

Newly Diagnosed/Awaiting Assessment Header

These are some essential starting points we feel are helpful for parents with newly diagnosed children or who are waiting on an assessment.

It can be overwhelming, confusing and daunting at the beginning of this journey, but you will learn, you will cope and there are people here to help you. There is a whole new language and terminology to learn and many new roles and agencies to interact with. This takes time to get to grips with and you may feel like you will never be able to do what is needed. Just take one step at a time.

This section aims to highlight some key issues which are very relevant at the beginning of your journey.

Firstly, there will be lots of paperwork and application forms. These always look much more difficult than they are and some of the language can seem very formal. The best way to approach this is to be organised. This will help you feel less stressed and overwhelmed. Initially there can be a lot of form-filling and applications, but this reduces over time. Our Parent Information Officer can help if you are experiencing difficulty in this area.

trish@autismsupportlouth.com or 086 078 7356

Prepare

- Get a few lever arch files & dividers.
- Keep a copy of everything you send out in the file. This is **very** important.
- Have a control sheet at the front of the file recording who you rang, what they said and when they said they will get back to you.
- It is advisable to send application forms to the Department of Social Protection by registered post.
- Be polite but persistent when following up appointments and assessments.
- Even if a form looks terrifying the best thing to do is to get started, complete the name, address etc. sections i.e. write what you know straight away and generally you will have a quarter of it done. Then keep working through it.
- Ask for help – please contact us for help (details below). There are also a lot of very helpful parent support groups on Facebook. We have a private facebook group for parents and close relatives called “Autism Support Louth&Meath”. There is a very strong history of parents supporting other parents who are starting off, so never be afraid to ask a question or ask for help and support. Your best support will be other parents of autistic children so getting to know people in your area is highly beneficial.

How is Autism Diagnosed

Autism can be diagnosed by a Clinical Psychologist or a Psychiatrist. A multi-disciplinary assessment would also include an occupational therapist and a speech and language therapist who inform the diagnostic process. It is preferable to have a multi-d team but not necessary.

The two main manuals available to professionals when looking at the criteria for Autism are the DSM-5 and the ICD-10. These manuals also include the diagnostic criteria for a range of other conditions and mental health disorders. Essentially these are the criteria that the assessment team will use in the process of seeking an autism diagnosis for your child. According to the DSM-5, autism is characterised by persistent challenges with social communication and interaction coupled with restricted or repetitive patterns of behaviour, interests or activities. Sensory difficulties are also highlighted.

There are a number of “tools” professionals use for assessments. These are essentially questionnaires and measurement questions which allow them to carry out a standard assessment meeting the criteria of DSM 5. There are a number of these but the two most frequently used in Ireland are the ADOS and the ADI-R

The ADOS (Autism Diagnostic Observation Schedule) - A semi-structured observational assessment of social communication and behaviour eg play based observation.

The ADI-R (Autism Diagnostic Interview-Revised) – usually an interview conducted with the parents of individuals who have been referred for Autism Assessment

If a diagnosis is present under the DSM this will be further split into levels 1,2 or 3.

Level 1 – Requiring Support

Level 2 – Requiring Substantial Support

Level 3 – Requiring Very Substantial Support

It is important to note that the DSM-5 and ICD-11 are medical diagnostic standards and use scientific language for clarity which can sound harsh to parents.

Assessment of Need/Referral to Children's Disability Network Team

If you are concerned about your child's development you should contact your GP or Public Health Nurse. They can refer your child to the Assessment of Need process or directly to the Children's Disability Network Team (CDNT). You can also refer your child to the AON and CDNT yourself.

Try and list down reasons that you believe your child could possibly be autistic or need assessment before you meet them. An autism diagnosis is not a simple 'yes or no' test, but a process with several different stages and professionals.

Your GP or Public Health Nurse can apply for an assessment of need. You can also apply for this directly yourself. The assessment of need may not lead to a full diagnostic assessment but it is still helpful to get this done. The wait time for both the early intervention team and the assessment of need can be quite long but it is best to go on the waiting list for both of these services.

Your GP can then refer you to the Children's Disability Network Team or you can refer yourself.

Private Diagnosis

Due to the long public waiting lists parents often opt for Private Diagnosis.

A private diagnosis will be recognised by the Department of Education for School Applications and also by the Department of Social Welfare for applications such as DCA and Carers Benefit or Allowance.

Typically, the waiting lists for a private assessment are much shorter than waiting lists for public assessments. However, this process can be very expensive. If you do decide to access a private autism assessment for your child, it is important to check that private professional or clinic you go is appropriately qualified.

A private diagnosis can be carried out while waiting for contact by the CDNT. You can send your private diagnosis to the CDNT. Minister Anne Rabbitte said last year that families should be reimbursed for the cost of private assessment but the mechanism is not in place for this yet. - But you can claim the cost of assessment on some Health Insurance policies and as medical expenses on your tax return.

What is an Assessment of Need (AON)

The Assessment of Need is an assessment carried out by the HSE for children and young people with disabilities. This identifies your child's health needs and what health services are needed to meet your child's needs.

If you have concerns about your child, you can ask for an Assessment of Need. The AON process is set out in the Disability Act of 2005 (click here to for more on this :

<https://www.ahead.ie/disabilityact>

Anyone born after 1 June 2002 can apply.

Legally this should be completed and reports finished and given to you, six months after the date of your application. Parents can apply directly for the AON. You do not have to get an AON to avail of disability services.

Application Process

You can apply directly for AON using this form:

<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 Assessment Officer must acknowledge your application within 14 days. The assessment must then start within 3 months and must finish within a further 3 months by law. The AON Officer may contact you for more information and will then decide if the application is eligible.

The assessment should be carried out by a multi-disciplinary team which will usually comprise of some or all of the following professionals:

- Psychologist
- Occupational Therapist
- Social Worker
- Speech & Language Therapist

The assessors may be HSE employees or the assessment can be subcontracted by the HSE to suitably qualified and experienced professionals.

After the assessment, the Assessment Officer creates a report, which you'll get. If your child is found to have a disability, the report goes to the Liaison Officer, who uses it to create a service statement that you'll also receive. Even if your child isn't deemed to have a disability, you'll still receive an assessment report.

The assessment report sets out whether the child or young person has a disability.

Simply put the assessment report is:

- A document describing the disability.
- A document listing the health and education needs resulting from the disability.
- A document outlining the services required to address those needs.
- A document stating when a review of the assessment will happen, which must be within a year of the assessment report.

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

Please note, the AON does not necessarily provide a diagnosis, nor does it give your child the automatic right to services.

Assessment of Need Officer Co. Louth

Robyn Power – Assessment Officer

HSE, Disability Services (Louth),
Manor hamilton House,
Carrick Road,
Dundalk,
Co. Louth
Email: robyn.power@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 you would like to make a complaint, you can contact the Disability Complaints Officer by submitting a complaint form. You can get a complaint form from the Assessment Officer, Liaison Officer or from the Disability Complaints Officer.

You can also contact the Complaints Officer directly on Tel: 045-880400 or you can email aon.complaints@hse.ie

Appeals Procedure

If the HSE doesn't address the recommendations from the Disability Complaints Officer, you have two options. You can either appeal to the Disability Appeals Officer or go to the Circuit Court to request an enforcement order.

The Disability Appeals Officer is impartial and appointed by the Minister for Health, operating independently from the HSE. For details on how to initiate an appeal, you can get in touch with the Disability Appeals Office at LoCall 1850 211 583, email appeal@ado.ie, or visit their website at www.odaio.ie.

Children's Disability Network Team (CDNT)

The CDNT provides specialised support and services for children who have a disability and complex needs until the age of 18. The team is typically comprised of occupational therapists, speech and language therapists, psychologists, physiotherapists and social workers.

Usually if you apply for an AON you will automatically be referred to the relevant CDNT team but you can refer your child to the CDNT team directly yourself. You will need to complete the basic referral form and then include the additional information form depending on your child's age. Forms should be posted to your local CDNT (Appendix A) below).

Your family and the CDNT will create an individual family support plan. This will help you work out the issues your family needs help with so that you can access support and set goals. The main area of support available is parent training in the form of information sessions, talks, workshops and group work. Your child may have some one-to-one therapy for the purpose of creating a home plan for you to work on with your child.

Parents can refer their child to the CDNT directly.

https://assets.hse.ie/media/documents/Childrens_Services_Referral_Form.pdf

Additional forms (choose the one that matches your child's age)

Birth to 11 months:

<https://assets.hse.ie/media/documents/additional-information-form-for-children-aged-from-birth-to-11-months.pdf>

12 months to 2 years 11 months:

https://assets.hse.ie/media/documents/Additional_Information_Form_for_Children_aged_12_Months_to_2_Years_11_Months_.pdf

3 years to 5 years 11 months :

https://assets.hse.ie/media/documents/Additional_Information_Form_for_Children_aged_3_Years_to_5_Years_11_Months.pdf

6 years to 11 years 11 months:

https://assets.hse.ie/media/documents/Additional_Information_Form_for_Children_aged_6_Years_to_11_Years_11_Months_rxHlkQV.pdf

12 years to 17 years 11 months :

https://assets.hse.ie/media/documents/Additional_Information_Form_for_Children_aged_12_Years_to_18_Years.pdf

Benefits and Entitlements

There are a number of benefits and entitlements you may be entitled to and these are detailed here . But we would bring your attention to the following two:

- **DCA – Domiciliary Care allowance** is a monthly payment made to parents of children with a substantial care need over and above that of a child of the same age. You do not have to have a diagnosis to apply for DCA as it is based on care needs. Click here [/assets/uploads/November 23 ASLM Benefits Entitlements.pdf](#) for more info.
- **Carers Leave/Carers Benefit.** This is relevant to people who are currently working and need to take sometime off to care for someone who needs care. This period of Carers Leave can be up to two years and your job is held open for you (similar to maternity leave) . During this time you can apply for Carers Benefit which is a weekly payment. Carers Benefit is not means tested. Click here for more info [/assets/uploads/November 23 ASLM Benefits Entitlements.pdf](#)
- Carers Benefit is a particularly useful payment as you may be contemplating having to give up work to look after your newly diagnosed child or person with care needs. At the beginning there can be a lot of assessments and appointments. But if you are able to take some time off from work at this stage in a years' or two years' time you might be in a position to return to work.

Contact Us

Jacinta Walsh - jacinta@autismsupportlouth.com or [087 240 7431](tel:0872407431) with any queries.

Trish Flood, Parent Information Officer: trish@autismsupportlouth.com or 086 078 7356

Elsa Roddy, Policy & Programme Co-ordinator elsa@autismsupportlouth.com or 086 176 4095

Join our private facebook page for carers and close family members of autistic persons – Autism Support Louth&Meath

Checklist

- Lever arch file – note all phone calls or correspondence – note all actions
- Request Assessment of Need (see links to forms above)
- Refer your child to CDNT (if this has not been done already)
- Apply for domiciliary care allowance DCA (not means tested – based on care needs and not disability)
- Apply for carers allowance or carers benefit if you are eligible (see benefits & entitlements document)
- Advertise for a home tutor if your child is eligible.
- Contact pre-school/early intervention classes/primary school in your area to set up a suitable school placement. Contact your local SENO to inform them of your child's needs.
- Apply for Incapacitated Child Tax Credit via revenue online.
- Join our private facebook group – Autism Support Louth&Meath / Attend parent coffee mornings and meet ups.
- Link up with other parents with autistic children of a similar age to your child.
- Attend any training offered by the CDNT. This will help you feel better equipped to support your child.
- Subscribe to the Middletown Centre for Autism email listing