

# Starting the **Autism Journey**

(for Parents and Guardians)



LUCENA CLINIC SERVICES

# CONTENTS

<b>FOREWORDS.....</b>	<b>2</b>
<b>WHAT IS AUTISM?.....</b>	<b>3</b>
<b>WHAT IS THE DIAGNOSTIC CRITERIA FOR AUTISM?.....</b>	<b>4</b>
<b>WHAT DOES IT MEAN TO BE ‘ASSESSED’?.....</b>	<b>4</b>
<b>WHAT TO EXPECT FROM AN ASSESSMENT.....</b>	<b>5</b>
<b>HOW TO GET AN AUTISM ASSESSMENT (FOR YOUR CHILD).....</b>	<b>6</b>
Public Assessment.....	6
Applying directly to the Early Intervention and School Age teams.....	7
How do I request a diagnosis through the Early Intervention or School Age teams?.....	7
Apply for an assessment of need.....	8
How do I apply for an Assessment of Need?.....	9
How to get a Private Autism Assessment.....	10
<b>PROFESSIONALS INVOLVED IN THE ASSESSMENT.....</b>	<b>11</b>
Meet the Multidisciplinary Team.....	13
<b>AUTISM AND LANGUAGE ACCEPTANCE .....</b>	<b>16</b>
<b>DIVERSITY AND STRENGTHS OF AUTISM.....</b>	<b>19</b>
<b>VOICES OF THE COMMUNITY .....</b>	<b>20</b>
<b>SCHOOL SUPPORTS .....</b>	<b>22</b>
Special Needs Assistants /Inclusion Support Assistants.....	22
School plans and supports.....	23
School Transport .....	24
<b>COMMUNITY SUPPORT GROUPS .....</b>	<b>25</b>
<b>FINANCIAL SUPPORTS AND RESOURCES .....</b>	<b>26</b>
Disability Allowance.....	26
Domiciliary Care Allowance (DCA).....	26
Carers’ Allowance.....	27
Incapacitated Tax Credit.....	27
Home Carer Tax Credit.....	28
VAT Refunds on Aids and Appliances.....	28
Housing Adaption Grant.....	28

# Forewords

Hello, from the Community Support Team at AslAm, 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.

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

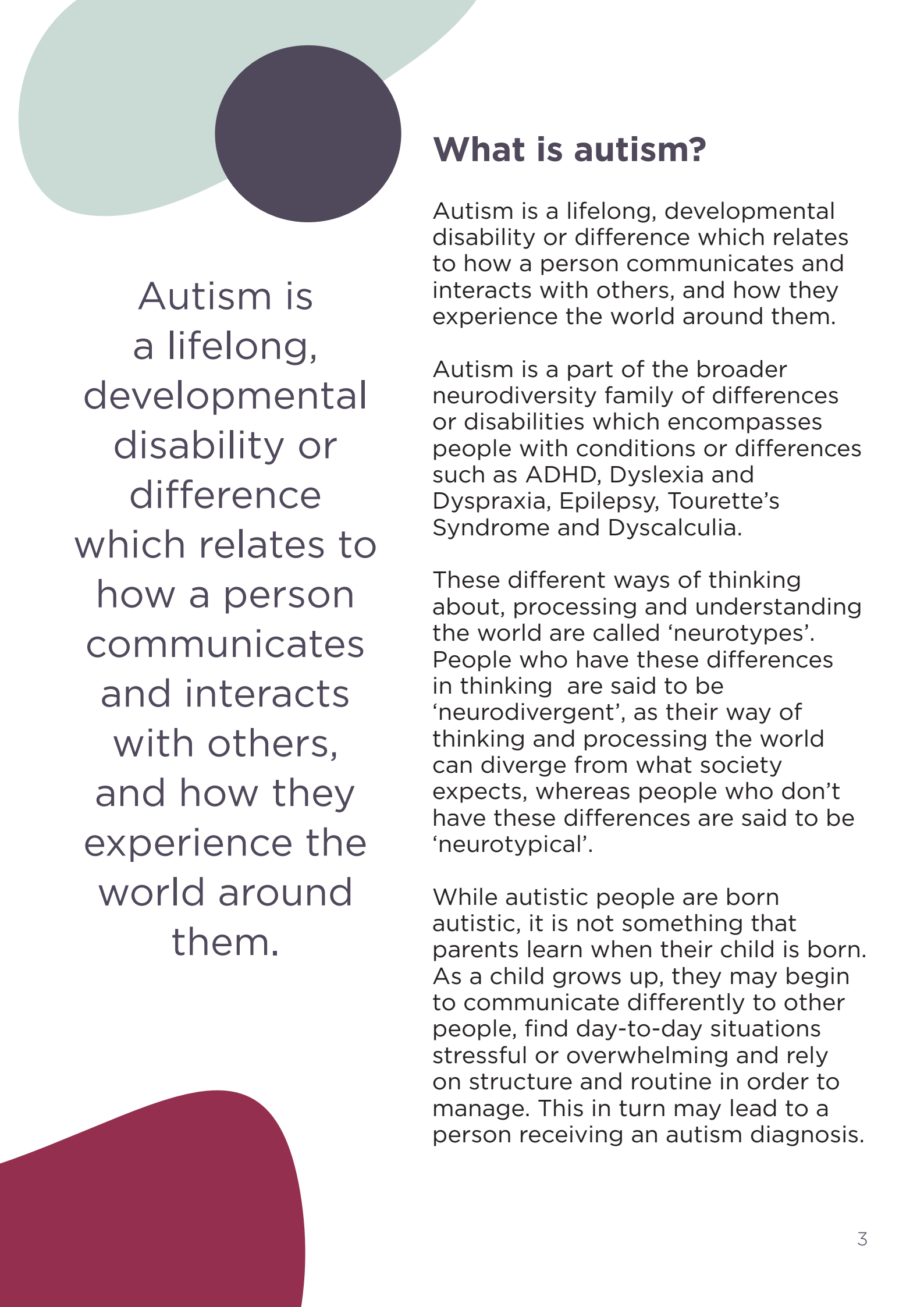
For more information on the work we do please see our website **AslAm.ie**.

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 AslAm 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](http://sjogfoundation.ie)**. For more information about Lucena CAMHS please see **[www.lucenaclinic.ie](http://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 neurodiversity 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 self-identify as autistic or consider their children autistic. Some might be happy with this self-diagnosis and decide against a formal assessment to confirm this diagnosis.

To get a professional diagnosis, the child is 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 (e.g. a psychiatrist or clinical psychologist). 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 difficulties with social communication (e.g. is there difficulty making friends or forming romantic relationships);
- Are there restricted or repetitive behaviours or interests (e.g. does the individual thrive on routine and may become distressed if there are changes to routine);
- Is there a difference in 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.



## 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 TWO different routes to an autism assessment publicly for your child (although both now result in a diagnostic assessment with the same HSE team).

## 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), Early Intervention (EIT) and School Age Disability Team (SAT).

The teams that assess for autism (as well as other complex developmental needs) are typically called the Early Intervention Team (for children 0-6) and the School Age Disability Team (for children 6-18). Although the HSE are moving towards all disability services being provided in the same way nationally (through a plan called Progressing Disability Services) there are still regional variations and depending where you live these teams might be called different names or organised slightly differently.

## 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.



### EXAMPLE:

When Jack was 4 and a half – Jack’s parents asked their local GP to put a referral in for him to be assessed for autism. Jack has been on the waiting list for 18 months – Jack is now 6 years old and has ‘aged out’ of the Early Intervention Team and must now be referred to the School Age Team. The School Age team is separate to the Early Intervention Team. Jack must now join a waiting list for the School Age Disability Team – this may take up until another 2 years before Jack is assessed.

If you are confused about how the Disability Teams are organised in your local area, ask at your local health centre.

### APPLY FOR AN ASSESSMENT OF NEED

Option 2 for a **public** assessment is to apply for an Assessment of Need. You can apply for this if your child was born after 1st June 2002 and you feel they have a disability (autism is classified as a disability). The aim of the assessment is to assess and identify the health and educational needs of an individual.

Prior to February 2020, an Assessment of Need could lead to an official diagnostic assessment of Autism if indicated. However, under the new Assessment of Need Guidelines, children going forward will receive a brief “preliminary team assessment” and not a diagnostic assessment (so your child could not be given a diagnosis of autism following this initial brief assessment alone). However, if concerns are raised during this brief preliminary team assessment, your child would then be put on a separate second waiting list with your local Early Intervention or School Age Disability teams.



## HOW DO I APPLY 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 will need to fill out an Assessment of Need Form. You can find the form online [here](https://www.hse.ie/eng/services/list/4/disability/disability-assessment/application-for-assess-of-need-2017.pdf):

[www.hse.ie/eng/services/list/4/disability/disability-assessment/application-for-assess-of-need-2017.pdf](https://www.hse.ie/eng/services/list/4/disability/disability-assessment/application-for-assess-of-need-2017.pdf)

You will send the form to your local Assessment of Need Officer -  
your local officer contact details can be found [here](https://www.hse.ie/eng/services/list/4/disability/disability-assessment/assessment-officers):

[www.hse.ie/eng/services/list/4/disability/disability-assessment/assessment-officers](https://www.hse.ie/eng/services/list/4/disability/disability-assessment/assessment-officers)

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.

Once the HSE receives your application in writing, they must start the assessment within 3 months and must finish the assessment within a further 3 months. An Assessment of Need starts when the Assessment Officer arranges the referral to the assessors, if needed.

In exceptional circumstances, the assessment may take longer than 3 months. If there is a delay in completing the assessment, you must be told the reason and given a timescale for when it will be completed.

**NOTE:** In some areas applying for an Assessment of Need may result in the child being seen sooner than a referral to the Early Intervention or School Age Team. In other areas, the Assessment of Need and Early Intervention/School Age Team waiting lists are merged and there is no benefit to applying for both. You can talk to your GP or Public Health Nurse about whether applying for both is necessary or needed where you live, but on balance it is recommended you apply for both.



## HOW TO GET A PRIVATE AUTISM ASSESSMENT

Some parents also access autism assessments privately. Your first step would be to contact your local GP or Public Health Nurse for a referral letter. A lot of private assessors will require one, while others do not – but it is better to have a referral letter for your child in case they do.

Private assessments can be expensive – the costs for such assessments vary, depending on the practice/clinical professional – this is due to the in-depth nature of these assessments and the detail that is necessary in the final report. Your child will be seen usually by a multi-disciplinary team including a psychologist/speech and language therapist/occupational therapist.

### **Here are a few tips when finding the right private assessment for your child:**

1. We would recommend contacting a few different organisations as each organisation will have their own individual prices.
2. Different clinics will also have different waiting times- waiting lists can be up to 6 months for some clinics and less with others.
3. It is important to be aware that to access HSE services in the future, the private assessment and report needs to include specific areas.

### **If accessing a private assessment, find out beforehand if your child's report will include the following:**

1. A cognitive or developmental assessment (this is particularly important in Dublin, where often access to services depends on it).
2. If the Autism Diagnostic Observation Schedule (ADOS) assessment is undertaken in a multi-disciplinary way.
3. If the report will include a detailed parent interview such as the Autism Diagnosis Interview-Revised (ADIR), or Diagnostic Interview for Social and Communication Disorders (DISCO)

When searching for an assessor, be sure to seek clarity on their qualifications and ensure they are accredited by the Psychological Society of Ireland (the governing body for psychology). Psychologists will soon be regulated by CORU and will each have a license number. It is important to ensure that a detailed report of the assessment process and a profile of strengths and needs will be included with the assessment.

## SUMMARY

- Your child is assessed much quicker in comparison to public services
- Private assessments can be expensive
- No public financial assistance is available to parents for private assessments



# **PROFESSIONALS INVOLVED IN THE ASSESSMENT**



### 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 and explain any concerns you may have. If you would like to use the HSE public services, I will write a letter of referral for your child to the Early Intervention or School-Age team. You will then be put on a waiting list before someone contacts you. If you want to use private services, I can also write the letter of referral to a clinical psychologist/psychiatrist.



### 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 our Early Intervention or School Age Team for an autism assessment. 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. My role could involve meeting with your child and with your family throughout the assessment. I sometimes provide support to families going through autism assessments. I may also assist the psychologist in the assessment with my own reports and observations. 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 will 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.



## 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.

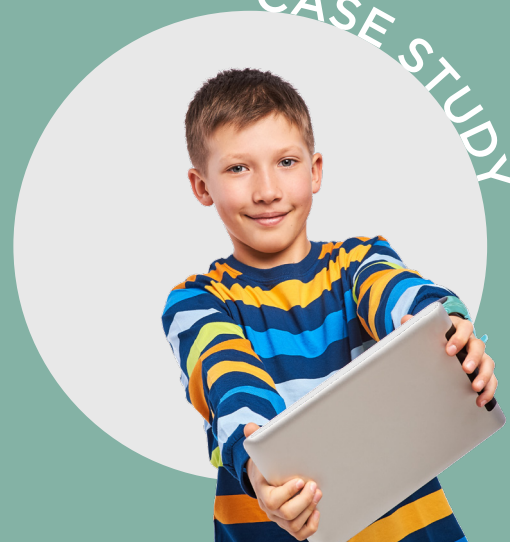
## CASE STUDY

"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. 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."



## CASE STUDY



"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 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."

## 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 pre-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 my own Special Needs Assistant and his name is Brian. He helps me with my schoolwork, toileting, eating my lunch and we seem to be getting on fine. I also have something called 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 an “Early Intervention Team”. I see a Speech and Language Therapist called Tom. He is helping me develop my communication skills. We use the Picture Exchange Communication System (PECS) and I am getting better at telling people what I need. I am getting happier now as I can now tell my family and teachers what I need using the pictures.

### 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 mainstream 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 School Age Going Team. Vicky is an Occupational Therapist, and she is super nice. We work together each week to develop my ‘life skills’. 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 mainstream 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. My mum is concerned about this, so she told me she is going to try to get me an appointment with something called CAMHS. I hear they listen to and help young people like me, so it seems like a good idea.



### **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 / Board of Management 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 support. Parents/guardians should bring any reports to the attention of the school.





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, a behavioural plan, 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, special 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 a special 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>.

## 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. Specialty support groups such as Prism Dún Laoghaire Rathdown (Prism DLR) group provide special interest group activities, i.e Lego clubs, while Snowflakes autism support group in North Dublin provides play therapies and workshops in addition to support group meetings.

The Fingal Development Community Support Groups work with families of autistic children in areas such as advocacy and creating social networks, while Laois/Offaly Families for Autism Community Support groups also provide activities and therapies. To find resources in your local area please visit our interactive map which can be found on **[www.asiam.ie](http://www.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](http://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](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 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](http://www.citizensinformation.ie)**





## 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 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.



LUCENA CLINIC SERVICES

Designed by cnocii.ie, ©AsIAm 2021.  
AsIAm is registered with the Charities Regulatory Authority.  
Our Registered Charity Number is (RCN): 20144838 and our CHY number is 21201.