

FAQs about the diagnostic process

What do I do if I think my family member may be autistic?

If you think that a person may be autistic the first port of call will be your General Practitioner (GP). After the initial appointment your GP may decide to refer the person on to an autism diagnostic pathway or a different pathway if appropriate.

What kind of questions will my GP ask me?

Your GP may ask a range of development related questions for example what age did they start crawling, walking etc. We recommend putting together a timeline of key dates prior to the appointment, as it can be difficult to think back in time. It is also useful to have any information from professionals involved with the person such as school.

How long does it take to be put onto the diagnostic pathway?

The autism diagnostic process should start within three months after referral to the diagnostic team but be aware that in reality this may take longer due to demand and can vary depending on the area you live in. If initial discussions are insufficient to prompt a referral, you may be asked to consider a period of what clinicians refer to as watchful waiting.

What does the process involve?

The diagnostic process may involve:

- A discussion with the person (where appropriate).
- Observations of the person in a variety of settings.
- Detailed discussion about the person – you may be asked questions about the persons early years and family history.
- Physical examination.
- Medical investigations, these are not routinely carried out as part of the autism diagnostic assessment, however genetic testing may be needed.

Can I access support whilst waiting for a diagnosis?

Waiting for the assessment process to start can be a very difficult time for parents/carers. At this point it may be worth tapping into a support service such as your local carer's organisation. Due to the length of the waiting lists and the time that it can take to get a diagnosis, there are services that offer pre-diagnosis support including ourselves.

What assessment tools do clinicians use to diagnose a person as autistic?

There are a variety of different assessments that could be used to construct a personal profile, these assessments may include:

- Autism specific tools.
- Speech, language, and communication.
- Physical health and nutrition.
- Gross and fine motor skills.
- Mental and emotional health.
- Sensory processing.
- Intellectual ability.

How is autism diagnosed? Is there a diagnostic criterion that a person has to meet in order to be diagnosed?

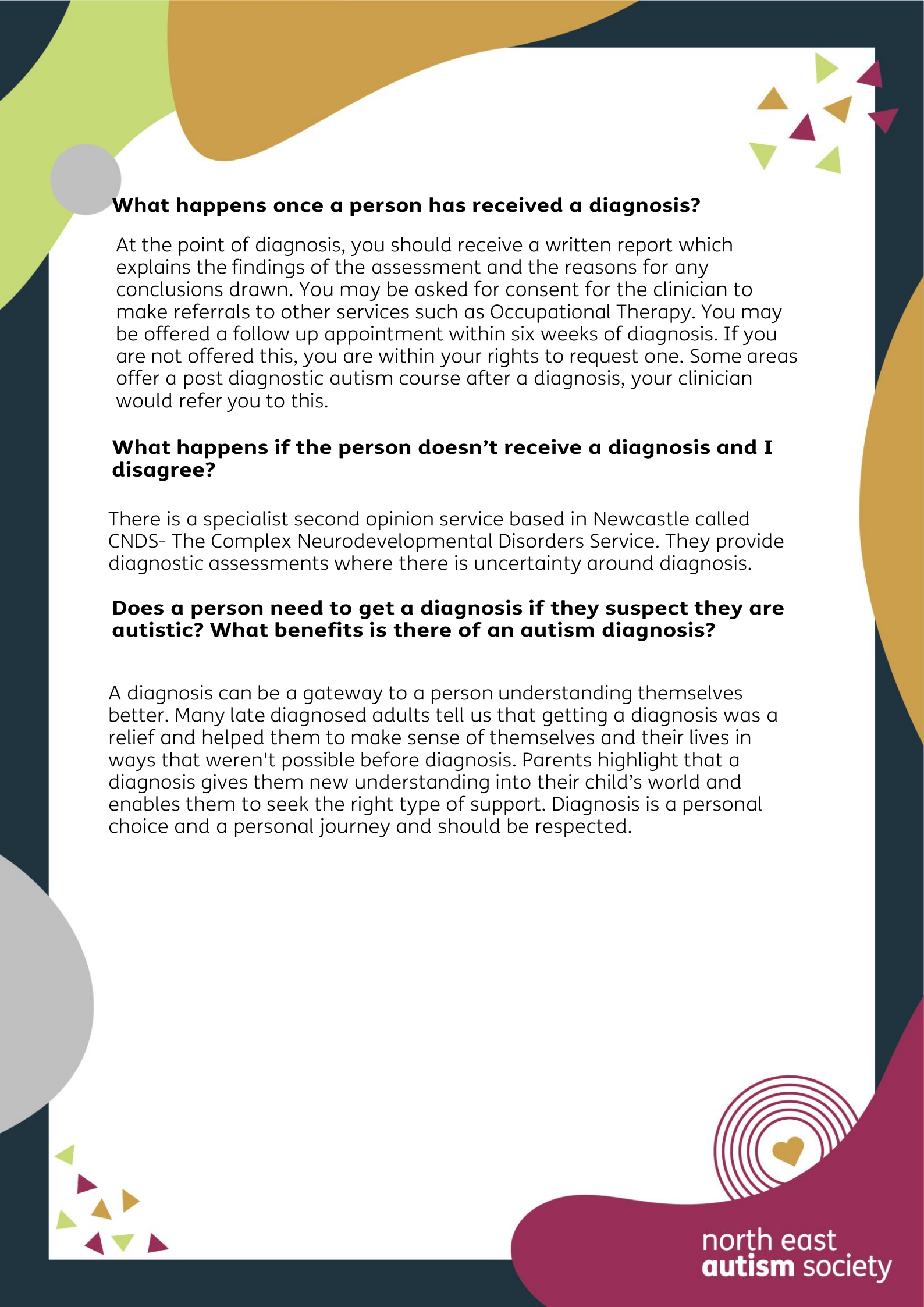
There are two main diagnostic manuals that are used by clinicians the Diagnostic statistical manual (DSM) and the International Classification of Diseases (ICD).

The diagnostic manual defines autism as: persistent difficulties with social communication and social interaction, restricted and repetitive patterns of behaviours, activities, or interests (this includes sensory behaviours), the behaviour should have been present since early childhood, and to the extent that these "limit and impair everyday functioning".

We recommend parent/carers looking at 'Autism in under 18s: Recognition, Referral and Diagnosis (Nice clinical guidelines). It is important to bear in mind that the characteristics of autism vary from person to person.

What professionals will be involved in the process?

We recommend you looking at our information sheet 'a glossary of professionals' to get an idea of who may be involved and be working with you and the person.



What happens once a person has received a diagnosis?

At the point of diagnosis, you should receive a written report which explains the findings of the assessment and the reasons for any conclusions drawn. You may be asked for consent for the clinician to make referrals to other services such as Occupational Therapy. You may be offered a follow up appointment within six weeks of diagnosis. If you are not offered this, you are within your rights to request one. Some areas offer a post diagnostic autism course after a diagnosis, your clinician would refer you to this.

What happens if the person doesn't receive a diagnosis and I disagree?

There is a specialist second opinion service based in Newcastle called CNDS- The Complex Neurodevelopmental Disorders Service. They provide diagnostic assessments where there is uncertainty around diagnosis.

Does a person need to get a diagnosis if they suspect they are autistic? What benefits is there of an autism diagnosis?

A diagnosis can be a gateway to a person understanding themselves better. Many late diagnosed adults tell us that getting a diagnosis was a relief and helped them to make sense of themselves and their lives in ways that weren't possible before diagnosis. Parents highlight that a diagnosis gives them new understanding into their child's world and enables them to seek the right type of support. Diagnosis is a personal choice and a personal journey and should be respected.