

2024 version



# Understanding your child's Autism diagnosis



IRELAND'S AUTISM CHARITY

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## Foreword

Welcome to the autism community. Today is the start of a new journey for you, your child and your family.

Starting any new journey can bring with it a mix of feelings and emotions. As a parent or guardian you may be feeling concerned, confused or uncertain about the future or you may be feeling happy, content and assured of your child's recent diagnosis. It is a time where many emotions are at play and it is important to note that each emotion is as valid as the other.

Receiving a diagnosis can answer many previously unanswered questions you had as a parent/guardian and indeed it can raise many new questions for the autistic person.

We hope the information contained in this resource pack provides you with the knowledge you require to understand your child's autism to understand your child's autism and support them in the best possible way. Before you begin to read the information contained in this pack, do remember that your family is now part of a wonderfully rich community.

From the [AsIAm.ie](http://AsIAm.ie) team

Lucena Child and Adolescent Mental Health Services (CAMHS) provides services for young people under age 18 with moderate/severe mental health concerns. We were delighted to partner with AsIAm to support the development and publication of this much needed resource, which is one of a three-part series. The aim of Lucena CAMHS's involvement in these publications is to promote autism acceptance and widen public understanding of autism. As a CAMHS, we recognise the negative impact of late identification, stigmatisation, and environmental demands (e.g. school) can have on the mental health of autistic individuals. We hope that this publication goes some way to preventing moderate/ severe mental health concerns in the autistic community.

The publication of this resource has been supported by the Saint John of God (SJOG) Foundation. The Foundation fundraises on behalf of a range of SJOG Community Services who provide support to children and adolescents experiencing mental health challenges and to adults and children living with a range of intellectual disabilities. We thank the foundation, and the psychologists, occupational therapists and speech and language therapists on Team A Lucena CAMHS for their input into the development of this resource.

For more information about the work of Saint John of God Foundation see [sjogfoundation.ie](http://sjogfoundation.ie).

For more information about Lucena CAMHS please see [www.lucenaclinic.ie](http://www.lucenaclinic.ie).





## What is Autism?

Like all people, autistic people will have unique strengths and abilities and these strengths can very often be linked to seeing the world in a different way to other people. Examples might include the ability to focus intensely on areas of interest, or an innate sense of honesty, loyalty and fairness.

Autism is a lifelong, developmental difference or disability. It is characterised as a difference in communication and socialising preferences, and differences in how a person experiences the world around them.

Autism is a part of the broader neurodivergence family which encompasses differences or disabilities such as ADHD, Dyslexia and Dyspraxia, Epilepsy, Tourette's Syndrome and Dyscalculia. Whilst autistic people are born autistic, it is not something that parents learn of when their child is born.

As a child grows up, they may begin to communicate differently to other people, find day-to-day situations stressful or overwhelming and rely on structure and routine in order to manage. This in turn may lead to a person receiving an autism diagnosis. Previously, there were other diagnoses such as Asperger Syndrome and PDD-NOS - these are no longer used by professionals and 'autism' is now used as an umbrella term to capture the different ways that autism can present in individual people.

As autistic people develop differently from others and experience the world in a different way, autistic peoples' thought processes and approaches to situations may be different to most people.

Many autistic people have a different sensory profile to non-autistic people which means day to day environments can be challenging to manage or are experienced differently.



## Why is Autism Known as a Spectrum?

Autism is **not** a linear scale or line with people at one end being 'mildly autistic' and experiencing few barriers in any area and then people at the other end being 'severely affected' and experiencing all of the barriers all of the time. This linear scale does not reflect how people experience autism.

Thinking of autism as being a circular spectrum is a much more helpful and accurate way to understand the variation and individuality across autistic people.

Autistic people are often said to have scattered skill sets; this means that the gap between areas of strength and areas where a person requires support can be much greater than for non-autistic people. This means it is easy to both overlook the challenges a person may be experiencing or to underestimate a person's abilities.

Autism is said to be a spectrum because while autistic people can experience the world differently in specific areas (like sensory processing, social interaction and communication) not all people will have the same profile of differences. So, you could have one autistic person who enjoys public speaking and has a very strong preference for routine. But another autistic person could be non-speaking and quite enjoys going to new places with little preparation. Also, these experiences can vary depending on the day, situation or even year depending on what else is going on in someone's life. Other autistic people might really enjoy going to rock concerts on one day, but on another find the ticking of a clock unbearable.

Being autistic is a highly individual experience and is different for every person, depending on a number of different factors in the person's life at any one time.





## What Do the Various 'Levels' of Autism in the DSM-5 Mean?

The DSM-5 is the current version of the diagnostic manual that clinicians use to determine if someone meets the criteria for a diagnosis of autism.

It outlines 3 levels of required support for those diagnosed as autistic.

Level 1 meaning that they "require support"

Level 2 "require substantial support"

Level 3 "require very substantial support".



While it is positive that the DSM-5 acknowledges that autistic people require various levels of support and focuses on support needs rather than their perceived capacity or ability, it does not recognise that sometimes people may require substantial support in one area of their life and no support in other areas.

It also does not take into account that the amount of support required in any individual area can vary depending on the day or situation.

The DSM-5 model is an improvement from the linear 'high' versus 'low' functioning view that the DSM-4 imposed but there is still room for it to improve to describe the spectrum nature of the diagnosis and the full diversity of traits that autistic people experience.

## My child has received their diagnosis...what next?

It is important to take your time in learning about this whole new world which you may have never known about before.

You are of course your child's greatest advocate but it is important to not put yourself under pressure, or to constantly think you are not doing enough. Going on this journey, you will learn lots and undoubtedly not get everything right - but that is part of learning and part of every family's story.

It is a good idea to make a list of what you need to do and work through it, at your own pace. Finding a local support group in your area can be a great space to learn from other parents and families and to also share your own experiences.

Read about autism, whether through Autistic-led websites, online support groups or books, or watching videos or programmes about autism. AsIAM.ie have a range of advice and support you may find helpful.

Whether you are a parent of an autistic child or an autistic adult (you can of course be both), it is important to learn about autism through the autistic voice; hearing about experiences directly from autistic people.

There is a huge body of knowledge out there available in the form of books, online content, social media postings, information leaflets etc, that has been produced by autistic people.

Following autistic advocates on social media is a great way to learn about what the autistic community cares about and what supports they need.

Forming a strong understanding of **what autism is** and **what autism isn't** is going to be a great basis going forward for how you support your child or yourself.

You can access information on 'rights and entitlements' by accessing autism advice and guidance at [AsIAM.ie](http://AsIAM.ie).





## Understanding My Child's Autism

When your child receives their autism diagnosis, it is natural that you will have many questions. You will have received a report that should include recommendations of support. This could include areas such as psychological support, speech and language therapy and/or occupational therapy recommendations, and educational requirements.



It is important to take a strengths-based approach to your child's autism diagnosis. In a society where autistic people face many barriers, it is totally understandable that it may take some time for you to process and understand your child's diagnosis. You may feel a range of emotions and it is important to recognise those emotions and to ask for support where you need it.

It is equally important to ensure your child has the opportunity to hear about their autism in a positive way in the post-diagnosis period. Focus on what your child can do, rather than what they cannot do. Too often we focus on the areas a person needs support in, instead of identifying an individual's strengths and interests and using these to support a person in developing new skills in areas in which they may require support. Understanding your child's strengths and interests will help you understand your child's autism.

**Below are some of the characteristics an autistic person might display, this list is by no means exhaustive:**

Passionate and driven about interests

Detail oriented

Intense focus when engaged in a task

Strong memory

Honesty

Loyalty

Compassionate

Empathetic

Strong sense of right and wrong

Non-judgemental

Creative

Thinks outside the box

Rich sensory experience of the world

It is very important for parents to remember first and foremost that your child has not changed because of their autism diagnosis. They are still the same child they were before they received their diagnosis. Seeking a diagnosis has just allowed you as parents/ guardians to get some answers for some questions you or your child may have had. It has also identified your child's areas of support and strengths. Indeed, for the young person it may also give them a better understanding of themselves.

Autism is a difference in how one thinks and experiences the world, which can range from differences in communication to processing the sensory environment. The world is built with those without neurodivergence in mind, and does not take into consideration that not everyone thinks or experiences the world the same way. This can make many aspects of day-to-day life disabling, however there is nothing negative or wrong about thinking differently.



Whilst autism is considered a disability by society, we shouldn't see disability as a 'bad' or 'wrong' thing or as anything to be ashamed of. Nor should it be seen as 'a lack of capacity or ability'. Often, the opposite is true! Having a disability or a difference like autism is not a negative experience, but a part of who your child is as a person. Or indeed who you are as an autistic young person. There are many strengths that come from understanding and experiencing the world in a different way.

Focusing on autistic strengths can aid your own understanding of your child's experience. Many autistic people's strengths and abilities derive from this different perspective on life. An autism diagnosis may mean your child requires additional support and may have a different journey through life, however it does not have to limit a person's future or opportunities.



## Common Characteristics of Autism

We have listed the main characteristics related to autism. It is important to remember that everyone is different, and that this list is not exhaustive.

### Autistic Communication

Autistic people have differences in how they prefer to communicate.

- May be verbal or non-speaking
- May need more time to take in verbal information and understand it
- May have an unusual use of words/have a different understanding of vocabulary
- Might have issues with finding the right words to say to certain people and in certain situations
- Could take phrases/idioms literally
- May interpret jokes differently or have a different sense of humor
- May find it difficult to articulate frustrations/anxiety/distress or causes of emotional dysregulation, and might communicate this differently
- May speak in a different tone of voice, a different accent, or at a different rate or volume
- May engage in **Echolalia** (this term is explained further on)
- May have a flat affect or show little emotion on their face, even if they are feeling very intense emotions
- May interpret differently, or miss, facial expressions or non-verbal social cues

## How can I support my child?

- To avoid confusion, limit your use of irony and sarcasm – speak clearly and concisely, and say exactly what you mean.
- Don't speak with lengthy sentences or ask more than one question at a time - give step-by-step instructions, say and/or ask one at a time, and give time for the person to process the information given.
- Don't rephrase instructions/questions – just repeat them.
- Try not to pressure your child - be patient and give your child as much time as they need to process what you say.
- Don't insist on verbal responses - provide alternative communication modes if your child has difficulties with finding the right words to speak. i.e. PECS, notepad, pictures, etc.



## Play and Social Preferences

Autistic people have different preferences for how they engage socially with others. What might be common characteristics of autism regarding social interaction?

- May avoid eye contact, may find eye contact to be unnatural, too intimate or painful. May alternatively have intense eye contact.
- Differences reading emotions of others, or in showing their own/displaying emotion.
- May not read social cues as non-autistic people do - some may miss social cues like boredom, irritation, flirtation, or may find it difficult to know when a conversation is finished.
- May find it difficult to know how to start a conversation with someone and to keep it going.
- May not get the point of 'small talk' and may have a preference instead for talking about things they (or their conversational partner) have an interest or passion in.
- There may be a preference all or some of the time for their own company/spending majority of time alone.
- May socialise in accordance with their preferences and passions e.g., might enjoy socialising with others through online gaming, or through clubs related to their hobbies.
- May not in the same way read social cues in a typical way - they may miss social cues, or find it more difficult to initiate, maintain or finish conversations.
- For many reasons (such as sensory overwhelm and communication preferences), an autistic person may have difficulty interacting with people in group settings and may find social gatherings such as parties uncomfortable, or socialising particularly in unfamiliar environments uncomfortable.

- Might like to use their interests to socialise i.e., membership of a club.
- May enjoy need for consistency in social situations.
- May feel anxious or distressed when unexpected events happen in a social situation e.g., a person arriving who was not expected.
- May be compelled to hide their true self in social interactions e.g. may use scripted language, may force eye contact etc. Research suggests that engaging in these behaviours can impact negatively on self-esteem and mental health.
- May find friendship difficult e.g. making friends and/or keeping friends.
- May have different understanding of, and preferences for romantic relationships.
- Learning some lines of conversation which can be inserted into specific social situations.
- May have a particular preference for pattern based play – for example, collecting objects, sorting/arranging, colour coding, or lining up.
- May have a special interest, passion, and particular toys or hobbies which they wish to study, talk about or be engaged with all the time.

### How can I support my child?

- First, most importantly, **do try not to force or impose social situations on autistic children who appear reluctant to take part in these situations.** Take, for example, a situation most adults find unnerving or uncomfortable, such as being invited to a party where you might only know a few people. Such an occasion can be overwhelming and can increase one's anxiety. Similar feelings are experienced when autistic children are forced into certain social situations such as unexpected playdates, playing a sport, or doing an activity they don't like, or being with other children.
- Secondly, you can encourage your autistic child to engage in socialising without raising their anxiety. Support your autistic child in socialising in ways they find rewarding and enjoyable. This will involve an open-mind, patience and possible trial and error when trying to work out which situations and ways are best. A key element to this is **deepening your understanding of your autistic child's interests and listening to them when they communicate their preferences.** By doing so, you will be better able to support and locate opportunities for your child's socialising preferences, whatever they may be and take part in clubs related to their interests, if they want to. For example, find social outlets for your child that link with their passions e.g. a club based on their interest. This will make socialising easier for your child and more in line with their preferences.

### Some ways to encourage socialising include:

1. Help your child understand what a friend is by using social stories, books or scenes from films or television programmes.
2. Support your child in being their authentic self in social situations and with finding friends who accept your child for who they are.
3. Advocate for your child with their school to foster a more inclusive environment that respects and embraces difference. Help raise awareness of current understandings of autism in this setting.
4. Talk to your child about social situations that cause distress and problem solve ways to ease this distress. Can the environment be changed? Does your child want to learn how to manage this situation differently? Remember, it is important to avoid 'treatments' targeting autism directly or those that try to make an autistic person something they are not.
5. If you are the parent/guardian of an older child, try to engage your child in autism specific teenage programmes. Please see [AsIAm.ie](http://AsIAm.ie) for further information on such programmes.



## Sensory Processing

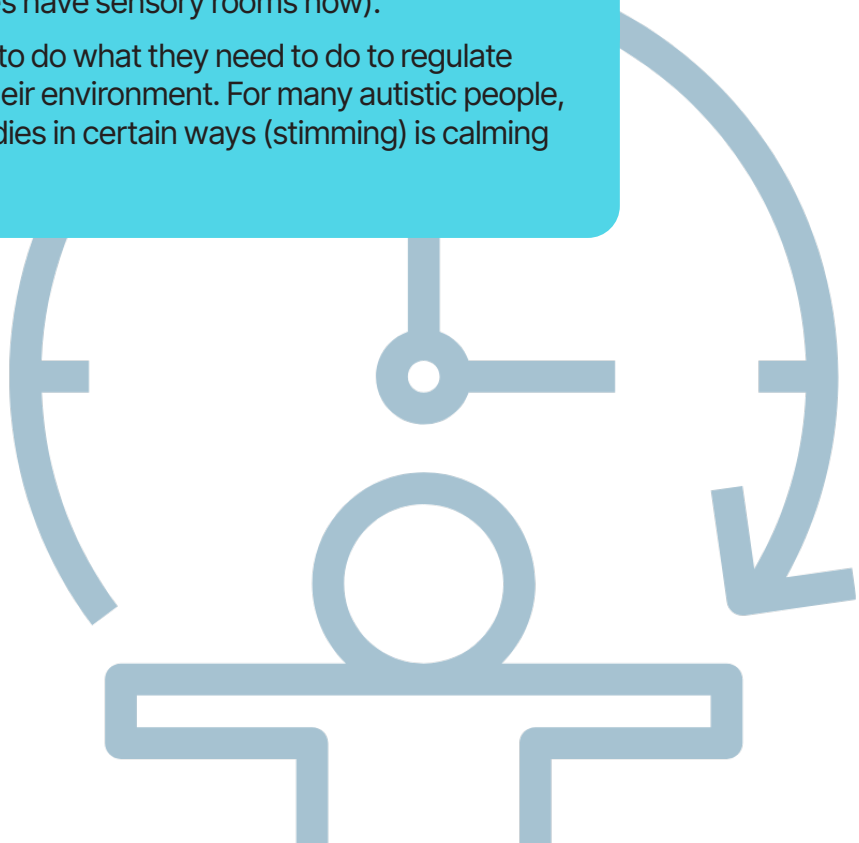
Autistic people may experience the world differently through the senses of taste, touch, smell, sound, movement and sight.

- An individual may more intensely feel certain sounds, smells, colours or textures, sometimes to the point that it can be overwhelming and/or impact physically (e.g., painful, nauseating). Equally may be attracted to and enjoy other sounds, smells, colours or textures, and may have favourite textures, sounds, colours or smells. This might mean an autistic person might have specific preferences for things such as foods, clothes and activities.
- May find crowded spaces, certain environments (such as school or supermarkets) and group conversations harder to manage from a sensory perspective.
- May use voice experimentation, for example might enjoy saying certain words/phrases, making certain sounds, or speaking a certain way, and these vocalisations might be out of context.
- May have a high/low pain threshold.
- May become overwhelmed to the point of “meltdowns” or “shutdowns” if their communication and sensory needs are not met. Autistic children have described meltdowns as feeling totally out of control externally, and shutdowns as feeling out of control internally.
- May 'stim' (short for self-stimulatory behaviour), which is a series of repetitive actions/movements that an autistic person may do when excited, anxious, stressed or stimulated, or when they wish to communicate but can't find the words (e.g. flapping hands, rocking, pacing, repeating phrases). Almost everyone stims to some degree in their own way (e.g. cracking knuckles, tapping feet, or humming/whistling). Autistic people are usually more overt when stimming, or may need to stim more often than non-autistic people (e.g. for regulation).
- May require routine, structure and certainty to compensate for an unstructured and at times overwhelming world



## How can I support my child?

- Every child is different, so no child will experience the same sensory processing differences. Some may be hyper or oversensitive while others may be hypo or undersensitive, and may seek loud sounds or lots of different sounds. It is important to find out what the stress triggers are for your own child before making the changes necessary in their immediate environment.
- Home should be a safe and comfortable space. Perform your own **evaluation** of the home environment. Is there anything that could potentially be causing your child stress e.g. the feel of their bedclothes, smells from the kitchen, clocks ticking?
- Keep in mind that even though the sensory information (e.g sounds) might not bother you, it can be overwhelming for a child or young person with sensory aversions.
- Think too about the sensory aspects of your home your child might enjoy and create more opportunities for this e.g. having a trampoline, or creating a sensory space with certain toys (fidget, soft/cuddly, squishy, gloopy), certain noises, certain smells, etc.
- Be aware of other environments your child is going to be in and support their sensory needs in these environments e.g. providing sunglasses if lights are too bright and **ear defenders** if sounds are too loud.
- Both at home and out and about, allow your child or young person opportunities for time outs to relax and recharge, such as quiet corners or chillout spaces (some large shopping centres have sensory rooms now).
- Allow your child to do what they need to do to regulate themselves in their environment. For many autistic people, moving their bodies in certain ways (stimming) is calming and soothing.





## How can I support my child?

- Encourage their passions, and allow them space to engage in how they prefer to play with toys/objects. Allow plenty of time for transitions away from these preferred activities.
- Consider, support and find and encourage outlets for high levels of energy e.g. movement breaks during homework.
- You can help a child who is stimming by giving them enough time and space to do what they need to do to regulate themselves and by not drawing attention or interfering with how they stim unless they are at risk to themselves or others around them.
- In as much as possible, keep a consistent routine. Think before you change things up and ask if it needs to change - some autistic children are ok with big and small changes to the environment, others are not. Think before you move things around the house (e.g. how things are organised in their bedroom), consider big transitions (e.g. new schools, holidays), and think about other changes to their environment that might have a negative or positive impact.
- If changes have to happen (as they sometimes do) there are many things as a parent/guardian you can do to support your child with this change:
  1. Allow time for the individual to process the change. Let them know sooner rather than later that the change is happening so they can understand and prepare.
  2. Use clear and concise language and, depending on the child, consider supporting verbal language with visuals e.g. first/then boards and social stories.
  3. Validate their feelings with comforting language, such as "it is ok to feel this way, I know this is a change in routine/schedule and that makes you worried/scared. That is ok." Let them know that you are there if they need you.
  4. Create positive associations with the new change. If the change is that their school is closed for the day, talk about an activity they really enjoy that they can now do instead.
  5. Allow your child to engage in self-calming activities such as stimming, deep breathing and preferred activities.

## *How do I tell my child they are Autistic?*

As a parent, you love your child unconditionally and you don't want your child to feel any hurt or pain. You might worry that telling your child that they are autistic might 'label' them and will have a negative effect on them. Yet, research has suggested that children who understand that they are autistic generally struggle less with their mental health. We also know that autistic adults who were diagnosed later in life almost all say that they wish that they had known about, and understood, their autism at a younger age. They report always knowing they were different, they just didn't have a name for it. Most speak with huge positivity about now having an explanation.

There is no absolute 'right' way to tell your child that they are autistic. It is important to adapt how you talk about autism to the age and needs of your child, keeping in mind their level of understanding of their difference. The best way of introducing this to your child is talking about it as early as possible. It can be useful to start with small references to what makes them unique and/or what autism is and to build on these over time. Talk to your child about neurodivergence and how lots of different people have lots of different types of brains. Explain to your child that being autistic is a term that describes how their brain works, how they like to communicate and how they experience the world.

Speak positively about being autistic and show your child that there are many autistic people who are just like them. Speaking about autism with your child positively and openly can have a really positive impact on their wellbeing. Normalise differences at home, and let your child know that the world is made a better, more creative and more inclusive place thanks to their unique brain types and ways of thinking and understanding. Normalising the diagnosis can create an accepting and de-stigmatised environment for your child.



## VOICES OF THE COMMUNITY

Aaron, aged 5



My name is Aaron, I am 5 years old, and I am autistic and non-speaking. I started school this year in an autism classroom. An autism classroom is a class for autistic students and somewhere where I can get extra support with my learning and development. I have the support of a Special Needs Assistant and his name is Brian. He helps me with my schoolwork, toileting, eating my lunch. I also have ADHD which means I find it difficult to concentrate and sit still in school. My mum brings me to see a group of people called the Childrens Disability Network Teams". I see a Speech and Language Therapist called Tom. He is helping me develop my communication skills. We use Augmentative and Alternative Communication (AAC), which helps people understand my needs.

Jessica, aged 9



Hello, my name is Jessica, I am 9 years old, and I am autistic. I am currently in 3rd class in my local school. I really like school and I have a lot of fun there. I have a Special Needs Assistant. Her name is Cathy, and she helps me in the class with my schoolwork and anything else I need. Sometimes she comes with me when I need to take a sensory break. The classroom can be very loud, especially at lunch time so sometimes I just need to go to a quiet space. Outside of school, I get support from something called the Childrens Disability Network Teams (CDNT). Vicky is an Occupational Therapist, and she is super nice. With the support of Vicky, I can now dress myself without mum's help and brush my own hair. I have come a long way and I am very proud. Every second weekend, my dad brings me to a place called JumpZone... there are trampolines everywhere! I like to play by myself, and this helps me to self-regulate without having to worry about anyone else!

Ciara, aged 16

My name is Ciara, I am 16 years old, and I am autistic. I go to the local secondary school. I am a very good student, and my teachers say I am very clever. My best friend in school is Sarah and we do everything together. I do not really understand a lot of the girls in my year, but Sarah understands me. Being in school makes me very tired, so when I get home, I like to stay in my room and listen to my favourite music. School can be overwhelming, and I often feel very anxious about going and I have been feeling very low about this for some time. Mum has said she is going to book me in with a mental health professional to help support me.



Chris, aged 12

Hello, my name is Chris. I am 12 years old, and I am autistic. My family told me last year about my autism. I guess this makes sense... you see, I really love Minecraft. I could play and talk about it all day long. Autism makes me very passionate about things I have an interest in! I am also very good at remembering things... if you need to know about geological facts or world flags, I am your guy. I also love to eat chips and pasta! I do not understand why some people put red liquid on their food... there is something not right there. I also sometimes need to be reminded to do some stuff others might find easy to just remember, but that is okay, as my mum has put in some visual reminders around the house to remind me to... for example I must remember to brush my hair and clean my teeth, before I go running around outside with all my friends!



## What support is available to my child after receiving an autism diagnosis?

The support autistic people need is person dependent. Because there is nothing 'wrong' with being autistic, any "treatments" or support should not target autism in general. Rather, the supports or treatments an autistic person might need are focused on the difficulties or barriers they experience as an individual. For example, if an autistic person is experiencing difficulty with communicating in a specific situation they might visit a Speech and Language Therapist (SLT). Together with the Speech and Language Therapist, they can look at supports the individual might need to achieve their goal.

On the other hand, an Occupational Therapist (or OT) can be a useful support for autistic people who experience sensory processing differences, or significant anxiety and/or distress that impacts on daily activities, and can help them develop skills to manage these challenges.

If a child is experiencing significant mental health concerns, it might be helpful to attend a psychologist or psychotherapist to help specifically with their anxiety (ensuring the therapist has a good, modern understanding of autism and what can help).

As a parent, if your child has just received a diagnosis of autism, the most important thing you can do is fully accept and understand your child as they are, and recognise where they currently need support.

Such support is available through public or private services. Information about accessing services can be found in our previously published resource pack 'Starting the Autism Journey: A Guide for Parents and Guardians'.



## How do I know what 'therapies' are safe for my child?

The most important thing to keep in mind with regards to 'treatments' is that there should be no therapy which targets autism in general. Autism itself is not something that needs to be 'treated' or 'cured'. However, your child may have specific challenges or experience specific barriers in different areas in which they could use some support. Unfortunately, there are many "treatments" for autism out there that are not evidence-based and can actually be detrimental to your child's progression.

It is very important that you choose supports or therapies that are credible and provided by reliable, accredited professionals who practice in line with current understandings of autism.

The first thing to do when you are looking at therapies for your child is to think 'what is the goal of this therapy?' If you are looking to support your child so that they will behave 'not autistically' or more typically, then you should scrap this goal. This will only harm your autistic child in the long run. Supporting your autistic child should be about embracing your child's differences, uniqueness, and strengths.

The goal of seeking support for your child should be about your child being happier, more engaged and embracing their identity as their autistic self.

A good way to gauge whether a "treatment" or support will have a positive effect on your child is by looking for feedback from the autistic community, particularly from autistic people themselves. Autistic adults are fantastic experts because of their lived experience. They are best placed to share their experiences of certain therapies and supports, and to advise which are 'right' or 'safe' for your child and which to avoid.

Choosing an appropriate support or therapy is very important, however it is also important to note that just because a 'treatment' is 'evidence-based' does not mean that it will suit your child or that it is a safe treatment. It is important that the therapy/ supports you pick for your child have been researched correctly and are in-line with current understandings of autism.

Keep a critical perspective of the treatments you are considering for your child. Ensure the person providing the support is fully qualified and accredited. Ask for the person's qualifications and check with their governing bodies to see if this is in line with their operating standards, such as the PSI (Psychological Society Ireland), the IACP (Irish Association for Counselling and Psychotherapy), the IASLT (Irish Association for Speech and Language Therapists), The Association of Occupational Therapists of Ireland (AOTI) and CORU. **It is very important to ask in advance of seeing any therapist if they have experience of working with autistic people, and the kinds of strategies and models they use and follow.**

Finally, in accessing reliable information and making decisions for your child it is important to remember that no one knows your child better than you. Trust your instinct and intuition as a parent/guardian to make informed, safe decisions for your child and family.



## *If my child is autistic, can they be diagnosed with co-occurring differences or disabilities?*

Autistic people can (and very often do) have and are diagnosed with co-occurring differences or disabilities such as ADHD, Dyspraxia, Dyslexia, Epilepsy, or co-occurring mental health conditions such as anxiety, mood disorders, eating disorders, or Obsessive Compulsive Disorder. They may also be diagnosed with a physical disability, learning disability, or intellectual disability.

Sometimes someone who is autistic might also be diagnosed with a number of differences or disabilities alongside autism. For example, an occupational therapy assessment can be useful for identifying these co-occurring differences like dyspraxia.

As a society, our understanding of various differences and disabilities is improving over time and therefore, gradually, it is becoming more and more common for people to pick up on these multiple differences and to receive formal diagnoses for more than one difference or disability.

In Ireland, unfortunately it can sometimes be difficult to get the appropriate support if you are autistic and also have co-occurring mental health conditions. This is because currently our Disability Services and Mental Health Services are separate. This means that your child may be sent to different teams to receive different support.

It is also true that often there is a lack of professional awareness on how to identify and treat/manage the co-occurrence of mental health concerns in autism and often treatment requires specialist knowledge (e.g. in the case of treating eating disorders in autism).



## Communication Supports - Advice from a Speech and Language Therapist

### What is Speech, Language and Communication?

Speech, language and communication are terms used to describe how someone communicates. Communication can be by speaking, writing, drawing, signing, using gestures and/or using a communication device. For autistic individuals, differences in speech, language and communication are present from birth. However, they may not be noticeable until the child is older. Autistic individuals may also not have differences present in every area of communication. These communication needs may vary greatly from person to person.

#### Language Differences:

Autistic children may have a different journey than neurotypical children towards speaking, using words and/or signs. Some autistic people may have no spoken words and are usually referred to as "non-speaking" or "partially-speaking" and may communicate through devices, visuals or signs, or a combination of all three. This is called **alternative communication**.

Other autistic individuals may have some spoken language that is supported with the use of devices, visuals and/or sign language. This is called **augmentative communication** as the person is using a combination of spoken language and alternative forms of communication to deliver and receive information.

Some autistic people may not have spoken any words in early childhood and parents may have started to worry or grow concerned. They then may have a sudden spurt of language development in a short period of time where it seems that the children are relatively quiet one day and then unexpectedly starting to speak in sentences or using advanced vocabulary rapidly.

Other autistic children may have advanced language development with a sophisticated vocabulary beyond their years, they are called early talkers. However, if an autistic person remains non-speaking and does not acquire spoken language in the way that you might expect, this is OK too, as there are lots of ways to communicate with your child as mentioned earlier that don't involve using our words. We as a society can learn to understand and accept different types of minds and differences in how people wish to communicate and express themselves.

Autistic people may also use **echolalia** in their communication. Another unique language characteristic may be the presence of **neologisms**.

- **Echolalia** can be immediate (child repeats back straight away) or delayed (may repeat back at a later stage).
- **Neologisms** are made-up words that stand in for real words. An example of a neologism may be for example, using the words 'hot rain' to mean 'steam'.

## How Can I Support My Child's Communication Development?

There are many ways in which we communicate and every child will be different in how they communicate. It is important to adapt the support you provide for your child based on what differences in communication they actually experience. For example, one autistic child may have a very good understanding of humour whereas another may interpret language very literally.

Playing games, doing joint activities, and spending time in another person's company can also be forms of communication. It is important that communication is supported through listening and speaking or using signs/communication devices. With younger children, this may look like making sure to be face-to-face with your child, following your child's lead in the play/activity and adding language (words and/or signs) to what your child is saying.

Autistic children who have sensory interests/preferences might benefit from having their interests become part of the play and/or activity. Using interests and passions that the child has can also lead to a rewarding interaction.

For older, more verbal autistic children or autistic children who are more fluent in using signs/visuals on a device, communication can also be supported by modelling and following their lead in conversations, games and tasks.

A useful strategy to use is **specific praise**. Specific praise is when you tell someone exactly what you liked about what they did and how they communicated. So instead of just saying "well done!", you would say, "I really liked the way you offered me a turn first, that was very kind of you." Supporting communication across multiple settings is extremely important. Communication at its most basic definition is a two-way process between a listener and a speaker. Someone is sending a message, and someone is receiving a message. However, this can look very different depending on the context;

**Who** are we communicating with?

**When** are we communicating with them?

**Where** are we communicating?

**What** are we communicating about?

**Why** are we communicating?

**How** are we communicating?

Depending on the stage of development your child is at, they may need support in developing their speech, language, and communication needs. If this is the case, then an assessment by a speech and language therapist may be useful.

The speech and language therapist can then advise what strengths and needs the person presents with and what is the most helpful therapeutic support for their particular need.

## Augmentative and Alternative Communication (AAC)

### Augmentative and Alternative Communication (AAC)

Autistic individuals can use different ways to communicate but also, they can process information in different ways.

If an autistic person is pre-verbal or partially speaking, they may use an Alternative and/or Augmentative Communication method or app, like the following:

Picture books

Visual communication charts

Signs and adapted signs e.g. Lámh

Communication boards

Symbols

ProLoquou2Go

Snap and core

Gestures

Language acquisition through motor planning (LAMP)

## Using Visuals to Support Understanding

Visual aids can be a great source of support for your autistic child. Some autistic individuals may be strong visual learners and can benefit from visual support and can observe details that a neurotypical person wouldn't necessarily be aware of. Visuals can be a useful way of breaking down tasks, helping with transitions, managing time and increasing their understanding.

Visual timetables

Visual schedules

First/Then board

Visual countdowns

Sequential steps

To do lists

Phone lists

Phone apps



## Explaining Social Situations

Using visual supports can be helpful for your child; visual supports can explain social situations and also allow for discussion to take place and different perspectives explored. They can also be used to help talk about more appropriate strategies

Social stories by Dr. Carol Gray is an example of visual guides that can be used to help navigate everyday social situations and/or increase understanding of different people's perspectives. This should be a joint exercise that is done with your autistic child as a way of facilitating understanding of both sides of the social interaction. It also gives your child a way of communicating their perception of what happened. Some individuals may prefer drawing out the scenario or using objects to explain the situation.

Roleplays and planning for different social situations can also help the autistic person know what to expect and gain more confidence in navigating social situations.



I can still go for a short walk. Going for a walk helps my physical and mental health.

Here are some things that will be different than normal;

I should not walk further than 2 kilometres from my house. This is roughly a 20 minute walk. Walking 2 kilometres from my house and back will give me 40 minutes of light exercise and keep me feeling well.

I will need to stay 2 metres away from other walkers.

Remember, whether I am home, in a supermarket or walking, I must remember to wash or sanitise my hands and cough or sneeze into my elbow.

## Formal Supports

- If formal support is needed in any of these areas, you can access speech and language either through the child's disability team or through primary care speech and language.

## Sensory Processing - Advice from an Occupational Therapist

Our bodies have 8 senses which provide us with information about what is happening inside and outside our bodies. The first 5 external senses are; **sight** (visual), **hearing** (auditory), **taste** (gustatory), **smell** (olfactory) and **touch** (tactile).

In addition to this, there are 3 other less commonly known internal senses. These are called; vestibular (information processed by the inner ear and brain about movement and balance), proprioception (awareness of position and movement of the body) and interoception (awareness of what is happening in the body e.g., heartbeat, needing the bathroom, breathing rate etc).

### Processing Sensory Information

Information comes into our brains from all these senses all of the time. The brain notices and registers information from the senses, and processes it. This helps us to be able to respond in an appropriate manner to the situation we are in. This cycle of input and output is termed 'sensory processing'.

There is a lot of sensory information coming into the brain all at once, so our brain needs to sort and filter the sensory information that comes in so we are only aware of enough sensory information to be able to pay attention. For example, in the morning we may notice the feel of our clothes as we put them on. However, after a few minutes we start filtering out/getting used to the message from our skin about the feel of our clothes so we can take in more important information such as the time on the clock to get us ready on time!

Your child may have different ways of processing, sorting and filtering the information received from their senses. This can result in their brains getting too much sensory or not enough sensory information for the situation they are in. This in turn can affect their ability to respond to their situation or environment. For example, in a noisy environment such as a school hall, your child may have difficulty in filtering out background sounds. This can cause their sensory system to become overloaded with sensory information which may be reflected in how they might react to this information, such as covering their ears, becoming upset or moving away or out of the room.







## Sensory Regulation

In order to help our brains process the information coming in, we all also use 'sensory regulation' to help us stay calm, alert and focused. Regulating our senses helps us to increase or decrease the sensory input to our brain to improve our ability to respond to our situation. An example of this is turning the car radio up louder in the morning to help us to attend to the driving, or tapping a pencil or changing position when sitting in a meeting to help us to maintain attention. If we are feeling overloaded, we may choose to chew our nails, go for a run or listen to music to help us feel calmer.

Autistic individuals have different ways of filtering and processing the information in their brain, they may need more intense or frequent ways of processing their sensory inputs to help them remain calm, alert and focused. For autistic people, these are known as 'Stimming', short for self-stimulatory movements. These 'stims' are the child's attempt to regulate (by increasing or decreasing) the sensory input coming into their bodies. These movements or actions may be repetitive in nature and tend to increase during times of stress or during stressful activities/ environments. Common 'stims' used by autistic children are; running backwards and forwards, rocking, hand flapping, making a sound etc. As these stims serve a purpose, if they do not cause harm or distress to your child or others, then you can let your child do what they need to do to regulate themselves.

## Sensory Profile

Sensory Profile is a term used by Occupational Therapists to describe your child's sensory likes and dislikes and existing sensory regulation strategies that your child is already using. The Occupational Therapist usually uses a combination of standardised questionnaires and parental interviews to gather this information. The occupational therapist will also be aware that your child's sensory preferences connect heavily to their level of anxiety, and the situation they are in.

## Strategies

Following assessment, the Occupational Therapist can work with your child and family to recognise the early warning signs of sensory dysregulation and to help identify tools and strategies to address this. These tools and strategies may be physical (e.g., blocking the sound with ear defenders), cognitive (e.g., using a social script to prepare a child), or emotional. Primarily, the tools and strategies will be aimed at adapting the environment around the child.

The choice of tool will depend on your child's individual needs and what activity and situation they are in. Your child may already be using their own stim and other strategies successfully and may not need additional strategies.

If an Occupational Therapist provides you with sensory strategies the aim will usually be to either temporarily calm the nervous system or to alert the nervous system.

## Executive Functioning

These are a range of skills that everybody uses to manage their day, which can range from following a plan, remembering what to do next, or starting or moving onto a different task. This is known as 'executive functioning'.

Many autistic people have a harder time with executive functioning and may need more support with this. For instance, some autistic people may want to do something, but may not be able to or know how to do it without having additional support.

General Calming Strategies	General Alerting Strategies
Slow movements (gentle walk, swing, rocking)	Movement (jumping jacks, bouncing)
Deep pressure massage	Drink some cold water
Quiet space	Chew chewing gum
Cool temperatures	Use a fidget tool
Slow music	Listening to fast tempo music
Dim lighting	Bright colours

### Formal Supports

- If formal support is needed in any of these areas, you can access Occupational Therapy either through the child's disability team or through primary care Speech and Language Therapy.

## Autism and Mental Health - Advice from Psychology

### Managing Anxiety

Autistic children can experience higher levels of anxiety than non-autistic children. There are many strategies you can use that can support your child to manage their anxiety. For most autistic people, much of their anxiety stems from their environment. The environment can be stressful when not autism friendly. Anxiety can be caused by other people's lack of understanding of autism, lack of context/not knowing what to do, and autistic people needing to 'mask' or pretend to be someone they are not in order to conform to environmental expectations (which can be particularly stressful). As a society, we should recognise what is stressful for autistic people, whether at school or at home, and examine what we can change to support/accommodate autistic people. Here are some examples of things that could help:

#### Examples of things that could help:

- Being very open about autism with everyone in your child's life, and educating them that behaving "autistically" is completely valid and what works for your child.
- Surround your child with people who let them be their autistic selves.
- Allowing for and facilitating stimming (motor and vocal) at home and school is important. Allow your child to move and make noises as they come naturally. This can help the individual regulate, and we know that suppressing stims can lead to an increase in anxiety over time.
- Understanding a child's sensory profile and changing the environment accordingly e.g. reducing noise at home or at school, finding a school with a lower class size.
- Advocating for sensory spaces in schools, shopping centres etc. These can be quiet and regulating spaces for all people overwhelmed by sensory input.
- Create a calm sensory or safe space at home to regulate after being in an overwhelming situation: dim or switch off harsh lighting when possible; provide sensory input the child finds calming (e.g., soft music, nice fabrics to touch, calming smells, theraputty); provide opportunities to engage in preferred activities/passions.

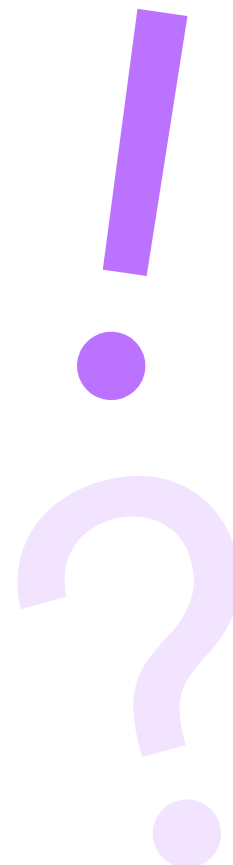
It is not always possible to change or control every environment. Sometimes we can make changes to how we interact with that environment.



Here are some examples of what we mean:

- If a school with a smaller class size is not possible, we can instead facilitate regular movement breaks or quiet times throughout the day.
- Look at how you or your child is spending their energy, and try to balance the energy they spend on different activities. If social interaction causes them to become anxious, balance that energy with an activity they enjoy (e.g. engaging or talking about a passion)
- Learn to understand your child's anxiety triggers and figure out how you can manage these triggers when they happen. For example, if you know your child becomes particularly anxious in school prepare them for when they come home, perhaps provide a sensory blanket or a quiet space.
- Reducing sensory input for your child e.g., wearing noise cancelling headphones or allowing them to wear clothes they find comfortable.
- Predictability is a great way to keep your child calm. Trying to keep the environment as predictable as possible, but when change needs to happen introducing these changes in advance so your child can anticipate and prepare for the change.

Learn to understand your child's anxiety triggers and figure out how you can manage these triggers when they happen. Finding ways to support your child with anxiety might take some time but do not give up - small changes across the child's environment and social world will build up to larger positive changes over time.



## What Can I Try at Home to Support My Child?

Although it is preferable to prevent anxiety provoking scenarios, even with the best supports your child might still experience anxiety. The world is not yet set up to accommodate their differences and preferences.

There are things you can do to support your child in managing the anxiety they experience.

- Understanding emotions can be more difficult for autistic children. Reading books or watching videos about emotions can help your child better understand how they are feeling. This can be further supported by labelling emotions for them as you see them, e.g. "It looks like you are frustrated with that zipper." or "You are sad the ice-cream fell." As your child begins to develop an understanding of their feelings, start asking them "how are you feeling?" or give the option between a couple of feelings.
- For some individuals (not all), tools such as meditation and breathing exercises are useful (although may take practice!) e.g., guided relaxation, tummy breathing, box breathing.
- Consider again the recommendations outlined in the 'Common Characteristics of Autism' section of this resource. Most would have a positive impact on the anxiety experienced by autistic people.

## What Should I Do If My Child is Having a Meltdown?

Put simply, a meltdown is an anxiety/stress reaction to an overwhelming experience. First of all, it is very important to read and learn about meltdowns from an autistic perspective so you can best support your autistic child. It is important to listen to autistic people describing how meltdowns are experienced (there are many autistic people who share about their experience of meltdowns and shutdowns, through blogs, social media posts or YouTube videos).

Forming a true understanding of the process of a meltdown is helpful for understanding the causes for your own child, and understanding the triggers of anxiety for your child is helpful to learning how to prevent a meltdown as best as you can. All the strategies mentioned in this resource above will help manage your child's anxiety, and will also support preventing meltdowns. The most important place to put your energy is to prevent meltdowns from happening in the first place.

Once a meltdown happens there isn't much you can do except to remain calm, and sit and wait for your child to process it. Children might not be able to rationalise their heightened anxiety, or take deep breaths to help them manage their meltdowns. Sometimes children might say things that they don't mean, make threats, or they could lash out and hurt you or themselves. Remember, this is a reaction to extreme stress/anxiety and their behaviour is not intentional.

Meltdowns can be scary for parents and trigger a lot of different, difficult emotions including anger and frustration. This is natural. It is important that, despite those big feelings, to remain calm yourself. Your child needs understanding at this moment. Reacting in an agitated or angry manner can prolong a meltdown or further increase your child's anxiety. Some children want you to stay close to them when having a meltdown, and some children prefer their parents to sit further away from them.

Treat each meltdown as a learning experience, looking at where it usually happens and what usually happens before they happen. Experiment with what works to help soothe your child e.g. deep pressure, dimming the lights, complete silence/darkness. If they are calm (or after the fact), you could try asking your child what they think would help when they have a meltdown or shutdown.





## Educational Supports for Autistic Students

### Early Childhood Care and Education (Access Inclusion Model 3+ Years)

The Early Childhood Care and Education (ECCE) Scheme provides early childhood care and education for children of pre-school age in Ireland. Children are eligible to start the ECCE scheme in the September of the year that they turn 3 years old.

The scheme is offered for 2 school years in early years settings (pre-schools, Montessori, creches, playgroups) for 3 hours a day, 5 days a week, 38 weeks of the year. In order to support children with Special Education Needs (SEN) to access free pre-school, a programme of support (the Access and Inclusion Model or AIM) has been introduced.

AIM is a child-centred programme of support designed to ensure that children with additional needs can access the ECCE in mainstream pre-school settings and can participate fully in the pre-school curriculum alongside their peers.

AIM is designed with seven levels of progressive support based on individualised needs of both the child and the setting and follows a child centred ethos. As a framework AIM offers tailored, practical support, based on need without the requirement for an official SEN diagnosis.

For further information on the supports provided by AIM, including help in searching for a pre-school, visit [aim.gov.ie/for-parents](http://aim.gov.ie/for-parents).

### Home tuition

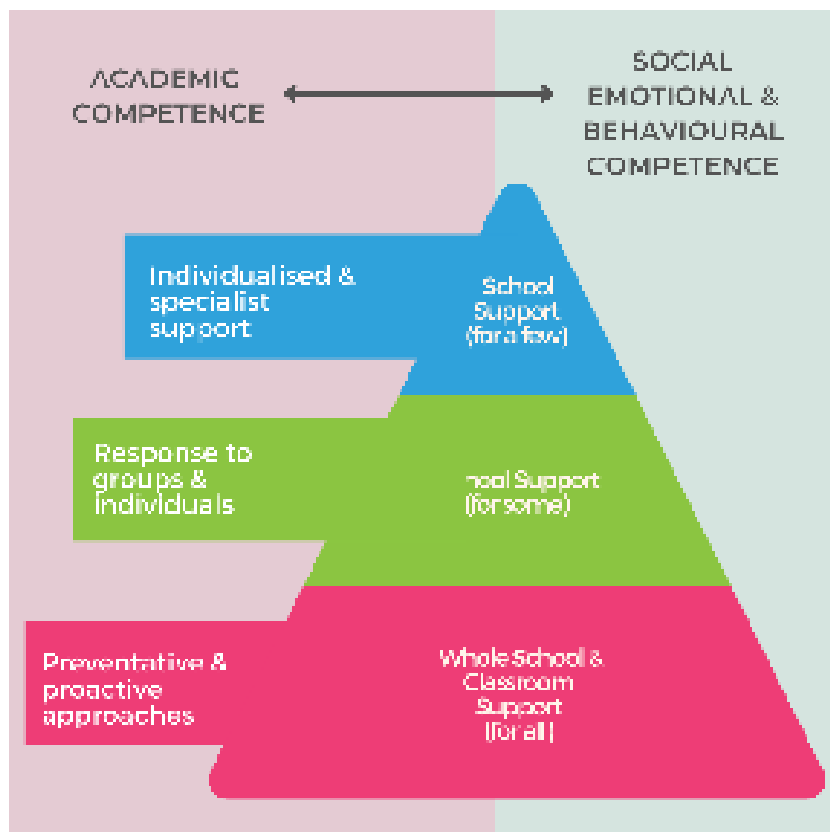
The Home Tuition Scheme provides a compensatory educational service for pre-school autistic students who need early educational intervention. The scheme also provides for autistic students that are seeking suitable educational placement, as well as students with significant medical or mental health needs that may cause challenges for them in school.

The funding provides 10 hours home tuition weekly for autistic students aged between 2 and 3 years, and 20 hours a week for students aged 3. The scheme is not eligible if there is a place available to the student in a preschool or other early education setting.

Application forms for the scheme are on the website of the Department of Education and Skills (DES)  
[www.education.ie/en/parents/services/home-tuition](http://www.education.ie/en/parents/services/home-tuition).

## Primary and Post-Primary Supports

The support your child receives from their school is dependent on the strengths and needs/challenges of your child. Schools are allocated a number of resource supports from the Department of Education/NCSE each year. The allocation of these resources to individual or groups of students is the responsibility and decision of the school. How a school does this and supports the learning of students who have additional need is based on the Continuum of Support model. The concept behind this is based on the idea that the student with the greatest level of need will receive the greatest level of support. Additional education supports made available through this model are outlined as follows:



## Classroom Support

The first level of the Continuum of Support model is '**Classroom Support,**' also known as *Support for All*. All children in a primary or post-primary classroom are entitled to this type of education once a need has been identified.

It is the classroom teacher's and/or support teacher's role to gather information and put together a Student Support Plan for this child.

A teacher may use specific teaching strategies with the whole class to benefit an individual child or may focus on a particular child's needs through a whole class intervention. In these ways, the school delivers 'support for all.'

## School Support

The second level of the Continuum of Support model is 'School Support,' also known as *Support for Some*. This provides more individual forms of education support and can be accessed if 'Classroom Support' does not in itself provide adequate support for the child at school.

At this point, a Special Education Teacher (SET) may take the lead in putting together a Student Support File and delivering this level of support to the child. Specific targets will be set for the child relating to teaching, learning and/or sensory regulation where appropriate. Additional support and/or focused teaching time may be delivered by the SET team. The SET team may use a specific support programme: they may work one-to-one with the child; or within a small group of children with similar support needs.

Depending on the school, this additional teaching time may be accessed in-class, through withdrawal or by a combination of both methods. It is important to note that while a child is receiving 'School Support,' that they are still entitled to receive 'Classroom Support' at the same time.

## School Support Plus

The third and final level of the Continuum of Support model is 'School Support Plus,' also known as *Support for Few*. This level involves support through external professionals and support services, such as Psychologists, Occupational Therapists (OTs), Speech and Language Therapists (SLTs), Physiotherapists, and other therapies or supports which can support your child at school. These professionals may work one-to-one with the child or may act in an advisory capacity for the school to supplement education support.

It is important to note that at present with the exception of NEPS, such in-school support would be rare to get (with the exception of special schools). However, a 'Pilot School Inclusion Model' is in place in some schools around the country which provides for onsite professional support, from Occupational Therapists and Speech and Language Therapists, with the plan to roll-out this pilot scheme nationwide.

Students whose needs are being met at the highest level of the Continuum of Support model should have a Student Support File or individual education plan (IEP) in place. This plan outlines information gathered over time relative to the student's abilities, their support needs at school, and educational performance. The Student Support File/IEP will also be used to set short-term and long-term targets for the child, noting the supports that will be in place to assist the child in meeting these targets.



It is essential that the IEP/Student Support File is a collaborative document between the classroom teacher, SET team, the child's parents/guardians as well as the child themselves, where appropriate.

It is important to note that while a child is receiving 'School Support Plus,' they are still entitled to receive both 'School Support' and 'Classroom Support' at the same time.

All support plans created for a pupil, regardless of the level of education support being received, should be regularly reviewed by the professionals and parents/guardians involved.

### *Accessing an Autism Class*

Given the diverse support needs of the autistic community, autistic children may attend special schools or autism classes within mainstream schools. **For your child to access an autism class a formal diagnosis of autism is required.** The number of children in an autism class is usually quite small (no more than 6), so that the teaching and support staff can attend effectively to their students' needs.

Autism classes can be set up in both primary and secondary schools, where the need is apparent. The needs of the children attending an autism class will vary greatly from one child to the next. One child may need to spend most of their day in the autism class, learning from a curriculum that has been specially tailored to meet their needs. Another child, on the other hand, may need to be in the autism class for a short period during each day, and can participate in the mainstream curriculum once they have access to this support.

It is important to note that all children availing of a school place in an autism class are entitled to integrate with their peers in mainstream, regardless of their needs. This means they will have access to a seat in the autism class and a seat in the mainstream class every day. It is important to talk to your child's Special Education Needs Officer (SENO) when looking for an appropriate school place for your child.

## Accessing a Special School

Some parents / guardians, whose children have more higher support needs, may want to consider whether their child would be better supported by attending a special school. Some special schools cater specifically for autistic students while others cater for general intellectual disability and may also have Autism specific classes.

Each special school will have a specific student teacher ratio. Special schools cater for students from both primary and post-primary and will have certain enrolment criteria. Special schools provide a range of services such as speech and language therapists, physiotherapists, school nurses, specialist swimming teachers, and staff who have been trained to use evidence- based supports specific to student needs.

Many schools also have specialist resources and equipment such as therapy pools, sensory rooms, and adapted outdoor play equipment. Students in special schools follow curricula and teaching appropriate to their needs, with progress and attainment closely monitored, in smaller classes. To search for a list of special schools, please see the Department of Education's 'find a school' section on their website [www.education.ie/en/find-a-school](http://www.education.ie/en/find-a-school).



## Accessing a Special Needs Assistant/Inclusion Support Assistant

A student with additional needs may need the support of a special needs assistant (SNA), sometimes referred to as Inclusion Support Assistant (ISA). SNA/ISA's are not assigned to any particular student, and are deployed within the school to those students needing support to meet primary care e.g. safety, toileting, supervision. Schools apply to the NCSE for SNA allocation hours based on the care needs of their student population. In December 2019, the Irish Government approved the national roll out of a new frontloading model for the allocation of Special Needs Assistant (SNAs) support to mainstream primary and post-primary schools, which will be based on school profile.

SNA duties are assigned at the discretion of the Principal and are monitored on an ongoing basis, focusing on particular care needs of students in the school. A diagnosis of disability and/or professional report **will not be required** for a student to access SNA support. However, if professional reports are available regarding a student's needs, they should be used to guide schools in planning supports. Parents/guardians should bring any reports to the attention of the school to facilitate and inform appropriate interventions.

## SUMMER Education Programme

The Summer Programme provides educational supports during the summer to children with additional needs and those at most risk of educational disadvantage.

The Summer Programme includes:

- School-based summer programme for children with additional educational needs and children who are at risk of educational disadvantage. It includes children in autism classes, special schools and mainstream schools who are in receipt of additional resources.
- Home-based provision for children with high support needs (where a school-based programme is not available)
- Summer camps in DEIS schools focussing on numeracy and literacy

All primary schools and post-primary schools including DEIS schools have the opportunity to provide a summer programme for mainstream pupils with high support needs and those at greatest risk of educational disadvantage.

The Summer Programme is based on **July Provision** which was delivered to children with additional educational needs in previous years by the Department of Education.

If your child is in receipt of school transport under the additional needs transport scheme, school transport may be provided. If additional educational needs transport services are not available, you can apply for grant funding after your child has completed the programme.

For further information on the above, please do check out the Department of Education's website or citizens information for further information.



## School Transport

A child with additional educational needs is eligible for the School Transport Scheme which is funded by the Department of Education and Skills (DES). They may avail of this scheme once they are attending their nearest recognised special school or autism class in a mainstream school.

Applications for school transport can be made to the school principal, who will contact the local SENO on your behalf. Once the SENO has reviewed the application, they will forward the application to the School Transport Section of the Department of Education and Skills.



## Supporting my Child's Siblings

Being a good enough parent to any child is tough, but also incredibly rewarding. Many parents can find it difficult to balance the demands of supporting their autistic child, while at the same time giving equal attention to their other children. You are your autistic child's biggest advocate for support, and this responsibility can take a lot of your time and energy.

Be mindful that your non-autistic child(ren) may need support too. It is understandable that your other children might at times feel a little lost or left-out. It is important to make them feel important and included.

The below are some helpful tips in supporting your non-autistic children:

- Encourage your child to have their own passions/activities outside of the family home. This gives them some time to focus on themselves and a sense of achievement. Acknowledge their successes in these areas and support them in these achievements.
- Make time for them. Ensure you "level the playing field" by ensuring each child has some alone time or 'special time' with you to do something they enjoy. A top tip is to schedule this as protected time each week.
- Be sure to praise and thank your other children when they do something kind or demonstrate acceptance for their autistic sibling's differences.
- Siblings of autistic children, unbeknownst to themselves, can take on a 'mini-parent role'. They, like you, will also worry about their autistic sibling and feel obliged to act more mature or independent around them. These feelings and urges are all very natural and common experiences in autistic families. Ensure your non-autistic child knows they can talk to you about these feelings. If these experiences are negatively impacting on your non-autistic child, contact relevant professional support services, such as your local GP, to access relevant supports. Some communities have sibling groups that your child might be interested in attending.

## Helping your neurotypical child understand Autism

Your non-autistic child might not fully understand autism. It is important to take time to explain to them the differences and preferences of the autistic community and those of their sibling in particular, in an age appropriate way.

It is important for them to understand why your family might be different and may do things differently from others. This type of conversation can help them understand their autistic sibling better and foster an environment of acceptance.

There are many books available online that can help you to explain this to your child in an age appropriate way, such as:

- 'Autism in my family' Sandra Tucker
- 'What autism can be like' Sue Adams
- 'Y'know that kid?' Noeleen Smith
- 'The Awesome Autistic Go-To Guide A Practical Handbook for Autistic Teens and Tweens' Yenn Purkis & Tanya Masterman

## Autism and Language Acceptance

Language can be a powerful way of describing ourselves. The language around autism, autistic people, and disability more generally, has changed and evolved a great deal in recent years. It continues to change as our understanding of autism shifts and as more autistic people are sharing their experience of what it's like to be autistic.

Many autistic people have different ways of talking about their autism and have different ways that they want to identify themselves.

These are:

- Identity-first language ("autistic people", "disabled people");
- Person-first language ("people with disabilities", "people with autism", "lives with autism").

What should we say?	Why
Autistic person/Autistic	<p>Many autistic people use “Autistic person” because they see their autism as a core part of their identity, and as central to who they are and how they experience and understand the world.</p> <p>Many autistic people also see their autism as a natural part of human thinking that has always existed. Many autistic people see their autism as both a difference and a disability.</p>
Autism is a difference/disability	<p>Whilst autism is first and foremost a different way of understanding the world, it is also considered a disability, not least in the sense that not everyone in society will always understand, accommodate or include autistic ways of thinking, understanding or processing the world.</p> <p>There are aspects of how society is organised and structured which can all shape how an autistic person might feel accepted and included in society: like the physical and sensory environments, how we communicate, how we socialise, access to services and supports, or society’s attitudes to autistic people.</p> <p>If these access needs are not addressed, this can disable autistic people from being accepted and included in society, and from being treated equally.</p>
Support needs	<p>This refers to the level and the type of support that an autistic person might need in aspects like education or everyday living. These can differ from person to person as set out by the DSM-5. This replaced functioning labels used by previous DSMs to adjudicate an autistic person’s level of support needs.</p> <p>These range from: <b>Level 1 (“Requiring support”)</b>, where an autistic person might need some supports, <b>Level 2 (“Requiring substantial support”)</b>, where an autistic person might need more substantial or intense support. and <b>Level 3 (“Requiring very substantial support”)</b>, where an autistic person may require a lot of support or more intense supports, to go about their everyday lives.</p>

*What terms should we avoid when talking about autistic people?*

Avoid	Why	Say
<ul style="list-style-type: none"> <li>• Has autism / Suffers from autism</li> <li>• Is a victim of autism</li> <li>• Autism is a disease or illness</li> </ul>	<p>Clinical professionals are closely involved in diagnosing autism and developing strategies that support autistic people to meet their support needs. Many autistic people feel strongly about how autism is referred to by professionals, which can often be different to how many Autistic people wish to identify themselves.</p> <p>Autism shouldn't be considered an illness or disease, and autistic people aren't broken people that need to be treated or fixed because of their autism.</p>	<ul style="list-style-type: none"> <li>• ...is autistic</li> <li>• Autistic people</li> </ul>
<ul style="list-style-type: none"> <li>• Autism is a disorder</li> <li>• Autism Spectrum Disorder</li> <li>• ASD</li> </ul>	<p>While autism is sometimes seen as a 'disorder', often by people who are not autistic, a lot of Autistic people don't like using 'disorder' to describe being autistic.</p> <p>Many Autistic people do believe that their autism diagnosis is a "difference", rather than a "disorder". This is because an autistic person's way of thinking is not "wrong" or "broken" - just different. Autistic people don't want treatments or cures for their autism or their autistic traits. Instead, everyone in society can make adjustments to accept and include Autistic people and families with autistic people. An autistic person might be disabled by an environment not set up to accommodate their differences.</p>	<ul style="list-style-type: none"> <li>• Autism</li> <li>• Autism Spectrum Condition</li> <li>• ASC</li> <li>• ... is autistic</li> <li>• Autistic</li> </ul>
<ul style="list-style-type: none"> <li>• ASD Unit</li> <li>• Autism Unit</li> </ul>	<p>The word "unit" carries medicalised assumptions around how autistic people are educated, and presumes that all autistic pupils need to be educated in segregated settings, even though this is not the case.</p> <p>Many autistic people are educated in mainstream classrooms. For many autistic people and their families, the word "unit" implies that pupils who are in autism classes are in clinical settings and that they always need to be educated away from their peers, in separate classrooms or schools.</p>	<ul style="list-style-type: none"> <li>• Autism Class</li> <li>• ASC Class</li> </ul>

Avoid	Why	Say
<ul style="list-style-type: none"> <li>• High-Functioning</li> <li>• Low-Functioning</li> <li>• Mild autism</li> <li>• Moderate autism</li> <li>• Severe autism</li> </ul>	<p>These labels can have harmful effects on autistic people, as they are very broad, and don't fully capture how Autistic people experience being autistic. Autism is such a diverse spectrum of traits and differences that no two people will experience being autistic the same way, or have exactly the same access needs.</p> <p>An individual's support needs might also change over time, and/or across environments depending on their profile and supports available. Having terms like 'mild' or 'high functioning' might mean that an individual might not be given supports when they need them, and those labelled as 'severe' or 'low functioning' might be denied opportunities they are capable of and/or enjoy.</p>	<ul style="list-style-type: none"> <li>• Support Needs</li> </ul>
<ul style="list-style-type: none"> <li>• Asperger Syndrome</li> </ul>	<p>Asperger Syndrome is no longer an official diagnosis used by clinical professionals. Asperger Syndrome refers to people who experience no speech differences, who are seen to have average or higher levels of intelligence, and who may not need a lot of support. However, it reinforced preconceived ideas around autism, which may not fully reflect what it's actually like to be autistic for many people.</p>	<ul style="list-style-type: none"> <li>• Autistic</li> </ul>
<ul style="list-style-type: none"> <li>• Backward</li> <li>• Deranged</li> <li>• Handicapped</li> <li>• R*tarded</li> </ul>	<p>Understanding of autism and disability has greatly evolved in recent years. For years, people have used outdated terms about autistic people and disabled people which reinforced harmful stereotypes around autism and disability.</p> <p>Although many autistic people may also experience an intellectual disability or mental health condition, it is wrong to use these terms to 'other' autistic people and disabled people.</p> <p>Many autistic people see their autism as a part of who they are and don't wish to use terms that minimise or separate their disability or difference from their worth, experience or achievements as a person.</p>	<ul style="list-style-type: none"> <li>• Disabled people</li> <li>• Autistic people</li> <li>• People with a learning disability</li> <li>• People with a developmental difference or disability</li> <li>• People with an intellectual disability</li> </ul>

Avoid	Why	Say
<ul style="list-style-type: none"> <li>Special needs</li> <li>Special Needs children, Children with Special Needs</li> <li>Special</li> </ul>	<p>Many disabled people consider “special” or “special needs” to be patronising and inappropriate, as it can reinforce outdated attitudes around autism and disability - that see autistic people as objects of pity, rather than having rights.</p> <p>It’s really important to remember that the needs or rights of autistic and disabled people are not “extra” or “special”. Autistic and disabled people have the same rights as everybody else, even if they might sometimes need different supports to access or enjoy these rights.</p> <p>“Special needs” can be used in an educational context to refer to pupils with additional needs (i.e. some autistic people, or disabled people who have additional needs related to their education) who might attend a special school or an autism class for part or all of their school week.</p> <p>Whilst ‘special needs’ and ‘special education’ are terms in use in schools and other settings to refer to the needs of autistic and disabled children, it is better to avoid using “special needs” to refer to autism (or disability more generally) as many in the autism and disability communities take offence to the use of these terms.</p>	<ul style="list-style-type: none"> <li>Disabled people</li> <li>Autistic people</li> <li>Disabled people</li> <li>Within an education context, you can also use:</li> <li>Support needs</li> <li>Additional needs</li> </ul>
<ul style="list-style-type: none"> <li>Normally developing children</li> </ul>	<p>Using “normal” when referring to non-autistic people implies that autistic people are somehow ‘abnormal’ or ‘broken’ for developing differently from their neurotypical peers or that they need to be ‘fixed’ or ‘cured’.</p> <p>We should see autism and disability as something to embrace as a part of human diversity.</p>	<ul style="list-style-type: none"> <li>Neurotypical</li> <li>Non-autistic children</li> </ul>



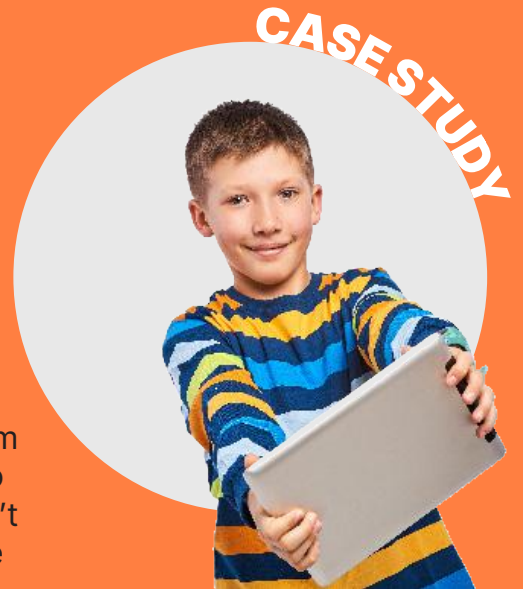
Avoid	Why	Say
<ul style="list-style-type: none"> <li>• Diffability</li> <li>• Handicapable</li> <li>• DisABILITY</li> <li>• Differently abled</li> <li>• Overcame their autism /disability</li> <li>• Despite/ in spite of their autism / disability</li> <li>• Inspirational</li> <li>• Defying their autism /disability</li> <li>• Their autism / disability did not stop them from..</li> </ul>	<p>Whilst some people can use these terms to try to normalise or celebrate autistic people or disabled people, they can reinforce negative stereotypes or can suggest that it is not OK to simply be autistic or disabled, that they must also be inspirational in some way. It also implies that their disability or autism itself is keeping them from ever doing what they want to do.</p> <p>Whilst your child isn't inspirational just because they are autistic or disabled, they have lots of positive personal traits that you might find inspiring and that could help them to succeed and be happy with in their life. THIS is something to celebrate and embrace about your child. Whilst some people may use these terms or identify with them, they should be avoided generally speaking.</p> <p>Autism and disability aren't dirty words. It shouldn't be seen as something that is taboo, a negative aspect of a person to avoid, or an obstacle to overcome. It is absolutely possible to be successful, do well in life and achieve great things, and still be disabled or autistic.</p> <p>We needn't be afraid of using these terms when talking about autistic and disabled people, as these are the terms that the Autistic and much of the disability community want to use.</p>	<ul style="list-style-type: none"> <li>• Autistic</li> <li>• Disabled</li> </ul>

"Hi I'm Conor! I'm in 4th class at school, and I'm autistic.

I'm really interested in science and technology, and I want to be a scientist when I grow up. I don't know what kind of science I want to be an expert in, but there's lots of different scientific fields that I want to study and learn about!

I don't see my autism as a bad thing. Even though some doctors might think of autism as a 'disorder', I don't think there's anything wrong with being autistic. I don't suffer from being autistic, even though sometimes I can find it harder to make friends, or to know what the right thing to say is. I don't see it as a disorder, but a different way of thinking about the world.

I don't see being autistic as a barrier to who I want to be when I grow up. Sometimes I'm proud of being autistic, as I am part of a group where many autistic people are also scientists who have made amazing discoveries which changed how people think about the world. I know that my autism diagnosis can also come with lots of strengths. When I see Greta Thunberg on TV, I am really happy to see somebody who is passionate about the environment and who is not afraid to say what she thinks, even if it's not always popular. She's not afraid to be her autistic self. I think that autistic people can thrive when society includes us as we are, by accepting our differences and by helping us when we need it."



"I'm Emily, and I was diagnosed with autism. I really like music, and I'm obsessed with Ed Sheeran. I really like art and I like to draw and to paint in my free time.

I sometimes find it hard to think of the right words to say, so sometimes I like to use my iPad to communicate to my friends or my teacher. My teacher gives me the space I need to communicate so that I feel part of the class when I'm there. My parents do the same for me when I'm at home.

There are some parts of school that I'm good at and there other parts that I struggle with and need support. I sometimes go to an autism class to get help from my SNA. I don't like it when some people say that my class is a unit as I'm not there all the time - just when I need to get support when I'm having trouble with something. I have a younger brother, Noah, who is also autistic but has higher support needs and he also attends a special class. He really likes animals and he particularly likes horses - he finds them really relaxing. While he goes to a special class, I feel like he doesn't have 'special needs' - he wants to go to school and have fun just like me, even if sometimes he needs different ways of doing these same things."



## COMMUNITY SUPPORT GROUPS

Community support groups are there to provide parental support, information and guidance. They empower family members with autistic children to share insights and information with one another, such as information on local supports, sharing lived experiences and working with different professionals.

Support Groups can provide parents with an outlet to speak about their own experience, feelings and emotions. Interacting with support groups, parents get an opportunity to hear about training workshops, school supports, and attend events that may be beneficial, including social outings.

Without guidance, it's easy to feel uninformed or lost after a child receives an autism diagnosis. You may not know what to expect. Advice from family and friends, while well intentioned, may prove impractical. Engaging directly with other parents and support groups can provide the assurances needed.

Autism community support groups can provide a platform for parents to understand 'what's next' following an autism diagnosis. Advice from other parents on financial entitlements, educational placement and navigating the State system in pursuit of services available is so important. They can also provide information on what supports are available to you as a parent, such as respite and carers supports.

Autism support groups can be a space for you to learn as parents but also a space for your children to meet other autistic children. There are many social opportunities with the autism community. These social support vary from county to county

To find out more about local and regional community support groups please contact the **AsIAM Autism Information line on 0818 234 234** or email [support@asiam.ie](mailto:support@asiam.ie).

## Financial Supports

Receiving an autism diagnosis does not automatically entitle an individual to financial support or assistance. Support is dependent on two things; the nature of disability and in some cases, there will be a means test for some supports. The below information is an overview of some of the supports that are available to a family or individual.

### Disability Allowance

This is a payment made to people between the ages of 16 and 65, who pass a means-test and are thought to be “substantially restricted” from undertaking work which would be otherwise suitable for someone of their age, experience, and qualification. If you qualify for this benefit, you may also be eligible for further entitlements such as the household utility package and a free travel pass. For further information see Citizens Information Disability Allowance ([citizensinformation.ie](http://citizensinformation.ie))

### Domiciliary Care Allowance (DCA)

Domiciliary Care Allowance is a monthly payment for a child with significant complex support needs. The payment is not based on the type of disability but is based on the impact of the disability. Eligibility is based on a child who requires ongoing care and attention, substantially over and above the care and attention usually required by a child of the same age. Unlike other payments of this nature, Domiciliary Care Allowance is not means tested. Since 2017 all children in receipt of DCA are entitled to a medical card. For more information on Domiciliary Care Allowance see Citizens Information Domiciliary Care Allowance ([citizensinformation.ie](http://citizensinformation.ie))

### Carers' Allowance

Carers' Allowance is a means-tested payment paid to people who provide full-time care to a child or adult who needs support because of age, disability, or illness (including mental health conditions). In qualifying for a carer payment, you may also be entitled to access other services such as Free Household Benefits (if you are living with the person you are caring for) and a free travel pass and a Carer GP visit card. For more information on support for carers please see Family Carers Ireland website.

### Entitlements under the Medical Card Scheme

Medical cards are issued by the Health Service Executive (HSE) and allow the holder to receive certain health services free of charge. They allow people to access a Family Doctor or GP services, community health services, dental services, prescription medicine costs, hospital care and a range of other benefits free of charge, which includes but not limited to:

- Paediatric Special Needs Buggies
- Wheelchairs (automatic/manual)
- Augmentative, Alternative Communication (AAC) and Assistive Technology and Mounts
- Oral motor aids

### ***Incapacitated 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. To qualify the child must be either: Under 18 years of age, or Over 18 years of age and unable to support themselves. In this situation the child must have become permanently incapacitated before they were 21, or after they were 21 if they were still in full-time education or training for a trade or profession for a minimum of 2 years. For more information on Revenue's financial supports see Family Carers Ireland website.

### ***Home Carer Tax Credit***

A Home Carer Tax Credit is a tax credit given to married couples or civil partners (who are jointly assessed for tax) where one spouse or civil partner works in the home caring for a dependent person. The tax you are liable to pay is calculated as a percentage of your income. A tax credit is deducted from this to give the actual amount of tax that you have to pay. A tax credit has the effect of reducing your payable tax by the amount of the credit. For more information on this see Citizens Information Home Carer Tax Credit ([citizensinformation.ie](http://citizensinformation.ie))

### ***VAT Refunds on Aids and Appliances***

If you live in Ireland and you have a disability, you may get a refund of Value Added Tax (VAT) on certain assistive aids and appliances that you need. In some cases, people who pay for aids and appliances that are for the exclusive use of a person with a disability can also claim the VAT refund. People with both physical and cognitive disabilities can avail of these refunds. This scheme of VAT refunds on aids and appliances can also apply to adaptation and installation work being carried out to make a home more suitable for an older person or for a person with a disability.

### ***Housing Adaptation Grant***

A Housing Adaptation Grant for People with a Disability is available from local authorities if you need to make changes to a home to make it more suitable for a person with a physical, sensory, or intellectual disability or mental health condition. For more information on the above please see Citizens Information.

### ***Free Nappy Scheme***

If your child is three years or older and is not yet ready or unable to be toilet trained; you are entitled to apply for free nappies. This can be done by contacting your local Public Health Nurse.



IRELAND'S **AUTISM** CHARITY

## How Can AsI Am Support You and Your child?

AsI Am is Ireland's national autism charity. Our vision is to create a more inclusive Ireland for autistic people. We run a range of programmes which aim to support the autistic community and families. We provide support to our community through our wide-ranging programmes in our community support, adult support and training teams. Our purpose is to advocate for an inclusive society for autistic people that is accessible, accepting and affirming. We work to support the autistic community and our families to fully engage in Irish life and build the capacity of society to facilitate true inclusion.

### **COMMUNITY/FAMILY SUPPORT**

We provide information and guidance to families and individuals through our full-time signposting service available through our **AUTISM INFORMATION LINE ON 0818 234 234** or at [support@asiam.ie](mailto:support@asiam.ie), we also have an Instant Messaging service available on our website.

Through our Family Support Programme, we offer a range of events and activities for autistic children under 18 and their families. The Family Support Programme offers a range of online and in person opportunities to connect with AsI Am, and each other to build the capacity of families to have their needs acknowledged and supported and to connect autistic children and families through special interests.

Through the work of our Policy Team, we lobby government and public representatives to ensure better services for autistic people and families.

### **EDUCATION AND TRAINING**

We believe for society to be inclusive of autistic people, it is important and necessary to mainstream awareness and knowledge about the condition. AsI Am works in partnership with businesses within the private and public sector to enhance autism understanding within the workplace and in schools.

### **ADULT SUPPORT AND EMPLOYMENT**

We offer Adult Support and Employment Programmes to provide much-needed support for autistic adults through our different programs, all of which are available to view on our website.

### **AUTISM ID CARD**

AsI Am has provided many children and adults with an Autism ID card. You can find more information about the Autism ID card on our website. Please visit our website ([AsI Am.ie](http://AsI Am.ie)) to find out more about the work we do.





# Important Organisations

## Advocacy / Support agencies

- ADHD Ireland - the national ADHD charity providing non-medication management supports of ADHD
- Aiseanna Tacaíochta - Supporting Independent Living
- BodyWhys- the national voluntary organisation supporting people affected by eating disorders
- Children's Rights Alliance - Advocacy organisation for children in Ireland
- Disabled Women Ireland
- Down Syndrome Ireland
- Dyslexia Association of Ireland
- Dyspraxia Association of Ireland
- Family Carers Ireland - Supporting carers in Ireland
- Inclusion Ireland - National association for people with an intellectual disability
- Independent Living Movement Ireland - Supporting independent living
- Middletown Centre for Autism
- National Autistic Society (UK)
- National Council for Special Education
- National Disability Authority (NDA)
- National Platform for Self-Advocates (Self-advocacy organisation for people with intellectual disabilities)

## Employment and Education

- AHEAD- Association for Higher Education Access in Ireland
- Irish Association of Supported Employment (IASE)
- National Learning Centre
- National Learning network
- Not So Different.ie
- Open Doors Initiative - Pathways to work
- Solas - Further Education & Training Authority
- Specialisterne Ireland - Recruitment employment agency for autistics
- WALK (Walkinstown Centre for People with an Intellectual Disability)

## Professional bodies

- Independent Speech - Language Therapists of Ireland
- Irish Academy of Audiology
- Irish Association for Counselling and Psychotherapy
- Irish Nutrition and Dietetic Institute
- Irish Society of Chartered Physiotherapists
- Association of Occupational Therapists of Ireland
- Psychological Society of Ireland

## STATE AGENCIES

- Child and Adolescent Mental Health Services (CAMHS)
- National Educational Psychological Service (NEPS)
- Primary Care Occupational Therapy
- Primary Care Psychology
- Primary Care Speech and Language Therapy
- Children's Community Disability Network Teams (CDNT)

THANK YOU



The Hospital  
Saturday Fund®

The creators of this resource would like to extend their gratitude to **The Hospital Saturday Fund (HSF)**. The Hospital Saturday Fund is a registered charity whose aims are to provide assistance for registered health charities, hospices, medical organisations and individuals with a medical condition or disability.

The HSF provides grants for medical projects, care, research or support of medical training within the United Kingdom and the Republic of Ireland.



NOTES





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