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## About this guide

This guide tells you how, and why, the Health Service Executive (HSE), the Health Research Board (HRB) and service providers gather and store information about the disability-funded services you use and need.

This guide answers some of the questions you may have about:

- what the reporting system that collects your information does
- how the reporting system works
- what the information on the reporting system is used for
- how your information is stored and protected
- your rights, including your right to see your information, and your right to complain.

The National Ability Supports System (NASS) is a national database that records information about disability-funded services. NASS is managed by the HSE and the HRB. For the purposes of the General Data Protection Regulation (GDPR), the HSE and HRB jointly decide why and how personal data is processed. This makes us ‘joint data controllers’.

# 1.

## What is NASS?

The National Ability Supports System (NASS) is a national database which records information about the disability-funded services that people use and need, such as:

- residential services
- respite care
- day services
- personal assistants
- specialist supports like occupational therapy or physiotherapy.

# 2.

## What is NASS used for?

NASS is used to:

- help plan, develop and organise disability services and supports
- tell other health professionals about the number and types of services that people with disabilities need
- show why funding is needed for disability services and supports
- enable the HRB to carry out research using data without using names and addresses or any other identifying data.

Information is recorded about you if you receive or need services or supports that are paid for from the HSE disability budget. If you are not sure if the service you use or need is funded from the HSE disability budget, you can ask your service provider.

### 3.

## How does NASS work?

The NASS system works by first collecting information and then storing this information.

### Step 1 – Collecting information

- Your service provider will ask you (or your parent or guardian) questions about the services you use or need and other information.
- They will record this information on NASS. (See Section 4 on the next page for examples of the information stored on NASS.)

The HSE and HRB legally<sup>1</sup> collect this information to help the HSE plan and provide disability services.

### Step 2 – Storing your information

- Your data (information) is stored in a secure database.

<sup>1</sup> HSE: Articles 6(1)(e) and 9(2)(h) of the General Data Protection Regulation (GDPR) and Section 52 of the Data Protection Act 2018.

HRB: Articles 6(1)(e) and 9(2)(j) of the General Data Protection Regulation (GDPR) and Section 54 of the Data Protection Act 2018.

## 4.

# What information is collected on NASS?

### Personal details

- your name
- your date of birth
- your sex
- your ethnic/cultural background
- your contact details
- your employment/principal status
- where you live and who you live with
- contact details for your nominated person (if you are under 16 years)
- details about your primary carer (if you have one).

### Details about your disability

- information about the type of disability you have

### Details about the disability-funded services you use or will need to use. These include:

- residential services
- day services
- respite services (whether during the day or overnight)
- specialist supports like occupational therapy or physiotherapy.

If you are using a service, you will be asked:

- who provides it
- how often you receive it
- how much support you receive.

If you need a service, you will be asked in what year you will need it.

**You may be asked for details of any aids (such as wheelchairs, grab rails, hoists) that you use or need.**

**You may be asked for details of any difficulties you have with activities such as:**

- getting dressed
- walking or standing for a long time
- joining in community activities.

**Your information will be reviewed each year by the HSE or your service provider, with your help where possible.**

## 5.

### What is my information used for?

Your information is used to:

- look at the services that people with disabilities get now
- understand what services may be needed
- see which services are needed the most
- support the planning of services
- do research to improve disability services and supports.

The HRB will publish reports using statistical information from NASS. Statistical information is number-related information, for example, the number of people who get a service. The reports will not include your name or address or identify you in any way.

This also applies to any research carried out using NASS data, which also will **not** identify you in any way.

## 6.

### Who sees my personal information?

Staff from your service provider(s) and HSE/HRB personnel with special permissions can see your personal information.

Your personal information is **not** shared with any other government body unless there is a legal reason to do so.

## 7.

### How is my information on NASS protected?

By law, your information must be protected to make sure it is not lost or misused. This means only people who have been given password-protected access can see your information. Checks are carried out to make sure that your information is secure.

NASS information provided to researchers is **anonymous** (this means it does not include your name or address or any other identifying details). Only people that are approved can use this information, and they must fill in a form saying why they need it before they can see it.



## 8.

### How long will my information be kept on NASS?

Your information will be kept on NASS for as long as you use or need a disability-funded service. After that, your information will be kept for **eight years** then deleted in line with the HSE data retention policy (retention means keep).

The HRB will keep data which does not contain your name or address in a separate file to help with research and planning and to see changes over time.

## 9.

### Do I have a right to my information?

Yes, you have many rights. You have the right to:

- get a copy of the personal data held about you
- ask to correct any inaccurate personal information or update any incomplete information
- object to how your personal information is used
- ask to get your personal information in a format that you can access and read
- ask to restrict the way information about you is processed in certain circumstances.

## 10.

### Subject Access Request

Under the General Data Protection Regulation (GDPR), it is your right to request a copy of any personal data held on you. You can make the request in writing, or fill in a form called a **Subject Access Request Form**.

You can get this form from your service provider or local HSE office. You can also use the HSE's online form:

<https://www.hse.ie/eng/gdpr/sarsform.pdf>

Send the completed Subject Access Request Form **or** a letter to your local service provider where you think your records are held. You can find more information about the Subject Access Request process at: <https://www.hse.ie/eng/gdpr/>

All subject access requests will be dealt with within one month.

## 11.

### Do I have to pay to see my information?

No, you do not have to pay to see your information, or to ask for changes to be made.

## 12.

### Contact details

If you want more information about how your personal information is used or if you are unhappy with the way your personal information has been handled, you should contact your local service provider **or**:

- the HSE's Data Protection Officer at [dpo@hse.ie](mailto:dpo@hse.ie) - or one of its deputy officers in your region (see the table on the back cover of this leaflet) **or**
- the HRB's Data Protection Officer at [dpo@hrb.ie](mailto:dpo@hrb.ie)

You also have the right to complain to the Data Protection Commissioner at:

t: +353 (0)761 104 800

e: [dpo@dataprotection.ie](mailto:dpo@dataprotection.ie)

w: [www.dataprotection.ie](http://www.dataprotection.ie)

**If you have any questions or suggestions about NASS, you can contact the HRB NASS Team at [nass@hrb.ie](mailto:nass@hrb.ie)**

There is also an easy-to-read version of this guide with pictures. You can ask for it at the NASS email address above or get a copy from your service provider

## HSE Deputy Data Protection Officers

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