

Information for Parents/Guardians of Children and Young People who are Deafblind / with dual sensory loss

This brochure was developed as a collaboration between the Anne Sullivan Centre and the National Council for Special Education (NCSE)



What does deafblind mean?

Children get much of the basic information they need about their environment through seeing and hearing.

The term 'deafblind' is used internationally when a child has difficulties with both their vision and hearing. There is a very wide range in the level of difficulties that these children can experience. For example, one child who is deafblind may have some useful vision but little or no hearing and another may have useful hearing but virtually no useful sight. Some children who are deafblind may have additional learning difficulties which can make it more difficult for them to learn about their environment.

Children who are deafblind are sometimes described as having 'dual sensory loss'. This means that there is a loss in both hearing and sight.

Deafblindness can arise for many different reasons. It can be part of certain syndromes, for example, Usher's Syndrome, Charge Syndrome, Rubella Syndrome, Wolfram Syndrome, Cytomegalovirus, Mitochondrial Disease, Down Syndrome, Alstrom Syndrome, and Autism. It can also be due to a premature birth.

No matter what the cause of deafblindness, the most important thing is that the child and family are supported to develop a mode of communication that suits their needs.

How do I find out if my child is deafblind?

The HSE provides an integrated screening, diagnostic and audiology service for babies and children of all ages. This service is free for children from 0 -18 years.

Sight loss in babies and young children is generally discovered through the child developmental checks carried out by the Public Health Nurse in the local health centres. If you have any concerns about your child's hearing or vision, you should immediately raise these concerns with your public health nurse or GP.



Assessment of need

The parents/guardians of any child born after the 1st June 2002 may apply to the HSE for an Assessment of Need if they think that their child may have a disability. Following the assessment, the parents will receive an Assessment Report stating their child's needs, if any, and the services required to support those needs.

Where a need for health supports is identified, a service statement is prepared which specifies the health services to be provided to the child with reference to the available resources.

Getting support

If you discover that your child has both sight and hearing loss, it is advisable that you immediately seek the support that is available to you. This support can come from Public Health Nurses, GPs, specialist services from ophthalmologists and audiologists, visiting teachers for children who are blind/visually impaired and deaf/hard of hearing, other parents/guardians of children who are deafblind and from family and friends.

One of the most important things parents can do from the start is to give their baby a sense of bonding and security. By holding your baby in your arms, s/he will learn how you move and will feel safe and secure as s/he encounters events of the day with you. Rather than feeling alone and isolated in their own world, babies begin to learn about a larger world that includes caring people and a variety of interesting movements, things to touch, textures, smells and perhaps some sounds and sights.

It is important that your child is supported to be as independent as possible from an early age. This will involve supporting your child to explore their environment, to develop a communication system that both of you are able to use, to develop good orientation, to take part in community and social activities and to learn to use technology that may enhance your child's sight and hearing.

Your Child's Education

You and your child can access support from the following services:

1. National Council for Special Education (NCSE) Support Service

Visiting teachers offer longitudinal support to children, their families and schools from the time of referral through to the end of post-primary education.

Children may be referred to the NCSE by their parents/guardians, HSE audiology or ophthalmology services, their school, or others if:

- ▶ either their hearing and vision are both seriously affected and
- ▶ where visual and hearing difficulties are not satisfactorily corrected using relevant equipment e.g. glasses.

2. Anne Sullivan Centre (ASC) in collaboration with the NCSE

The ASC is a not for profit organisation that provides a range of services including outreach support to infants, children and adults who are deafblind. The ASC also supports children who are deafblind with additional difficulties/disabilities.

The ASC outreach specialist consultants can support you and your child by:

- ▶ working directly with the allocated visiting teacher to add expertise in deafblindness to the support that is already provided
- ▶ providing specialist support in the area of communication tools and techniques.

Your Child's Education - Early Intervention and Pre-School

It is very important for children who are deafblind to receive support as early as possible in life. This will assist their general cognitive development, the development of their communication skills and help them to



develop independence. Children who are deafblind often require support to develop alternative communication methods such as hand over hand (tactile) sign language or using objects of reference.

Objects of reference are small symbols that represent real things, for example, a spoon that represents "snack time". Each child may experience deafblindness differently and therefore their communication system should meet their individual needs.

For babies and younger children, the visiting teacher interacts directly with the child to support his/her development. Support is usually provided in the home in the presence of the parents and visits take place by mutual agreement.

The visiting teacher may:

- ▶ provide information and advice to parents about their child's hearing loss or visual impairment
- ▶ reinforce and model good communication and language support for children with hearing loss or visual impairment, through everyday activities, interaction and play
- ▶ inform parents about the range of communication options available, including spoken and sign language
- ▶ work on stimulating vision and provide support in the development of pre-braille skills and mobility for children with visual impairment
- ▶ discuss and demonstrate the management of amplification devices, low vision aids and assistive technologies
- ▶ help parents to monitor and celebrate their child's progress
- ▶ provide information on the range of education options available to assist parents in choosing a school for their child as the child approaches school age
- ▶ make recommendations to the school regarding assistive technologies that may be required when the child is enrolled in school, and
- ▶ facilitate contact with other parents of children who are deaf/hard of hearing or blind/visually impaired so that parents can share experiences and information and can provide mutual support.



Your Child's Education – Primary and Post-primary

Children and young people who are deafblind may attend their local mainstream primary and post-primary schools. Some children with more complex needs attend a special school or special class.

The classroom teacher supports children and young people with special educational needs and may adapt lessons or tasks to suit the individual. Special Education Teachers (SETs) are available to provide additional teaching if it is required.

The SNA scheme is designed to provide schools with additional adult support staff who can assist with students with complex and significant care needs. Once the school has been provided with the relevant professional reports they apply directly to the SENO for SNA access.

Special Education Needs Organisers (SENOs) within the NCSE interact with parents, visiting teachers and schools and liaise with the HSE. They allocate special needs assistants supports to schools. They process applications for other school support, including assistive technology, transport, home tuition and assist in planning the transition of children to school, between schools and onwards from school.

Additional school support provided by the visiting teacher at primary level may include:

- ▶ direct teaching, particularly in the areas of language and communication
- ▶ modelling teaching approaches for special education teachers and mainstream class teachers
- ▶ contributing to the child's school support plan in cooperation with parents and teachers
- ▶ assessing and recording the child's progress in reaching learning targets
- ▶ empowering mainstream staff to deliver the curriculum by advising them of the potential educational and social impact of hearing loss or visual impairment on a child's development
- ▶ making recommendations and advising teachers on the use of assistive technologies, amplification equipment, low vision aids
- ▶ advising on the acoustics (in the case of deafness) and safe environment (in case of visual impairment) in the classroom, and
- ▶ liaising with other professionals and agencies who provide services for children with hearing loss or visual impairment.

In advance of transition to post-primary school, the visiting teacher works with the parents and schools to assist with the transition process. In addition to the type of support provided at primary school level, the visiting teacher at post-primary level:

- ▶ makes recommendations regarding reasonable accommodations provided by the State Examinations Commission, and supports schools' application for such accommodations, where appropriate and
- ▶ prepares a transition report which the student may provide to disability officers in third level education, further education and training agencies, or potential employers.



Access to the Curriculum

The national curriculum for Ireland's primary and post-primary schools is determined by the Minister for Education and Skills who is advised by the National Council for Curriculum and Assessment (NCCA). A flexible approach to curriculum adaptation and delivery is facilitated by teachers to ensure your child can access the curriculum at an appropriate level. This means that your child will have access to the same curriculum as is available for all children in school. Your child will be assisted to access this curriculum by his/her classroom teacher and where necessary, by the special education teacher and the relevant visiting teacher.

Teachers adopt a flexible approach to teaching the curriculum and will make the adaptations necessary to ensure that your child has access to the curriculum, to the greatest possible extent in line with his/her ability.

Further Information

Further information for parents/guardians can be found in the NCSE publications:

- ▶ Children with Special Educational Needs: Information Booklet for Parents
- ▶ Choosing a School: A Guide for Parents and Guardians of Children and Young People with Special Educational Needs
- ▶ Post-School Education and Training Information on Options for Adults and School Leavers with Disabilities
- ▶ Brochures for parents on supporting students who are deaf/hard of hearing and blind/visually impaired.

All of these publications are available on the NCSE website at:

<http://ncse.ie/information-booklets-pamphlets-2>

Useful Contacts

Your local SENO can be contacted through the school or from the NCSE website at www.ncse.ie

Department of Education and Skills: www.education.ie

Contact details for visiting teachers are available at www.ncse.ie/VT_Contact_Details

Local health centre: www.hse.ie

Information about other supports you may be entitled to is available from the Citizens Information Board at www.citizensinformation.ie or from the relevant Government Departments.

Support Organisations

The Anne Sullivan Centre: www.annesullivan.ie

National Braille Production Centre: www.braille.ie

Childvision: <https://childvision.ie/site/>

National Council for the Blind: <http://www.ncbi.ie/>

National Parents Council Primary: www.npc.ie

National Parents Council Post-Primary: www.npcpp.ie

CHIME <https://www.chime.ie/>

Irish Deaf Society: www.irishdeafsociety.ie

Catholic Institute for Deaf People: www.cidp.ie