How is the information used?

Information on this Database is used to:

- monitor current services
- assess future service needs
- prioritise service needs
- support the planning of services
- help research

Statistical information from the Database is made available each year in the Annual Report of the National Disability Database Committee, published by the Health Research Board.

How long will your information be kept on the Database?

Your information will be kept on the Database while you are receiving or needing services. Your information will be updated regularly.

What rights do individuals and their families have to this information?

1. Under the terms of the Data Protection Act, 1988, and the Data Protection (Amendment) Act, 2003, an individual, or in the case of a child, his or her parent or guardian, has the following rights:

   - They can request a copy of the information held about them on the Database. (They should contact the Database Co-ordinator in their Health Service Executive Local Health Office).
   - They have a right to have any wrong information held on the Database corrected or erased.

   Information leaflets about the Acts are available free of charge from the Data Protection Commissioner, Block 6, Irish Life Centre, Lower Abbey Street, Dublin 1

2. The Freedom of Information Act, 1997, and the Freedom of Information (Amendment) Act, 2003, confirms an individuals' right to access their own personal data.

If you have any questions or suggestions about the Database, contact the Disability Office in your Health Service Executive Local Health Office.

Planning Services for People with Disabilities

A Guide to the Physical and Sensory Disability Database

Prepared by the National Physical and Sensory
Disability Database Committee in association with
the Department of Health and Children

What is the Physical and Sensory Disability Database?

The Physical and Sensory Disability Database is a set of information on the specialised health services currently used or needed by people with a physical and/or sensory disability. This information is kept on computer.

Information is collected from people who:

- Have an on-going disabling condition that is physical or sensory. Sensory refers to seeing and hearing;
- May have more than one type of disabling condition but where the main condition is physical or sensory;
- Are less than 66 years of age;
- Are receiving or need a specialist services that is related to their disabling condition; and
- Have consented to being included on the database.

Why is a Database needed?

The Database provides us with information that identifies the service needs of people with physical and/or sensory disabilities. It helps us to plan, develop and organise services and it is hoped that it will prove successful in getting funding for services. A similar database exists for people with intellectual disabilities.

How does the Database work?

The first step is the completion of a database form for each individual. The information is gathered by service providers (both Health Service Executive and non-statutory) who have contact with people with physical and/or sensory disabilities.

The service providers send this information to the Database Co-ordinator in their Health Service Executive Local Health Offices. At this point all of the information is put onto computer.

This information, *without any names, addresses or telephone numbers* is extracted from the computer system by the Department of Health and Children.

The Disability Databases Division in the Health Research Board analyses the data from the Database and produces reports. The Health Research Board does not have access to any identifying information (e.g. names, addresses, or telephone numbers).

What information is on the Database?

The database consists of the following information. All items, except those in red, will be sent to the Department of Health and Children.

1. **PERSONAL DETAILS**
   - Personal Identification Number
   - Name, Address, Telephone number
   - Next of Kin details
   - Date of birth, Gender
   - HSE area of residence/Local Health Office
   - Primary carer
   - Type of living accommodation/living arrangements
   - Type of physical and/or sensory disability
2. **BARRIERS & CHALLENGES**
   - Barriers and challenges to participation in age appropriate life activities
   - Extent to which participation in various activities has been restricted over the past twelve months.
   - Difficulties experienced due to physical and/or sensory disability
3. **USE OF CURRENT SERVICES AND FUTURE SERVICE NEEDS**
   - Therapeutic intervention and rehabilitation services
   - Personal assistance and support services
   - Respite services
   - Day services
   - Residential services

If you are currently using a service, you will be asked what agency is giving you this service.
If you need a service, you will be asked in what year it is needed.

4. **TECHNICAL AIDS AND APPLIANCES**
   - Type of technical aids and appliances used and/or required in the next five years
   - whether assessment is required; if yes, the year assessment is required
5. **ADMINISTRATIVE DETAILS**
   - Name of the person who administered the data form
   - Preferred method of correspondence
   - Date of completion/Date consent received
   - Agency responsible for returning information to Database
   - Medical card/Long term illness card holder

Arrangements are in place to ensure that the information is reviewed on an annual basis.

Who sees the individual records on the Database?

- The individual, or in the case of a child, his or her parent or guardian,
- the individual's service provider, and
- the individual's Health Service Executive area.

Only a small number of specific people in these organisations have access to your information on computer. Each of these people uses their name and a password that is known only to them in order to look at the information on computer.

Information on names and addresses will not be made available to unauthorised third parties.

Who has access to statistical information from the Database?

Statistical information is anonymous information from the Database. It does not contain names, addresses, or telephone numbers.

Statistical information is only available to:

- the Department of Health and Children,
- the Health Research Board, and
- approved researchers.

How is access to the information controlled?

A National Database Committee considers requests for access to statistical information from the Database and only where appropriate makes this information available.