

The Assessment and Diagnosis Process

Why pursue a diagnosis?

Some parents might be very reluctant to pursue an autism assessment and diagnosis for their child.

We appreciate that the “What if?” stage can be a highly stressful time, and that often, well-meaning family members and friends feed into the confusion by telling parents things like, “Don’t worry,” or “I don’t know why children need labels,” or “Why don’t you just wait and see what happens?”

Here are some of the key reasons why we so strongly encourage parents to seek answers as soon as they start to have concerns that their child might have autism:

- A diagnosis gives access to funding. Early Detection = Early Intervention
- Teachers and schools will have information that will allow them to more effectively support your child
- Your child will be entitled to accommodations and disability provisions (if needed)
- You will gain a better understanding of how your child processes the world
- Your child will understand themselves better and know that they are connected to a larger group of people on the autism spectrum

Not surprisingly, the vast majority of parents of children with an autism diagnosis wish that they had received answers even earlier.

Finally, even if your child is assessed and is NOT diagnosed with autism, a robust assessment process still has immense value: it can help reveal the specific reasons for a child’s challenges and the most effective support for them.

Who is entitled to a diagnosis?

Your child is entitled to an assessment if you are of the opinion that they have a disability. From 1st June 2018, a young person over the age of 16 is entitled to apply themselves.

The disability legislation states that a “substantial restriction” means that they have a restriction which is permanent or likely to be permanent, results in a significant difficulty in communication, learning or mobility or in significantly disordered cognitive processes, and means that he or she has a need for services to be provided continually or that they have the need for services to be provided early in life to ameliorate the disability.

Application Process

An application can be made for any child that is born after the 1st June, 2002 where disability is suspected. From the 1st June, 2018 an application can be made by a young person if they are 16 years and over.

Your first step is to contact your Doctor or your local assessment office. Parents with concerns about their child’s condition are referred by their GP or Pediatrician to their local Autism Service Provider for an assessment. As a parent you can also self-refer your child.

All applications must be made in writing to the HSE using the Application of Assessment of Needs under Disability Act 2005.

<https://www.hse.ie/eng/services/list/4/disability/disability-assessment/application-for-assessment-of-need-2017.pdf>

Assessment Process

Once you have made a written application, the HSE must acknowledge your application within 14 days.

This assessment is carried out by a multi-disciplinary team. The assessment team will normally comprise of some or all of the following professionals – Speech & Language Therapist, Psychologist, Occupational Therapist and a Social Worker.

The objective of the assessment is to decide what health and educational needs arise from your child's disability if one has been diagnosed.

A team will start your child's assessment within 3 months of sending in your application. In some cases, there may be a delay for clinical or other reasons, an assessment officer will contact you to discuss any delay in the process.

After the assessment begins there will be a further 3 months to complete the Assessment Report.

On completion of the assessment, the Assessment Officer writes an assessment report which is given to you, the HSE and if appropriate the NCSE.

The assessment report sets out whether the child or young person has a disability and, if they have, it sets out:

- A statement of the nature and extent of the disability
- A statement of the health and education needs arising from the disability
- A statement of the appropriate services to meet those needs
- A statement of the period within which a review of the assessment should be carried out (this must be no later than a year from the date the assessment report is issued)

If your child is assessed to have a disability, the Assessment Officer will send the assessment report to a Liaison Officer. The Liaison Officer uses the assessment report to draw up a Service Statement which outlines the following:

- The health services which will be provided
- The location(s) where the health service will be provided
- The timeframe within which they will be provided
- The date from which the statement will take effect
- The date for review of the provision of services specified in the Service Statement

Assessment of Need Officer Co. Louth

Cora Higgins – Assessment Officer

HSE, Disability Services (Louth),

Manor hamilton House,

Carrick Road,

Dundalk,

Co. Louth

Email: cora.higgins@hse.ie

Tel: 041 6858062

Assessment of Need Officer Co. Meath

Louise Mc Dermott – Assessment Officer

HSE Lisieux House,

St. Josephs Hospital Complex,

Trim,

Co. Meath

Email: louise.mcdermott@hse.ie

Tel: 046 9481128

Complaints Procedure

If you are not happy with the assessment or the Service Statement you can make a complaint under the Disability Act 2005 to the HSE. You can make a complaint if:

- Your child is found not to have a disability and you do not agree
- The assessment is not done in line with the standards set by the Health Information and Quality Authority
- An assessment is not started and completed within the agreed timeframes
- You believe that the content of the Service Statement is inaccurate or incorrect
- The services in the Service Statement are not being delivered

If your complaint is about the assessment process, please contact the Assessment Officer. If the complaint is about the Service Statement, please contact the Liaison Officer. They should be your first point of contact to seek a resolution.

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 Tel: 045-880400.

Appeals Procedure

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. An information leaflet and an application form for this appeals process will always be included in the Complaints Officer's final report.

The Disability Appeals Officer is independent and is appointed by the Minister for Health. The Appeals Officer is not part of the HSE. For more information about making an appeal, contact the Disability Appeals Office on LoCall 1850 211 583 or at www.odaio.ie

How is Autism Diagnosed?

Diagnosing Autism Spectrum Disorder can be challenging, since there are no medical tests, like a blood test, to diagnose the disorders. It's vital to get a full assessment and diagnosis from a qualified and reliable professional or team of professionals using proper assessment tools.

Autism should be diagnosed by a specialist multi-disciplinary team, pediatrician, psychiatrist or clinical psychologist using the current Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

Diagnostic Tools

The DSM and ICD-10(International Criteria for Diseases) criteria create the foundation for diagnostic tools such as the DISCO (Diagnostic Interview for Social and Communication Disorders), the ADI-R (Autism Diagnostic Interview - Revised), and the ADOS (Autism Diagnostic Observation Schedule).

These, and other diagnostic tools, are used to collect information in order to help to decide whether someone is on the autism spectrum or not. The criteria form the basis for the diagnosis, but the individual clinician's judgement is crucial.

Private Assessments & Diagnosis

Due to the importance of early intervention and the lengthy waiting lists for the assessment of needs, parents often choose to go down the private diagnosis route. It is important to check that the private diagnosing professional is recognised by the HSE.

A confirmed diagnosis of autism will allow you to access resource teaching hours and apply for an SNA (Special Needs Assistant) if one is required. A private diagnosis will also allow the parent of the child to apply for such allowances as Domiciliary Care Allowance, Carers Allowance and the Incapacitated Child Tax Credit.

Even if you have a private diagnosis you will still need to be seen, assessed and diagnosed by the state service provider (HSE). The reason for this is that normally the service provider will provide the services such as speech & language therapy and occupational therapy for your child post diagnosis.

Local Resources for Early Intervention and Diagnosis

Below are the details of the Early Intervention and Disability Teams in Co. Louth and Co. Meath

County Louth Early Intervention Team

Unit20 Boyne Business Park, Greenhills, Drogheda, Co. Louth A92 ED91
Tel: 041-9842423
Email: Liam.callaghan@hse.ie

Who is the service for?

Children from 0-6years of age who live in County Louth Local Health Area and present with:

- Physical disability
- Sensory disability
- Intellectual disability
- Pervasive developmental delay
- Diagnosis (or diagnostic query) of Autism Spectrum Disorder (ASD)
- Requiring ongoing team-based interventions

Co. Louth Children's Disability Team (6-18yrs)

Address: Mount Hamilton House, Carrick Road, Dundalk, Co.Louth
Tel: 0429381400
Mobile: 0868542429
Email: michaelj.murphy@hse.ie

Who is the service for?

Children from 6-18 years of age who live in County Louth Local Health Area and present with:

- Physical disability
- Sensory disability
- Intellectual disability
- Pervasive developmental delay
- Diagnosis (or diagnostic query) of Autism Spectrum Disorder (ASD)
- Requiring ongoing team-based interventions

Co. Meath Enable Ireland Meath Early Services

Address: Unit 13 Mullaghboy Industrial Estate, Navan, Co. Meath
Tel: 046-9092530
Email: adminmeath@enableireland.ie

Who is the service for?

Children 0-6 years who live in Co Meath and have a disability or query of a disability such as Down Syndrome, Cerebral Palsy, a Physical and Sensory disability, Autism or query Autism and require ongoing team based intervention. Also seen are children with complex difficulties associated with Development Coordination Disorder, or Developmental Language Disorder

Co. Meath Child Development Team 6-18years

Address: Bailis Resource Centre, Johnstown, Navan, Co Meath
Tel: 046 9091400
Email: bailis.resourcecentre@hse.ie

Who is the service for?

Children 6-18 years who live in Co Meath and are on the Autism Spectrum, or have an Intellectual Disability, Cerebral Palsy, or a Physical and Sensory disability. Also seen are children with complex difficulties associated with Development Coordination Disorder, or Development Language Disorder.

When your child is diagnosed – What Next?

Your child has just been diagnosed with Autism Spectrum Disorder. No matter how prepared you are the chances are you are now worrying about the future, what happens next and how you and your family are going to manage. We are all different and how we deal with diagnosis differs from family to family and person to person.

If there is one piece of advice that can help at this stage it is “don’t panic”. That might be easier said than done. Yes, it is important that you find out more information about Autism, interventions, strategies, education and future planning but receiving a diagnosis is part of a journey that began when your child was born and will continue during your child’s lifetime. This is the Journey with Autism. There are times this is an interesting and fascinating journey but at other times a very challenging and difficult time.

Where do you start? Begin with understanding how your child’s Autism affects them. The social world can be a very confusing and frightening place when you are not able to understand why things are happening and to comprehend the bigger picture even within your own home. Fear and anxiety are for the triggers for the behaviours that your child exhibits. As a parent, you can feel powerless to manage your child’s behaviour. But understanding why they are reacting as they do means you can look to your child’s environment and try to change the cause of the reaction. When a child is overloaded they are unable to cope and will react, sometimes badly, to things or people around them. Teaching a child to cope and manage can take a long time, it has to be gradual and the child has to build their own confidence and control in coping in that situation.

N.B. Throughout the assessment and diagnostic process, you will have received appointment letters, copies of report etc. Now is the time to set up a filing system so you can keep all this information together. Keep all information together because it will be relevant, maybe not straight away but in the future.