



Parent Handbook

East Galway & South Roscommon Children's Disability Network team



This pack will introduce the service and answer frequently asked questions. If you can't find an answer in this booklet, please call or email reception on 091872701 / cdnt8.chw@hse.ie

East Galway and South Roscommon Children's Disability Network Team 2024

Foireann Líonra do Pháistí faoi Mhíchumas in Oirthear na Gaillimhe & i nDeisceart Ros
Comáin 1872701 cdnt8.chw@hse.ie

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Getting to know each other...

Purpose of this booklet

The aim of this booklet is to provide information about

- how the team works
- what the service looks like
- supports and services available to families

What is a Children's Disability Network team?

A Children's Disability Network Team (CDNT) provides **specialised support and services** for children and young people, aged from birth to 18 years, who have a disability and/ or developmental delay and live in a named geographical area called a network.

The team supports a **child's** development, well-being and participation in family and community life.

It is the role of the CDNT to share knowledge, information and skills with **families** so that they will feel empowered to support their child's unique growth, learning, and participation in everyday activities.

The support and services provided by the team go beyond "therapy". Our aim is for every child/ young person to have a childhood of **inclusive experiences** where they can have fun, develop interests, and form relationships with others in every setting.



Children's Disability Network Team



There are nine children's disability network teams across counties Galway, Mayo and Roscommon. Our **East Galway and South Roscommon** network area, also known as network 8, reaches eastwards from Killooran to the river Shannon, and northwards from Woodford to Kilkerrin/Ballygar/Lecarrow.



Our base is located in the campus of St. Brendan's near the lake in Loughrea.

Team members meet children, youths and their families in locations across the network including home, school and clinics.

Our team members work for the HSE, Brothers of Charity & Western Care and services include community nursing, occupational therapy (ot), physiotherapy, psychology, social care(scl), social work(sw), and speech & language therapy(slt). An up-to-date list of our team members, a description of their roles and contact details can be found in Appendix A.



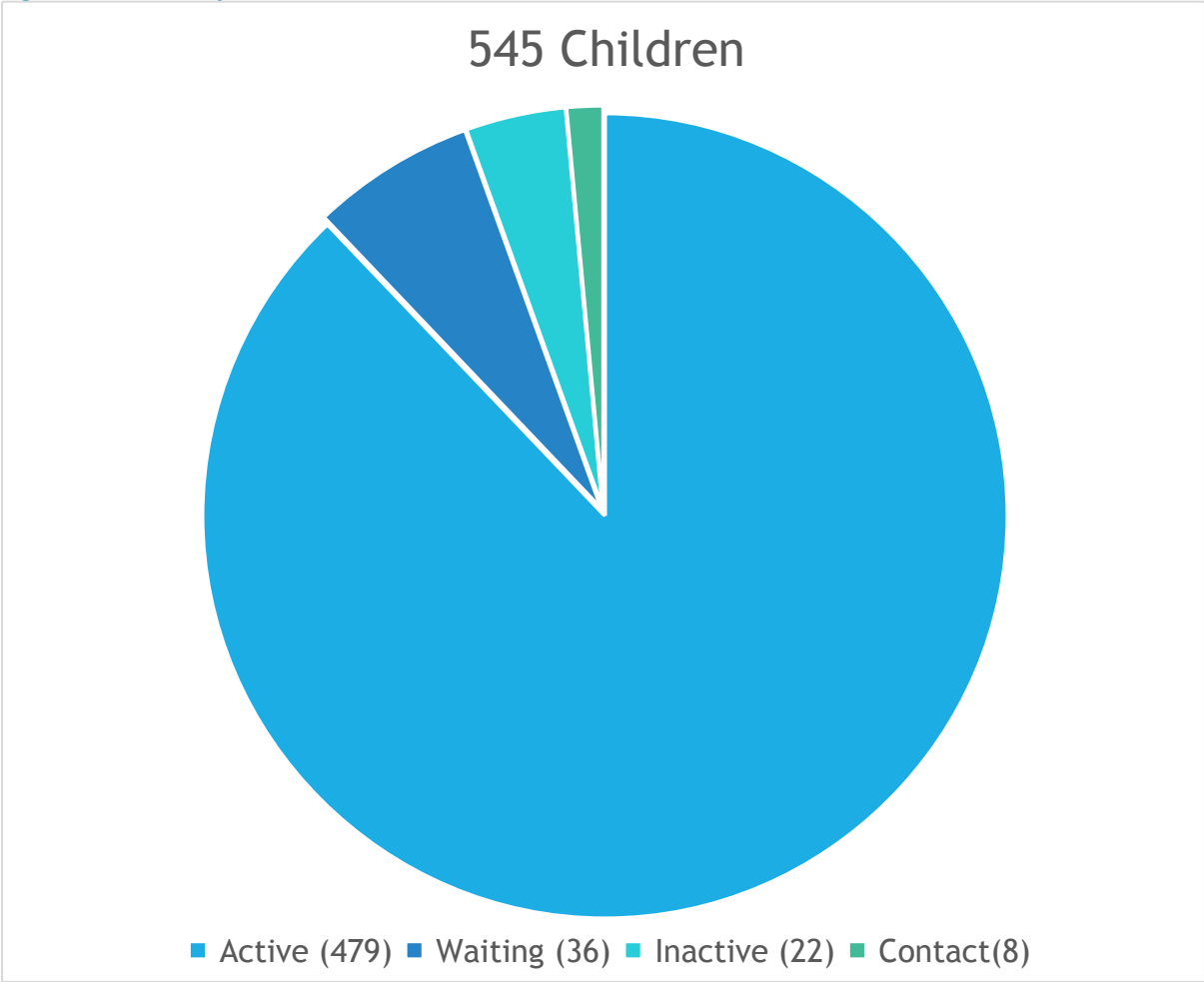
Families have asked for information on the number of team members and children/young people in the service May 2024 - see below in Table 1. & Graph 1.

Table 1 Staffing May 2024

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Staffing	
Approved Staffing May 2024 24.84 Total (inc 2 agency) 4 administrative staff including manager Therapist to Child Ratio: 545:21 26 :1	Current Staffing May 2024 20 Total (inc 3 agency) 23 people 4 administrative staff including manager Therapist to Child Ratio: 545: 16 34 :1
	Vacancies Total 6.85 (OT;SLT;SW;Physio;Behav Support)

Figure 1 Caseload May 2024



Getting to know each other...

Families at the centre of all services



As parents you are the main people who are, and will continue to be, involved in your child's life. You know your child and family best and you will have the **biggest impact** on your child's development.

Therefore, we aim to work with your family as active and **equal partners**. We will do this by building on your family's and child/ young person's strengths and interests, and supporting you and your child's skills and abilities.

We, as a team value your experience and opinion as a way to shape service delivery. The aim of the family forum is to afford families an opportunity to contribute. Your feedback is appreciated at any time (see Appendix A for information on Family Forum and Newsletter for upcoming dates).

*Everyone who supports
your family and your child
is part of your team*



Along with your family, the team considers your **extended family and support network**. This can include siblings, grandparents, cousins, friends, community and other formal supports such as e.g. GP. The team will work together with your family network to ensure the best outcomes for your child and family.

We know that every family is **unique**. Team supports and services will be as responsive and flexible as possible to meet your family's needs. We may ask about your family's **culture, values and beliefs** because we want to be respectful and to know what is important to you.

Additional supports such as interpreters and/ or translation of information is available if needed. Please ask us if you would like either of these services so we can organise this in advance of visits/ appointments.

What to expect...

Your child at home and in the community

The team will support your child to take part in a meaningful way in their daily life at **home**, at **preschool** or **school**, and in the **community**.

We will **work together** with preschool staff, teachers, and other service providers to build an **inclusive routine and setting**. The team will plan transitions to preschool, school and adult services with you including helping you to access specialist supports and resources if required.

Some of the supports available in preschool and school settings are included in Appendix B.

...use the everyday to develop skills you are working on...

Your child learns through **everyday experiences** with familiar people and activities they are interested in. Your daily family routine and everyday activities are a perfect **opportunity** for your child to **practice and build their skills with your support**. The team will be asking you about you and your family's daily routine to build on what's happening now.



What to expect...

Team around your child

Intervention has been shown to work best for children when everyone **works together as a team around your child**.

There will be one team member called a **keyworker**, who will be working with your family. A key worker is your family's **main point of contact** with the team and can be from any discipline.

See Appendix A for more detail about the role.



Waiting times vary with many families waiting more than a year to be assigned a keyworker. In the meantime if you have any questions, concerns, or worries, please contact reception **091-872701** cdnt8.chw@hse.ie.

The team decides how to use their time with the help of national guidelines. Individual Children/Young People are seen in date order of acceptance unless any of the following apply:

- Family or child in crisis
- Risk to health and safety
- Upcoming transition e.g. preschool, school, adult services
- Placement breakdown
- Waiting for a year or longer

www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/national-policy-on-prioritisation-of-referrals-for-cdnts.pdf

The team prioritises the allocation of a keyworker to every family. This means you may have a keyworker but wait to see another team member i.e. psychologist, occupational therapist, physiotherapist, social worker, social care worker, community nurse.

What to expect...

Building everyone's knowledge and skills

Your family, along with other important people in your child's life such as childcare staff, spend the most time with your child. **Building your knowledge, skills and confidence** will have the **biggest impact** on your child's learning and development.

It is what happens outside therapy sessions that makes the difference

For families this means:

All team members will start by finding out **what you already know, what you have tried that works, and then working with you to achieve your family goals.**

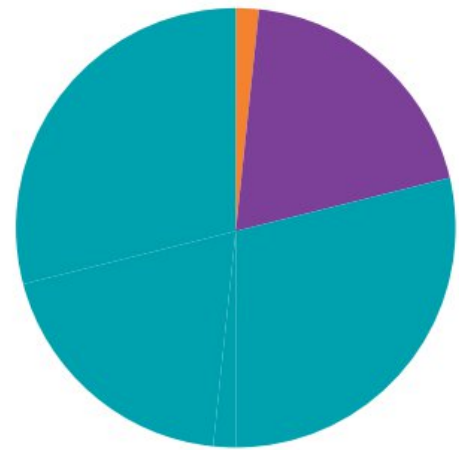
They will use **coaching** (where they will talk you through the situation giving you suggestions in the moment) and **modelling** (e.g. showing you a specific strategy) to enable you to build your skills. Our team will do this through phone calls, home and community visits, or in group interventions.

Parent information and education groups run by the team are a chance to learn (e.g. toileting or communication) as well as **share skills and connect with other parents.**

What to expect...

Building everyone's knowledge and skills continued...

Who has the greatest impact on a child's development?



■ Family ■ Child Care ■ Therapy

Diagram: 3 year old - average week - family - up to 80 awake hours (up to 10 hours sleep per night), 20 hours in child care/ preschool and 1 hour of therapy



For preschool staff, school staff, and community partners this means:

Your team will use **coaching, collaboration, and consultation** to help staff in supporting the inclusion of your child at crèche, preschool, or school. This can happen on a **1:1 basis**, through phone calls, in person visits, and on a **group basis** through education / information sessions.

*Catch me a fish
and I'll eat for a day.
Teach me to fish
and I'll eat for a lifetime*

All relevant people supporting your child will be involved in **looking at issues and learning opportunities throughout your child's day**. In this way, we identify a plan that works for everyone and which will have the best outcomes for your child.



Please refer to Appendix C for details on some of the **supports** available within the team for families and community partners.

What to expect...

What you want for your child and family

Every family on the team has an **Individual Family Support Plan (IFSP)** where their goals are written down. The team will come up with a plan for supporting the goals in your IFSP which will **fit in with your everyday life** and so work best for your situation.



Your family goals may focus on things like:

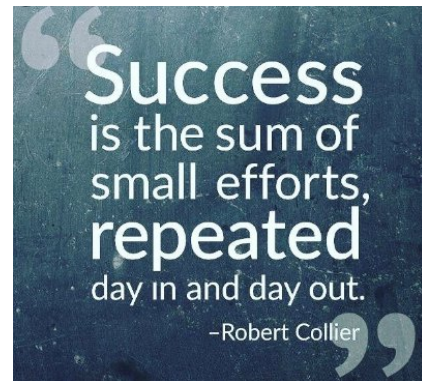
- Your life and family experience (e.g. eating breakfast in the morning, going to the supermarket, visiting grandparents, being able to go for a walk outdoors, going to the cinema)
- Your child's developmental and learning needs (e.g. for your child to roll or crawl, for your child to communicate what they want, for your child to develop friendships and navigate relationships)
- Your health and wellbeing (e.g. to find some time for yourself, to return to education, to get better quality of sleep, to learn English, to re-establish or maintain important social networks)
- Your child's health and wellbeing (e.g. to help your child to cope with change, toilet training, for your child to learn about themselves and their strengths)
- Your child's inclusion in community settings (e.g. to play/hang out with a friend, to decide on the best education setting for your child/young person, to join a club/sport, to prepare for college/ adult education)



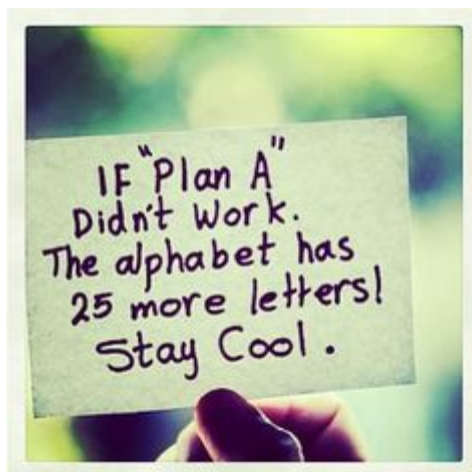
What to expect...

What you want for your child and family

Big goals can be achieved through success at lots of smaller goals. Sometimes parents aren't sure of the immediate goals for their child or how to break down long term goals into more manageable goals. Your key worker and other team members can guide you through this with **providing relevant information you need to make informed decisions.**



These goals are reviewed on a regular basis to see **what's going well, what has worked or not worked for your family, and what's most important for your family at this time.**



When problem-solving together, the first solution doesn't always go as planned. Everything you try will provide more information and help us to learn, adapt, and come up with a plan that works best for you and your family.

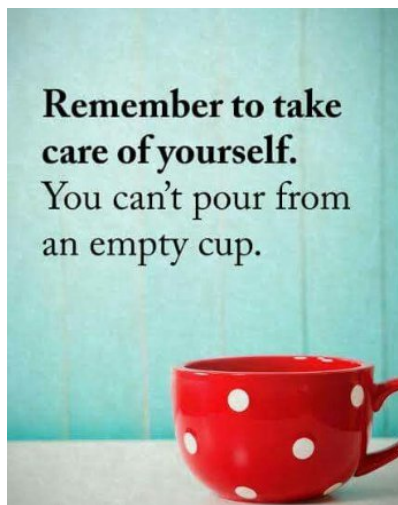
Community supports...

Emotional supports

Parents have told us that providing **emotional support**, along with supporting families to access other resources and services which specialise in this area, is very important to them.

All too often, parents share their struggle with **finding time for themselves**. They have told us that making time for their own health and wellbeing is often sacrificed for the needs of others in their family.

Research has shown that parents raising children with developmental or medical needs **often experience high levels of stress**. With this in mind, it's very important to acknowledge the importance of finding time for yourself and to consider small ways you can support your wellbeing and re-charge your batteries or **"fill your cup"**.



The phrase **"you can't pour from an empty cup"** reminds us that we can't offer what we don't have. If our cup is empty, we can't give to others.

Families have told us about the importance of **"filling their cup"** so that they are able to support their child. If you would like more support from the team in this area, please let us know.

More information on supports available to promote your emotional wellbeing is included in Appendix D. There are also many community-based groups and networks which can be a source of support to parents. These are listed in Appendix F.

Community supports...

Financial benefits and entitlements

Families have told us of the importance in sharing information about financial benefits and entitlements. This information is useful to support families with looking at the different **options** available to them and making an **informed decision about what will work for them as a family**.



/05/2

Various financial benefits and supports are all included in Appendix E. If you want to discuss any of these then please contact your key worker.



Community supports...

Community groups

Community groups can be both a practical and/ or emotional support for families. They can provide **opportunities to connect** with other families who are on their own journey.

There are many organisations and groups which **provide information and advice** to parents and families. This can include general information and/or advice, for example information on children's therapy services or more specific information and/or advice, for example a parent group for children with autism.



We have included some links and contact details of community groups and organisations in Appendix F. We will make every effort to keep these accurate and up-to-date but please let us know if there are any issues with them.

As you can imagine, there are a lot of organisations and groups available. If you or your family have experience of a group/ organisation which has been useful for you, and which is not included in the list, then please let us know and we will add it in.



Community supports...

Other therapies and supports

Families who are being supported by the team often attend other private therapies or appointments. We ask that you let us know if your child is attending private therapies to ensure that we are all working together to **achieve better outcomes** for you and your child.

Our team is always happy to **link and work together** with other professionals involved in you, your child, and your family's life. With your permission, the team can share their knowledge and expertise with other professionals and take the opportunity to learn from the experience of others involved in your family life.



There is some **guidance** on what to look out for if deciding to work with private therapists in Appendix G. This is general information including where to check if a professional is registered to practice. If you have any questions about any of this information then please talk to your key worker.

Appendix A

A journey through Children's Disability Network team...

- First you will meet your **key worker** or a **team member**. We will ask you and your child about:
 - your **child, family** and **daily life**
 - **what's most important to you and your family**
- Next, you and your child will decide on your **goals** and **make a plan** (IFSP)
- Then **services are provided** based on this plan (e.g. autism assessment, information session on language development/ regulation, troubleshooting about toileting/ meltdowns/ sleep etc.)
- We will work with other services involved with you and your child



Your child's world grows and expands...

- Thinking about **preschool / school** & asking for information on school supports available
- Working together with the team to **support your child** with this change

And still growing...

- Working together with the team to **support your child's transition to secondary school**
- Supporting your child to identify **what is important to them** and to **actively participate** in their own care
- Preparing for the future

- Support with **moving on** once your child reaches 18 years of age or leaves school
- Referral to **onward agencies**

Appendix A

Meet the team



Claudia, Teesh, Eileen & Anne

The Admin Team

We are receptionist and administrators....

Eileen Keane, Anne Rice, Claudia Padureanu

Reception in Loughrea is the information hub of the team. The administrative team are available 9 to 5 every day to welcome families who come to the clinic and to

answer and field any email or phone queries. We are the main link between families and the team.

We are also kept busy by administrative work generated by the team e.g. co-ordination of training, record keeping, filing.

I am the team manager....

Teesh Walsh

The team manager maintains an overview of the team and the service provided. They work with the team to make the most of resources available to meet the needs of families. They are the link between the team and the family forum, national groups and other departments locally including human resources, recruitment, health and safety and management.

The Clinical Team



Lauren, Joanne & Fidelma

I am the Community Nurse...

Fidelma Loughnane

The community nurse supports families with babies and toddlers until they start preschool. They will

- provide developmental information and emotional and practical support
- provide advice and support on your child's medical needs
- work closely with your child's Paediatrician and other health professionals

I am the Social Care Worker (SCW)....

Joanne Hoban

The social care worker supports families' goals providing information on services and entitlements, strategies and supports for the child/young person and liaison with schools and other significant people in a child's life.

"I have a particular interest in Lego therapy".

I am the Dietitian ...

Lauren Devereux

Dietitians are responsible for the nutritional management of individuals who are referred to their care. The Dietitian can help in the following ways:

- The dietitian will assess the individual's nutritional needs taking into account diagnosis, medical history, bloods and medications. Dietitians can tailor advice depending on the individual's calorie, protein, fluid and micronutrient needs.
- The use of oral nutritional supplements (ONS) and or Enteral tube feeding (ETF) should be supported by a dietitian
- The dietitian may also be able to help with symptoms such as bowel habits, stomach problems or sensitivities with certain foods
- The dietitian will also be responsible for monitoring and reviewing the nutritional plan based on changes for the individual
As part of the dietetic consultation the dietitian will also take measurements including weights, height/length to assess the individuals growth

We are Occupational Therapists (OTs)...

Caoimhe Greaney, Aisling Jones, Kerrin Hickey, Colette Caffrey & Ciara Flynn Murphy



Caoimhe, Aisling, Kerrin, Colette & Ciara (absent from photo)

“Occupation” is an everyday activity that brings meaning and purpose to life. It includes things people need to, want to, and are expected to do.

“We will promote and support your child’s participation in everyday activities such as eating, playing, making friends or homework”.

We are Physiotherapists (PTs)...

Josephine Nugent, Cara Maher & Ciara O’MalleyMooney



Josephine, Cara & Ciara (absent from photo)

Physiotherapy supports families to understand how

- your child learns, plans, and uses movement
- how this influences your child’s overall development

A physiotherapist will look at how your child moves and plays in different settings and work with you and your child to develop these skills.

“We will provide your family with information and ideas on how to support your child’s movement, with activities that can be easily incorporated into your family’s daily routine”.

We are Psychologists...

Lillian Stanley, Mary Kenirons, Roisin Hogan



Lillian, Mary, Róisín

Psychologists will:

- share information on particular areas of strength and challenge for your child
- promote a child/young person’s social, emotional, and behavioural development and wellbeing
- plan for educational placements.

“Our aim is to provide your family with information and support to strengthen your family’s ability and confidence in caring for your child.”

We are Speech & Language Therapists (SLTs)...

Hazel Walsh, Nicola Finnerty, Lorraine Hynes, Evelyn Burke, Ciara Tuohy



Hazel, Nicola, Lorraine, Evelyn, Ciara (absent from photo)

SLTs work with families to support their child's communication skills. They will share knowledge and skills to facilitate you to maximise your child's communication skills e.g. pre-verbal (e.g. waving bye-bye), early language skills (e.g. understanding words), speech sounds, and alternative communication approaches such (e.g. signs, pictures, or electronic devices). SLTs also support children with feeding, eating, drinking or swallowing (FEDS) difficulties.

We are Social Workers (SW)

Vacant

Social Workers offer practical and emotional support to help families find solutions to challenges that may arise. Solutions that are positive, inclusive and work for families. Understanding and supporting each family is central to social work. Every family is different with its own strengths and ways of coping. Social workers also

work closely with community organisations to best meet the needs of children and their families.

“We will work with you to find solutions for your child and your family”.

I am the Keyworker...

Anyone of the clinical team

The keyworker will

- **work closely** with you and your family in identifying goals and developing strategies
- **coordinate** information, services and supports
- **share information, knowledge and skills** to enable you to make informed decisions and support your child
- act as a **link** with the other members of the team and the people who spend the most with your child including preschool / school staff
- help with the **transition** of your child to community groups, childcare, preschool, school or adult services.

We are the Family Forum...

Family members, parent representatives, team manager & facilitators

The Family Forum is one method by which families can engage with the team and it forms part of the governance structure of Progressing Disabilities both locally and nationally. Family Forums are your chance to say - “this is my idea about how we move forward, this is what I think isn’t working and this is what I’d love more of.”

Our forum started to meet in 2023 with one meeting in June and one in October. The review of this information pack by parent volunteers was an outcome of the October meeting.

CHO Governance of Children’s Disability Network Services (Family forum 7.5 & 7.6)

www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/community-healthcare-organisation-governance-of-children-s-disability-network-service.pdf

Appendix B

Preschool, School and Transition to Adults supports

Preschool & Early Intervention

Preschool services and supports in the community include:

ECCE Programme:

The Early Childhood Care and Education (ECCE) programme provides early childhood care and education for children of preschool age. The programme is offered in early years settings (preschools, Montessori's, crèches, playgroups) for 3 hours a day, 5 days a week, 38 weeks of the year. All children are entitled to 2 full academic years on the ECCE programme.

More information available at:

<https://www.earlychildhoodireland.ie/work/information-parents/choosing-childcare/ecce-free-preschool-year/>

The Access and Inclusion Model (AIM):

This is a model of supports designed to ensure that children with disabilities can access the ECCE programme. AIM is a child-centred model, involving seven levels of progressive support, based on the needs of the child and the preschool service (e.g. sharing information with staff to access to a piece of specialised equipment or a reduced ratio of children to adults in the room). More information available at: <https://aim.gov.ie/>

Early Intervention Classes, Department of Education & Skills:

Early intervention classes are available for children aged 3-5 years with a diagnosis of autism spectrum disorder (ASD). These classes are intended to provide early support for children with ASD before they start school. This does not mean that the child will be required to attend a special class once they move on to school. Transport is available to your nearest Early Intervention class. More information available at: https://ncse.ie/wp-content/uploads/2014/10/Pamphlet-3-Autism-01_09_14.pdf

Other more specialised preschool placement options:

Both Children's Language Development Preschool (CLDP) Athenry, at <http://www.cldp.ie/> and the Therapeutic Learning Centre (TLC), Ballinasloe at <https://www.ballinasloesocialservices.ie/therapeutic-learning-centre.php> provide additional preschool supports in East Galway. Juniper Tree at <https://www.schoolandcollegelistings.com/IE/Athlone/734255266692954/Juniper-Tree-Autism-Services> and Lean ar Aghaidh, at <https://west.brothersofcharity.ie/services/childrens-services/child-development-centres-and-early-childhood-rc/>, are other placement options in Monksland/Roscommon which can be explored based on your child's needs.

A home tuition grant scheme for children aged between 3 and 4 years of age with a diagnosis of ASD can be applied for when a placement in an Early Intervention setting is not available.

Home tuition is also provided for children with ASD aged between 2 ½ and 3 years of age as they cannot enrol in school. More information available at: www.education.ie or link to nsce.ie as shown above. See below in *Educational Supports & Services* for links and further info.

Primary & Secondary School

Primary & Secondary School Mainstream Setting:

Children can attend their local mainstream primary and/or secondary school. They may require additional supports in the form of assistance of an SNA or Special Education Teaching. More information available at both links above.

Autism Class in a Mainstream School (Primary & Secondary):

Some mainstream schools have special classes for children with ASD within their school. These classes have approximately 6 pupils with a teacher and 2 special needs assistants (SNA's). Further details can be found at links above.

Special Schools: Special schools support students with more severe and/or complex special educational needs. Classes tend to have small numbers of students. For more details, please see the NCSE website and refer to the booklet as mentioned above.

Post School Options for Young People with a Disability

- Your Career Guidance/Teacher may support you and your child to think about post school options.
- HSE Occupational Guidance Service helps people with a disability to find a training option or support service that is suited to their needs.

People can avail of

- HSE Rehabilitative Training Programme or
- HSE Day Service or
- Mainstream Education/Training

Referrals should be made to the HSE at least 13 months in advance of leaving school. Students can be referred from the age of 16 for future planning purposes.

Referrals can be made by Parents/Guardians, Schools/ CDNT Keyworker

Educational Supports & Services

The National Council for Special Education (NCSE):

The NCSE service is delivered through a national network of **Special Education Needs Organisers (SENOs)** who interact with parents and schools and liaise with the HSE in providing resources to support children with special educational needs.

For contact information for the SENO assigned to your child's school speak to your school principal or follow the link below:

<https://ncse.ie/seno-contact-information#WestTeam1>

An online meeting for parents is organised by SENOs in this area once a year to provide information to families about school supports.

Below is a link to a useful information booklet for parents on all of the school supports available:

<https://ncse.ie/wp-content/uploads/2019/07/Web-Ready-03178-NCSE-Children-SEN-InfoBook-Parents2-Proof17-VISUAL-ONLY.pdf>

More information is available on the NCSE website: <https://ncse.ie/for-parents>

Visiting Teachers

Visiting teachers are qualified teachers with particular skills and knowledge of the development and education of children with varying degrees of hearing loss and/or visual impairment. They offer longitudinal support to children, their families and schools from the time of referral through to the end of post-primary education.

<https://ncse.ie/visiting-teacher-support#:~:text=Visiting%20teachers%20are%20qualified%20teachers,loss%20and%2F or%20visual%20impairment.>

National Educational Psychological Service (NEPS)

NEPS psychologists work with both primary and post-primary schools and are concerned with learning, behaviour, social and emotional development. Each psychologist is assigned to a group of schools.

NEPS psychologists work in partnership with teachers, parents and children in identifying educational needs. They offer a range of services aimed at meeting these needs, for example, supporting individual students (through consultation and assessment), special projects and research.

<https://www.gov.ie/en/service/5ef45c-neps/>

Home tuition, Department of Education & Skills:

The purpose of the Home Tuition Grant Scheme is to provide funding towards the provision of a compensatory educational service for

- (a) Early educational intervention for children with autism who meet the scheme's eligibility criteria
- (b) Students with special educational needs seeking an educational placement in a recognised school
- (c) Students, enrolled in schools, with a significant medical condition, or school phobia and/or associated depression/anxiety, which has caused, and is likely to continue to cause, major disruption to their attendance at school.

<https://www.gov.ie/en/circular/67f37-home-tuition-grant-scheme-20232024-special-education-component/>

Summer Programme Department of Education & Skills

The summer programme is for students with complex special educational needs and those at risk of educational disadvantage. More information is available at <http://www.gov.ie/summerprovision>

Where a child's school is not running a school-based programme, parents can contact the Department of Education via email at schoolsummerprogramme@education.gov.ie expressing their interest for their child to participate on a school-based programme. If a place becomes available in another location, the child's participation in a programme may be organised.

Educational Welfare Officer

<https://www.tusla.ie/tess/information-for-parents-and-guardians-tess/education-welfare-service/how-does-the-educational-welfare-service-work/>

Educational Welfare Officers (EWOs) are based throughout the country to offer advice and guidance to parents who need support in ensuring that their child attends schools regularly.

iScoil

iScoil is a non-profit online learning service that offers young people a pathway to learning, accreditation and progression.

We provide a safe learning environment where young people can re-engage with education, achieve recognised QQI certification and access further education, training and employment opportunities.

<https://iscoil.ie/>

School Avoidance

Clare School Avoidance Toolkit - This comprehensive toolkit details the roles of those involved in the Students support network and provides guidance and strategies for all involved. This booklet has plenty of information (which may be overwhelming!) Appendix A has worksheets that will provide an insight into the child's perspective, which supports the development of a child centred plan.

https://www.cypsc.ie/_fileupload/Clare%20CYPSC/uploads/ClareSAT-Final-November%202021%20web.pdf

Meath Emotionally Based School Avoidance Resource Pack - This pack offers information on navigating the system (who to contact and when) as well as guidance & support to students, parents/guardians/carers and teachers.

<https://enableireland.ie/sites/default/files/publication/Meath%20Emotionally%20Based%20School%20Avoidance%20Pack%20Final%20PDF%20Version%20Jan%202023.pdf>

Anxiety Based School Avoidance: Middletown Resource - This toolkit is reader friendly, with brief explanations and some simple approach strategies.

https://www.middletownautism.com/files/shares/Resources/Tues_27_Sept_Resource_Pack_STRIVE_NI.pdf

Appendix C

Supports Available on the Team

Learning in Groups

Group Training for Parents & Educators is currently delivered in two ways:

- **Interactive Group** session drawing on individual knowledge and experience to explore a particular topic in a group setting e.g. Parents Plus, AAC workshop.
- **Information sharing** & may include a 1:1 follow up to apply the knowledge to your individual family and situation.

Interactive Groups:

Parents Plus Special Needs Programme - for families raising a child or young person with a disability. Goals of the programme are to support parents to manage challenges that arise, improve family's well-being and strengthen their links with other parents.

Gestalt Language Processing Parent Training - This is a parent training which focuses on gestalt language processing which is how 75% - 90% of autistic children learn language. This training typically consists of two theory sessions and one in person session where an SLT will coach you through the strategies with your child present. The sessions focus on the following:

- What is Gestalt Language Processing (GLP) and how is it different from typical language development
- What are the different stages of autistic language development/ GLP
- How to figure out what stage of development your child is at
- How to support your child to communicate

Supporting Children with communication difficulties in the classroom - This is a training series designed to support school staff with their understanding of communication differences and how to support these communication differences in the classroom. There are three types of communication trainings for schools:

- Supporting Gestalt Language Processors in the classroom
- Supporting children with communication differences in the preschool and Primary school classroom for children under the age of eight.

Hanen: More Than Words - a parent training programme which was designed specifically for parents of children with social communication difficulties and/ or ASD. This programme provides parents with the tools, strategies, and support they need to help their children reach their full communication potential. It is a

combination of parent only group sessions and 1:1 parent and child coaching sessions.

Lámh Training - provides training in Module 1 of the Lámh programme where you will learn all of the Lámh signs included in this module.

Lámh: Family Lámh Training - provides information on “communication” and what Lámh signing is; teaches you a large number of Lámh signs; open for parents, grandparents, siblings, preschool and school staff and other important people in your child’s life.

Assistive Technology Workshop

A workshop led by occupational therapists offering information on application process, a decision tree, and practical advice on tools and technology.

Group Activities with your children

Hydrotherapy - a water based group which focuses on activities and exercises to encourage your child’s gross motor development, helps attention and listening skills and increases your child’s confidence in the water.

Baby Massage - a group focusing on infant massage which promotes a baby’s overall development, including movement and early communication. It is also important for early contact, bonding, and trust.

Information sharing

Emotional Regulation Programme - this usually consists of two or more group information sessions where we share knowledge, practical tips and tools with parents/school staff so they can support children with sensory, emotional, and/or behavioural challenges. There is an optional follow up one to one appointment with a member of the team to personalise strategies and supports for your child.

Understanding Autism- This training has been designed to develop our understanding of autism and explore strategies for supporting autistic children. It is a space to learn, discuss and reflect on what is working well and what is challenging. This typically consists of two group workshops.

Appendix D

Emotional supports

- Aware - offers services for people affected by depression including a confidential phone line service at 1800 80 48 48. More information available at: www.aware.ie

- Barnardos - offers a wide range of services for children, families and communities and can be contacted on (01) 454 9699. More information available at: www.barnardos.ie
- Counselling in Primary Care (CIPC), HSE - this is a short-term counselling service that provides up to 8 counselling sessions with a professionally qualified and accredited Counsellor/Therapist. It is a service for medical card holders, who are 18 years of age or over
- Family Resource Centre Programme - More information available at: www.familyresource.ie
- Irish Association for Counselling and Psychotherapy at <https://iacp.ie/page>
- Jigsaw - Jigsaw is an organisation which supports young people (aged 12-25) with their mental health. Please contact Jigsaw on (091) 549 252 or email (galway@jigsaw.ie) for further details. Further information can also be obtained from their website <https://jigsaw.ie/>.
- One Family (Ireland) - offers services and support to one parent families including training, education and a confidential helpline on (01) 662 9212 or 1890 662 212; email: info@onefamily.ie or more information available at: www.onefamily.ie
- Parentline - confidential helpline for parents under stress or who are worried about any aspect of their parenting; contact: (01) 873 3500 or 1890 927 277; email: info@parentline.ie or see more information at: www.parentline.ie
- Pieta House - provides a free, therapeutic approach to people who are in distress and those who engage in self-harm. They also offer a free phone number for anyone who is in distress and needs someone to talk to at 1800 247 247 or you can simply text HELP to 51444. More information available at www.pieta.ie
- Rollercoaster - an online resource which provides practical advice on the challenges facing parents. More information available at: www.rollercoaster.ie
- Youth Work Ireland- YWI is an organisation that offers support to young people (aged 10-22) YWI offers various services including mental health supports, anxiety programmes, drug and alcohol supports, and LGBT+ youth work, club development, employability programmes and counselling services. YWI has services based in Ballinasloe, Loughrea and Athlone. Please call 091 - 561637 (Ballinasloe), 091 - 561637 (Loughrea),

or 090 647 7075 (Athlone) for further information. Alternatively please visit their website <http://www.youthworkgalway.ie> for further details.

Appendix E

Financial benefits and entitlements

Further information on all of these benefits and entitlements are available on the Citizen's Information website at www.citizensinformation.ie

Domiciliary Care Allowance:

Domiciliary Care Allowance (DCA) is a monthly payment for a child aged under 16 with a severe disability, who requires ongoing care and attention, substantially over and above the care and attention usually required by a child of the same age. It is not means tested. There is a webinar available from the team to guide you through the application process. Contact reception for more information. Also, see information available at:

https://www.gov.ie/en/service/30fac9-domiciliary-care-allowance/?referrer=https://www.welfare.ie/en/Pages/1078_Domiciliary-Care-Allowance.aspx

Carer's Allowance:

Carer's Allowance is a payment to people on low incomes who are looking after a person who needs support because of age, disability or illness. If you qualify for Carer's Allowance you may also qualify for free household benefits and a Free Travel Pass. More details available at:

https://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/carers/carers_allowance.html

Household Benefits Package:

If you are receiving the Carer's Allowance (full or half-rate payment) and are living with the person you are caring for, you are eligible for the Household Benefits Package. This helps with the cost of your electricity or gas bill and your TV licence. More information is available at:

<https://www.citizensinformation.ie/en/social-welfare/social-welfare-payments/extra-social-welfare-benefits/household-benefits-package/#e8ca54>

Carer's Benefit:

Carer's Benefit is a payment made to insured people who leave the workforce to care for a person(s) in need of full-time care and attention. If you get Carer's Benefit, you are eligible for a GP visit card.

https://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/carers/carers_benefit.html

Respite care grant or Carer's Support Grant:

The Carer's Support Grant is an annual payment made to carers by the Department of Employment Affairs and Social Protection. It was formerly called the Respite Care Grant. It is paid on the first Thursday in June of each year. More information available at:

https://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/carers/carers_benefit.html

Carer's Leave:

Your right to carer's leave from employment complements the Carer's Benefit Scheme. Carer's leave allows you to leave your employment temporarily for up to 104 weeks to provide full-time care for people in need of full-time care and attention. The leave is unpaid but people who take carer's leave have their jobs kept open for the duration of the leave. You do not have to be eligible for Carer's Benefit to get carer's leave. More information at:

https://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/carers/carers_benefit.html

Incapacitated Child Tax Allowance:

You can claim an Incapacitated Child Tax Credit if you are the parent or guardian of a child/ young person who has a disability. More details at:

https://www.citizensinformation.ie/en/money_and_tax/tax/tax_credits_and_reliefs_for_people_with_disabilities/incapacitated_child_tax_credit.html

VAT Refunds on Aids and Appliances used by People with Disabilities:

You may get a refund of VAT on certain special aids and appliances that you need for your child or items recommended by professionals or which are necessary to support your child at home. More information is available at:

<https://www.revenue.ie/en/vat/repayments-to-unregistered-persons/disabled-persons/how-to-reclaim-vat-on-aids-and-appliances-for-persons-with-a-disability.aspx>

Medical Expenses:

You can reclaim some of the medical expenses you and your family incur. You generally receive tax relief for health expenses at your standard rate of tax (20%).

If your child has additional needs, you may claim additional tax relief on professional fees, hygiene products, excessive hospital travel and overnight accommodation. More information is available at:

<https://www.revenue.ie/en/personal-tax-credits-reliefs-and-exemptions/health-and-age/health-expenses/index.aspx>

Home Carer's Tax Credit:

You can claim this tax credit if you are married or in a civil partnership, and one of you is a stay-at-home parent to care for your child. You can only claim one credit regardless of the number of people you care for.

<https://www.revenue.ie/en/personal-tax-credits-reliefs-and-exemptions/health-and-age/home-carer-credit/index.aspx>

Homemaker's Scheme:

If you have given up work to provide full-time care for your child then you can claim credits towards your PRSI. In this way, years spent out of the workforce while caring for your child are credited with credits awarded at the same rate as your last paid PRSI contribution.

https://www.citizensinformation.ie/en/social_welfare/irish_social_welfare_system/social_insurance_prsi/homemakers_scheme.html

Housing Adaptation Grant:

A housing adaptation grant is available from your local council if you need to make changes to a home to make it more suitable for a child with a physical, sensory, or intellectual disability. More information is available

at: https://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/housing_adaptation_grant_for_people_with_disability.html

Mobility Aids Grant Scheme:

The Mobility Aids Grant Scheme is means-tested and provides grants for works designed to address mobility problems in the home such as installation of a level access shower, ramps to access the home, or a downstairs toilet.

https://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/mobility_aids_grant_scheme.html

Local Property Tax Relief:

If you have completed adaptation works on your home to make it more suitable for your child, you may be eligible for a reduction in your local property tax if the works resulted in an increase on the value of your home.

<https://www.revenue.ie/en/property/documents/lpt/guidelines-reliefs-disabled-incapacitated.pdf>

Disabled Drivers and Disabled Passengers Scheme:

This provides a range of tax reliefs linked to the purchase and use of a specially adapted vehicle for your child. Under the scheme, you can claim for remission or repayment of vehicle registration tax (VRT), or VAT on the purchase of the vehicle or cost of adapting a vehicle. If you avail of this scheme, you may get additional exemptions/ benefits including an exemption from motor tax, toll road fees, or a fuel grant.

https://www.citizensinformation.ie/en/travel_and_recreation/transport_and_disability/tax_relief_for_disabled_drivers_and_disabled_passengers.html

Free Nappy Scheme:

This scheme provides nappies free of charge to children who have a disability and are 3 years of age or older. The scheme is overseen by your local health centre in conjunction with your local Public Health Nurse (PHN). Please contact your local PHN if you think you are eligible for this scheme.

Appendix F

Community groups and supports

General information and supports for parents:

- Citizens Information website at <https://www.citizensinformation.ie/en/>
- Accessible Parking
<https://www.galwaycity.ie/disabled-parking-information>
<https://www.galway.ie/en/services/roads/trafficmanagement/parking/>
- Early Childhood Intervention Australia at www.ecia.org.au - includes useful resources and booklets for parents such as “Every Possibility A Parents Guide: Early Childhood Intervention”
- Family Carer’s Ireland - providing support for those caring for loved ones at home - details at <https://familycarers.ie/> or Tel: 093 30060
- Inclusion Ireland at <http://www.inclusionireland.ie/> which is a national association for people with an intellectual disability promoting advocacy for people with an intellectual disability
- Informing Families at <http://www.informingfamilies.ie/> - independent information for families where they have concerns that their child has a developmental delay and/ or disability
- Loughrea Family Resource Centre
<http://www.loughreafamilyresourcecentre.ie/>
- [Mychild.ie](http://mychild.ie) - HSE website with information for parents
- Progressing Disabilities for Children and Young People website at <https://www.hse.ie/progressingdisabilityservices/>
- Special Needs Parents Association - at <https://specialneedsparents.ie/> has links to national support organisations, local support groups, and clubs and activities across the country
- AIRC Midlands: Supporting families with additional needs. For more information visit our website: <https://www.aircmidlands.com/> or join us on Facebook: <https://www.facebook.com/aircmidlands> sports

- **FUSS** stands for Families Unite for Services and Support. They aim to fight for timely access to children's disability services in Ireland.
<https://www.fussireland.com/>
Also on Instagram and Facebook
- **Open Up**
<https://open-up.ie/>
Open Up is your complete guide to youth and family services in Laois and Offaly. Whether you're a young person, parent or friend, teacher or professional, this website may be of use to you. It contains a full directory of all the services available to you in the two counties, if you or someone you know is in need of help or support.
- **Parenting24seven**
<https://www.tusla.ie/parenting-24-seven/>
Welcome to Parenting24seven - key messages on what works best for children and families at different ages and stages. Parenting24seven is part of the [Supporting Parenting](#) project in Prevention Partnership and Family Support service within Tusla. You can choose your child's age range or look through our different articles.

Autism groups and supports

- As I Am at <https://asiam.ie/> - national autism charity and advocacy organisation which has links to all local supports on main page: "Find Support in Your Local Area" at <https://asiam.ie/interactive-map/>
- Autism Assistance Dogs Ireland (AADI) - www.autismassistancedogsireland.ie
- P.A.L.S. Autism Support Group: you can become a member by emailing an expression of interest to palsgroup20@gmail.com. There is a private WhatsApp group and two facebook pages (one public and one private) with up-to-date events and support.
<https://www.facebook.com/groups/803421997489870/> - public
<https://www.facebook.com/groups/1404662353044374/> - private
<https://www.eventbrite.ie/o/pals-autism-support-group-61185510323>
Most events are set to private and so can be accessed after joining the group.

- Infinity Friends social club, now affiliated with Youth Work Midlands, caters for autistic children from Athlone and the surrounding region, enabling attendees to grow in confidence through regular participation in community based, self-care and leisure activities.
<https://www.facebook.com/groups/762351741649772/?mibextid=oMANbw>
- Galway Autism Partnership (GAP) which has information on supports they provide locally @ <https://www.galwayautismpartnership.com/>
- ANOA (Autism/Neurodiversity Oranmore & Athenry) has a private facebook page <https://www.facebook.com/groups/1262431521338905/>
- Irish Society for Autism - www.autism.ie
- Middletown Centre for Autism at <https://www.middletownautism.com/> which was established by the Dept. of Education and Skills in Ireland and Dept. of Education in Northern Ireland to support the promotion of excellence in the education of children and young people with ASD.

A-Z of community groups and supports:

- ADHD Ireland at <https://adhdireland.ie/>
- Angelman Syndrome Ireland at <http://www.angelman.ie/>
- CanChild at <https://www.canchild.ca/> which focuses on supporting children, families, young people and adults with cerebral palsy and developmental coordination disorder (DCD)
- Down Syndrome Galway at <https://downsyndromegalway.ie/> with local branch - Down Syndrome Galway East Centre in Claregalway

- Down Syndrome Ireland at <https://downsyndrome.ie/>
- Dyspraxia DCD Ireland at: <https://www.dyspraxia.ie/> which includes details of parent support groups in Galway
- Epilepsy Ireland at <https://www.epilepsy.ie/>
- Foróige: Supporting young people to get involved in their community. For more information visit www.foroige.ie or Facebook <https://www.facebook.com/ForoigeEastGalway/>
- Genetics and Rare Disorders Organisation (GRDO) at <http://www.grdo.ie/>
- Hand in Hand at <http://www.handinhand.ie/> which supports families affected by childhood cancer and is based in Loughrea
- Irish Fragile X Society at <http://fragilexireland.org/>
- Irish Wheelchair Association (IWA) including IWA sport pages at: <https://iwasport.com/>
- Jack & Jill Foundation at <https://www.jackandjill.ie/> is a nationwide charity that offers support, advocacy and an in-home nursing service to help children and their families under 5 years who have a significant neurodevelopmental delay involving severe learning difficulties
- Lámh at <https://www.lamh.org/> which is an organisation that supports communication
- Muscular Dystrophy Ireland at <https://www.mdi.ie/>
- Prader Willi Syndrome Association of Ireland (PWSAI) at <https://pwsai.ie/>
- Spina Bifida and Hydrocephalus Ireland (SPHI) at <https://www.sbhi.ie/>
- Social Farming Ireland - social farming provides people who use services with the opportunity for inclusion, to increase self-esteem and to improve health and well-being by taking part in day-to-day farm activities on a family farm. Placement blocks can run for 8-12 weeks. For further information or to find a farm near you, visit <https://www.socialfarmingireland.ie/> or Facebook <https://www.facebook.com/SocialFarmingIreland/>

- Youthreach: an organisation who provide education, training and work experience programmes for young people aged 16-20 years who have left school early. There are seven Youthreach centres across Galway and Roscommon. <https://gretb.ie/youth/youthreach/>
- Youthwork Ireland: Support, empower and inspire young people to reach their full potential in a manner which is non-judgmental, welcoming, and open, in a safe and supportive environment. Visit <https://www.youthworkireland.ie/> to find out about groups or Facebook <https://www.facebook.com/youthworkireland/>

Sports Organisations

- Special Olympics Ireland at <https://www.specialolympics.ie/> including details on how to join local clubs
- Sports Ireland at: <https://www.sportireland.ie/participation/local-sports-partnerships> including details of Sports Inclusion Disability Officers in each area
Details of inclusive camps and cycling events to be found on websites and social media.
Galway Sports Partnership <http://www.galwayactive.ie/>
Roscommon Sports Partnership <https://rosactive.org/>
- Judo Assist Ireland at <http://specialneedsjudo.com/>
- Galway Speeders: Provide safe, fun and inclusive and accessible sports events for children and adults with physical disabilities. Join us on Facebook: <https://www.facebook.com/p/Galway-Speeders-100057593043951/> Email for further information: galwayspeeders@iwasport.com

Vision and/or Hearing challenges

- Irish Guide Dogs National Headquarters and Training Centre at www.guidedogs.ie
- NCBI at <https://www.ncbi.ie/> who work for people with sight loss
- Féach at <http://www.feach.ie/> for kids with low or no vision

- The Anne Sullivan Centre for people who are deafblind at <https://www.annesullivan.ie/>
- Irish Deaf Society at <https://www.irishdeafsociety.ie/>
- Chime at <https://www.chime.ie/> a national charity for deafness and hearing loss

Respite

Respite services are provided by a number of providers external to the team.

Respite is a break from caring for a family and includes:

- Community support (within the home or community)
- Home sharing
- Camps/Groups
- Centre based respite (evenings/weekends/overnights)

Our team will signpost you to a possible provider, to whom you will make an application. The team will provide a summary of support needs on request to accompany your application if required. Unfortunately, some children will be ineligible for any of the respite options listed.

Below please find details of respite providers in your area

Ability West Respite

Eligibility	Must attend Ability West School: St Teresa's Ballinasloe, St Oliver's Tuam, and St Joseph's Galway
Respite Options	Community Support Workers Home Sharing In Home Support Centre Based Respite

Enable Ireland

Respite Options	In home Personal Assistant/Family Support Service to support 0 to 18 children and their families within the home environment as needs are identified Community after school activity and connections - supporting children from 10 to 18 yrs to access their local communities, foster independence, connecting with their peer groups and engaging in activities of interest
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Brothers of Charity Respite Services Galway & Roscommon

Respite Options:	Social Groups Self-directed funding Home sharing In home support Centre based respite
Eligibility:	Intellectual Disability/Global Developmental Delay Does not attend Ability West School

Respite

St Hilda's Respite Athlone

Respite Options	Centre Based Respite (Wed -Sun) evenings and overnights
Eligibility	5-18yrs with a disability Historically included home addresses in Offaly, Westmeath & Roscommon. Will consider applications with Galway address.

Please note

If your child is **already in receipt** of respite and your needs are not being met, it is important to highlight your unmet need with your provider.

Provider Contact details:

- Brothers of Charity; Darragh Fahy, 087-3424502, Darragh.fahy@bocsi.ie
- Ability West; Loretta O'Donnell, 087-6940926, lorettaod@abilitywest.ie
- St Hilda's: Sinead McCarthy, 087-9673751, smccarthy@sthildas.ie or Geraldine O'Rourke gorourke@sthildas.ie
- Enable Ireland, Laura Higgins, 085-8721504, lhiggins@enableireland.ie

Appendix G

Other therapies and supports

Our team are happy to work together with any private therapies or supports you and your family are attending, with your consent. We do ask that you let us know if your child is attending private therapies elsewhere so we can all work together to ensure positive outcomes for your child.

For families who wish to explore additional services for their children, it is important to know about CORU which is the health regulator for Health & Social Care Professionals in Ireland.

Their role is to protect the public by promoting high standards of professional conduct, education, training and competence through statutory registration.

You can ensure that a therapist has met these standards and is safe to practice in Ireland by checking the CORU register at <https://www.coru.ie/public-protection/>

In addition to CORU, there are professional organisations which represent each area to ensure appropriate governance and practice standards. These professional bodies also hold details of private therapists available around the country. Further information is available at:

Association of Occupational Therapists of Ireland: <https://www.aoti.ie/>

Irish Association of Social Workers: <https://www.iasw.ie/>

Irish Association of Speech & Language Therapists: <https://www.iaslt.ie/>

Irish Society of Chartered Physiotherapists: <https://www.iscp.ie/>

Nursing and Midwifery Board of Ireland: <https://www.nmbi.ie/Home>

The Psychological Society of Ireland: <https://www.psychologicalsociety.ie/>

Irish Nutrition and Dietetic Institute <https://www.indi.ie/>

Appendix H

Development of the booklet

This booklet was originally designed in response to feedback from families on the Galway South & East Early Intervention team in 2020.

Families told us that, based on their experience, a written package of information upon their introduction to the service would have been helpful. They also told us

what content they felt would be most useful to other families starting off their journey with the team.

The aim of this booklet is to provide information about supports and services available to families, including what a journey through the children's disability team might look like. This booklet also enables families to choose when to seek out certain information and move at their own pace.

Children's therapy services have changed over the years based on research evidence and family input. This means services may look different to what families might expect. This booklet will provide consistent, up-to-date and evidenced-based information about how services are currently provided.

This booklet is periodically reviewed and we will continue to improve the booklet in response to your feedback, therefore, let us know what you think...



Finally, and most importantly, we would like to say a huge thank you to all of the families who have contributed to this booklet. This includes families who generously gave up their time to give us feedback on what matters to them, to every family we have met along the way.

Information in this booklet was adapted from: "Choosing Quality Early Childhood Intervention Services and Supports for Your Child: What you need to know" Early Childhood Intervention Australia (2017)