

Guide to Supports and Services for Children and Young People with Disabilities in Laois and Offaly



Forward

On behalf of the Laois Offaly Child and Young Person's Services Committee (CYPSC) Learning and Development Subgroup, we hope the information in this document will benefit you. Supporting disabilities is a key priority for the Laois/Offaly CYPSC committee.

There has been an information gap in supports for disabilities in Laois and Offaly for a long time. We hope this document will go some way to meet that gap in information and empower you as the reader to be supported as you navigate the stages of life in supporting a child or young person with a disability.

Our subgroup is made up of Parents and Service providers. We have been guided by some Parents who have huge experience in navigating the disability sector in preparing this document. Services represented on the subgroup are Offaly County Childcare Committee, Offaly Library Service, Laois Library Service, Laois and Offaly Sports Partnerships, Laois Partnership, Inclusion Ireland, LOFFA, IPPN.

Particular thanks to our researcher Angela Locke Reilly who has vast experience from an academic and family experience of the disability sector in Ireland. We set out originally to compile a listings of disability services. From our in depth conversations with people in many roles we realised that this document was an opportunity to share much more than a listing of services across Laois and Offaly.

Advocacy plays a very big part in supporting a child or young person with a disability. While one may never expect or imagine themselves as an advocate, from a very early stage you begin to realise that you are a champion for your child or young person.

Sincere thanks to the parents and staff working in education and disability services who reviewed the draft and took the time to add their comments, feedback, suggestions and edits. We really appreciate the time you gave to carry out this task so thoroughly from your knowledge of the disability sector. A huge thank you to Claudine Leonard Design who has been so supportive in understanding the design brief for this document and has gone above and beyond her design role and Deirdre Phelan for her support with the document.

Thank you to Westmeath County Childcare Committee who were so helpful as we embarked on this project sharing their disability directory content and experience as they have pioneered the publication of a Disability Directory in the Midlands for Longford and Westmeath and continue to update the valuable resource that they created.

Please see [Section 1.1](#) on how this directory can be used and where to check for updates to the content as over time some of the details may change so we want to try ensure that you are reading the most current information. For updates or edits to this resource over time please contact Laois Offaly Children and Young People Services Committee Co-Ordinator.

Please note this directory was printed in December 2022. So if you are reading it as a hard copy, please check our website www.open-up.ie for any recent updates to the content in this document.

Laois Offaly CYPSC Subgroup supported by Inclusion Ireland



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Section 1

Introduction

1. 1 How can this directory be used?

Welcome!

This directory is designed to be used at different stages of a person's life. It is not meant to be read as a full document, we recommend you scroll through the table of contents and follow the headings which start from birth through to adulthood. At the back of this document is a list of disabilities and relative contact/support groups for each disability.

We do not want to overwhelm you with the size of this document, however we felt it was necessary to have all this information in one place. Although certain sections may be of no interest to you at the moment, it is no harm to know that there is a whole range of organisations and opportunities at different stages of life e.g., Post School Options ([See Section 9](#)).

While it is very daunting getting familiar with all the terminology and roles within services, we hope that this document can act as a guide to explaining and supporting you on the road to understanding the Disability Sector.

Symbols throughout the directory

There are some areas that overlap and that are linked, when you see this butterfly symbol you will know there are other areas that may be of interest to you.



There are also useful tips throughout the document which are indicated by this book symbol.



If you are reading this document online, all the websites featured are hyperlinked so you can click on the links and go to them directly for more information.

1. 2 Parent/Carer Support

It is important as a parent or carer that you feel supported in your role. There are many forms that support can take including community support groups, online forums, one-to-one support, and more informal support from within your own network of family and friends. Whatever your need, be it a friendly phone call, to give advice based on their own experience or something else, there is usually a simple way to receive it and, here, we will guide you on your way.

Please see [Section 4.1](#) for Parent Support Groups in Laois and Offaly.



1. 3 Areas of Disability Covered

- **Physical**
- **Sensory**
- **Intellectual**
- **Learning**

1. 4 Tips for Respectful Communication and Inclusion

- **Speak Directly to the person**

Always communicate directly with the person and not through their personal assistant or companion.



- **Offer to shake hands (unless hygiene restrictions do not allow e.g., due to Covid-19)**

However, some people may not wish to do this so do not be offended if this happens, just move on to the conversation. When meeting a person with a disability, respect them as you would any person.

- **Identify yourself when speaking to a person who is blind**

Always let a person who is blind know that you are there or if you are leaving the space that they are in so that they feel more comfortable.

- **Offer your assistance if appropriate but always wait for a response**

Do not presume that somebody wants or needs assistance. Then listen to the person's response and/or ask for suggestions or instructions.

- **Treat adults as adults**

Do not talk to an adult as though they were a child. Refrain from patronising or condescending language and never make decisions for a person or talk over them. Also do not be over familiar or invade a person's personal space unless they have invited you to.

- **Do not hang or lean on a person's wheelchair**

Wheelchair users often see their wheelchair as a part of them and just as you would not wish a stranger to lean on your limbs or body, they do not appreciate their chair being leaned on or moved unless they have asked for it to be so.

- **Listen attentively**

If a person takes longer to complete a sentence, be patient and wait for them to finish. Do not try to finish the sentence for them or assume you know what they are going to say. Ask for them to repeat it if necessary and never pretend that you understood if you did not. Short questions that require a yes or no answer might sometimes be helpful but remember, they may love to talk! They may not want to only have short yes/no conversations so take your time and listen.

- **Speak to people at eye level**

When speaking to a person who is using a wheelchair then do it at eye level. Sit in a chair or bend down a little to properly include them in the conversation. Also, make room for their wheelchair in the space you are in so that their inclusion is respected and valued.

- **Not Everyone Uses Eye Contact**

Some conditions mean that a person might not feel comfortable making eye contact, that they cannot or simply would rather not. Respect this and never force it. Some people communicate differently and that's ok!

- **Tap a person who is deaf on her/his shoulder**

To get the attention of someone who is deaf, tap the person on the shoulder or wave a hand or nod in her/his direction in a polite manner (you are not hailing a bus!). Once you have the person's attention speak how you normally would without covering your mouth or changing tone or volume. Be aware also that those who are culturally deaf consider sign to be their first language. Do not assume that they read lips or that they would even want to.

- **Congratulate New Parents**

The birth of a child is a happy occasion, and all children deserve their life to be celebrated. If a child has been born with a disability, they may need more support to experience the world, but their presence is as valid and valued as every other child. Welcome them. Congratulate their parents and family. Offer support after a few days if appropriate but for now, smile, there is a new life to celebrate.

- **Language Etiquette**

When referring to a person's condition some people prefer people first language, however in some instances the condition is mentioned first. For example, some people prefer to be called autistic instead of being called a person with autism as they celebrate their autism as an integral part of who they are. Others feel that they are not defined by their autism and wish to be referred to as a person with autism (hence the term person first language). Be immediately willing to adapt to this and respect the individual's identity.


Talking about Down syndrome


 **I am not Downs.**

 **I have Down syndrome.**

 **I do not suffer from DS.**

 **I am a child with Down syndrome.**

 **I am not a Down syndrome child.**

 **I have a learning disability.**

 **I am not handicapped.**

 **I have a genetic condition.**

 **I do not have a disease.**

 **I experience all emotions.**

 **I am not always happy.**

**Please don't forget I am someone's child,
brother, sister, aunt, uncle, loved one.**

I am me.

- **People not Patients**

People with disabilities are not sick. Their condition, sometimes called an impairment, be it physical, intellectual, sensory etc, is a part of them. In some circumstances an illness may be causing or exacerbating their disability but never assume a person is sick just because of their disability. In fact, many people will be hurt or offended to be referred to as such. Also do not refer to a condition as a negative e.g., saying "Joe suffers from Down syndrome". Joe does not suffer from Down syndrome; he HAS Down syndrome.

- **Respect the Individual**

Every person is an individual with their own personal traits and characteristics. Never define a person by stereotypical versions of their diagnosis. All people with the same condition are NOT the same person.

- **Organising social gatherings**

When arranging a gathering ensure that it's inclusive and accessible. This doesn't just mean building access. It can mean sensory (lighting or loud music, for example), dietary (allergies, preferences) and more. Be sure to ask what would make a child's experience better and if their parent, carer, or companion might also need support. Having a chat with staff at a venue can sometimes help too. But, as always, if in doubt just ask! Never EVER leave a child out especially from gatherings such as birthday parties that they will hear about from other children in the playground.

- **Social Media**

When posting an image on a social media account be aware that not everybody can see it and may be consuming their media content via assistive technology such as a reader. So that everyone may enjoy your message add in an image description to let them know what the picture contains. It is really important to remember this if you are putting up a poster with information on it.

When writing hashtags that contain more than one word, capitalise each one so that reader software can recognise individual words. If you do not do this your hashtag will just be a long jumble that makes no sense.

Readers will also read out every single emoji! So, keep that in mind when adding those ten palm trees to your holiday post.

Always remember to add captions to your videos. Some social media platforms will add this automatically but on some you must select it in your settings.

Section 2

The early days

2. 1 Developmental Milestones and Checks



Developmental checks are carried out on babies and young children at different stages in their growth and development. They are to check if the baby is growing according to their age and stage and is reaching their milestones (able to do all that a typical baby or child of that age should be able to do). Checks relate to different areas of development such as physical growth and development and speech and language development as well as sight and hearing.

Please refer to the HSE Website link below for the full guide to Health and development checks and milestones. There you can find out what to expect as your child develops and what happens at their regular health and development reviews.

<https://www2.hse.ie/babies-children/checks-milestones/>

*Table 1 - Physical Developmental Milestones and Language Communication
Developmental Milestones categorised by age*

Age	Physical Developmental Milestones	Language and Communication Developmental Milestones	Checks
0-3 mths	Hold their head up for short periods of time. Respond to your voice. Cry, Coo, Smile Look at faces. Turn their heads towards light. Grows and gains weight	Responds to their name	The Heal Prick Test at birth First developmental check with PHN 6 Week health check with GP Check for developmental dislocation of the hip at 6-8 weeks. Congenital heart disease 6- 8 weeks by GP

Age	Physical Developmental Milestones	Language and Communication Developmental Milestones	Checks
3-6 mths	<p>Kick vigorously</p> <p>Keep their head up with little support.</p> <p>Put weight on their feet when held standing up.</p> <p>Sit with support.</p> <p>Roll from their front to their back.</p> <p>Grab small objects.</p>	<p>Responds to familiar voices.</p> <p>Responds appropriately to friendly or angry tones</p> <p>Vocalisation with intonation</p>	Developmental Checks with Public Health Nurse at 3 months
6-9mths	<p>Baby may understand significant events.</p> <p>Can respond to their name.</p> <p>More mobile – pushing themselves up and rolling.</p> <p>Sit without being held or supported.</p> <p>Attempt to crawl</p> <p>Can hold toys between thumb and forefinger.</p> <p>Continues to grow and gain weight</p>	<p>Understands simple instructions especially when accompanied by vocal and physical cues</p>	

Section 2 | The Early Days

Age	Physical Developmental Milestones	Language and Communication Developmental Milestones	Checks
9-12mths	<p>Pull themselves into a standing position.</p> <p>Attempt walking</p> <p>Use your index finger to poke small objects.</p> <p>Display emotion by holding body stiff when you pick them up.</p> <p>Walk using furniture for support.</p> <p>Begin to stop drooling and putting objects in their mouths.</p> <p>Continues to grow and gain weight.</p>	<p>Uses one or more words with meaning (may be broken words).</p> <p>Is aware of the value of speech</p>	Developmental checks with Public Health Nurse at 9 mths
12-18 mths	<p>Walk with arms out to balance.</p> <p>Carrying objects while walking</p> <p>Crawl up and down stairs.</p> <p>Scribble using crayons.</p> <p>Throw objects to the floor to watch where they fall.</p> <p>Continues to grow and gain weight</p>	<p>Can use up to 20 words.</p> <p>Is able to follow simple commands.</p> <p>Tends to repeat familiar words.</p>	

Section 2 | The Early Days

Age	Physical Developmental Milestones	Language and Communication Developmental Milestones	Checks
18 mths - 24 mths	<p>Becomes more stable on their feet</p> <p>Drags objects along the floor</p> <p>Walks upstairs with help</p> <p>Climbing on furniture</p> <p>Engages with parents and enjoys to help with household tasks</p> <p>Continues to grow and gain weight</p>	<p>Using more words</p> <p>Following simple commands</p> <p>Talking to themselves</p> <p>Use books and holds pencils</p>	Developmental checks with Public Health Nurse between 18 and 24 mths
2 – 3 yrs	<p>Can use the stairs</p> <p>Can use a pencil in the preferred hand to use</p> <p>Continues to grow and gain weight</p>	<p>Engaging in conversations with others</p>	Developmental check with Public Health Nurse between 3 years and 3 years and 6 mths.
4 – 5 yrs	<p>Become responsible for simple self-care such as teeth cleaning, brushing hair etc</p> <p>Becomes more independent</p> <p>Continues to grow and gain weight</p>	<p>Begins to problem solve</p> <p>Can be demanding and asserts themselves</p> <p>Aware and interest of others and their needs</p>	<p>Provisions of services through school years includes:</p> <ul style="list-style-type: none"> • Screening • Immunisation • Health advice • Growth and weight measurement

- Parents or carers can refer to the timelines and look for delays. Remember that each child develops differently and may achieve a milestone at a different time to another child.
- If you feel there is a delay, discuss it with your child's GP doctor or if you have any concerns about your child's development or growth, please discuss this with your Public Health Nurse.
- It is also important to be aware that certain conditions impact developments in growth, motor skills and communication. Children with these conditions, like all children, develop at their own pace and are individuals.
- Not all children with the same condition will develop at the same pace or in the same way and should not be compared with each other. However adapted charts have been developed so that comparison with other typical peers is unnecessary.

Special growth charts* exist for:

Down syndrome	Prader-Willi syndrome
Turner syndrome	Sickle Cell Disease
Marfan syndrome	Achondroplasia
William syndrome	Cerebral Palsy
Noonan syndrome	Wolf Hirschhorn (0-48 months)

* There are many limitations to these special growth charts that affect their accuracy. The percentiles are often based on a small sample size of children with the condition, and the condition may have a variety of associated medical problems that would affect growth. Therefore, some professionals recommend using the standard growth charts for tracking the growth of a child with special health care needs.

Link to growth charts for children with special healthcare needs:

<https://abilitypath.org/ap-resources/growth-and-growth-charts-for-children-with-special-health-care-needs/>

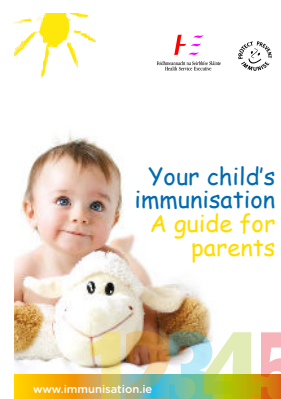
<https://downsyndrome.ie/support-detail/health/>

2. 2 Vaccines for your child

Table 2 - Current Schedule of immunisations categorised by age and Schedule of immunisations for babies born after 01/10/16

Please refer to the HSE website in this link below to learn all about Vaccines for children.

<https://www2.hse.ie/babies-children/vaccines-your-child/>



Schedule 1: Current Schedule			Schedule 2: Schedule for babies born after 01/10/16	
Age	Immunisations	No of Injections	Immunisations	No of Injections
Birth	BCG VIT K	One	BCG VIT k	One
2 mths	6 in 1 PCV	Two	6 in 1 PCV MenB Rotavirus	Three + oral
4 mths	6 in 1 MenC	Two	6 in 1 MenC Rotavirus	Two + oral
6 mths	6 in 1 PCV	Two	6 in 1 PCV MenC	Three
12 mths	MMR PCV	Two	MMR MenB	Two
13 mths	MenC Hib	Two	MenC + Hib PCV	Two
4 – 5 yrs	4 in 1 MMR	Two	4 in 1 MMR	Two
11-14 yrs	T-Dap	One	T-Dap	One
Females in first year of secondary school	HPV	Two doses	HPV	Two doses

For current guidelines about the Covid-19 vaccine details can be found at <https://www2.hse.ie/screening-and-vaccinations/covid-19-vaccine/get-the-vaccine/children>

Section 3

Making Connections

3. 1 Advocating for your family

Sometimes, as parents or carers, it is necessary for us to advocate or speak out for ourselves or for those in our care. It's not always easy, simple, or comfortable but with some guidance and resources you may find it more manageable.

For an additional guide to what advocating for someone else is and how it is best carried out, you can find an easy read guide developed by Inclusion Ireland at

<https://inclusionireland.ie/wp-content/uploads/2020/10/guidetoadvocacy20112.pdf>

3. 1. 1 Know Your Child's Unique Journey

- What barriers does your child face? These can be social, communication, attitudinal, physical, sensorial, educational, or other.
- What might support your child in these areas?
- What opportunities could be helpful for your child?
- Is there assistive technology available that may be appropriate?

3. 1. 2 Communicate with Your Child Frequently

- Involve them in all discussions about them when appropriate or possible.
- Check in with them and ask them what barriers they would like help with.
- Not all children use talking as their first language. Many children will communicate with behaviour, gesture, mood or other. To be your child's voice you must first try to find out what they would like to say.
- As a parent, you are always preparing your child for a time when they will likely be advocating for themselves. Be aware of this but don't become too focused on it or you will add too much pressure to the present task and not every moment needs to be a teachable one. Let them learn what skills they can in a natural way so that they feel empowered, confident and safe to do so.



3. 1. 3 Know Who All the Stakeholders Are

- Who are the decision makers? The key players?
- Can anyone else be brought in to support these people e.g., through training, liaison, advice consultation etc.
- If you wish to contact one of these people, do you know how to do that?

- Do you know what each of these people's roles are and how they are involved in the life and environment of your child?
- What organisation do they work for and what is the staff structure? Who is in charge?

3. 1. 4 Know Your Own Role and Responsibilities

- "Advocacy is concerned with getting one's needs, wants, opinions and hopes taken seriously and acted upon. The Commission believes that advocacy is essential because it allows people to participate more fully in society by expressing their own viewpoints, by participating in management and decision making and by availing of the rights to which they are entitled" (**Report of the Commission on the Status of People with Disabilities**, 1996, p. 106).
- There are many groups you can join to learn about training events or to meet other family members of children with disabilities.
- Consider joining organisations that give you a louder voice, facilitate educational opportunities, lobby, and/or have active social media platforms informing parents about current events. Examples of these include Inclusion Ireland and Family Carers Ireland. ([See Section 4.2](#)).

3. 1. 5 Know Your Rights and Entitlements

- When dealing with an organisation or institution you may ask for their policies and procedures.
- How do you make complaints/appeals in relevant situations?
- Legislation V Policy: Know the difference. Legislation is law, a legal framework of compulsory standards and procedures. An example of this is The Disability Act (2005). Policy is a framework of goals and ideal standards but may be subject to variables such as the economic climate. An example of this is the New Directions policy.
- What is the local, national, international legislation?
- What is the local, national, international policy?
- Can you bring somebody with you to meetings if you need to?
- Inclusion Ireland on How To Complain www.howtocomplain.ie
- **Confidential Recipient** A Confidential Recipient is an independent person appointed by the HSE to receive concerns and allegations of abuse, negligence,

mistreatment or poor care practices in HSE or HSE funded residential care facilities in good faith from patients, service users, families, other concerned individuals and staff members.

3. 1. 6 Question, Record and Save.



- Always bring a notebook and pen to meetings and take notes. Record a note of any phone calls to include time, date, and content.
- Prior to any scheduled communication write down any questions or comments that you want to say. During a discussion it can be easy to forget something important that you wanted to ask.
- Bring relevant documentation if you think it may be needed.
- Ask for as much in writing as possible. If decisions are made over the phone or at a meeting, it is helpful to ask that the key points be summarised and emailed to you.
- Save everything! Sometimes documents such as reports may be needed years later, or you may wish to look at progression over time or for connections in your child's medical history.

3. 1. 7 Communicate Effectively

- Always be clear, concise, and respectful in your communications.
- Keep commentary to the issue at hand and relevant to your child.
- Always summarise the communication at the end. If this is written, then a couple of sentences to frame what you feel the correspondence said. If verbal, then repeat what you feel were the main points and outcomes. This avoids any later misunderstandings or miscommunications.
- If you didn't understand something, then ask for it to be repeated or rephrased until you do.
- If you have support needs around communication, then let those in your child's support circle know so that they can accommodate you in this.

3. 1. 8 Resolving Conflict



- Sometimes disagreements will inevitably happen, but these can be opportunities for growth, if you remember to stay calm, cool, collected, and confident!

- Keep to the issue at hand.

Start with an informal approach, discussing the issue with the people involved. If this doesn't come to a satisfactory conclusion you may then wish to contact management or the governing body of the organisation or institution.

National Advocacy Service for People with Disabilities (NAS)

The National Advocacy Service (NAS) is an organisation which helps adults with disabilities. NAS Advocates provide representative advocacy around the issue you are having.

email: info@advocacy.ie

website: advocacy.ie/

Tel: [0761 07 3000](tel:0761073000)

Patient Advocacy Service

The Patient Advocacy Service is an independent, free and confidential service that provides information and support to people who want to make a complaint about an experience they have had in a Public Acute Hospital or HSE-operated Nursing Home.

email: info@patientadvocacyservice.ie

website: www.patientadvocacyservice.ie

Tel: [0818 293003](tel:0818293003)

Section 4

Getting Support – Community

This section gives contact details for support groups and services for supporting people with a disability and their families, as there are so many, we have broken them into the following categories:

- 4.1 Parent support groups
- 4.2 Community & voluntary supports
- 4.3 Family wellness support locally
- 4.4 Respite services explainer and directory

4. 1 Parent support groups

4. 1. 1 ÁIRC Midlands

Supporting children and young adults with additional needs

Operating in Westmeath, Longford, Offaly and Roscommon (currently developing a Laois committee) Áirc Midlands supports children and their whole support circle, which may include family, friends, professionals, babysitters etc. They take additional need to include disability, long term illness and autism. Supports include inclusive and accessible family events and activities, workshops, information days, training events for support staff, disability awareness training, liaising and collaboration with other organisations and statutory bodies, emergency respite and equipment grants.



Support	ÁIRC Midlands		
Purpose	Support organisation for children with any disability and their family and friends. Offer a range of supports including emotional, educational financial and social.		
Phone	085 1194041	Email	aircmidlands@gmail.com
Facebook	www.facebook.com/aircmidlands		

4. 1. 2 Down Syndrome groups in Laois and Offaly

The Down Syndrome Centre Midlands (DS Centre Midlands)

DSC Midlands operates out of Portlaoise and provides essential services, information, and support to people with Down syndrome and their families in Laois, Offaly, and Kildare. They have an active social media presence, and the main DSC website is a fantastic resource. It hosts information for parents (including new or expectant parents) and schools and features personal blogs and articles by professionals.

Support	The Down Syndrome Centre Midlands (DSC Midlands)		
Purpose	Support organisation for People with Down syndrome and their families.		
Phone	(087) 173 4767	Email	dscmidlands@gmail.com
Facebook	www.facebook.com/downsyndromecentremidlands		

Laois Down Syndrome

Laois Down Syndrome was established in 1995. It is one of 25 Branches countrywide under the umbrella of our national body Down Syndrome Ireland (DSI). Laois Down Syndrome operates independently under the Constitution of our national body. The Branch has no employees and all Branch work is done by volunteer Parents and siblings of our members with Down Syndrome. The Branch operates solely through voluntary donations from the general public in Laois and fundraisers by individuals and organisations around the county.



Support	Supports include heavily rebated Occupational Therapy, Speech and Language Therapy, Physiotherapy, Chiropody, Reflexology, Family Counselling Services, Swimming lessons, to name a few. These supports are delivered from our Laois Down Syndrome Family Centre in Gort Na nOir Abbeyleigh. We host family outings and events all year round.		
Purpose	Laois Down Syndrome operates a whole family support system including siblings and any other significant people in the lives of our members with Down Syndrome.		
Facebook	https://www.facebook.com/laoisdownsyndrome		
Phone	086 8279942 086 0491633	Website	http://www.laoisdownsyndrome.ie/ or www.downsyndromeireland.ie national website

Offaly Down Syndrome Ireland (Offaly DSI)

Offaly DSI is a parent led group that provides supports for people with Down Syndrome and their families. They facilitate social events, activities and provide home resource teaching hours. Their meetings are monthly, and they strive for the empowerment of people with Down syndrome, supporting parent led advocacy but leading with the support of self-advocacy.



Support	Offaly Down Syndrome Ireland (DSI)		
Purpose	Support organisation for People with Down syndrome and their families.		
Facebook	www.facebook.com/downsynoffaly		
Phone	(089) 605 8346	Email	chair@dsoffaly.org

4. 1. 3 Laois Offaly Families for Autism

Laois Offaly Families for Autism (LOFFA) is a local midlands-based group ran by parents of autistic children and adults. They provide health, educational and support services including subsidised access to therapies, accessible social activities for children, sibling events and parent support groups. They are currently running monthly in person meetings.



Support	Laois Offaly Families for Autism (LOFFA)		
Purpose	A parent led support group for families of autistic children, teens and adults.		
Meetings	Advertised on Facebook	Email	info@loffa.ie
Facebook	www.facebook.com/laoisoffalyfamiliesforautism		

4. 1. 4 Laois and Offaly ADHD Parent Support

A parent led support group that supports parents of children with ADHD as either a primary or secondary diagnosis. Their active Facebook page provides both support and information on current events, news and other matters regarding ADHD and community.



Support	Laois and Offaly ADHD Parent Support		
Purpose	Supporting parents of children with ADHD		
Phone	(085) 7833764 Seona (085) 246 1983 Bernadette	Email	Laoisoffalyadhdparentgroup@gmail.com

4. 1. 5 Laois Arch Club

Support	Laois Arch Club		
Purpose	To provide a positive supportive friendly secure social environment for people		
Phone	087 683 6156	Email	laoisarchclub@gmail.com

4. 1. 6 Bravehearts Portarlinton

Support	Bravehearts Portarlinton		
Purpose	Social Inclusion Club		
Phone	086 847 1994	Facebook	https://www.facebook.com/Brave-Hearts-1678047042242405

4. 2 Community & voluntary supports**4. 2. 1 Inclusion Ireland****Inclusion Ireland**

The National Association for People with an Intellectual Disability.

Inclusion Ireland is a national rights-based advocacy organisation that promotes the rights, independence, dignity, and equality of people with an intellectual disability and their families. The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Their website publications all include easy read versions in plain English and their research, workshops and conferences are informed and led by people with disabilities such as their recent *19 Stories of Social Inclusion*. Through their Connect Family Network they are working to bring about greater participation of people with an intellectual disability and their family members in the design and delivery of disability services and supports. This network is your opportunity to connect with other families, learn information and skills to support you, and have your voice heard.

Go to: www.inclusionireland.ie or Tel: 01 855 9891

4. 2. 2 Family Carers Ireland - Laois/Offaly (National Office)

Family Carers Ireland seeks to provide supports for the caring community “promoting the health, wellbeing and quality of life of family carers and those for whom they carer”. They provide supports such as respite breaks, educational workshops, and courses, facilitate peer supports and provide information on rights and entitlements, among many other services.



On their website you can also find their publications including reports on national services.

Support	Family Carers Ireland		
Purpose	Support organisation for those who care for a loved one such as children or adults with a disability, those with palliative care needs or those living with chronic illnesses, mental ill health or addiction.		
Phone	057 9322920	Email	bwogan@familycarers.ie
Facebook	www.facebook.com/familycarers		
Website	www.familycarers.ie		
Address	Market Square, Tullamore, Co Offaly, R35 PW50		

4. 2. 3 Disability Federation of Ireland

email: info@disability-federation.ie

website: www.disability-federation.ie

Tel: [01 454 7978](tel:014547978)



4. 2. 4 Dyslexia Groups

Offaly Dyslexia Group provides supports and information for children and adults with Dyslexia. They facilitate workshops, for both children and parents, meet ups, activities, a parent support line and work towards a more aware community in the local area.

Support	Offaly Dyslexia Group (ODG)		
Purpose	Support organisation for children and adults with Dyslexia.		
Phone Gen Enquiries	086 2309009	Email	hello@offalydyslexiagroup.org
Phone	Laois Offaly ETB for evening classes for people with Dyslexia (Tullamore) 057 9349 424		

4. 2. 5 SAGE Advocacy

A national organisation that provides free independent advocacy and support services to older people, adults who may be vulnerable and healthcare patients.



4. 3 Family wellness supports locally

4. 3. 1 Local Special Olympics Clubs

The Special Olympics are a sports organisation that facilitates and promotes sport for people with intellectual disability, aged four and over. Representing almost 8000 athletes across 15 sports and all counties they provide the opportunity to nurture a healthy mind, body and soul through sports, health, and leadership programmes. Local clubs are also a great way for young people and their families to meet their peers and make lasting friendships.



There are a number of Special Olympics Clubs listed in the table. If you contact Special Olympics Ireland, they will direct you to these clubs.

Sport	Special Olympics Ireland		
Purpose	Sport organisation for people with intellectual disability		
Phone Head Office	01 882 3972	Email	info@specialolympics.ie
Leinster	01 629 6999	Email	leinster@specialolympics.ie

Name of Special Olympics Club:	Activities provided:
Ballinamere	<ul style="list-style-type: none"> Swimming club at Clara Swimming Pool Athletics at Tullamore Harriers Athletic Stadium Kayaking at Tullamore Canoe Club
Camcor Warriors Special Olympics Club	<ul style="list-style-type: none"> Athletics at Crinkle Sports and Recreation Hall Swimming at Birr Leisure Centre
Kare Edenderry Local Services	<ul style="list-style-type: none"> Swimming at Edenderry Swimming Pool (not a club open to the general public)
Tullamore Special Olympics Club	<ul style="list-style-type: none"> Horse Riding at Annaharvey Farm Equestrian Centre Football at Tullamore Harriers Tenpin Bowling at Cosmic Bowl, Tullamore

4. 3. 2 The Local Sports Partnerships

The Sports Partnerships were set up under Sport Ireland to develop and promote sport in local communities. Sport Inclusion Officers work to facilitate sporting activities that are inclusive and accessible in the framework of their Sports Inclusion Disability (SID) Program (and for other communities that find barriers to participation in sport). Their website includes great downloadable content for you to learn more such as Sport for All (guidelines for inclusion), The Benefits of Physical Activity and Exercise, and their Disability Plan. The Laois Sport Inclusion Officer is Catriona Slattery and the Offaly Sport Inclusion Officer is Jean Brady.



Sport	Laois Sports Partnership		
Purpose	The development and promotion of physical activity and sports in the Laois area		
Phone	057 867 1253	Email	info@laoissports.ie
		Website	www.laoissports.ie

Sport	Offaly Sports Partnership		
Purpose	The development and promotion of physical activity and sports in the Offaly area		
Phone	(057) 935 7462	Email	info@offalysports.ie
		Website	www.offalysports.ie

4. 3. 3 Parents First CLG (Laois/Offaly)

Parents first is an organisation that provides support for parents of young children in the form of an early intervention model, with practical and natural support mechanisms. They seek to address issues such as social isolation, loneliness and depression and strive to empower parents to provide a positive and nurturing environment for their family.



Support	Parent First (Laois/Offaly) CLG		
Purpose	To support parents of young children		
	(086) 1959 221		
Phone	(057) 9322 996	Email	office@parentsfirst.ie

4. 3. 4 Family Resource Centres

Portlaoise Family Resource Centre	Childcare, Training, Support Groups, Counselling, Holistic Therapy, Youth Work	Joan Bolger	057 868 6151 manager@portlaoisefrc.ie	Portlaoise Family Resource Centre , Harpurs Lane, Knockmay, Portlaoise, Co.Laois
http://www.portlaoisefrc.ie/				
Mountmellick Youth and family Resource Centre	Family support, groupwork, homework clubs	Michael Farrell	057 826 24525 mydc@mdaltd.ie	Moutmellick Development Association, Irishtown, Mountmellick, Co. Laois.
http://www.mountmellickdevelopment.com/m-y-d-c.htm				
Clara Community and Family Resource Centre	Counselling, homework, targeted support group, Youth Zone, Carers Support Group	Liz Fleming	(057) 933 1928 coordinator@clarafrfc.ie	Clara Community and Family Resource Centre, Clara, Co. Offaly
Arden View Family Resource Centre	Community Counselling, Women's Groups, Men's Shed, Parent and Toddler, Triple P	Margaret Murphy	0579320598 coordinator@tfrc.ie	223 Arden View, Tullamore, Co Offaly R35 AD82

4. 4 Day Centres, Residential and Respite Services

A number of organisations provide these various services in Laois and Offaly. They are provided and managed by private, voluntary (charitable) and public organisations.

- **Day centres** provide a range of services. They include social and rehabilitative services, recreational services, sports and leisure facilities and a combination of medical and rehabilitative services.

Day Services	AVISTA Disability Support Services (South Offaly and Tipperary) & Sean Ross Villas: St Anne's Centre, Sean Ross Abbey Roscrea, Co. Tipperary	Tel: 0505 22046
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- **Residential services** provide accommodation for people with a disability who are unable to live in their family home. In most cases a financial contribution will be made by an adult with a disability.

Residential Services	<ul style="list-style-type: none"> • St. Anne's Community Residential Services & Sean Ross Villas • Clochán House
<p>Clochán House is a newly refurbished Residential Respite Centre located on the HSE grounds in Tullamore, Co. Offaly.</p> <p>It provides a respite service for leaders who have a sensory or physical disability ages between 18 and 65 years of age.</p>	

- **Respite care service** provides alternative family or private care to allow the individual with a disability, carer, or parents to have a short break, holiday, or rest. It can vary in length, from a few hours to a number of days/nights. There are schemes called share a break or home sharing where the person with additional needs goes to stay with another family who can provide for their needs.

Respite Services	<ul style="list-style-type: none"> • Claddagh Children's Respite • Hillside Adult Respite House • Host Carers - Home Sharing i.e., The Muiríosa Foundation
The Muiríosa Foundation: This offers services to children and young adults with moderate to severe intellectual disability including the home sharing model of respite where individuals are matched with host families. They share a break in a family environment that promotes self-direction, friendships, and future support networks.	
Home Sharing – Laois & Offaly Muiríosa Foundation Triest House, Lea Road, Portarlinton, Co. Laois. R32 PX65	Tel: 057 8623055

- **Independent living supports**, (also known as the Person Centred Wing or Supports) promotes, and enables equal opportunity and choice for people with disabilities. Independent living advocates for full participation in society and achieves this by working in partnership with people with disabilities by supporting and developing skills. It is generally funded through the HSE and administered through various service providers.

Offaly Independent Living Movement Ireland	
Clonminch Rd, Tullamore, Co Offaly	Tel: 057 932 7632

- Outreach work identifies and highlights services within the community, to people with disabilities that may support that person.

4. 5 Mental Health Support

4. 5. 1 What is it?

Mental health difficulties can affect how we think, feel and act; they can affect moods and behavior.

A mental health problem occurs when someone's thoughts or feelings are troubling them, to the extent of affecting their day-to-day activities or relationships.

4. 5. 2 When to get help for low mood or depression

If negative feelings don't go away you may need to make some changes and get extra support.

If you're still feeling down after a couple of weeks, talk to your GP. Your GP can discuss your symptoms with you and signpost you to other supports or services.

4. 5. 3 What types of help are available?

If you're diagnosed with depression your GP will discuss treatment options with you. These options include self-help, talking therapies and antidepressants, and a range of approaches to support your wellness.

4. 5. 4 Self-help

Whether you have depression or find yourself feeling down for a while, it could be worth trying some self-help techniques.

Life changes can help you feel more in control and more able to cope.

For example:

- getting a regular good night's sleep
- reducing alcohol intake
- increasing the amount of exercise you do

Self-help techniques include activities like meditation.

Tools such as self-help books and online counselling can be very effective.



4. 5. 5 Talking therapies

There are lots of different types of talking therapies available. To decide which one would most suit you, talk to your GP or read about the different types of talking therapies.

<https://www2.hse.ie/wellbeing/mental-health/therapies-talking-and-self-help/talking-therapies.html>

Reference: yourmentalhealth.ie



4. 5. 6 Supports

For some people it may be difficult to talk about mental health, but it can help to talk about how you are feeling. People you can talk to might include friends, family, counsellor, or GP. Most national helplines will provide a listening service, give information and advice, provide emotional support, and point you in the direction of other services.

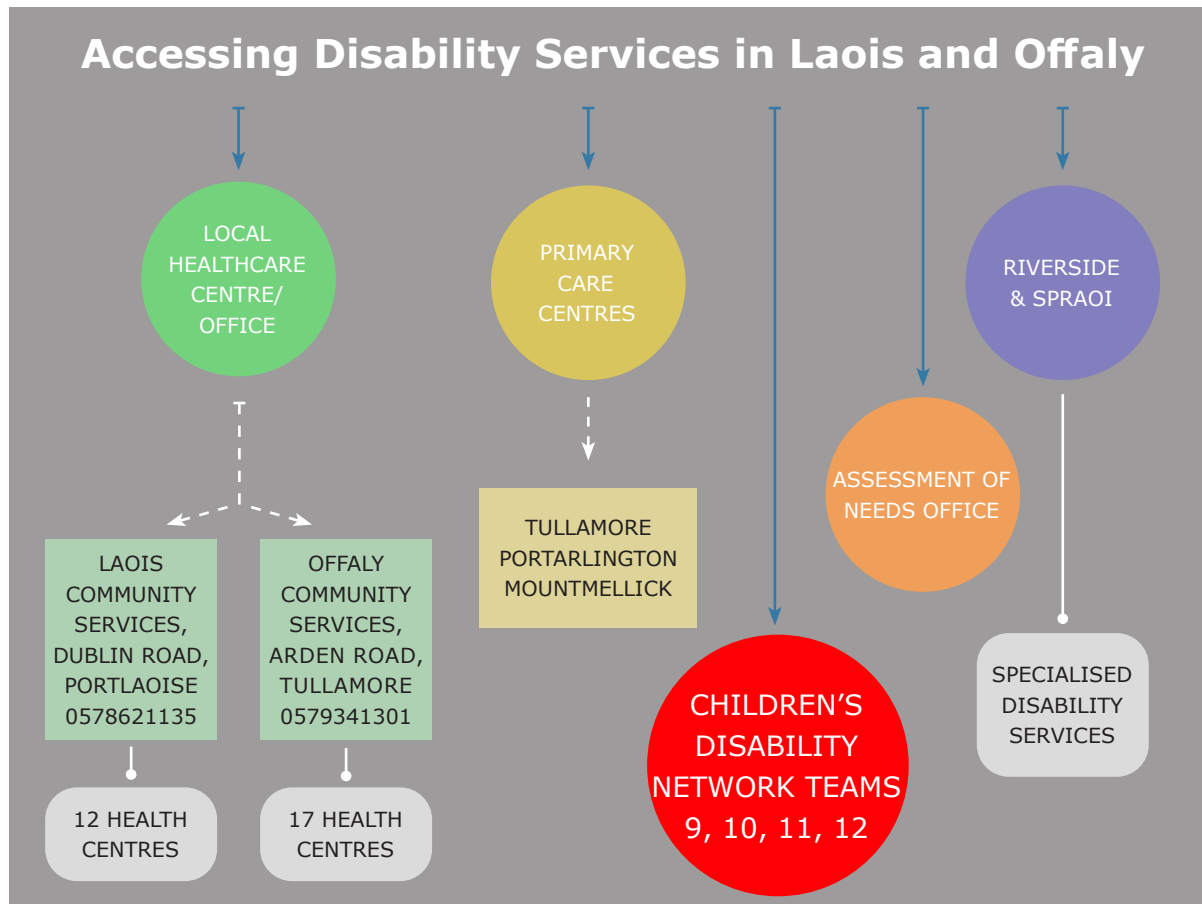
Local Mental Health Supports	
St. Fintan's Hospital, Portlaoise	Tel: 057 862 1364
Community Mental Health Birr	Tel: 057 912 0540
Community Mental Health Portlaoise	Tel: 057 862 2925
Community Mental Health Tullamore	Tel: 057 931 5900
Community Mental Health Rathdowney	Tel: 0505 46560
Child and Adolescent Mental Health Services (CAMHS) Portlaoise	Tel: 057 869 6152
Child and Adolescent Mental Health Services (CAMHS) PCT Tullamore	Tel: 057 931 9400
Suicide Resource Office	Tel: 086 815 7850
Community Psychology Services Tullamore	Tel: 057 931 9599
Community Psychology Services Portlaoise	Tel: 057 869 2564 or Tel: 057 869 2598
Jigsaw Laois/Offaly, Cormac St, Tullamore, Co Offaly, R35 XH74	Tel: 057 935 2871
Accessible Counselling Tullamore	Tel: 057 935 2879

National Mental Health Support Services		
The Samaritans: Emotional support	116123 – Freephone Email: jo@samaritans.ie	www.samaritans.org
SpunOut.ie: Youth information website	01 6753554	www.spunout.ie hello@spunout.ie
Teenline Ireland Helpline: Teen emotional support	1800 833 634 Freephone 24 hour or Free Text: Teen to 50015	www.teenireland.ie
Pieta House: Suicide and self harm	01 623 5606 Dublin 09064 24111 Athlone	www.pieta.ie info@pieta.ie
Childline: Child emotional support	1800 666666 – Free phone	www.childline.ie
Grow: Mental health support and recovery	1890 474 474	www.grow.ie
IACP: Counselling and Psychotherapy	01 230 3536	www.iacp.ie
Aware: Depression, bi-polar, anxiety	1800 80 48 48 - Free Phone	www.aware.ie
Shine: Mental health supports	01 5413715	www.shine.ie
Reachout.com- Online youth and mental health service	01 764 5666	general@reachout.com
Bodywhys – Eating disorders association of Ireland	01 2107906 Helpline 01 2834963 Office	www.bodywhys.ie info@bodywhys.ie
Irish Advocacy Network: Peer advocacy in mental health	01 872 8684	www.irishadvocacynetwork.com admin@irishadvocacynetwork.com
Mental Health Ireland: mental health supports	01 284 1166	www.mentalhealthireland.ie info@mentalhealthireland.ie

Section 5

Getting Support – HSE

5. 1 HSE Structure of Supports & Services



5. 1. 1 First Point of Contact

If you are worried that your child is developing in a delayed manner or may have a disability you should speak to your GP or Public Health Nurse. Depending on the concerns and age, your child may be referred to Children's Disability Network Team or another service more appropriate to the needs of the child. See page 53 for the referral form and how to make a referral, and page 52 for a list of the areas covered by each CDNT team.



*For the purposes of this document a child is referred to as a 0-18 year old.
A young adult is an 18-24 year old.*

5. 1. 2 Public Health Nurse (PHN)

Your public Health Nurse is based in the local health office. For information on the role of the Public Health Nurse please see here

<https://www.hse.ie/eng/services/list/1/lho/laois-offaly/public-health-nursing/>

Initial contacts may be made with the Local Health Office at the following contacts in Laois and Offaly:

Laois Health Offices	
Abbeyleix Health Centre, Public Health Nurse & Dental, Abbeyleix, Co. Laois	Tel: (057) 875 7196
Abbeyleix Health Centre, GP, Abbeyleix, Co. Laois.	Tel: (057) 873 1359
Abbeyleix Health Centre, Abbeyleix, Co. Laois	Tel: (057) 873 1649
Ballylynan Health Centre, Ballylynan, Co. Laois	Tel: (059) 862 5009
Borris-in-Ossory Health Centre, Public Health Nurse/GP, Borris-in-Ossory, Co. Laois	Tel: (050) 541172
Clonaslee Health Centre, Clonaslee, Clonaslee, Co. Laois	Tel: (057) 864 8033
Clonaslee Health Centre, GP, Clonaslee, Co. Laois	Tel: (057) 864 8170
Durrow Health Centre, GP, Durrow, Co. Laois	Tel: (057) 873 6585
Durrow Health Centre, Public Health Nurse, Durrow, Co. Laois	Tel: (057) 873 6133
Mountmellick Primary Care Centre, Connolly Street, Mountmellick, Co. Laois.	Tel: (057) 869 7500
Mountrath Health Centre, Public Health Nurse, Mountrath, Co. Laois	Tel: (057) 873 2422
Mountrath Health Centre, Mountrath, Co. Laois	Tel: (057) 873 2203
Mountrath Health Centre, GP, Mountrath, Co. Laois	Tel: (057) 873 2203 or in case of emergency: Tel: (087) 2511847
Portarlington Primary Care Centre, Community Welfare Office, Kilnacourt House, Bracklone Street, Portarlington, Co. Laois	Tel: (057) 868 4202
Portarlington Primary Care Centre, Dental, Kilnacourt House, Bracklone Street, Portarlington, Co. Laois	Tel: (057) 868 4203
Portarlington Primary Care Centre, PHN, Kilnacourt House, Bracklone Street, Portarlington, Co. Laois	Tel: (057) 868 4200
Portlaoise Health Centre, Portlaoise, Co. Laois	Tel: (057) 862 1135
Rathdowney Health Centre, Public Health Nurse & Community Welfare Officer & Dental, Rathdowney, Co. Laois	Tel: (050) 546276
Stradbally Health Centre, Public Health Nurse & Community Welfare Officer, Stradbally, Co. Laois	Tel: (057) 862 5415

Offaly Health Offices	
Banagher, Primary care Centre, Banagher, Co Offaly R42 XW40	Tel: (057) 915 1247
Birr Health Centre, Birr, Co Offaly.	Tel: (057) 912 0486
Blueball Health Centre, Pallas, Blueball, Co. Offaly.	Tel: (057) 935 4044
Clara Health Centre, The Green, Clara, Co. Offaly.	Tel: (057) 933 1242
Cloghan Health Centre, Castle Street, Cloghan, Co. Offaly.	Tel: (090) 645 7119
Clonbullogue Health Centre, Clonbullogue, Co Offaly, R45 P381	Tel: (0469) 730 9109
Cloneygowan Health centre, Tullamore, Co Offaly	Tel: (057) 934 3552
Daingean Health Centre, Main Street R35, Daingean, Co Offaly.	Tel: (057) 935 3142
Edenderry Health Centre, Ofalia House, St. Mary's Street, Edenderry, Co. Offaly.	Tel: (046) 973 3517
Ferbane Health Centre, Ferbane, Co Offaly, R42 PK22.	Tel: (090) 645 4916
Kilcormac Health Centre, Freagh, Kilcormac, Co. Offaly.	Tel: (057) 913 5030
Kinnity Health Centre, Castletown, Kinnity, Co. Offaly.	Tel: (057) 913 7061
Moneygall Health Centre, Moneygall, Co Offaly, E53 FC92.	Tel: (0505) 45272
Rhode Health Centre, Rhode, Co Offaly, R35 DK16.	Tel: (046) 9737955
Shinrone Health Centre, Roscrea Road, Shinrone, Co. Offaly.	Tel: (0505) 47312

Local Health Office: The Local Health Office works with a range of voluntary services in the area of Offaly and Laois to provide care, training and development for children and adults with a learning or physical disability.

5. 1. 3 Progressing Disability Services Rollout

- A national program called 'Progressing Disability Services for Children and Young People' is evolving the provision of services in Ireland so that they can be accessed by children equitably and consistently no matter their circumstance or location.
- According to HSE Children's Disability Services, known now as Children's Disability Network Teams, the aim is to provide for easy access to services, equity of service provision (everyone gets what they need regardless of diagnosis or living situation), and that it would be a collaborative effort joining families, schools, community and disability service providers.

- The Progressing Disability Services program is currently being implemented across all counties. These services are replacing the traditional Early Intervention and School Age Teams. *Previously services were set up to work with children aged 0-5 known as the Early Intervention Team and the School Age team for those over age 5. These teams are no longer in place and are replaced by the Children's Disability Network Teams for 0-18 year olds.* As the service delivery model is rolled out a child will remain in the same pathway until adulthood ensuring a continuum of care.

5. 1. 4 The HSE Support Pathways for Children with Disabilities

Primary Care Teams – Many children with delays in development can have their needs met by their local general practice services also known as Primary Care Teams who work in a multi-disciplinary framework and incorporate outside community support if their need is identified. Teams may include (but are not limited to) the Public Health Nurse (PHN), Speech and Language therapist (SLT), family doctor/ GP, Dietician, Occupational Therapist (OT) or physiotherapist. Laois/Offaly Primary Care teams are located in Primary Care Centres Tullamore, Portarlinton and Mountmellick.

Table - Laois/Offaly Primary Care Centres

	Location	Phone Number
Primary Care Centre Tullamore	Primary Care Centre, Church View, Tullamore, Co. Offaly. R35 K1W4	057 9319599
Primary Care Centre Portarlinton	Primary Care Centre, Kilnacourt House, Bracklone Street, Portarlinton, Co. Laois. R32 Y038	057 8684200
Primary Care Centre Mountmellick	Mountmellick Primary Care Centre, Connolly Street, Mountmellick, Co. Laois. R32 E704	057 8697500
Primary Care Centre Portlaoise	Primary Care Centre Portlaoise Spraoi Building, St. Fintan's Campus, Dublin Road, Portlaoise, Co. Laois, R32 XENO	

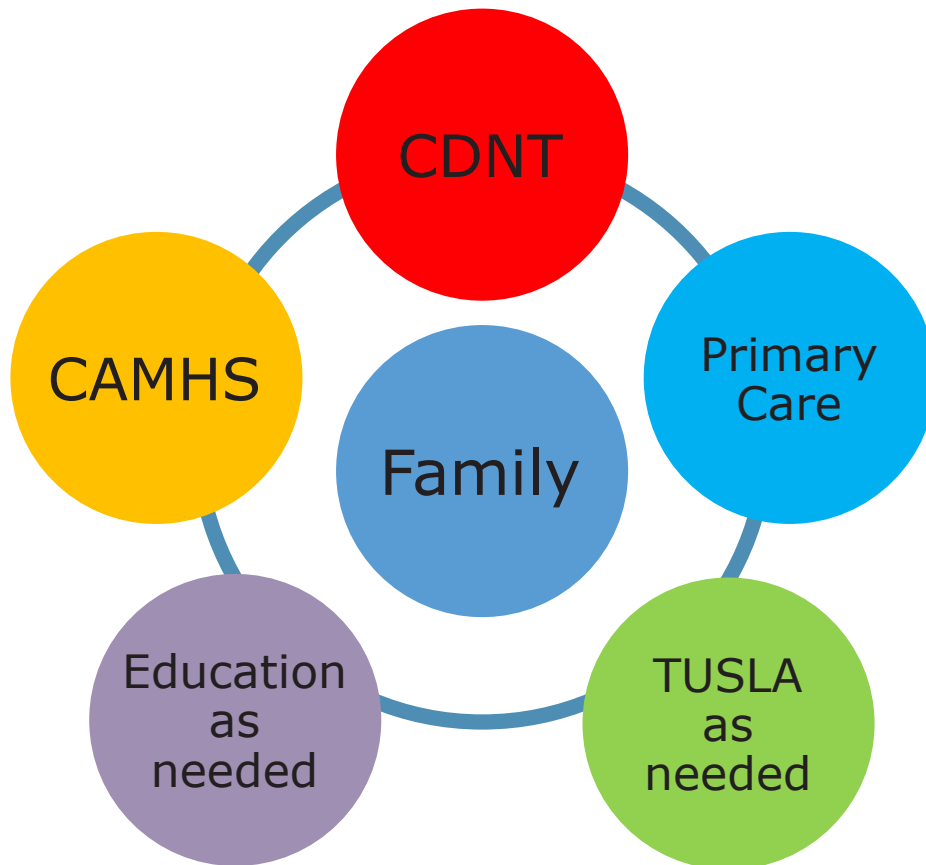
Children’s Disability Network Teams – Children’s Disability Network Teams are interdisciplinary teams supporting children with complex support needs and their families, regardless of the child’s diagnosis or where he or she goes to school (e.g., mainstream, special education etc.)

Table - Laois/Offaly Children’s Disability Network Teams

	Areas covered:	Contact details:	Locations
CDNT 9 Clonbrusk Children’s Disability network Team	Athlone, Moate, Ferbane	Tel: 090 64 71118 Email: clonbrusk. cdnt@hse.ie Link Person (CDNM): Sinead Power	Arcadia, Clonbrusk, Athlone, Co. Westmeath, N37 P8P8
CDNT 10 Riverside Children’s Disability Network Team	Tullamore, Daingean, Clara, Banagher, Birr, Shinrone.	Tel: 057 93 66300 057 86 96970 Email: riverside. centre@hse.ie Link Person (CDNM): Linda Ryall	Riverside Centre, Riverside, Tullamore, Co. Offaly, R35 EE33
CDNT 11 Barrow Children’s Disability Network Team	Portarlinton, Mountmellick, Edenderry, some of Geashill, Rosenalis, Rhode and Daingean	Tel: 086 4649397 Link Person(CDNM): Wendy Von Mullendorf Email: barrow.cdnt@ hse.ie	Spraoi Building, St. Fintan’s Campus, Dublin Road, Portlaoise, Co. Laois, R32 XENO
CDNT 12 Spraoi Children’s Disability Network Team	Portlaoise, Stradbally, Mountrath, Borris-in-Ossary, Abbeyleix, Ballickmoyler.	Tel: 057 86 96945 Link Person (CDNM): Nicole Dyrssen Email: Spraoi.cdnt@ hse.ie	Spraoi Building, St. Fintan’s Campus, Dublin Road, Portlaoise, Co. Laois, R32 XENO

Integrated Children’s Services Forum - When it is unclear which service will best support your child or when joined up services are the most appropriate then representatives from each service will discuss it together. This is so your child gets support that suits their individual support needs. It is called the Integrated Children’s Services Forum.

Integrated Children's Services Forum Diagram: sample of the professionals who may meet to identify the best pathway of support for an individual. Some children might also be attending CAMHS, TUSLA, Mental Health Intellectual Disability Services, therefore it is important for the forum to work together to support the child and family.



5. 2 Access to Referrals

5. 2. 1 How to make a referral?

The Children's Disability Network Team Manager accepts referrals from Parents, GPs, PHN, Early Years or other Care and Health Professionals. The referrals are for children with queried developmental needs, who are having trouble in their ability to function successfully across a variety of environments.

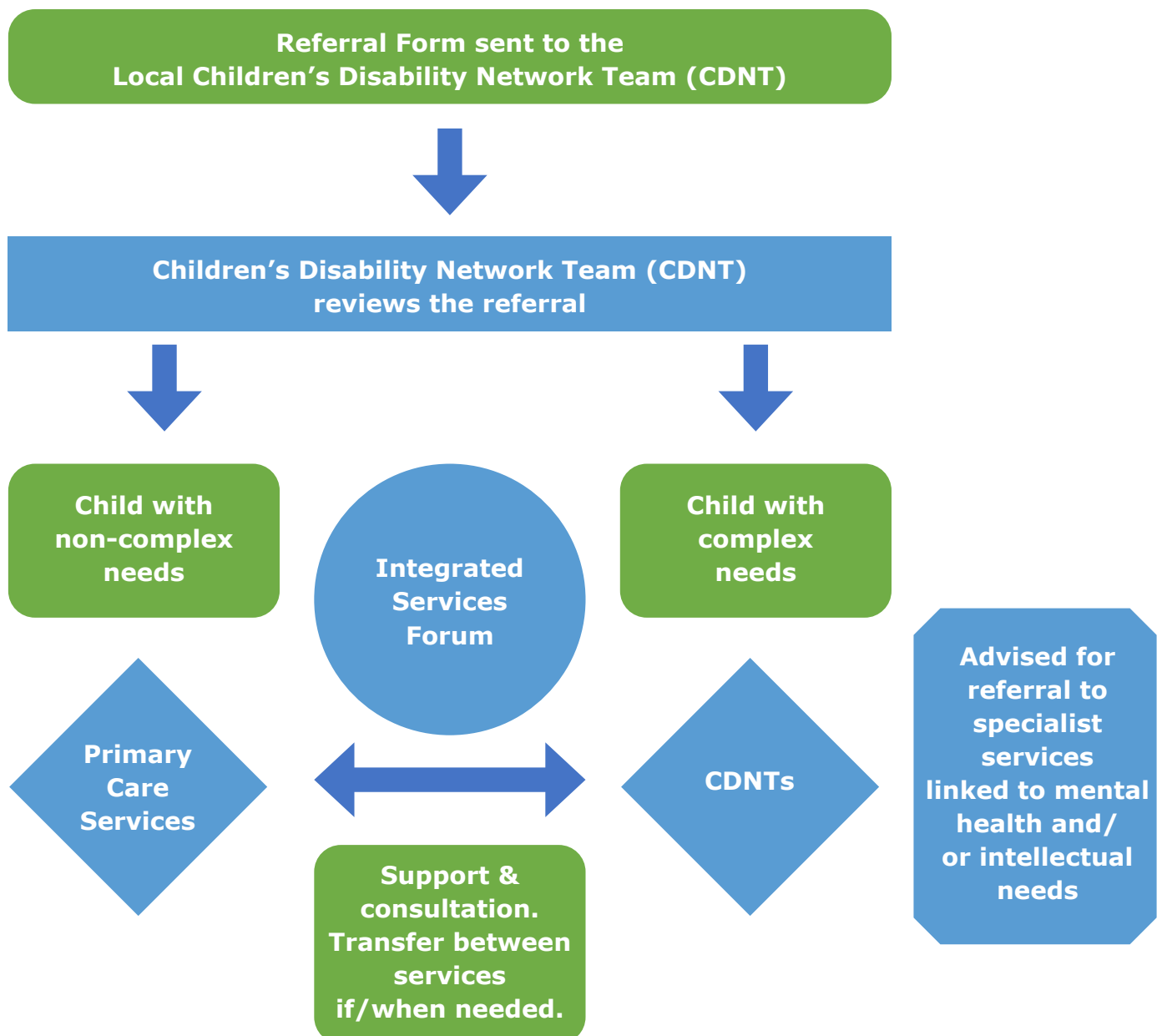
Referral forms:

<https://www2.hse.ie/services/disability-support-and-services/childrens-disability-services/get-a-referral-for-childrens-disability-services.html>

5. 2. 2 What happens after making a referral?

Following referral, the Children’s Disability Network Team Members will review the information contained within the referral forms to talk about the most appropriate service for the child. It might be that another service is more appropriate and that CDNT can help the referral to the right place, e.g. Primary Care, speech and language therapist, occupational therapist, psychologist or physiotherapist, or CAMHS. Referral to CAMHS must come through the GP to CAMHS. Once a decision is reached you will receive communication from the CDNT or Primary Care or both.

5. 2. 3 Progressing Disabilities Service Pathways of support





5. 2. 4 What area do you link with for services?

The Midland counties of Laois, Offaly, Longford and Westmeath are divided into 6 CDNT areas. You will link with the CDNT area that you live in. HSE staff are assigned to these areas. Each CDNT area is made up of the following staff with different professions.

For more information about the new services check out <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/> The CDNT works as an interdisciplinary team using a family centred approach. The team supports the child and family based on the needs and priorities, usually outlined in the individual family support plan. The members of the team include a number of professions as per the diagram. Any member of the team may work with a child/family based on the needs.

5. 3 The Professional's Roles

5. 3. 1 Occupational Therapy

- An occupational therapist (commonly referred to as an O.T) assesses your child, their environment and their goals and helps them to interact within them.
- They will construct a programme that will focus support on what your child finds difficult based on their individual support needs, independence, and environment. This environment could be school, home or in their community.
- They can be of great assistance in supporting life skills, such as hygiene, eating, dressing, learning, shopping, sport etc.
- They may work in collaboration with other team members e.g. your physio therapist to support mobility and access.
- Your O.T can also be a great support in obtaining equipment, adaptations (home, car etc), software, or assistive technology.
- You can show a copy of the programme individually developed for your child to other people within their support circle such as their teacher, SNA, bus escort, family members etc. It can be very helpful to have everyone on board.
- As always, maintain open communication with your child and allow them to have input and give feedback.

If you wish to get private sessions with an O.T you can find a list of accredited professionals and suggested qualifications on the CORU website:

<https://coru.ie/check-the-register/>

5. 3. 2 Physiotherapy

- A physiotherapist supports your child in the areas of movement and function.
- They will assess your child addressing areas of difficulty or delay caused within the body (bones, muscles, or nervous system).
- They will construct a programme that will support your child to either develop in these areas or to manage/adapt to them.
- The field of physiotherapy includes expertise in the processes involved and required to develop mobility, so consistency and continuity are important aspects of a physio programme i.e. it may take time, commitment and dedication but stick with it and keep regular contact with the therapist.

- Ask your physiotherapist to show you ways to fit physiotherapy into your daily routine or activities (they will probably suggest this to you themselves). Make it fun and mix it up. It's not always about exercises. It can be about all types of functional movement including dance, cooking, play, sport and lots more.
- You can show a copy of the programme individually developed for your child to other people within their support circle such as their teacher, SNA, bus escort, family members etc. It can be very helpful to have everyone on board.
- As always, maintain open communication with your child and allow them to have input and give feedback.

If you wish to get private sessions with a Physio you can find a list of accredited professionals and suggested qualifications on the CORU website:

<https://coru.ie/check-the-register>

5. 3. 3 Speech and Language Therapy

- A Speech and Language Therapist (often referred to as an SLT) helps by supporting your child in the areas of communication and feeding.
- They will assess your child's needs and long-term goals, and then development a programme split into a development process of smaller short terms goals.
- They can be of support in many areas including social interaction, sign, speech, chewing, swallowing, expression, language, and lots more.
- They can assist you in obtaining visuals, software, equipment, adaptations, or assistive technology that will support your child's communication and feeding, or assessments such as for hearing or feeding.
- They may liaise with the school or other support services so that your child's communication needs are supported.
- Sessions may be one-to-one or group sessions depending on your child's needs and preference. Group sessions can be great fun especially if music, dancing, or drama is involved.

If you wish to get private sessions with an SLT you can find a list of accredited professionals and suggested qualifications on the CORU website:

<https://coru.ie/check-the-register>

5. 3. 4 Dietician

- A dietician assists your child in developing a healthy diet that meets all of their needs.
- A dietician must consider lots of parts of a child's life including weight management, feeding method, lifestyle, exercise, immune system, mobility, medical conditions etc.
- A dietician works closely with all members of the support circle including healthcare professionals, school, therapists, social worker, and family (natural supports).
- Diet is of great importance for all growing children but may have particular focus if your child has weight management issues, alternative or adaptive feeding methods, or a medical condition such as diabetes, bowel issues, allergies etc.

If you wish to get private sessions with a Dietician, you can find a list of accredited professionals and suggested qualifications on the CORU website:

<https://coru.ie/check-the-register>

5. 3. 5 Paediatrician

- A Paediatrician is a person whose expertise is assessing, diagnosing, and treating children in a medical capacity.
- They inform you on medication and, if needed, required training such as medicine administration, feeding tubes etc.
- They connect with other health professionals and can refer on to specialists such as orthopaedic consultants, mental health services, dieticians, cardiologists, endocrinologists etc.
- They monitor your child and keep track of their progress and health development.
- They provide ongoing support, advice, and care to children with life-long conditions, chronic illnesses, and genetic conditions.
- They work to support child protection processes.

5. 3. 6 Social Worker

- A social worker works to support the child and their family in all areas of their life.
- They can work collaboratively with other services and support providers or refer on as needed, helping you to connect with resources and support within the community.
- They might meet you at home or at the disability services centre.
- They can help you access supports, complete applications, navigate the housing system, connect with supports and activity providers within your community, and supply a wide range of information and advice.
- They can meet you alone so that you may speak freely without your child there if you feel a need to and can discuss anything that you or other family members may be finding challenging. Everyone finds things challenging sometimes and these challenges can be in all sorts of areas like budgeting, health, parenting, safety, coping, getting back to work or education and lots more. The social worker is there to support you and not to judge. They can help you to access resources such as courses or workshops, MABS (Money Advice and Budgeting Service), financial aid (such as housing adaptation grants) etc.
- They may facilitate group experiences such as support groups or coffee meet ups so that you might meet others who are in similar circumstances to you or be of a support to you.
- The social worker will focus more on supporting your child directly as they get older and can be a great support to them by helping them access social opportunities, mental health supports etc.
- They work to support and assist families in ensuring a healthy, nurturing, and supportive environment for their child.

You can find a list of accredited professionals including Social Workers and suggested qualifications on the CORU website: <https://coru.ie/check-the-register>

5.3.7 Psychologist

- A psychologist can assess your child's learning, emotional and behavioural difficulties.

The psychologist may assess your child's progress in these areas:

- Learning, thinking and problem-solving
- Play skills
- Social skills
- Emotional and behavioural development
- Skills for independence

A psychologist's assessment may involve:

- talking to you about your child's strengths and needs
- talking to your child's teachers
- observing your child at home, at school and at the centre
- playing with and talking to your child
- using formal tests of ability with your child. Your child may be asked to play with books, puzzles, toys and to look at pictures
- Based on this assessment, and by working with your child's teachers, they can also advise you on schools and education.

Treatment programme

The psychologist may offer to:

- work with your family to encourage positive behaviour and social-emotional skills
- provide parent training
- support you when you are making a decision about starting your child in pre-school, primary school or secondary school
- support you to explore the impact of your child's special needs on the family as a whole
- You can find a list of accredited Psychologists on this website
https://www.psychologicalsociety.ie/pd/?pd_s=&pd_d=

5. 3. 8 What do I do when my child is waiting to be assessed or receive services, if their services are not frequent enough, or if I am not happy with the services provided?

You have several options here which are to:

- Continue with your programme at home/school if you have one.
- Make a complaint or request to the relevant person, organisation, or office (refer to Section 12.2.1).
- Obtain private or independent therapy services (see below).
- Seek out complementary or alternative therapeutic or support options.
- Attend offered workshops/educational courses that are recommended by professionals.



5. 3. 9 Private, independent, complementary, or alternative therapy

- Accessing private, independent, complementary, or alternative forms of therapy must not affect the child's place on a waiting list, or the services offered to them. There is an exception to this though. The therapy being accessed independent of the CDNT must not, for any clinical reason, be in conflict with the services offered by the team. The CDNT must inform you of the conflict and let you choose which to proceed with.
- It is good practice to keep the team informed of any therapeutic interventions that you might be seeking out or have obtained.
- It is important to let the team know if you intend to have any assessments carried out privately as some cannot be repeated within a certain timeframe which may render a further assessment by the team of no use.
- Always verify the credentials of any therapist you seek out. These can be found on the CORU website at <https://coru.ie/check-the-register/>
- The policy guidelines for CDNT's regarding families accessing private, independent, complementary, or alternative therapies can be found here <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/pds-programme/documents/national-policy-for-cdnts-on-private-therapies.pdf>

Some popular types of therapies include play therapy, equine therapy, art, dance, and music. There are regulatory bodies for all of these which can be found below:

Equine Therapy: Festina Lente	
Address	Festina Lente, Old Connaught Avenue, Bray, Co. Wicklow, A98 F702.
Phone	Dr Jill Carey 01-2720704
Website	www.festinalente.ie
Email	info@festinalente.ie
Horse Riding for the Disabled Association Ireland	
Address	Stradbally, Laois
Website	www.rdaireland.org
Email	South-East Area Rep. Elizabeth Cunningham emprcunningham@gmail.com Area Coach Julia Watson juliawatson707@gmail.com
Play Therapy Ireland	
Website	www.playtherapy.ie
Email	Janette Casey contact@ptirl.ie
Irish Association of Play Therapy and Psychotherapy	
Address	IAPTP, 27 Clonard, Westbury, Corbally, Co. Clare. V94 N9YX
Website	www.iaptp.ie
Email	iaptpinfo@gmail.com
Irish Association of Creative Art Therapies (inc. art, dance, expressive arts, movement, drama, music)	
Website	www.iacat.ie
Phone	087 9921746
Email	info@iacat.ie
Social Media	IG iacat_ireland Twitter @theiacat www.facebook.com/iacatireland

Note: Inclusion on this list is for sign posting purposes only and must not be perceived as an endorsement.

5. 4 Assessment of Needs & Outcomes

Assessment of Need

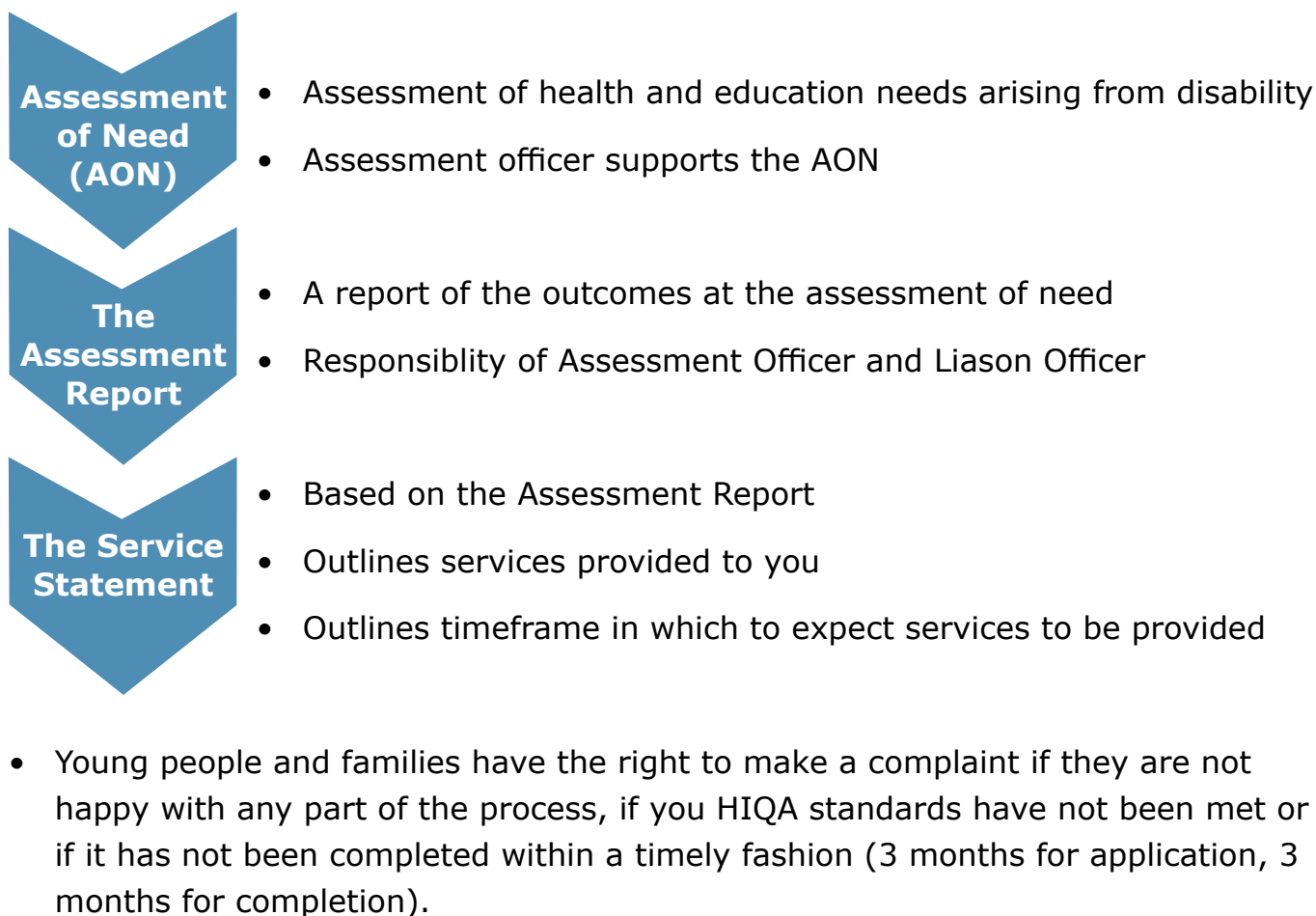
If your child was born after June 1st, 2002 then they are eligible to apply for an independent Assessment of Need (AON) under the Disability Act (2005) regardless of their age at the time of application. A child of 16 or 17 may make their own application or it may be made by a parent, legal guardian, or advocate. This will determine the presence of a disability, its nature and extent. Then it will identify the supports and services required by the young person to enable them to develop to their own potential and participate as fully in life as possible in a Service Statement. This will state the young person's health and educational needs along with when their supports and services should begin and how long they will continue to be provided for. This is a statement of services, it should be noted, and there should not be an expectation of diagnosis within it.

Application for assessment in Laois and Offaly can be made to:

Laois Offaly Assessment of Need Officers, Alvernia House,
Dublin Road, Portlaoise, Co. Laois.

Tel: 057 86 92868
057 86 92815

Children who qualify for an assessment of need under the Act have a right to:



Assessment of Need Outcomes

Young people and families have the right to make a complaint if they are not happy with any part of the process or if it has not been completed within a timely fashion (3 months of application for completion of assessment, with a further 1 month for the Service Statement). These complaints should be made via your Assessment Officer. An appeal may also be made if you disagree with the findings and guidelines in the Service Statement. Complaints about the Service Statement are made via the Liaison Officer who may work towards a resolution with you. If no satisfactory resolution can be made you may wish to make further complaints to the Disability Complaints Officer (DCO). The DCO is an independent and impartial body. Forms are accessible via the Assessment Officer or the Liaison Officer. The DCO can be directly contacted also on Tel:(045)880400 or by email at aon.complaints@hse.ie

Laois Offaly Assessment of Need Officers, Alvernia House,
Dublin Road, Portlaoise, Co. Laois.

Tel: 057 86 92868
057 86 92815

Section 6

Getting Support – Public Services

6. 1 Benefits and Allowances

6. 1. 1 Financial Supports

The Department of Social Protection as well as other organisations including the HSE and Revenue Commissioners, provide certain allowances and entitlements for people with particular special needs including those who are carers for people with special needs.

Department of Social Protection

email: info@welfare.ie

website:

<https://www.gov.ie/en/organisation/departments/departments-of-social-protection/>

Tel: [01 704 3000](tel:017043000)

Rates of allowances are subject to change so check with the local Citizens Information office or look up www.citizensinformation.ie or your Local Social Welfare Office.



An Roinn Coimirce Sóisialaí
Department of Social Protection

Intreo Centre Tullamore		
Address: Castle Building, Tara St, Kilcrutin, Tullamore, Co Offaly, R35 T2F2		Tel: 057 931 8500
Social Welfare Branch Office Birr		
Address: Green St, Townparks, Birr, Co Offaly, R42 R271		Tel: 057 916 9040
Intreo Centre Edenderry		
Address: IDA Park, Carrick Rd, Edenderry, Co Offaly.		Tel: 076 628 5100
Social Welfare Branch Office Portlaoise		
Address: Government Office, Church St, Moneyballytyrrell, Portlaoise, Co Laois, R32 WY06		Tel: 057 867 8010
Social Welfare Branch Office Portarlinton		
Address: Goodwin House, Main St, Droughill, Portarlinton, Co Laois, R32 FK3K		Tel: 057 864 2110
Social Welfare Branch Office Rathdowney		
Main St, Rathdowney, Co Laois, R32 RY26		Tel: 0505 46920

For financial guidance you can also contact the Money Advice and Budgeting Service (MABS).

Laois MABS	
Address: Railway Mews, Railway St, Portlaoise, Co Laois, R32 K298	Tel: 0818 072 620
Offaly MABS	
Address: Unit 23A, The Bridge Centre, Tullamore, R35 P923	Tel: 0818 072 710
Citizens Information Centre Tullamore	
Address: The Bridge Centre, Level One, Tullamore, Co Offaly, R35 Y6Y7	Tel: 0818 076 295
Citizens Information Centre Birr	
Address: The Courtyard Office Centre, Emmet St, Townparks, Birr, Co Offaly, R42 HW63	0818 076 260
Citizens Information Centre Edenderry	
Address: St Mary's St, Edenderry, Co Offaly, R45 PD79	Tel: 0818 076 280
Citizens Information Centre Portlaoise	
Address: Kellyville Centre, Lyster Square, Portlaoise, Co Laois, R32 K6PY	Tel: 0818 075 590

Some of the more common allowances include the following:

6. 1. 2 Domiciliary Care Allowance (DCA):

This is a monthly payment to the care giver of a child aged under 16 with a severe disability, who requires ongoing care and attention in excess of that of a typical child of the same age. The Department of Social Protection assesses applications for this allowance.

To Qualify:

- The child must have a severe disability that is likely to last for at least 1 year requiring continuous care
- Be aged under 16 (after 16 the child can apply for a means tested Disability Allowance)
- Live at home with the person claiming the allowance for 5 or more days a week
- Meet the medical criteria
- In addition, the person claiming the allowance for the child must:
- Provide for the care of the child
- Reside in the State
- The Department's Medical Assessor looks at all the following before giving an opinion on whether your child meets the medical criteria:

- The history of the case
- All medical reports received (your GP fills out a medical report and you should include reports from any relevant specialists)
- Your description of the care and attention required by your child. (The form allows you to state what extra care your child needs under a number of headings.)

Children who are being cared for on a full-time basis in residential homes or other institutions are not eligible for the allowance. However, children in residential care who go home may receive a half-rate payment if they are at home for 2 days or more per week. If the child is getting medical or other treatment in hospital payment may continue for up to 13 weeks.

To apply, fill in a Domiciliary Care Allowance form. You can also get an application form by texting FORM DCA followed by your name and address to 51909 (standard text rates apply) or from your Intreo Centre or social welfare local office or local Citizens Information Service.



Note: All Counties send application form to this address:

Domiciliary Care Allowance
Social Welfare Services Office
Department of Social Protection
College Road
Sligo Phone (071) 915 7100
Lo-Call 1890 500 000

www.welfare.ie

If you wish to talk to someone face-to-face about your entitlements, you can visit your local Citizens Information Centre, local social welfare office or Intreo Centre.

6. 1. 3 Carer's Allowance:

Carer's allowance is a payment to people, who reside in Ireland and are looking after a person who is in need of support due to age, disability or illness. The means-test for this was broadened in the 2022 Budget to allow receipt of the payment for couples with a weekly income of up to €750, and single people with an income of €350.

To qualify for a Carer's Allowance you must

- Live with or provide full time care and attention to the person in need of care
- Be a residing in the state

- Be over 18
- Not in employment or education over 18.5 hours per week
- The person being cared for must be:
- Over 16 and dependent on full time care
- Or under 16 and carer must have previously qualified for Domiciliary Care Allowance

6. 1. 4 Carer's Benefit

Carer's Benefit is a payment made to people who have been paying PRSI (Pay Related Social Insurance), in Ireland, who leave the workforce to care for a person or persons in need of full-time care. This benefit is payable for a total period of 104 weeks (2 years) for each person being cared for.

6. 1. 5 Carer's Support Grant

The Carer's Support Grant (formally Respite Care Grant) is an annual payment made to carers who have successfully applied, by the Department of Social Protection. Carers can use the grant in whatever way they wish. There is an initial application process and thereafter In June of each year the Department of Social Protection pays the grant automatically to carers getting Carer's Allowance, Carer's Benefit, Domiciliary Care Allowance or Prescribed Relative's Allowance from the Department. Only one Carer's Support Grant can be paid for each person getting care. The current total of a full rate Carer Support Grant is €1850.

For more information and to get a Carer's Support Grant application form, contact your local social welfare local office or Citizens Information Centre or contact Department of Social Protection, Carers Support Grant Section, PO Box 10085, Dublin 2, Phone 01 673 2222.

6. 1. 6 Disability Allowance

Disability Allowance is a means-tested weekly payment for people with a disability aged between 16 and 65, whose income falls below certain limits.

To Qualify:

- The claimant must have an injury, disease or physical and mental disability that has continued or may be expected to continue for at least one year and restricts the ability to work
- Be aged between 16 and 65

- Satisfy a means test
- Be a resident in Ireland

For further details on eligibility and more information on the application process for grants contact your local Social Protection Office Intreo Centre.

For more information go to www.citizensinformation.ie

6. 1. 7 Medical Card

A medical card may be issued by the HSE to the parents of a child or children with special needs or to the child themselves if they are over 16. Medical cards are means tested and the named holder of the card entitles the person to a suite of health services free of charge. This includes

- GP services
- Prescription medication (not all)
- Public hospital services
- Dental services

If you do not qualify for a medical card, you may be eligible for a GP Visit Card.

For more information contact your Local Health Office.

Lo-call 1890 252 919 clientregistration@hse.ie

You can apply online for a medical card at www.medicalcard.ie

GP visit cards

If an applicant does not qualify for a Medical Card, an application for a GP visit Card may be successful. A GP visit card allows individuals and families to visit their family doctor for free.

GP Visit Cards for children under six

In Budget 2023 it was announced that GP visit cards will be extended to children aged 6 and 7 by the end of 2022. These changes require legislation. With the GP Visit Card children under the age of six are entitled to free GP visits, assessments at age 2 and 5 and care for children with asthma from July 1st, 2015.



[\(See
Section
5.1.2\)](#)

To apply for a GP Visit Card, access a form from the link www.hse.ie/eng/services/list/1/schemes/mc/gpvc/under6applicationform.pdf and send to:

GP Visit Card – Under 6s

Po Box 12629 Dublin 11 Lo-call 1890 252 919 www.hse.ie

6. 1. 8 Incapacitated Child Tax Credit

You can claim an Incapacitated Child Tax Credit if you are the parent or guardian of a child who is permanently incapacitated, either physically or mentally and

- Became so before reaching 21 years of age or
- Becomes permanently incapacitated after reaching the age of 21, but while still in full-time education or while training for a trade or profession for a minimum of 2 years.
- Go to: www.citizensinformation.ie

There are a number of additional benefits, allowances and schemes in relation to people with disabilities, these include but not limited to:

- Revenue Allowances and VAT refunds
- Medical and Surgical Appliances
- Blind Pension
- Household benefits Package
- Fuel Allowance
- Homemakers Scheme

Further Information including the application process for these can be found at your local Citizens Information Centre, ([See Section 6.1.1](#)).



6. 1. 9 Cross Border Directive - CBD

The HSE operates the Cross-Border Healthcare Directive (CBD), for people entitled to public patient healthcare in Ireland who are seeking to avail of that healthcare in another EU/EEA* member state

The CBD can provide for the cost of publicly funded healthcare in Ireland to be availed of in an EU/EEA* member state and the costs to be reimbursed subject to application terms. Patients must familiarise themselves with the administration requirements of the HSE prior to availing of cross border healthcare in order to confirm entitlement or for reimbursement of treatment costs. The HSE has established a National Contact Point (NCP) office for the administration of the CBD in

Ireland and the contact details for the NCP are:

National Contact Point, Cross-Border Healthcare Directive, St. Canice's Hospital,
Dublin Road, Kilkenny

Phone: 056 778 4546 Email: crossborderdirective@hse.ie

6. 2 Transport

6. 2. 1 School Transport



The Department of Education and Skills (DES) provide school transport services for young people with special educational needs. You can apply to your child's school for special transport arrangements. There are criteria to be met in order to qualify for transport arrangements. The school will then apply to the DES for school transport with consent from parents and with the support of the SENO'S.

6. 2. 2 School Transport Scheme

Where the transport cannot be provided, you may be eligible for a Special Transport Scheme to help with the cost of making private transport arrangements.

The application form can be found at <https://schooltransport.buseireann.ie/Account/Register>

6. 2. 3 Escort Provision

If a child's care and safety needs require an escort, applications can be made by the SENO to the Department of Education and Skills to employ an escort to accompany the child.

To apply for the Special Transport Scheme contact:

Service DEPARTMENT OF EDUCATION AND SKILLS School Transport Section,
Portlaoise Rd, Tullamore, Co. Offaly.

Phone: 057 9325466/7

Website: www.education.ie

Email: School-transport@education.gov.ie

6. 2. 4 JAM Card

The JAM card, also now available as an app, has been developed as a simple, effective and discreet way to allow people to know that a person may need 'Just A Minute' due to a range of different communication barriers. These can be physical, intellectual, sensorial etc. You can find the JAM card on their website or pick up a free plastic JAM card in train and bus stations. Their website is www.jamcard.org or they can be contacted at Tel: 028 9043 6400

**6. 2. 5 The Disabled Drivers Association of Ireland (DDAI)**

DDAI Works in partnership with people with disabilities through promoting independence and equal opportunity by offering supports, services information and advocacy for drivers and mobility requirements.

Go to: www.ddai.ie

6. 2. 6 Irish Wheelchair Association (IWA)

The IWA provide a range of transport and mobility supports and services to people with limited mobility, go to: www.iwa.ie/services/motoring

Both the DDAI and the IWA offer information and supports on the following Schemes:

- The Disabled Drivers and Disabled Passengers Scheme: Provide a range of tax reliefs for disabled drivers and disabled passengers. Disabled drivers can qualify for a significant reduction on VRT (Vehicle Registration Tax) and VAT (Value Added Tax) on the purchase of a vehicle adapted for their particular disability.
- Disabled Persons Parking Permit or European Parking Card: This Scheme provides free parking for disabled drivers and passengers in Ireland. To apply for this, you must write to the Disabled Drivers Association or the Irish Wheelchair Association.
- Free Travel Pass: People with a disability may qualify for a free travel pass allowing to travel free of charge on public transportation. In some situations, a person may be entitled to accompany you, free of charge with a Free Travel Companion Pass. Drivers may be entitled to other schemes including:

- Fuel Grant Scheme
- Toll Roads Exemption
- Motor Tax Scheme

For more information on these schemes and more on transport supports go to:
www.ddai.ie www.iwa.ie/services/motoring www.citizensinformation.ie

6. 2. 7 Local Link – Laois Offaly Community Transport LTD

Provide safe and secure public transport services in local and rural Ireland. Local Link accept Free Travel Pass. TFI Local Link Laois Offaly, County Hall, Portlaoise, Co. Laois, R32 EHP9

Website: <https://locallinklaoisoffaly.ie>

Phone: (057) 8692168

Email: lo@locallink.ie



6. 3 Housing and Residential

6. 3. 1 Housing Supports

Local Authority Housing in Laois and Offaly are the main providers of social housing for people who cannot afford to buy their own homes. Local authority housing is allocated according to eligibility and need. Rents are based on the household's ability to pay. Specific criteria need to be met by applicants to qualify for Local Authority Housing.

Social housing support can provide Council Housing to those eligible if you are applying for support based on a disability you are required to provide:

- A completed Medical and/or Disability Information Form (HMD-Form 1), available from your local authority
<https://www.offaly.ie/eng/Services/Housing/Forms-Publications/Forms/>
- Occupational therapist's report which may highlight any specific accommodation requirements.

Table - Laois/Offaly Housing Departments in Local Authorities

Address:	Contact Details:
Offaly County Council Áras an Chontae Charleville Road Tullamore Co. Offaly R35 F893	Phone: 057 9346800 Email: housing@offalycoco.ie Website: www.offaly.ie https://www.offaly.ie/eng/Services/Housing/Local-Authority-Housing-Options/
Laois County Council Áras an Chontae JFL Avenue Portlaoise Co. Laois R32 EHP9	Phone: 057 86 64000 Website: www.laois.ie https://laois.ie/departments/housing/social-housing/

Approved Housing Bodies (AHBs) can receive nominations from the County Council to provide social housing for people who cannot afford to buy their own homes.

Housing associations provide affordable rented housing for people who cannot afford to pay private sector rents or buy their own homes. Go to www.housing.gov.ie

For further information and lists of social housing agencies in your area contact:

Service:	Irish Council for Social Housing, 50 Merrion Square East, Dublin 2
Phone:	(01) 661 8334
Website:	www.icsh.ie
Email:	info@isch.ie

Note: A person may only be in receipt of supports with one housing body

The Mobility Aids Grant Scheme - provides grants for works designed to address mobility problems in the home such as stair lifts, access ramps and grab rails. The grant is primarily for older people but people with disabilities can also access the scheme. It is administered by the local authority.

A Housing Adaptation Grant - is available where changes need to be made to a home to make it suitable for a person with a physical, sensory or intellectual

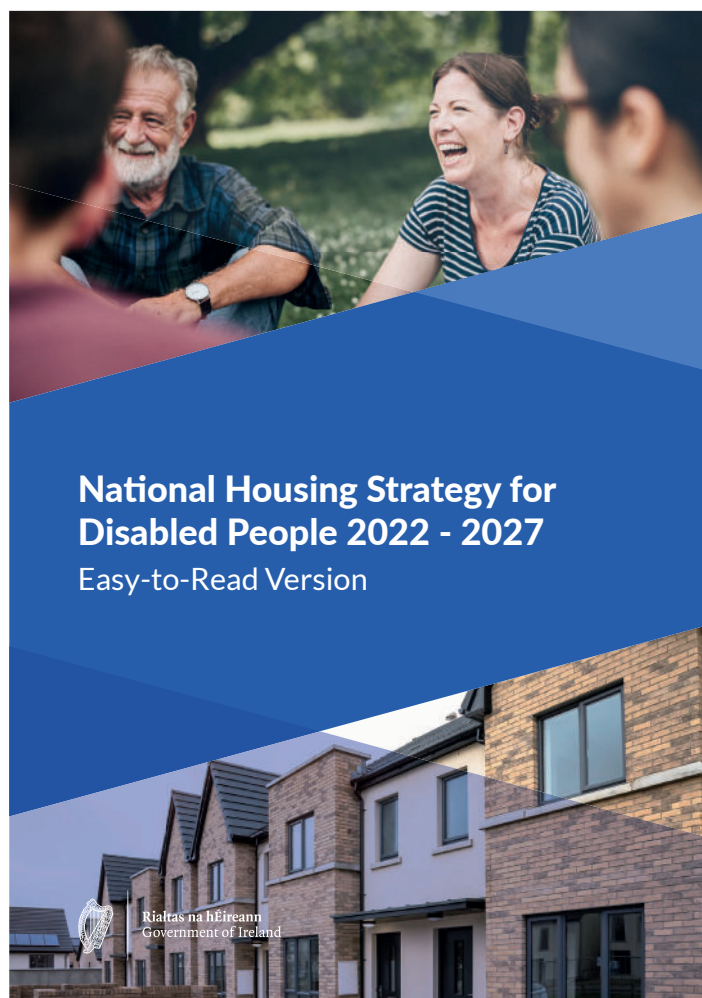
disability or mental health difficulty to live in.

Social Housing – qualifying is in accordance with up-to-date legislation and eligibility criteria and allocation of a property, in due course, is in accordance with the 'Scheme of Letting Priorities'. The purpose of this scheme is to determine the order of priority for allocation of housing.

6. 3. 2 Housing Strategy for Disabled People 2022 – 2027

This recently launched strategy aims to enable disabled people to live independently wherever they choose with whatever support they need to live what they believe is a good life.

The strategy has four sections in it including ones that look at the past and present housing situation, the desired future of housing and accommodation, and ways in which we hope to get there. Download this strategy from here: <https://www.gov.ie/en/publication/60d76-national-housing-strategy-for-disabled-people-2022-2027/>



It is made stronger because it is underpinned by other pieces of legislation such as the United Nations Convention on the Rights of Persons with Disabilities, in particular Article 9 (accessibility), Article 19 (living independently and participating in the community), and Article 28 (standards of living to lead a safe, supported and healthy life). Also the Government's plan for housing called Housing for All aims to ensure that people with a range of different housing needs will be supported to live good, safe and healthy lives in their community. The Housing Strategy for Disabled People 2022 – 2027 also includes ways in which many different stakeholders (people involved or affected by housing issues) will work together on a local level to move the steps in the strategy forward. These are called Local Housing and Disability Steering Groups. They hope to include representatives from Housing Agencies, the County Councils, Health Services and (importantly) Disabled People's Organisations.

For further information on housing and grants go to:

www.citizensinformation.ie/housing

www.inclusionireland.ie/?s=housing

Section 7

Life stages 0-18 Education

7. 1 Early years 0-3

7. 1. 1 Preparing for Early Childhood Education

Starting early childhood education is the first major transition in most children's lives and can be an anxious time for both them and their parents. There are, however, things you can do to ease this transition for all of you. Here we will give a guide on choosing an early learning setting including appropriate support when needed, preparing your child for the transition, and the process of entering the early learning system.

7. 1. 2 Choosing the Type of Setting, Method and Provider

Early childhood education refers to the optional education of a child before the age of six, after which all children in Ireland are considered school age. This includes pre-school classes and infant classes in primary schools (from the age of four).

The Early Childhood Care and Education (ECCE) scheme provides TWO free years of childhood care and education running for three hours per day, five days a week over the course of thirty-eight weeks per year. It runs from September to June each year. Children are eligible for the ECCE scheme the year that they turn three years of age (they must have turned two years and eight months by September 1st of the year they are enrolling and not turn five years and six months of age on or before June 30th of the programme year). Services receiving the support of the ECCE programme must adhere to Síolta guidelines which can be viewed here: www.siolta.ie/principles.php

The state supports early interventions for children with special educational needs through the following services:

These can include:

- Early intervention supports attached to mainstream and special schools
- Early intervention supports attached to HSE funded service providers
- Private pre-school supported by HSE grants
- Private pre-school supported by the ECCE scheme
- Home tuition.

These are some of the main types of early education settings, but this list is not exhaustive.

7. 2 Pre-School

Pre-school settings are specifically designed environments within which a child can prepare for school. Here they can get used to an educational environment in a safe and well semi-structured and supported play-based framework before entering the more structured school setting. Curriculums may include table-top activities, outdoor play, creative subjects such as art or music and imaginative play. It is a slightly more structured and directed setting than preschool.

7. 2 . 2 Montessori

The Montessori method of early education focuses on emphasising independence, acknowledging children as hungry to learn by nature and allowing children to be the instigators in the learning process within a supportive structure. Teachers qualified in Montessori teaching guide the children in self-directed, action-based (learning through experience), and collaborative learning. There may be various activity stations which children may choose from themselves at their own pace with the teacher moving through the classroom as opposed to standing at the head of it. Children of mixed ages are grouped together encouraging inclusion and acceptance while learning from each other.

7. 2. 3 High Scope

In a High Scope environment adults and children share control and responsibility for the learning experience each day. Working on a Plan- Do- Review framework they begin each day by discussing and planning what they would like to do that day and what their desired outcomes are. They then carry out their ideas and review how it all went at the end of each day.

This process has many positive benefits, progressively building skills such as social skills, teamwork, critical thinking, initiative, problem solving, and self-reflection. The environment is split into areas of interest and younger learners are given space and opportunities to work on motor skills whilst implementing a partnership approach with parents and caregivers. Children are introduced to a diversity of topics including (but not limited to) science, numeracy, literacy, the environment, and relationships.

7. 2. 4 Naíonraí

Similar in framework to a preschool, the Naíonraí setting uses a play-based framework incorporating activities using age-appropriate toys, sensory play, creative arts, and games for children aged 3-5 years. The Irish language is used by the Stiúrthóir throughout, though children may begin to phase out their first language at their own pace. The development of skills in numeracy, literacy, comprehension, language, and social skills takes place in a fun relaxed environment during a daily 2-3 hr session. You can find more information, including a video helping you choose a Naíonraí here www.gaeloideachas.ie/i-am-a-parent-pupil/naionrai

7. 2. 5 Specialised or Developmental Centres

These are preschool settings that have a higher ratio of adult to learner with all staff being experienced and qualified in the area of early learning for children with a variety of additional needs. Parents of children with more complex support needs may choose a Developmental Centre as they are often equipped with better facilities for early intervention and higher levels of specialised support for their children. The focus is on helping get the child ready for a more structured educational setting whilst developing social skills, numeracy, literacy, self-care and life skills. Not all regions have specialised preschools or developmental centres, but your local community services office or primary care centre should be able to inform you if there is one in your area.

7. 2. 6 Steiner Preschools

The Steiner philosophy is that a child must be supported to develop their emotional, physical, and social foundation skills before moving on to any sort of formal education. Emphasis is on using natural materials, artistic expression, outdoor play, and baking with creativity and imagination encouraged throughout the process. The aim is to provide a nurturing and harmonious space where careful consideration is made about the child's connection to the natural environment.

7. 2. 7 The Waldorf Method

Similar to the Steiner preschools, the Waldorf philosophy focuses on connections to the natural environment, however there is a more intense emphasis on developing life skills within the environment such as gardening, woodwork, storytelling, cooking, sewing, and art. Seasonal celebration, imagination and a respect for the natural world is central to this method.

7. 3 Pre-School Additional Support

7. 3. 1 The Better Start Access and Inclusion Model (AIM)

AIM is a child-centred model of supports that has been designed to provide supports to children with disabilities that will enable them to participate fully in Early Childhood Care and Education (ECCE) in an inclusive (mainstream environment). Instead of being based on diagnosis it is based on the support needs of the individual allowing for better access to targeted, effective, and equitable supports. This is in a framework of progression with 7 levels of support that respond to each child's individual needs. In this way, each child is supported in a way that works for them instead of a one size fits all model. Application to the AIM model is open throughout the year but it must be noted that parents and service providers are encouraged to apply early for children with complex support needs.

7.2.5 How to apply for AIM

<https://aim.gov.ie/>



Targeted Supports

AIM targeted supports cater to a wide range of abilities and are focused on the needs of the child and do not need a diagnosis of disability.



Universal Supports

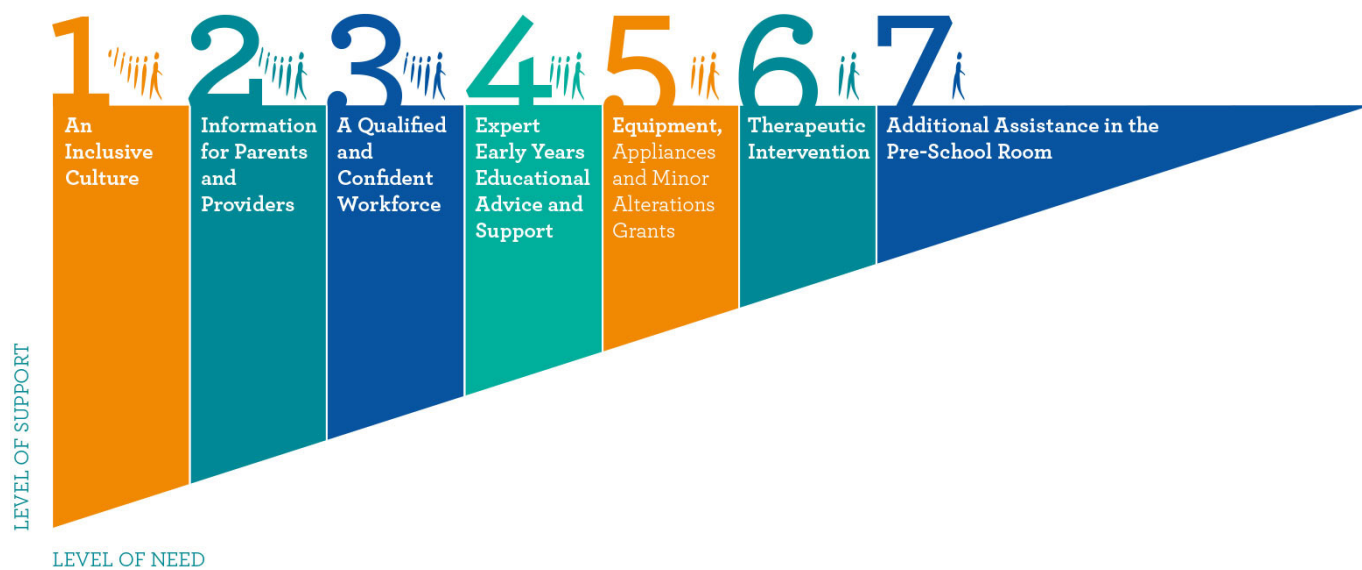
AIM universal supports benefit the whole pre-school environment through empowering pre-school providers to create a more inclusive culture in their settings.

AIM supports are provided through the ECCE programme. The main supports are grouped into universal or targeted supports. Universal supports are designed to create a more inclusive culture in Early Learning and Care settings, through training courses and qualifications for staff. Where universal supports are not enough to meet the needs of an individual child, targeted supports are available to ensure the child can meaningfully participate in pre-school.

Learn more about AIM and Universal and targeted supports here:

<https://aim.gov.ie/aim-supports/> (or click on the images)

7. 3. 2 Guide to AIM levels



7. 4 NEPS and School Support/NCSE and School Support

7. 4. 1 Inclusive Education

Education is classed as inclusive when certain criteria are met so that ALL children can actively participate in the educational environment together. A commitment to inclusive education means doing whatever is needed to support each child so that they have access to it.

It involves child centred practices that acknowledge that every child can learn but that they may require different supports to do so and should have ready and timely access to those supports.

Different modes and methods of teaching and learning must be used because not all children process information the same way or respond positively to the same learning environment.

Inclusion respects that each child has their own identity to celebrate and nurture with differences in age, gender, religion, ethnicity, ability, neurotype, culture, sexual orientation or health status.

It requires cultural changes in attitude and behaviour, normalising difference and celebrating diversity. It incorporates openness to adapt and an awareness that we must constantly be learning as new knowledge becomes available.

A collaborative effort between schools, families and community supports and services is required to maximise the likelihood of successful inclusion. Learning does not just happen in the classroom.

Inclusive education leaves no child behind, ensuring that each individual is valued and has a sense of belonging.

Inclusive education has many benefits including greater engagement, peer to peer learning, sense of belonging, a variety of teaching methods and more. So why are some parents you know not on board? Globally even in places where inclusion has seemed to work, certain children still do not have a place and are home-schooled. These tend to be children with more complex needs. Inclusive education is widely considered the best practice and our ultimate goal in education, however for complete inclusion the education system must be in a state of readiness which, at present ours is not. Schools require adequate funding to implement training, equipment and facilities. There have been positive developments though.

The Inclusive Education Framework was developed by the NCSE in 2011 and the education system is evolving. Lots of training and support resources are available from NCSE, Aistear and the Department of Education which are available to download on their websites.

The Charter for Inclusive Teaching and Learning was developed by the Higher Education Authority and AHEAD in 2009 and, more recently, we saw the establishment of the Inclusive Higher Education Forum (INHEF).

Legislation and policy that provides for diversity and/or inclusion in education includes:

- Education Act 1998
- Equal Status Act 2000
- Education (Welfare) Act 2000
- Equality Act 2004
- Education for Persons with Special Educational Needs (EPSEN) Act 2004
- Disability Act 2005
- UN Convention on the Rights of the Child 1992 (in particular the 'General Principles' articles 2/3/6/12 and articles 28/29)
- UN Convention on the Rights of Persons with Disabilities 2006 (in particular the 'General Principles' article 3 and articles 5/7/9/24. Article 24 is the 'Education' article)
- The National Plan for Equity and Access to Higher Education 2008-2013
- National Disability Inclusion Strategy 2017-2021
- Education (Admission to Schools) Act 2018

Table: Education supports

National Council for Special Education	Website www.ncse.ie	Tel: 01 6033200
Children's Rights Alliance	Website: www.childrensrights.ie Email: info@childrensrights.ie	Helpline Tel: 01 9020494
Association for Higher Education Access and Disability	Website: www.ahead.ie Email: ahead@ahead.ie	Tel: 01 7164396
National Childhood Network	Website: ncn.ie Email: info@ncn.ie	Tel: 047 724469
Inclusive National Higher Education Forum	Email info@inhef.ie Website www.inhef.ie	Tel: 087 6858828

7. 4. 2 Choosing which type of Education

- Choosing which type of education you would like your child to get can seem like an overwhelmingly difficult task that may have disastrous consequences affecting your child's whole life.
- First let us say that if you send your child to one type and they don't like it, or it isn't matched well with their ability or even their learning style then you can change schools.
- Give it long enough to be absolutely sure and discuss it with your child's support people (family and professional). Then they will support your child through the transition. It is not failing to pick the right one it is just that some children may suit both in different ways so it can be tricky.
- Every child's progress and development should be periodically reviewed as their needs change over time. Some children may move from special primary to mainstream secondary or vice versa.

Do not let this decision overwhelm you and ask for support from a Special Education Needs Organiser (SENO). These provide a service to the parents and teachers of children with special education needs in primary and post primary schools, and liaise with the HSE. ([See Section 7.5.4 for list of SENOs in Laois/Offaly](#)).



7. 4. 3 Special Schools:

- Special Schools usually have a higher ratio of teachers to student and smaller classes.
- Staff have a varied and broad spectrum of experience supporting and teaching children with additional needs.
- There are SNAs in each classroom, depending on the needs of the children.
- Special schools tend to be more aware and equipped with a diverse range of tools, equipment, methods and modes of teaching and facilities that suit the needs of children with additional needs e.g., changing facilities, sensory room, OT gym etc.
- Integrated services: members of Disability Network Teams are usually permitted to carry out their sessions in school, during school time, and will, with your permission, involve your child's teacher and SNA's in updates that may support or give insight to them on the child's needs and progress.
- Progress and success are not solely based on academic performance.
- Social skills and life skills are taught.
- The academic curriculum may be less diverse than in a mainstream school, but it is responsive to the needs of the student. Children can still take the Leaving cert for example but there are also exams they can take that are on a lower level of the QQI framework but equip them with important skills for life.
- In general, there is no mixing with their typical peers which, it can be argued, this has benefits and drawbacks. They meet a much narrower range of ability, experience and neurotypes which does not prepare them for life in adulthood.

St Francis Special School	Borris Rd, Portlaoise, Co Laois.	Email: office@stfrancisschool.ie	Tel: 057 8621847
The Kolbe Special School	Block Rd, Portlaoise, Co Laois.	Email: kolbeschool100@gmail.com	Tel: 057 8620329
Offaly School of Special Education	Kilcruttin Business Park, Tullamore, Co Offaly.	Email: info@osse.ie	Tel: 057 9320537

- **St Francis** is a school providing educational services for students with mild & moderate intellectual disabilities with co-occurring needs aged from 5 to 18 years. At St. Francis they look at the individual needs of each student and act as a catalyst in helping them overcome their specific difficulties in order to realise their full potential and to foster those skills which they will need for life.
- **Kolbe Special School** specifically caters for children (age 4-18) within the severe to profound learning disability spectrum and/or autism. Kolbe Special School provides an inclusive environment where all students develop an optimum personal level of independence through an individualised approach to educational development and personal care. Kolbe Special School aspires to be a school of excellence operating within the guidelines of Department of Education and Science and under the patronage of the SCJMS which commits to the educational development of each pupil.
- **Offaly School of Special Education** provides education for children aged four to eighteen and caters for those who would have a full spectrum of disability in five classes. They work closely with their multi-disciplinary team to provide a dynamic and comprehensive range of education and life support while maintaining a strong relationship with the wider community to further enrich the educational opportunities of their students.

7. 4. 4 Mainstream Schools:

- Academic expectations are high. This may maximize the educational potential of a child and provide a good learning environment. (NCSE).
- Access to an SNA may be allocated on an individual or shared basis, determined by need.
- There are grants available to schools for equipment, adaptations and assistive technology. These are needs based grants so are allocated only when a child is prevented from accessing the curriculum.

- The development framework for children with SEN's in mainstream school is being implemented step by step so things are improving.
- A continuum of support is now considered to be best practice and students are supported through the education system with the aim of preparing them for the next step into adulthood.
- When using the Continuum of Support model children may be given access to additional targeted support either individually or as part of small groups or via in class support and co teaching.
- There are lots of professionals that will support your child and the school staff such as their School Age or Disability Network Team, NEPs psychologist, EWO etc.
- Schools may also apply for resource teaching support from the NCSE through the area SENO.
- The NCSE also have produced many publications to be used as information resources for parents and professionals.

Parents: <https://ncse.ie/parent-resources>

Professionals: <https://ncse.ie/for-teachers>

- Many teachers in mainstream schools are now electing to do extra qualifications and training to better support children with SEN's.
- Some have a special class in or attached to the school as a third option. A list of special classes in mainstream schools can be found here https://ncse.ie/wp-content/uploads/2021/05/Special-Classes-for-website-21-22_26.05.2021.pdf

7. 4. 5 Tips for choosing a School

- As with choosing your child's early learning environment, get started as soon as possible.
- Research the school or schools you have in mind.
- You may ring the SENO for your area to get information on things such as local schools and placements.
- Some schools may not be able to support certain medical needs and may require the provision of a school nurse.
- Ask around for personal accounts of the school. Social media provides a good platform to chat to other parents who may have children at the school.



- Review their website and keep things like access, social opportunities, facilities and school culture in mind. School culture means the attitudes, traditions and approaches of the people there.
- Do you feel welcome and that your child will gain a sense of belonging and community there? Ask yourself this again after you have visited the school.
- Contact the school and enquire if there is an open day or other opportunity to visit the school.
- Write down any questions you have. It can be a nervous moment and it is easy to forget something you want to ask.
- Bring a notepad and a smartphone or camera to take pictures for your passport, transition documents and/or social stories ([Section 8.1.5 & 8.1.6](#)). Always ask for permission to take photos especially if it is of a person e.g. Your child's teacher.
- Ask lots of questions. Questions could include:
 - What are their policies and procedures?
 - What are their facilities?
 - What extracurricular or social activities happen at the school?
 - If mainstream, what has been their past experience of enrolling children with SENs?
 - A good way to assess the culture of the school can be to ask what additional training with regards to SENs have the staff members taken? Are they open to learn more?
 - Who are the key people who will be involved with your child?
- Don't be nervous! The teachers and principals are used to being asked questions and will be proud to tell you how their school performs.



7. 4. 6 Preparing for Primary School

- Update your transition tools and documents such as passports, social stories ([See Section 8.1.5 & 8.1.6](#)) etc.
- Talk to the principal and/or the SET regarding any modifications, assistive technology or accommodations that may help your child. There are grants available to schools to help with this such as the Minor Works Grant (<https://www.education.ie/en/Schools-Colleges/Services/Building-Works/Minor-Works-Grant/>), which is available for things such as ramps, automatic doors etc and the Assistive Technology Grant (<https://www.education.ie/en/Schools-Colleges/Services/Grants-and-Additional-Support/Assistive-Technology-Grant/>). Do this as early as possible.
- Help your child prepare the area where they will be doing their studying and provide as many opportunities as possible for them to tell you any feelings or thoughts that they might be having difficulty with.
- Travel the transport route together. If there is difficulty for you bringing your child to school yourself but they are not able to travel independently, then you may be eligible for the School Transport Scheme for Children with Special Educational needs arising from a Diagnosed Disability. Again, do this as early as possible. Find more information here: https://www.citizensinformation.ie/en/education/primary_and_post_primary_education/going_to_primary_school/school_transport_for_children_with_special_needs.html
- Take photos or video. Ask the school if you can video it when it is empty to provide your child with as much visual information as possible prior to entry.
- If your child struggles with changes of routine or transitions it may be helpful for the weeks leading up to going to school to practice packing their school bag and eating a packed lunch. You could make it into a fun role play and even turn it into a picnic when the weather is good.
- Talk to your child's other close support circle members, family, friends, neighbours etc. They may have ways to offer support that you haven't thought of and also may just want to be included.
- The professionals already involved with your child e.g., the Disability Network Team, CAMHS etc. will provide support through the whole process.



7.5 School supporting roles

7.5.1 What is NEPS?



- NEPS stands for the National Educational Psychological Service. They are Psychologists who work with the education system to support children in primary and post-primary schools.
- Each Psychologist is assigned a number of schools and they provide supports around learning, behaviour, and social and emotional development.
- They work together with teachers, parents and children providing lots of services around psychological support including consultation, assessment, projects and research. Schools are allocated a very small number of assessments each academic year.
- To receive supports your child's teacher or the school will make the referral to the NEPS psychologist for their school which is free of charge. Not all schools have an assigned NEPS psychologist so you may have to talk to your child's teacher around what the situation and procedure is for your area.
- Sometimes a situation may arise that is outside of the skill or resources of a school to appropriately respond to, and this is called a Critical Incident. In this case a NEPS psychologist is brought in, even in schools that do not have one assigned to them.
- There are guidelines for schools about how to respond to a Critical Incident, including templates for policy, communication and health and safety here <https://www.education.ie/en/Schools-Colleges/Services/National-Educational-Psychological-Service-NEPS-/Critical-Incidents.html>

NEPS, Grattan House, Dublin Road, Portlaoise, Co. Laois, R32 RY6V



7. 5. 2 What is an SET?

- SET stands for Special Education Teacher. They work in mainstream schools as resource teachers (either within the classroom or in a separate class), as visiting teachers or with children with specific needs within special schools.
- They use a variety of methods and resources to provide a person-centred educational experience that suits the learning style and need of children with special educational needs.
- Their approach might include team-teaching (lessons are planned with the other teacher), co-operative teaching (where they work along-side the other teacher), early intervention, and group or individual supports.
- A Student Support Plan (SSP) or Individual Education Plan (IEP) clearly sets down the student's needs, goals (short term and long term), and any methodologies, interventions or resources that will be used to reach those goals.
- The support of the SET is reviewed over time to decide if it is continuing to be effective. It may no longer be required, or a higher level of support may be needed. You should always be kept updated on any changes.
- Learning Support Teachers, Special Support Class Teachers, Special Education Resource Teachers, Language Support Teachers and Visiting Teachers all now come under the SET umbrella.

7. 5. 3 What is an SNA?

- SNA stands for Special Needs Assistant, and they provide support for children with Special Educational Needs in school.
- They do not teach the children. They assist with any additional and significant care needs of students such as toileting, dressing, feeding, medication and mobility.
- An SNA helps to develop a child's independence and life skills, providing support for their development and progression through the school system.
- Schools are now allocated resources based on the educational profile of the school using indicators such as number of children with complex needs and the social context of the school. Then SNAs are allocated to the school, and it is the responsibility of the Principal to assign them.
- A great booklet about school supports can be found here <https://ncse.ie/wp-content/uploads/2019/07/Web-Ready-03178-NCSE-Children-SEN-InfoBook-Parents2-Proof17-VISUAL-ONLY.pdf>.

7. 5. 4 What is a SENO?

- SENO stands for Special Educational Needs Organiser, and they provide services to the parents and teachers of children with Special Educational Needs in primary and post primary schools and liaise with the HSE.
- SENOs are assigned by area providing resources to schools and monitoring that they are being used efficiently and correctly in accordance with Department of Education policy guidelines.
- They offer advice, guidance and resources including equipment, assistive technology, transport, transitions, grants, placement and progression to higher education.

Belinda Fitzgerald	NCSE, 1 Waterside, Ashe Quay, Fermoy, Co. Cork.P61 P798	01 6033292	belinda.fitzgerald@ncse.ie
Carmel Callery	NCSE, 1st Fl, Government Buildings, St. Conlon's Road, Nenagh, Co. Tipperary. E45 T611	01 6033242	carmel.callery@ncse.ie
Deirdre Kirwan	NCSE, Block 6, Central Business Park, Clonminch, Tullamore, Co. Offaly, R35 Y2N5	01 6033334	deirdre.kirwan@ncse.ie
Maria Moriarty	NCSE, 1 Waterside, Ashe Quay, Fermoy, Co. Cork. P61 P798	01 6033376	maria.moriarty@ncse.ie
Olivia Ridgeway	NCSE, Block 6, Central Business Park, Clonminch, Tullamore, Co. Offaly, R35 Y2N5	01 6033434	olivia.ridgeway@ncse.ie

7. 5. 5 Home Tuition Scheme

The home tuition scheme provides a compensatory educational service for students who are unable to attend school for reasons such as chronic illness or for children with Special Educational Needs in need of an educational placement with provision also made for early intervention autistic students.

If granted, the home tutor must be recruited by the parents, qualified in the relevant sector and registered with the Teaching Council of Ireland. A site has been set up to assist in finding tutors for the Summer Programme, also known as July Provision Scheme, however, it has now evolved to cover all types of tuition and after school tutor requirements.

You can find it here [Summer Programme](#)

For further information on who is eligible and how you may apply check out here <https://www.education.ie/en/Parents/Services/Home-Tuition/>



7. 5. 6 What are STens Tests?

- Standardised Tests or STens are taken in May/June by children in 2nd, 4th and 6th class.
- They test a child's ability in English and Irish Reading and Maths and their results are compared to other children of the same age.
- The child is given a score out of ten and this may assist a teacher in determining if the child has a special educational need or if they are struggling and require some additional support.
- Results are an **indication** of how the student is doing but they can be affected by many factors on the day of the test. It also can not give a definitive answer as to whether your child requires additional supports so an average or higher result should not act as a barrier to these. No matter your child's score your encouragement and support plays a huge role in their educational experience.
- A good guide to STen tests can be found here www.ncca/media/1400/english_tip_sheet_sten.pdf



7. 6 Transition to Post Primary Education

Post primary can mean secondary school, special schools, community or comprehensive, Education and Training Boards (ETB's) and Educate Together schools.

See [Inclusion Ireland Post School Options](#) (Section 9)

7. 6. 1 Tips for choosing a Secondary School



- As with choosing your child's primary school, get started as soon as possible. The NCSE suggests at least two years if your child has complex support needs.
- Research the school or schools you have in mind.
- You may ring the SENO for your area to get information on things such as local schools and placements.
- Some schools may not be able to support certain medical needs and may require the provision of a school nurse.
- Ask around for personal accounts of the school. Social media provides a good platform to chat to other parents who may have children at the school.
- Review their website and keep things like access, social opportunities, facilities and school culture in mind. School culture means the attitudes, traditions and approaches of the people there.
- Do you feel welcome and that your child will gain a sense of belonging and community there? Ask yourself this again after you have visited the school.
- Contact the school and enquire if there is an open day or other opportunity to visit the school. Your child may choose to come along too.
- Write down any questions you have. It can be a nervous moment and it is easy to forget something you want to ask.
- Bring a note pad and a smart phone or camera to take pictures for your passport, transition documents and/or social stories. Always ask for permission to take photos especially if it is of a person e.g. Your child's teacher.
- Ask lots of questions. Questions could include:
 - What are their policies and procedures?
 - What are their facilities?
 - What steps have they taken to be accessible and inclusive?

- How can you help the school to support and include your child?
- What extracurricular or social activities happen at the school?
- If mainstream, what has been their past experience of enrolling children with SENs?
- A good way to assess the culture of the school can be to ask what additional training with regards to SENs have the staff members taken? Are they open to learn more?
- Who are the key people who will be involved with your child?
- How will you contact them if necessary in the event that your child is having difficulty?
- How will they communicate with you or give feedback?
- Don't be nervous! The teachers and principals are used to being asked questions and will be proud to tell you how their school performs.
- The professionals already involved with your child e.g., their School Age (or Disability Network) Team, NEPS psychologist, CAMHS etc can be a great support when choosing the best school progression for your child.
- As always, involve your child in the process. Ask them what their opinions and feelings are.

Occasionally the situation arises where you cannot find a suitable placement due to a school being over-subscribed (more students applied than there are places) or that a special school doesn't have a place available.

There are people to assist you in such circumstances. You can contact them here:

Special Educational Needs Organiser

<https://ncse.ie/regional-services-contact-list>

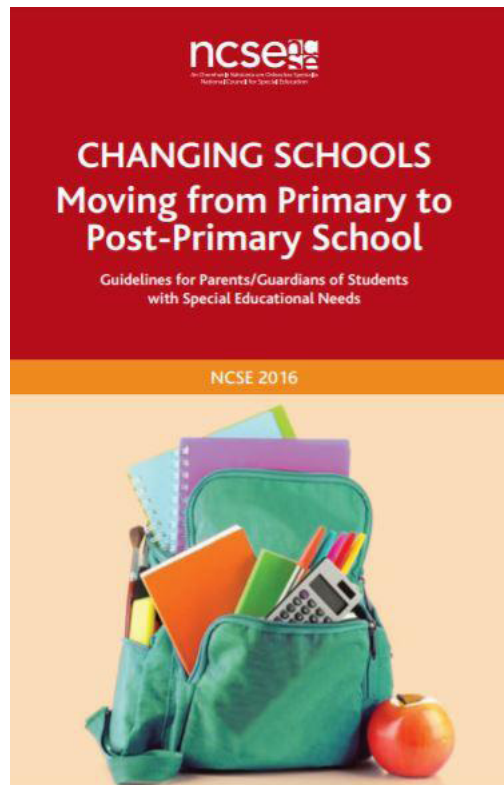
Educational Welfare Service

<http://www.tusla.ie/get-in-touch/education-and-welfare/>



7. 6. 2 Preparing for Secondary School

- Refer to Preparing for Primary School (Section 7.4.6)
- There is also a useful guide by the NCSE previously referred to that you can find here <https://www.sess.ie/sites/default/files/inline-files/02156-NCSE-2016-Changing-Schools-PrimarytoPost-final-08.02.16.pdf>



7. 7 Progressing to Third Level Education Supports

7. 7. 1 Disability Access Route to Education (DARE)

- Enables students to be offered third level courses on a reduced CAO points system (approx. 10-15% reduction) by 18 higher education Institutions in Ireland.
 - If a student has a disability or specific learning difficulty, they can select the box on the CAO application form that asks the question “Do you have a Disability/Specific Learning Disability?”.
 - This will redirect them to the Supplementary Information Form. It should be noted though that currently only 18 Higher Education Institutions are offering the DARE access system.



- Application differs slightly to the typical route in that you also are required to supply completed an Educational Impact Statement and an Evidence of Disability form. These will provide information about your support needs and the significant impact that they have had on your educational experience so far.
- For more information check out the Association for Higher Education Access and Disability (AHEAD) website.

AHEAD	www.ahead.ie/dare www.ahead.ie/cao
Access College Website (assistance page for providing evidence of a disability)	http://accesscollege.ie/dare/providing-evidence-of-your-disability/

7. 7. 2 Association for Higher Education Access and Disability (AHEAD)

AHEAD is an independent organisation that actively promotes and furthers inclusive environments and opportunities for people with disabilities in further education and training, higher education, and graduate employment.



Employing a rights-based approach and promoting the principles of Universal Design in Learning (UDL), they conduct national research and consult on national policy developments. AHEAD also provides supports to build the capacity of staff members involved in further education and higher education to integrate UDL in accessible and inclusive educational platforms. They are also an invaluable information resource to all stakeholders in education from students and graduates to parents and educational professionals.



Their GetAHEAD initiative, supporting students and graduates since 2005, provides training and work experience to those transitioning from third-level education into employment. Willing Able Mentoring (WAM) collaborates with employers (WAM leaders) participating in the initiative, to provide graduates with mentored, paid work placement. AHEAD focuses on ensuring work is of benefit to all parties and provides meaningful experience and a genuine educational endeavour to the graduates.

Association for Higher Education and Disability: AHEAD	Website	www.ahead.ie
	Phone	01 7164396
	Email	ahead@ahead.ie
	Address	East Hall, UCD, Carysfort Avenue, Blackrock, Co Dublin.
	WAM Phone	01 7168844

7. 7. 3 Youthreach: 15-20 years

Provided by the Department of Education and Skills, Youthreach facilitates both training and work experience for those who have left mainstream education early. It supports young people with discovering what it is that they would like to do in their adult life by offering certification in their area of interest.



This can be Junior Certificate, Leaving Certificate, QQI (FETAC) or Leaving Cert Applied (LCA), depending what steps are needed to bring the student closer to their goal. Youthreach programmes run all year with a rolling application and, upon entering the programme, a learner centred plan is developed to maximise all opportunities that the Youthreach centre can offer them.

One of the most significant benefits of Youthreach is that it provides education in a different mode of learning to their previous education so it may be of particular support to those who find typical mainstream education does not suit their style of learning. It is a programme that employs strength-based approaches, promoting mental health, wellbeing, and personal development.

The aim is to offer an encouraging and supportive learning environment for those who may have struggled in traditional secondary education or those with learning difficulties. You can find out more about your local Youthreach Programmes by contacting your Education and Training Board (ETB) office or searching the Qualifax website.

Laois & Offaly ETB	Address	Mountrath Road, Portlaoise, Co.Laois R32 XWY1
	Phone	057 8621352
	Website	www.loetb.ie
	Email	info@loetb.ie
Qualifax (student> course finder> Youthreach)		www.qualifax.ie

7. 7. 4 The Ability Programme (Pobal)



- Designed to support young adults with disabilities aged between 15 and 29 years across Ireland to access meaningful employment opportunities and maximise their participation in the labour market.
- With 27 programmes operating in a local, regional, and national capacity, Ability was launched to empower individuals by building skills, confidence, and personal development experiences for those who wish to engage in education, training or employment but have not yet done so.
- Their new software innovation the Ability 27 Padlet makes learning about programmes that are going to help you reach your potential and has information on all programmes including ones developed by DCU, the Cope Foundation, Down Syndrome Ireland, the Central Remedial Clinic and many more.
- These work within person-centred frameworks offering a range of supports that may include training opportunities, mentorship, employee retention and capacity building supports for mainstream employers and providers of education and training services. You can access the Ability 27 Padlet here to learn more: <https://padlet.com/Ability27/Ability27>

7. 7. 5 Employability Midlands

<https://www.employabilitymidlands.com/>



- A free and confidential service providing supports to people with disabilities so that they may gain better access to paid employment in the open labour market.
- These supports include
 - career planning
 - job sourcing
 - job coaching
 - workplace integration.
- They can also advise both employers and prospective employees, advice on supports such as
 - Wage subsidies scheme
 - Reasonable Accommodation Fund
 - Equipment

- Adaptation grants
- Interview interpreter support
- Personal Reader Grant
- Disability awareness training.
- You can contact the Laois/Offaly office, based in Tullamore, on Tel: 057 9323901.

7. 8 Careers Portal

This is an online hub of information created to provide all of the up-to-date career information and guidance materials for:



- 2nd Level School Students
- Early School Leavers
- College Students and Graduates
- Adult Learners
- Parents and Guardians
- Guidance Professionals
- Teachers and Tutors in Education
- Jobseekers and their support services
- Information Providers

The information is laid out in an engaging and easy to navigate manner with sections on courses, careers, and apprenticeships. It's a one-stop-shop for all career information and current or upcoming events, even offering a diverse array of search tools to make sourcing information easier on many topics including career progression pathways, employee or college profiles, CAO points calculation, courses at all levels and more.

Careers Portal	Tel:	01 440 2314 / 01 209 0797
	Website:	https://careersportal.ie
	Email:	info@careersportal.ie
		College House (1 st Floor) 71-73 Rock Road, Blackrock Co. Dublin, A94 F9X9

7. 9 Supporting Adolescence and the Teenage Years

The teenage or adolescent years are difficult to navigate for anyone, but for teens who have the additional barriers that people living with a disability can be met with, it can be much more so. Currently disability intersectionality is a topic regularly discussed by support providers. It sounds complicated but it is just a fancy way of explaining something that is common sense, which is that people with disability are met with more than barriers due to disability.

Many young people are part of other communities that suffer discrimination, social barriers and lack of opportunities too such as the LGBTQ+ Community, the Traveller Community, BIPOC or Non-White Racial Groups etc. Tackling so many different challenges whilst experiencing puberty or the transition into adulthood, especially in the current pandemic and post pandemic climate, must be extremely difficult. It is important to know the support that is there both for you and for your children.

Emergency Help			
GP Services	HSE Online Service Finder	www.hse.ie/eng/services/maps/	
MIDOC: Out of Hours GP	Tel: 1850 302 702	Offaly	Ofalia House, St Mary's St, Edenderry, Co Offaly
			Midland Regional Hospital, Arden Rd, Tullamore, Co Offaly
		Laois	St Fintan's Hospital, Dublin Rd, Portlaoise, Co Laois
Hospital	HSE Online Service Finder	www.hse.ie/eng/services/maps/	
Pieta House	Helpline: 1800 247 274	www.pieta.ie	
Samaritans	Helpline: 1800 116 123	www.samaritans.ie	
Childline	Helpline: 1800 66 66 66	Text BULLY or TALK or HELP to 50101 from 10am – 4pm	
Aware (Depression, Bi-Polar Disorder & Anxiety)	Helpline: 1800 80 48 48	Email: supportmail@aware.ie	

Sexual Health Centre Details	
Email	info@sexualhealthcentre.com
Website	www.sexualhealthcentre.com
Twitter	@SHC_Cork
Facebook	@BeSexyStayHealthy
YouTube	The Sexual Health Centre - Cork
Instagram	@SHC_Cork
Address	16 Peters Street, Cork

Services at a Sexual Health Centre	
Sexual Health Workshops	Full STI Screening
Crisis Pregnancy Support	Rapid HIV Testing and Support
Disability Support	Sex Workers Support
Free Condoms & Pregnancy Tests	Helpline: 021 427 6676

Laois Sexual Health Clinic	
Address	Sexual Health Clinic, Outpatients Dept, Midland Regional Hospital, Block Rd, Portlaoise.
Testing & Services	086 859 1273
PEP	Available at the Emergency Department, with follow-up at the clinic
PrEP	Available Tuesdays 2pm-4pm by appointment only. Currently accepting new clients.

Supports and Services		
Al Anon/Alateen	http://www.al-anon-ireland.org/alateen/	Tel: 01 873 2699
There are no in person Alateen supports currently in Ireland		
BodyWhys		Tel: 01 210 7906

BodyWhys supports people affected by an eating disorder and those who may have someone they wish to support who has an eating disorder. Check out their online support groups for young people aged 13-18yrs <https://www.bodywhys.ie/recovery-support-treatment/youthconnect/> or for those aged 19+ check out their Bodywhys Connect groups <https://www.bodywhys.ie/recovery-support-treatment/online-support-groups/>

CARI – Shining a Light for Children	www.cari.ie	Tel: 1890 924 567
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CARI provides child centred specialised therapy and support to children, families and groups affected by child sexual abuse, regardless of means.

ISPCC Teenline	24hr 365 days p/yr.	Tel: 1800 833 634
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National free active listening service for children and young people up to the age of 18yrs in Ireland. Provides a confidential, safe space to talk. The service is non-directive and non-judgemental

Jigsaw: Young People's Health in Mind	www.jigsaw.ie	You can access online chat services here www.jigsaw.ie/talk-online
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Jigsaw is an early intervention, primary care service for young people's mental health. Services are available to young people age 12-25yrs, concerned parent/guardian/adult or health professionals looking for supports for a young person.

Teen Parents Support Programme	www.tpsp.ie	Email: tpsps@treoir.ie Tel: 087 2518428
--------------------------------	----------------------------------------------	---------------------------------------------------------------------------------

The TPSP is a support service for young mothers, young fathers and their families from their pregnancy until the baby is 2 years of age. They offer support, advocacy and information.

CanTeen Ireland	Tel: 01 8722012	info@canteen.ie
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CanTeen Ireland is a cancer support group for young people aged 12 – 25yrs who have or have had cancer. They seek to empower, support and develop especially through the means of peer support.

Triple-P Fear-Less	Tel: need contact	https://www.triplep.net/provider-training-find-a-course/en/triple-p-training/
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Supports for Young Travellers

Exchange House Ireland	Tel: 01 8721094	info@exchangehouse.ie
Exchange House Ireland National Traveller Services is a Traveller specific front line service provider providing a diversity of supports including family support, after-school projects, on site youth services, Outreach youth services, mental health services and much more.		
Laois Travellers Action Group (LTAG)	Tel: 057 8682210	Email: info@itag.ie
LTAG is a Traveller organisation that represents, promotes, supports and empowers travellers with services including a primary healthcare programme and a Community Development Worker.		
Offaly Traveller Movement (OTM)	Tel: 057 9352438	Email via the contact form found here www.otm.ie/contact-us/
The OTM youth project young travellers supports in many areas with informal, social and educational supports with activities including youth clubs, sports programmes, seasonal events, links with educational institutions and much more. The OTM also provides supports such as counselling, primary health care and community development.		

LGBTQ+ Supports and Services

Belong To	Tel: 01 6706223	Email: info@belongto.org
Belong To is the national organisation providing support to lesbian, gay, bisexual, transgender and intersex people between 14-23 yrs. They also offer support and information to parents, carers, teachers and professionals and you can find a free training portal for their In the Know training to learn more about LGBTI issues.		
Luck Out	Tel: 057 8665010	clive@ywilaois.com
Luck out is a safe space for young LGBTQIA+ people aged 15-24 yrs. in Laois.		
Midlands LGBTI+ Project (18+)	www.ywilaois.com/lgbti-project/	Email: laoislgbt@ywilaois.com
The Midlands LGBTI+ Project provides supports through virtual meet ups, peer support, raising awareness, parents support groups and social platforms.		

Transgender Equality Network Ireland (TENI)	www.teni.ie Gender Identity Family Support Line: 01 9073707	Facebook /TransEquality Instagram @tenipics
TENI fights for Trans rights and equality while also providing support and empowerment for trans people and their families through advocacy, education and a range of supports.		
Bi+ Ireland	www.biireland.com	Email: biirelandnetwork@gmail.com
Bi+ Ireland aims to create a space where bi+ people can socialise, access peer support and combat isolation.		
Greenbow Deaf LGBT Ireland	Tel: 087 4504343	Facebook @GBWDeafLGBT
Greenbow provides an information platform for Deaf LGBTQI+ adults and organise regular social events.		
LGBT Pavee Support Group	Contact page: www.lgbtpavee.yolasite.com/contact-us.php	
LGBT Pavee Support Group provides support, information and advice to members of the Travelling and Roma community who are also part of the LGBTQI+ community.		
Full Spectrum Ireland	fullspectrumireland@gmail.com	Facebook @FullSpectrumIRL
Full Spectrum Ireland is a peer support group for disabled people who also identify as being part of the LGBTQI+ Community.		

Section 8

Assistive Technology & Useful Tools

8. 1 Communication Tools

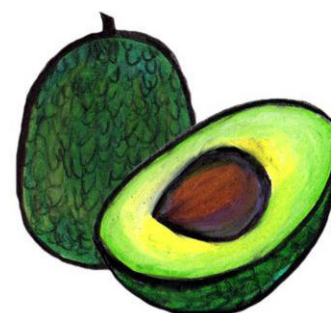
8. 1. 1 Assistive Technology

- This refers to any technical hardware or software that may assist your child in communication and/or in their studies.
- May include laptops, brailers, tablet, software, audiology equipment, switch devices, dynamic/digital braille display, mouthsticks, VoiceOver, computer/smart applications, screen readers, text-to-speech software, Eye gaze etc.
- The school may apply to the National Council for Special Education via the SENO for a grant for assistive technology equipment so long as there is sufficient evidence that a child has a significant need for it having physical and/or communication difficulties that prevent them from participating in an educational environment. ([See Section 7.5.4](#)).
- Grants can be for no more than €3800.



8. 1 . 2 Picture Exchange Communication System (PECS)

- A communication system that uses cards with pictures on.
- Pictures are exchanged for an item, request or desired action with another person.
- Can be used to communicate or identify an emotion i.e., Happy, sad, worried etc.
- Parents can learn this form of communication and there are also tech applications that can assist such as on tablets or a computer enabling parents to expand their skills or print off visual supports.
- Follows a programme of 6 phases.
- Can be used to create visual schedules so that the child knows the order of the day and can predict their activities.
- A child can build up a folder of their pictures and some teachers/parents even have key rings with several of the child's most used visuals.
- PECs may support more than just academic learning, helping a child to build confidence, affect their environment and make choices.



avocado

8. 1. 3 Lámh (Sign Communication System)

- Lámh is a sign language system used by children and adults with communication needs and a disability in Ireland.
- It is an alternative method of communication can be used by people of all ages.
- Lámh is used after an assessment is carried out to determine where or not it is a suitable form of communication to use with a child.

Lámh Development Office, Innovation Centre, Carlow I.T., Kilkenny Rd, Carlow		
Phone	059 9139657	
Website	www.lamh.org	Email: info@lamh.org
Facebook	www.facebook.com/lamhsign	
YouTube	www.youtube.com/user/Lamhsignsystem	

8. 1. 4 Communication Boards

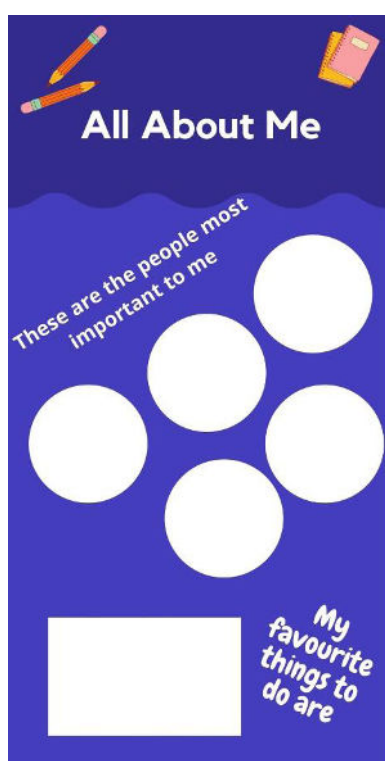
- These are large boards clearly displayed with pictures or symbols that represent places, things, facilities, gestures etc. Similar in concept to PECS.
- They are not just useful for those who do not communicate verbally but also those who experience other communication barriers such as mental health factors or a language barrier.
- Pictures should be of an appropriate size and evenly spaced so that those who have motor or coordination difficulties can use them.
- Very useful for simple enquiries or requests such as “may I go to the bathroom” or “I have a tummy ache”.
- Can also display things such as menus, schedules, recipes etc and/or be grouped by subject or context.
- As the individual learns more, they can use more complex boards. These may use something called the Fitzgerald Key which assigns different types of words to different colours. For example, nouns are orange and emergency, or important function words are red.
- Pictures can be drawn, digital, photographs etc depending on the choice of the person/persons who will use it.
- Boardmaker.com is a good starting place for finding visuals and has a good support network. <https://goboardmaker.com/pages/discover>

8. 1. 5 Social Stories

- Social stories can be in written format, pictures or video.
- They are developed to communicate information and can be of particular use to those children who have difficulty with transitions or need extra information in certain contexts. Social Stories provide information that accurately describe an achievement, skill or context that is descriptive and socially, emotionally and physically safe for the child using a patient and supportive tone.
- They may also be used to explain the process of activities that may cause anxiety or upset such as medical appointments, visiting a new place, or even bereavement.

8. 1. 6 Communication Passports

- Passports are a useful tool for handovers or transitions when dealing with professionals or just for recording historical information for yourself.
- They come in lots of different forms such as health, communication, education, sports and more.
- You may find it useful to have just one passport with all of those things in it for convenience.
- They comprise a book or folder with sections of information that help a person understand and support your child or your family.



MY MEDICAL HISTORY	
NAME OF CHILD	
MEDICATIONS	VACCINATIONS
SURGICAL PROCEDURES	ALLERGIES
ANY OTHER INFORMATION	NAME/ADDRESS OF FAMILY DOCTOR

8.1.7 Numicon - a maths teaching aid

Numicon is a maths programme which is considered a highly effective teaching tool, used by educators all around the world to support maths and numeracy development. Numicon is a system of flat plastic shapes with holes in them. Each shape represents a number from one to 10 and each number has its own colour. Numicon can be used across all age groups. Its approach to teaching maths helps young people to visualise numbers in terms of size and quantity.

**8.1.8 Handwriting Without Tears**

This handwriting program was developed in 1977 when Jan Olsen set out on a mission to help her son. Responding to John's tears over handwriting in first grade, Jan used her occupational therapy training and background to develop strategies to facilitate his handwriting.

By using Handwriting Without Tears techniques, children will learn the essentials of handwriting and develop a solid foundation to become proficient with letter formation, placement of letters on lines, spacing between letters and words, and differentiating the size of capital and lowercase letters.

Handwriting without tears has a plethora of hands-on activities, digital resources and manipulatives use, Handwriting Without Tears can be a very engaging way of learning to write by hand.

The program and resources are now called learning without tears.

<https://www.lwtears.com/>

<https://www.sensationalkids.ie/product-category/handwriting-without-tears/>

8.1.9 Touch Type Read and Spell (TTRS)

TTRS is a multisensory, structured, online typing course which assists students to learn at their own pace. In addition to developing typing skills, TTRS is designed to benefit students of all ages, in particular those who experience spelling, reading or writing difficulties. Learners with dyslexia or literacy issues have also found it helpful.

Contact Laois and Offaly libraries to access TTRS.

8. 2 Laois & Offaly Library Resources

Join your local library for free where you can avail of support, resources, sensory areas, sensory events and programmes.



Laois & Offaly Libraries Virtual tour of sensory resources in the libraries
(a must watch on YouTube)

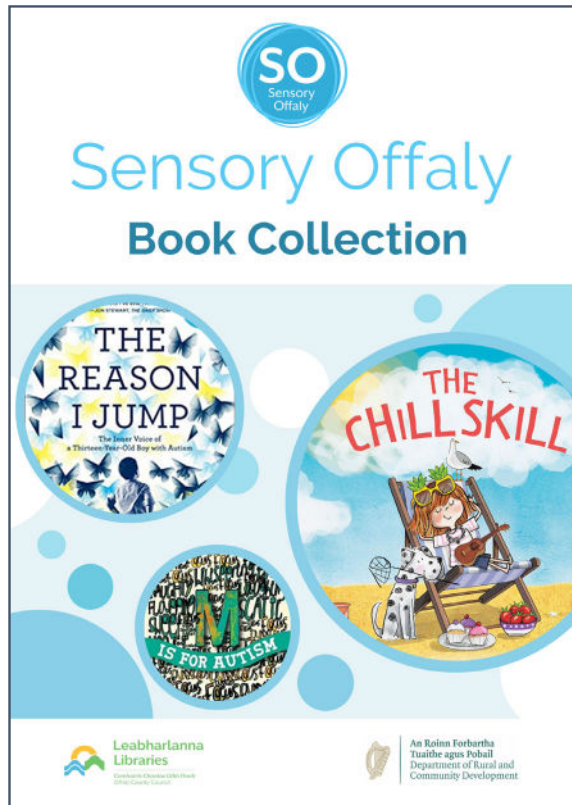
<https://youtu.be/Utwfu3EfJCQ> Laois Library

<https://laois.ie/wp-content/uploads/Laois-Library-Sensory-Toy-Booklet.pdf>



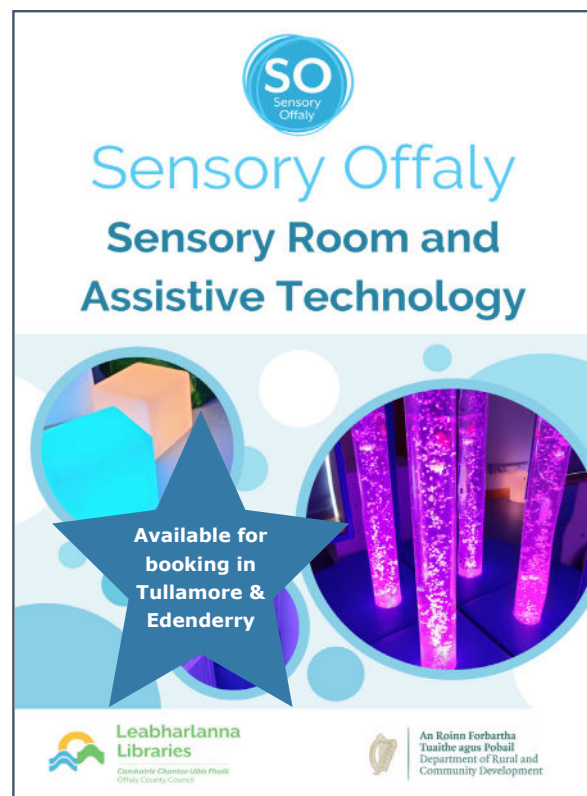
The Sensory Offaly collections and programme are available to support children, young adults and adults with disabilities, additional needs, and learning challenges, along with their families, educators and caregivers. These may be accessed free of charge by anyone who lives, works or is in education in Offaly.

[See the full Sensory Offaly collection here.](#)



Click on each cover to see the resource

Available to borrow or try out in the libraries



Available for booking in Tullamore & Edenderry

Section 9

Post School Options

For Parents and Young People looking at life options post School can be a very daunting task and there can be huge uncertainty over what direction is best suited to the young people finishing school. With this in mind the Inclusion Ireland website has extensive information and contact details of Post School Options under the following areas of 1. Planning, 2. Education, 3. Community Supports and 4. Employment.

Please refer to the links below to find out more about the range of services and support available:

Area:	Links:
<p><u>9. 1 Planning</u></p> 	<p>Post-school Planning Directory</p> <p>https://inclusionireland.ie/decision-making/</p> <p>Video: Post-school Options For Young People with an Intellectual Disability</p> <p>https://youtu.be/j0pfL0xExLg</p>
<p><u>9. 2 Education</u></p> 	<p>Post-school Education Directory</p> <p>https://inclusionireland.ie/pathways-to-progress-education/</p> <p>Video: Third Level Education Options for People with an Intellectual Disability</p> <p>https://youtu.be/pZIirbENARo</p>
<p><u>9. 3 Community Supports</u></p> 	<p>Community Supports Directory</p> <p>https://inclusionireland.ie/social-welfare-supports/</p> <p>Video: Community Supports for Young People with an Intellectual Disability</p> <p>https://youtu.be/9ull-_X3JZw</p>
<p><u>9. 4 Employment</u></p> 	<p>Post-school Employment Directory</p> <p>https://inclusionireland.ie/employment/</p> <p>Video: Employment Opportunities for People with Intellectual Disabilities</p> <p>https://youtu.be/613MV6ZC4i8</p>

Section 10

Adult Services – HSE

10. 1 HSE Adult Day Services for Disability

Access to day services for adults with disabilities

Adult day services are HSE funded programmes to provide day services supports to people age 18 and over, with intellectual disabilities, autism, or people with complex physical disabilities. The programmes assist people to make choices and plans and to be an active, independent member of the community.

Referrals for adult day services should be sent to the local HSE disability day service office.

Contact your Local Health Office:

Laois Community Services, Dublin Road, Portlaoise. Tel: (057) 862 1135

Offaly Community Services, Arden Road, Tullamore. Tel: (057) 934 1301 and services are provided at a range of different locations.

10. 1. 1 Day Centres, Residential and Respite Services



A number of organisations provide these various services in Laois and Offaly. They are provided and managed by private, voluntary (charitable) and public organisations. ([See Section 4.4](#)).

- Day centres provide a range of services. They include social and rehabilitative services, recreational services, sports and leisure facilities and a combination of medical and rehabilitative services.
- Residential services provide accommodation for people with a disability who are unable to live in their family home. In most cases a financial contribution will be made by an adult with a disability.
- Respite care service provides alternative family or private care to allow the individual with a disability, carer, or parents to have a short break, holiday, or rest. It can vary in length, from a few hours to a number of days/nights. There are schemes called share a break or home sharing where the child or young adult goes to stay with another family who can provide for their needs.
- If you feel that you are in need of respite services do not delay in applying as there are often long waiting lists. Attach any supporting documentation you might have such as therapists reports or assessments or letters pertaining to your own needs from a doctor or mental health support professional if you have them.

- Independent living supports, promotes, and enables equal opportunity and choice for people with disabilities. Independent living advocates for full participation in society and achieves this by working in partnership with people with disabilities by supporting and developing skills. It is generally funded through the HSE and administered through various service providers.
- Outreach work identifies and highlights services within the community, to people with disabilities that may support that person.

Avista Disability Support Services (South Offaly and Tipperary)	
St Anne's Centre Sean Ross Abbey Roscrea Co. Tipperary	Tel: 0505 22046 https://avista.ie/who-we-are/about-us/
Respite Services <ul style="list-style-type: none"> • Claddagh Children's Respite • Hillside Adult Respite House Residential Services <ul style="list-style-type: none"> • St. Anne's Community Residential Services • Sean Ross Villas 	Day Services <ul style="list-style-type: none"> • St. Anne's Day Services Children's Services <ul style="list-style-type: none"> • Sean Ross Villas Host Carers <ul style="list-style-type: none"> • Home Sharing Scheme
Offaly Centre for Independent Living	
Clonminch Rd, Tullamore, Co Offaly	Tel: 057 932 7632
Clochán House is a newly refurbished Residential Respite Centre located on the HSE grounds in Tullamore, Co. Offaly. It provides a respite service for leaders who have a sensory or physical disability ages between 18 and 65 years of age.	
The Muiríosa Foundation	
Home Sharing – Laois & Offaly Muiríosa Foundation Triest House, Lea Road, Portarlinton, Co. Laois, R32 PX65	Tel: 057 8623055
The Muiríosa Foundation offer services to children and young adults with moderate to severe intellectual disability including the home sharing model of respite where individuals are matched with host families. They share a break in a family environment that promotes self-direction, friendships, and future support networks.	

RehabCare Portlaoise

22 Lower Main St,
Dunamais Resource Centre, 2nd floor,
Triogue Hub, 1st floor, Portlaoise

(057) 866 0426

10. 1. 2 New Directions

New Directions is the HSE's approach to supporting adults with disabilities who use day services in Ireland. New Directions sets out twelve supports that should be available to people with disabilities using 'day services'. It proposes that 'day services' should take the form of individualised outcome-focussed supports to allow adults using those services to live a life of their choosing in accordance with their own wishes, needs and aspirations. There is a structure set up within the nine HSE Community Healthcare Organisations (CHO) nationally to implement New Directions. These CHO New Directions Implementation Groups have representatives from every HSE funded adult day Service Provider within the CHO area.

<https://www.hse.ie/eng/services/list/4/disability/newdirections/>

10. 1. 3 Personal Outcome Measures – The Key to Quality in Service and Supports®

MY SELF

- Connection to natural support circle or network
- Intimate relationships
- Safety
- Equity and equality
- All health needs met
- Individuals are informed of and can exercise their rights
- Freedom from neglect or abuse
- Access and input into their own life plans
- Continuity of support, security, and standards
- Individuals have control over who sees any data about them including plans, charts, assessments etc.

MY WORLD

- Individuals get to choose who they live with and where
- Choice of employment and access to support where required
- Integrated, accessible and inclusive environments
- Social engagement and community connection
- Social roles are varied and accessible
- Individuals choose their supports and services to their own unique desires and needs

MY DREAMS

- Individuals choose and realise the goals and dreams that they set for themselves
- Individuals have roles within their community
- Friends and connections are nurtured
- Respect and dignity are central

10. 2 Person Centred Planning

10. 2. 1 What is Person-Centred Planning?

- Person-centred planning is a process through which an individual's own indicators of a good life are identified and a framework of actions and measures is constructed to ensure that the individual's goals and aspirations are met.
- Focusing on the individual involved, person-centred planning adopts a whole person, strength-based frame of reference by which their personal vision of a good quality of life can be measured and developed.
- It responds to the changing needs of individuals and acknowledges the benefit of integrating a person's natural supports instead of relying wholly on formal service-centred support.
- Person-centred planning has been adopted into many health and social care systems including all forms of disability services. However, it can be applied in many different contexts to help reach a goal such as in an organisation, a day service, independent living or just life in general.

When your child enters adulthood and is looking at what they wish their life to look like it can seem a daunting, sometimes overwhelming process but there will be people to help facilitate the planning process and guide them, and you, on this journey. To help with this journey and focus the planning process, facilitators can use person-centred planning tools that have been developed. These involve clear steps that take the individual to their goal, identifying a support infrastructure by using all the resources they have access to. They should also support your child in accessing currently unavailable resources.

10. 2. 2 Person Centred Planning Tools

There are many types of planning tools that vary in their design but have common processes. Some even work well when initiated simultaneously or in succession. For example, Essential Lifestyle Planning which was originally developed to support people who had just left institutions and been moved into community living to give them a voice and develop long needed individualised supports. However, it is now used in many day services as it is a fantastic way for all involved in supporting the individual, including new people entering their lives, to get to know them, understanding what motivates them, and what their needs and desires are. It is very practical and includes developing valued social roles in the community.

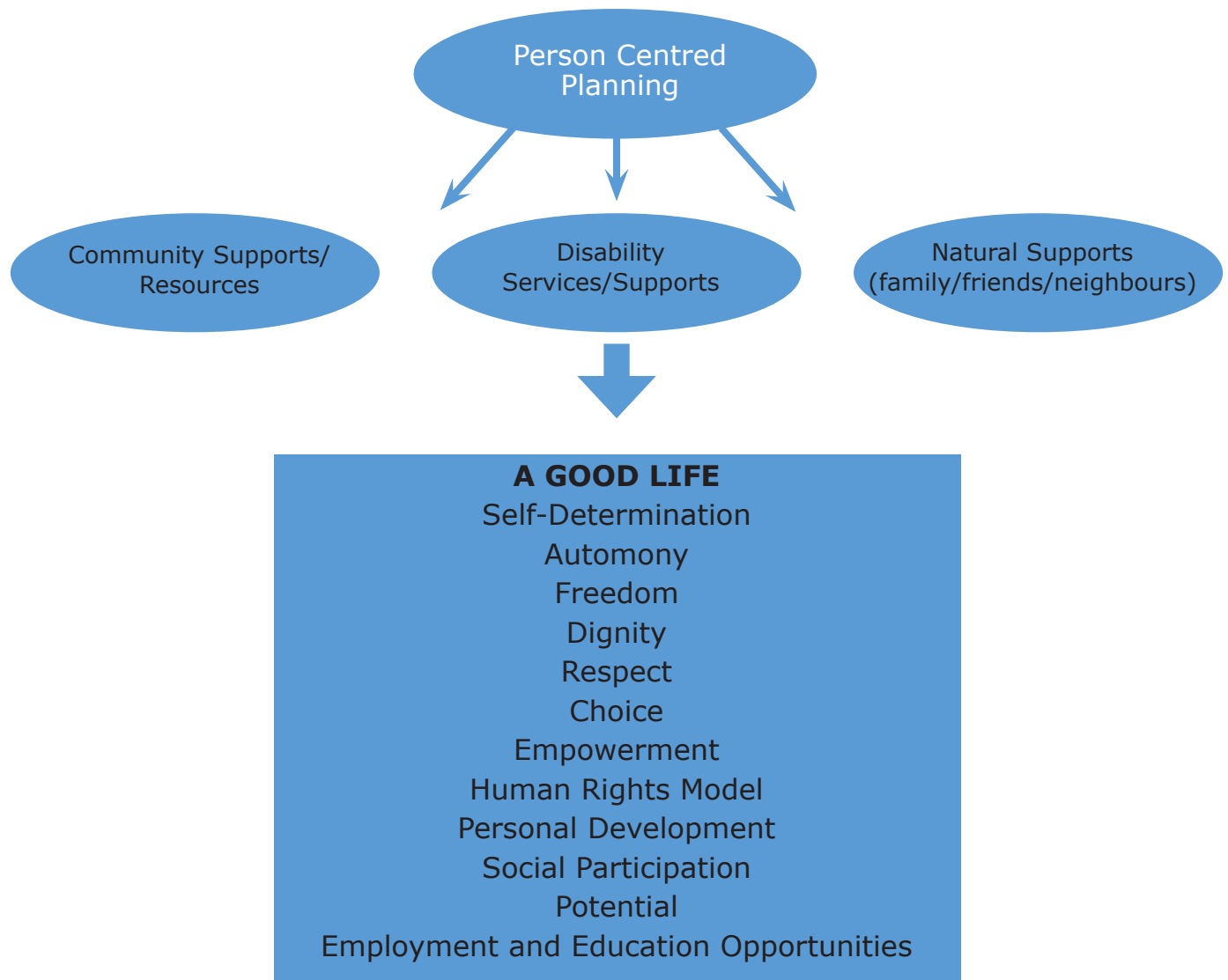


Personal Outcome Measures (POMs) is a system that allows us to identify and measure factors that will ensure an individual's quality of life in way that gives them choices and control.

Planning Alternative Tomorrows with Hope or PATH, looks at a vision of a person's ideal future or dream. It then reverse-engineers this dream and looks at how to get there, who can help and what barriers may be tackled. Whatever tool is used, the person's family and important support circle members should be involved unless that person is expressly against it. It is an extremely visual, creative, inspiring and fun process.

10. 2 . 3 Good Person Centred Planning

- Should **always** keep your family member at the centre of the plan and give them a voice.
- Respect individuality.
- Be human rights based.
- Safeguard dignity.
- Use whole organisation approaches.
- Value the input of natural supports (such as family and friends).
- Be responsive and adapt to changing needs.
- Involve joined up services and constantly be under review/evaluation.
- Respect the dignity of risk



Section 11

Life Planning

11. 1 Decision Support Service

In 2015 the Assisted Decision-Making (Capacity) Act was passed so that people would be better supported to make their own decisions and be able to direct their lives according to their own will and preference. This means that no matter how a person communicates that what they want to say is heard. Some people will require support in this and that support must come in flexible and person-centred manner that is guided by the individual involved. To do this the Act provided for a Decision Support service.

The Decision Support Service has several important roles. It is their job to keep a record of support arrangements and also make sure that they are being planned and carried out in the right way. They have a panel of people who are trained in supporting people to make decisions who can act in different ways including representing individuals, giving support, being a court friend etc.

The service also works in other ways around the Decision-Making (Capacity) Act such as promoting awareness, training, and carrying out investigations when reports of violations are made. The service is not yet fully operational though they are making strong progress. When they have implemented all their services there will be several ways to access a support arrangement:

Decision-making assistant	If you need support making decisions these supporters will assist you
Co-Decision-maker	
Decision-making representative	
Designated healthcare representative	If you may require support making decisions in the future these supporters can help you
Attorney	

For more information about these roles, training, progress of the Decision Support Service, Easy to Read documents etc you can learn more using the details below:

Decision Support Service	
Website: https://www.decisionsupportservice.ie/	Email: dss@mhcir.ie
Phone: 01 636 2420 or 087 4395268	Address: Waterloo Exchange, Waterloo Road, Dublin 4 Eircode: D04 E5W7
https://inclusionireland.ie/assisted-decision-making/	

11. 2 Guide to Hospital Stays

11. 2 . 1 Hospital Stays and Patients Rights

Many of the hospital websites now have sections that contain advice about admission, social stories, videos, information or activity booklets, advice about hospital restrictions and initiatives to improve the patient experience. It is hoped to build stronger trust in healthcare services and ensure a person-centred approach but the main thing you need to know is that you will be involved and supported. Also, important to understand now is that the three children's hospitals in Dublin have now joined together so it is possible that your child's treatment may be in one hospital for one stay but then move to another the next time.

Temple Street Booklets (inc. My Hospital Diary, I Spy, Detective Trail and Word Search. <https://www.cuh.ie/activity-booklets-2/>

Our Lady's Hospital Crumlin (OLHC) <https://www.olhc.ie/Children-Family/Preparing-for-your-Hospital-Visit/>

OLHC Admissions Office (01) 409 6152 or (01) 409 6213 The Admissions Department is located on the ground floor of the Hospital adjacent to the shop.

Opening Hours:

Monday to Friday 7.00am to 8.00 pm

Sunday & Bank Holidays 1.00pm to 5.00 pm

Please attend for admission before 5.00 pm

Contact the Admission Officer if you will be attending after 5.00pm as the ward and medical team must be informed.

Health Information and Quality Authority

email: info@hiqa.ie

website: www.hiqa.ie

Tel: [021 240 9300](tel:0212409300)

11. 2. 2 The National Healthcare Charter for Children

This child-centred document was based on the United Nation's Convention on the Rights of the Child, paying particular attention to Article 24 which states that national healthcare services should make sure all children get access to the highest standard of healthcare or rehabilitation. Healthcare services should ensure that parents are supported and informed so that they can ensure their children keep as healthy as possible which may include advice on preventative measures such as good diet, exercise, check-ups and medication management. Similar to the National Healthcare Charter; You and Your Health Service, it is built on a number of principles. These principles are adapted to include child protection processes, children's experiences of illness, injury and disability, prioritising of the voice of the child and support for appropriate advocacy that responds to the evolving needs of growing children. These principles are:

- Access
- Dignity and Respect
- Safe, Appropriate and Effective Care
- Communication and Information
- Participation
- Play, Education and Recreation
- Privacy
- Promoting Health and Wellbeing
- Giving Feedback
- Protection of Children

More information on the national Healthcare Charter for Children can be found here: <https://www.cuh.ie/wp-content/uploads/2019/11/HSE-National-Healthcare-Charter-for-Children-2018.pdf>

11. 2. 3 The National Healthcare Charter; You and Your Health Service

This document, developed by the Dept of Health and the Health Service Executive (HSE), is a statement of commitment by the HSE clearly explaining what services users should expect from Healthcare Providers underpinning all public health and social care services, including community care services and acute hospital services. The charter also establishes the roles and responsibilities of both the service provider and the service user. The charter was written with input from patient advocacy groups and individual advocates to “inform and empower individuals, families and communities to actively look after their own health and to influence the quality of healthcare in Ireland” (HSE, 2012).

It is built upon 8 key principles as outlined here:

- Access
- Dignity and Respect
- Safe and Effective Services
- Communication and Information
- Participation
- Privacy
- Improving Health
- Accountability

You can find more information about the charter here: <https://www.hse.ie/eng/about/who/qid/person-family-engagement/national-healthcare-charter/national-healthcare-charter.pdf>

11. 3 Financial Planning

Financial planning is always advised in support of a family member.

Financial Wellbeing (Special Needs Trust Planning)	
Website: https://www.financialwellbeing.ie/	Email: info@financialwellbeing.ie
Phone: 021 4823635	Address: Unit 34 Rivergrove, Glanmire, Co. Cork. T45 T862

Financial Wellbeing provide Special Needs Trust Planning (Note: Inclusion here is for sign posting purposes only and must not be perceived as an endorsement.)

11. 4 Disability Entitlements

<https://thinkingdisabilities.ie/category/thinking-entitlements/adult-entitlements-thinking-entitlements>

Section 12

Resources/Toolkit

12. 2 Making a complaint - Hospital, HSE, School

12. 2. 1 HSE Complaints: Your Service Your Say

The Your Service Your Say initiative was set up by the HSE to encourage service users to provide feedback on what they think has worked, not worked or could be improved. Feedback can be given in several ways so choose the one (or more) which suits you and that you feel comfortable with. This may include:

- Telling those involved directly in frontline services (your carers, therapists, key workers etc).
- Fill in the online feedback form which can be found at <https://www2.hse.ie/services/hse-complaints-and-feedback/your-service-your-say.html>
- Email the HSE at yoursay@hse.ie
- Fill out a hard copy (paper form) of the feedback form, which should be readily available at any HSE facility, and pop it in the box provided (or give it to any member of staff).
- Ask a staff member for contact details of who to send a letter to so that you can give feedback.
- Call the HSE feedback line on 1890 424 555 from 9am-5pm, Monday to Friday OR (if you're calling from a mobile phone) call 045 880 429
- Call HSELive on 1850 241 850 from 8am to 8pm Monday to Friday OR (if you're calling from a mobile phone) call 041 685 0300

12. 2. 2 School Complaints

What is Section 29?

- If a school (Board of Management) have made the decision to exclude, suspend or refuse enrolment of a child to their school then the parents (or the student in the case that they have reached the age of 18 years old), may appeal to the Secretary General of the Department of Education under Section 29 of the Education Act 1998.
- To do this you must submit the application form, along with the letter received from the schools Board of Management within 42 calendar days. In this you must state what you felt was unfair about the decision and/or why you felt that it was incorrect or went against the school's policy.

- You will be contacted by a facilitator who will support you in resolving the matter if you so wish but, in the case where this proves unsuccessful then things will proceed to a hearing.
- For more information check here <https://www.education.ie/en/Parents/Services/Appeal-against-Permanent-Exclusion-Suspension-or-Refusal-to-Enrol/section-29-appeals-information-note-faqs-for-parents-and-schools.pdf>
- In the case of a school that is established or maintained by an Education and Training Board the procedure is slightly different and you can find more information regarding that here https://www.education.ie/en/Parents/Services/Appeal-against-Permanent-Exclusion-Suspension-or-Refusal-to-Enrol/Procedures_Section29_ETB_Schools.pdf

12. 2. 3 The Ombudsman

If you feel unfairly treated by a public service provider (this may include government departments, local authorities, the HSE, nursing homes and publicly funded third level education institutions according to www.ombudsman.ie), you may choose to have your case examined by the Ombudsman. The office of the Ombudsman advises that you first try to resolve the matter with the service provider involved but that if this comes to an unsatisfactory conclusion that you should then bring it to the Ombudsman (providing it is within 12 months of the initial complaint unless in extenuating circumstances). A list of bodies applicable to this process can be found at www.ombudsman.ie/making-a-complaint/who-we-can-investigate/bodies-under-remit-of-the/ however it does state that the list may have left some out so, if the body relevant to you isn't on there, contact the office of the ombudsman to enquire.



Service	The Ombudsman		
Address	The Office of the Ombudsman, 6 Earlsfort Terrace, Dublin 2, D02 W773		
	01 6395600		
	Office hours:		
Phone	9:15am-5pm	Online complaints	www.ombudsman.ie/making-a-complaint/

12. 2. 4 Ombudsman for Children



This is an institution set up to protect the rights of children and young people in Ireland who investigates complaints about public organisations that provide services for those children. Complaints may be made by the child themselves or by a concerned adult on their behalf including a parent, carer, residential care worker, teacher, SNA etc. The office advises that you first seek to resolve the matter with the service provider involved, keeping written documentation where available and noting dates, who you spoke to and their response. If this doesn't provide you with a satisfactory resolution, then you should make a formal complaint to the organisation. Again, record any interactions in written format, be concise, clear and use respectful language outlining the outcome you hope to achieve. This could include an apology, revision of services, more person-centred planning etc. This gives the service a chance to work with you to reach your desired goal.

After this if you are still not happy with the outcome then you should contact the Ombudsman for Children's Office. This can be done in the following ways:

- Make an online complaint by filling in an online (as Gaeilge, English and many other languages are available) form at <https://www.oco.ie/complaints/make-a-complaint/online-complaint-form/>
- Print and fill a complaint form, available at https://www.oco.ie/app/uploads/2017/09/14057_oco_complaintform_english_web.pdf and mail to the OCO.
- Talk to a caseworker by calling Freephone 1800 20 20 40

Service	The Ombudsman for Children's Office (OCO)		
Address	The Ombudsman for Children's Office, Millennium House, 52-56 Great Strand Street, Dublin 1.		
Phone	Freephone 1800 20 20 40	Email	ococomplaint@oco.ie

12. 2. 5 Complaints Under the Disability Act

Section 38 of the Disability Act provides for individuals to make a formal complaint about their services. This complaint may also be made by a concerned person such as a parent or relative, guardian, legal representative or advocate provided by the Citizens Information Board or via the National Advocacy Service. Firstly, you must complain to the governance or head of the service provider or body detailing your complaint (be clear and concise, using respectful language, and keep written records of all interactions). These bodies are required by The Act to have independent Inquiry

Officers who will investigate the complaint and provide a written report of their findings. If they then feel it is warranted, then their report must also include the steps that they will be taking to rectify the situation.

If, after this is completed, you are still unhappy with the outcome you may request the Office of the Ombudsman to look into the matter further.

12. 4 Policy & Legislation

12. 4. 1 Education for Persons with Special Educational Needs Act (EPSEN) 2004

Though not fully implemented yet, the EPSEN Act aimed to ensure that children with special educational needs had the right, galvanised in Irish law, to be educated in an inclusive environment that encouraged and supported them to reach their educational potential. It provided for the establishment of the National Council for Special Education, which you can read about in the education section of this guide. It outlined the obligations of the schools and Boards of Management regarding the provision of special education and supports. The right to an Educational Assessment and Individualised Education Plans (IEPs) were introduced.

For more information check out www.ncse.ie

12. 4. 2 Disability Act 2005

The Disability Act introduced the Assessment of Need and subsequent Service Statement. It encouraged a mainstreaming of services, set down obligations for improved access to public buildings, services and information and provided that public bodies must actively seek to employ more people with disabilities. Also saw the establishment of the National Disability authority (www.nda.ie). For more information you can check out www.ahead.ie/disabilityact for a good breakdown.

12. 4. 3 United Nations Convention for the Rights of People with Disabilities 2006

The Convention on the Rights of Persons with Disabilities (CRPD) is a human rights treaty which was written to protect the human rights of people with disabilities and strengthen national policies of member states around the issue of disability rights. Though Ireland signed the treaty in 2007 it was not until 2018 after many years of fierce campaigning by advocates that we ratified the treaty. However, we have still refrained from signing the Optional Protocol which means that we have limited accountability regarding our adherence to the articles in the treaty. Article 33 calls for an independent monitoring mechanism that will ensure progress and adherence

to the treaty. The Irish Human Rights and Equality Commission works with the National Disability Authority to serve this function and does so with the support of the Disability Advisory Committee, which is made up of people with disabilities and a variety of lived experience. More information about the CRPD and how to report on the convention as an individual can be found at www.ihrec.ie/crpd

Article 24 and Inclusive Education:

https://www.unicef.org/eca/sites/unicef.org.eca/files/IE_summary_accessible_220917_0.pdf

Child Friendly versions of the UNCRPD:

https://www.unicef.org/Child_friendly_CRPD.pdf

<https://www.unicef.org/reports/its-about-ability>

UNICEF Report on Combatting the Cost of Exclusion

<https://www.unicef.org/reports/combating-costs-exclusion>



12. 4. 4. United Nations Convention on the Rights of the Child

The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty which identifies and protects the fundamental rights of children including their civil, economic, social, health, political and cultural rights. It includes articles which cover areas such as discrimination, access to quality healthcare, a right to be heard, exploitation, education privacy, child protection and more.

A fantastic summary developed by UNICEF can be found here http://www.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_summary-1.pdf

Save The Children child friendly version of the UNCRC <https://www.savethechildren.org.uk/content/dam/global/reports/uncrc-child-friendly-version1.pdf>

12. 4. 5 Sharing the Vision: A Mental Health Policy for Everyone 2020

When the 10-year health strategy A Vision for Change expired in 2016 it was more than time for the government to respond to the needs of the 1 in every 4 people (www.mentalhealth.ie) who live with some sort of mental health issue in Ireland. Addressing the ethos of reformation and transformation set down in Ireland's ten-year plan for evolving and improving Health and Social Care, Sláintecare, it recommends a whole system approach to mental health with strong community support systems. This document was informed by extensive consultation with those with lived experience of mental health issues, family, community and voluntary sector groups and professionals. The policy can be found at www.gov.ie but for

a great breakdown of how the policy can be applied check out <https://www.mentalhealthireland.ie/sharing-the-vision-translating-policy-into-practice-webinar/>

UNICEF Report A Rights-Based Approach to Disability in the Context of Mental Health <https://www.unicef.org/documents/rights-based-approach-disability-context-mental-health>

12. 4. 6 My World Survey Reports 1 and 2

Published in 2012 and 2019, these reports were developed by the UCD School of Psychology and Jigsaw and are the largest Irish study of youth mental health capturing the voices of over 19,000 young people. The study signposts the fact that adolescence and early adulthood are the peak time for the emergence of mental health difficulties highlighting the need for upstream investment in this area as many of these young people will continue to struggle with these issues into adulthood. The findings of the study are eye opening, and some points of notes are:

- 40% of young people suffer with depression that exceeds the range expected
- 49% of young people experience anxiety that exceeds the range expected
- 24% of young people, that's almost 1 in every 4, do not have a significant adult that they can go to in a time of need

To access the survey and get more information check out www.myworldsurvey.ie

Comprehensive Review of the Special Needs Assistant Scheme: A New School Inclusion Model to Deliver the Right Support at the Right Time to Students with Additional Care Needs. (NCSE Policy Advise Paper No. 6), 2018

Found that SNAs were often involved in a much more holistic and wide-ranging list of supports for children that extended beyond the limitations of their job description. It identified gaps in the support system and highlighted the point that children required additional supports in the area of life skills and the transition from second level education to adulthood. It proposed a new more comprehensive model of support wherein SNAs would be renamed as Inclusion Support Assistants and suggesting a Continuum of Support Framework. More information and a copy of the report can be found at www.ncse.ie

12. 4. 7 Transforming Lives 2016

This is the reform programme set up as the Irish population grew to make sure that the disability services and supports provided would improve and grow to meet the needs of individuals with disabilities. It ensures the recommendations of Value for Money (VFM) & Policy Review of Disability Services in Ireland in 2016 are followed. This review focused on reports including Time to Move on (From Congregated Settings), New Directions (The Provision of Day Services) and Progressing Children's Services (0-18 years Therapy Services).

More information can be found on the NDA website

<https://nda.ie/Publications/Disability-Supports/Transforming-Lives.html>

12. 4. 8 Housing Strategy for People with Disabilities 2011-2016 **(later extended to 2020)**

Informed by the mental health policy Vision for Change and, also by the recommendations of the Working Group on Congregated Settings (2008) regarding transitioning from institutionalised situations into community-based living including the provision of supports that are accessible in mainstream community services. Individuals are entitled to a *Statement of Accommodation Need* whereby a housing assessment by the Housing Department is carried out so that appropriate accommodation of the individuals choosing can be found and, if necessary, adapted to suit their needs. Individuals can choose to live alone or with others and they will be assessed on what supports they will need. Tenancy Sustainment Training can be facilitated for individuals if needed. For more information go to www.housing.gov.ie

National Disability Inclusion Strategy 2017-2021

Key points in this strategy were that it would support the implementation of the Comprehensive Employment Strategy for People with Disabilities (2015 – 2024), work with the European Commission and Council of Europe to develop and strengthen policy in line with best practice, facilitate corporate governance of the NDA along with the aid of financial supports. It focused on 8 headings including Equality and Choice, Joined-Up Policies and Public Services, Education, Employment, Health and Well Being, Person-Centred Disability Services, Living in the Community and Transport and Accessible Places. For more information on the strategy and progress reports go to www.nda.ie

12. 4. 9 Committee on the Future of Healthcare; The Sláintecare Report 2017

This is a ten-year healthcare reform plan that intends to improve the experience of the main stakeholders in healthcare, namely the patient, service user and clinician, while lowering costs to achieve better outcomes. It seeks to implement better access pathways to free treatment from GPs, primary care and hospital care, and utilise eHealth systems (online consultations for example), integrated care and joined up services with primary and community care supports. The importance of healthcare promotion and access to information about preventative measures, lifestyle and clinical management at home. The report calls for shorter wait times for diagnostics, in-patient and out-patient services and Emergency Departments with an increase in the healthcare workforce. It also highlights the need for a legislative framework for clinical governance and accountability protocols. An implementation strategy was developed in 2018 and refined into an action plan in 2019, however the Covid-19 crisis curtailed these plans and funding was not forthcoming. In response to this a new Sláintecare Strategy and Action Plan 2021-2023 was launched in May of 2021 focusing on two programmes covering eleven projects. These programmes include:

Improving safe timely access to care; and promoting health and well-being.

Addressing health inequalities, moving towards universal healthcare.

The aim of these is to achieve timely affordable care that can be easily accessed near to where service users live. Prevention initiatives promoting health and well-being will be carried out underpinned by the Health Ireland Strategic Action Plan 2021-25, also launched in May 2021.

The Sláintecare Report: <https://www.gov.ie/en/publication/0d2d60-slaintecare-publications/#the-slaintecare-report>

The Sláintecare Implementation Strategy: <https://www.gov.ie/en/publication/6011cf-slaintecare-implementation-strategy/>

Sláintecare Developments:

<https://www.gov.ie/en/campaigns/slaintecare-implementation-strategy/>

Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014-2020

This framework was a promise from the Government to children that they will rigorously endeavour to make Ireland a great place for a child to live and grow up in by 2020.

A simple version of the framework can be found here

<https://assets.gov.ie/26410/a21171547fe2401ca394c761aa6e3ded.pdf>

12. 4. 10 National Framework for Children and Young People's Participation in Decision-Making 2021

<https://hubnanog.ie/participation-framework/>

12. 4. 11 Covid-19 Related Resources

UNICEF Practical Guide to Remote Learning

<https://www.unicef.org/reports/practical-guide>

12. 5 The Bigger Picture: Models of Disability

In advocating for your child you may notice that many problems or barriers that you find are systemic. Basically, this means that they involve the whole framework of supports and services and are rooted at a policy and legislative level. Policy and legislation that is subject to, and often limited by, economic, logistical, and attitudinal barriers. You will hear about *Models of Disability*, and it is important to understand a little about the main ones, how they have shaped our concept of disability, and how they have evolved in response to society, research, culture, and expectations. Once you learn about these models you will be able to clearly see how legislation and policy have developed over the decades, why they did so and where they should be heading in the future. This will help you to envisage what you would like to see change and how you might influence that.

12. 5. 1 The Medical Model (also known as the Biological Model)

This is probably the oldest model of disability, dating back to prehistory when, if you were born with a disability you were separated from the community and viewed through a lens of impairment. Obviously as society evolved this concept of disability did also, but elements of this attitude remained. Historically in Ireland this has seen people with disabilities sent away from their families and communities to asylums or religious institutions. Its focuses on a person's impairments and lack of ability, relying on diagnosis and evaluations of function to access support.

This model sees people as patients, with professionals and academics driving the framework of supports and services. Individuals rarely get to make decisions for themselves and their capacity to do so is presumed to be minimal. Anything involving disability matters is provided for by specialised services and people with disabilities are totally disenfranchised.

12. 5. 2 The Social Model

People first started to talk about a social model in the 1960s as the civil rights movement in America inspired disability rights advocates to create their own movement. Rooted in a human rights model, the Social Model puts the individual in the driver's seat and the rallying cry of the Disability Rights Movement became "Nothing about us without us!". What this means is that individuals with disabilities are involved in every stage and facet of our response to disability including vision, discussion, development, implementation, and review. It views disability in the context of external barriers and notes a person's environment as being disabling (encompassing physical and social environment).

A common example used is that if we had ramps, lifts, and hoists everywhere then how disabled would a wheelchair user be? The transition to a social model, however, has taken several decades and due to economic climate, attitudes and logistics, the tendency is to slip back to a medical model. For example, the National Disability Strategy of 1997, called for mainstreaming of services and promised access to an assessment of need for children. However, assessment waiting lists continue to be far too long and, along with other services, such as July Provision and primary medical certificate, dependent on a diagnosis. This model calls for a political response, but implementation is key. The work needed here is pressure to get the job done!

12. 5. 3 The Biopsychosocial Model

It is a bit of a mouthful, but the biopsychosocial model combines elements of both the medical model and the social model (**Bi**ological, **Psy**chological and **Social**). It recognises that we cannot abandon the medical completely, and nor should we. After all we are all patients some of the time, needing rehabilitative intervention to recover, whether that be clinical, surgical, or therapeutic. The Medical Model has its place, though it should certainly not drive policy, legislative development, or best practices in the community.

Introduced by the World Health Organisation way back in 2001, the biopsychosocial model is still emerging and taking shape within political frameworks. As you are probably realising by now, change of this scope takes time. A lot of it. Within this model, people with disabilities and those with lived experience (such as carers) are heavily involved in the consultation, development, and review of national and international policy. Implementation is seen as paramount, and the aim is for full and wholly inclusive participation in life. People with disabilities are empowered to direct their own life and future with whatever support that they need. Emphasis is on a person centred, strength based, whole community approach that brings in natural

supports such as family and friends and incorporates the seven guiding principles of Universal Design. It is more dynamic and responds to every nuance and complexity of the needs and wants of people with disabilities, evolving with them over their lifetime. Social valorisation, self-efficacy and self-advocacy are empowered, and these are the objectives that drive policy and best practice.

This is introduced in policy documents such as New Directions (reviewing adult day services), Transforming Lives (supporting person-centred services), and the Mental Health Strategy: A Vision for Change (2006). To see the progression of the model you can then view the National Inclusion Strategy 2017-2021 and Sharing the Vision: A Mental Health Policy for Everyone (2020).

Now that you know more about these models you will see the evolution of our attitudes and political response to disability. You may also have a new understanding of the different movements and responses by the disability community and their allies throughout the years. The most recent of these resulting in the ratification by the Irish Government of the landmark international document, The United Nations Convention of the Rights of People with Disabilities (UNCRPD) which safeguards the fundamental human rights of individuals with disabilities.

These are some handy infographics about the models of disability on the following pages.

THE MEDICAL MODEL



1 IMPAIRMENT FOCUSED

Focus is always on **DISability** not ability and the individual is seen as the problem.

2 PEOPLE AS PATIENTS

Supports and services are delivered according to diagnosis and are, therefore, frequently one size fits all and more difficult to access. The medical and therapeutic professionals are gatekeepers to supports.

3 SPECIALISED SERVICES

Anything that involves supporting the disability community is ran by a disability specific organisation or department. This means hospitals, institutions, government, policy, legislation etc.

4 REHABILITATION DRIVEN

The goal is to rehabilitate, cure or fix the person. There is an end goal and the focus is not on actual participation in life.

5 EXCLUSION

Individuals with disabilities take part in separate activities away from people who do not have disabilities instead of being accommodated/supported to integrate with the larger community. The population is "othered" or considered not a part of the whole.

6 DEFICIT BASED LANGUAGE

Language is very negative and assumes the disability as making an individual "less than". It represents people as victims of their disability e.g. "The person suffers from ..."

7 ABLEIST ATTITUDES

Supports and services are delivered with a purpose of making the individual more like the typical. Normalisation is the goal. More able = more acceptable.

8 LED BY PROFESSIONALS

Professional and academic hegemony, meaning **THEY** are the experts. They drive services, policy, legislative change. They choose the aims, goals and framework of support.

THE SOCIAL MODEL OF DISABILITY



1 BARRIERS CAUSE DISABILITY

Recognises the world can be disabling with barriers including educational, environmental, social, attitudinal and organisational.

2 INCLUSION

Individuals are supported in being able to integrate with their community and fully participate in any activity they choose to. Accommodations **MUST** be made to make this so.

3 MAINSTREAMED SERVICES

Supports and services for individuals with disabilities are included in mainstream services and policies. For example, sectoral plans for transport must include developments and supports to enable individuals with disabilities to access transport as easily as everyone else.

4 PERSON-CENTRED

Supports and services are individualised to meet the unique needs and wants of the individual.

5 SELF ADVOCACY AND SELF EFFICACY

The individual is in the drivers seat. They are supported and empowered to represent themselves in whatever way is possible. They choose the actions that shape what they feel is their best life.

6 HUMAN RIGHTS DRIVEN

Disability rights are human rights. Policy and legislation supports individuals with disabilities to receive equal status and protects their fundamental rights. People with disabilities are involved in all stages of discussion, planning, development and implementation of anything affecting them "Nothing about us without us."

7 SUPPORT NEED DRIVEN

Services are delivered according to support needs and not diagnosis. This enables better access and allows for a dynamic and evolving framework as needs change over a lifespan.

BIO- PSYCHO- SOCIAL MODEL OF DISABILITY



COMPREHENSIVE AND HOLISTIC

Combines elements of the medical and the social model and umbrellas biological, psychological and social frameworks



BIOLOGICAL

This can be influenced by factors such as gender, neurology and genetics that are interior to the individual

PSYCHOLOGICAL

This encompasses relationships and experiences, accounting for others in the individuals life such as their families or friends and supporting mental health and wellness.



SOCIAL



This involves societal attitudes, environmental barriers, access and socio-economic status. It leads us to call for a political and societal response

12. 6 Universal Design

Universal design is described in the Disability Act 2005 as “...the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size or having any particular physical, sensory, mental health or intellectual ability or disability.”

Simply put, it is a series of guiding principles that, when followed, allow for the greatest potential accessibility, usability and comfort that includes absolutely everyone. The National Disability Authority states that “Universal Design is good design” highlighting the fact that if you make something accessible, safe, and pleasant to use for a wide range of needs and preferences then it can only make it better. It is important to have at least a basic understanding of these principles because, once you know what they are, you will be much better equipped to evaluate spaces and systems that your child will need to enter into. You will be able to critically assess them for usability, adaptability, and comfort so that if you need to request an adaptation or accommodation then you can effectively do so.

Universal Design can be applied to anything. Originally conceived to be applied to architecture and engineering, it has now been adapted to relate to systems from web design to education. The Universal Design for Learning (known as UDL) has been widely accepted as the most effective framework for inclusive education and has guidelines to implementing multiple means of engagement, representation, action, and expression. The principles of Universal Design are integrated into policy and legislation at a national, European, and global level (in the United Nations Convention on the Rights of Persons with Disabilities). Further reading on this can be done on the National Disability Authority website dedicated to Universal Design at www.universaldesign.ie. Below you can see the 7 guiding principles and examples of how they might be applied.

Principle	Guidelines
Equitable use	This means that the environment is inclusive and accessible to the maximum amount of people possible, offering equal or equitable use and experience. For example, websites that facilitate read aloud software for the blind or visually impaired.
Flexibility in use	The environment should offer flexible and adaptable methods of use accommodating a diversity of preference and ability. This includes accounting for different levels of accuracy and precision, or if the user is left or right-handed. For example, school desks that may be altered in height to accommodate wheelchair users.

Simple and intuitive use	The method of use needs to be easy to understand by everyone, no matter their prior experience, knowledge, language comprehension or focus ability. For example, easy read guides in plain English or picture menus.
Perceptible information	The environment, and all that is in it, should provide information on how it should be used. This information needs to be accessible to everyone no matter how they experience the world or how they communicate. For example, the blister tiles (a type of Tactile Paving) beside road crossings for the blind or visually impaired which communicate to the user that the pavement is about to end.
Tolerance for error	This principle is mostly related to health and safety measures that ensure that, if the environment or product is used incorrectly or accidentally that it is safe to do so without danger or adverse consequences. For example, the emergency stop device on a treadmill that instantly halts the movement of the belt if the user falls. It can also be seen in less dangerous examples such as the undo-typing option on computer software which allows a mistake to be undone with ease.
Low physical effort	The minimum amount of effort possible should be needed by the user to ensure comfortable use with ease. For example, the installation of power assisted doors for those who do not have the strength to push or pull a heavy door or using lever door handles instead of a door pull for those with less grip strength.
Size and space for approach of use	The user should not be constrained, obstructed or encumbered due to the size of the space they are required to enter. For example, bathroom cubicles should accommodate a user's wheelchair and allow it to turn 360°.

GOLDEN PAGES SECTION

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13. 1 Acquired Brain Injury

13. 1. 1 What is it?

Acquired Brain Injury (ABI) is caused by any sudden damage to the brain or Traumatic Brain Injury (TBI) as a result of external force and not as a result of a trauma at birth.

Acquired brain injury:

- Will vary greatly depending on the extent of the injury which may range from mild to moderate to severe.
- Can include memory problems, poor concentration, communication difficulties, pain, headaches, tiredness, dizziness, visual and/or hearing problems, physical or cognitive disability, sensory processing issues and changes in behaviour.

13. 1. 2 Diagnosis

A doctor will examine an individual and diagnose based on tests that may include (but not be limited to) cognitive, neuropsychological, speech/language and imaging testing (such as MRI).

Note: It is always important to see a doctor if your child has received a blow to the head and is displaying any signs of confusion, trouble breathing, dizziness, vomiting, lack of consciousness or any other symptoms which are out of character for the child.

13. 1. 3 Support and Information

Service	Headway: Brain Injury Services and Support, Blackhall Green, off Blackhall Place, Dublin DO7 RX67		
Purpose	Information and Support to people aged 18 and over		
Phone	1800 400478	Email	info@headway.ie
Website	Headway.ie	Facebook	Headway Ireland

Service	Acquired Brain Injury Ireland, National Office, Block A, Century Court, 100 Upper Georgia Street, Dun Laoghaire, Dublin, A96R2V3		
Purpose	Rehabilitation and Support		
Phone	01 2804164	Email	hello@abiireland.ie
Website	www.abiireland.ie		
Facebook	@abiireland.ie		

13. 2 Asthma

13. 2. 1 What is it?

- An inflammatory disease characterised by recurring attacks of breathlessness and wheezing.
- Caused by inflammation of the air passages in the lungs, during an attack it increases the sensitivity of nerve endings in the airways leading to swelling and narrowing of the air passages making breathing increasingly difficult.
- Occurs at all ages and varies in severity and frequency depending on the individual.

13. 2. 2 Symptoms

- Restlessness or difficulty in sleeping
- Increasing, but relatively painless tightness in the chest
- Shortness of breath
- A wheezing or whistling sound when breathing
- Coughing, sometimes accompanied by phlegm

13. 2. 3 Causes

- Asthma can be caused by allergies to pollen, dust, animals, moulds or even some foods.
- These are known as '**triggers**', and a variety of triggers can contribute to your asthma.
- Other causes can be allergens, viral infections, pollutants and drugs.
- It can sometimes be difficult to identify exactly what triggers asthma, as the effects can take up to 4-6 hours or longer before you notice them.

13. 2. 4 Treatment

- The medications used will depend on the severity and frequency of asthma symptoms.
- 'Reliever' inhalers are frequently used in the treatment of asthma attacks as they relax the muscles surrounding the narrowed airways.
- 'Preventers' are used over a long period of time and help to control the

swelling and inflammation in the airways, which helps reduce the risk of severe attacks.

5 STEP RULE

HOW TO DEAL WITH AN ASTHMA ATTACK

- 
1 SIT UP AND STAY CALM
DO NOT LIE DOWN

- 
2 TAKE SLOW STEADY BREATHS

- 
3 TAKE 1 PUFF OF RELIEVER INHALER USUALLY BLUE EVERY MINUTE USE A SPACER IF AVAILABLE
 PEOPLE AGED 6+ – UP TO 10 PUFFS IN 10 MINS
 CHILDREN UNDER 6 – UP TO 6 PUFFS IN 10 MINS

- 
4 CALL 112 OR 999 IF YOUR SYMPTOMS DO NOT IMPROVE AFTER 10 MINUTES

- 
5 REPEAT STEP 3 IF AN AMBULANCE HAS NOT ARRIVED IN 10 MINUTES

IF SOMEONE HAS AN ASTHMA ATTACK:

- Do not leave them on their own.
- Extra puffs of reliever inhaler (usually blue) are safe.

Image retrieved from with permission: www.asthma.ie

13. 2. 5 Support and Information:

It is essential at the onset to seek support with understanding asthma and associated medication. For all management of asthma contact your GP for specific advice.

The Asthma Society of Ireland aims to ensure that people with asthma have the information and ability to manage their asthma, so it does not affect their lives. A nurse from the Asthma Society can provide support to individuals to develop an asthma care plan which may be shared with education providers, caregivers etc so that everyone is aware of how they may best support the child. An Asthma Action

Plan empowers people living with asthma to take control of their condition.

Service	Asthma Society of Ireland, 42-43 Amiens Street, Dublin 1		
Purpose	Information, workshops, videos and literature and telephone helpline		
Phone	01 8178886	Email	nurse@asthma.ie, office@asthma.ie
Website	www.asthma.ie	Facebook	www.facebook.com/asthmasociety
Advice line	1800 44 54 64		

13. 3 Attention Deficit Hyperactive Disorder

13. 3. 1 What is it?

- Attention-deficit hyperactivity disorder (ADHD) is one of the most common childhood disorders that often continues through the teenage years and beyond.
- It is characterized by a persistent pattern of inattention and/or hyperactivity-impulsivity beyond the range of developmental norms, which may impact the child's functioning in many environments from classroom to family to social situations.
- ADHD is three to four times more common in boys than girls, but it is suggested that this may be due to girls being more likely to mask characteristics possibly leading to ADHD being missed or misdiagnosed in girls. Girls and boys may present very differently with girls often either not being hyperactive or masking hyperactivity in social situations.

13. 3. 2 Characteristics

ADHD may present at any age, affecting 5% or one in 20 persons in Ireland. Persistent problems with the following:

- Difficulty with focus and paying attention
- Organisation challenges
- Hyperactivity
- Difficulty with restlessness
- Impulsiveness and emotional regulation challenges

13. 3. 3 Diagnosis/Support

- A diagnosis of ADHD is made by a psychologist. This is done through a combination of observations and gathering information from parents and teachers about the child's behaviour.
- Play therapy, occupational therapy, self-development programmes or medication may be valuable in the support of children with ADHD.
- There are many ways to support the child using environmental management techniques (changing the way things are in the home or school), educational supports, peer support and mindfulness.
- Medication is often in the form of stimulants which may support the child in regulating physical and emotional responses. A psychiatrist is required to prescribe these.
- Though it can be challenging to live with, it is important that a child with ADHD understand that there are also positive aspects of having an ADHD diagnosis. People with ADHD are often creative, 'the life of the party', spontaneous, ambitious, great motivators and have a strong sense of justice and fairness. Many go on to be entrepreneurs, social advocates, artists, or musicians.

13. 3. 4 Support and Information

Service	ADHD Ireland, Carmichael House, North Brunswick Street, Dublin 7		
Purpose	Support and Information		
Phone	01 8748349	Email	info@adhdireland.ie
Website	www.adhdireland.ie		
Facebook	Facebook.com/adhdirelandonline		

13. 4 Autistic Spectrum Disorder (ASD)

13. 4. 1 What is it?

According to the Diagnostic and Statistical Manual of the American Psychiatric Association edition 5 (DSM5), Autistic Spectrum Disorder (ASD) is defined as a 'neuro developmental disability' which affects the development of the brain.

It mainly impacts on a person's

- Ability to communicate and form social relationships.
- Ability to make sense of the world around them.

<https://asiam.ie/advice-guidance/diagnosis-clinical-supports/starting-the-autism-journey-getting-a-child-diagnosed-and-next-steps/>

13. 4. 2 Characteristics

The characteristics of ASD vary greatly from one child to another but usually can be seen in four main areas of development:

- Language and communication
- Social Interaction
- Behaviour
- Sensory processing

13. 4. 3 Diagnosis

- Carried out by a clinical psychologist ideally as part of a multi-disciplinary team that may include speech and language therapist, occupational therapist, paediatrician etc.
- Made based on observations and using tests such as Autism Diagnostic Observation Schedule (ADOS) or Modified Checklist for Autism in Toddlers (M_CHAT) and guided by the Diagnostic and Statistical Manual 5th edition (DSM5). DSM5 has 3 levels on which it rates ASD.
- Though it may seem like you have to learn a whole new language of medical terms and acronyms these 'diagnostic tools' are simply tests, with lots of questions about how your child experiences the world. They are non-invasive, frequently carried out in a child friendly manner through play and will provide you with a clearer picture of how to support your child and what their needs may be.

13. 4. 5 Support and Information

- Early intervention is very important so the earlier the child is diagnosed the earlier education and support can begin.

<https://www.gov.ie/en/publication/8d539-autism-good-practice-guidance-for-schools-supporting-children-and-young-people/>

This is a new document published April 2022 as a guidance for schools in the education of autistic students.

- Four educational options for autistic children exist: mainstream school, mainstream school with specialised service (a unit), Specialised education or an autism specific special school (e.g., Saplings or Abacus).
- Many mainstream schools now have autism support classes attached which cater for children either at pre-school, primary or post-primary level. Typically, these classes have six children with a teacher and two Special Needs Assistants (SNA's).
- Most use a combination of methods of teaching such as the TEACCH programme, the use of Picture Exchange Communication Systems (PECS), social stories and sometimes, the use of assistive technology (e.g., Ipads, tablets, interactive white boards).
- Autistic children can avail of a range of supports that include Home Tuition (from aged 2 years 6 months up to 3 years and then further if and until an appropriate school placement is found), July provision (an extension of the school year), transport and financial supports.



**Autism Good Practice
Guidance for Schools**
Supporting Children and Young People

**13. 5 Applied Behaviour Analysis (ABA)****13. 5. 1 What is it?**

ABA is an evidence based scientific approach used to promote positive behaviour and to help with social interactions in children and people with ASD. ABA aims to improve the quality of life for the child/person with ASD and their family in the areas of speech and communication skills, social interaction, play, activities of daily living and positive behaviour reinforcement.

Go to: www.aba-ireland.com

Saplings Schools have the support of a Board-Certified Behaviour Analyst (BCBA) as an integral part of the Saplings school educational framework. Alternatively, you may wish to employ a private BCBA who can liaise with your child's school if they do not have their own.

Go to: www.saplingsmullingar.ie Phone 044 9384853

13. 5. 2 A Note on Neurodiversity

This refers to the belief that neurological differences such as autism or ADHD are due to people having different *neurotypes*, either being neurotypical or neurodiverse. Those who are neurodiverse view and experience the world differently. This, as highlighted by many self-advocates that we look to for insight, is neither good nor bad but merely different. It can have disadvantages but also advantages with autistic adults promoting self-belief, Autistic Pride, empowerment, and self-efficacy (taking control of your own world). For more information about neurodiversity check out www.asiam.ie, www.konfidentkidz.ie, ausometraining.com, www.studio3.org or www.middletonautism.com

13. 5. 3 Support and Information

Support	Laois Offaly Families for Autism (LOFFA)		
Purpose	A parent led support group for families of autistic children, teens and adults.		
Meetings	Advertised on Facebook	Email	info@loffa.ie
Facebook	www.facebook.com/laoisoffalyfamiliesforautism		

Service	MWB Autism Support.		
Purpose	A parent led support group for families of children diagnosed with an Autism Spectrum Disorder		
Phone	Michael Briton: 087 9877342 N Gerety: 087 6301666	Email	mwbautismchair1@gmail.com info@mwbautism.ie
Website	www.mwbautism.ie	Facebook	MWB Autism Support

Service	AsIAM, Rock House, Main Street, Blackrock, Co Dublin, A94 V9P1		
Purpose	Information, Support and Advocacy		
Phone	01 4453203	Email	info@asiam.ie
Website	www.asiam.i.e.	Facebook	www.facebook.com/asiamireland

Service	Irish Society for Autism, Unity Building, 16/17 Lower O'Connell Street, Dublin 1		
Purpose	Information, Support and Campaigning		
Phone	01 874 4684	Email	admin@autism.ie
Website	www.autism.ie	Facebook	/IrishSocietyforAutism

Service	The Asperger Syndrome Association of Ireland, Coleraine House, Carmichael Centre, Coleraine Street, Dublin 7		
Purpose	Parents supporting parents		
Phone	01 8780027/29	Email	info@aspireireland.ie
Website	www.aspireireland.ie		
Facebook	www.facebook.com/AspergerSyndromeAssoc		

Service	AADI, Mallow House, Shortcastle Street, Mallow, Co. Cork		
Purpose	Provides highly trained assistance dogs for children with ASD and their families		
Phone	022-43851		
	Or 0877998179	Email	info@aadi.ie
Website	Autismassistancedogsireland.ie		
Facebook	/autismassistancedogsirl		

Service	ÁIRC Midlands		
Purpose	Support organisation for children with any additional need (this may include disability, autism, long term illness etc) and their support circle. Offer a range of supports including emotional, educational financial and social.		
Phone	085 1194041	Email	aircmidlands@gmail.com
Facebook	/aircmidlands		

NCSE has valuable information on various programmes used in the Support of ASD. Go to: www.sess.ie/categories/autismautistic-spectrum-disorders/aspergers/autistic-spectrum-disorder-links

An up-to-date list of all ASD and special classes is listed on the NCSE website each year and can be accessed at: www.ncse.ie/special-classes

13. 6 Cerebral Palsy

13. 6. 1 What is it?

- It is a neurological condition which affects movement, muscle tone or posture and is the most common form of motor/movement disability of childhood.
- Caused by damage or failure of the brain to develop, usually before birth.
- In some cases, the damage is caused during childbirth or after birth. It is non-progressive.

There are four types of CP all of which will have different symptoms.

- Spastic Cerebral Palsy
- Dyskinetic Cerebral Palsy
- Ataxic Cerebral Palsy
- Mixed Cerebral Palsy

Children may or may not have associated (co-morbid) conditions such as a general learning disability, intellectual disability, epilepsy, or blindness.

13. 6. 2 Causes

- Cerebral palsy is caused by an abnormality in brain development in the specific areas that control movement, usually before a child is born.
- In many cases, the exact trigger of this abnormality is unknown.

13. 6. 3 Diagnosis

If there is a cause for concern that a child may have CP a full developmental history will be taken, and a neurological examination will be carried out. An MRI or CT scan will often be necessary, particularly if the cause of CP is unknown. When diagnosing the condition doctors will look for spastic movements, abnormal muscle movements, delayed development or coordination and balance.

13. 6. 4 Support and Information

Therapies, drugs and sometimes surgery will be used to enhance the quality of life for the child and most children will grow up to live independently or in supported living. Enable Ireland provides supports for people with physical disabilities.

www.enableireland.ie , email hello@enableireland.ie or tel: 01 8727155.

The Special Education Support Service (SESS) offers support to school-age children. www.sess.ie. Facebook support group (Cerebral Palsy Ireland Family Group): <https://www.facebook.com/groups/415254395178936>

13. 7 Cystic Fibrosis

13. 7. 1 What is it?

- Cystic fibrosis (CF) is an inherited condition and is genetic.
- A defect in one particular chromosome causes cystic fibrosis (CF). This gene produces a protein that controls salt and water in and out of your body's cells. In people who have CF, the gene makes a protein that does not work well causing the body to produce a sticky mucus that clogs the lungs leading to infections and /or prevents the pancreas functioning properly which prevents the adequate breakdown and absorption of food.

13. 7. 2 Symptoms

- CF primarily affects the lungs but may also affect the digestive system, the reproductive system and the pancreas.
- Salty tasting skin
- Persistent cough
- Higher incidence of chest infections than typical
- Shortness of breath
- Failure to thrive, poor weight gain/growth despite eating well
- Frequent greasy/bulky bowel movements that may be difficult to pass

13. 7. 3 Diagnosis

- If the parents know they are carriers of the CF gene, they may be offered prenatal tests which can determine whether the foetus has CF or not.
- Parents are offered the heel prick test when the baby is approximately 4 days old and this will determine if the child has CF.

13. 7. 4 Treatment

Treatments concentrate on prevention of infection, particularly in the lungs, and maintaining good nutrition. Physiotherapy is extremely important to keep the

airways clear. Some children will be on a continuous dose of antibiotic medicine, or use inhalers or steroids as needed. For very advanced loss of lung function a lifesaving lung transplant may be an option, however, this is not a cure for Cystic Fibrosis.

13. 7. 5 Support and Information:

It is important to note that recent years have seen huge gains in the areas of treatment and support for those living with Cystic Fibrosis (CF) including drug therapies that target underlying causes, improved CF Centres and strong support networks for both parents and individuals who live with CF. Cystic Fibrosis Ireland (CFI) is a voluntary organisation that was set up by parents in 1963 to improve the treatment and facilities for people with Cystic Fibrosis in Ireland. The CFI also co-operates with medical professionals to give maximum assistance to parents and children/adults with Cystic Fibrosis.

Go to: www.cfireland.ie Phone: 01 496 2433

For Midland support contacts go to: www.cfireland.ie/local-branches

Facebook: www.facebook.com/CysticFibrosisIreland/

13. 8 Deaf and Hard of Hearing

13. 8. 1 What is it?

- A hearing loss means a person cannot hear normally. One to two children per thousand are born with hearing loss, while hearing loss is much more common in adults. A person may have partial loss of hearing or be completely deaf.
- Two main types of hearing loss: conductive hearing loss and sensorineural hearing loss; some children can have a mixture of the two.
- Sensorineural hearing loss is caused by problems in the inner ear (cochlea).
- Some forms of deafness are genetic.
- Head injuries and brain tumours can cause hearing loss.
- Infections such as measles, mumps and meningitis can cause hearing loss/deafness.

13. 8. 2 Diagnosis

- It is possible to screen babies soon after birth. Nowadays young children may be fitted with hearing aids as early as 3 months of age.
- Parents should contact their GP or public health nurse if they have any concerns about their baby's hearing.

13. 8. 3 Symptoms

- Undiagnosed hearing loss in babies and young children can result in developmental delays. The hearing loss may not be obvious to others, as the child may be hearing some sounds and responding to them. Where a child is not reaching its developmental milestones – especially in relation to pre-lingual and speech milestones, the child's hearing should be checked.
- An older child may display signs which could indicate a hearing problem, such as speaking very loudly, ignoring others, turning up the TV or sitting very close to it, being disruptive at school when involved in listening activities or being extremely quiet. In these situations, the child's hearing should be checked.

13. 8. 4 Support and Information

Support and information are available to families and children. The audiologist and visiting teacher should provide parents with information on these services.

- Hearing aids are used by most children with hearing loss, while those with more severe or profound hearing loss may use cochlear implants.
- Irish Sign language (ISL) is used by Deaf people in Ireland and is best learned at as young an age as possible.
- Many children with hearing loss use lip reading to help with communication – so it is important to face them and speak clearly.

Service	Visiting Teacher (VT) Service supports children with loss of hearing in mainstream schools.		
Purpose	They provide direct teaching and support and advice for parents and mainstream teachers. They provide support in the home for parents and younger children.		
Westmeath	087-9675556	Email	marie.farrell@ncse.ie
Longford	087 9819359	Email	Amanda.duffy@ncse.ie
Website	www.ncse.ie		

Service	HSE Audiology Centre: Health Centre Portlaoise, Dublin Rd, Portlaoise, Co Laois.		
Phone	(057) 869 2539		
Service	HSE Audiology Centre: Health Centre Tullamore (Children's services only), Arden Rd, Tullamore, Co Offaly.		
Phone	(057) 869 2539	Email	midlandsc.audiology@hse.ie

Service	Irish Deaf Society (IDS), Deaf Village Ireland, Rathoath Road, Dublin 7		
Purpose	National Advocacy organisation that recognises Irish Sign Language as a means towards Deaf empowerment and equality.		
Phone	01 8601878	Email	info@irishdeafsociety.ie
Website	www.irishdeafsociety.ie	Facebook	/IrishDeafSociety

Service	Chime, 35 North Frederick Street, Dublin 1, Ireland.		
Purpose	A national charity providing specialist services to Deaf and Hard of Hearing people and their families.		
Phone	01 8175700	Email	info@chime.ie
Website	www.chime.ie		

Service	Deaf Sports Ireland, Deaf Village Ireland, Ratoath Road, Dublin 7, D07 V4KP		
Purpose	Promotes the social and community benefits of Deaf and Hard of Hearing people participating in sports.		
Website	www.deafsportsireland.com	Email	joeywatson@deafsportsireland.com
SMS	083 458800		

Service	The Irish Deaf Youth Association (IDYA)		
Purpose	Caters for children aged 13-17 through organised activities run by Irish Deaf Teens.		
Phone	085 1984166	Email	info@irishdeafyouth.com
Website	www.irishdeafyouth.com		

Service	Sign Language Association Ireland (SLAI)		
Phone	0860888202	Email	secretary@slaireland.com
Website	www.slaireland.com		

Service	Sharing the Journey –ISL app for smart phones and tablets		
			sharingthejourney2011@gmail.com
Website	www.sharingthejourney.ie	Email	chair@sharingthejourney.ie
Phone	085-722-5659		

13. 9 Diabetes

13. 9. 1 What is it?

- Diabetes mellitus refers to a group of diseases which affect how your body uses glucose (sugar). Diabetes mellitus is caused by a lack of insulin.
- No matter what type of diabetes you have it means you have too much glucose in your blood.
- There are two main types of diabetes characterised as type 1 and type 2.
- Type 1 diabetes is more prevalent in children and younger adults and usually requires treatment with insulin injections.
- Type 2 diabetes usually develops in adulthood. It can sometimes be treated with exercise and diet but may require anti-diabetic medicine or insulin injections.

13. 9. 2 Symptoms

The most common symptoms of diabetes in children are:

- A noticeable increase in thirst and frequency to urinate
- Tiredness
- Weight loss but often with an increased appetite
- An odour to the breath
- Changes in vision

It must be noted that some of these symptoms may have other related causes besides diabetes so a doctor should be consulted.

13. 9. 3 Diagnosis

Diabetes is diagnosed by blood and urine tests. The patient will usually be asked to fast prior to the tests and if blood sugar levels remain high when fasting this may indicate diabetes.

13. 9. 4 Support and Information

- Generally, blood sugar levels are monitored throughout the day at regular intervals.
- Insulin needs to be administered by way of injection.

- The diabetes Federation of Ireland has produced a useful booklet on diabetes for children. It is available at: www.diabetes.ie or tel 018428118.
- The HSE have information on diabetes available on their website at: hse.ie/eng/health/hl/living/diabetes/

Service	Diabetes Ireland, Laois Branch (parent support group type 1)		
Phone	(087) 675 8971	Email	Joebarry37@eircom.net

Service	Referrals CHO 8 (Laois, Offaly, Longford and Westmeath) Corina Glennon-Slattery, Community Dietician Manager, Primary Care Unit, St Loman's Hospital, Mullingar, Co Westmeath.		
Phone	044 938 4448	Email	Corina.glennon@hse.ie

Service	Diabetes Ireland		
Purpose	Provides support, education and motivation to everyone affected by diabetes.		
Phone	01 8428118	Email	info@diabetes.ie
Website	www.diabetes.ie	Facebook	www.facebook.com/DiabetesIreland/

13. 10 Down Syndrome

13. 10. 1 What is it?

- A person with Down Syndrome has an extra (3 instead of 2) chromosome 21 in most cases and due to this is also known as Trisomy 21.
- There are different types including Standard, Mosaic and Translocation.
- It is a complex condition which affects each child or young person differently.

13. 10. 2 Diagnosis

- Usually diagnosed during pregnancy, as a result of pre-natal tests, or soon after birth by a Paediatric Clinician.

13. 10. 3 Support and Information

Support may include play, physio, occupational or speech/language therapy. Children with Down syndrome are statistically more likely to be born with congenital heart defects than typical children and this sometimes requires corrective surgery. These surgeries are carried out in one of the national children's hospitals and have a high success rate. For more information and support regarding heart defects check out www.heartchildren.ie

Support	The Down Syndrome Centre Midlands (DSM Midlands)		
Purpose	Support organisation for People with Down syndrome and their families.		
Phone	(087) 173 4767	Email	dscmidlands@gmail.com
Facebook	www.facebook.com/dscmidlands		

Support	Laois Down Syndrome		
Purpose	Laois Down Syndrome operates a whole family support system including siblings and any other significant people in the lives of our members with Down Syndrome.		
Facebook	https://www.facebook.com/laoisdownsyndrome		
Phone	086 8279942 086 0491633	Website	http://www.laoisdownsyndrome.ie/ or www.downsyndromeireland.ie national website

Support	Offaly Down Syndrome Association		
Purpose	Support organisation for People with Down syndrome and their families.		
Facebook	www.facebook.com/downsynoffaly		
Phone	(089) 605 8346	Email	chair@dsoffaly.org

Down Syndrome Information booklet			
www.downsyndrome.ie/wp-content/uploads/2013/12/DSI_StudentPack_Home.pdf			
Facebook support and information group			
www.facebook.com/groups/577711845573217/			

13. 11 Dysgraphia

13. 11. 1 What is it?

- Dysgraphia is a condition that affects how a person writes regardless of reading ability.
- There are three types:
 - **Dyslexic Dysgraphia**
 - **Motor Dysgraphia**
 - **Spatial Dysgraphia**
- Children with dysgraphia can usually write but the writing will appear disorganised possibly with a mix of upper and lower-case letters, irregular sized letters and shapes.

- Children may have an unusual way to how they hold a pencil or sit and may experience discomfort when writing.
- Children may also have difficulty with skills such as tying shoes, opening and closing buttons and other tasks which require hand-eye co-ordination.
- The disorder is generally noticed when the child first starts writing. Letters may be inappropriately sized and letters poorly spaced. Many children will have a high IQ with no learning difficulties.

13. 11. 2 Symptoms

- Will take much longer to complete a written assignment.
- Will often become distressed when faced with the task of writing.
- The child will have difficulty writing between lines, use irregular size letters, may have spelling mistakes and some children will experience muscle cramping in the arm and shoulder.
- The level of difficulty will vary from child to child.

13. 11. 3 Diagnosis

A diagnosis is made by observing the child while writing. There will be a huge discrepancy between the child's writing ability and their ability to use a word processor.

13. 11. 4 Support and Information

Dysgraphia can be helped through the use of techniques to aid handwriting usually recommended by an OT, and/or by using another means of communication other than writing. Assistive technology and visuals can be of great support as can concepts such as mind mapping, adapted learning tasks and varied writing tools.

The Special Education Support Service (SESS) for support and information on Dysgraphia at: www.sess.ie/categories/specific-learning-disabilities/dysgraphia

Service	Dyslexia Association of Ireland		
Purpose	Support and Information		
Phone	01 8776001 Info: 0860562349 Appointment queries: 0860632786	Email	info@dyslexia.ie
Website	www.dyslexia.ie	www.facebook.com/DyslexiaIreland/	

Service	State Examinations Commission (SEC)		
Purpose	Provides supports for pupils in second-level examinations		
Phone	090 6442700	Email	sec_specialneeds@education.gov.ie
Website	www.examinations.ie		

13. 12 Dyslexia

13. 12. 1 What is it?

- A specific learning difficulty which presents challenges to people in the areas of reading, spelling and writing.
- Difficulties in organisation, sequencing and motor-skills may also present challenges.

13. 12. 2 Diagnosis

- Schools offer base-line assessments which give an indication of the child's development and learning. Standardised tests are often used for screening.
- A formal diagnosis is made by an educational psychologist through the school system or privately.

13. 12. 3 Support and Information

Support usually takes the form of extra tuition. In school, supports are in the form of class teacher support, support from a learning support teacher or the child may be granted resource hours. The Dyslexia Association of Ireland provide comprehensive supports and advocacy for people with Dyslexia including educational psychology assessments, group/individual tuition, in-service training for teachers, parent courses, awareness training and more. You can find them at www.dyslexia.ie or on their Facebook page www.facebook.com/dyslexiaireland

Service	Dyslexia Association of Ireland		
Purpose	Provides out-of-school supports for children with dyslexia either on a one-to-one basis or from a trained tutor		
Phone	01 8776001	Email	info@dyslexia.ie
	Info: 0860562349		
	Appointment queries: 0860632786		
Website	www.dyslexia.ie		

Service	Offaly Dyslexia Group
Purpose	To support children and adults with Dyslexia in the Midlands
Email	hello@offalydyslexiagroup.orgs
Phone	086 230 9009
Website	www.offalydyslexiagroup.org
Facebook	www.facebook.com/offalydyslexiagroup

13. 13. 1 Dyscalculia

13. 13. 2 What is it?

- A specific learning difficulty which presents challenges to people in the area of mathematics.
- Difficulties in organisation, sequencing and understanding mathematical concepts may also present challenges.

13. 13. 2 Diagnosis

- Schools offer base-line assessments which give an indication of the child's development and learning. Standardised tests are often used for screening.
- A formal diagnosis is made by an educational psychologist through the school system or privately.

13. 13. 3 Support and Information

Support usually takes the form of extra tuition. In school, supports are in the form of class teacher support, support from a learning support teacher or the child may be granted resource hours.

13. 14 Developmental Coordination Disorder (DCD)/ Dyspraxia

13. 14. 1 What is it?

- DCD is a difficulty with fine and/or gross motor co-ordination.
- It is a brain-based condition that poses problems with balance and posture.
- It can affect the development of skills such as climbing and running.
- DCD persists into adulthood and may present differently over time responding to environmental and social factors.

13. 14. 2 Symptoms

- Difficulty with dressing, e.g., opening and closing buttons, zips and putting on or taking off shoes.
- Difficulties with skills such as hopping, jumping, kicking a ball.
- Lateness in reaching milestones such as crawling, walking, sitting, or speaking.
- Difficulties in tasks such as jigsaw making or activities involving the use of pencil or paintbrushes.
- School age children will present with similar problems, with difficulties completing tasks, copying from the blackboard and may often have difficulty with following instruction.

13. 14. 3 Diagnosis

- A child first needs to have an assessment of need; this can be done by contacting your local Assessment Officer.
- Usually, an OT will be involved in your child's treatment in providing specific programmes to assist in his/her difficulties.
- Speech and language services may also be provided depending on the needs of the child.
- When there is a diagnosis of Dyspraxia/DCD your child may be sanctioned resource hours in school or the assistance of an SNA if needed.

13. 15 Developmental Language Disorder**(Specific Speech and Language Impairment)****13. 15. 1 What is it?**

Developmental Language Disorder (previously known as Specific Speech and Language Impairment) can affect both the spoken word (expressive language) and understanding (receptive language). This is a developmental language impairment and not related or caused by other developmental impairments such as hearing loss, cognitive or brain injury.

13. 15. 2 Symptoms

- Difficulty with spoken language, may have very limited vocabulary for his or her

age and a poor grasp of grammar.

- Varied profile of language difficulties which may include speech, grammar, vocabulary, conversational skills, and effecting understanding and expression (IASLT, 2017).
- Although understanding of language might be quite good, it may impact on social development and imaginative play.
- If the child has difficulty with receptive language, they are most likely to have difficulties in listening, following instructions and generally understanding direction.
- Some children may have difficulties in both spoken language and receptive language.

13. 15. 3 Diagnosis

Parents or the Public Health Nurse (PHN) may identify a problem at an early stage. School age children will normally be assessed by a Psychologist and Speech and Language Therapist if it is suspected that the child has a specific SLI. The Department of Education and Skills require this before they will grant extra supports to a child.

13. 15. 4 Support and Information

Support involves implementing a programme by the Speech and Language Therapist (SLT) which is usually supported by the parents and the school, if the child is school age. This programme will address the specific area the child has difficulties with. The Department of Education and Skills require an assessment by a Psychologist and a Speech and Language Therapist before they will grant extra supports to a child.

HSE Speech and Language Therapy Services			
Offaly Phone	057 932 1501	Laois Phone	057 869 6945 057 931 9598

The National Council for Special education (NCSE) has a list of all speech and language classes in the country. Go to: www.ncse.ie

For a list of Independent Speech and Language Therapists in the Laois Offaly area check the ISTI website here <https://isti.ie/find-a-therapist/>

13. 16 Epilepsy

13. 16. 1 What is it?

- Epilepsy is a neurological condition which affects the brain. Abnormal electrical activity in the brain causes the person with epilepsy to have recurring seizures.
- Epilepsy can also be triggered by other underlying disorders. If the underlying disorder is treated, sometimes the epilepsy may be stopped.

13. 16. 2 Symptoms

- Symptoms of epilepsy can vary a lot from person to person as it depends on the part of the brain affected.
- Seizures can affect the whole brain causing generalised seizures or affect specific parts of the brain causing partial seizures.
- Generalised seizures occur when a large part of the brain is affected, and the child/person loses consciousness.
- Partial seizures also vary depending on the type, duration and severity of the seizure. Some people may stay awake and aware but may experience unusual sensations relating to the senses. Others may experience a brief loss of consciousness and may twitch, blink, chew or smack their lips but these seizures usually last no more than two minutes.

13. 16. 3 Diagnosis

Initially a doctor will take a complete medical history relating to family history and details about the seizure. The patient will then be recommended for diagnostic tests such as an EEG which reads the brains electrical activity, brain imaging, blood tests and developmental or neurological tests.

13. 16. 4 Support and Information

Epilepsy is most commonly treated by medication. The medication may help stop the seizures from occurring. However, a holistic approach including medication, mental health/stress management, positive sleep hygiene and self-efficacy/empowerment of the individual has been shown to be very effective.

Service	Epilepsy Ireland (formerly Brainwave)		
Purpose	Tullamore branch covering Offaly, Longford, Laois and Westmeath		
Phone	(057) 93 46790	Email	cmolloy@epilepsy.ie
Website	www.epilepsy.ie	Facebook	www.facebook.com/epilepsy.ie

13. 17 Fragile X Syndrome

13. 17. 1 What is it?

- Fragile X syndrome is a condition that affects both boys and girls.
- It primarily causes learning difficulties and is the most common identifiable inherited cause of intellectual disability, according to the Fragile X Ireland website.

13. 17. 2 Symptoms

- Often babies are slow to smile, sit and walk and may have disturbed sleep patterns.
- Boys will be more likely to present with learning difficulties with up to a third of girls presenting with learning difficulty.
- Language delay is often apparent at an early age and behavioural features may include short attention span, difficulty focusing, emotional regulation challenges and hyperactivity.

13. 17. 3 Support and Information

Fragile X syndrome is diagnosed by a blood test.

Special Education Support Service: www.sess.ie/categories/assessed-syndromes/fragile-x

Service	Irish Fragile X Society (IFXS), c/o Inclusion Ireland, Unit C2, The Steel Works, Foley Street, Dublin 1		
	Or Maria Panza, Branganstown, Kilcock, Co. Kildare		
Purpose	Support and Information		
Facebook	www.facebook.com/IrishFragileXSociety/		
Phone	01 6519689 Or Maria: 0876573089	Email	info@fragilexireland.org
Website	www.fragilexireland.org		

13. 18 Muscular Dystrophy

13. 18. 1 What is it?

- Muscular Dystrophy (MD) is characterised by progressive weakening and wasting of the muscles of the body caused by a defect in one of the genes. This gene affects the muscles, and you can be a carrier but never develop MD.
- There are nine different types of MD. Duchenne MD is the most common.
- Duchenne MD is genetic, and it tends to run in families.

13. 18. 2 Symptoms

- Babies may not initially show any symptoms, but may be 'floppy' or have difficulty reaching gross motor milestones such as sit to stand. MD usually begins to appear in children before the age of six.
- The first signs of MD usually affect movements, such as falling often, difficulty in running and jumping, walking on the toes, stiffness, or pain in the muscles.
- As the condition progresses walking and movement becomes more difficult.

13. 18. 3 Diagnosis

Since the condition is inherited, families are often aware of the genetic link. However, for some there will be no genetic link and the condition occurs spontaneously. The condition is usually formally diagnosed by a blood test in addition to a biopsy, which may only be carried out at specialised hospital departments so as to acquire a high-quality sample for reliable diagnosis. In some cases, diagnosis can happen via amniocentesis at around 10 weeks gestation.

13. 18. 4 Support and Information

- Medications and therapy can help manage the condition to make the child's quality of life as good as possible.
- Physiotherapy helps considerably.
- Occupational therapy is also very important and enables the child in self-care skills such as washing, dressing and self-feeding.
- Hydrotherapy (water therapy) is often recommended as limb movement is much easier in water and it is a very low impact activity on the muscles.

- Speech therapy and mobility aids are important for the child to be out and about and communicate and socialise as much as possible.
- Assistive technology and mobility aids such as electric wheelchairs and adapted seating are of great importance and can be accessed via an occupational therapist.

Support and Information

Service	Muscular Dystrophy Ireland Midlands Region
Purpose	Support and Information
Website	www.mdi.ie
Laois Family Support	Marie Kealy Tel: 086 6066107 Email: mariek@mdi.ie
Youth Respite Worker	Sinead Glennon Tel: 086 3899285 Email: sinead@mdi.ie

Service	Muscular Dystrophy Society of Ireland Ltd., 75 Lucan Road, Chapelizod, Dublin, D20DR77		
Purpose	Provide information and support to people with neuromuscular conditions and their families through a range of support services		
Phone	01 6236414	Email	reception@mdi.ie / info@mdi.ie
Website	www.mdi.ie	Facebook	www.facebook.com/mdiireland/

13. 19 Oppositional Defiant Disorder and Conduct

Disorder

13. 19. 1 What is it?

- Oppositional Defiant Disorder (ODD) is characterised by repeated defiance by the child to authority figures, usually in school, which has a negative impact on the child's ability to function within the school system and socially with their peers.
- Conduct disorder (CD) is more challenging and more socially disruptive than oppositional defiant disorder (ODD) although sometimes one is mistaken for the other.

13. 19. 2 Symptoms

- A person with CD often displays more physical aggression and threatening behaviour than a person with ODD and often appear to lack empathy for others.
- It is rare to present with ODD alone and additional (co-morbid) conditions often occur such as ADHD.
- Children with CD may often carry out disruptive or damaging activities such as breaking things or lighting fires.

13. 19. 3 Support and Information

Children and young people with ODD are usually taught self-regulation and coping strategies. Many children with CD often have very complex problems and usually involve a team of agencies and professionals working together on a comprehensive plan.

The Special Education Support Service provide information and support for parents and schools: www.sess.ie/categories/emotional-disturbance-and/or-behavioural-problems/conduct-disorder

13. 20 Prader-Willi Syndrome**13. 20. 1 What is it?**

Prader-Willi syndrome is a complex genetic condition that affects many parts of the body. PWS is a rare syndrome caused by an abnormality of chromosome 15.

PWS is a multiphase syndrome:

1. In infancy, this condition is characterized by weak muscle tone (hypotonia), feeding difficulties, poor growth, and delayed development.
2. Beginning in childhood, affected individuals develop an insatiable appetite, which if not managed can lead to chronic overeating (hyperphagia) and obesity.
3. The development of an insatiable appetite/drive to eat, accompanied by intense or relentless food-seeking usually begins from 8 years of age onwards

13. 20. 2 Symptoms

- An unregulated appetite and easy weight gain – morbid obesity, excessive weight and associated health problems.

- People with Prader-Willi syndrome typically have mild to moderate intellectual impairment and learning disabilities.
- Behavioural problems are common, including temperamental outbursts, stubbornness, difficulty controlling emotions and compulsive behaviour such as picking at the skin.
- Sleep abnormalities
- Lack of sexual development
- PWS is a spectrum disorder and symptoms vary in severity and occurrence among individuals.

13. 20. 3 Supports

- Multidisciplinary team approach to a care plan
- Healthy Eating Habits
- Environmental Management (usually including locked food access) and psychological food security.
- Behaviour Management Strategies

13. 20. 4 Support and Information

Special Education Support Service:

www.sess.ie/categories/assessed-syndromes/prader-willi-syndrome

Service	Prader-Willi Syndrome Association Ireland (PWSAI), Carmichael Centre, North Brunswick Street, Dublin 7.		
Website	www.pwsai.ie		
Phone	087		
	2522832 or		
Phone	0873851387	Email	info@pwsai.ie
Facebook	www.facebook.com/Prader-Willi-Syndrome		

13. 21 Rare Disease and Rare Chromosome Conditions

13. 21. 1 What is it?

If a disease is to be known as rare/orphan, it must affect under 1 in every 2000 people. 80% of the 6000 known rare diseases originate in the genes and it is estimated that there are more than 30 million individuals living with rare diseases in Europe. Rare diseases include Prader-Willi syndrome, Wolf-Hirschhorn syndrome and Ehlers-Danlos syndrome (EDS) but there are many that go undiagnosed due to insufficient diagnostic testing techniques. These are known as SWANs or Syndromes Without a Name.

13. 21. 2 Symptoms

- Chromosome disorders occur when the whole copy of one or more genes has been compromised and are also known as chromosome aberrations. These can be numeric or structural.
- Often accompanied by co-morbid conditions such as autism, intellectual disability or epilepsy.
- In 2013 the National Clinical Programme for Rare Diseases was set up between the HSE and the Royal College of Physicians of Ireland. The aim was to improve and develop access, quality and value in services, care and diagnostics. They published their Model of Care for Rare Diseases in 2018.

13. 21. 3 Support and Information

- An international network of people with rare diseases has been developed by EURORDIS- Rare Diseases Europe and Care4Rare Canada called RareConnect, a patient led community platform.
- Rare Disease Ireland (formally GRDO) is an NGO that acts as a national alliance for voluntary groups that represent the opinions, needs and aspirations of the Rare community. Find out more at www.rdi.ie
- RARE Ireland is a support organisation supporting approximately 600 families of children with rare conditions that include but aren't limited to chromosome abnormalities, neurological conditions, SWANs and childhood cancers. They have a strong community network and provide supports including days out, family friendly events and an active social media that serves as an information hub and online support system.

Service	RARE Ireland		
Website			
Phone	Tel: 089 422 0228	Email	
Facebook	www.facebook.com/rareireland		

13. 22 Spina Bifida and Hydrocephalus

13. 22. 1 What is it?

- Spina Bifida causes incomplete development of the spinal cord in the womb.
- The spine is made up of bones called vertebrae which protect the spinal cord, sometimes one or more of these bones do not completely form and split and protrude out onto the back in a bulge.
- There are 3 types:
 1. Spina bifida occulta
 2. Spina bifida meningocele
 3. Myelomeningocele
- It is a Latin term which literally means a split in the spine.

13. 22. 2 Symptoms

There are three main types of Spina Bifida, and the symptoms will depend on the type and form of spina bifida and to the extent which the spinal cord has been exposed. The three most common forms of spina bifida are Spina Bifida Occulta, Meningocele and Myelomeningocele.

Effects of Spina Bifida can vary from mild to severe. These can include hydrocephalus (water on the brain), varying degrees of paralysis, and loss of sensation in the lower limbs, pressure sores and bladder and bowel incontinence.

13. 22. 3 Diagnosis

Spina Bifida is usually diagnosed before birth. Mild cases may not be picked up until after birth.

13. 22. 4 Support and Information

Support varies depending on the type and severity of the condition and is provided through a medical practitioner and early intervention team. Spina Bifida and

Hydrocephalus Ireland (SBHI) provide comprehensive support for individuals living with Spina Bifida, Parents and professionals with services including education, respite, catheterisation training, peer support programmes and more.

Service	Longford / Westmeath SBHI Support Worker		
Phone	085 7119062	Email	sjacobsen@sbhi.ie

Service	Spina Bifida hydrocephalus Ireland (SBHI), National resource Centre, Old Nangor Road, Clondakin, Dublin. D22 W5C1		
Phone	01 457 2329	Email	info@sbhi.ie
Facebook	www.facebook.com/SBHIreland		

13. 23 Visual Impairment

13. 23. 1 What is it?

The World Health Organisation (WHO) defines visual function at four different levels:

- Normal vision
- Moderate visual impairment
- Severe visual impairment
- Blindness

13. 23. 2 Symptoms

- Symptoms will vary with age.
- School age children may have difficulty with copying work from white/black board or show difficulties with activities which require good vision.
- Older children may have unusual eye movements, have cloudy or bloodshot eyes, or appear clumsy with poor hand eye coordination.

13. 23. 3 Diagnosis

Diagnosis depends on the type and cause of the visual impairment. All babies' eyes are examined after birth and at developmental checks.

13. 23. 4 Support and Information

- Support will depend on the cause and symptoms of the impairment.
- It may vary from surgery to medication.
- Efforts may be on supporting the child to work with their blindness or impairment.
- Visually impaired children will be entitled to low vision aids and the services of a teacher for the visually impaired when they are in school.
- The National Council for the Blind (NCBI) have a shop from which aids can be purchased, including a 'talking book service' and a 'braille book service'.

Service	NCBI Alvernia House, St. Fintan's Campus, Dublin Road, Portlaoise, Co. Laois, R32 YFW6		
Purpose	Support and Information		
Website	www.ncbi.ie/		
Phone	1850 33 43 53	Email	info@ncbi.ie

Service	National Council for the Blind of Ireland (NCBI), Whitworth Road, Drumcondra, Dublin 9		
Website	www.ncbi.ie		
Phone	1850 334353	Email	info@ncbi.ie

Service	ChildVision: National Education Centre for Blind Children, Grace Park Rd., Dublin 9		
Phone	01 8373635	Email	info@childvision.ie
Facebook	www.facebook.com/ChildVisionVI		
Website	www.childvision.ie		

Service	National Council for Special Education (NCSE)		
Purpose	Information for Parents/Guardians of Children and Young People who are Blind/Visually Impaired		
Phone	046 9486400	Email	info@ncse.ie
Website	www.ncse.ie		

Service	Visiting Teacher (VT) Service Supporting Children with Visual Impairment in Mainstream Schools		
Purpose	They provide direct teaching and support advice for parents and mainstream teachers. They provide support in the home for parents and younger children		
Phone	Geraldine Carr: 0858701308	Email	Geraldine.carr@ncse.ie
Website	www.ncse.ie		

Service	Fighting Blindness, 3rd Floor, 7 Ely Place, Dublin 2, D02 TW98		
Website	www.fightingblindness.ie		
Phone	01 6789004	Email	info@fightingblindness.ie
Facebook	www.facebook.com/Fighting.Blindness.Ireland/		

Service	Irish Guide Dogs, National Headquarters and Training Centre, Model Farm Road, Cork		
Email	info@guidedogs.ie		
Phone	1850 506 300		
Website	www.irishguidedogs.ie	Facebook	www.facebook.com/irishguidedogs/

Service	Feach, PO Box 11581, Dublin 18		
Purpose	A support group for parents of blind and visually impaired children		
Website	www.feach.ie	Email	feachmail@gmail.com
Facebook	www.facebook.com/FeachVIP/		

GLOSSARY & JARGON BUSTER

Common Acronyms

ABA	Applied Behaviour Analysis
ABI	Acquired Brain Injury
ADHD	Attention Deficit Disorder
AIMS	Access and Inclusion Model
AON	Assessment of Need
ASD	Autistic Spectrum Disorder
BOM	Board of Management (school)
CAMHS	Child and Adolescent Mental Health Service
CARS	Childhood Autism Rating Scale
CCC	County Childcare Committee
CD	Conduct Disorder
CDNT	Children's Disability Network Teams
CF	Cystic Fibrosis
CP	Cerebral Palsy
CT (Scan)	Computed Tomography Scan
CYPMHC	Child and Young Person Mental Health Coalition
DCD	Developmental Coordination Disorder
DEIS	Delivering Equality of Opportunity in Schools
DES	Department of Education and Skills
DFI	Disability Federation Ireland
DLD	Developmental Language Disorder
DS	Down Syndrome
DSI	Down Syndrome Ireland
ECCE	Early Childhood Care and Education
EIT	Early Intervention Team
ELP	Essential Lifestyle Planning
EPSEN	Education for Persons with Special Educational Needs
EWO	Education Welfare Officer
EYP	Early Years Practitioner
GLD	General Learning Disability
GP	General Practitioner
HSE	Health Service Executive

Glossary & Jargon Buster

IDG	Inter-Departmental Group
IDP	Individual Development Plan
IEP	Individual Education Plan
INHEF	Inclusive National Higher Education Forum
ISL	Irish Sign Language
MD	Muscular Dystrophy
MDI	Muscular Dystrophy Ireland
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
NAS	National Advocacy Service
NBSS	National Behaviour Support Service
NCPD	National Council for People with Disabilities
NCSE	National Council for Special Education
NDA	National Disability Authority
NEPS	National Educational Psychological Service
OLHC	Our Lady's Hospital Crumlin
ODD	Oppositional Defiant Disorder
OT	Occupational Therapist
PATH	Planning Alternative Tomorrows with Hope
PDA	Pathological Demand Avoidance
PHN	Public Health Nurse
PSI	Psychological Society of Ireland
SEN	Special Educational Needs
SENCO	Special Education Needs Coordinator
SENO	Special Education Needs Organiser
SET	Special Education Teacher
SLT	Speech and Language Therapist
SSLD	Specific Speech and Language Disorder
SSP / F	Student Support Plan / File
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
YAMHS	Young Adult Mental Health Service

