

# The Toby Henderson Trust Multi-disciplinary Private Adult Autism Assessment

# Who we are

We are a registered charity and Company Limited by Guarantee, who have been working within the field of autism for over 22 years, the last 10 of which have been heavily invested in assessment and diagnostic work. The Toby Henderson Trust's clinical team consists of staff who are experienced and skilled in the assessment and diagnostic process.

The Toby Henderson Trust offer private autism assessments for children, young people and adults. We are also commissioned by ICB's in a number of North Eastern localities and the Cumbria, Northumberland Tyne & Wear NHS Foundation Trust (CNTW) to undertake assessment and diagnosis for autism in children and adults. This is over a range of locations ie: Newcastle/Gateshead, South Tyneside and Northumberland.



## **Our assessment** pathway

You have perhaps wondered for some time now if you might be autistic, or you may have just recently started to think about it and this has led you to wanting to seek an autism assessment. A formal diagnosis can often be a recognition of some difficulties you may have experienced throughout your life, and it can often validate those feelings that you have felt different or that you may find some things challenging.

#### Feedback from people who have already sought, and received, an autism diagnosis from us have told us the following:



- \* "I felt an immense sense of relief."
- "It gave me clarity as to why I feel the way I do and why I do and think things differently that I have wondered about my whole life."

# "It allowed others to understand me better and I understood myself better."

- ★ "My university lecturer was able to support me better and made sure that I achieved the best I could."
- \* "I was able to explain to my employer and my colleagues that I was autistic, and this gave me huge peace of mind that I wasn't being judged for saying, thinking and doing things in a certain way. They may not understand autism, but they understood who I am."

# National Institute for Health and Care Excellence

The Toby Henderson Trust follow the National Institute of Care and Excellence (NICE) guidance and provide a very thorough but clear and transparent assessment pathway. We have a number of very experienced and knowledgeable clinicians who are able to offer a multi-disciplinary approach to make sure that we carry out a very thorough assessment to reach a well-considered diagnostic decision.



"Can I just take this opportunity to say a big thank you to everyone at The Toby Henderson Trust for making the diagnosis process as comfortable as possible. Special thanks to Julie for really helping me relax during the developmental history interview, which I knew would be challenging, and everyone else, from yourself, Lynda and Lesley, right through to everyone involved in the actual diagnosis - you were all just wonderful. While any diagnosis process can of course not eliminate stress altogether, you all went to great lengths to minimise it. I feel the report was a very fair and accurate summary of my strengths and weaknesses and have every confidence in the diagnosis."

# Our process

#### \* Pre assessment triage

After you have carefully considered all of the information we have provided for you about our pathway, and you decide that you would like to proceed with an autism assessment, we will send out a standardised screener and mental health and social care assessment. The cost for this triage service is £100 and is non refundable (This cost is in addition to the cost of the assessment). These should be completed and returned, along with the payment for £100.00. Upon returning the forms they will be reviewed by one of the clinical team members to ensure that this is the correct pathway for you. One of our team will then contact you to explain the outcome of the review and whether we are able to proceed to the next stage of our autism assessment pathway.

#### Proceed with assessment

You will then be sent an email containing all the relevant paperwork in order to proceed, including the invoice for the deposit and details of how to pay this (Please note that the remaining balance will only be invoiced to you on completion of the assessment when you receive all of the reports). Furthermore, you will also be given some provisional appointments for your assessment to begin.

#### K Neuro-developmental history

A key element of the assessment process is to gather information about your development, particularly around Mum's pregnancy and birth, early milestones, as well as your education and career, your play as a youngster and communication skills, your interests, and possible sensory sensitivities. This will be in in-depth discussion which may take between 3 – 4 hours to complete and can be done via Zoom video conferencing call, by telephone or Face to Face at Toby House, which ever you would prefer.

It may be beneficial for you to have someone who can support you through your assessment at this point and this could be a parent, a friend, or a partner. We will need to gather information about your Mum's pregnancy with you and your birth (if possible), and also about your early years development, so it might be useful if that person has known you from an early age.

If you are not comfortable having anyone with you, then we can arrange for a set of 'early development questions' to be sent out in advance of the Developmental History consultation in the event that you may be able to collate this information for us in advance of the assessment starting.

## Autism Diagnostic Observation Schedule (ADOS assessment)

You will be invited to our centre, 'Toby House' in Bedlington, Northumberland, for an ADOS assessment. Here, two members of our clinical team will welcome you and complete the assessment with you and it is anticipated that this appointment may take in excess of an hour to complete.

The Autism Diagnostic Observation Schedule (ADOS-2) is an individually administered task based assessment, which is semi-structured and can provide a standardised measure for a person's social communication skills. Please note that the ADOS was designed to contribute to a clinical diagnosis but not to provide a diagnosis in its own right.

The ADOS consists of five separate modules. Each module is designed to provide lots of opportunities for the person to demonstrate their ability to communicate clearly, relate socially and to use imagination and creativity to engage in tasks. The most appropriate module for the individual is selected on the basis of their language.

### Multi-disciplinary Team Meeting

Once all the elements of the assessment have been completed, the team involved in your assessment will then write up their findings and observations in a report. These are then collated together and presented to our Multi-Disciplinary Team (MDT) for consideration of an autism diagnosis.

The team includes 7 members of staff who are ADOS trained. The team consists of a Practitioner Psychologist, Autism Nurse Consultants, Occupational Therapists, Speech & Language Therapists, Autism Nurse Practitioners, Autism Specialist Practitioners. A number of the team also have teaching qualifications and are registered nurses.

Our team will meet to review and discuss the information we have collated in line with the diagnostic criteria set out in the Diagnostic and Statistical Manual of Mental Disorders (edition 5), known more commonly as DSM-5.

Well considered diagnostic decisions are made by the team and the outcome is shared with you verbally in the first instance. Following this, your GP will be notified of the diagnostic decision by post.



#### **Diagnostic report**

Within 2-3 weeks of you receiving your diagnostic outcome verbally from one of our team , you will then be sent a diagnostic letter confirming the diagnosis given. A copy of this letter will also be sent to your GP for the purpose of being uploaded to your medical records.

The diagnostic letter will also contain information about you and more specifically how your presentation met the DSM 5 diagnostic criteria for autism .

It also contains information and signposting to other relevant services that could potentially support you after you have received your diagnostic outcome.

#### Finally...

Our diagnostic pathway and process usually takes an average of 12 weeks from the date of your first appointment (but may be more timely).

#### Contact us

If you have any questions regarding our autism assessment pathway, then please do not hesitate to get in touch with us and we would be happy to answer any further questions you may have.



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