

### What is the information used for?

- To monitor current service provision
- To predict future service requirements
- For research

A summary of the current level of service provision is provided each year in the Annual Report of the National Intellectual Disability Database Committee.

The document *Services to Persons with a mental handicap/ intellectual disability* - An assessment of need 1997-2001 outlines the service requirements of people with intellectual disability.

### How long are records kept on the database?

The information is retained on the Database while the individual is in receipt of or in need of services.

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

Under the terms of the Data Protection Act 1988, an individual, or in the case of a child, his or her parent or guardian:

- has a right to request a copy of the information held about him or her on the database (by contacting the Database Co-ordinator in your Health Board area). A nominal fee to cover the administrative cost may be charged but this fee may not exceed £5.
- has a right to have any inaccurate information held on the database rectified or erased.

**A number of information pamphlets and leaflets about the Act are available free of charge on request from the Data Protection Commissioner, Block 4, Irish Life Centre, Talbot Street, Dublin 1.**

The Freedom of Information Act, 1997, also gives individuals similar rights in relation to their personal information.

**If you have any questions about the Database or would like to make any suggestions, contact the Database Co-ordinator in your local Health Board area.**

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR EASTERN HEALTH BOARD**

Services for Persons with Disabilities  
Dr. Steeven's Hospital, Dublin 8  
Tel: 01-6790700

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR MIDLAND HEALTH BOARD**

Arden Road, Tullamore, Co. Offaly  
Tel: 0506-41301

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR MID-WESTERN HEALTH BOARD**

Disabilities Services Unit  
87 O'Connell Street, Limerick  
Tel: 061-483391

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR NORTH-EASTERN HEALTH BOARD**

Services for People with Disabilities  
Dublin Road, Dundalk, Co. Louth  
Tel: 042-32287

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR NORTH-WESTERN HEALTH BOARD**

Markievicz House, Barrack Street, Sligo  
Tel: 071-55119

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR SOUTH-EASTERN HEALTH BOARD**

Services for People with Disabilities,  
Lacken, Dublin Road, Kilkenny  
Tel: 056-51702

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR SOUTHERN HEALTH BOARD**

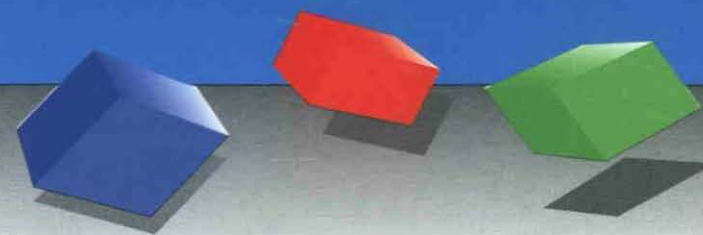
Mental Handicap Services  
Wilton, Cork  
Tel: 021-545011

#### **INTELLECTUAL DISABILITY DATABASE CO-ORDINATOR WESTERN HEALTH BOARD**

Woodlands Centre, Renmore, Galway  
Tel: 091-755241

# Planning Services for People with Disabilities

## A Guide to the Intellectual Disability Database



**Prepared by the National Intellectual Disability Database Committee in association with the Department of Health and Children and N.A.M.H.I.**



## What is the Intellectual Disability Database?

The Intellectual Disability Database is a set of information on people who are in receipt of, and/or in need of intellectual disability services. This information is stored on computer.

## Why is a Database needed?

The Database provides accurate information that identifies the service needs of people with intellectual disability and their families. It helps us to plan and develop appropriate services and to co-ordinate the delivery of those services.

## How does the Database work?

The first step is the completion of a database form for each individual. The information is gathered by the following groups who have contact with people with intellectual disability:

- service providers (health boards and voluntary bodies),
- persons responsible for Community Care areas, and
- school principals.

Some service providers store this information on computer, others keep the information on the paper forms. The information (on computer diskette or paper) is sent to the Database Co-ordinator in each Health Board. At this point all of the information is put onto computer and is known as the 'Regional Database'.

The Health Board sends the information, *without the individual's or next of kin's name and address*, to the Department of Health and Children twice a year. The information from the eight Health Boards is then merged to form the 'National Database'.

The Intellectual Disability Database Section in the Health Research Board analyses the data from the National Database and produces the Annual Report. The Health Research Board does not have access to identifying information.

## What information is on the Database

All items, *with the exception of those in italics*, are sent by the Health Boards to the Department of Health and Children twice a year.

### PERSONAL DETAILS

<i>Name</i>	} <i>not supplied to the Department of Health and Children</i>
<i>Address</i>	
<i>Next of Kin contact details</i>	
Personal Identification Number	
Date of Birth	
Health Board with responsibility for providing service (including Community Care Area, and Planning Area)	
Gender	
Degree of intellectual disability	
Types of principal allowances received by the individual (Medical Card, Disability Allowance, Rehabilitation Maintenance Allowance, Domiciliary Care Allowance)	

## Current Service Provision

Type of day/residential services  
Agency providing day/residential services  
Level of supervision received in these day/residential services

## Future Service Requirements

Day/Residential services required in next five years  
Year in which day/residential services are required  
Level of supervision required in these day/residential services  
Contingency (back-up) Day/Residential service plans and level of supervision required in these contingency services

Date of completion  
Date of removal from database and reason

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

## Who sees the individual records on the Database?

The database record is available to

- 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 Board.

Only a small number of people within these organisations have access to the computerised database record. Each of these designated persons must use their name and a password that is known only to them in order to look at the computerised database records.

## Who has access to statistical information from Database records?

Statistical information refers to anonymous information or data from the database record and contains no identifying information such as the individual or next of kin's names and addresses.

Statistical information is made available to:

- the Department of Health and Children,
- the Department of Education,
- the Health Research Board, and
- Researchers, and others with a legitimate research interest.

## How is access to the information controlled?

Each Health Board has a Committee that considers requests for access to statistical information from the Regional Database, and where appropriate makes this information available.

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