



Coventry and Warwickshire Neurodiversity and Autism Stakeholder Newsletter

Welcome to the Coventry and Warwickshire Neurodiversity and Autism Stakeholder Newsletter

Neurodiversity and Autism remains a top priority and through working with partner organisations from across Coventry and Warwickshire, we aim to improve the lives of neurodiverse and autistic children and adults and help them feel part of their communities.



Working with our Neuro Partners on Children's Neurodevelopmental Assessments

The Coventry and Warwickshire Partnership NHS Trust Neurodevelopmental Team has been working with a number of 'Neuro Partners' over recent months. This has meant that more children and young people have been seen for an assessment, thus reducing the waiting list.

Each of the Neuro Partners have their own acceptance criteria and many of them use an online platform for their assessments. When allocating children and young people to these partners, the referrals all go through a comprehensive triage with a clinician every time. A number of factors will be considered which may mean the child/young person needs to stay within the Neurodevelopmental Team for their assessment, rather than going to one of the Neuro Partners.

As a result, this may mean that we don't always see children/young people for their assessment in the order that they were referred. We appreciate that there may be some confusion and/or concern for families if they are continuing to wait when others referred more recently are being seen. The team want to reassure families that this is to ensure the children/young people receive the most appropriate assessment and service to meet their needs and this is based on clinical judgement.

Join us at the Coventry Together with Autism Conference

Following the success of the conferences in Warwick in April and Nuneaton in November, the next will take place on **Saturday 21st January 2023 at Whitley Academy in Coventry.**

The free conferences are for professionals, parents and carers of autistic children, autistic adults and for anybody wanting to better understand autism.

[Register your place online](https://bit.ly/TwAC2023Coventry) or scan the QR code.

actforautism.co.uk IN PARTNERSHIP WITH
actforautism

Together with Autism Conference 2023 **FREE Event**

For professionals, parents and carers of autistic children, adults and for anybody wanting to better understand autism.

actforautism and partners will be launching the autism strategy.

Please join us for inspiring talks, workshops and meet with your local services representatives.

Workshops include:
 Sensory support
 Getting into employment
 School challenges
 Autism and ADHD

Stalls include:
 Autism and girls
 Equine Therapy
 Dimensions Trust
 SENDs, Family support service,
 CASS Coventry and Warwickshire Mind
 Neurodevelopmental Team
 And many other service providers

Saturday 21st January 2023: 10am - 4.30pm
 Meadow Park School, Abbey Rd, Coventry CV3 4BD
 This is a funded event, open to Coventry and Warwickshire residents only.
 Entrance only with a ticket from:
<https://bit.ly/TwAC2023Coventry>

FREE Tea & Coffee

NB: Lunch is not provided

For queries and information: info@actforautism.co.uk
 @actforautismnow @actforautism @actforautism



Shaping the Future for Autism Services in Coventry and Warwickshire

On 24th November, Coventry and Warwickshire Partnership NHS Trust led its third conference for the local health and care system around how we are shaping the future for Autism services in Coventry and Warwickshire.

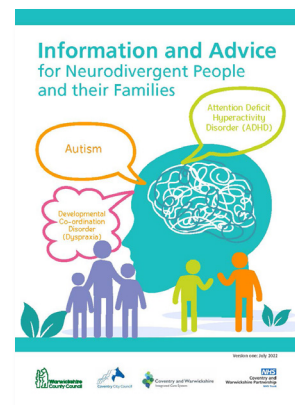
Leads of the five priorities of the newly launched local Autism Strategy met with key representatives from across the health and care system to agree and outline the key deliverables in Year 2 and Year 3. These were presented at the conference.

Two key examples of progress to date included the launch of the e-booklet of information and advice for neurodivergent people and their families, plus the NHS England pilots for neuro-liaison and differential diagnosis.

We also wanted to focus on how we are developing co-production across Coventry and Warwickshire.

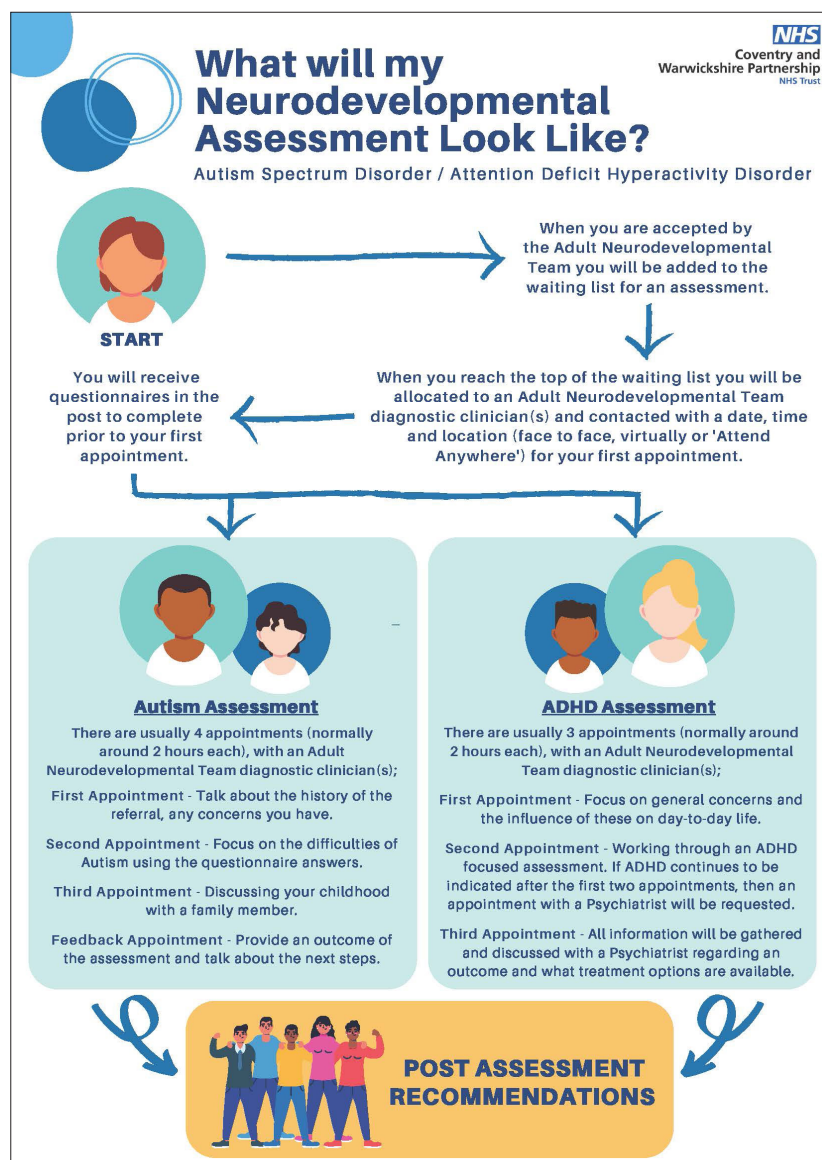
The conference heard from Coventry and Warwickshire Local Authorities, plus Coventry and Warwickshire Partnership NHS Trust on the progress made and the intended future next steps. We recognise that this is an important area for us in ensuring the voice of our neurodiverse people are being heard in shaping the delivery of our services.

Remember you can find out about local and national information and advice for support for neurodivergent people and their families on the [Dimensions Tool website](#).



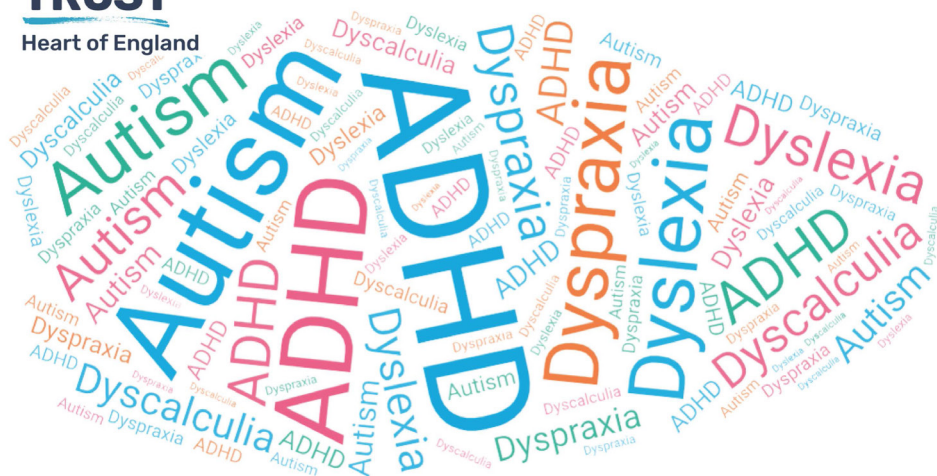
What does Adult Neurodevelopmental Assessment look like?

If you are sent for a neurodevelopmental assessment by your GP and your referral is accepted by the Adult Neurodevelopmental Team for assessment for Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD), this is what your journey will look like.



**CARERS
TRUST**

Heart of England



Across the Spectrum

**Information and support for those who care for people
of all-ages living with Neurodiverse conditions.**

**If you support someone who has a neurodiverse condition and would like
to meet with other people in a similar situation, we provide a range of:**

- Face to Face Support Group Sessions
- One to One Support
- Virtual Support Groups

For further information contact

E: melissa.murray@carerstrusthofe.org.uk or 02476 101040 ext 205

Website: www.carerstrusthofe.org.uk
Registered charity: 1057024
Company Limited by Guarantee number: 03206963

**CARERS
TRUST**
Heart of England



Caring for Carers

**Carers Trust Heart of England operates across
Coventry and Warwickshire offering support for
carers of all ages (young and adult carers) and
those they care for by providing the highest
possible quality, individually tailored care and
support services which improve lives.**

The organisation offers a range of information, advice,
and support, including Carers Needs Assessments,
Group and 1-1 based services and also Regulated Care
at Home services for people with care needs.

They are happy to come and speak with individuals

and teams about the work that they do and how any
future work could be shaped to best meet the needs
of carers and those who they care for, so please get
in touch if you would like to arrange something.

For more detailed information about the services we
offer across Coventry and Warwickshire and how to
contact us, please visit the following websites:

www.carerstrusthofe.org.uk

www.caringtogetherwarwickshire.org.uk





Research on the Treatment of Anxiety in Adults with an Autism Diagnosis

Researchers at the Universities of Bristol and Warwick are inviting adults who have a diagnosis of autism and experience anxiety to take part in a research study which is taking place within Coventry and Warwickshire Partnership NHS Trust.

The study is called STRATA (SerTRaline for AnxieTy in adults with a diagnosis of Autism). It has been co-produced with experienced clinicians, researchers, and autistic people to investigate the treatment of anxiety in adults with a diagnosis of autism.

You can learn more about what is involved in taking part by reading the [Participant Information](#). Please read the information carefully and feel free to discuss it with family, friends, carers or others if you wish.

To take part in this study you must:

- be aged 18 years or over
- have a diagnosis of autism (including variations such as Asperger syndrome)
- experience anxiety for which you are willing to try treatment with medication
- be able to complete online or paper questionnaires about things such as your anxiety, other symptoms, and healthcare usage
- be able to provide informed consent to take part

How long does it take?

Participants will be enrolled to the study for up to 52 weeks (1 year), during which time they will be asked to take the study medication as directed, and complete 4 questionnaires (with their time reimbursed with a £10 voucher for each). In addition, there will be 5 brief safety check appointments to discuss how participants are getting on with the medication and carefully monitor any side effects. All study appointments can be done via video or phone call, or in person appointments (any travel expenses reimbursed) can be arranged according to participant preference.

What do I do next?

If you are interested in taking part in the study, please complete the [online Expression of Interest form](#) or scan the QR code:

Alternatively, if you have any questions or would like further information or assistance, please contact the STRATA team by email: strata-takepart@bristol.ac.uk or phone: 0117 428 3001.

Thank you.



Experts by Experience Area



Warwickshire Parent Carer Voice

Warwickshire Parent Carer Voice are the recognised parent carer forum for Warwickshire. They are a parent carer led organisation that exists to enable the voice of parent carers to be heard so that the needs of children and young people (aged 0-25) with Special Educational Needs and/or Disability (SEND) and their families are met. They do this by engaging with the parent carer community and using this information to work to co-produce information, policies, strategies and services to support families with SEND.

A 'parent carer' is anyone who has parental responsibility for a child or young person with additional needs (they don't need a diagnosis) and they welcome parent carers who live in Warwickshire (or who use Warwickshire services) to become a member. Those who want to be more involved can join their online 'Parent Carer Panel' where they have opportunities for parent carers to give feedback, become their representatives on projects or join their Co-production and Engagement sessions, taking the collective voice and using this to shape the work.

Find out more at:

Website:

www.warwickshireparentcarervoice.org

Email: hello@warwickshireparentcarervoice.org

Facebook: www.facebook.com/Warksparentcarervoice

Coventry Parent Carer Forum

The organisation Contact is currently supporting local parent carers to build a new Parent Carer Forum for Coventry. Coventry Parent Carer Forum is being re-established as an independent, non-profit organisation working to improve services for children and young people aged 0-25 years with Special Educational Needs and/or Disabilities and/or health needs.

Find out more at:

Website: www.coventrypcf.com or their [Facebook page](#)



Grapevine's Expert by Experience Project

A message from Expert by Experience, Remie

“ I was diagnosed with autism aged 27, and over the last year I have been actively involved with Grapevine's Expert by Experience (EbE) project. I had been on a difficult journey in life, but I really wanted to draw on these experiences and work with others to help keep improving information and support for other neurodivergent people.

Recently, I have been helping to lead a project around Neurodivergent Language and Terminology. Neurodivergent language can feel like a daunting and controversial topic, even as an autistic person. Working with other EbEs and professionals, together we are expanding the existing glossary at the end of the [E-booklet for Neurodivergent People and their Families](#). We are also creating an animation exploring 'Why neurodivergent language is important'.

“I really value the opportunity to help co-ordinate this work, because it has allowed me to develop my skillset and confidence even further. Already, the project has started many valuable conversations and I hope that, once created, the resources will help more people to feel comfortable and confident when using neurodivergent language and terminology.”

An invitation from Grapevine

You can have your voice heard as an Expert by Experience through sitting on important decision-making meetings, attending focus groups, sharing your story and being an EbE interviewer. If you would like to be involved in the Experts by Experience Co-production Service and you:

- are neurodivergent or
- have a learning disability or
- are a parent or carer of someone who is neurodivergent and/or has a learning disability

please email ebe@grapevinecoventryandwarwickshire.co.uk and Sophie or Suzie will give you a call to find out a little bit more about you. This is an opportunity for you to share your insights and use your lived experience to make a change.



Professionals Corner

How to make a good GP referral into the Adult Neurodevelopmental Service

What makes a good referral?

The best referrals received are when a patient describes their own concerns regarding why they think they might have Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD).

Often patients will attend their GP after completing some research on Autism or ADHD and visit their GP to explain this.

For the Adult Neurodevelopmental Service to receive a full referral it must include:

1. Adult ADHD Self-Report Scale (ASRS) screening tool for ADHD

And/ Or

2. Autism Spectrum Quotient (AQ10), a screening tool for Autism
3. GP to write a description of concerns including the impact this is having on the client.



Required Referral Information

Referrals should include information about presenting difficulties along with a brief description of concerns.

Autism Referrals

Significant functional impairment in two or more areas (family life, work, education, self-care, social life)

One or more of the following:

- Persistent difficulties in social interaction
- Persistent difficulties in social communication
- Stereotypic (rigid and repetitive) behaviours, resistance to change, restricted interests

Plus one or more of the following:

- Problems in obtaining or sustaining employment or education
- Difficulty in initiating or sustaining social relationships

ADHD Referrals

Significant functional impairment in two or more areas (family life, work, education, self-care, social life, risk taking)

Inattention

(eg forgetfulness, difficulty listening, disorganisation, distractibility, poor attention, poor concept of time, poor attention to detail, procrastination, loses important things, poor finisher completer)

and / or Hyperactivity

(eg fidgety, restless, excessive talking, over scheduling, poor sleep)

Impulsivity

(eg blurting out answers, difficulty waiting a turn, interrupting, poor frustration tolerance, prone to addiction, reckless driving, ending jobs / relationships abruptly, anger)

Symptoms must have been present in childhood into adulthood. Impairment must be in 2 domains i.e. education / employment, relationships and friendships



GP Referral Process

a) Autism

- Adult older than 16 years 6 months
- Registered with Coventry or Warwickshire GP
- No previous diagnosis of Autism Spectrum Disorder (ASD)
- Not currently under the care of Acute or Community Mental Health Services
- No known Learning Disability
- AQ10 Autism Questionnaire score greater than 6 with referral: [Link to AQ10](#)

b) ADHD

- Adult aged over 16 years 6 months
- Registered with Coventry or Warwickshire GP
- No previous diagnosis of ADHD
- Not currently under the care of Acute or Community Mental Health Services
- No known Learning Disability
- Completed ADHD Self Report Scale Form with referral [Link to Adult ADHD Self Report Scale ASRS](#)
- Patient to complete part A and B of symptom checklist
- Part A: score greater than 4 highly consistent with adult ADHD and further investigation warranted
- Part B: frequency scores provide further symptom sensitivity

A GP referral should always include narrative on the impact on function

Where to send it?

Please email the full referral (narrative and screening tool) to:
AdultNeurodevelopmental Team@covwarkpt.nhs.uk

For professionals: How to make a good referral into the Pre-school Autism Service

New referral forms have been launched for both Coventry and Warwickshire Pre-school Autism Service referrals, as part of the new local Autism Strategy.

The new referral forms will help to gather relevant information to determine if an assessment is required and whether a referral needs to be prioritised.

The individual postal and email addresses will help to reduce delays in receiving the referrals and to ensure they are sent to the correct team.

Both new Coventry and Warwickshire Pre-school Autism Assessment Referral Forms can be found on the [Coventry and Warwickshire Partnership NHS Trust Children's Neurodevelopmental Team website page](#)



Useful documents for professionals

[More than Words: Supporting effective communication with Autistic people in health care settings](#) is a very helpful guide on reasonable adjustments.

[The Neurodiversity Affirmative Language Guide](#) by The Adult Autism Practice and Thriving Autistic

[NHS England Sensory-friendly Resource Pack](#): Resources to improve the sensory environment for autistic people

[NHS England 10 Sensory Principles poster](#)

