



A guide to the National Ability Supports System (NASS)



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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 we use the information on the reporting system for
- how we store and protect your information
- 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?

NASS collects and stores 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?

We use NASS 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
- prove why we need funding for disability services and supports.

We record information about you if you receive or require 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 point 4 on the next page for examples of the information stored on NASS).

By law¹, the HSE collects this information to help it plan and provide disability services.

Step 2 – Storing your information

- By law, we must protect your information and make sure it is not lost or misused.
- To do this, we make sure that only people we allow can access your information which is stored securely in a web-based system. Only people with passwords can access your information.

¹ Article 6(1)(e) and Article 9(2)(h) of the General Data Protection Regulation (GDPR) and Section 52 of the Data Protection Act 2018

4.

What information does NASS collect?

Personal details

- your name and address
- your date of birth
- your gender
- your email address and phone number
- your employment status
- the type of accommodation you live in and who you live with
- your ethnicity
- 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 at the moment or will need to use. These may 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.

Details of any aids (such as wheelchairs, grab rails, hoists) that you use or need

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.

5.

What do you use my information for?

We use your information 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 from the HSE. 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 information?

We only allow staff from your service provider(s) and the HSE with special permission to see your personal information.

These staff each have a unique password that only they know. They must use this password and a computer to access your information.

Apart from the staff mentioned above, your name and address and other personal data relating to you are not shared with the HRB or anyone outside your service(s).

We only use your information to help plan disability services. It is **not** shared with any other government body unless we are legally obliged to do so.

7.

How does NASS protect my information?

We control access to your information very carefully.

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

8.

How long will NASS keep my information?

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

We will keep anonymous data about disability-funded services used or needed to help us with research and planning and to see changes. Anonymous data does not contain your name or address or any other identifying factors.

9.

Do I have a right to my information?

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

- obtain a copy of the personal data we hold about you
- ask us to correct any inaccurate personal information that we hold 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 us to restrict the way we process information about you 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:

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. Further information on the Subject Access Request process can be found at: www.hse.ie/eng/gdpr/

If you ask us to change or correct any details, we will deal with your request within one month.

Please do not send the request to the HRB, as these requests will be handled by HSE staff.

11.

Do I have to pay to see my information?

No, you do not have to pay to see your information, or to ask us to make changes to it.

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:

- the HSE's Data Protection Officer at 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

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

t: +353 (0)761 104 800

e: dpo@dataprotection.ie

w: www.dataprotection.ie

If you have any questions or suggestions about NASS, you can contact us at nass@hrb.ie

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

HSE Deputy Data Protection Officers

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