



## Mid-West Children's Disability Services Data Protection Information Leaflet

We respect your rights to privacy & to the protection of your personal information. The purpose of this leaflet is to explain how we collect & use personal information for the provision of our services & the day-to-day running of our Children's Disability Network Teams (CDNTs). Our CDNTs are made up of a mix of staff from the Health Service Executive (HSE) & Contracted Service Providers funded by the HSE (Brothers of Charity; Daughters of Charity; Enable Ireland; & St. Gabriel's Foundation).

Personal information is collected & stored by our CDNT staff when your child/children attend a CDNT. This information is used to give your child/children quality care & to improve the services we provide. It includes your child/children's contact details & date of birth; parent/carer names, postal addresses, mobile phone numbers & relationship to the child; & siblings; names, ages & whether they are in the service. We will store your records in our Management Information System going forward. Historical paper-based records will be continue to be held, as part of existing client's record.

### What the law says

Our CDNTs need a legal basis to process personal information. There are 6 provided for under the EU General Data Protection Regulation (GDPR); & we must make sure that one or more of these apply when we process your information. The 6 provided for are:

1. The consent of the individual;
2. For the performance of a contract;
3. Compliance with a legal obligation;
4. Necessary to protect the vital interests of a person;
5. Necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the Data Controller; &
6. Legitimate interest.

In general, we process personal information in the exercise of our official authority (i.e. number 5 above). For the HSE & Contracted Service Providers, this official authority is vested in us through the Health Act 2004 (as amended). However, we may rely on some of the other above legal basis depending on circumstances that may arise.

In addition, under GDPR, the processing of special categories of personal data (which includes health data) shall be lawful where it is necessary:

- (a) for the purposes of preventative or occupational medicine;
- (b) for the assessment of the working capacity of an employee;
- (c) for medical diagnosis;
- (d) for the provision of medical care, treatment or social care;
- (e) for the management of health or social care systems and services; or
- (f) pursuant to a contract with a health practitioner (Health Identifiers Act 2014).

Processing is lawful where it is undertaken by or under the responsibility of:

- (a) a health practitioner; or
- (b) a person who in the circumstances owes a duty of confidentiality to the data subject that is equivalent to that which would exist if that person were a health practitioner. For example, the CDNT administrator.

If the processing of special categories of data is not covered by the categories above, the HSE may use another lawful basis such as:

- explicit consent; or
- the processing is necessary for reasons of substantial public interest; or
- the processing is necessary for reasons of public interest in the area of public health; or
- the processing is necessary to protect the vital interests of the data subject or another natural person.



This means that the law allows us to process personal data to:

- Provide the most appropriate service for your child/children & family;
- Help us to develop better services in the future; &
- Manage our health systems & services.

### Type of data we collect

Under Irish Data Protection law, this data has two parts: 'personal data' & 'special categories of personal data.' You can read about these categories below:

1. **Personal data (or information)** includes contact details & date of birth; parent/carer names, addresses, mobile phone numbers & relationship to the child; & sibling's names & ages, & whether they too attend our services; &
2. **Special Categories of data** includes health data like your child/children's service notes & notes or reports about their health needs (<https://gdpr-info.eu/art-9-gdpr/>).

### How we obtain data

Along with the information you provide us, we may obtain your information from a variety of sources including, for example, third parties like your GP, your Social Worker or your Public Health Nurse (PHN).

### What we do with the data that we collect

The data we collect are used to give a record to your child's/children's CDNT. They use this to work out the best way to give your child/children the high quality support your child/children need. Your child's/children's data allows your CDNT to see what has worked to help your child/children in the past & helps them to work out how best to help your child/children now & in future.

We also use the data we collect to:

- Review the care we provide for your child/children & family to ensure it is of the highest standard;
- Provide you with information, literature, & invitations to group information sessions;
- Send reminders of appointments by post or text to the mobile number provided;
- Investigate complaints, legal claims or adverse incidents;
- Protect wider public health interests;
- Provide information for planning so we can meet future needs for children's disability services;
- Provide information to prepare statistics on health service performance, for example, how many people use the service;
- Carry out health service audit; & to
- Provide training & development.

Any information that we use in our reports is anonymised. In other words, the information is not filed with your child/children's name or any means of identifying your child/children. This means that your child/children's identity is never made public. Fully anonymised information may also be used as part of our training or service development of CDNTs.

We do not transfer your child's information overseas.

### Who has access to your child/children's information?

- HSE or Contracted Service Provider staff who work with your CDNT;
- A small number of HSE support & administration staff;
- Staff from the Health Research Board (HRB) via the National Abilities Support System (NASS). You can find out more about the data that the NASS collects at: [https://www.hrb.ie/fileadmin/2\\_Plugin\\_related\\_files/Publications/2019\\_Publication\\_files/2019\\_HIE/NASS/NASS\\_Plain\\_English\\_information\\_leaflet.pdf](https://www.hrb.ie/fileadmin/2_Plugin_related_files/Publications/2019_Publication_files/2019_HIE/NASS/NASS_Plain_English_information_leaflet.pdf); &



- Staff from two Information Technology (IT) companies called EBCS & TEKenable Ltd. who provide technical & IT development support to our CDNTs. Both are bound by confidentiality agreements with the HSE & by data protection laws.

### **How do we keep your record secure & confidential?**

We are committed to ensuring that your information is secure with us. We have a number of security precautions in place to prevent the loss, misuse or alteration of your information:

- All CDNT members have a legal duty to keep information about you confidential;
- All CDNT members are trained in information security & confidentiality;
- Our services have strict information security policies & procedures in place to ensure that information about you is stored safely;
- Our historical paper-based records are kept in locked filing cabinets in locked rooms;
- Our Management Information System (where your information is stored) has full traceability on all changes to your information i.e. it provides full details of who accessed your information, when they did so; & what changes they made; &
- To ensure that entries to your record are completed & saved by the appropriate CDNT member, a unique Personal Identification Number (PIN) needs to be entered by the logged-in user. This serves as each CDNT member's electronic signature on notes & reports.

### **Who else might see my information?**

If you receive services from a CDNT, the CDNT will, as part of this service provision:

- When using our service, we may share your child's & family's information with the other services (e.g., Primary Care, Mental Health or other HSE Services; HSE-funded or Contracted Service Providers or Voluntary Organisations), when, for example, your child's referral is more appropriate to other services, or when there is a need for shared care or care that requires input from more than one service;
- Where necessary, share your information with other agencies such as the Department of Education; Tusla, Child and Family Service; Emergency Services; and the Gardai; and may
- Contact other services (e.g., Primary Care or Mental Health Services; non-HSE services) to obtain (& share) relevant information in order to understand & address your child's needs as might be addressed by input from a variety of other professionals including Hospital Consultants (e.g., Paediatricians); Health & Social Care Professionals [HSCP's] such as Psychologists, & Speech & Language Therapists; Teachers; Assessment Officers; Liaison Officers; & approved volunteers & students (e.g., Nurses; HSCP's) who might work with your child under the clinical supervision of a more senior & qualified clinician.

Therefore, for example, if you receive services from our CDNT, we may link & share your information with other professionals who are or have been involved in your child's health or education.

### **Where will my information be kept?**

Historical paper-based records in locked filing cabinets in locked rooms.

We will store your record in our Management Information System, whose records are backed up daily at night. Your child's data on this system is stored on a secure, central computer system that the HSE manages & controls. It is stored in line with HSE information Security Policies that are aligned to industry good practice.

### **How long is my information kept?**

Historical paper records and current electronic records are kept in accordance with the HSE policy for Record Retention Periods 2013 HCR10

(<https://www.hse.ie/eng/services/list/3/acutehospitals/hospitals/ulh/staff/resources/pppgs/rm/recr2013.pdf>). This notes that records in relation to children & young people are retained 'until the patients 25<sup>th</sup> birthday or 26<sup>th</sup> birthday if the young person was 17 at the conclusion of treatment, or 8 years after death. If the illness or death could have potential relevance to adult conditions or have genetic implications, the advice of clinicians should be sought as to whether to retain the records for longer periods'; & records created under Childcare Acts are 'to be retained in perpetuity (forever)' (p.8).



However, this does not apply for people who have a mental disorder as defined in the Mental Health Acts 1945 to 2001. Their data is kept for 20 years after their last treatment or 8 years after their death. It should be noted that this policy references 'at the conclusion of treatment' (p.8); therefore if the child is still attending the HSE/agency disability services as an adult, then the records can remain until 8 years after final entry or 8 years after death.

### **Can I see a copy of my information?**

Yes. You can

1. Apply to the Lead Agency for your CDNT for a copy of your child/children's records under the Data Protection law. If you do this, it is called a Subject Access Request (SAR). You can get a SAR form at [www.hse.ie/eng/gdpr](http://www.hse.ie/eng/gdpr). Complete this form & send or give it to your child's/children's CDNT; or
2. You can write a letter asking for a copy of your child/children's records. To assist with your application, you will need to provide a clear description of the information you are seeking, & evidence of your identity & your relationship to the child; or
3. You can apply for a copy of your child's/children's record under the Freedom of Information (FOI) Act 2014. To do this, you must write to the Lead Agency for your CDNT that holds the records you are seeking & state that you are requesting a copy of the records under the FOI Act. A copy of government issued photographic identification along with evidence of your relationship to the child will be required.

### **Rights under GDPR**

You have certain legal rights concerning your information/your child's/children's information & the manner in which we process it. This includes:

1. A right to get ask for access to the personal information;
2. A right to request us to correct inaccurate information, or update incomplete information;
3. A right to request that we restrict the processing of the information in certain circumstances;
4. A right to data portability in certain circumstances; &
5. A right to object to us processing the personal information in certain circumstances.

Regarding any requests you have regarding any or all of the above rights, you can ask your CDNT Manager.

You also have the right to complain to the Data Protection Commissioner if you feel your rights are not being respected.

### **If you have questions about how your child/children's data is stored**

Ask a member of your CDNT (e.g., Administrator; Health & Social Care Professional). They may not have an answer for you straightaway but will get back to you as soon as they can.

You can also get more information about your child/children's privacy rights from <https://www.hse.ie/eng/privacy-statement/>

You can also contact the the Lead Agency for your CDNT Data Protection Officer or the relevant member of his/her team. Your CDNT will provide you with details of this team.