



Coventry and Warwickshire Integrated Care System 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 neurodivergent and autistic children and adults and help them feel part of their communities.



Top tips for Christmas and the holiday period

Contribution from the Community Autism Support Service (CASS)

It can feel hard to believe that it is December already, and that we are approaching Christmas and New Year.

As we know, the holiday period can be difficult for many, including autistic children, young people and adults, due to expectations from others and society as a whole. Some people embrace this time of year with sparkle, but other choose to shy away from it.

Not everyone feels jolly and bright, nor in the spirit of things. It's important to recognise that this is okay, and that some people may need extra time to do tasks and spend time looking after themselves as well as saying no.

The Community Autism Support Service has explored some ideas around managing at Christmas time and have the following suggestions:

- Be clear about when people can visit, schedule these visits in to avoid drop-ins! Ensure everyone knows what is happening, when and with who.
- Have Christmas on your terms; think about how you want to enjoy it, not what is expected of you.
- Consider a one-day Christmas, such as just having one day of decorations, gifts and special food; this limits the change to one day.
- Have a designated place for some quiet space at home, somewhere away from everything else going on.

- Prioritise who to see, you don't have to say yes to everyone.
- If visiting other people, tell them about anything that could help make your time with them as stress-free as it can be.
- Make a list of presents you would like to receive and share this list. This removes any element of surprise.

Suggestions have been adapted from the following useful resources:

'How to'... have an autism-friendly Christmas – Autism Together

Christmas tips for autistic people and their families - Shout 85258

Christmas tips for autistic people and their families National Autistic Society

You may also want to have a look at some other resources for managing at Christmas:

An autistic person's guide to an autism-friendly Christmas - Autistic not Weird

What's it like being autistic at Christmas? Indy Andy

Autism and Christmas. Preparation is key -Living Autism

Helpful approaches for a PDA profile of autism at Christmas - National Autistic Society

Why can Christmas be hard for autistic children? - Caudwell Children











Autism Central: New autism support launched for families and carers



Support is available for families and carers of autistic children and adults thanks to a new, free education

programme being launched across England.

The **Autism Central website** aims to build knowledge and understanding of autism and empower families and carers to advocate for autistic people they support to get the right understanding and adjustments in place across the services they use.

Commissioned by NHS England and informed by or co-produced with autistic people, parents and carers, the programme offers one-to-one and group sessions complemented by high-quality online learning and information.

Families and carers can also talk to people with similar experiences by joining workshops, drop-in

sessions, coffee mornings or virtual meetups.

Each session is delivered by parents and carers of autistic people who have been trained to share their knowledge and experience with others, as peer educators.

Information, guidance and events are now available on the Autism Central website, which includes:

- **Exploring topics:** find key information from partners and other trusted sources on topics such as diagnosis, employment and mental health.
- **Finding help:** search for a regional hub to find group and one-to-one sessions with information and services available in your area.
- **Events:** talk to people who share similar experiences by joining a workshop, drop-in session, coffee morning or virtual meet-up.
- **Online learning:** sign up to access further learning resources and personal stories from other parents and carers.

Read the whole news release



Personalised Care and Coaching helps towards a healthier lifestyle

"My name is Matt Vaughan and I am a Personalised Care Lead

and Health and Wellbeing Coach working for South Warwickshire GP Federation. I supported an autistic gentleman and here is how we have worked together.

"John* is a 43 year old man who is on the severe mental health illness register. At our first appointment he advised me that he was autistic and also that he was a visual learner. Through the Health and Wellbeing Coaching Pathway, I aimed to empower John to take control of his own health, by helping him to understand how different lifestyle changes, like diet to exercise, can help how he feels.

The main focus was to help understand how best to live a healthy life. To support John, we used visual images of food and put them into the different food groups, for example bread into carbohydrates, using the 'Eat Well' plate image as a guide to healthy choices. Another visual guide we used was the amount of sugar in drinks being consumed and we talked about possible healthier alternatives. The next focus was supporting John in bringing these changes into everyday life, and how he could build a healthy routine. Using a visual routine guide, John found himself able to take on exercise routines, make better food choices and develop ways to relax that suit his lifestyle.

John has now lost over a stone in weight and is feeling more empowered in his choices, due to a better understanding of food groups and how they individually impact on weight gain or loss. He is also more active after building his own routine planner to support exercise and social events."

Find out more about personalised care at your local GP surgery; ask if there is a social prescriber, care coordinator or health and wellbeing coach available. Or for further information, contact Jo Taylor, Ambassador – Personalised Care, Coventry and Warwickshire Training Hub via email:

jo.taylor@southwarwickshiregps.nhs.uk

* Patient's name has been changed for confidentiality reasons

Rugby Autism Network receives the King's Award for Voluntary Service



Rugby Autism Network, a group of volunteers based in Rugby, Warwickshire, has been awarded the King's Award for Voluntary Service. This is the highest award a local voluntary group can received in the UK and is equivalent to an MBE.

Kay McSorley, Founder of the Rugby Autism Network

Rugby Autism Network was created by Fay McSorley in 2009. The Registered Charity supports parents and carers of autistic children and

young people, in and around Rugby. Five volunteers support Associate Member families. Their fundraising provides funding for bespoke days out, annual passes for local country parks, and activities during school holidays. Autism-friendly events, access to learning materials and workshops, and a lending library of books and equipment, are also part of the offer. Social support is given via real-life meet ups, and a moderated 24/7 online chat forum.

Rugby Autism Network is one of 262 local charities, social enterprises and voluntary groups to receive the prestigious award this year. Their work, along with others from across the UK, reminds us of all the ways fantastic volunteers are contributing to their local communities and working to make life better for those around them. The King's Award for Voluntary Service aims to recognise outstanding work by local volunteer groups to the benefit of their communities. It was created in 2002 to celebrate Queen Elizabeth II's Golden Jubilee and, following his accession, His Majesty the King emphasised his desire to continue the award. Recipients are announced annually on 14th November, the King's birthday. Two volunteers from the Rugby Autism Network will attend a Garden Party at Buckingham Palace in Summer 2024, along with other recipients of this year's Award.



Chairperson, Fay McSorley, said: "I am delighted that our work has been recognised. Our wonderful volunteers, past and present, have each brought a wealth of knowledge and experience to our members and we are all so proud of what we do. We have exciting plans ahead and will continue to support local families. This award is an amazing boost and will motivate us to keep giving our best, providing a service that simply did not exist when my own children were small. I hope our success will encourage others to volunteer and create their own support networks together to help overcome life's challenges."

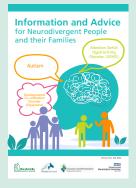
For further information, visit the **Rugby Autism Network website** or email them at: **admin@rugbyautismnetwork.co.uk**

COMMUNITY Autism Support Service (CASS) training and education offer

There is a wide variety of courses available from CASS for both professionals and parents/carers and family members of autistic individuals. From bite-sized topical workshops to full-day professional courses, our training provides a high level of understanding, peer support and signposting to other services.

Take a look at the latest CASS training newsletter





Remember you can find out about local and national information and advice for neurodivergent people and their families in the e-booklet on the Dimensions Tool website



Missed the latest Warwickshire SEND e-bulletin? Read a copy now

New Coventry and Warwickshire resource provides unique insight into neurodivergent language

A new resource has launched to encourage people to think about the words they use when talking about neurodiversity.

Coventry and Warwickshire Integrated Care System (ICS) is pleased to share the release of an **informative video**, presented by a local Expert by Experience and with professional input, aimed at empowering people to feel more confident when talking about neurodiversity.

Adapted from an interactive live webinar delivered in June 2023 which attracted over 150 people, the video offers practical tips and unique insight to anyone wondering how to approach the topic of neurodiversity.

Delivered in the style of a webinar, the recorded session explores the topic of neurodivergent language from different perspectives to give people a better, more inclusive understanding by dispelling common assumptions and stereotypes about neurodivergence.

By encouraging people to reflect on their choice of words and sharing the wisdom of neurodivergent individuals and their families, the video aims to build people's confidence to talk about neurodiversity, whether that be in the workplace, at home with friends or family, or as a professional working with neurodivergent individuals.

Bringing first-hand knowledge and a personal perspective, Expert by Experience Remie Colledge, talks about the unique aspects of neurodivergent language by sharing the experiences of neurodivergent people and their families and carers across Coventry and Warwickshire.

Remie is joined by Karen Scorer, Coventry and Warwickshire Integrated Care System's Lead Trainer for the Oliver McGowan mandatory training on Learning Disability and Autism, who provides professional expertise and personal insights into the topic.

The video covers key elements including:

• An introduction to the co-production work around neurodivergent language in Coventry and Warwickshire

- The influence of language in shaping perceptions
- Addressing language-related stereotypes
- Neurodiversity and identity
- Understanding different perspectives
- Six key themes from people with lived experience
- Practical tips and advice to take away

The audience is also encouraged to pause and reflect at set points throughout the video as Remie and Karen pose questions based on the topics discussed.

Dr Angela Brady, Chief Medical Officer, NHS Coventry and Warwickshire Integrated Care Board, said:

- "With partners across Coventry and Warwickshire working together to understand more about the experiences of neurodivergent people and their families across the area, this video is a fantastic opportunity to share this positive progress more widely and to encourage people to think more carefully about the words they use when talking about neurodiversity.
- " Stereotypes can often lead to misunderstandings, and if we want to see real change in the way our neurodivergent communities are heard and represented, we need to work together to challenge those assumptions. I would like to personally thank everyone who has shared their experiences with us through this work and recommend this video to all."

The video is available to watch now on YouTube.

The production of this video is one element of wider co-production work to improve the support for neurodivergent people and their families across Coventry and Warwickshire



The impact of IMPACT, the Young **impact People's Forum for SEND in Warwickshire**

IMPACT is the Young People's Forum for SEND in Warwickshire. Any young person, who has a special educational need and/or disability, who is 12 – 25 years old and lives in Warwickshire or has their education in a Warwickshire setting, is welcome to join and can get in touch: www.warwickshire.gov.uk/ypvoice

Young people have said that IMPACT is "relatable"; they feel "listened to" and feel "more confident", have the "best positive moods at an IMPACT session" and feel "acceptance", but also "meet new people and have a laugh". Someone also said, "if there was no IMPACT, I would be genuinely upset, and it may push me over the edge".

Young people believe that through IMPACT they can change people's and schools' understanding and help other children and young people. Young people have spoken at the Head Teachers' Conference in the summer and the SEND Conference this autumn, been involved in interviews as part of recruitment, and IMPACT are now represented on the SEND and Inclusion Partnership Board, which is a key place where decisions are made.

Another young person said, "IMPACT has helped me so much. It's given me a place I am valued for my autism, and where I really have a voice. The opportunities I've had with the interviews means I know what a job interview looks like, and I know the people, which means I feel much more comfortable to speak up when things bother me. Actually, it's part of the reason I am so comfortable with my autism. Sam has been such an incredible person, she always has just the right vibe for whatever group, she understands the people she works with and does everything she can to make the group accessible; she did an online meeting in my house so I could access the meeting once. Everything about IMPACT is brilliant."

Having a voice and having an influence is so impactful for young people. One of IMPACT's priorities is experience in school; they have developed a survey for children and young people to share their experiences. If someone attends a Warwickshire education setting then please let them know they can share their views with IMPACT to help others to understand what school is like for children and young people across Warwickshire: www.warwickshire.gov.uk/schoolexp

For more information about the work of IMPACT and how you can get involved, email Sam Craven: samcraven@warwickshire.gov.uk

Gemma Cartwright becomes Midlands Region Clinical Director for Autism



Earlier this year, Gemma Cartwright, who many of you may have met during her 20 years working locally as an Occupational Therapist, became Coventry and Warwickshire's System Clinical Lead for Neurodiversity.

Now Gemma has been successful in gaining a new role working for NHS England as one of the Midlands Region Clinical Director for Autism.

She isn't leaving us and will remain within her role in Coventry and Warwickshire but will be sharing her knowledge and experience with others across the Midlands. Gemma is really keen that co-production, co-design and collaboration are at the centre of

the work regionally. She wants to ensure that good practice, great ideas and success, as well as learning, is shared across the different places in the Midlands by bringing people together.

Gemma said: "It's very important to me that as we move forward as a region, there is a culture whereby autistic and otherwise neurodivergent individuals feel recognised, valued and free to be their true authentic selves. I want everyone to experience flexible and responsive access, opportunities and resources without facing unnecessary barriers, plus a sensitive approach which supports dignity, compassion and wellbeing.

"I also want to ensure that the amazing work across our local system is shared and celebrated and that we take learning from others."



Gemma Cartwright attends the National Autism Practitioner Network for England Event

Gemma Cartwright, Coventry and Warwickshire System Clinical Lead for Neurodiversity, attended the 'Autism Practitioner Network for England' event on 16 October. This network now has 100 members from across the country. At the event, an overview of recent and planned work by the National Autism Team was presented by Claire Dowling, National Programme Director, NHS England.

She provided some quite hard-hitting facts in her overview:

- There has been a 40% increase in referrals for people waiting for an autism assessment between June 2022 and June 2023; 143,00 people are waiting and of those 118,000 are waiting over 13 weeks. Demand is outstripping supply by 4,000 per month.
- There has been a 96% increase in autistic people who do not have a learning disability entering inpatient mental health services since March 2015.
- 76% of the autistic patients who do not have a learning disability and are aged under 18 years were female.

Claire shared with the network that there needs to be specific community provision to meet the needs of autistic people accessing mental health services, including crisis support, to prevent these avoidable admissions, as well as appropriate support to aid quicker and successful discharge.

Co-design, co-production and collaboration would need to be at the centre of any service/support created and co-produced and co-delivered training was also part of the need to ensure mental health services are able to meet individual needs and the workforce feel confident in doing so.

The National Autism Programmes have the following vision:

- Improve quality of and access to all NHS services for autistic people.
- Improve quality of and access to autism assessment services.
- Reduce health inequalities that autistic people face.
- Improve community support and provision for autistic people, their families and carers.
- Improve access to and quality of care for autistic people in inpatient mental health settings.
- Cultural shift in awareness, understanding, expertise and knowledge.

From a Coventry and Warwickshire perspective, this vision aligns with our **Local Autism Strategy** and the five priority areas we have to deliver our local vision. There is much to celebrate locally, such as the reduction in waiting times for children and young people, the extended offer from the Community Autism Support Service (CASS), as well as the work being done with employment and housing services. Health, Social Care, Education and our charity and voluntary sector partners are all working together as a system to make a difference. However, there is still a lot to do, but thank you to everyone who has helped Coventry and Warwickshire move closer to the inclusive community we aspire to be.

Our local priority areas are shown in the diagram below.

If you live in Coventry or Warwickshire and would like to be involved in the delivery of our Local Autism Strategy and the workstreams please contact: **disabilitiescommissioning@warwickshire.gov.uk**

Priority 1	Support autistic people and people with social, communication and emotional health needs to help themselves pre and post diagnosis		
Priority 2	Reduce inequalities for autistic people and make Coventry and Warwickshire autism friendly places to live	 ***	• **
Priority 3	Develop a range of organisations locally with the skills to support autistic people	***	*. **
Priority 4	Develop the all age autism specialist support offer		• • •
Priority 5	Co-produce, work together and learn about autism		

生产

Find out more about lived experience roles in the NHS

Coventry and Warwickshire Partnership NHS Trust (CWPT) is holding an exciting event on 5th March 2024 9.30am - 4.00pm at the Welcome Centre in Coventry.

Here they will be:

- Hearing from leading national experts in the field of lived experience roles
- Showcasing and celebrating the array of roles they already have in CWPT
- Highlighting the difference in all of the lived experience roles, ie Peer Support Workers, Experts By Experience, Lived Experience Trainers, etc

- Showcasing how staff in non-lived experience roles are also being empowered to utilise lived experience
- Inspiring ideas of where we can go next in CWPT

The event is co-produced by a number of people and we are aiming to ensure it's as inclusive as possible. Further information will follow to those who book a place at the event.

To book your place, please email working.together@covwarkpt.nhs.uk



Local community organisations offering mental health and emotional wellbeing support

The voluntary and community sector organisations listed below offer mental health and emotional wellbeing support to local people. All of them offer support and work with neurodivergent people and their families and carers. Why not take a look at what they offer on their website, or follow them on their Facebook channel.





Organisations / Group	Facebook group	Website/Group Page
Light House Christian Care	www.facebook.com/thelighthousecoventry	https://lighthousechristiancare.co.uk
Moat House Community Trust (MHCT)	www.facebook.com/MoatHouseCT	
New Hope Counselling	www.facebook.com/NewHopeChristianCounselling	www.newhopecounselling.org.uk
Notables	www.facebook.com/notablesband	www.notables.org.uk
Parenting Project	www.facebook.com/Parentingproject	https://parentingproject.org.uk
Positive Impact Foundation CIC	www.facebook.com/PIFoundationCiC	www.pifoundation.co.uk
Radford Community Allotment	www.facebook.com/radfordcommunityallotment	
Safeline Counselling	www.facebook.com/SafelineOrg	https://safeline.org.uk
Sky Blues in the Com- munity	https://en-gb.facebook.com/SBitC	www.ccfc.co.uk/community/about-sky-blues-in- the-community
South Warwickshire and Worcestershire Mind	https://en-gb.facebook.com/springfield.mind	www.springfieldmind.org.uk
Spencer's Retreat	www.facebook.com/berkswellretreat	www.spencerscharityfarm.com
Sycamore Counselling		http://sycamorecounselling.org.uk
The Hangry 1 (TH1)	https://ne-np.facebook.com/th1club	
The Horse and Peo- ple Project	www.facebook.com/people/The-Horse-and-People- Project	www.thehorseandpeopleproject.co.uk
Together UK	Twitter, LinkedIn and Instagram only	www.together-uk.org/projects/warwickshire-hous- ing-related-support
Warwickshire Wildlife Trust	www.facebook.com/WarwickshireWT	www.warwickshirewildlifetrust.org.uk





Experts by Experience Area





My name is Sonia Lal. I am an Expert by Experience (EbE) working with the Dimensions Team at Coventry and Warwickshire Partnership NHS Trust (CWPT).

We, in the Dimensions Team, created an ambitious plan to get feedback on the experience of using the Dimensions Tool across a range of stakeholders. The aim was to ensure that it is a live tool, evolving, fit for purpose, and meets the needs of

neurodivergent communities and their families; also, that the language, content, and accessibility are spot on. Dimensions is an innovative and pragmatic tool, the first of its kind across the NHS, paving the way forward.

The EbE's who I have met are incredibly talented. Their vast lived knowledge and experience mean it is a privilege to work with and to learn from them. The professionals, Experts by Training (EbT), are dedicated and determined. I feel humbled to be able to work with such a committed and capable team of people, who are passionate about changing the experience of neurodivergent people and their families and improving the quality of their lives. I also feel a massive responsibility to be able to deliver on my work and ensure that I contribute effectively to this cause.

I have learned skills around creative, digital, and innovative methods to engage with a diverse audience. I have learned to practice active listening and working together to understand and support each other to find a common goal.

One of the highlights of this work was really taking the time to understand the current position. It has taken time to ensure the whole team has an understanding of the history of Dimensions and where it has come from; to really thrash out the conversations about where we each feel Dimensions is focussed; and then to finally come to a shared and common understanding of how and what needs to happen next, both in the short and long term. We have created terms of engagement, a working together agreement, and a mapping exercise of upcoming community engagement events and specific workshops to obtain the needed feedback.

The action plan is deliberately ambitious, mapping out the aspirations for the future. It feeds into the wider Autism Strategy, as well as across other priority workstreams. This means it has a high impact on future objectives. The Dimensions Team realise that there are limitations on what can be achieved both short and long-term in isolation. So, the longer-term ambitions require buy-in from the commissioning team and others where the decision-making is outside the capacity of the Dimensions remit.

We have actively used the model of co-production, requiring listening, being patient, taking a step back, allowing space for others to contribute and bring their energy and experience to the table, being open to new and different ways of being and doing, staying positive and optimistic, having a common vision for the future. Co-production is an excellent structure for joint working which ensures mutual respect, understanding, growth, commitment, and validation.

The feedback continues to be implemented at an exponential rate. The whole team has been developing the content of the website, Dimensions questionnaire, descriptors, and ratings. The selfcare flyers and FAQs are also being evolved. The team lead has been working hard to establish the positioning of Dimensions within the Trust and secure future sustainability.

Take a look at the **Dimensions of Health** and Wellbeing

For more information or to find out how you can get involved, email: **dimensions@covwarkpt.nhs.uk**



Professionals Corner

Joint guiding principles for Integrated Care Systems: learning disability and autism

The Local Government Association and the Association of Directors of Adult Social Services, who work together as Partners in Care and Health, have been working alongside NHS England to develop a set of guiding principles for integrated care systems, setting out how partners in local systems can work together to improve the lives and outcomes of people with a learning disability and autistic people, of all ages.

It is intended that these principles encourage a partnership approach, across health, local government, and wider partners, within local systems.

Read more on the NHS England website

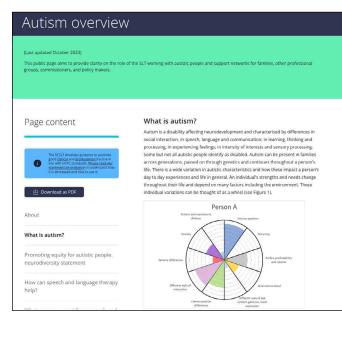


PRINCIPLES How partners in Integrated Care Systems should

work together to improve the health and lives of people with a learning disability and autistic people



Updated guidance for supporting autistic people from The Royal College of Speech and Language Therapy



Autism is a disability affecting neurodevelopment and characterised by differences in social interaction, in speech, language and communication; in learning, thinking and processing; in experiencing feelings; in intensity of interests and sensory processing. Some but not all autistic people identify as disabled.

The Royal College of Speech and Language Therapy has updated its guidance for supporting autistic people.

Take a look at the new guidance now

