

2023 Version

Starting the **Autism Journey**

(for Parents and Guardians)



LUCENA CLINIC SERVICES

TABLE OF CONTENTS

FOREWORDS.....	2
WHAT IS AUTISM.....	3
WHAT IS THE DIAGNOSTIC CRITERIA FOR AUTISM?.....	4
WHAT DOES IT MEAN TO BE ‘ASSESSED’?.....	4
WHAT TO EXPECT FROM AN ASSESSMENT.....	5
HOW TO GET AN AUTISM ASSESSMENT (FOR YOUR CHILD).....	6
PUBLIC ASSESSMENT.....	6
ASSESSMENT OF NEED	8
APPLYING FOR AN ASSESSMENT OF NEED	8
DISABILITY IDENTIFIED.....	9
CHILDREN’S DISABILITY SERVICES (CDNT).....	10
HOW DO I GET A REFERRAL TO THE CDNT?.....	10
PRIVATE AUTISM ASSESSMENTS.....	11
PROFESSIONALS YOU MAY MEET.....	13
MEET THE MULTIDISCIPLINARY TEAM.....	15
AUTISM AND LANGUAGE ACCEPTANCE	18
DIVERSITY AND STRENGTHS OF AUTISM.....	21
VOICES OF THE COMMUNITY	22
SCHOOL SUPPORTS	24
SPECIAL NEEDS ASSISTANTS /INCLUSION SUPPORT ASSISTANTS.....	24
SCHOOL PLANS AND SUPPORTS.....	25
SCHOOL TRANSPORT	26
THE NATIONAL EDUCATIONAL PSYCHOLOGICAL SERVICES	26
COMMUNITY SUPPORT GROUPS	27
FINANCIAL SUPPORTS AND RESOURCES	28
DISABILITY ALLOWANCE.....	28
DOMICILIARY CARE ALLOWANCE (DCA)	28
CARERS’ ALLOWANCE.....	29
INCAPACITATED TAX CREDIT.....	29
FREE NAPPY SCHEME.....	29
HOME CARER TAX CREDIT.....	30
VAT REFUNDS ON AIDS AND APPLIANCES.....	30
HOUSING ADAPTION GRANT.....	30
ENTITLEMENTS UNDER THE MEDICAL CARD SCHEME.....	30
HOW CAN ASIAM SUPPORT YOU AND YOUR CHILD?	31

Forewords

Hello, from the Community Support Team at AsIAM, Ireland's National Autism Charity.

We are delighted to present to you in conjunction with the St. John of God Foundation the first of three resource packs for parents/guardians starting or exploring the journey behind getting an autism assessment for your child.

The idea behind this resource came from the high volume of families contacting our office daily looking for information and support on getting an autism assessment. This resource pack we hope, will offer parents/guardians the knowledge and knowhow in starting the journey towards an assessment for your child. By providing insights on 'what is autism', the professionals you may encounter on your journey and how an individual is assessed inter alia.

Every new journey brings with it concerns, questions and unknowns, and we hope that this resource pack will provide you with the knowledge you require to understand the assessment journey better.

AsIAM provides support and information to the autistic community. We support and signpost families to services and resources that are available to them.


For more information on the work we do please see our website AsIAM.ie.

This publication has been supported by the Saint John of God (SJOG) Foundation. The Foundation fundraises on behalf of a range of SJOG Community Services who are dedicated to providing support to children and adolescents experiencing mental health challenges and to adults and children living with a range of intellectual disability. Lucena Child and Adolescent Mental Health Services (CAMHS) in Dublin is one of the community services Saint John of God Foundation supports. CAMHS provides services for young people under age 18 with moderate/severe mental health concerns.

It has been a great privilege for the Foundation and Lucena CAMHS to partner with AsIAM and to be involved in the publication of 'Starting the Autism Journey', which is one of a three part autism resource 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.

For more information about the work of Saint John of God Foundation see sjogfoundation.ie. For more information about Lucena CAMHS please see www.lucenaclinic.ie.



Autism is a lifelong, developmental disability or difference which relates to how a person communicates and interacts with others, and how they experience the world around them.

What is autism?

Autism is a lifelong, developmental disability or difference which relates to how a person communicates and interacts with others, and how they experience the world around them.

Autism is a part of the broader neurodivergent family of differences or disabilities which encompasses people with conditions or differences such as ADHD, Dyslexia and Dyspraxia, Epilepsy, Tourette's Syndrome and Dyscalculia.

These different ways of thinking about, processing and understanding the world are called 'neurotypes'. People who have these differences in thinking are said to be 'neurodivergent', as their way of thinking and processing the world can diverge from what society expects, whereas people who don't have these differences are said to be 'neurotypical'.

While autistic people are born autistic, it is not something that parents learn 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.

WHAT IS THE DIAGNOSTIC CRITERIA FOR AUTISM?

The DSM-V outlines the diagnostic criteria for the assessment and diagnosis of a variety of differences, disabilities and mental health conditions. This is the criteria the assessment team will use in the process of seeking an autism diagnosis.

According to the DSM-V:

‘Autism is characterised by persistent challenges with social communication and interaction coupled with restricted or repetitive patterns of behaviour, interests or activities.

There are some benefits to getting assessed for autism including (but not limited to):

- Gaining clarity on something you are unsure of
- Gaining a better understanding of self and/or your child
- Gaining a better understanding of the individual’s strengths, differences and needs
- Accessing autism/disability specific supports and services

WHAT DOES IT MEAN TO BE ‘ASSESSED’?

Many people may know or learn about autism and see autistic traits in themselves and/or someone they know (such as their child).

After learning about autism, many might identify themselves as autistic or consider their children to be autistic.

To receive a professional diagnosis, the child is required to be assessed by a clinician, or a team of clinicians, with expert knowledge in autism.



WHAT TO EXPECT FROM AN ASSESSMENT

Autism assessments usually involve at least one clinician with relevant training and expert knowledge. Teams of clinicians including psychiatrists, psychologists, speech and language therapists, and/or occupational therapists can work together to complete an assessment. These are called Multi-Disciplinary Teams (MDTs).

There is currently no biological way to test for autism – there is no blood test, genetic screen or scan. Clinicians use diagnostic criteria, or a checklist of observable traits or characteristics, to determine if a child is autistic. These criteria have changed over time based on a growing understanding of autism.

Currently, when a clinician is assessing for autism, they are looking to see:

- Are there current and past differences in social communication (e.g., is there a preference to communicate without eye contact)
- Are there interests and focuses that are specific or intense or passionate
- Is there a difference in the sensory experience of the world (e.g. might be very sensitive to noise)?

To explore this, an assessment for ‘autism’ should involve several components. As autism is a lifelong neurodevelopmental disability and will be present throughout life, it is important that the assessing clinician(s) interview those who know or who knew your child when they were young. Most clinicians ask what your child was like around their 5th birthday. They might ask about your child’s life and any mental health concerns, their learning needs, their medical history, and about significant life events.

The clinician will always want to spend time with the child being assessed and get to know them.

To see what autistic traits a child might have, they should observe how they might react to different situations, and will likely use a standardised test/ tool to help them with this. The clinician will ask the child to talk on certain topics, to do puzzles and/or play games with them. For an older child they will likely ask questions about their own experience of autistic traits and their own understanding of self.

Depending on the individual, it is useful for the clinician to have a measure of cognitive functioning or capacity (for example, decision-making, attention, intelligence and problem solving). They may assess this, along with a measure of what everyday tasks your child can do independently at home, in education and in the community.

When making a diagnosis, the clinician uses their judgement based on what they have been told by the child, the people who know them well, and what the clinician has seen first-hand when they have met with them. They might provide an alternative suggestion as to why the individual may be feeling different from others and/ or experience difficulties.

You should meet with the clinician or the clinical team to get feedback on the assessment, and you should be provided with a report detailing the individual's strengths and needs. The report should include recommendations for appropriate supports for the child at home, in school and in the community. You should be able to see that these reports are individualised to your child.



HOW TO GET AN AUTISM ASSESSMENT (FOR YOUR CHILD)

Applying for an autism assessment for your child can be a confusing process.

If you need to access an autism assessment for your child, there are two different routes available to you, Public and Private.

PUBLIC ASSESSMENT

Public assessment is free of charge. Currently there are **THREE** different routes to an autism assessment publicly for your child.

APPLYING DIRECTLY TO THE EARLY INTERVENTION AND SCHOOL AGE TEAMS

The HSE has local teams supporting children across Ireland. Each of these teams supports children with different levels and types of needs. These teams usually include Primary Care, Child & Adolescent Mental Health (CAMHS), Children's Children's Community Disability Network Teams (CDNTs)

HOW DO I REQUEST A DIAGNOSIS THROUGH THE EARLY INTERVENTION OR SCHOOL AGE TEAMS?

To request an assessment or therapy services from the Early Intervention or School Age Teams, you need a referral from a health care professional (e.g., your public health nurse, GP, Occupational Therapist or Speech & Language Therapist etc).

If the Early Intervention or School Age team accepts your referral (i.e., if they agree that your child is showing significant and complex difficulties in more than one area of functioning), you will be put on a waiting list for an assessment with that team. Unfortunately, services are very stretched at present, and the waiting time is likely to be long. You will be given an approximate wait time when you are added to the waitlist.

It is important to note that Early Intervention Teams and the School Age Disability Teams operate separately. As mentioned previously, your child may be waiting up until 3 years to get an autism assessment, so sometimes children may "age out" of the team, meaning the process must start over again, and your child will be put on another waiting list for the other team.



ASSESSMENT OF NEED

The Assessment of Need (also known as AON) was established under the Disability Act, 2005. An Assessment of Need is an assessment carried out by the HSE for children or young people with a disability (autism is classified as a disability). If your child has a disability or you think they may have a disability, you can apply for an Assessment of Need.

In recent times the AON has been a source of legal wrangling. In 2020 a new system was introduced called the Standard Operations Procedure under the AON Guidelines, which introduced the Preliminary Team Assessment. The Preliminary Team Assessment evidenced the presence of a disability but did not provide any formal diagnosis. This then had a knock-on effect on families seeking to access autism specific supports (e.g., an autism class).

The High Court has since stated that this new procedure introduced in 2020 was unlawful and not in keeping with the Disability Act, 2005 because it did not meet the standards to provide a diagnostic assessment. Under the Act a child/young person should receive (i) a full and complete assessment of their needs and (ii) a service statement stipulating the services required to address the needs identified in the assessment.

The above represents a changing and fluid situation, we would encourage parents/guardians to visit our website or the HSE's for the latest information on this. If you do have any questions on the AON process, our Information Line Team would be happy to speak through these with you.

APPLYING FOR AN ASSESSMENT OF NEED

To apply for an Assessment of Need you need to contact your local Assessment Officer (found by calling your local health centre) and they will guide you through the application process. Alternatively, you can fill in the Assessment of Need application form and send it to your local Assessment Officer.

After you send in your application, you will get a letter from the HSE confirming they have received your application and the date when the assessment will start. The HSE must send you this letter within 14 days of your application.

If the Assessment Officer is satisfied that your child needs an assessment, they must arrange this referral within 3 months



of receiving your completed application. Once this referral is made there will be a further 3 months to assess your child and complete the Assessment Report this is legally mandated under the Disability Act 2005, please see section 14(1) of this Act for more information on this.

DISABILITY IDENTIFIED

You will get a Service Statement if your child is deemed to have a disability. A Service Statement lists the services the HSE proposes to provide to meet your child's needs and the timeframe in which those services should be provided.

It is prepared by a Liaison Officer and must be completed within one month of the assessment report being completed.

By law, the HSE must provide the services named in the Service Statement. The Service Statement must be clear and easily understood.

If Assessment has not commenced with 3 months of completed application

Where an Assessment of Need is formally commenced but not completed within 3 months, the parent/guardian should as soon as possible for them make a complaint to DISABILITY COMPLAINTS OFFICER with a request that the complaint be processed within 30 days. You can get a complaint form from your Assessment Officer, Liaison Officer or directly from the Disability Complaints Officer.

You can contact the Disability Complaints Officer by calling 045 880 400 or by e-mailing aon.complaints@hse.ie

If a complaint is made and not processed within 30 days, parent/guardian should seek legal advice on this.

If my Service Statement is not completed or provided for within the statutory timelines

You can make a complaint within 3 months of the date on which you became aware of the cause of the complaint. In the first instance, you can contact your Liaison Officer. If you are still not happy and wish to escalate your complaint, you can contact the Disability Complaints Officer.

You can ask the Assessment Officer or Liaison Officer for a form to complete. This form also lists the grounds on which you can make a complaint. The form, when completed, needs to be returned to the Complaints Officer. The Complaints Officer is an independent body. This means that the Complaints Officer will look at your complaint objectively and fairly.

You can also contact the Complaints Officer directly on 045 880 400 or by e-mail to aon.complaints@hse.ie

If you are unhappy with the findings and recommendations of the Complaints Officer, you can appeal to the Disability Appeals Officer. If

the HSE has not acted on the recommendations of the Complaints Officer, you can appeal to the Disability Appeals Officer or you can go to the Circuit Court to seek an enforcement order.

CHILDREN'S DISABILITY SERVICES

If your child has a difficulty or difference in one area (e.g., a speech delay), it is likely a referral to Disability Services will result in you being seen by, or on the waiting list for, Primary Care. However, if your child requires specialist services delivered by more than one professional together as part of a team, they will be seen by the Children's Disability Network Team (CDNT). The CDNT provides specialist support for children who have a disability and complex health needs associated with their disability.

If your child is assessed by the CDNT, it is likely they will be seen by the occupational therapist and/or speech and language therapist in the first instance. The therapists will likely want to observe your child playing. This is so they can gain insight into a wide range of your child's skills and preferences.

The therapists will also want to have a discussion with you to gain your perspective on your child's developmental history, their strengths and interests, and the past and current barriers to your child's participation at home and in school.

Based on these observations and discussions, the team psychologist, alongside the occupational therapist and/or speech and language therapist, may decide to proceed with a standardised diagnostic tool for autism, such as the ADOS. Much like we described with the AON process above, how autism is assessed is currently a changing and fluid process.

HOW DO I GET A REFERRAL TO THE CDNT?

As a parent/guardian, you can self-refer your child to the CDNT. You do this by completing the electronic forms housed on the HSE Children's Disability Services webpage. The team will review the forms you submit and based on this information will contact you regarding next steps.

Should I apply for an AON and self-refer to the CDNT?

Given the ever-changing processes in place, you may feel the best opportunity your child has to be seen is by completing both referrals. It is worth noting that the CDNT does not exist purely for assessment, and it is not diagnosis led. Therefore, if your child

presents with a complex need in communication, sensory processing, cognition, motor skills and/or emotion that requires multi-professional input, they can in theory receive support from the CDNT.

PRIVATE AUTISM ASSESSMENTS

Why do people get a private assessment?

Due to the waiting lists and confusion regarding assessment routes, many parents may choose to seek a private assessment. This means it is an autism assessment carried out by a chartered psychologist who is working privately, and not in the HSE. As the cost of a private assessment can range between one to two thousand euro, this is often only an option for families who have the financial means to do so.

How do I know I have obtained a reputable assessment?

Many families face anxiety regarding selecting a reputable private assessor. This anxiety can be compounded by the fact there is currently no regulation of psychologists in Ireland. This makes it frighteningly easy for an individual who has not completed the full psychologist training to present as one.

If you are considering a private psychologist to complete the assessment, check the Psychological Society of Ireland (PSI) website to see if they hold Chartered Membership. If you are concerned that the psychologist you are considering does not hold Chartered Membership, ask them for their 2023 PSI Chartered Membership certificate.

It is critically important to research the professional in advance of the assessment. Any chartered psychologist will be more than happy to clarify their credentials and qualifications to you and will understand why you need to request this information.

Once you have confirmed this, you should also consider the following in making your choice:

Are they neurodiversity affirmative?

When you look on their website, is the language they use neurodiversity affirmative (exploring neuro differences, highlighting strengths and areas of support) or medicalised (referring to autism as autism spectrum disorder, focusing on difficulties and impairments)? It is hugely important that your child's experience of the assessment does not reinforce any negative stereotypes they hold of themselves, and instead empowers and supports them. Additionally, as your child grows up, it is likely they will want to see their diagnostic report. This document should not leave them feeling it was a confirmation of 'deficit'. Instead, it should accurately capture their experience of the world, their strengths, and where they need more support.

What assessments do they conduct?

The ADOS is currently considered the gold standard of assessment tools in diagnosing autism, and it is also one of the assessment tools that the HSE use. However, a diagnosis should not be given based on the ADOS alone. The ADOS

is designed to be used alongside a parent interview, a child interview (if suitable) and clinical observations carried out by the professional.

If your child is also being seen by a speech and language therapist or occupational therapist as part of the assessment, they may also conduct assessments such as the Sensory Processing Measure.

You should ask exactly what standardised tools are being used, and the purpose in using these.

What should the diagnostic report include?

While there is some variation, a diagnostic report will often include:

- Credentials of assessor
- Background and reasons for assessment
- Demographics of child
- Standardised tests used (with descriptions).
- Results of tests (you will usually see tables here)
- Interpretation of tests (what do those numbers mean?)
- Parent narrative/feedback arising from interview
- Child narrative/feedback arising from interview
- Conclusion and summary of needs and strengths
- Recommendations. This section is KEY! Often parents look for the conclusion (has the child been diagnosed) and worry less for the recommendations/summary of needs. However, the recommendations of the diagnosing professional are crucial when it comes to applying for certain school supports and even social welfare payments. These recommendations should go across multiple domains of the child's life; school, home, community etc. Finally, these recommendations should be individualised to your child, should educate you about your child's autistic experience, and empower you as an advocate.



**PROFESSIONALS
YOU MAY MEET**

GENERAL PRACTITIONER

“Hi - Peter here, I am your local General Practitioner, but you can also call me your GP, or your local doctor. Not only can you go to me when you are feeling unwell, but I can also be a point of contact if you would like to access any other primary and secondary care mental health/disability services – including an autism assessment. If you want your child to go for an autism assessment, you can make a regular appointment with me to discuss why you would like your child to be referred. If you would like to use the HSE public services, I can write a letter of referral to the Children’s Community Disability Network Teams (CDNT’s). You will then be put on a waiting list before someone to contact you. Due to demand on these services your child may experience delays in accessing these services. If you want to use private services, I can also write the letter of referral for such a service.”



PUBLIC HEALTH NURSE

“I’m Varsha, and I am your local Public Health Nurse. I work with the HSE primary care services. My job involves carrying out a wide range of duties, not just in the doctor’s office, but in the community. You may also find me working in schools, day services, community centres and even people’s homes. One of my duties includes working with expectant mothers and young children, so if you have young children, you might see me regularly. Like a GP, I can also refer your child to the Children’s Community Disability Network Teams. All you need to do is make a regular appointment to see me and explain why you would like your child to go for an autism assessment. I can then write a letter of referral to either our public health services, or if you want to go private, to a prospective clinical psychologist/psychiatrist”

SOCIAL WORKER

“Hi there. My name is Lisa. I am a social worker. You might meet me a few times throughout the assessment process, although I am not directly involved in the assessment. My role could involve meeting with your child and with your family throughout the diagnostic assessment. I may also assist the clinician in the assessment with my own reports and observations of your child. I am also here to help you and your family, if you need any guidance or advice throughout the assessment.”



MEET THE MULTIDISCIPLINARY TEAM

When undergoing an autism assessment, you and your child may meet with several professionals. Each professional has a specific role in the assessment.



CLINICAL PSYCHOLOGIST

“I’m Stephen and I am a Clinical Psychologist. I work with both adults and children and support them through a wide range of areas. Clinical Psychologists have years of extensive training and experience. We have specialised knowledge about child development, and the challenges that children, teenagers and families can face throughout life. One of our main roles is to carry out different psychological assessments on children/adolescents/adults – including autism assessments. **My role in the autism assessment involves conducting interviews with you, as a parent/guardian.** These interviews include a structured Parent Interview (ADI-R) and a detailed developmental history interview. **My role in the assessment also involves spending time with your child to observe patterns or certain behaviours, and to assess their developmental and cognitive abilities.** If your child is a teenager – this will involve a more detailed clinical interview.”



EDUCATIONAL PSYCHOLOGIST

“Hello! My name is Janet, I am an Educational Psychologist. Like a clinical psychologist, I can provide an autism assessment/diagnosis of your child, I can also provide ongoing supports throughout the educational lifecycle”.

PSYCHIATRIST

“My name is Anna, and I am a psychiatrist. A psychiatrist is a medical doctor that specialises in mental health. I am trained to provide mental health services, but because I trained as a doctor, I can also prescribe medication to my clients. My role in an autism assessment is the same as a clinical psychologist – so when called for an assessment, your child will see either a psychiatrist or a clinical psychologist. **We complete the psychological element of the assessment, and we are equally as qualified.** It just depends on who your primary care service/clinic has access to – this varies across the country.”



SPEECH AND LANGUAGE THERAPIST



“Hi there! My name is Tom, I am a Speech and Language Therapist (SLT). SLTs are trained extensively in speech, language, social communication, and social interaction. My role involves meeting with your child over a few months – this is done to establish whether a pattern exists in your child’s speech, social communication, and interaction. During this time, **I will complete a formal assessment through a variety of age-appropriate activities.** These include listening activities (such as pointing to a particular picture as requested) and speaking activities (storytelling). Your child may also be shown a sequence of pictures and asked to describe what is happening and verbalise solutions to certain fictional problems”

OCCUPATIONAL THERAPIST

“Hi! My name is Vicky. I am an Occupational Therapist. I help people to do the everyday activities that they want and need to do when faced with illness, injury, and disability. I do this by providing support to people whose ability to complete tasks is impacted by their physical, psychological, or developmental condition. It can be sometimes difficult for an autistic person to process and act on the information given by their sensory environment. **My role in the assessment involves meeting your child regularly to establish their skills/abilities and areas in which they might have difficulty.** During this time, there may be parent/guardian questionnaires and play-observation. I may also use screening assessments to measure functional and sensory capabilities by asking your child to complete tasks.”



AUTISM AND LANGUAGE ACCEPTANCE

As autism has enjoyed greater visibility, understanding and acceptance in recent years, some people might be unsure around what to say when we are talking about autism and the experiences of autistic people.

Language around autism has evolved over time as we know more about what it means to be autistic - people might have used functioning labels (like “high-functioning” or “mild” or “severe”) to describe how somebody close to them experiences being autistic.

Some people might also use Asperger Syndrome - a condition previously used to refer to people who experience no differences in speech, who are perceived to have average to above-average intelligence and who may not require extensive support - to describe their experience of being autistic.

Whilst these descriptors were commonly used by clinicians to categorise people’s perceived experiences of being autistic, and are still used as more colloquial terms today, the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders), the manual used by psychologists, psychiatrists and clinical experts to diagnose neurodevelopmental differences, conditions and disabilities, phased out these terms, including Asperger Syndrome, and combined all these different characteristics under the umbrella term “autism”.

It also phased out some of the more clinical descriptors, including functioning labels, that would have characterised how a person might experience being autistic, and replaced this with using ‘support needs’ to describe the kinds of support they need. It also includes sensory processing differences for the first time, which can range from sensitivity to lights, smells or sounds to hyposensitivity, as a key trait which many autistic people experience. These changes more closely reflect both how people experience being autistic as well as capture more closely the wide diversity of traits and characteristics that autistic people experience.

Language can be a powerful way of describing ourselves and many autistic people might have different ways of talking about autism, and how they might choose to identify themselves.

These are:

Identity-first language (“autistic people”, “disabled people”);
Person-first language (“people with disabilities”).



Many autistic people use ‘autistic person’, as opposed to ‘person with autism’, to identify themselves as they see their autism as a core and central part of their identity.

Many autistic people use ‘autistic person’, as opposed to ‘person with autism’, to identify themselves as they see their autism as a core and central part of their identity.

They see being autistic as both a difference and a disability that is a central part of how they think about the world, and as a natural part of the human experience. This is informed by the idea that an autistic person’s environment, and how they interact with the environment, can also play a part in how an autistic person can experience the world around them and deal with everyday situations. The physical environment, communication, social factors, access to services, and wider society’s attitudes to autism can all play a part on how an autistic person might feel accepted and included in the community. Rather than expecting your child to change who they are to fit into society, we as a society, can make changes to what we do to address barriers which can make it harder for autistic people to live in society and feel accepted.

By addressing these barriers, whether through accommodation, positive action or other measures, we can make society a better and more inclusive place for your child.

The most important thing is to accept an autistic person as they are. Asking an autistic person how they would like to be referred to is a great way of showing respect for their preferences. If the autistic person might be non-speaking, pre-verbal or have a preference for using different forms of communication, try to respect their communication preferences where you can. If there are family members, carers or advocates who are supporting the autistic person, you can also ask them and they might be able to assist you if you are unsure.

CASE STUDY

“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. 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.”



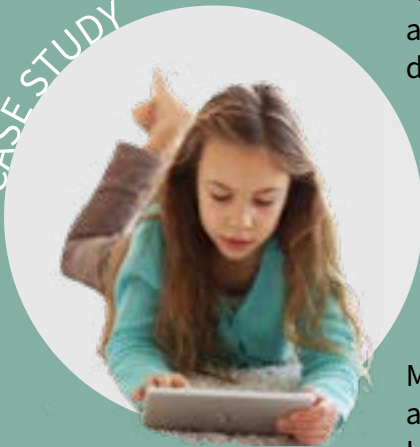
“I’m Emily, and I was diagnosed with autism. I really like music, and I’m obsessed with Ed Sheeran. I really like art and I like to draw and to paint in my free time.

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.

My parents tell me that I have ‘mild’ or ‘high-functioning’ autism, although I’m not really sure these labels fit me. I guess I have a different way of seeing being autistic to my parents!

There are some parts of school that I’m good at and there are 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 an autism class. He really likes animals and he particularly likes horses - he finds them really relaxing. While he goes to an autism 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.”

CASE STUDY



DIVERSITY AND STRENGTHS OF AUTISM

Searching the web for an answer to the question ‘What is Autism?’ presents a large quantity of information which can be overpowering and difficult to read. Autism exists as a spectrum which means it impacts different people, in different ways, to differing degrees, at different times and in different situations. This means that if you have met one autistic person, you have met one autistic person. No two autistic people are the same.

The areas of difference and diversity for those on the spectrum can largely be summed up under the following headings:

- Communication
- Social Interaction
- Repetitive and restrictive patterns of behaviour
- Sensory Processing

Autistic people think in a different way from the majority of people. This can make many aspects of day-to-day life challenging however there is nothing negative or wrong about thinking differently.

Many autistic people’s strengths and abilities derive from this different perspective on life. Autistic people often have an ability to focus on detail, are consistent, have a strong sense of honesty and loyalty and can focus on, and even excel, in areas they are interested in.

Autistic people are said to have scattered skill sets –this means the things a person is good at, they might be very strong in, even if they may find other areas exceptionally difficult. 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.

Autistic people who have a broad range of strengths and abilities, live in every community and work in all walks of life. An autism diagnosis may mean a person requires additional support and may have a different journey through life however it does not have to limit a person’s future or opportunities.

Autism exists as a spectrum which means it impacts different people, in different ways, to differing degrees, at different times and in different situations.

Autism does not have to limit a person’s future or opportunities.

Autistic people often have an ability to focus on detail, are consistent and have a strong sense of honesty.

AARON, AGED 5



My name is Aaron, I am 5 years old, and I am autistic and non-speaking -verbal. 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 Children's Community 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) and I am getting better at telling people what I need.

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 Children's Community 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!



SCHOOL SUPPORTS

SPECIAL NEEDS ASSISTANTS /INCLUSION SUPPORT ASSISTANTS

Autistic students with additional learning 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 most in need to meet the primary care needs of students. Schools apply to the National Council for Special Education (NCSE) for ISA/SNA allocation hours based on the care needs of their student population.

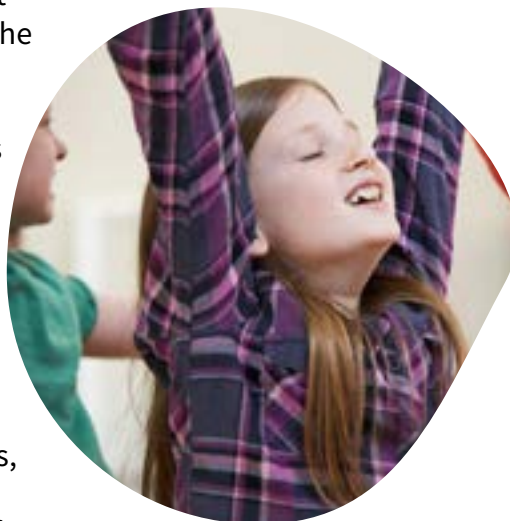
The duties of an SNA are assigned at the discretion of the Principal and are monitored on an ongoing basis, focusing on particular care needs of students in the school. A diagnosis of disability will not be required for a student to access SNA support. However, if professional reports are available regarding a student's needs, they should be used to guide schools in planning for the support your child may require. Parents/guardians should bring any reports to the attention of the school to assist with the allocation of resources.



SCHOOL PLANS AND SUPPORTS

If your child is offered a school placement then you should help that school plan for the education of your child to ensure that the best possible educational practices can be in place when school begins. Open and honest communication is important between parents/guardians and the school.

A copy of any relevant paperwork like reports and assessments from professionals should be provided to the school. Having a link between previous school placements and the new school can be very beneficial. It is important that you discuss the following with new school; learning needs, social and communication needs, care needs, mobility and medication needs, sensory needs and physical needs that require environmental adaptations that are particular to your child. All of these will ensure the school is aware of your child's strengths, abilities and needs. This information will also help the school develop an individualised support plan for them. There are different types of plans that may be developed including a general plan for support, an individual learning profile or an individualised educational plan (IEP) depending on the student's needs.



IEP - INDIVIDUALISED EDUCATION PLAN

- The Principal, mainstream class teacher, Special Education Teacher (SET), parents/guardians, and the student (where appropriate) will work together to develop an IEP for the student.
- An IEP is a detailed support plan setting out clear goals and strategies to meet specific student's needs, in line with the National Educational Psychological Service (NEPS) Continuum of Support Guidelines.
- Support plans address your child's needs in some or all of the following areas, as appropriate to the student: academic learning, social and communication, emotional, behaviour, life skill
- These include independence, care needs such as dressing, toileting, mobility, medical needs, physical needs that require environmental adaptations such as adaptations to the school building, adapted seating or other specialised equipment and sensory needs.
- Only the areas of identified need arising from an assessment will be addressed in the IEP.
- The amount of adaptation and support will vary according to the individual learning needs of your child.
- Some children with more complex needs may require significant educational modifications.
- The IEP therefore should be individualised, child-centred and available and comprehensible to all involved in working with your child's and reviewed regularly.
- The review documents your child's progress through the targets set, and any recommendations and changes must be agreed upon and shared by all parties involved in working with your child.



SCHOOL TRANSPORT

School transport is provided for students with additional needs who are attending the nearest recognised mainstream school, autism class/special school. Schools can work with parents/guardians to complete application forms for transport for eligible students, which must be signed by the school principal and Special Education Needs Officer (SENO) also. The SENO will then forward the application form to the relevant department. Certain criteria must be met for students to qualify for the free transport scheme including attendance of the nearest recognised school that meets the student's special educational needs. If your child is enrolled in an autism class and subsequently integrates into mainstream in their school, they will retain their transport eligibility for the duration of their education in that school. If your child transfers to another school, they must engage in the application process again. Further information and forms are available at <https://ncse.ie/for-schools>.

THE NATIONAL EDUCATIONAL PSYCHOLOGICAL SERVICES

(NEPS) provides educational psychological support to all recognised primary and post-primary schools in Ireland. This involves direct support in the event of a critical incident, access to national and regional support and development work to build school capacity to support students, access to a NEPS psychologist for responses to queries arising, and access to individual pupil casework where there is such need.

The transition from primary to post-primary can be a stressful event for some pupils and some pupils may need additional support. Schools may use the NEPS case work service to support the transition of some pupils.

If you feel your child could benefit from this transition from primary to post-primary school support under NEPS please speak to your child's school principal or directly get in touch directly with the National Educational Psychological Services.

COMMUNITY SUPPORT GROUPS

One of the biggest challenges faced by Irish families who have autistic children is the period awaiting an assessment and the weeks following a diagnosis. One invaluable resource during this period and indeed in the days after is the community support groups that are out there. Support groups are a rich resource for the autism community, from individuals on the spectrum, to families and professionals.

Community support groups are there to provide parental support, information and guidance. They empower family members 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 services, 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 and advice from family and friends, while well-intentioned, may prove impractical, but by 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.

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



FINANCIAL SUPPORTS AND RESOURCES

Receiving an autism diagnosis does not automatically entitle an individual to financial support or assistance. Support is dependent on two things; 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.

DISABILITY ALLOWANCE

This is a payment made to people between the age 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).

DOMICILIARY CARE ALLOWANCE (DCA)

Domiciliary Care Allowance is a monthly payment for a child with significant complex 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).



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 illness). 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 Rights & Entitlements | Family Carers.

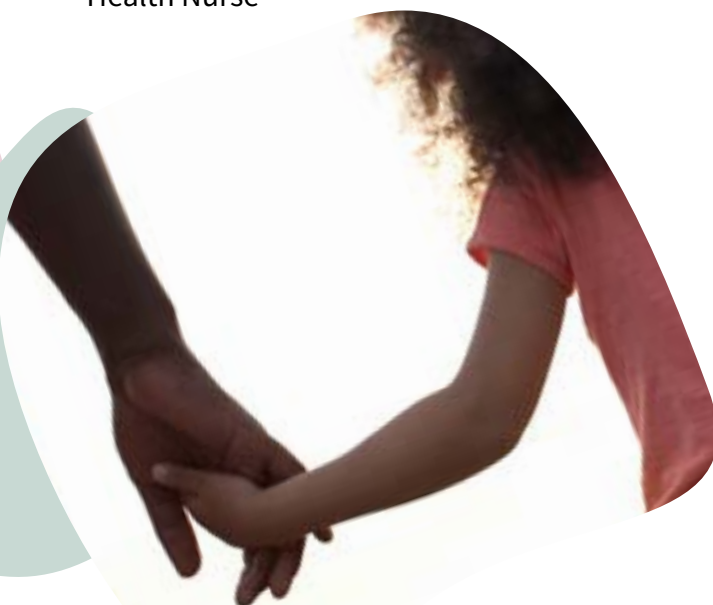
INCAPACITATED TAX CREDIT

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 financial supports, please see Citizens Information:
www.citizensinformation.ie

FREE NAPPY SCHEME

As your child approaches three years 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



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)

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 special 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 ADAPTION 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 difficulty.

For more information on the above please see Citizens Information.

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.

HOW CAN ASIAM SUPPORT YOU AND YOUR CHILD?

AsIAM 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 on 0818 234 234 or at 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/activity for autistic children under 18 and their families. The Family Support Programme offers a range of online and in person opportunities to connect with AsIAM, 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 Officer, 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. AsIAM works in partnership with businesses within the private and public sector to enhance autism understanding within the workplace and in schools to ensure a better understanding of the condition.

ADULT SUPPORT AND EMPLOYMENT

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

AUTISM ID CARD

AsIAM 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 (AsIAM.ie) to find out more about the work we do.



LUCENA CLINIC SERVICES

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