

# Family Information Pack

## Children's Disability Network Team Central Meath (Navan/Slane)





## **TABLE OF CONTENTS**

- 1. Welcome & Introduction
- 2. Who & Where we are
- 3. What we do?
- 4. Who works in the CDNT?
- 5. How do we work?
- 6. Family Centred Practice
- 7. Appointments
- 8. Accessing supports outside the CDNT
- 9. Policies & Guidelines
- 10. Your child's rights
- 11. Comments/Complaints/Suggestions
- 12. Contract







## 1. Welcome & Introduction

Welcome to the Central Meath (Navan/Slane) Children's Disability Network Team.

Children's Disability Network Teams deliver therapeutic services to children aged 0-18 years, who are deemed to have complex needs and requires a number of different disciplines working closely together to help the child and family meet their goals.

This information pack is for parents, guardians and care givers of children with complex needs, and contains details of how services are delivered by the team who cover the catchment area of Central Meath (Navan/Slane).

If you have questions, do ask your Children's Disability Network Manager or a Key Contact that may be allocated to you.

We look forward to working in partnership with you, your child and family.

Kind regards,

Anine Willemse, CDNM Central Meath (Navan/Slane) Children's Disability Network Team







## 2. Who & Where we are

#### **Contact Details:**

- ♣ Enable Ireland, Unit 13 Mullaghboy Industrial Estate, Navan, C15 C927
- Phone: 046 909 2530
- E-mail: admin.navan@enableireland.ie

The lead agency for your team is Enable Ireland

#### Hours:

The service is contactable Monday to Friday from 9:00 am to 4:30pm, excluding Bank Holidays.







## 3. What we do

Children who have delays in their development get help from Primary Care Services like Speech and Language Therapists or Physiotherapists. Children's Disability Network Teams assist kids from birth to age 18 years who have bigger and more complicated needs due to their disability.

We work closely together to provide services and supports for your child and family's development, well-being and participation in family and community life. The team you meet and how often depends on your child's needs, which will be discussed with you.

Intervention works best when everyone teams up around your child. Team members combine their skills for your child's benefit, either together or separately as needed.

This teamwork follows international best practice from places like Australia, Canada and the USA. Team members share knowledge and skills with your family so you can support your child's development at home and out and about in the community. This helps kids learn and enjoy everyday activities. The team can meet you ate home, in school or pre-school or in the center.

We offer intervention in various ways, from parent education sessions to groups. We often bring kids and parents together for learning. This also allows families the opportunity to share experiences and learn from each other.

You can access a video on how the service operates here: <u>https://youtu.be/58pmS7R6KDE</u>







## 4. Who works in the CDNT?

The team consists of occupational therapists, psychologists, physiotherapists, social workers, speech and language therapists and liaison nurses. Some teams also have assistant therapists.

The teams are led by a Children's Disability Network Manager (CDNM) and also have administration staff.

Do note that your team members may change over time.

#### **Occupational Therapy**

The Occupational Therapist (OT) looks at what skills your child requires to participate in everyday activities. And if your child will have a specific difficulty with developing that skill the OT will look at how the environment or activity can be adapted so your child can participate within his/her/their level of ability.

The skills the OT may work on with your child can be used at home, in school and in the community. Home skills include dressing, feeding, bathing, toileting, play and kitchen skills. School skills include handwriting, play, P.E. Community skills include hobbies, sports, shopping, travel and leisure opportunities.

The OT will work with you and your child to break down everyday tasks and activities into smaller and easier steps. This may include work on developing and maintaining posture, developing skills and muscles to use the hands and arms, teaching parents and teachers to support sensory regulation and maybe recommending assistive technology. This will help your child to achieve as much independence as possible and to learn everyday skills. The OT may also visit your child at home and/or pre/school to recommend and/or provide specialised equipment that may help your child in every day skills.

#### Psychology

The Child Psychologist can assess your child's developmental and learning abilities, highlighting each child's strengths and weaknesses. S/he can also assess your child's behavioural and emotional reactions to different situations. They will look at all of your child's abilities and difficulties in the context of your family.







S/he can also provide support and advice to parents on the emotional impact of caring for a child with special needs.

The Child Psychologist will work with you and your child to help understand and manage your child's difficult emotional or behavioural reactions. They can also help with developing your understanding of your child's social and emotional development, as well as provide advice on your child's sleeping, eating, and toileting. The Psychologist will support your child in accessing preschool and school placements, and if necessary making recommendations for extra resources. They can provide a support service to families who are coming to terms with a recent diagnosis or who at times find it difficult to cope.

#### Physiotherapy

Physiotherapy can help children with disabilities to improve movement and function in the body caused by problems with muscles, bones or the nervous system. They also provide advice, equipment and therapy to support and maintain optimal posture and positions for activities. They may prescribe equipment such as walkers or sleep systems and also advise on supporting footwear like orthotics or splints.

The physiotherapist (PT) has specialised knowledge and experience of how children develop and acquire physical skills. They can help to encourage and maximize your child's participation in activities in school and the community settings.

The PT will work with you and your child to perhaps move in certain ways or to help them learn a new movement, by stretching and strengthening certain muscle groups. Sometimes, specific activities that help your child sit, crawl, and walk will be recommended by the PT to enhance your child's general mobility, balance, co-ordination, strength and/or fitness, depending on his/her needs for practice at home. The PT can teach you techniques and activities to do with your child that may help to develop and improve their movement skills in all areas of daily life or perhaps to better manage their condition. Advice and education can also be given to all those who work with your child, for example, your childminder, teacher, or special needs assistant.

Some children will need physiotherapy for a few months. For other children physiotherapy will be helpful at different times throughout their lives. It may be given in individual sessions or group sessions. At times the PT may involve other colleagues from the team depending on your child's needs.







Children's needs change and so do the needs of families. The PT may want to see your child very often at some stages and less often at other times.

#### Speech and language therapy

Speech and Language Therapists (SLT's) provide intervention, support and care for people who have difficulties with communication, or with feeding, eating, drinking and swallowing (FEDS). A SLTs role is to assess, diagnose and support people with communication needs to fulfil their social, educational, emotional and vocational potential and to ensure safe swallowing for those with FEDS needs.

The SLT will assess your child's speech, language and communication needs. This can be achieved using standardised or informal assessments, or may be play based. The SLT will also speak to you about your child's communication in everyday situations. The SLT will assess your child's speech production and use of words, their use and understanding of language, and their interaction skills, for example, conversation skills, their use of facial expression and gestures or how they use their language or body to communicate with others. The Speech and Language Therapist will assess how your child can communicate their wants and needs. Your child's mouth, cheek and jaw muscles may be assessed, as will any drooling, if this is required.

If your child has any feeding eating drinking or swallowing difficulties, the Speech and Language Therapist can arrange to observe these in a feeding clinic or at home if needed. The Speech and Language Therapist will ask you questions about the variety and type of food and drink your child is having. They will ask about a typical day of eating and drinking. They will also observe your child having some food and may complete assessments to determine your child's safety with eating and drinking. Your child's oral motor skills may also be assessed.

The SLT will support you to help your child develop their speech, language and communication skills as is important and beneficial for them. This may include directly developing their speech and language skills but can also include providing and supporting your child to use augmentative and alternative communication systems such as signs, gestures, pictures and high tech devices.







The SLT may make recommendations on how to make eating and drinking safer for your child. This may include changes to the mealtime environment, posture, equipment or the food and drink itself.

#### Social work

The team Social Worker works with parents and others caring for a child with a disability who have extra needs for support due to challenges they are facing. The Social Worker may visit you at your home or in the office. They will also sometimes offer groups for parents to meet and share experiences.

As your child gets older the focus of social work may include working directly with them individually and through groups.

A social worker may be able to help you by providing:

- space and time to think about the emotional impact of their child attending a service, their diagnosis or extra needs
- opportunities to discuss how your child's disability affects other family members
- support to develop the extra skills needed in parenting a child with a disability
- help to find resources in the community that may be of benefit to your child and family
- help with applications for benefits and services, for example to access the social welfare system, navigate the housing system
- opportunities to connect with other families of children with disabilities through meetings and discussions at the various stages, or around common experiences, of a child's life
- connections with support groups in the community
- support when you're coping with health issues, relationships or money

They can also help you with referrals to other services, if you need them. They work closely with the other members of the children's disability team. Our goal is to work together to empower and enable you to give your child the best start in life.

#### Liaison Nurse

The Liaison nurse provides support to parents to manage the needs related to their child's diagnosis. The liaison nurse can link with your child's medical team







and help you understand the terms and the impact this has on your life. S/he can also apply for nursing supports art home should that be required to help you are for your child.

The liaison nurse can advise on what bed is suitable if your child requires physical care and will support with advice around continence care or developing skills in toileting. For older children they provide advice and support with sexuality and support with referrals to the adult service team.

#### Receptionist and administrative support

When families attend appointments at our office they are welcomed by our receptionist. Our receptionist supports the team by co-ordinating information, training, and intervention groups with families, preschool staff, and school staff.

#### Children's Disability Network Manager

The Children's Disability Network Manager (CDNM) is someone with clinical training who has previously worked in a clinical role. They oversee the running of the team, ensure all administrative work is completed for your child when they are first referred to the team and that all appropriate team members receive this information. They are available to support you if you are experiencing any difficulties.







## 5. How do we work?

#### How do we get to know your child?

We learn a lot about your child from the initial assessment and/or the Individual Family Support Plan (IFSP).

As you are the expert on your child you are the most valuable resource that the team has to help us get to know your child.

We take a holistic approach of your child and acknowledge that each child has their own individual strength and abilities we will look to build on these.

#### How do we work?

We use a Family Centre Practice approach which is internationally considered best practice in supporting the development, learning and wellbeing of children with developmental delay. This approach places the family at the center of service delivery and all of those involved recognise:

- That each family, and their circumstances, are unique.
- That the family is the constant in their child's life
- That they are the expert on their child.

This approach differs to the previous medical model in which therapists were seen as the "expert" on child development and they would deliver therapy to the child. The goal of Family Centred Practice is to empower you and your family with the knowledge and strategies to help you reach your goals. There is a recognition that by giving the families the skills and confidence to maximize their child's development therapists are improving outcomes for service users.

As we have changed the way we deliver our services the types of supports and interventions have also changed.

Historically therapy would have been delivered to the child on a 1-to-1 clinic based setting but in recent times this has been changing. The team will decide which type of support is most appropriate for your child at any given time. Some of the types of supports that we will offer you are:

#### **Universal Strategies/Supports**







#### **Universal Strategies/Supports**

This is general information which is provided in relation to one of your child's presenting difficulties. This type of support is usually offered following initial assessment or while you wait for other supports. These can also take the form of information sessions or workshops, inperson or virtually, that will form the building blocks for future input. This will give you some strategies which you can put in place at home to help your child

#### **Targeted Strategies/Supports**

These are mainly group based interventions which will give you more indepth information about how to help your child meet their goals. Some of these will also give you the opportunity to meet with other families and share your experiences

#### Intensive/Individual Intervention

This is a more specialised input and is most often delivered on a 1-1 basis with you and/ or your child. These are offered for a defined period of time and responsibilities will be agreed before they begin.

This is a tiered model of service so the universal and/or targeted supports will be offered and should be attended first before more intensive interventions can be accessed. This will ensure that families have a background knowledge of the strategies which will be discussed and have had the opportunity to try some of these at home.

The majority of the supports that you will receive will fall into the universal or targeted interventions categories. Interventions offered by the team may also include liaising with school, linking in with outside agencies, telephone calls or problem solving current difficulties.

Sometimes, we may need to link with other services involved in your child's care and development, such as a paediatrician, dietician, audiologist, hospitals and specialist clinics or family support groups. If needed, and with your agreement, we will refer your child to other services and organisations as required.







## 6. Family Centred Practice

Children's Disability Network Teams use a **Family Centred Practice** approach.

All children develop and learn by taking part in daily life and activities with their family, pre-school, school and community. Your child's family and those who are with your child every day are the most important people to help your child learn and develop.

The team work with you and others important to your child to support your child's development.

#### **Family Centred Practice means**

- We will take time to get to know you and your child so that we can work together.
- We will find out what your goals are for your child.
- We will work with you on a support plan. This support plan is known as the Individual Family Service Plan or IFSP. It will be unique to every child and family.
- We will help you to use everyday activities to achieve your goals.

## Why does the Children's Disability Network Team use Family Centred Practice?

- The child shows greater improvements in their development
- Parents get a better understanding of their child's needs
- Families can take part in activities that support their child's development
- Families are more satisfied with services







#### Individual Family Service Plan (IFSP)

You will be working with the team to identify very specific and clear goals for you and your child. You identify goals based on your everyday life.

These goals will be used to determine what intervention will best support you. Once a goal is reached a new goal will be set.

As mentioned above, supports will be linked to very specific goals. Supports are based on the needs identified within the IFSP and can be a combination of:

- Parent workshops/training
- Information sessions on particular topics
- Groups to develop specific skills
- Phone/telehealth supports
- Individual programmes for home or pre-school/school
- School/preschool supports
- Individual therapy sessions in person or online

Schools can request supports with your informed consent and supports will be provided in line with the goals identified as part of the IFSP.







## 7. Appointments

#### Preparing for your child's appointments:

You will be provided with a lot of information at your child's assessment or intervention.

You may find it helpful to write down what you want to ask before going into any appointments and meetings.

You may also wish to take a pen and paper with you to write down the answers

Please do not be afraid to ask what you really want to know. If you don't understand the answer or the words being used, don't be afraid to say so and ask for an explanation. It is your child who is being discussed so you will need to understand what is being said.

You may also wish to take a friend or family member. If you need an interpreter please let the team know t know which language you require and this will be booked for you.

- Remember to bring these to appointments:
- ♦ Glasses / hearing aid
- Any aids or equipment for mobility
- Drink and snack for your child
- Favourite toy
- ♦ List of questions you may have

#### Some general information on appointments:

We aim to run our service as efficiently as possible by making sure that our appointments' system runs smoothly.

Any missed appointment is a misuse of therapy time and means that another child could have used the missed appointment.

- Our service deliver interventions both face-to-face and virtually. If you have difficulty accessing on-line sessions for any reason please link in with the team.
- We will provide you with your appointments in writing, face-toface or by telephone/email. Please ensure we have a current







telephone number in case we need to notify you of a change of appointment.

- If your child is unable to attend his/her appointment, please let Admin know as soon as possible. It can then be offered to another child if appropriate. <u>Do not cancel via e-mail</u>
- Please give us at least 24 hours' notice if your child cannot make their appointment
- If your child is unwell, please cancel your child's appointment. This is because if they are unwell, they may not be able to do the activities in their appointment.
- Either you, or the person caring for your child, must come to the appointment with your child, and stay with them during this appointment.
- Please do not be late for your child's appointments. You may need to allow time for parking, for example, or for transfer from car to chair.
- If you are late for an appointment, your child will only be seen for the remainder of the appointment time.
- If you are more than 15 minutes late, we may not be able to see you at all.
- If your child misses some appointments, a team member will contact you, in case you are having problems with getting to appointments or appointment times.
- If there is a high incidence of repeated appointments the Team Manager may contact you to see if there is anything we can do to help attendances. This is because your child was referred for help with their development needs, and we need to ensure they get this help to develop to the best of their potential. We may also contact the person that referred your child to us.

**Please note:** The welfare of all children that are referred to us or that we see is of great importance to us. Parents have the main responsibility for the care and protection of their children. If we think that your child's safety and well-being will be affected by missed appointments and reviews, we are legally obliged, under the Children First National Guidelines, to inform your child's local Child Protection Social Work Team of our concerns about your child.







## 8. Accessing supports outside the CDNT

It is important that you tell us if your child is attending a private therapist. We need to talk to them about how we can both help your child. Please ask the private therapist to contact us.

You should also let the team know about any private assessments you arrange for your child. This is because certain assessments cannot be repeated within a period of time.

If the private therapy being provided conflicts with the intervention being provided by the team we will discuss this with you. If you choose to continue attending the private therapist, the team may have to defer providing intervention.

This policy is available to read on: <a href="https://www.hse.ie/eng/services/list/4/disability/progressing-disability/">https://www.hse.ie/eng/services/list/4/disability/progressing-disability/</a>

If you do look for a private therapist to provide supports *please consider* the following:

- Occupational therapists, speech and language therapists and physiotherapists who work privately all have to be registered with CORU (www.coru.ie – check their details on the website)
- They should ideally be members of their professional body, so <u>www.aoti.ie</u>, <u>www.iaslt.ie</u> or <u>www.ispc.ie</u>
- Psychologists do not yet have to be registered with Coru this will hopefully happen soon. You do need to ask the psychologist if he/she has had their qualification validated through the Psychological Society of Ireland and/or the Department of Health. Ideally they should be a member of their professional body - <u>www.psychologicalsociety.ie</u> – but this is not mandatory.
- It is important to ask if the person has experience working with children with various needs as well







## 9. Policies and Guidelines

We operate within policies from the HSE, Enable Ireland and the National Progressing Disability Services (PDS) programme.

We are highlighting the following policies as they impact significantly on how we work:

#### • National Policy on Access to services for Children and Young People with Disability or Developmental Delay

Children will not need to have a particular diagnosis to get services from the Children's Disability Network Team. They will have to present with significant and complex needs that require ongoing intervention from an inter-disciplinary team. Services and supports are provided based on the child's home address.

#### • Professional code of good practice

All health professional staff abide by the Professional codes of conduct and standards of practice as outlined by the different Professional bodies in Ireland. Staff from a number of disciplines also have to be registered with CORU (<u>www.coru.ie</u>) in order to practice in Ireland.

#### • Children First

We want to make sure that all children are kept safe and free from harm. Enable Ireland has a policy regarding the health and welfare of a child.

This policy is in line with the Children First Act of 2015. Staff on the team are mandated to report any concerns about the health and well-being of a child to Tusla.

#### • Health and Safety Legislation

We aim to provide and maintain safe and healthy working conditions, equipment and systems of work for employees, families and visitors to our service.

Safety precautions must be adhered to by everyone to prevent accidents.







Parents are required to remain on the premises while a child is attending for any therapy sessions.

If a child is sick, we ask that you do not attend the service and cancel your appointment with as much notice as possible.

#### • *Freedom of Information & Data Protection Legislation* We abide by the legislation under Freedom of Information and Data Protection.

This means that we strive to keep your information safe and secure and we also require your consent at various times throughout your time with us.

Should you wish to get a copy of any of the records we hold you can request that in writing to the CDNM.

#### • *Family engagement and attendance policy* This policy is available to read on: https://www.hse.ie/eng/services/list/4/disability/progressing-disability/

#### • Dignity at Work Policy

All members of the CDNT have a right to be treated with dignity and respect and to have a safe working environment which is free from all forms of bullying, sexual harassment and harassment. Any form of bullying and or harassment by a family may result in services being withdrawn.







## 10. Your Child's Rights

In providing and planning for health services, the CDNT records and maintains a wealth of both personal and health information.

We will not share these with anyone unless you have provided us with your permission to do so on the 'Parent/Guardian Consent Form'. We will only hold information which is deemed relevant to delivering a service to you and your child in line with GDPR guidelines.

Sometimes, however, there are certain situations that mean we are required by law to share information that we have received from children, family members or others with certain departments or organisations.

This is because we have a duty to ensure that all of the children we see are safe and protected from harm.

These situations include where there is evidence of abuse or neglect, or where a child or family member discloses an intention to self-harm or to harm others. At such times, information will be shared in the best interests of your child on a 'need to know bases.

You have legal rights as a parent and member of the public to access your child's personal information and general information held by the CDNT. You can request this information under the Freedom of Information Act or under a Data Subject Access Request.

Forms to apply for these are available from the Admin team.







## 11. Comments/Complaints/Suggestions

The Central Meath (Navan/Slane) CDNT aims to provide as responsive a service as is possible to children and their families. We welcome families who use our services to bring to our attention any suggestions, compliments and/or complaints they may have.

Any feedback or comments, whether positive or negative, is important as it will help us improve our service.

#### How can you provide feedback?

- Talk to the team member you are dealing with at the time
- You can write a letter and drop it in/post it
- Write us an e-mail at <u>admin.navan@enableireland.ie</u>
- You can also e-mail yoursay@hse.ie

All complaints will be managed as per the Enable Ireland Complaints Policy – a copy of this can be requested from the team.







## 12. Contract

It is important that we work together to achieve the goals we set. This contract lets you know what our commitment is to you and outlines the commitment we require from you.

#### What can you expect from us?

- To work in partnership with you. We will value your opinions and insights into your child and family's needs
- To work with you and relevant other people in you and your child's lives to set clear and appropriate goals through the Individual Family Support Plan. This is a plan for you and your child that contains information on what your child needs to develop to the best of their potential.
- To provide a range of supports based on your child's needs and the goals you have set within the resources we have available
- Supports are generally delivered virtually or in the clinic setting. We will liaise with school and will advise as and when required but this will not be the primary location for therapy.
- To provide support, information and professional advice in line with current best practice and within established policies and guidelines
- We will provide support and information in the transition of your child to settings such as preschool and school, and in the transfer of your child's therapy and care to other services.
- We will treat you and your family members with courtesy & respect at all times.







#### What do we expect from you?

- We would ask that you attend with or without your child (as appropriate) for groups and/or individual sessions as agreed by you and the Team in your Individualised Family Service Plan
- To participate fully in all activities in the centre and at home, including carrying out Home Programmes if provided
- Cancel appointments in a timely fashion if necessary
- Communicate with the team on any questions or issues you may have, preferably via phone
- Persistent failure to attend individual or group sessions without contacting us may result in discharge from the team.
- Use and care for equipment provided for your child. Return equipment when no longer required in as best state as possible.
- Notify the team of any changes in address or contact details
- We would ask that you are an active member of the team that is working with your child.
- We would ask that you treat all team members with courtesy & respect at all times.



