Submission to the Department of Justice (Equality Division) on the National Disability Inclusion Strategy

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
- 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.
- A Personal Assistant (PA) system in line with the UNCRPD
- Support for Deafblind people to be mobile in their own communities (Provision of adequate transport and intervenors)
- Recognition among the State and public/professional bodies of Irish Sign Language (ISL) and augmentative and alternative forms of communication (such as tactile signing/objects of reference/PECS) as formal communication systems.
- Deafblind persons to be consulted in the development of Universal Design Policy and Legislation
- Deafblind persons to be consulted in the development of all disability policy and legislation

- 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 transitionary 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 benefit those who are Deafblind

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. Articles which will have a specific impact on the needs on Deafblind people include:

Article 9: Accessibility

People who are Deafblind need to have full, safe and unencumbered access to public transport and the built environment in order to lead inclusive lives in the community

Article 20: Personal mobility

Most people who are Deafblind do not have sufficient residual sight to be able to travel safely by relying on their eyesight. They consequently need to learn alternative techniques

that utilises kinaesthetic and tactile senses; this is likely to involve the use of a "long cane", a guide dog, vision aids, electronic mobility aids and global positioning systems.

Article 21: Freedom of expression and access to information

Two of the principal disabilities arising from audiovisual loss are the abilities to communicate and to access information. Deafblind people need to have access to a myriad of assistive technologies that facilitate their access to information and expression.

Articles 23 &24: Education

Deafblind infants and young children and their parents need the active and continuing support of qualified professionals who can advise on the social, psychological, physical and educational development of infants and children with audio-visual loss. Early identification, diagnosis and referral to agencies that can offer these professional support services are crucial to long-term optimum academic and social development.

Article 27: Work and employment

Deafblind people can work successfully in professional jobs in adapted environments where intervenors or personal assistants and assistive technologies are available.

Articles 29 &30: The right to participate in political, cultural and public life, recreation and sport.

Ultimately, parties to the Convention must raise awareness of the human rights of persons with disabilities

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.

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

<u>CHARGE Syndrome</u>

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**eart, **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.