THE
Anne Sullivan
CENTRE FOR DEAFBLIND

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.

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.

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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.

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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 **lenglish@annesullivancentre.ie** or **086 3617316**

Many Thanks for your Support,

Laura English
Research Co ordinator,
The Anne Sullivan Centre

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*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
- ☐ Offaly
- ☐ Roscommon
- ☐ Sligo
- ☐ Tipperary
- ☐ Tyrone
- ☐ 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
- ☐ Visting 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 whether you preferred method of communication and provide contact details below.

☐ Post ☐ Telephone ☐ Email

Address:

Telephone:

Mobile:

Email:

Thanks for taking the time to fill in this questionnaire.

PULL OUT CONSENT FORM

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**.

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If you have any further questions
please do not hesitate to contact
Laura English, Research Coordinator
lenglish@annesullivancentre.ie
086 361731

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