vision and hearing (Lyng, *n.d.*). Deafblindness in old age represents the largest diagnostic group within the Deafblind population by far and has been estimated at 74% in the UK (Robertson and Emerson, 2010:11). 72% in Denmark (Mortensen, *n.d.*) and 69% in Canada (Wittich *et al.* 2012:248). Significantly, this number is set to rise dramatically in the coming years. Research from the UK has predicted that the number of older people who are Deafblind will rise from 254,000 in 2015 to 418,000 in 2030 (Robertson and Emerson, 2011:11). As previous data concerning the prevalence of combined vision and hearing loss is not available in the Irish context, it is impossible to evaluate whether a similar trend is emerging here. However, one can assume based on the CSO's prediction that the number of people aged 65 and over will increase from 11.6% in 2011 to 22% in 2041 (CSO cited in CARI, 2010), that the results of studies produced elsewhere will be replicated here.

Usher Syndrome

Usher Syndrome is now the most common cause of Deafblindness worldwide, after age-related Deafblindness (Möller cited in Wahlqvist *et al.*, 2013:209). Three subtypes of the condition have been found and are characterized as follows; People with Usher I are congenitally deaf and start to lose vision early in childhood. They also face balance difficulties due to problems in the vestibular system; Individuals with Usher II experience hearing loss but are not profoundly deaf. They have no noticeable problems with balance; Individuals with Usher syndrome III are not congenitally deaf, but a gradual loss of hearing and vision is experienced and balance may or may not be affected (Dammeyer, 2012:16). In its most severe form, Usher's syndrome causes profound deafness at birth, with the onset of Retinitis Pigmentosa (RP) as early as age 10 and functional blindness by 20 (Roach, 2009). Despite major scientific breakthroughs which have identified new genes in Usher Syndrome, the prevalence of the condition remains unclear (Spandau and Rohrschneider, 2002: 495). Most studies have been performed in Northern Europe, revealing rates of 3.5 per 100,000 in Finland, 5 per 100,000 in Denmark, and 6.2 per 100,000 in the population over 15 years in Birmingham, UK. A study in the USA estimated a prevalence of 4.4 per 100,000 and recent research in Heidelberg, Germany indicated that 6.2 per 100,000 inhabitants could be diagnosed with the condition (*ibid.*). In addition, 3%-6% of all deaf and hard of hearing children are estimated to be affected by the condition (Wittich *et al.*, 2012:243). It is important to note however, that Ushers is a hereditary syndrome and therefore, may be more common in certain areas of the world than in others (Mortensen, 2007). This has been illustrated in Louisiana, USA, in the North of Sweden and on the island of Margarita off the coast of Venezuela in South America, where the prevalence of Usher I is as high as 76 per 100,000 (*ibid.*).

Other identified Aetiologies

There are several disorders, syndromes, infectious diseases, and adventitious conditions that may result in an individual being deafblind (Wolff Heller and Kennedy, 1994). Thus, while the conditions outlined above account for the majority of cases where people experience a combination of vision and hearing loss, a large number of other diagnostic combinations have also emerged. According to the University of South Dakota, USA, the most common causes and associated conditions, excluding Usher Syndrome, include CHARGE Syndrome, Cytomegalovirus (CMV), Down Syndrome and Prematurity (USD, *n.d*). Trisomy 13, Alstrom Syndrome, and Autism have also been identified as associated conditions. As Wittich et al. (2012), points out, the great heterogeneity of the group, as demonstrated above, has potentially problematic consequences for service providers planning interventions because one size is unlikely to fit all.

International Research into the prevalence of Deafblindness

Several countries internationally have undertaken efforts to count the population of people who are Deafblind in their respective countries and / or to establish national Registries. The methodologies employed across research studies have varied significantly, with many countries choosing to count those who are Congenitally Deafblind separately to those who have acquired Deafblindness. A selection of these studies is presented below.

United Kingdom (Robertson and Emerson, 2010 – Centre for Disability Research)

In 2010, Sense commissioned a study to estimate the 'Number of People with Co-Occurring Vision and Hearing Impairments in the in the UK' and Northern Ireland. It used existing national data sources to estimate that, 212 people per 100,000 of the general population in the UK had more severe impairments of both hearing and vision. It indicated that nearly three quarters of all people with more severe impairments of both hearing and vision are aged 70 or over. Significantly, the report also found that the figure was set to rise to 343 people per 100,000 if age and gender-specific prevalence rates remain consistent. The prevalence rates calculated as part of this research were also recently used by the EDbN to estimate the number of people who are Deafblind across Europe.

Canada (Watters and Owen, 2005).

In 1998, the Canadian Deafblind and Rubella Association (CDBRA) embarked on a journey similar to that being undertaken here. Following on from the recommendations of a report by the 'Task Force on Services to Deaf-Blind Persons in Canada' fourteen years earlier, the CDBRA set about establishing a voluntary register of all persons who were deafblind in Canada (Munroe, 2001). As is the intention with the research being discussed here, the CDBRA enlisted the help of 50 relevant organisations throughout the country to locate persons with Deafblindness to participate in the study. It succeeded in registering 777 people as Deafblind but concluded that a safe estimate would suggest there was between 3,100 and 4,650 people in the population. Usher Syndrome and Congenital Rubella Syndrome were the primary reported causes of Deafblindness in the study, accounting for 29.9% and 18.7% respectively.

United States

Interestingly, in the US there is no complete registry of people who are Deafblind. Instead, there is a mandatory National Census of Deafblind Children and youth aged 0-21, produced for the Federal Office of Special Education Programmes and a separate National Registry of People over the age of 21 maintained by the Helen Keller Institute (Munroe, 2001). A total of 9,387 infants, children and young adults were identified as Deafblind by the state/multi-state projects in 2011 (NCDB, 2012). However, an 83.1% discrepancy is noted between these figures and the much higher estimate which includes Deafblind children who are classified by state agencies as being developmentally delayed, multiply disabled, visually impaired or hearing impaired (*ibid.*). Although the Helen Keller National Centre for DeafBlind Youth and Adults compiles a National Registry, its voluntary nature means that accurate information on the number of adults who are Deafblind is difficult to find. Estimates indicate that there are between 35-40,000 adults with the disability in the US (Watson and Watson, 1993).

Chapter 3



Background to the Research

Literature on Deafblindness in the Irish context consists solely of single-subject research designs and has not yet investigated issues concerning the prevalence of the disability, or the availability of services for people who are Deafblind. While previous research has focused on people who are Congenitally Deafblind or people who are Deafblind with learning disabilities in Ireland (Deasy and Lyddy 2006, 2009a, 2009b, Colson-Osbourne 2010, Roher and Bracken 2014), none have included reference to people who acquire Deafblindness later in life. As such, no large-scale research has ever been conducted into the situation of people who are Deafblind in Ireland. This study aims to narrow that significant gap in research by providing an estimate of the number of people who are Deafblind in Ireland, their demographic profile and location.

The study, commissioned by the Anne Sullivan Centre, will take place over a six month period beginning in October 2013. Funding for the project will be provided by the Anne Sullivan Foundation and Deafblind Ireland.

The Steering Committee for the project outlined the following specific tasks as objectives for the research project:

- Gain a more accurate picture of the number of individuals who experience Deafblindness/ Multi-Sensory Impairment in Ireland.
- Discover the age profile and location of people who are Deafblind/ Multi-Sensory Impaired
- Determine the different levels of sensory impairment that exist
- Gather basic information on the services that people who are Deafblind/ Multi- Sensory Impaired are availing of
- Raise Awareness of Deafblindness and Highlight the campaign for Deafblindness to be recognised as a separate and unique disability in Irish Law
- Meet international standards in Deafblind research and service provision

Methodology

A mixed-method approach was chosen to achieve the objectives outlined above, as each approach will have some liabilities and all can benefit from a combination of one or more other methods (Brewer and Hunter, 1989 cited in Check and Schutt, 2011). In an effort to gather information on the situation of Deafblindness in Ireland specifically, surveys were sent to people identified as having a combination of vision and hearing loss, by both the Anne Sullivan Centre and other cooperating organisations nationwide that provide services to people who are Deafblind (See Appendix 1).

Returned surveys were used to compile a National Registry of People who are Deafblind in Ireland and provided invaluable, albeit limited, information on the profile of people living with Deafblindness in Ireland. This approach is closely aligned to that taken by the Canadian Deafblind Rubella Association (CDBRA) in 2001 and Ravenscroft et al. who distributed leaflets and questionnaires to healthcare professionals, schools and social workers in an effort to identify the number of children who were vision impaired in Scotland (NCSE, 2009: 37).

In addition, secondary research was carried out to determine whether statistical data on the number of people who are Deafblind in Ireland was available from existing sources. Further, desk research was conducted to supplement the findings of primary research and offer a broader understanding of relevant issues. The findings of both the primary and secondary research will be presented together in the following Chapter.

Involvement of 'Gatekeeper' Organisations

As Bosk notes, fieldwork is a 'body-contact' sport; with a few exceptions, you need to actually interact with other people (including online interaction) to collect your data (cited in Maxwell, 2013:90). However, as Maxwell (2013) points out, *"Total access is rarely needed, what you need are relationships that allow you to ethically gain the information that can answer your research question"*.

Thus, this research project involved requesting the support of organisations that offer services to, or advocate for people who are Deaf or Hard of Hearing or Blind or Vision Impaired. Organisations that responded positively were asked to distribute Information Booklets to people they had identified as having a combination of vision and hearing loss. The information Booklet, containing a Questionnaire and Consent Form was then made available to potential participants in Large Print, Braille and Audio CD format (See Appendix 2). The survey responses gathered from participants formed the basis of the primary research and were added to a National Registry of people who are Deafblind in Ireland.

Ethical Considerations

It was acknowledged in the initial stages of the research process, that a proportion of the target population may have difficulty responding to a written questionnaire because of issues around incapacity or age. After consultation with the Office of Data Protection, it was agreed that only the person who is deafblind could provide the information needed. However, exceptions were permitted in situations where a person had the capacity to consent but was unable to complete the questionnaire independently. In instances where for reasons of incapacity or age consent could not be given, it was provided by a parent or next of kin. To ensure implementation of this approach a Consent Form was attached to each questionnaire.

Limitations

The absence of a strong support network of people who are Deafblind in Ireland made accessing members of the population for research purposes particularly difficult. However, the involvement of cooperating organisations that interact with people who are Deafblind compensated for this to some degree. Larger organisations, who were not in a position to distribute questionnaires via their staff, agreed to send the information by post. As the proportion of people who respond to postal surveys is generally quite low using this method limits the number of potential respondents (Deanscombe, 2010:13). The turnaround time involved in posting and returning questionnaires also resulted in significant delays.

As the majority of Deaf people are not able to get much meaning from print, (Goldin-Meadow and Mayberry, 2001: 224) the fact that data was collected through written questionnaires may also have limited participation.

Finally, as this report relies heavily on the use of self-report data the fact that a proportion of the Deafblind population choose not to identify with the term (See Chapter 2), was recognised as a key concern. In an effort to address the issue, a presentation on the project was delivered at regional or team meetings of cooperating organisations around the country and a National Deafblind Awareness Day was held. Local Radio and Newspapers were contacted and information about the project featured on a current affairs programme on RTE 1 Television. In addition, the Anne Sullivan Centre dedicated a section of their website to the project.

Chapter 4



Research Findings and Discussion

The following chapter outlines the results of both the secondary and primary research carried out as part of this study. It presents data gathered from 103 people who identified themselves as Deafblind in Ireland and compares it to the findings of similar research conducted internationally. Efforts are made throughout this chapter to link the findings of the primary survey research with the key themes that emerged from desk research into the topic.

Prevalence of Deafblindness in Ireland

The initial stage of this research included reviewing data from a number of different sources to ascertain the number of people who are Deafblind in Ireland. This included requesting information from the National Physical Sensory Disability Database, the National Council for the Blind's database of service users (See Appendix 3) and the Central Statistics Office (CSO). While the former data sources are invaluable in terms of providing information relevant to service provision, the figures offered by the CSO are the most reliable available when tasked with assessing the prevalence of the disability. They present comprehensive data across all age ranges, obtained through the National Census rather than voluntary survey research. The following section of this report estimates the number of people who are Deafblind in Ireland based on information provided by the CSO. It also presents an alternative estimate provided by the European Deafblind Network. The latter is based on prevalence rates used by and Robertson and Emerson at the Centre for disability Research in the UK.

Findings from the Central Statistics Office

Question 16 of the 2011 Census was a seven-part question aimed at gathering data on the prevalence of disability in Ireland (NDA, 2005:16) (Figure 1). The data collected indicated that there were 51,718 people with 'Blindness or a serious vision impairment' and 92,060 people with 'Deafness or a serious hearing impairment' (CSO, 2012:52).

In November 2013, a request was sent from the Anne Sullivan Centre to the Central Statistics Office (CSO), for a special cross-tabulation of these data to ascertain the number of people who were Deafblind in Ireland. For the purpose of data analysis, Deafblind was defined by the CSO as, *"a combination of Blindness or a serious vision Impairment and Deafness or a serious hearing Impairment"*. While this differs from the definition used in this study (see page 18), the results are considered representative of the population being investigated. Further correspondence with the CSO provided an additional breakdown of the number of people who were Deafblind in specific age categories in each county (See Appendix 4).

16

Do you have any of the following long-lasting conditions or difficulties?

(a) Blindness or a serious vision impairment	Yes <input type="checkbox"/>	No <input type="checkbox"/>
(b) Deafness or a serious hearing impairment	Yes <input type="checkbox"/>	No <input type="checkbox"/>
(c) A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying	Yes <input type="checkbox"/>	No <input type="checkbox"/>
(d) An intellectual disability	Yes <input type="checkbox"/>	No <input type="checkbox"/>
(e) A difficulty with learning, remembering or concentrating	Yes <input type="checkbox"/>	No <input type="checkbox"/>
(f) A psychological or emotional condition	Yes <input type="checkbox"/>	No <input type="checkbox"/>
(g) A difficulty with pain, breathing, or any other chronic illness or condition	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Figure 1

Summary of Results

The results of the Special cross tabulation indicate that, based on 2011 statistics:

1,749 people are Deafblind in Ireland (CSO, 2013).

This figure is equivalent to 57 people in every 100,000

EU Comparison

In June 2014, based on prevalence rates developed in the UK, the European Deafblind Network (EDbN) estimated that there were almost 3 million people living with Deafblindness in Europe. (EDbN, 2014:16). The estimate of the number of people who are Deafblind in Ireland provided by EDbN is substantially higher than that produced by the CSO.

Summary of Results

According to EDbN, there are

17,206 people in Ireland are Deafblind

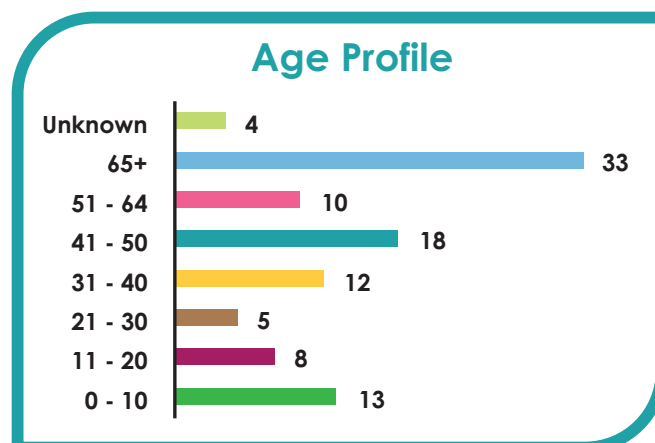
7,442 are below the age of 64 and 9,765 are over 65.

Conclusion

Research from the European Deafblind Network suggests that data provided by the CSO grossly underestimates the number of people who are Deafblind in Ireland. This is likely to be a reflection of the fact that only people with “a combination of Blindness or a **serious** vision Impairment and Deafness or a **serious** hearing Impairment” were recorded on the Census while the Centre for Disability Research used criteria that included people with less severe impairments of both vision and hearing. It should also be noted that a key recommendation from EDbN's report was to establish standardised Census questions where information on the number of people with sight and hearing impairments could be collected. The fact that Census information is available in the Irish context should be commended. Notwithstanding this, the sizeable discrepancy between estimates emphasises the need for further research in the area.

Demographic Profile of people who are Deafblind in Ireland

Of the 103 people surveyed, 54 were male and 49 were female. While this indicates gender balance across the deafblind population, differences were evident in the younger age category. Of the 20 respondents aged 20 or under, 15 were male and only five were female. The relatively small number of young people surveyed makes it difficult to assess how representative this is of the group overall. Based on the fact that the gender balance of 55% male and 45% female reported for this age category in the US is said to be indicative of other such studies (Baldwin, 1993:68), the discrepancy noted here is most likely coincidental.



One third of respondents were aged 65 years or over and 22% of the total number were aged 80 years or over. This finding is consistent with international research on the topic, which confirms that acquired deafblindness in old age represents the largest diagnostic group of people with a combination of vision and hearing loss. However, based on the results of similar studies, the prevalence of age-related deafblindness suggested here is almost certainly underestimated by at least 30% (See Chapter 2).

Location

Unsurprisingly, the highest proportions of people who are Deafblind in Ireland were recorded on the Census in more densely populated areas around larger towns and cities. It is interesting to note the slightly higher number of people in Donegal compared to other rural counties, apparent in both the CSO figures (Summary Figure 1.2) and the National Registry of people who are Deafblind in Ireland (Figure 1.3).

Location	CSO	County	n
Dublin	518	Cavan, Clare	0
Cork	186	Leitrim, Monaghan, Offaly, Sligo, Westmeath, Wexford	1
Limerick	75	Carlow, Kildare, Kilkenny, Laois, Longford, Meath, Tipperary	2
Galway	88	Louth, Roscommon, Wicklow	3
Donegal	82	Donegal, Kerry, Mayo, Waterford	4
Waterford	50	Limerick	5
		Galway	10
		Cork	15
		Dublin	28
		Total	103

Figure 1.3 – Number of People who identified themselves as Deafblind by County

Characteristics of the Deafblind Population

Acquired Deafblindness in Old Age

As mentioned above, acquired Deafblindness in old age represents by far the largest diagnostic group within the Deafblind population. One third of respondents in this research were aged 65 or over. The overriding cause of age-related deafblindness, as identified by research conducted in Denmark, is age-related hearing loss (presbycusis) and age-related changes in the retina, such as macular degeneration (Mortensen, *n.d*). Four of the 33 respondents in this research aged 65 and over cited age-related macular degeneration as the cause of their sight loss. However, as an open-ended question was used to acquire information on 'other impairments or conditions', this number is likely to have been underestimated.

Interestingly, recent ground-breaking research conducted by Professor John Nolan in Waterford Institute of Technology, found the estimated prevalence of Age-Related Macular Degeneration

in Ireland at 7% (Fighting Blindness, 2013). This is significant given the fact that researchers from Turkey found that in subjects with macular degeneration 50% had mild hearing loss, 20% had moderate hearing loss, and 6% had severe hearing loss (Eiden, 2011). While further research is necessary to confirm the association, the evidence suggests that the rate of Deafblindness in old-age is higher than previously estimated.

Usher Syndrome

Almost 20% of respondents were diagnosed as having Usher Syndrome. Of these, all were congenitally Deaf and experienced either profound or severe hearing loss. Only three respondents indicated that their hearing loss was improved with the use of hearing aids. Vision loss was adventitious for all of the respondents in this category with the majority beginning to lose their sight before the age of 30. Only five of the 19 indicated they were blind with the remaining 14 experiencing moderate vision impairment. Two-thirds were under the age of 65 and all five respondents experiencing complete blindness were over the age of 65.

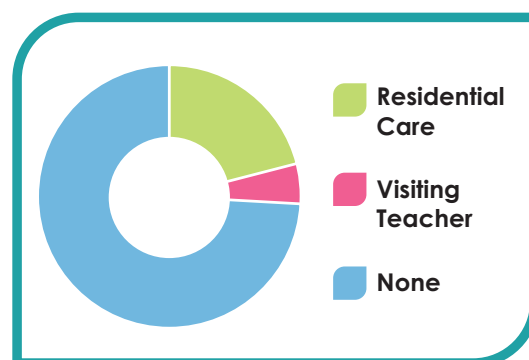


Figure 1.3 – Services Accessed by people with Usher Syndrome

As previously noted in Chapter two, a relatively large proportion of people with Usher Syndrome chose not to identify with the term 'Deafblind' and reportedly adopt avoidance behaviours during the intermediate stages in the progression of the disease (Côté *et. al*, 2013:140). This has a significant impact on the development of appropriate rehabilitation services for the group. Of the 19 people surveyed as part of this research, only five indicated that they were engaged with a service provider. Of these, four were over the age of 65, were blind and were in full -time residential care (Figure 1.3).

Several studies have also pointed to the difficulties associated with adapting to Usher Syndrome (*ibid.*). Research has shown that learning to receive messages in a new modality, when a person's ability to see signs and to lip-read are lost little by little, can be tiresome which contributes to withdrawal (Möller, 2008:67). In addition, the aggravated visual impairment is experienced as an ongoing loss, which is a threat to the social role 'able deaf' and threatens the possibility to communicate with other people (*ibid.*). Major problems involving headache, fatigue, depression, suicidal thoughts, and suicide attempts were also found to effect participants in research into the physical and psychological health of people with Usher Syndrome in Sweden (Wahlqvist *et al.*, 2013:213).

Despite this, it is important to note that people respond differently to their diagnosis of Usher Syndrome. Research conducted in Birmingham, UK found that some experiences are positive and that "there are many things which suggest that people with Usher can do many of the things they want to – they sometimes have to find a way round it – but they can (Ellis and Hodges, 2013:225)".

Congenital Deafblindness and Other identified Aetiologies

10 people indicated that they had a diagnosis of Congenital Rubella Syndrome. Of the 10, 8 people were in the 35-45 years age category and two were younger. Four of the respondents were both blind and profoundly deaf with the remaining six experiencing either severe or

profound hearing loss with moderate vision impairment. Eight of the 10 respondents in this category lived in a residential care facility and the remaining two receive respite care. It is interesting to note that, CRS reporting (as a distinct entity) only became notifiable on January 1st 2004 (HPSC, 2007). Prior to this, CRS cases were identified through other surveillance systems (British Paediatric Surveillance Unit (BPSU), or through European Surveillance of Congenital Anomalies (EUROCAT)). Both BPSU and EUROCAT were contacted for information on historical CRS incidence in Ireland. Four cases were known to BPSU (since 1989) and two cases in EUROCAT (plus most recent case reported) (*ibid.*).

Almost 7% of respondents listed CHARGE Syndrome as an additional condition or impairment. Of these, only 1 was over the age of 18. All respondents diagnosed with CHARGE indicated they had congenital hearing loss that was either profound or severe and congenital sight loss that was either moderate (5 respondents) or unable to test. As is characteristic of the syndrome, all respondents had additional conditions most notably defects of the heart.

Over 90% of respondents below the age of 20 indicated that they had one or more additional disability. This finding is consistent with data produced as part of the National Child Count in the US. It found that overall the number of children with additional disabilities had increased and that in 2011, 42% of children had four or more additional disabilities.

Additional conditions listed by respondents in this research (predominately below children) were as follows: (*Please note: respondents with multiple disabilities may be counted more than once*).

Arthritis	Epilepsy
Age-related Macular Degeneration	Developmental Delay / Intellectual Disability
Alzheimer's	Down Syndrome
Mobility Issues / Balance Problems	Dyspraxia
Cerebral Palsy	Usher Syndrome
CHARGE	Weidemann Steiner Syndrome
Heart Defect	Trisomy 7p
Feeding problems / Peg-fed	Peroxisomal biogenesis Disorder
Autism	Freidreich's Alaxia

Living with Deafblindness

As the majority of international research into the lives of people who are Deafblind use qualitative data, it is difficult to compare it to the results of the quantitative data gathered as part of this study. However, people who are Deafblind in Ireland are presumably not immune to the difficulties associated with independence, communication and isolation, which emerge consistently throughout the research. Large-scale studies of people who are Deafblind (Bodsworth et. al., 2011; Sense and Deafblind UK 1999 cited in Hersh, 2013:450), found that the majority of them require

one-to-one support. However, informal support from family members was more frequent than formal support from professionals and volunteers and there was a demand for more formal support (Hersh, 2013:450). People with a long term hearing or visual impairment who developed a second sensory impairment later in life were found to have little knowledge of appropriate services and younger deafblind people were found to rarely receive the support necessary for success as adults (Petroff, cited in Hersh, 2013:450). Interestingly, Munroe (2011), notes that in Canada, people who are congenitally deafblind usually have strong advocates or family involvement but it is much more difficult to reach individuals from the acquired group.

Living Arrangements

Almost two-thirds of respondents to this research lived with family. Fewer than 15% lived alone and almost 20% lived in a residential care facility.

Services being Received

Of the 20 people surveyed under the age of 20, 16 had access to a visiting teacher for the Blind and visually impaired or the Deaf and Hard of Hearing and 8 attended a special school. An additional 8 people in this group also received respite care, which was usually limited and based on the discretion of Service Providers.

Visiting Teacher	70%
Special Ed. School	45%
Respite	20%
Day Service	20%
Personal Assistant	30%

**Services Accessed by
0-20year olds**

A little over 16% of respondents received full-time residential care. The majority of these were either Congenitally Deafblind or were over the age of 65. 55% of people who are Deafblind are not in receipt of any services. This is likely to be an underestimation as the proportion of people relying on family and voluntary support are more difficult to access for research purposes.

Chapter 5



Recommendations and Conclusions

Campaign for Awareness and Enabling Legislation

As noted in Chapter two, a general lack of awareness about Deafblindness amongst the public can result in people who are Deafblind withdrawing from society and disengaging with the world around them (Gullacksen, 2011 and Schneider, 2009). The potential effect that raising awareness about Deafblindness can have on reducing instances where people feel isolated in this way, should therefore be highlighted in the Irish context. The fact that people who are Deafblind reported feeling distressed in situations where they were wrongly perceived as being 'sick' or felt pitied (Schneider 2009: 38), indicates that raising awareness can have a positive impact on eliminating preconceived ideas about the disability and on improving the life experiences of people who are Deafblind.

In addition, official recognition of the rights of people who are Deafblind is essential if the needs and experiences of the group are to be considered in disability legislation and policy changes. It is therefore, vitally important that Ireland adopt Written Declaration 2004/1 recognising Deafblindness as a separate and unique disability and immediately ratifies the UN Convention on the Rights of Persons with Disabilities.

Advocacy

While efforts have been made in the past to establish support groups specifically for people who are Deafblind, none have been maintained to a standard that allows somebody recently diagnosed or their family to connect with people in a similar situation for support and advice. According to Hersh (2013), involvement with an organisation of Deafblind people enables newly Deafblind or blind people the opportunity to meet other (deaf)blind people who frequently act as role models, show them what is possible with regard to activities and lifestyles and even teach them particular skills. Networks of informal support, whether meeting in person or online were found to be as helpful for some as support from formal agencies set up to do this (Hodges and Ellis, 2013: 228). It is important that such groups also advocate for the rights of people who are Deafblind and are supported to lobby for improvements in the provision of Deafblind services.

The value of parents and family members being in contact with each other is also difficult to underestimate. Certainly, the planning and provision of services requires the involvement of, or consultation with deafblind people and/ or their families, to ensure their needs are fully met and their views are respected. Thus, the establishment of peer and family support groups is recommended to bring people who are Deafblind and their families together to share experiences, offer support and advocate for the provision of services and the adoption of enabling legislation.

Development of Deafblind Specific Services

The very limited data available on Deafblindness in Ireland suggests that the majority of the Deafblind population do not have access to Deafblind specific services. This ignores the evidence that Deafblindness requires an approach that differs significantly from that used with individuals who are challenged by blindness, deafness or who have other severe multiple disabilities. As the case studies outlined in Chapter one illustrate, the development of Deafblind specific services internationally has greatly enhanced the lives of people who are Deafblind around the world.

The EDbN found that the shortage of specific Deafblind services stretches the capacities of other organisations and does no good for Deafblind people who want specialised support to communicate or be mobile (2014:51). They also note that the fact that Deafblind service provision is still an emerging entity should be seen as an opportunity, not a drawback. Thus, as well as encouraging cooperation between countries, the development of Deafblind specific services with full access to experts in the field of Deafblindness should be made a priority in the Irish context. This needs to include, but should not be limited to, the development of recognised and accredited training courses aimed at providing professionals with the expertise necessary to provide services and support to people who are Deafblind.

Further Research

Overall, 1,000 surveys were distributed by cooperating organisations as part of the research presented here, usually via post but occasionally by professionals working directly with people who are Deafblind. 103 of those sent were returned by post in a four month period, representing a 10.3% response rate. In comparison, a similar study conducted in Canada succeeded in registering 777 people as Deafblind, representing a response rate of 32.1%. It should however be noted that, Canadian study took place over a period of almost two years, involved eight researchers and an advisory committee and reflected an ambition to build on previous work conducted by the Task Force on Services to Deaf-blind Persons in Canada (Munroe, 2001).

Thus, in terms of gathering basic demographic data about people who are Deafblind in Ireland and locating it in the context of international studies, the research presented here achieved its aims. However, while the quantitative data gathered is an invaluable source of information, qualitative data is required to further understand the needs and circumstances of the deafblind population in Ireland. While basic information on the type of services that Deafblind people are engaging with was gathered, the focus of this study did not allow for an in-depth analysis of the adequacy of current service provision. Nor did it offer the opportunity to consult with people who are Deafblind and their families about the type of services they require. As has been mentioned above, it is vital that organisations aimed at providing services to people who are Deafblind take a user-led approach to the development of services.

Despite the obvious successes of this project, several important questions remain unanswered. For example, the scope of this project did not allow for an investigation of whether Clark and Matthews (1999) claim that, *“services are often provided to congenitally Deafblind people by agencies for mentally retarded people”* is valid in the Irish context. Or whether, if this is the case, the group would benefit from the intervention of Deafblind specific services. Similarly, it did not offer the opportunity to explore whether family and friends typically provided the majority of support to people who acquire Deafblindness as was found in other studies conducted in the area or whether support services were accessible to people. In addition, the methods of assessment used by medical professionals to identify a person as Deafblind and the system used to refer patients to Deaf, blind and other services was not highlighted as part of this report. Further research into the area of Deafblindness in Ireland is therefore, identified as a priority to ensure that policy makers and service providers make informed decisions about the development of services based on the results of meaningful consultation with people who are Deafblind and their families.

Conclusion



The data uncovered in this report are critical to any policy or service planning strategies for people who are Deafblind in Ireland as they provide the only available evidence of Deafblindness in the Irish context. This report has provided an estimate of the number of people affected by the disability and has gathered important data on the demographic profile and characteristics of the population. It has also outlined basic information on the type of services people who are Deafblind are engaging with and has used relevant international literature to supplement primary research. The findings of the report are consistent with much of the international evidence on Deafblindness but further research is required to ascertain the true number of people affected by the disability and understand more about the needs of the diverse group.

This research highlights the need for greater awareness of Deafblindness in Irish society and provides a strong rationale for the development of Deafblind specific services. Despite the obvious difficulties associated with measuring whether the objective of raising awareness was successful, it's fair to say that significant advances were made. In particular, the decision to enlist the help of cooperating organisations put the issue of Deafblindness on the agenda at regional and team meetings held in every branch of both the NCBI and Deafhear across the country. It also highlighted the issue among all visiting teachers for the Deaf or hard of hearing and Blind or Visually impaired, as well as in a number of additional deaf, blind and disability services throughout Ireland. Information sessions delivered to the majority of cooperating organisations as part of the project, also offered staff in those services the opportunity to ask questions and share knowledge about Deafblindness.

In addition, the National Deafblind Awareness Day organised as part of the project, brought Deafblind people, their families and the professionals working with them together to highlight the need for action on the issue. The speech delivered by Fr. Cyril Axelrod, the world's first Deafblind priest, also captivated those in attendance and demonstrated the potential of people who are Deafblind. The media coverage generated by the project and more specifically the Awareness day, which included local radio interviews, articles in local papers and an interview of RTE 1 television, also contributed massively to raising awareness about Deafblindness.

Finally, it is recognised that tackling the issue of Deafblindness requires collective action from families, communities, professionals, policy makers, blind and other disability organisations, the deaf community and political leaders. It also requires the input of people who are Deafblind themselves and their families. It is essential that people who are Deafblind are facilitated to participate and engage with policy decisions that affect the quality of their lives. Ensuring that the needs of people who are Deafblind are met will impact positively on the rights of people with disability more generally and will ensure that Ireland does not lag behind its European counterparts in the provision of services to people with additional needs. This report has succeeded in establishing important links with people who are Deafblind, their families and the professionals working with them to facilitate further research and advance efforts to improve the services available to people who are Deafblind into the future.

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APPENDIX 1: LIST OF COOPERATING ORGANISATIONS

Child Vision	Irish Deaf Society
Cork Deaf Association	Jack and Jill Foundation
DeafHear <ul style="list-style-type: none"> - Dublin North, - Dublin South, - Dundalk, - Galway, - Killarney, - Kilkenny, - Letterkenny, - Limerick, - Mayo, - Sligo, - Tullamore, - Waterford 	NCBI <ul style="list-style-type: none"> - Dublin South, Kildare and Wicklow, - Dublin North, Louth, Meath, Cavan, Monaghan, - North West (Donegal, Sligo and Leitrim), - West (Galway, Mayo, Roscommon), - Midwest (Limerick, Clare and North Tipperary), - Midlands (Westmeath, Laois, Offaly, Longford), - South (Cork and Kerry), - South East (Wexford, Waterford, Carlow, South Tipperary, Kilkenny).
Department of Education – Visiting Teachers for the Blind and Visually Impaired and Deaf and Hearing Impaired,	St. Joseph's Centre for Deaf and Deafblind
Fighting Blindness,	

APPENDIX 2: INFORMATION BOOKLET, CONSENT FORM AND QUESTIONNAIRE

Who Are We?

The Anne Sullivan Centre opened in 1996 and is the first residential home service for Deafblind individuals in the country. It currently provides support to Deafblind adults between the age of 21 and 45 with additional disabilities.

The Centre is named after Anne Sullivan, an Irish Immigrant whose family left Limerick to escape the Great Famine over a century ago. In 1886, Anne was hired by the Keller family to teach their deafblind daughter, Helen and rescued her from a life of isolation.

The Anne Sullivan Centre aims to perpetuate Anne's legacy by facilitating deaf blind adults to pursue meaningful, active and fulfilling lives. The centre aims to embrace the uniqueness of each individual service user by offering them personalised activity and communication plans and encouraging them to make their own decisions.



A Study into Deafblindness in Ireland



The Anne Sullivan Centre, supported by the Anne Sullivan Foundation and Deafblind Ireland are delighted to announce the commencement of a nationwide project aimed at gathering information to improve the lives of Deafblind people across the country.



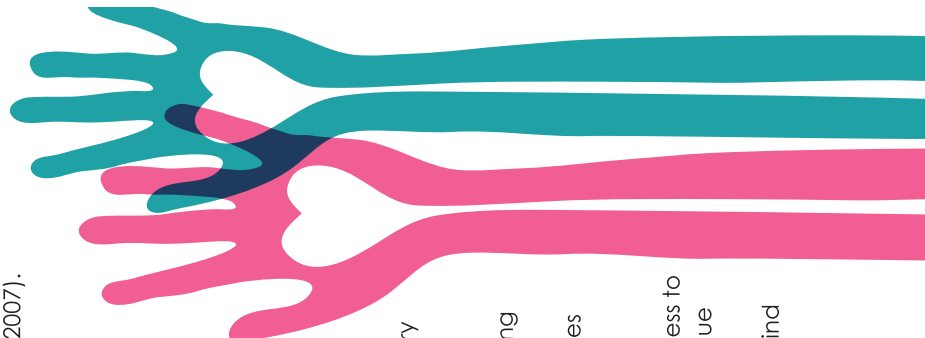
What is Deafblindness?

A person is regarded as deafblind if their combined sight and hearing impairment causes difficulty with communication, access to information and mobility. The term includes people with a progressive sight and hearing loss and can be congenital or acquired in origin. (Nordisk Lederforum, 2007).

Aims of the Study

The primary objective of the study is to gain a more accurate picture of the number of deafblind individuals in Ireland. In addition the project aims to

- Discover the age profile and location of people who are deafblind
- Determine the different levels of sensory impairment that exist
- Gain a greater understanding of the prevalence of various conditions relating to Deafblindness.
- Gather basic information on the services that people who are deafblind are availing of
- Highlight the campaign for deafblindness to be recognised as a separate and unique disability in Irish Law
- Meet international standards in deafblind research and service provision



Why is a study into Deafblindness needed?

To provide the information necessary to plan, develop and organise services for people who are deafblind

To raise awareness of deafblindness and the unique challenges it presents

To encourage greater cooperation between people who are deafblind, their families and service providers

Who can participate?

Anyone with a combined vision and hearing loss which causes difficulty with communication, access to information and mobility can participate.



▲ PULL OUT CONSENT FORM ▲

Consent Form

Name of the person who is Deafblind

If the person does not have the capacity to consent or is below the age of 18, please state the name of the individual giving consent

Relationship to person who is Deafblind

- ☐ I agree that my details can be added to a register of individuals with deafblindness/Dual Sensory loss
- ☐ I understand that I may withdraw my consent to share information or receive additional information at any time
- ☐ I agree that the information I have provided can be used to create statistical information for the purpose of this research project
- ☐ I understand that the information I have provided will be kept strictly confidential and will not be shared with any third party without my consent

Signed:

Study of Deafblindness in Ireland

The following Questionnaire offers deafblind people, their families and carers the opportunity to contribute to research into deafblindness in Ireland.

Should you need any additional assistance completing this questionnaire please do not hesitate to contact **english@annesullivancentre.ie** or **086 3617316**

Many Thanks for your Support,

Laura English
Research Co ordinator,
The Anne Sullivan Centre



Correspondent* Information

*Where the deafblind individual is unable to enter the information required below independently, information can be entered on their behalf. The person providing the information **MUST** have the explicit consent of the deafblind individual to do so. In instances where for reasons of incapacity or age the deafblind person is unable to consent to participate in this research, explicit consent must only be given by a parent or legal guardian.

Name:

Address:

Telephone:

Are you

- ☐ a) Supporting a Deafblind person to complete this form?
- ☐ b) Completing this form on behalf of a Deafblind person?

What is your relationship to the Deafblind person?

Participant* Details

*The participant is the deafblind person to whom the research relates.

Name:

Age:

Gender:

☐ Male☐ Female

Location:

- ☐ Carlow
☐ Cavan
☐ Clare
☐ Cork
☐ Donegal
☐ Dublin
☐ Galway
☐ Kerry
☐ Kildare

- ☐ Kilkenny
☐ Laois
☐ Leitrim
☐ Limerick
☐ Longford
☐ Louth
☐ Mayo
☐ Meath
☐ Monaghan

- ☐ Offaly
☐ Roscommon
☐ Sligo
☐ Tipperary
☐ Waterford
☐ Westmeath
☐ Wexford
☐ Wicklow

(Tick Multiple boxes if required)

Hearing

Onset of Hearing Loss:

☐ Congenital (present at birth)

☐ Prelingual (hearing lost before language was present)

☐ Adventitious (after language acquisition) at age:

☐ Unknown

Degree of Hearing Loss

☐ Mild (26 – 45dB)

☐ Moderate (46-70 dB)

☐ Severe (71-90 dB)

☐ Profound (91-110dB)

☐ Unable to Test –Uses Hearing

☐ Unable to Test – Does Not Use Hearing

☐ Improved with the use of hearing aid(s)

☐ Unknown

Sight

Onset of Vision Loss:

☐ Congenital – present at birth

☐ Adventitious – vision lost later in life at age:

☐ Unknown

Degree of Vision Loss

☐ Blindness

☐ Moderate vision Impairment

☐ Mild Vision Impairment

☐ Unable to Test – Uses Vision

☐ Unable to Test – Does not Use Vision

☐ Unknown

Additional Impairments or Conditions (if any):

Please tick the box that best describes your current living arrangement.

I live

☐ Alone

☐ With family

☐ In a residential care facility

☐ In an independent living facility

☐ Other

Are you currently in receipt of any of the following services?

☐ Residential Care

☐ Respite Care

☐ Day Service

☐ Visiting Teacher

☐ Personal Assistant/ Special Needs Assistant

☐ Special Education School

☐ Other (Please specify)

Add Comments if necessary:

Do you wish to receive information from the Anne Sullivan Centre on upcoming events and services that become available in the future?

☐ Yes

☐ No

If yes, please indicate how you would like to be contacted and enter your details below.

☐ Post

☐ Telephone

☐ Email

Address:

Telephone:

Mobile:

Email:

Thanks for taking the time to fill in this questionnaire.

Consent

Where the individual who is deafblind needs assistance to enter the information required, it can be entered on their behalf.

The person entering the information MUST have the explicit consent of the individual who is deafblind to do so.

In instances where for reasons of incapacity or age the deafblind person is unable to consent to participate in this research, explicit consent must only be given by a parent or legal guardian.

Each questionnaire must be accompanied by a signed consent form.

Get Involved

You can get involved by making service users, their family and friends aware that the study is taking place or by assisting a deafblind person to complete the questionnaire.

Who has access to Information and how is it used?

Information is available to the individual or his or her parent or guardian and to a small number of specific people within the Anne Sullivan Centre, who are responsible for collecting and analysing the data.

Each of these people use their name and a password to access any information and are acutely aware of keeping all personal data confidential.

Only anonymous statistical information will be published. Information on names and addresses or contact details will not be made available to any unauthorised third parties and are protected under Data Protection legislation.

Under the Data Protection Act 1988 and the Data Protection Amendment Act, 2003, anyone who registers themselves as deafblind or their parents or guardians are entitled to

- Request a copy of the information held about them
- Have any wrong information held about them corrected or erased

The Anne Sullivan Centre's Policy on the Protection of Data is available for research participants on request.

Our Partners:

The Anne Sullivan Foundation

The Anne Sullivan Foundation provides support and advice to people who are deafblind, their families and carers or interveners. It provides an outreach service to children and adults who are deafblind. The Anne Sullivan Foundation also fundraises and accepts charitable donations on behalf of people who are deafblind nationally. For more information visit www.annesullivan.ie.

Deafblind Ireland

Deafblind Ireland is a support network for people who are deafblind, their families and the professionals working with them. The organisation seeks to raise awareness of deafblindness as a separate and unique disability and offers training to professionals working with people who are deafblind. In 2013, Deafblind Ireland delivered the first professional training course in Deafblindness in Ireland. For more information visit www.deafblindireland.ie.



THE
Anne Sullivan
CENTRE FOR DEAFBLIND

If you have any further questions
please do not hesitate to contact
Laura English, Research Coordinator
lenglish@annesullivancentre.ie
086 361 7316

Large print and Braille copies of this document
are available on request.



APPENDIX 3: STATISTICS FROM THE NATIONAL PHYSICAL SENSORY DISABILITY DATABASE (requested from the Health Research Board).

HEALTH RESEARCH BOARD (2011)

Type of Disability	n	%
Hearing Loss/ deafness & visual	116	24.3
Physical, Hearing Loss/ deafness & visual	201	42.1
Hearing & visual & speech and/or language	41	8.6
Physical & Hearing & visual & speech and/ or language	120	25.1
Total	478	100.0

APPENDIX 4: STATISTICS FROM THE CENTRAL STATISTICS OFFICE

Persons, males and females who are deafblind and deafblind* with one other disability or more and enumerated in each province, county and city, classified by age group, 2011*

Province, county and city	Persons					
	Deafblindness*			Deafblindness* with one other disability or more		
	Total	Age Group		Total	Age Group	
		0-64 Years	65 years & over		0-64 Years	65 years & over
Leinster	964	391	573	5,398	1,453	3,945
Carlow	28	9	19	118	34	84
Dublin	518	190	328	2,915	786	2,129
Dublin City	279	101	178	1,648	406	1,242
Dún Laoghaire - Rathdown	85	18	67	464	80	384
Fingal	68	33	35	377	145	232
South Dublin	86	38	48	426	155	271
Kildare	62	33	29	343	93	250
Kilkenny	23	8	15	194	43	151
Laois	25	12	13	153	47	106
Longford	15	5	10	104	28	76
Louth	58	26	32	305	82	223
Meath	67	37	30	300	72	228
Offaly	30	10	20	170	49	121
Westmeath	28	11	17	204	66	138
Wexford	61	24	37	325	82	243
Wicklow	49	26	23	267	71	196
Munster	471	189	282	2,930	732	2,198
Clare	35	11	24	250	66	184
Cork	186	76	110	1,192	291	901
Cork City	67	21	46	423	116	307
Cork County	119	55	64	769	175	594

Province, county and city	Persons					
	Deafblindness*			Deafblindness* with one other disability or more		
	Total	Age Group		Total	Age Group	
		0-64 Years	65 years & over		0-64 Years	65 years & over
Kerry	54	21	33	331	68	263
Limerick	75	32	43	444	136	308
Limerick City	27	8	19	177	60	117
Limerick County	48	24	24	267	76	191
North Tipperary	27	16	11	189	41	148
South Tipperary	44	15	29	246	78	168
Waterford	50	18	32	278	52	226
Waterford City	24	7	17	136	31	105
Waterford County	26	11	15	142	21	121
Connacht	196	75	121	1,326	301	1,025
Galway	88	33	55	524	134	390
Galway City	30	11	19	128	45	83
Galway County	58	22	36	396	89	307
Leitrim	9	5	4	75	12	63
Mayo	48	14	34	372	82	290
Roscommon	22	9	13	172	33	139
Sligo	29	14	15	183	40	143
Ulster (part of)	118	44	74	711	158	553
Cavan	20	7	13	154	37	117
Donegal	82	31	51	414	88	326
Monaghan	16	6	10	143	33	110
State	1,749	699	1,050	10,365	2,644	7,721

* Those persons with both blindness or a serious vision impairment and deafness or a serious hearing impairment only

