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Freedom of Information Act Disclosure log - Reply Extract

You asked

1. What is your current autism waiting time (average, shortest, longest) referral to diagnosis for children?

For young people assessed through our pre-school pathway who received an outcome in November 2018, the average wait from an assessment being requested to the outcome being shared was 51 weeks. The shortest was 40 weeks and the longest was 54 weeks.

For young people assessed through our school-age pathway who received an outcome in November 2018, the average wait from an assessment being requested to the outcome being shared was 73 weeks. The shortest was 60 weeks and the longest was 95 weeks.

2. Can you break this down to referral to first appointment and give the waiting time (average, shortest, longest)?

For young people assessed through our pre-school pathway who received an outcome in November 2018, the average wait from an assessment being requested to their first appointment was 40 weeks. The shortest was 25 weeks and the longest 44 weeks.

For young people assessed through our school-age pathway who received an outcome in November 2018, the average wait from an assessment being requested to their first appointment was 49 weeks. The shortest was 43 weeks and the longest was 61 weeks.

3. How many children are awaiting diagnosis currently? Please can you break down the number of children with a booked future appointment and those waiting without an appointment?

For our pre-school pathway, 63 young people are currently awaiting or undergoing assessment of which 14 have appointments booked. The longest wait without an appointment is 35 weeks.

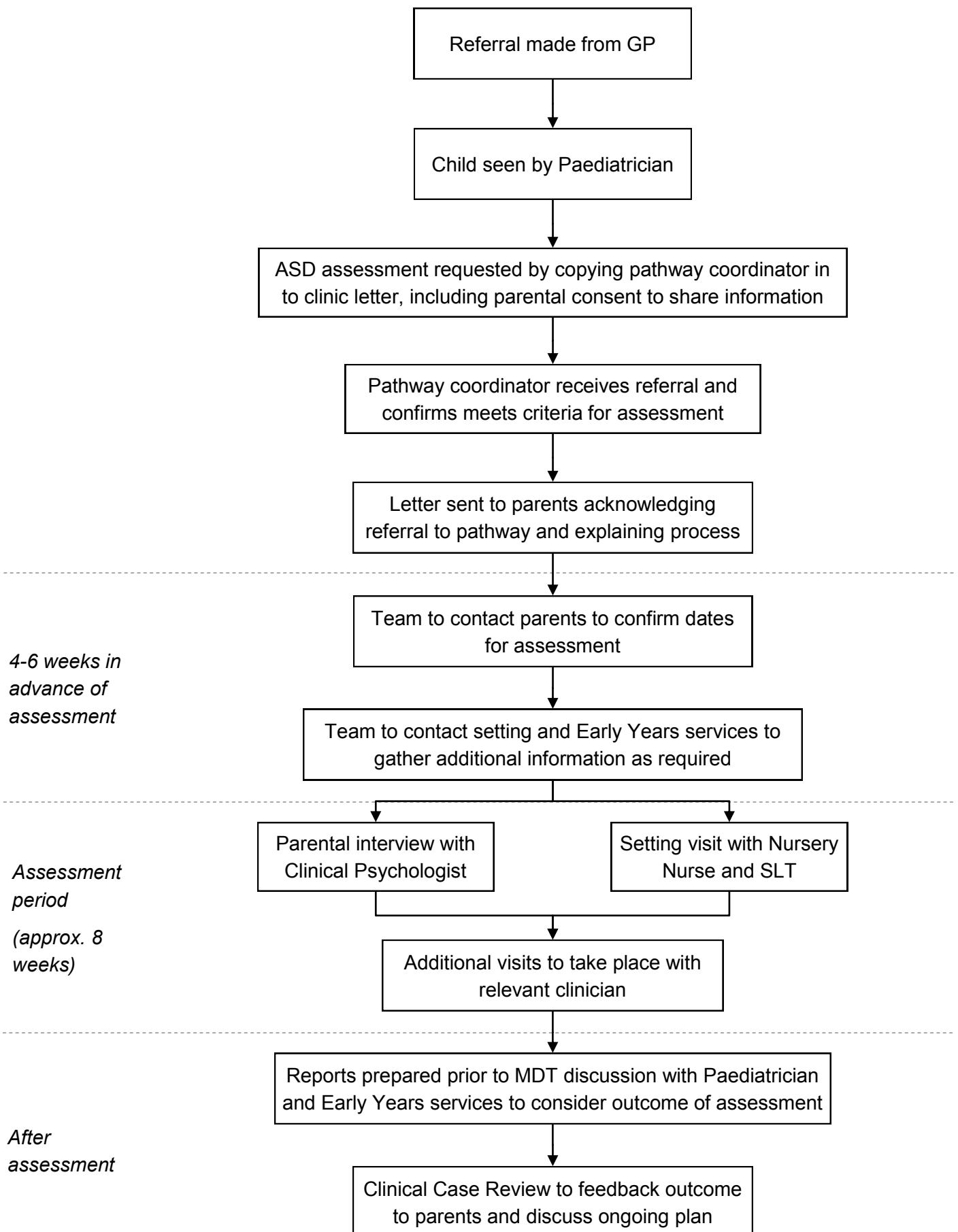
For our school-age pathway, 257 young people are currently awaiting or undergoing assessment of which 71 have appointments booked. The longest wait without an appointment is 28 weeks.

4. Can you provide a copy of the diagnosis pathway, please?

Please find four attachments.

Attachments included: Yes

Pre-school social communication pathway





**University Hospitals
Plymouth**
NHS Trust

Autistic Spectrum Disorder pathway for school-age children

This leaflet is available in large print and other formats and languages.

Please contact the ASD pathway team on 01752 439420 for more information.

**Child Development Centre
Women and Children's Care Group
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Why has my child been referred to the Autistic Spectrum Disorder (ASD) pathway?

Your Paediatrician will have referred your child as they feel they may meet the criteria for an Autistic Spectrum Disorder (ASD). The assessment pathway allows us to think about whether ASD is the right diagnosis for a child.

Autistic Spectrum Disorder encompasses other terms such as autism and asperger syndrome. Sometimes the term Autistic Spectrum Condition is used instead.

Why a spectrum?

Autism is often referred to as being part of a spectrum. This means that everyone will have a slightly different presentation, albeit with difficulties in common area.

There are lots of areas we can look at as part of our assessment. Each area may represent a relative strength or area of need, and this will vary from person to person. This means that each person on the autism spectrum will be unique.

Some of the areas we may look at include:

- Language and communication skills
- Social and interaction skills
- Attention and concentration
- Ability to adapt to change
- Learning ability
- Understanding of emotions in themselves and others
- Creativity and imagination

- Educational Psychology –

Educational Psychologists specialise in learning and education, helping those working with a young person to understand the factors which impact on their learning and how best these can be managed. This could include specific learning difficulties, medical issues or difficulties with emotional wellbeing. The Educational Psychology Service is provided by the local authority, but we have some dedicated time from their team for the ASD assessment pathway.

- Multi-Agency Support Team (MAST) –

MAST are part of the Excellence Cluster in Plymouth, and offer a range of services to mainstream primary schools. This includes Learning Mentors, Family Support Workers and Therapists. The exact services offered will vary between schools.

- Speech & Language Therapy –

Community Speech & Language services in Plymouth are provided by Livewell Southwest on behalf of the NHS. They are able to provide ongoing support around a range of speech, language and communication needs. We do also have Speech & Language Therapists as part of the ASD assessment pathway; they are separate from Community Speech & Language Service, but regularly liaise regarding specific cases.

Where can I find more information?

There is lots of information about Autistic Spectrum Disorders on the internet. Some sources of information are more reliable than others. We would suggest visiting the National Autistic Society website at www.autism.org.uk. As part of this website there is a specific page all about diagnosis.

Can we expedite assessments?

Unfortunately we are unable to prioritise individual assessments. In doing so we would be prolonging the waiting times for other young people. We see young people in the order in which they were referred to the pathway by their Paediatrician.


What happens after the pathway is finished?


Receiving a diagnosis does not automatically lead to additional support. This should instead be based on each young person's individual needs, and can be considered without a diagnosis being in place.


We will make sure, with your consent, that the outcome from our assessment is communicated with your child's school and with any other professionals working with your child. We know that receiving a diagnosis can help us to understand some of the reasons behind a child's needs.

To access further information about schools and special educational needs you may wish to speak to:

Plymouth Information, Advice and Support for SEND

 www.plymouthias.org.uk

 01752 258933 or 0800 953 1131

 pias@plymouth.gov.uk

What other professionals may work with my child?

- Communication Interaction Team (CIT) –

The Communication Interaction Team predominantly works with mainstream schools, offering specialist advice and guidance for those young people with social communication difficulties or specific speech & language difficulties. Their team is made up of Advisory Teachers and Specialist Support Workers.

What happens during the pathway?

The aim of this pathway is to gain a better understanding of a young person's social communication & interaction skills and consider whether a diagnosis may be appropriate. There is no single 'test' we can use. Instead we use a combination of formal assessment, observations and discussion with parents & professionals. This process varies depending on each young person's individual strengths and needs.

We hope that, as an outcome of our assessment, we do not just say 'yes' or 'no' to an autism spectrum diagnosis. Instead we aim to bring together a profile of each young person, recognising areas in which they have strengths as well as those in which they may need additional support. We know that around 30% of young people we assess will not receive an autism spectrum diagnosis. However, our hope would still be to gain some greater understanding of any challenges experienced by a young person.

In specifically considering an autism spectrum diagnosis, there are two areas we look at:

1. Does a young person present with characteristics we would expect to see in a young person on the autism spectrum?
2. Can these characteristics be explained in other ways?

We know that there are other reasons that young people can present with characteristics which we can see with individuals on the autism spectrum. These may include:

- Delays or difficulties with speech & language
- Difficulties with learning
- Anxiety

If our assessment indicates difficulties in these areas we will, with your permission, endeavour to arrange appropriate support. We also recognise that these difficulties may occur alongside an autistic spectrum disorder.

Who will we meet?

There are two assessments which may need to take place following your visit to the Paediatrician. One is with a Speech & Language Therapist, and the other is with a Psychologist. These assessments will look to see whether your child displays the characteristics we would expect to see in a young person with an ASD.

You may be asked to see the Speech & Language Therapist or Psychologist at the Child Development Centre. They may also visit your child at school. The specific assessments required will depend on any recent involvement from Speech & Language or Psychology services. We can sometimes use information from their recent assessments rather than repeating them ourselves.

Where there have been recent reports which provide us with relevant information we may consider other ways of carrying out our assessment. This can include the use of specific assessment tools such as the ADOS (Autism Diagnostic Observation Schedule). The ADOS is carried out at the Child Development Centre and consists of a range of tasks & activities which are assessed against standardised criteria.

As part of our assessment pathway we work with both Educational and Clinical Psychologists. A decision is made as to whether a young person should meet with a Clinical or Educational Psychologist based on their individual needs.

Please note that our team is separate from the Community Speech & Language Services offered by Livewell Southwest. However, we work closely together to make sure we have access to any relevant information and assessments.

Once the assessments are complete the professionals involved, including your Paediatrician, will meet together to consider a diagnosis. You will receive feedback from the Paediatrician, and their report will include details of any assessments we have carried out.

I have already seen a Speech & Language Therapist or Psychologist?

We will always try and utilise information which has been gathered from previous assessments. We need to consider how long ago the assessment took place and whether they covered the areas we need. Often we can use this information but need to supplement it with further assessment. This is something we will consider on an individual basis.

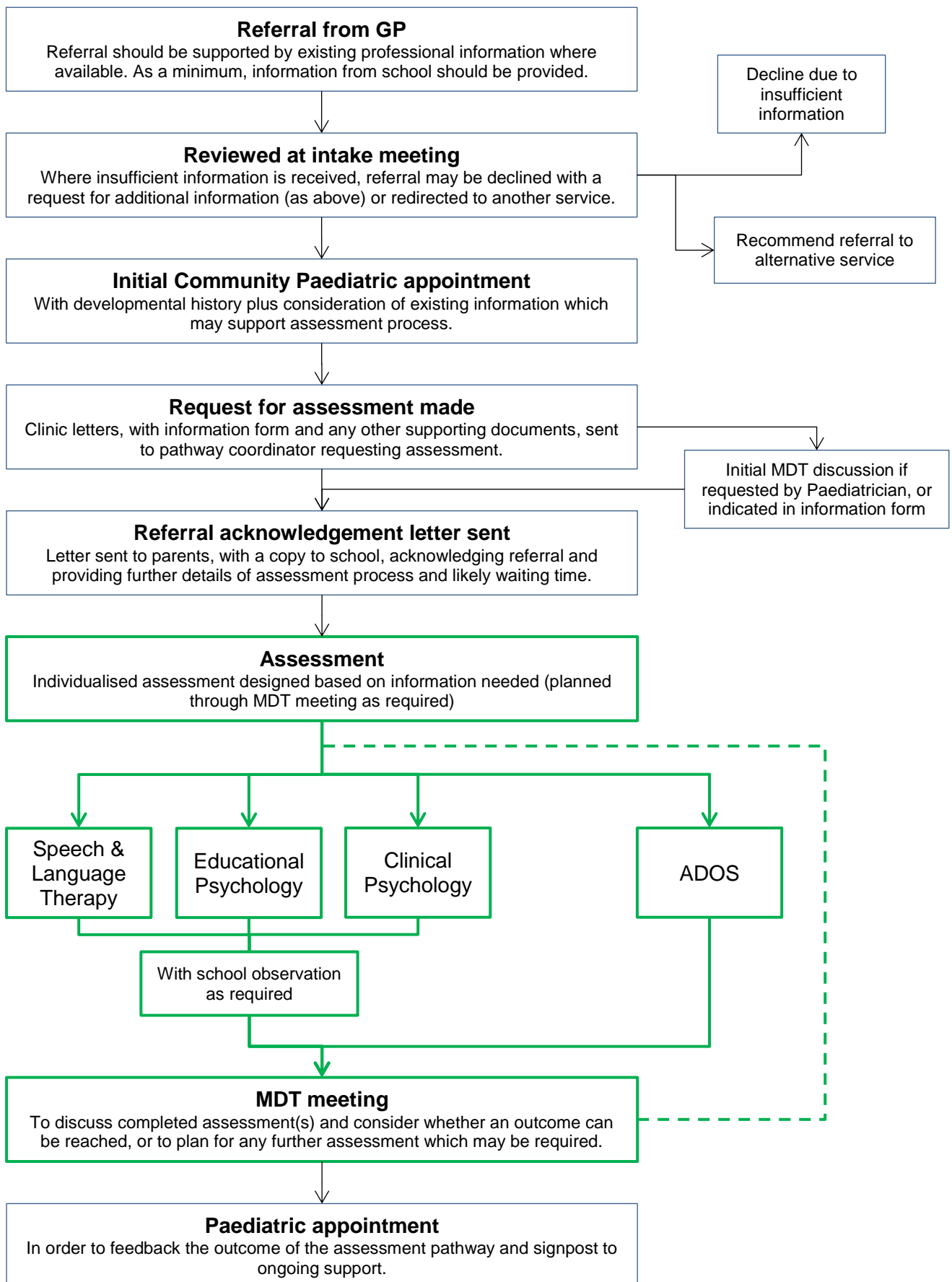
There may have also been recent involvement from other services and, with your permission, we may contact them. The information they provide will help to inform our assessment.

What are the possible outcomes from the assessment?

Typically there are three outcomes we will reach:

1. We agree that a young person meets the criteria for an autism spectrum disorder.
2. We feel that an autism spectrum disorder is not appropriate, but will still aim to give an understanding of a young person's strengths and needs. This may include consideration of an alternative diagnosis.
3. We feel that, even after comprehensive assessment, we cannot clearly reach an outcome at the present time. We appreciate this can be a frustrating outcome for parents. However, we want to ensure we are making the correct diagnosis for each young person and have sufficient information to support it.

If we are unable to reach an outcome we will try and put a plan in place as to what will happen next. This may include revisiting the assessment after a set period of time, or asking other services to offer support to address specific difficulties.



Where can I find more information?

There is lots of information about Autistic Spectrum Disorders on the internet. Some sources of information are more reliable than others. We would suggest visiting the National Autistic Society website at www.autism.org.uk. As part of this website there is a specific page all about diagnosis.

Social communication pathway for children of pre-school age

This leaflet is available in large print and other formats and languages.

Please contact the pathway team on
01752 439420 for more information.

**Child Development Centre
Women and Children's Care Group
Community Paediatric Service Line**
University Hospitals Plymouth NHS Trust
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Plymouth PL2 2PQ

Tel: 01752 439400
www.plymouthhospitals.nhs.uk



Why has my child been referred to the social communication pathway?

Your Paediatrician will have referred your child as they feel they may have a social communication difficulty such as an autistic spectrum disorder. This is usually indicated by difficulties in communication, social interaction and imagination or play. The assessment pathway allows us to think about whether a diagnosis is appropriate for a child and what support they may need.

Autistic spectrum disorder encompasses other terms such as autism and asperger syndrome.

Who is involved as part of the assessment?

Our core assessment team includes a Speech & Language Therapist, Clinical Psychologist and Specialist Nursery Nurse. We also liaise closely with other services who may be working with your child including their nursery or school, Portage workers, Advisory Teachers, Educational Psychologists and Community Speech & Language Therapists.

What happens during the pathway?

When we are ready to carry out our assessments we will contact you directly. We will talk more about the process and make sure all our details are correct.

We will usually invite you to the Child Development Centre to meet with a member of the assessment team. This appointment will just be for you as parents or carers, and allows us to spend more time talking about your concerns and building our understanding of your child.

At around the same time we will arrange to visit your child in their nursery or school setting. This visit allows us to learn a little more about your child and plan how best we can carry out our assessment. If your child is not in a nursery or school then we may come and see you at home.

What we do next will vary depending on the needs of your child and how we feel we can best engage then in assessment. We may:

- Arrange further formal assessment at the Child Development Centre with our Speech & Language Therapist or Clinical Psychologist
- Carry out further visits to nursery/school or home
- Speak with other professionals/agencies who know your child to gather additional information

What are the possible outcomes from the assessment?

There are three likely outcomes from our assessment:

1. Your child is felt to have a diagnosis (for example, an Autistic Spectrum Disorder)
2. It is unclear whether your child has a diagnosis, and it is agreed that further information or assessment is required
3. Your child is not felt to have a diagnosis, although areas for further support may have been identified.

Regardless of the outcome, your child will receive a report summarising any needs which have been identified. With younger children it is sometimes harder to reach a definite outcome, and we have to consider the impact of a child's age and overall development. In some cases we will suggest that further support is provided and a diagnosis reconsidered at a later date.

What happens next?

We will make sure, with your consent, that any diagnosis is shared with any professionals working with you or your child. We know that receiving a diagnosis can help us to understand some of the reasons behind a child's needs. This can assist in determining any support which may be needed, although any help offered will depend on individual circumstances.