



# Progressing Disability Services (PDS) for Children & Young People (0-18Years)

## Dublin North City and County

### Transparency Notice July 2021

#### Introduction

This transparency notice explains the PDS model of service as delivered through the Children's Disability Network Teams (CDNT). This notice provides information regarding the transfer of your child's records from your current service provider to the CDNT during the reconfiguration of children's disability services. We are required to give you this information under data protection law. You will be aware that we have been engaging and communicating with you regarding this change programme since February this year.

#### Who we are

The 'Progressing Disability Services for Children and Young People' Programme is a national programme which provides for Children's Disability Networks with teams of health and social care professionals under a lead agency approach within each of the Community Healthcare Organisations, therefore offering greater utilisation of service provision and equity of access to vital services and supports for children and young people with a disability.

The HSE, Central Remedial Clinic, Daughters of Charity and St Michael's house are establishing one unified regional network service of 12 Children's Disability Network Teams (CDNTs) for Dublin North City and County.

The Children's Disability Network Team (CDNT) supports children and young people with complex needs. This service is for children who require the supports of an interdisciplinary team. The CDNT is an interdisciplinary team who work collaboratively with the child and family to identify the needs and priorities of the child and family, plan goals and develop an Individual Family Service Plan.

Each Children's Disability Network Team (CDNT), operates within the legislative context for health services in Ireland and follows the direction of national strategy and policy. CDNTs are delivered and managed by a range of service providers including the HSE and the Voluntary Organisations. Each CDNT operates under a Lead Agency model where the Lead Agency has responsibility for the service provision in an assigned area in line with the National Policy on the Lead Agency Model.

The details for each Network team are listed below

CDNT:	Agency	CDNM & Contact Details
Balbriggan	CRC	Stasia Conncannon <a href="mailto:cdntbalbriggan@crc.ie">cdntbalbriggan@crc.ie</a>
Swords	CRC	Barbara Shinnors <a href="mailto:cdntwords@crc.ie">cdntwords@crc.ie</a>
Coastal	St. Michael's House	Aoife Quinn <a href="mailto:cdntcoastal@smh.ie">cdntcoastal@smh.ie</a>
Coolock	St. Michael's House	Niamh Giltinan <a href="mailto:cdntcoolock@smh.ie">cdntcoolock@smh.ie</a>
Kilbarrack	St. Michaels House	Sinéad O'Sullivan <a href="mailto:cdntkilbarrack@smh.ie">cdntkilbarrack@smh.ie</a>
Clontarf	CRC	Elaine Doherty <a href="mailto:cdntclontarf@crc.ie">cdntclontarf@crc.ie</a>
Ballymun	St Michaels House	Tomás Flanagan <a href="mailto:cdntballymun@smh.ie">cdntballymun@smh.ie</a>
North Inner City	HSE	Laura O'Connell <a href="mailto:cdntnic@hse.ie">cdntnic@hse.ie</a>
Finglas	HSE	Sinéad English <a href="mailto:cdntfinglas@hse.ie">cdntfinglas@hse.ie</a>
Cabra/ Grange Gorman	Daughters of Charity	Vivienne Finn <a href="mailto:cdntcabra@docservice.ie">cdntcabra@docservice.ie</a>
Blakestown	Daughters of Charity	Elaine Finn <a href="mailto:cdntblakestown@docservice.ie">cdntblakestown@docservice.ie</a>
Blanchardstown	Daughters of Charity	Deepak Kumar <a href="mailto:cdntblanchardstown@docservice.ie">cdntblanchardstown@docservice.ie</a>

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## Your child's records

Your current service provider collects your child's information in order to identify the most appropriate service to support your child's health and care needs and to fulfil our statutory duties.

This information will transfer to the CDNT in order for the new service to support your child's health and care needs.

Children's files are stored securely in paper files, electronic record systems and information systems and are accessed on a 'need to know basis' only. Information is shared only where it is appropriate and legal to do so. Where this is necessary, we are required to comply with all aspects of the Data Protection Act 2018.

In all cases we comply with the provisions and exemptions of General Data Protection Regulation (GDPR) and Data Protection Act 2018 when processing your personal information.

## Description of Data Shared relating to children

Data collected by the service, which will be shared between staff working on the CDNT in respect of providing health & personal social services, includes:

- Personal data;
- Special category data (including health data);
- Anonymised data.

Data is received from numerous sources, including but not limited to:

- Families of children referred to the CDNT;
- Pre-schools;
- Access Inclusion Model (AIM) staff & Pobal;
- Schools;
- Special Education Needs Officer (SENO);
- Department of Education;
- Other agencies or professionals (e.g., GP, medical teams, TUSLA, etc.);
- Gardai;
- Assessment Officers &/or Liaison Officer;
- Approved volunteers & health & social care students (e.g., nursing, occupational therapy, physiotherapy, social work, speech & language therapy, psychology, & early intervention).

Examples of data held & available to staff on the Team, across these topics may include, the following:

- Child's personal & demographic details;
- Referral details;
- Details of contacts with the family, guardians or relevant service providers;
- Relevant notes service providers may deem necessary or appropriate over the course of service provision;
- Lists of all appointments including attendance history;
- Clinicians notes following each appointment;
- Uploaded relevant documents such as letters from doctors, forms completed etc.

The specific data held & available to staff, across these topics may include the following

- Child's name & address;

- Country of birth, first & other languages;
- Date of birth;
- GP & other relevant professionals;
- Details of schools attended including whether resource help is available;
- Any diagnosed conditions;
- Details of medical, GP Visit, Long-Term Illness & other relevant cards held;
- Siblings name, age & whether they are in the service;
- Any relevant school & background general notes;
- Parent / Carer names, addresses, contact details & relationship to the child;
- Current parenting status of parents / guardians;
- Whether currently in hospital;
- General notes in relation to Current Medication, Relevant Family Social History, & Any Other Relevant Information;
- Names of clinicians or other relevant individuals available for contact;
- Dates of appointments, history of attendance, list of those in attendance;
- General notes or observations arising from each appointment;
- Details of every contact, other than appointments, with the family. Summaries of the content of such phone calls or discussions. Observations arising from the phone calls or discussions;
- Service plans showing parental concerns, goals, actions agreed by the parents & actions agreed by the CDNTs;
- Notes in relation to the performance in achieving such goals;
- Relevant documents that are uploaded & held on the child's file. These can include doctors or consultants reports, referral forms, relevant correspondence etc.;
- Child protection concerns.

## Legal basis for data sharing

**Data Protection Legislation:** All applicable laws & regulations relating to the processing of personal data & privacy including the Data Protection Act 2018); the EU General Data Protection Regulation 2016/679 (or the 'GDPR'; <https://gdpr-info.eu/>); the European Communities (Electronic Communications, Networks & Services) (Privacy & Electronic Communications) Regulations 2011 (S.I. 336/2011); & any statutory instrument, order, rule or regulation made there under, as from time to time amended, extended, re-enacted or consolidated.

The legal basis on which the child's is shared amongst the Parties is covered in section 7 of the Health Act 2004 & section 52 of the Data Protection Act 2018. The legal basis for the transfer of service user files is underpinned by the Health Acts 1947-2020 & under GDPR 6.1(e) [public interest] & 9.2 (h) [provision of care].

The Principles of Data Protection found in Article 5 GDPR (<https://gdpr-info.eu/chapter-2/>) must be kept in mind at all times:

- Lawfulness, fairness, & transparency
- Purpose limitation;
- Data minimisation (e.g., necessity, proportionality & pseudonymisation);
- Accuracy;
- Storage limitation;
- Integrity & confidentiality; & Accountability.

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## Purpose of sharing data

Following the implementation of the national Progressing Children's Services for Children & Young People (PDS) programme, multi-agency CDNT's will be established within each CHO, with staff from St Michael's House, CRC, Daughters of Charity and HSE.

The Programme's overall vision is the achievement of best possible outcomes for children & their families through a combination of:

- One clear pathway to services for all children according to need;
- Effective teams working in partnership with parents & service users;
- Resources used to the greatest benefit for all children & families;
- Partnership between health & education to support children to achieve their potential.

In line with the principle of data minimisation, it is appropriate to share your child's records on a necessity & proportionality basis so as to provide children and their families with the required supports they need.

## Methods Used for Sharing Data

### Data relating to service users:

Data is shared by several methods:

1. Direct discussion with other CDNT staff (e.g., CDNT meetings, discussions between staff members, & joint working);
2. Telephone or text messaging (in the context of service provision);
3. Email (in the context of service provision);
4. Paper-based files;
5. Electronic files;
6. Networked shared drive;
7. Regional service meetings, including Clinical Managers' meetings, case management meetings & service planning meetings;
8. Through the Assessment of Need Process.

Data will be held in the following places:

- Paper-based records in locked filing cabinets; or information management system(s) either owned by the HSE (e.g., Management Information System) or by the CDNT Lead Agency.
- Lead Agency electronic records management systems;
- Local register-based records (e.g., complaints, FOI)
- Encrypted Laptops / PCs (e.g., for temporary storage).

## Security

We have appropriate security measures in place to prevent a child's records from being accidentally lost or used or accessed in an unauthorised way. We limit access to your child's records to those who have a genuine business need to know it. Those processing this information will do so only in an authorised manner and are subject to a duty of confidentiality.

We also have procedures in place to deal with any suspected data security breach. We will notify you and any applicable regulator of a suspected data security breach where we are legally required to do so.

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We maintain the security and confidentiality of all Personal Data & Special Categories of Personal Data shared.

We process all such data shared in accordance with the Data Protection Legislation.

## How long will we keep your child's records?

We only keep your child's records for as long as is required by law and in accordance with each of the lead agencies retention schedule for the Children's Disability Network Team, which you are transferring to.

## Your rights and access to information

Under data protection legislation you have the right to request access to the information that we hold about your child. You will be able to access this information from the Lead Agency of the Children's Disability Network Team that you are transferring to.