

Welcome to our Service Information Booklet





The vision for children's disability services

- > Easy access to the services children need.
- > Fairness in providing services.
- Families, health services and schools working together to support children in developing their potential.

Lead agencies managing Children's Disability Network Teams in Dublin South, Kildare, and West Wicklow.











Please keep this booklet for future reference





You have been given this booklet because your child, or the child you care for, has been accepted onto your local Children's Disability Network Team (CDNT) in the Dublin South, Kildare, and West Wicklow area. This booklet tells you how our 11 CDNTs work.

There are terms in this booklet that you might not have heard of before. We include a short explanation of what those terms mean at the end of this booklet (Glossary of terms).

If you would like help reading this booklet or have any questions about the information in it, please contact your CDNT. Our contact details are below or on our website, www.cho7cdnt.ie under the Our Teams section https://www.cho7cdnt.ie/teams/pages/. You can use the QR code at the top of the page to access these details on your phone.

We would like to thank the parents who contributed to the development of this booklet. We appreciate the time they gave to this work. Their help was invaluable.

We hope you find this booklet easy to understand and helpful to you as a family.

CDNT Name:	
Email:	
Telephone:	
Address:	



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What is a Children's Disability Network Team?

Children's Disability Network Teams (CDNTs) are made up of staff who have expertise and experience in different disciplines. The team members work together to provide therapeutic services to children who have complex needs arising from a disability, and who need different disciplines working closely together to help them and their families to meet their goals.

The CDNTs are often called 'interdisciplinary' teams. This is just another way of saying that the team members work closely together to achieve the best outcomes for your child. They share information, decision-making, and goal setting. They have common policies and procedures, and they communicate with each other regularly to keep everyone up to date. They work with the child and the family, who are all considered to be part of the team. Together, CDNTs create a support plan called an Individual Family Support Plan (IFSP). There is more information on this plan later in this booklet.

Each team provides therapeutic services for children and young people up to 18 years of age.

A Children's Disability Network Manager (CDNM) leads each team. CDNMs are responsible for developing and delivering a safe and quality children's disability service. They use the principles that are the foundation of the PDS model of service (see Glossary of Terms, page 25) to support:

- Day-to-day management
- > Leadership and team development
- Managing resources
- Ensuring best practice and working to regulatory clinical standards
- Quality improvements
- Managing risk
- Working closely with other services and community supports that families might access.





Who is on the team?

CDNTs typically include the following team members:

- ➤ Children's Disability Network Manager (CDNM)
- Administration
- Occupational Therapists (OTs)
- > Psychologists (Psych)
- > Physiotherapists (PTs)
- Social Workers (SWs)
- > Speech and Language Therapists (SLTs).

Teams may also have access to:

- > Behaviour Support Specialists
- Clinical Nurse Specialists (CNSs)
- Dietitians
- ➤ Early Years Practitioners/Early Years Nurse Practitioners (EYPs/EYNPs)
- > Family Support Workers (FSWs)
- > Therapy Assistants (TAs)

Each professional brings their own unique expertise to the team. Depending on your child's needs and goals, the roles and responsibilities of team members often overlap based on their area of expertise. This makes it easier for the child and family to work with the team to meet the goals set out in the IFSP.

See the next page for a brief explanation of the roles that are typically linked to a CDNT, or which a CDNT might also be able to access. They are listed alphabetically. Please note that not all teams will have this full list of disciplines working within their team.



Children's Disability Network Manager (CDNM)

Please see page 5 for a description of their role.

Administration

The administrators on the team will often be your main point of contact with the team, as they manage the CDNT's email inbox and phone line. They will support your interactions with the wider team.

Behaviour Support Specialist

A Behavioural Specialist will have special skills in breaking down and analysing behaviours. They develop and help put supports in place to help with behaviour. These supports aim to maximise your child's participation in school, home and in the wider community.

Clinical Nurse Specialist (CNS)

A CNS will be a registered nurse or midwife. They will assess the care needs of a child and develop nursing care pathways. They will also participate in team assessments across various settings (home, clinic, preschool, school, and community).

Dietitian

Children with complex medical needs often encounter feeding and nutritional problems. A dietitian can advise and support the child and family through oral or tube-feeding difficulties where they arise. Families frequently seek advice on such nutritional topics as growth, weight-management, food-aversion, infant feeding, and healthy eating.

Early Years Practitioner/Early Years Nurse Practitioner (EYP/EYNP)

An Early Years Practitioner/Early Years Nurse Practitioner will have a background in early childhood development and/or early childhood education. Using a holistic approach, they will support you and your child to reach their developmental potential. They will work with your child at home, in their preschool, in the clinic or in the community.

Family Support Worker (FSW)

A Family Support Worker assists and advises families experiencing short- or long-term challenges. They work under the supervision of a Social Worker.

Occupational Therapist (OT)

An Occupational Therapist will have special skills in assessing how a health condition or disability can affect a child's ability to take part in daily activities. They can support your child with gross motor skills and fine motor skills, and with sensory processing and integration. OTs also help with daily living skills and with sourcing equipment to help your child take part and engage in activities (for example, managing posture which they will work on with the Physiotherapist).

Physiotherapist (PT)

A Physiotherapist will have special skills that improve or maintain maximum and functional ability in someone's body. They will help support all aspects of your child's physical and motor development. This includes helping your child meet their physical potential to the best of your child's abilities. They are involved with providing equipment to enhance your child's physical abilities (for example, a walker or orthotics). They are also involved in managing posture with the OT.

Psychologist (Psych)

A psychologist has special skills in psychological assessment and psychological formulation (see Glossary of terms on page 25). They further provide support in areas such as emotions, behaviours, learning, and educational placements.

Speech and Language Therapist (SLT)

An SLT has expertise in understanding communication and the different ways people can express themselves. They also have expertise in feeding, eating, drinking and swallowing (FEDS).

Social Worker (SW)

A Social Worker has special skills in providing emotional and practical support to you, your child, and your family. They will help you to tap into and maximise the supports available to you within your family and wider community. This could include making sure you access all your rights and entitlements.

Therapy Assistant (TA)

A Therapy Assistant works under the supervision and direction of a supervising therapist within the CDNT. Their role includes clinical and administrative duties that support therapists on the team.



You can contact your CDNT if you have any queries, or if there is a change in your child's circumstances which you have significant concerns about. Also, please let us know if any of your contact details change.

The CDNT provides support in different ways. For example, you may be invited to join a group or attend a workshop, depending on your child's needs. We encourage you to attend these groups or workshops, and we usually ask for your feedback at the end. We value your feedback – it helps to improve how we deliver services.

When your child's case is opened, a team member will arrange to meet you and your child. At this meeting, we will explain what we do and what it means for you and your child. You will also have a chance to ask any questions.

You will work closely with the team using a wide range of services and supports. The team members you meet, and how often you meet them, will depend on your child's needs and goals. This will be discussed with you and your child when your Individual Family Support Plan (IFSP) is being designed.



What is family-centred practice?

We use a family-centred practice (FCP) approach. FCP is internationally considered to be the best way to support the development, learning and wellbeing of children with complex needs arising from a disability. (PDS policy framework for service delivery of children's disability network teams, revised May 2022.)

The FCP approach places the family at the centre of service delivery. It recognises that:

- > each family, and their circumstances, is unique
- > family members are the most constant people in a child's life and
- > family members are the experts on their child.

This approach is different to the traditional medical approach where therapists are seen as the 'experts'.

The FCP approach recognises that all children develop and learn through taking part in daily life and activities with their family, and at school or pre-school. This means the CDNT will support families to make the most of these everyday learning opportunities which will help your child to reach their full potential.

The goal of FCP is to empower you and your family by giving you the knowledge and strategies to help you all to reach the goals agreed in your Individual Family Support Plan (IFSP). We do this by working with you and others close to your child who are supporting your child's development in everyday settings – for example, at home and at school. Your family, along with other important people in your child's life – such as preschool and crèche teachers, teachers, childminders and grandparents – spend the most time with your child.

The FCP approach is a much more effective way to work with you, your child and family. It acknowledges that the adults who have the deepest relationships and spend the most time with a child have the skills to provide intervention on an ongoing basis. It's what





What kind of supports do the teams offer?

Model of CDNT Supports

We use a three-pronged approach to providing services:

Universal Supports (information sessions, talks and workshops)

Universal supports are designed to support all children and young people. They are available to all families receiving services, as well as families waiting for services, when available.

Examples of topics covered include:

- > How to help your child sleep through the night
- > Toilet training for children who have extra needs
- > Supporting your child to develop communication skills
- How to prepare your child for the move from primary to secondary school.

Targeted Supports (group work)

Targeted supports are designed to be provided in partnership with others. The group work is for children who have similar needs. Bringing children together in groups is more fun for them and they can learn from each other.

Group work is also where parents are educated together about how best to work with their child to support their development. It brings together parents who have common challenges, and gives them a chance to share their ideas and experiences.

Examples of group work include:

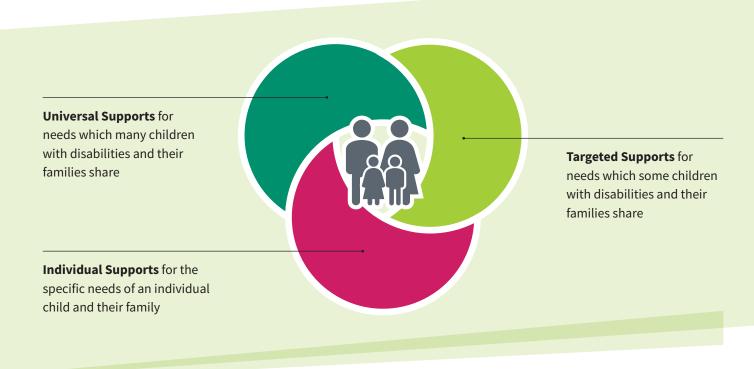
- ➤ Early Bird Training Programme for parents of children who have recently been given an autism diagnosis
- > Hanen programmes for developing communication
- > Triple P Positive Parenting Programmes
- > Family Lámh Courses.

Individual Supports (one-to-one work)

Individual supports are for children and young people whose goals are best met through working directly with a clinician. Not all children with complex needs, arising from a disability, will need individual supports.

Individual support might be needed for certain clinical needs, such as difficulties with postural management, feeding, eating, drinking, or swallowing.

All these approaches have equal value. Your child's needs may be met using just one approach, or they might benefit from a mix of two or three.



The team will consider what supports are needed, and they will recommend universal, targeted, or individual supports based on your child's needs and goals.

Do the teams work with other services?

Sometimes, we may need to link with other services involved in your child's care and development – for example, Child and Adolescent Mental Health Services (CAMHS), a paediatrician, schools, and hospitals. If we need to do this, we will make sure you're included, and we encourage you to let us know about any other services involved in your child's care.

What is an IFSP?

An Individualised Family Support Plan (IFSP) sets out the goals for your child. You will be invited to meet a clinician to discuss your first IFSP, and together you will identify what your main priorities are for your child. This meeting will either be in person or online, whichever suits the family.

After this meeting, the team will discuss your identified priorities. They will confirm the supports they can offer to help you achieve your child's goals. Once the IFSP is agreed, you get a written copy of it.

The IFSP will act as a guide to the services your child receives. The team will refer to it on an ongoing basis, and it will be reviewed to check that the goals are still relevant.





Think about the way your child is developing. Ask yourself what is most important to you and to your child right now. Talk to your family about this.

Think about what your child is good at and what they enjoy, as well as what they find difficult. It's a good idea to write down any questions or concerns you have and bring these to your IFSP meeting.

Some questions worth considering:

- > What is the priority for our child and our family at the moment?
- > What have we tried already? Was this successful?
- > How can we work on this priority?
- Is this the best time to work on this goal for us as a family?

How can I prepare for the first appointment?

Before you and your child come into the clinic for the first time, there are a few things you might want to think about. Ask yourself these questions:

- Do you know where to go and who to contact when you arrive at the clinic?
- Would your child benefit from extra supports for their first appointment, for example, a social story, photos of the building, or a quiet space?
- Are you concerned about how your child may manage attending an appointment in an unfamiliar environment?

If you need further support on any of these, please contact your CDNT or refer to the website https://www.cho7cdnt.ie/teams/pages/. Photographs of CDNT locations are also available on the website https://www.cho7cdnt.ie/teams/pages/.

Can't attend your appointment?

If you are unable to attend your appointment, please let us know so that the time slot can be given to another child and family.

Interpreter

If you need an interpreter, please contact the team to let them know which language you require for your appointment.



If I want to get in touch, who do I contact?

Generally, appointments are offered to you from the team. However if you need to speak to a member or members of the team, you can contact them using the CDNT's central email address and phone number. If you need to cancel or reschedule an appointment, please also use one of these contact options (email or phone) to let us know.



What can I expect from the team?

Respect and recognition

We will treat you and your family members with courtesy and respect at all times.

We will acknowledge and value you as the most important person in your child's life.

Clear CDNT contact points

We will give you a central email address and phone number to contact your CDNT. These CDNT contact points, which can be found on page 3, can be used to help with:

- > booking and managing appointments
- > service enquiries
- > service information
- > taking service feedback.

Support in different settings

We will deliver supports in a variety of settings depending on where your child will benefit most – for example, at home, at school, or in a clinic.

Individual Family Support Plan

We will develop an Individual Family Support Plan (IFSP) for you and your child. We will provide the support and services that we have available to meet the goals of the IFSP.

Support if your child is moving services

We will provide you with information and support if your child is moving on – for example, moving to a new setting such as preschool or school, or transferring to other services.



What does the team expect from me?

Respect

We ask that you treat all team members with courtesy and respect at all times.

Attendance as agreed - or tell us if there is an issue

We ask that you and your child attend all appointments or groups as agreed by you and the team, as set out in your Individual Family Support Plan. For parent-only groups, we ask that you attend without your child.

We ask that you let us know if you are going to be late or unable to attend your appointment.

Help with the Individual Family Support Plan

We ask that you share ideas and information and help us to develop the IFSP for your child.

Carry out agreed activities

We ask that you try to carry out the recommendations and activities agreed with the team. If you need more support to do this, please tell the team members you are working with.

Ask us questions if you want or need to

We ask that you talk with your CDNT if you have any queries or concerns about our service.



The above website for the Dublin South, Kildare, West Wicklow CDNTs provides more information on the following:

- ➤ Family Forums https://www.cho7cdnt.ie/teams/family-forums/
- Individual Family Support Plans (IFSPs) https://www.cho7cdnt.ie/teams/individual-family-support-plan/
- Education
 https://ncse.ie/
- Family Centered Practice (FCP) https://www.cho7cdnt.ie/teams/how-our-teams-work/
- CDNT supports available https://www.cho7cdnt.ie/support/
 - > Benefits and Allowances
 - National Supports
 - > Local Supports
 - > Universal Supports
- CDNT contact details, and catchment areas https://www.cho7cdnt.ie/teams/pages/

Giving us feedback

Comments, compliments and complaints

Your CDNT aims to provide high-quality health and social services. Please bring any comments, compliments and/or complaints you have to our attention. Your feedback helps us to learn what we are doing well and where we need to do better.

Sharing feedback or making a complaint about services received

As a first step, we ask you to share your feedback or make your complaint to the Children's Disability Network Manager (CDNM) of the team providing services to your family.

You will find contact details on our website, www.cho7cdnt.ie under the Our Teams section https://www.cho7cdnt.ie/teams/pages/. You can also use this QR code to access those details on your phone.







If you decide you want to take your complaint further, please contact the lead agency managing your CDNT. The lead agency for each team is listed below, as well as on our CDNT Team pages https://www.cho7cdnt.ie/teams/pages/.

HSE CHO7 Disability Services Team

- > Lead Agency for CDNTs 1, 3, 8 and 9
- Complaints procedure https://www2.hse.ie/complaints-feedback/
- > Email: yoursay@hse.ie

Complaints sent to <u>yoursay@hse.ie</u> that relate to CDNTs managed by another lead agency will be directed to the lead agency for a response.

Central Remedial Clinic (CRC)

- > Lead Agency for CDNT 4
- Complaints procedure https://www.crc.ie/have-your-say/
- > Email: haveyoursay@crc.ie

Enable Ireland

- > Lead Agency for CDNTs 2, 7 and 10
- Complaints procedure https://enableireland.ie/feedback-and-complaints

Kare

- > Lead Agency for CDNT 11/12
- Complaints procedure https://www.kare.ie/contact
- > Tel: (045) 448 700

Stewarts Care

- > Lead Agency for CDNTs 5 and 6
- Complaints procedure https://www.stewartscare.ie/contact/
- Complaints policy https://a.storyblok.com/f/46384/x/f645a9f7f8/complaints-policy-2023c-038-08-schedule-5-policy.pdf
- > Email: complaints@stewartscare.ie













Glossary of terms

Behaviour

The way somebody acts, especially towards someone else.

CAMHS – Child and Adolescent Mental Health Services

This is a service that provides assessment and treatment for young people and their families who are experiencing moderate to severe mental health difficulties.

CDNT – Children's Disability Network Team

This is the team of health and social care professionals responsible for delivering disability services to children aged up to 18 with complex needs, arising from a disability. Each CDNT covers a specific geographic area (catchment area).

CHO7 – Community Healthcare Organisation 7

Catchment areas are called CHO with a number to indicate what area they serve. CHO7 consists of Kildare/West Wicklow, Dublin West, Dublin South City, and Dublin South West.

Discipline

A particular subject area a person is trained in, usually by studying the subject at college or university. For example, your doctor's discipline is medicine.

FCA - Family-Centred Approach

A family-centred approach is a way of working in partnership with families to better understand the family's needs. It recognises parents and guardians as the experts on their child's needs.

Family forums

Forums are meetings that are open to all families receiving services or waiting to receive services from their CDNT. They are an opportunity for families to come together to discuss general issues and ideas about children's disability services in their area. They will take place at least twice a year.

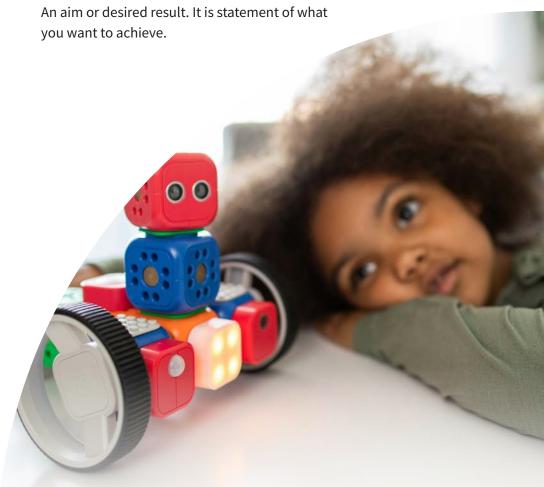
Fine motor skills

Fine motor skills are the small, precise movements we make with our hands, fingers, feet and toes. They involve co-ordinating muscles, joints, and nerves to make the movements necessary to complete a task. For example, doing up buttons, tying shoelaces, using cutlery, and so on.

Functional ability

This is someone's ability to perform activities of daily living according to their basic needs.

Goal





Gross motor skills

Gross motor skills are the big movements we make with the large muscles in our body – for example our legs and arms. Walking and waving your arms are examples of gross motor skills.

HSCPs – Health and Social Care Professionals

HSCPs provide a range of services to support the development, health and wellbeing of the child. For example, these services would include occupational therapists, psychologists, physiotherapists, social workers and speech and language therapists.

Intervention

An intervention is any support provided by the CDNT to help a child achieve their IFSP goals.

Interdisciplinary team

In healthcare, an interdisciplinary team is a group of professionals working together. They share skills, information and decision making, and work with the child and family to create a plan and set goals.

Lead agency

Lead agencies are the providers of disability services. They manage each of the CDNTs. The lead agency may be an HSE-funded non-statutory organisation or a CHO (Community Healthcare Organisation).

Mission

An aim of a group, an organisation, or a person.

Motor Skills

Motor skills describe your body's ability to manage how it moves its muscles in a coordinated way. There are two types of motor skills: gross and fine motor skills. Examples of gross motor skills would be a child holding their head up, crawling, or reaching. Fine motor skills would include being able to use a spoon or hold a pencil.

Partnership

Two or more people or groups working together on an activity or working together to reach a particular goal.

Policy

A policy is a plan of action proposed or adopted by an organisation or person.

Procedure

An agreed way to carry out an action.

PDS – Progressing Disability Services for Children and Young People

PDS is a national programme to ensure a unified approach across Ireland in the delivery of children's disability services. The programme was established by the HSE and is being run in partnership with voluntary organisations across Ireland.

The PDS model of service is defined by 12 Key Principles which are:

- 1 Accessibility
- 2 Accountability (who is responsible or answerable)
- 3 Bio-psychosocial model (an approach that looks at three factors: 1. biological, such as genetics; 2. psychological, such as mood and behaviour; and 3. social, such as family)
- 4 Clinical governance and evidence-based model
- **5** Cultural competence
- 6 Early identification of need
- 7 Equity of access
- 8 Evaluation of outcomes
- 9 Family-centred practice
- 10 Inclusion
- 11 Interdisciplinary Team Approach (see page 5)
- 12 Staff are valued and respected.

You can read more about these Principles here: Policy Framework for Service Delivery of Children's Disability Network Teams https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/policy-framework-for-children-s-disability-network-teams.pdf



Psychological formulation

Psychological formulation is a structured approach psychologists use to understand factors underlying a person's challenges, issues or behaviours. Typically, psychological formulations take place after an assessment period, and will inform the recommendations made by the psychologist and any intervention that may follow.

QR code

Quick response code – a square barcode used to share a link to a website from a smartphone.

Social Story

This is a learning tool to explain to a person what is happening in a particular situation and how they can deal with it. They will include text and images relevant to the situation, so the person can relate to them. For example, a child might benefit from a story about starting school so that they are prepared and know what to expect.









Dublin South, Kildare, and West Wicklow