Children's Disability Network Team

Children's Disability Network Team (CDNT)

Introductory Pack

With thanks and acknowledgement to CYPSC Kerry and the Central Meath Child Disability Network Team (Enable Ireland) for sharing their resources, which were integral to the creation of this pack.

The contents of this pack include:

We would like to take a moment to warmly welcome you and your child to Children's Disability Network Team 11- South East Cork City.

We understand this may be an uncertain time for you, and parents often have a lot of questions. This pack is intended to provide clear, helpful, and reliable information about our team, the services we offer, and what you can expect as we begin working together. Some terms used in this booklet may be unfamiliar to you. If a word is written **like this**, it is included in our glossary on Pages 12 – 13.

While this pack addresses the most common questions, we understand you may have more and you are welcome to contact us via the details below and we will respond as soon as possible. We usually reply to general queries within 2 working days. We acknowledge complex queries promptly but, if they require input from multiple staff, there may be a delay while your query is directed to the appropriate team for discussion and response.

You may receive other letters as you navigate supports and services for your child. All our letters are marked with the Children's Disability Network Team logo, shown above. Please contact us if you receive any paperwork you do not understand.

Email: cdnt11cork@enableireland.ie

Tel: 021 4663353

Address: Lavanagh Centre,
Carrigrohane Road, Curraheen, Cork,
T12 D768

Opening Hours: Monday to Friday 8:30am – 4pm excluding bank holidays.

We hope this booklet serves as a useful introduction, and the beginning of a positive partnership with you, your child, and your family.

What is a CDNT, and what does it do?

CDNTs provide specialised support and services for children who have **complex disability needs**. This is different to Primary Care, which supports children with non-complex disability needs. In HSE Southwest (counties Cork and Kerry), child disability services are not provided by the HSE directly, but by HSE-funded agencies. The lead agency in your CDNT is Enable Ireland.

A CDNT is an interdisciplinary team. This means staff from different disciplines work together to help your child reach common goals. This will sometimes be obvious – for example, a seating assessment means an occupational therapist and a physiotherapist work with you and your child in the same room, at the same time. Other times, one member of the team works with you and your child but brings knowledge from discussions with other members of staff.

CDNTs use an approach called **family-centred practice**. We work with each family to create an **Individual Family Service Plan (IFSP)**, which aims to empower you with the knowledge and strategies to best support your child.

It is important for us to involve your child in decisions, to give them information in a way that suits them, and to consider how they feel about interventions. This protects your child's rights, helps them feel heard and valued, and tailors their care to suit both their needs and their preferences.

What can I expect from a CDNT?

Your family is currently queued for a first appointment with the CDNT. We generally see children in order, based on the date of their referral. In line with national policy, we may need to prioritise children with urgent clinical needs, such as equipment breakdown. This means that sometimes, the earliest child or young person referred to our services may not receive the next available appointment. We understand that this is frustrating, and we work to meet families as soon as possible. **If your circumstances change and you are dealing with an emergency situation, please let us know.**

It is difficult to predict the length of time before a family receives their initial appointment or any follow-up appointments. This time can be impacted by high demand, staffing changes, and the number, need and complexity of families in the area covered by our team. In the interests of giving families clear and transparent information about our service, the **estimated** time before your child will be seen is provided below. These are **guidelines only** and accurate at the time of printing but **may change significantly** due to circumstances outside our control. Changes to these times are communicated at our **Family Forum**.

We expect to see you within 12 months.

We expect to see you within 18 months.

We expect to see you within 2 years.

The expected waiting time is over 2 years, and we cannot provide a reasonable estimate at this time.

In CDNT 11, children awaiting their initial appointment are split into 2 groups: Early Years (Birth -7 years 11 months) and School Age (8 years to 18 years). The time before your child is seen will differ, depending on their age group.

If your child is in Early Years, you can expect:

- Your initial appointment will be an **Individual Family Service Plan (IFSP) meeting**.
- This may take place as parent/guardian only, or as a parent/guardian and child appointment with members of our team. The meeting may happen at your home, in our clinic, or in another relevant place. During the appointment, we'll work together to set goals and strategies that fit your child and family's needs. Afterwards, we'll send you a summary document of what we discussed, including the goals and strategies we identified.

We expect to see you within 12 months.

If your child is in School Age years, you can expect:

- Your initial appointment will be an **Individual Family Service Plan (IFSP) meeting**.
- This may take place as parent/guardian only, or as a parent/guardian and child appointment with members of our team. The meeting may happen at your home, in our clinic, or in another relevant place. During the appointment, we'll work together to set goals and strategies that fit your child and family's needs. Afterwards, we'll send you a summary document of what we discussed, including the goals and strategies we identified.

- At this stage, we will also suggest interventions (supports or services) based on the goals we set. There may be some **extra waiting time** before these can begin.

This age group often experience the longest waiting times before their initial appointment. This is because family or school circumstances may change suddenly, requiring urgent intervention from our team. We understand this can be difficult for families to hear.

The expected waiting time is over 2 years, and we cannot provide a reasonable estimate at this time.

At the beginning of a child or young person's journey with us, we work in collaboration with you and your child to agree suitable goals and interventions. This discussion creates your **IFSP**. Interventions on your IFSP work toward very specific and clear goals for you and your child. There will be **additional waiting times** associated with these.

We recommend interventions and support based on what makes sense for a child or young person’s unique needs. Team interventions are delivered in the following ways:

- Information groups for parents or guardians.
- Group sessions with other children and young people, who are working toward a common goal.
- Meeting CDNT team members, either in a parent or guardian-only appointment or with your child.
- Meeting important people in a child or young person’s life, to discuss strategies and tools that help support them. This might involve other family members, or other professionals such as school staff, **CAMHS,** and **TUSLA**.

Who works in a CDNT?

Each CDNT includes staff from different disciplines, who work together to support your child’s participation in activities at home, in school, and in their community. We have listed the most common staff you might meet working in CDNT 11 based on your child/ young person’s needs.

While individual therapists bring different areas of expertise, they work together in the CDNT to support a child or young person. This means that, while a therapist may sometimes work with your family separately toward a goal that is specific to their discipline, most supports involve input from multiple team members. We describe some roles in the CDNT below, to help you understand how they fit as part of the team.

Occupational Therapist (OT)

- Builds independence by supporting skills around everyday activities. This might include eating, washing, getting dressed, going to the toilet, playing, shopping, or going to new places.
- Suggests ways to adapt these activities into smaller and easier steps. Sometimes, this might include a home, school or pre-school visit. They may suggest or provide special equipment to help with everyday activities.

Physiotherapist (PT)

- Knows how children develop physical skills and works with your child to improve how their body moves and works. Activities might include stretching and strengthening muscles or improving balance and co-ordination.
- Helps your child to maintain good posture and positions during activities. This might involve prescribed equipment like walkers, supporting footwear, or sleep systems.

Child Psychologist

- Recommends ways to help you support or accommodate your child's strengths, needs, and preferences around development and regulation.
- May, if necessary, provide recommendations for a particular school placement or advocate for additional resources in your child's school.

Speech and Language Therapist (SLT)

- Supports children's communication, feeding, eating, drinking and swallowing.
- Looks at your child's use and understanding of words, facial expressions, gestures, and body language. They might explore other communication methods like signs, gestures, or pictures, or the use of alternative and augmentative technology.

Social Worker

- Gives practical, emotional, and social support. This might include information about activities or support groups, help applying for benefits and services (see 'Where can I find out more about financial and educational supports?', Page 10), or support with issues around health, relationships, or money.

- Provides support and advice on the emotional impact of caring for a child with additional needs. This can help with supporting your child's siblings, coming to terms with a recent diagnosis, or generally finding it difficult to cope.

Nurse

- Links with your child's medical team, and helps you understand the terms they might use and the impact these may have on you, your child, and your family.
- Organises and attends Paediatric clinics with children.
- Organises and runs groups to support babies and young children's development as well as supporting families in relation to toileting and sleep.

Early Intervention Therapist

- To support each child's development, play and learning skills within their family, education settings and community.
- To support and promote a child's inclusion in their preschool and educational placement by liaising with staff and advocating for the child and family.
- Organise and run groups to support young children's development such as early learning and school readiness groups.

Intensive Support Worker/Behaviour Support:

- Analyse behaviours of concern to identify the message a child is communicating through their behaviour. They develop and help put supports in place in collaboration with other clinicians on the team to help with behaviour. These supports aim to maximise a child's participation at home, in school and in the wider community.

Therapy Assistants

- Support the provision of services to children and families. They work under the supervision and guidance of a therapist. They mainly work with speech and language therapists, occupational therapists, or physiotherapists.
- Collaborate with children, family, carers, and other staff in intervention planning and in the provision of support and advice.
- Carry out joint home/school/community assessments / follow up home/school/community visits with the supervising therapists.

Key Contact

- Some CDNTs assign a key contact to families, who acts as a point of contact for questions and concerns. **CDNT 11 does not currently work in this way.** You can still contact us directly with any questions and receive a response. As mentioned on Page 3, we usually reply to general queries within 2 working days. If the response requires input from multiple staff, it will be directed to the appropriate team meeting for discussion and response.

Administrative Support

- Manages our centralised email system, and co-ordinates appointments for team interventions.

Children's Disability Networking Manager (CDNM)

- Responsible for day-to-day management, leadership, and development of the team. They ensure best practice while working to regulatory clinical standards and work closely with community services and supports that may benefit children, young people, and their families. Your CDNM is **Audrey Falvey.**

I am considering private therapy for my child. How will this affect us?

We need to know if your child is attending a private therapist, to ensure we are working together to achieve the same goals and provide the most appropriate support for your child. You should also tell your CDNT if your child has completed, or is scheduled to complete, any private assessments. This is because certain assessments cannot be repeated within a set period of time.

Accessing private assessments or supports for your child can be costly. Health insurance companies offer individual policies for children, which may allow you to claim back up to 75% of the cost of private therapies. You can also claim 20% tax back on health expenses via your annual Med 1 form.

What can I do before my child's first appointment?

Before a family receives their child's first appointment, they often feel stuck and frustrated. This is completely understandable – but there are useful things you can do now, both to support yourself and your family and to prepare for this appointment.

Write down any questions and attend an information session if you are able.

We may invite you to parent supports before your child's initial appointment, such as information session, Family Forums, and coffee mornings. These are opportunities to learn about our service, meet our team, and meet other parents who use our service.

You and your child may have a lot of questions, and we encourage you to write these down so you can keep track of them. You can also bring these to your child's initial appointment. Please ask us what you really want to know and tell us if there's something you don't understand. It is our responsibility to speak in a way that makes sense to you and your family. If something is confusing, we need to know so we try to explain it differently.

Note any observations about your child, including those of other people in your child's life.

These might include specific concerns about your child's development, behaviour, communication, mobility, or learning. Include dated, real-life examples if you can, and any changes over time. Write down any approaches, activities, or resources that you use with your child, and how they respond. You may find it useful to take short videos of your child.

Gather relevant documents

Collect reports from your child's school or pre-school, reports from previous assessments (if any), and details of prior hospital visits or therapies. Keep a folder with your child's vaccination records, birth history, and other relevant health information.

Access local supports, find out more, and connect with others.

You may already be researching your child's needs, accessing supports in your community, or reaching out to other families of children with complex disability needs.

The team try to maintain a list of community supports. If you would like to discuss any potential supports that may be suited to your child/young person's needs, please get in touch with the team.

The following are some community supports that you may find useful:

- **Mahon Family Resource Centre:** Mahon Drive, Mahon, Co. Cork, T12 Y180

  Tel: 021 435 8866

  Web: https://mahonfamilycentre.wixsite.com/themahonfamilycentre

- **Cork Sports Partnership**

  Tel: 021 4347096

Email: info@corksports.ie

- **Citizens Information**

  Tel: 0818 07 4000

  Web: https://centres.citizensinformation.ie/county.php?county=cork

Stay in touch.

Make sure we have the correct contact details for you (phone number, email address, home address), so we can contact you with information and updates.

Where can I find out more about financial or educational supports?

'Support Pathways for Children with Additional Needs', created by the Children and Young People's Services Committee (CYPSC) in Kerry, outlines many supports and resources you may be able to access for your child. While this includes some resources specific to Co. Kerry, it provides broadly applicable and straightforward information about national initiatives available throughout the HSE to support you and your child. This includes preschool supports, primary and post-primary school supports, financial supports (including Domiciliary Care Allowance and Carer's Allowance), and government grants (including the Housing Adaptation Grant).

For this information and more, you can find 'Support Pathways for Children with Additional Needs' at: https://kerrychildrensservices.com/supports-for-children-with-additional-needs/ .

How can I give feedback about the service?

We aim to provide a responsive service for children and families, and we welcome comments, suggestions, or compliments from the people using our service. We can use this feedback to identify good practice, make changes, and improve the way we work.

If you are not happy with the way something is done, you have the right to say you are not happy. The first step is to discuss your complaint with our staff, which you can do in-person or via telephone, email, or letter, using the contact details provided. If the complaint cannot be resolved, you can contact the Complaints Officer at Enable Ireland in writing or through the team email address. The Complaints Officer will investigate your complaint in accordance with Enable Irelands Comments, Compliments, Concerns and Complaints Policy and Procedure.

If you are still not happy after this, and you would like to speak with someone outside of Enable Ireland, you can bring your complaint to the HSE via Your Service Your Say (yoursay@hse.ie or 1800 424 555).

If you think your child has been treated unfairly by a public body or an organisation funded by the government, you can make a complaint to the Ombudsman for Children. This service is free and independent and can be accessed at www.oco.ie/online-complaint.

Glossary of Terms

CAMHS

The **Child and Adolescent Mental Health Services** in Ireland. They provide specialised mental health care for young people up to the age of 18 who are experiencing moderate to severe mental health difficulties. CAMHS teams include professionals like psychiatrists, psychologists, nurses, social workers, and therapists. Psychiatrists are involved in prescribing and monitoring medications. Please note that CDNTs do not have psychiatrists as part of our team.

Complex disability needs

One or more needs that impact the child’s ability to participate in a range of everyday activities in a significant way. These needs require a number of health professionals working together with the family and the child, developing one plan of support.

Family-centred practice

A way of working that puts the family at the centre of a child’s care. It recognises that each family is unique, constant in their child’s life, and the expert on their child. This is different to the traditional medical approach, where therapists are seen as the experts. Children develop and learn by taking part in daily life, and through activities with their family, at school, and at pre-school. CDNTs help families make the most of these everyday learning opportunities by providing knowledge and strategies you can use outside of therapy sessions. This approach improves a child’s development, increases family satisfaction, and helps parents better understand and support their child.

Family Forum

Every CDNT has a Family Forum, where young people and families discuss children’s disability services in the area. These forums meet three times per year. Every family using or queued to use our service is invited to attend the Family Forum, and is provided with the minutes from each meeting. The Family Forum is attended by the Children's Disability Network Manager. We give an update on our service and staffing, but other topics are decided by the family group. This may include a relevant guest speaker.

If you would like to find out more about the Family Forum, speak to any member of staff.

Individual Family Service Plan (IFSP)

The Individual Family Service Plan is made with you, your child and the family. The plan will include:

- Priorities that you, the child or the family have.
- Things that are going well, and things you and your child would like to change.
- A number of goals, based on your identified priorities.
- Strategies you have agreed to work on.
- Supports that the team will offer.

The IFSP is a live document, which means it should adapt and change to suit your child. If your priorities or circumstances change, please let us know.

TUSLA

The Child and Family Agency in Ireland. They play a vital role in supporting and protecting children and families, and are responsible for **child welfare and protection, alternative care, educational welfare, family and community support, early years services, and domestic, sexual, and gender-based violence services.**

All interdisciplinary team members are mandated persons under the Childrens First Act 2015. This means that if a staff member has reason to belief that a child has been harmed or is at risk of harm a report must be made to TUSLA.