



Submission to the NCSE on the educational services and supports required by children who are Deafblind and the Special Needs Assistant (SNA) scheme

November 2016

Catherine McDonald  
Policy & Advocacy Lead,  
The Anne Sullivan Centre

## A summary of what is required

- Recognition of deafblindness as a distinct disability, as separate to deafness and blindness
- The provision of early intervention for Deafblind adults and children by a Deafblind Specialist. This is cost-effective in the long run.
- Better understanding of deafblindness by health and social care practitioners as well as those with responsibility for education.
- Data on the population of Deafblind people. (A good example is The National Child Count of Children and Youth who are Deafblind in the US).
- The availability of trained intervenors to support Deafblind and multi-sensory impaired children within the school setting
- Information and training in augmentative communication methods for those who are Deafblind, their family members and professionals supporting them.
- Financial assistance to purchase adaptive (ramps, mobility aids etc..) and assistive technology (screen readers etc.). Legal rights to special aids and equipment are present in the majority of States across Europe, this needs to be incorporated into the Irish system.
- Further research into the area of Deafblindness which includes greater consultation with people who are Deafblind.

*A*



*Deafblind child with severe hearing and vision impairment does not know what lies beyond their fingertips. If they cannot reach out and touch a person, they have no way to*

*communicate and no way to learn.*

### **The condition of Deafblindness**

Deafblindness is a multi-sensory impairment, affecting both sight **and** vision. In the case of congenital deafblindness, the ability to speak is also inhibited, resulting in a life of silence and extreme difficulty with communication.

Deafblindness is sometimes known as dual sensory impairment, dual sensory loss, audiovisual loss or multi-sensory impairment. The European Deafblind Network identify a person as Deafblind *“if their combined sight and hearing impairment cause difficulty with communication, access to information and mobility”*.

To date, the Irish government have not recognised deafblindness as a condition that requires the state to provide supports and services that are different to what is already in place to support people who are visually impaired or hearing impaired. It is evident that combined hearing and vision impairments create barriers to communication that can isolate people and jeopardise independence and well-being; when vision and hearing losses combine, a person’s ability to overcome these barriers becomes even further limited because one sense cannot adequately compensate for the loss of the other. Deafblindness is therefore a complex condition that requires intensive and unique supports.

Census 2011 found that there were 1,749 people in Ireland living with a severe combined hearing and vision impairment (See Appendix 1).

The Anne Sullivan Centre is an Irish organisation that provides care, advocacy and support services to adults and children who are Deafblind; the Centre is advocating for the increased provision of specific supports for those with combined hearing and vision loss. These supports include intervenors who are trained in augmentative communication skills, suitable means of transport to increase safety and reduce the risk of social isolation, information in accessible formats such as braille and the support of guide dogs. The extent and type of support needed differs depending on individual needs. To meet the complex and varied needs of individuals, the Irish government must recognise deafblindness as a separate disability to deafness and blindness and reflect this recognition in Irish policy and

legislation. By taking this crucial step, it is possible to achieve a shared understanding of the condition and facilitate the provision of suitable supports for people with combined hearing and vision loss.

The principal causes of deafblindness include Congenital Rubella Syndrome (CRS), CHARGE Syndrome, Usher Syndrome, other prenatal and perinatal conditions and syndromes, the aging deterioration experienced by some older people, some illnesses and the results of trauma/severe accident. Appendix 2 provides further details on the causes and complexities of deafblindness.

### **What we want to achieve and why?**

We want to see a society where all Deafblind people have equal opportunity to participate fully in society, in line with the commitments set down in the United Nations Convention on the Rights of People with Disabilities (UNCRPD) and the United Convention on the Rights of the Child as well as the measures contained in EU Written Declaration on the Rights of Deafblind Persons (Declaration 1/2004).

Those who are Deafblind need others in society to understand their abilities rather than focus on their disability. Quite often, they do need people to foster the development of these abilities through making conscious efforts to remove any barriers. We want people to reach out, assist and make a profound difference to the lives of those who may be feeling isolated and distressed as a result of dual sensory loss. We want at the earliest opportunity to ensure that all children and adults who are Deafblind receive early intervention services from a Deafblind specialist as well as support from trained intervenors in their day-to-day lives. Someone who is born deafblind has specific needs that cannot be met by those trained to support people who are blind or who are deaf; communication is undoubtedly the biggest challenge to a deafblind person and this has serious consequences in terms of a person's independence, isolation and positive mental health.

Early intervention and assessment by a Deafblind Specialist can introduce a child and their family to adapted forms of communication such as tactile (hand over hand) Irish sign language, lámh, Picture Exchange Communication System, pictures and objects of reference among others. A Deafblind specialist will help the child and their family to ascertain the best communication method for the child and can lead to the development of a formal

communication system and training for parents, grandparents, siblings and whoever else is closely involved in the child's life. The Deafblind Specialist will play a key role in creating a "Care Pathway" for a Deafblind person, ensuring they are provided with the supports they need right throughout their life- as a child at home and in school, as an adult in the workplace, in their community and in their own home.

Intervenors play an important role in the life of a Deafblind person, particularly in transitional stages of a person's life. When a child starts school, their family members or siblings will not be in the room with them. If they do have a Special Needs Assistant (SNA), that SNA will not have extensive knowledge of the child's communication system, developed over his/her early years. One-to-one work with Deafblind children carried out by trained intervenors both in the child's home and in the school setting is essential so that a child can maintain his/her own communication system, convey needs and preferences and understand what is happening in the environment around him/her. A Deafblind child with severe hearing and vision impairment does not **know what lies beyond their fingertips**. If they cannot reach out and touch a person, they have no way to communicate and no way to learn. A trained intervenor who works on a one-to-one basis with a child can adapt and communicate the school curriculum to a child in a manner that the child can understand and can facilitate communication and friendships between the child, the teacher and his/her peers. A key difference resulting from these changes is that a child can learn and socialise on an equal footing with their peers.

For those with acquired deafblindness, that can occur later in life, there is a need to provide rehabilitation supports so that people are provided with the necessary equipment and aids to support them to live independently and comfortably in their own homes. In addition, training of personnel who work with Deafblind persons is of critical importance-the ability to communicate and transfer information to a person with combined hearing and vision impairments is a skillset that should be integrated into training for all relevant bodies.

Older people may develop combined hearing and vision problems as part of the ageing process and they require an intervenor to help them to take an active part in everyday life. This may mean helping them to go shopping, sorting out their bills, or interpreting or intervening at a medical appointment - activities that older people who are Deafblind find next to near impossible. Having a trained intervenor will result in reducing social isolation

for older people and increase their ability to understand the advice of medical professionals ~ this has direct implications for their health and mental well-being and direct implications for the State in terms of costs. Economically it is better for the individual and the State that people continue to live with support in their own homes rather than in the care of the State.

### **How ratifying the UNCRPD will impact on the educational needs of Deafblind children**

It is 2017 and the UNCRPD has still not been ratified by the Irish government, despite many promises to do so. The UNCRPD is the first human rights treaty that promotes positive attitudinal changes to persons with disabilities. It views persons with disabilities as active members of society and not “objects” of charity or medical treatment. Ratification of articles 23 and 24 will have a specific impact on the supports provided to Deafblind children; these articles highlight the need for the active and continuing support of qualified professionals for Deafblind infants and young children and places particular emphasis on the need for early intervention and referral to agencies that can offer suitable support services.

### **How giving effect to the measures contained in EU Written Declaration of the Rights of Deafblind People (Declaration 1/2004) will benefit people who are Deafblind in Ireland**

This declaration was passed by the European parliament in 2004; it states that Deafblindness is a distinct disability that is a combination of both sight and hearing impairments and that Deafblind people need specific support provided by people with specialist knowledge. In particular, this declaration highlights that Deafblind people need supports to vote, to work and access training and should receive person-centred health and social care to participate in life-long learning from early intervention to vocational training.

Thirteen years on, significant disparities continue to exist between member states in relation to service provision and access to specialised support.

### **Recommendations for change specific to the current SNA scheme**

- i) The DES Circular 0030/2014 (pp.5-6) lists the primary care needs of children which would be considered significant and might require SNA support. The role of the SNA in assisting children who have severe communication difficulties is highlighted as “enabling curriculum access for pupils with physical disability or sensory needs”. The same document highlights on the following page (p.7) that SNA’s are recruited specifically to assist in care needs of pupils with disabilities however SNA’s do not have a pedagogical role and it would not be appropriate for pupils with special needs to be taught by unqualified personnel.

The DES Circular 0030/2014 (p.8) goes on to highlight that many children with special educational needs require additional teaching support and that in such circumstances, the classroom teacher will be supported by a resource teacher/learning support teacher. It states that “The classroom teacher and resource/learning support teacher will consider ways in which the curriculum can be differentiated or adapted to suit the needs of individual pupils...parents are consulted...support can be provided in a variety of ways such as team teaching, small groups or individually for a period of time”

**Recommendation 1:** Provide clarity around the roles of the SNA and the Resource/Learning support teacher in supporting pupils with physical and sensory needs to access the curriculum.

- ii) Current policy and legislation does not provide a person-centred approach to meeting the needs of Deafblind children. An SNA or a resource/learning teacher currently cannot adequately support a deafblind child to access the curriculum as each deafblind child is likely to have their own unique communication method, developed as a child with the support of professional intervention and family. Communication methods might include use of objects of reference, adapted ISL (hand-over-hand signing) or other forms, depending on their abilities. In the case of a Deafblind child who needs the full-time support of a professional person who understands that child’s alternative/augmentative communication system, the current SNA/Learning support teacher support system is not effective and cannot adequately support the type of child described here.

The DES Circular 0030/2014 (p.14) identifies the need for access to SNA support and highlights again that it is not the role of the SNA to act as a personal assistant to children or to act as an alternative teacher to children. It does mention that there are a relatively small number of children who for medical or sensory reasons associated with their condition required full-time attention and assistance at certain times of the school day and “for such children access to full day support will be provided for”. Acknowledgement of the need for more intense support and services and full-time one-to-one support is no doubt welcomed by the parents of a Deafblind child as well as the children themselves. It is evident that there is a

commitment to support all children to attend and succeed in school however there is a glaring gap in terms of an explanation as to how that commitment can be honoured.

**Recommendation 2:** Where it is determined by a multi-disciplinary team that a child needs one-to-one full-time support in school, ensure that this is provided by an intervenor with whom the child has a good relationship, who knows him/her and his family and has observed the child in his/her home environment.

- iii) The DES Circular 0030/2014 (p. 12) outlines the current SNA support for Children with Visual and Hearing Impairment. It states that children with acute sensory impairment such as visual and hearing impairment have “particular and distinct care needs which are of a non-teaching nature”, and the assistance of SNA support is required for those pupils to be able to attend school and access the curriculum. The same document acknowledges that, in addition to care needs, there are additional support needs which children with hearing impairment require, including the use of Sign Language support to assist with communication and socialisation. It goes on to say that SNA’s who work with Deaf and Hard of Hearing children must be equipped with the skills necessary to support the particular needs of these pupils, including capacity to use ISL where required. It also states that the most senior SNA staff in the schools should be trained in specialist skills.

**Recommendation 3:** A child who is Deafblind may have care needs but they will also certainly have extensive learning support needs. The term ‘distinct care needs’ should be replaced with ‘distinct learning support and/or care needs’ and the roles of the SNA and the resource/learning support teacher once again should be differentiated in this particular section in terms of how each role provides support to a child with visual and hearing impairments.

**Recommendation 4:** The condition of Deafblindness should be referred to in this section as well as the supports that are needed for a Deafblind child, as separate to the needs of a deaf child or a blind child i.e. use of augmentative or adapted communication methods such as hand over hand signing, or objects of reference.

**Recommendation 5:** One of the current problems for a Deafblind child starting school is the loss of people who can communicate with him/her. There must be coordinated care for Deafblind children that involves linkages between the child’s home life and school life. Whoever is placed in the role of supporting the deafblind child in their school should observe and spend sufficient time with him/her in their home in the first instance, should meet with members of the child’s multidisciplinary



team and should continue to be the link for the child between home and school. Providing training for SNA's/Resource teachers in specialist skills is a welcome investment but should be in addition to a person-centred approach that ensures each child with combined hearing and vision impairment has an intervenor who is trained to meet the specific needs of the child in the different environments they learn and socialize in.

## **Appendix 1**

### **Prevalence of deafblindness in Ireland**

To gain an understanding of the prevalence of deafblindness in Ireland the Anne Sullivan Centre undertook the first large scale research project in 2014. This project set out to ascertain the number and experiences of people who are Deafblind in Ireland.

Here are the key findings of this research:

- At least one third of the Deafblind population are over the age of 65, representing the largest diagnostic group within the population of Deafblind people
- 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 a quarter are engaged with a service provider
- 90% of Deafblind children and young adults have one or more additional disabilities
- Almost two third of people who are Deafblind live with family.
- 55% of people who are Deafblind are not in receipt of an appropriate level of service

Interestingly it identified a sizeable discrepancy between the estimates of people who are Deafblind provided by the CSO (1,749) and the estimate by the European Deafblind network (17,206)

Based on research conducted internationally, the CSO figure is likely to underestimate the number of people affected by Deafblindness. 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. The research project highlighted the need for further research in the area to better understand and plan for this cohort in our population

## **Appendix 2**

### **Deafblindness: Causes and complexities**

Deafblindness has many causes. Being deafblind affects each person differently. Deafblindness curtails access to the world and people who are deafblind have a different experience and knowledge of the world. Deafblindness carries colossal challenges for the affected individual and to those who provide direct care to them. Many people will be

neither completely deaf nor completely blind but will have some residual use of one or both senses. Some have additional intellectual disabilities.

Advances in science and in clinical practice, particularly in obstetrics have resulted in enhancing the chances of survival for infants born with significant disabilities however deafblindness is still viewed as a growing concern, mainly due to the ageing demographic in Ireland.

Deafblindness can be caused by either congenital conditions or it can be acquired.

### **Causes of Congenital deafblindness:**

Congenital Deafblindness means that the infant child never experiences vision, hearing, speech or communication as does the rest of the population. These children are commonly the victims of CHARGE and Rubella - there are other congenital causes with broadly similar effects.

#### Congenital Rubella Syndrome (CRS)

CRS is the German measles virus that affected some babies born about forty years ago. Rubella, in addition to causing deafness and blindness can seriously damage a foetus's organs in the early stages of pregnancy. Its effects vary from infant to infant. The following inabilities are common:

Ears: Hearing loss in one or both ears arising from malformation of inner-ear

Eyes: cataracts in the eye(s), rarer visual conditions or ongoing decline of residual sight as they grow older.

Heart: Rubella affects the heart resulting in malformations of that organ.

Brain: Rubella can also affect the brain and nervous system.

Rubella can affect the ability to swallow and immediate intervention can be vital. There can be liver, kidney and spleen damage. Some children suffer from microcephaly (undersized head) and alterations to their bones. The effects are not necessarily static but can become more severe

#### CHARGE Syndrome

The effects of Charge Syndrome are similar to CRS. The acronym CHARGE describes a range of diverse congenital abnormalities. Each letter stands for an associated disorder of the syndrome:

**CHARGE** Coloboma on the eye, **H**ear, **A**tresia of choane, **R**etardation of growth, **G**enital malformations, **E**ar malformations and/or deafness. CHARGE syndrome has an estimated birth incidence of 1 in 12,000 and is a common cause of congenital anomalies. Most affected individuals with CHARGE syndrome have mutations involving the chromodomain helicase DNA-binding protein-7” Again, the dominant – though by no means sole effect – is deafblindness

### **Causes of acquired deafblindness:**

A person who loses their sight and hearing after they have developed language in their early years is said to have acquired deafblindness. An individual may already have a sight or hearing impairment, and suddenly or gradually lose the other sense. It could be related to a specific genetic condition from birth, or resulting from an illness or accident. People who have Usher Syndrome, for example, will have grown up as deaf or hard-of-hearing, but then received the diagnosis that they are also losing their sight.

Due to their changed circumstances, a person’s sight or hearing loss will mean making lifestyle adjustments, such as in how they communicate, find and use information, or get around. While the diagnosis of sight and hearing loss can have a significant emotional impact, many people with acquired deafblindness lead active, independent and fulfilling lives.

