Children's
Disability
Network
Team

Information for Families about Children's Disability Network Teams

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1. What is a Children's Disability Network Team?

A Children's Disability Network Team (CDNT) provides services and supports for children from birth to 18 years who have complex needs as a result of a disability or developmental delay. Complex needs are defined as a range of significant difficulties requiring the services and support of an interdisciplinary disability team.

- The family and the team both have vital contributions to make.
- To ensure that families and the team work together they agree and share a plan. The plan is called an Individual Family Supports Plan (IFSP).

The Team's Expertise

- Each professional on the CDNT brings their training, skills, and experience of working with children with disabilities to the team. Depending on their needs and goals, a child and their family may not require support from all members of the team at the same time, and it is recognised that needs will change over time.
- Using their specific knowledge and skills, the CDNT supports the family with a wide range of issues such as feeding difficulties, challenging behaviour, mobility problems.

Other examples of support are:

- Organising aids and appliances such as walking aids or specialised seating.
- Advice on and supply of assistive technology, such as an adapted computer keyboard or communication aid.
- A sensory assessment and recommendations for home and school.
- A parent and baby group where they can get advice on early play and communication and meet other parents.

Members of the CDNT

Here is a brief description of the roles that are typically included in a CDNT. Please note this full list of professionals may not be on every team.

Occupational Therapist (OT)

An occupational therapist assesses how a health condition or disability can affect a child's participation in daily activities. They may support a child with play, gross and fine motor skills, and sensory needs. They also help with learning daily living skills and with sourcing adaptive equipment and with housing adaptations.

Physiotherapist

A physiotherapist supports all aspects of a child's physical and motor development. They are involved with providing equipment to enhance a child's physical abilities (for example, a walker or orthotics).

Psychologist

A psychologist supports children in areas such as emotions, behaviours, learning, and educational placements. A psychologist may also carry out a diagnostic assessment as needed.

Speech and Language Therapist (SLT)

A speech and language therapist has expertise in understanding communication and the different ways people can express themselves. They also have specialised knowledge and skills in feeding, eating, drinking and swallowing (known as FEDS).

Social Worker

A social worker has skills in providing emotional and practical support to a child and their family. They can help families access and maximise the supports available in their community.

Dietitian

Children with complex medical needs often have feeding and nutritional problems. Dieticians can support with weight management, food aversion, infant feeding and healthy eating.

Early Years Practitioner

An early years practitioner specialises in early childhood development and education. They can help with progressing a child's developmental milestones and can work with children at home, in their preschool, in the clinic or in the community.

Nurse

A nurse assesses the care needs of a child, and they may also participate in team assessments across various places such as home, clinic, preschool, school, and community.

Therapy Assistant

A therapy assistant works under the supervision and direction of a therapist. Their role may include working directly with children and families.

Behaviour Support Specialist

A behaviour support specialist has special skills in analysing behaviours. They develop and implement behaviour supports to help a child take part in school, at home and in the wider community.

Administration

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

Family Centred Approach

For many decades and across the world there has been a move towards a family-centered approach, and away from the 'expert' model of treating children with a disability or developmental delay.

We know that children develop and learn best when taking part in everyday life.

Life happens at home, in pre-school or school and with friends, not in a clinic. A child's family and those who are with them every day are the most important people in their lives.

A CDNT supports parents in gaining the extra knowledge and skills to help meet the demands of parenting a child with additional needs.

They advise parents on strategies they can use to manage everyday challenges, such as a tantrum in the supermarket, difficulties at mealtimes or bedtime and sleep issues. Being family centred does **not** mean training parents to be mini therapists.

The Six ‘F Words’ were developed by CanChild, a research hub in Canada. This can help us to focus on what is essential in children’s lives:

1 **FUNCTION** I might do things differently but I CAN do them. How I do it is not important. Please let me try!

2 **FAMILY** They know me best and I trust them to do what’s best for me. Listen to them. Talk to them. Hear them. Respect them.

3 **FITNESS** Everyone needs to stay fit and healthy, including me. Help me find ways to keep fit.

4 **FRIENDS** Having childhood friends is important. Please give me opportunities to make friends with my peers.

5 **FUN** Childhood is about fun and play. This is how I learn and grow. Please help me do the activities that I find the most fun.

6 **FUTURE** I will grow up one day, so please find ways for me to develop independence and be included in my community.

https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability

CanChild
www.canchild.ca

Proudly supported by The Allergan Foundation

Based on Rosenbaum, P. & Gorter, J.W (2012), The ‘F-words’ in childhood disability: I swear this is how we should think! Child: Care, Health and Development, (38) 4. Visit https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability for more resources.

WORLD CEREBRAL PALSY DAY
OCTOBER 6

2. Partnership

The aim of the family and the team working in partnership is to support a child to take full part in ordinary life at home, in their school and community, with their family and friends.

An example might be a child wanting to play outside at break time in school. There are many ways that the team, family and school can support this:

1. Improving a child’s ability to move around.
2. Developing their communication skills.
3. Removing any obstacles in the environment.

Some supports will require high levels of health professional expertise, such as providing a wheelchair or working on language development. The family and school can look at other aspects such as the accessibility of the playground. The end goal for everyone involved is for a child to take part and enjoy break time.

Partnership Essentials

- **Listening to each other so that families and team members all feel they understand and are understood.**
- **Developing respect and mutual trust.**
- **Families and team members working together to make decisions and solve problems.**

Cian’s Story

Development Through Play

Cian was born with a hearing impairment. He is now 18 months old, a bright and happy child who is delighted to explore his world.

His parents have three older children so are well-practised in parenting, but they want ideas from a children’s disability team about Cian’s particular needs.

They have found out from the CDNT about toys and simple games which encourage communication for hearing impaired children. They have also worked out with a member of the team that by just moving the furniture around they could create a suitable play area in their living room.

This now ensures that it’s easy for Cian to see the faces of others and engage with them when playing and interacting.

3. Planning Together

The team builds trust and a working partnership with families, listening to how they live their lives and what is important to them. They look for ways that a child with a disability can take part in everyday life, and they find opportunities for learning skills at home or in school.

To ensure that families and the CDNT work together in the best way possible they agree and share a plan, called an Individual Family Support Plan (IFSP). The plan sets out the goals and strategies according to each child's needs. Everyone can continually refer to the plan and know what they are working on.

This plan is ongoing and continually evolving as goals are achieved or priorities change. The number of goals in the plan needs to be realistic; usually between one and three is enough to work on at any one time.

Children and young people, as appropriate to their age and understanding, should be included in all aspects of making their own individual plan. It does not have to be a formal meeting between the family and the whole team. It can be developed and revised by the family and one or two team members during a centre appointment, home visit, online meeting or phone conversation.

To develop the best plan for a child and the family, the team finds out about the important issues from the family's view.

The team uses their collective experience with children who have disabilities and explain and advise what is needed at this stage in a child's development.

Depending on their specific challenges, a child may require physiotherapy assessment and intervention to progress their walking, or several members of the team may need to work together to address their feeding and swallowing issues.

Jane & Ruby's Story

Focusing on the Whole Family

Ruby aged 2 years has spastic quadriplegia and cannot support herself in sitting or standing. Her mother Jane was devoting a major part of the day to holding Ruby on her knee, talking and playing with her to encourage her development.

However, Jane found it very stressful to try and balance Ruby's needs with those of her older sister Lily and do everyday tasks around the home.

The CDNT advised and supported Jane to get a stander for Ruby. This means that Ruby regularly spends time in her stander, safe and well supported. She benefits from being in a good postural position and playing with toys on a tray in front of her. While Ruby needs someone close by while she is in the stander, it also means that Jane can more easily give Lily some time and attention.

4. Working Out Priorities

The CDNT works together with the child and family to identify their priorities. This means thinking about what is most important right now and what changes would make the most difference.

A priority for parents might be their child starting school, learning to ride a bicycle, eating a wider variety of foods, or sleeping through the night. Children and young people themselves should be encouraged and helped to choose and voice their own priorities, such as becoming more independent or joining in activities with friends.

Parents may like to have help and advice from the team in exploring what's most important, especially if they are new to thinking about this. CDNT members can advise parents about their child's condition and what the next steps are in supporting their maximum development and the interventions required.

Marie & Finn’s Story

How a Family and Team Work Out Priorities and Goals Together

Marie’s 4-year-old son Finn is autistic, and Marie feels anxious and helpless managing his behaviour. She learned online from other parents that he needs occupational therapy, and when she first met members of the CDNT, she said getting OT for Finn was her priority, though she was unsure what the OT would actually do.

The team helped Marie to focus on everyday life and how they could support her and Finn. They asked her to take them through a typical day, and it soon became clear that getting Finn dressed in the mornings was a major flashpoint, starting the day with frustration and exhaustion for both of them.

Marie and the team identified that a main priority was Finn getting dressed without tantrums and they worked out short steps towards that goal. The team introduced Marie to visual schedules for dressing and helped her and Finn to put this into practice every day at home.

By focusing on a specific priority and goal, Marie felt more empowered and positive about parenting Finn. She also planned to attend a Triple P Stepping Stones course with other parents. This helps with strategies to manage children’s behavior and gives parents the opportunity to share experiences with each other.

5. Forming Goals

Once they decide what to focus on for the next while, the CDNT, child and family work out goals.

A vague and over-ambitious goal is going to be frustrating and pointless for everyone, so the goals need to be SMART. Instead of *‘Tom will walk more’* the goal could be *‘In three months Tom will be walking to school once a week’*.

S	**Specific:**	clear and exact, using positive language.
M	**Measurable:**	how will we know the goal has been achieved?
A	**Achievable:**	the goal is realistic for a child, the family and the team to achieve.
R	**Relevant:**	functional and a part of real life for this child and family.
T	**Timebound:**	dates are agreed for the supports to be provided and the period this goal is going to be worked on.

Check out this interview with **Silvia Segales**, an Early Intervention Specialist with a CDNT, who is also the parent of a son with autism.

https://www.youtube.com/watch?v=5MRcFrRtCBY

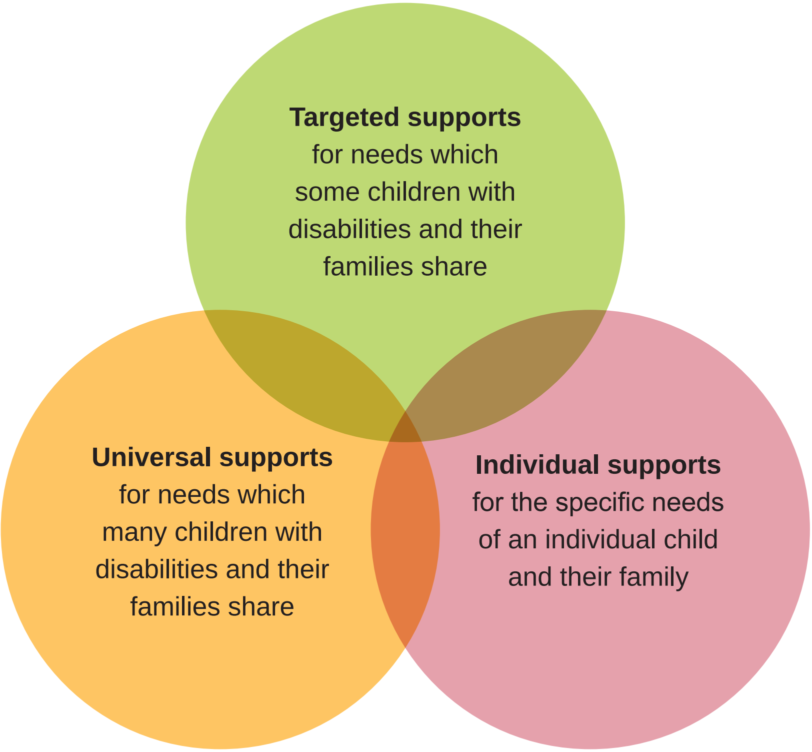
This conversation is about therapy in daily life, home programmes, goal setting and the Individual Family Supports Plan (IFSP).

6. CDNT Services & Supports

A CDNT provides different services and supports to achieve a child’s goals. That may include direct work with a child, information and courses for families, group interventions or indirect work through teachers. It may take place in various locations, such as a child’s school, home, the team’s centre, or online.

At any point in time, with the team, a child and family could be offered different kinds of interventions according to their current needs and issues.

Examples of Interventions



A child and their family can at any stage benefit from these different types of supports. It will depend on a child's needs and what is currently most important for the family. Sessions by a therapist one to one with a child may be the best option, but not always. Sometimes a child joining a group with other children has better results. Parents may find a workshop gives them the information they need for a particular issue.

The ways in which teams help is informed by evidence. This means that teams use tried and tested programmes and interventions. They offer the type of support found to be most effective with the issue that needs to be addressed. Sometimes the team needs to try a few different approaches to get the best results. There is no one solution that works for all children or all families.

A. Universal Supports

These are supports for needs which many children with disabilities and their families share. They include group information sessions, talks and workshops held in-person, virtually or both to best suit the family’s needs and circumstances.

Examples

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

Benefits of Universal Supports and Interventions for Children and Families

1. **Builds Understanding** of your child’s development as they grow.
2. **Empowers** you with strategies to use with their child daily.
3. **Provides Shared Understanding** that the CDNT can build upon with you and your child.
4. **Evidence Based** approach that is studied, researched and proven to work for children and families.
5. **Recognition** that you, the parents, are the most important support in your child’s daily life.
6. **Pro-active** and Preventative tools for you and your child.

B. Targeted Supports

These are programmes and groups for children with similar needs and their families. Bringing parents together who have similar challenges can be very powerful. It gives them an opportunity to meet each other and share ideas and experiences. Bringing children together in groups is generally more fun for them and they learn from each other. The programmes often include some individual sessions with a child or their parents as well as with the group.

Examples of Programmes Run by a CDNT

Hanen programmes (www.hanen.org) are designed to support the communication development of young children, particularly those with language delays or autism. They focus on children from birth to age 6 and are used worldwide with excellent results. The approach is based on the understanding that children learn best in natural environments where they can communicate with significant adults in their lives.

Key Programs include:

- More Than Words® designed for families of children with autism spectrum disorder (ASD).
- TalkAbility™ aimed at children between the ages of 4-12 who are already using sentences. This helps parents enhance their child's social communication skills.
- Learning Language and Loving It™ designed for educators and caregivers, supporting them how to support children's language development during everyday activities and interactions.

Triple P and Triple P Stepping Stones (www.triplep.net)

- The Triple P Positive Parenting Program® is the world's most widely researched parenting programme used successfully in 30 countries worldwide with hundreds of clinical trials and real-world studies to back it up.

Here are some examples of positive feedback from parents who attended a CDNT group programme or course:

Positive Mealtimes Course for Parents of Fussy Eaters

“ Taken the pressure off… Understanding that it’s very complex and not our fault that our child doesn’t eat.”

“ Knowing now that we are not alone, others have the same issues.”

“ I am encouraging my child to try and tolerate different foods slowly.”

Anxiety Workshop for Teens

“ I enjoyed talking about different things that we can do when feeling anxious.”

“ I enjoyed learning about tools we can use when anxious.”

“ It taught me to think more positively.”

“ I liked the group conversations.”

“ Nice to know that others feel the same and I’m not alone.”

Sleep Tight Programme

“ All aspects of this course have worked for us – the format, the delivery, the length and timing, the diary, the bedtime routine – everything worked.”

“ I cannot recommend this course highly enough. After 13 years without sleep we are all finally sleeping thanks to this course.”

“ The course was great in giving me a sense of direction in aiding my child towards a positive sleep and independence.”

Executive Functioning Skills Workshop for Parents

“ It was great to hear other parents’ experiences.”

“ I found all aspects of the workshop interesting and valuable. I also found other parents’ experiences and advice helpful.”

“ Both the theory and strategies were useful, to firstly understand why my child finds these skills challenging and then the practical ways of addressing the areas of need. We could immediately use several of the strategies and it has made a positive change to homework time. Also, I can now see my son starting to initiate sorting his school bag, ticking off his checklist, expressing that he needs to eat first and have a movement break.”

C. Individual Supports

These are one-to-one interventions provided to children with disabilities and complex health needs associated with their disability. These supports aim to equip families to help their child at home and in the community.

Examples

- **Difficulties with movement.** Children who have difficulties with their movement and posture are assessed by the relevant therapists. The family and therapists then agree a plan of action. This could include treatment or equipment.
- **Feeding, eating, drinking and swallowing.** There may be lots of different reasons why this is an issue for a child. Families bring their own typical food and drink for their child to help find out what is happening and following assessment the family and the team agree a plan of action.
- **School transition.** Transition to primary or secondary school is an important milestone for all children with disabilities. CDNT clinicians work collaboratively to provide support to parents, a child and the school. This may include parent workshops, groups for children, and school-based training.

7. Contact & Support

For more information, please visit Children’s disability services - HSE.ie

To connect with your local CDNT, please visit Find your local children’s disability network team (CDNT) - HSE.ie

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