

Welcome to the April - May issue of Surrey News

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Please note: Some of the articles in the front of the newsletter include information for young people and adults.

This newsletter should arrive at the start of **World Autism Awareness Week** which takes place between 29th March and 4th April. Do have a look at page 5 for the range of suggestions about how you can take part. There are even quiz questions that can help to promote an understanding of autism.

There is a lot going on related to autism in Surrey at the moment and we all hope this will improve services and the lives of autistic people. Specialist schools are in development and existing schools are being expanded. The All Age Autism Strategy Framework is about to be published and a new alliance to transform emotional wellbeing and mental health support for Surrey's children and young people is about to launch.

Sarah Mead, who has been a member of the committee for 19 years, is retiring due to family and work commitments. We would like to extend our thanks to her for her dedication and commitment to the Branch.

In this newsletter I also want to reach out to ask you to consider what you could do to support the Branch.

There are details of some of the roles available on page 4, which include helping with admin & publicity, technology & web and developing our social media. Do take a look at the roles and - if you can't help - consider whether there is someone else in your family who perhaps could.

Carol Teunon

Chair (volunteer)

NAS Surrey Branch

General email: NASSurreyBranch@nas.org.uk

Website: www.NASSurreyBranch.org

Facebook: @NASSurreyBranch

Donations: www.justgiving.com/nassurreybranch

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Sara Truman nas@mugsy.org

POSTAL ADDRESS

NAS Surrey Branch
c/o Walton Charities,
2 Quintet, Churchfield Road,
Walton on Thames KT12 2TZ

NB, no NAS staff or volunteers work here.

Other Useful Contacts

Unless clearly stated, organisations are not endorsed by NAS Surrey Branch or the NAS.

NAS website: www.autism.org.uk

NAS Helpline: Tel: 0808 800 4104 (10am – 4pm), or email autismhelpline@nas.org.uk

NAS Parent-to-Parent line 0808 800 4106

NAS national membership: 020 7903 3563
Email membership@nas.org.uk

Education Support

NAS Education Rights: 0808 800 4102

SEND Advice Surrey: 01737 737300

www.sendadvice.surrey.org.uk

SOS!SEN charity to support EHCPs etc, Tel: 020 8538 3731, Web: www.sossen.org.uk

Family Support & Representation

One Stop CAMHS / BEN Pathway family support 0300 222 5755

Portage – support for children with SEND under 3.5 years 0300 200 1004

Family Voice Surrey parent representation
www.familyvoicesurrey.org

Action for Carers tel: 0303 040 1234
CarerSupport@actionforcarers.org.uk

Parent Programmes

PAT-P for parents of under 5s.

Cygnets for parents of children aged 5 – 19. courses@sendteachingschool.co.uk
Tel: 020 8330 3009 ex 237

Redhill CAMHS group 01737-287002

Activities for children and young people

NAS Resource Centre, Godalming: 01483

521 744 SEResourceCentres@nas.org.uk

interAKTive, Epsom-based charity for children with ASCs and other difficulties
07876 762178 www.interaktive.org.uk

Adult Services

Surrey Adult Social Svcs: 0300 200 1005

NAS Surrey Service Tel: 01483 861600,
email: surrey.service@nas.org.uk

Employment Support

Employability for people with disabilities including ASCs Tel: 01483 806806, email: employability@surreychoices.com

Benefits advice

NAS Tips page – via www.autism.org.uk

Cerebra DLA guide:

<http://w3.cerebra.org.uk/> 0800 328 1159

Branch Online Parent Support Groups

We will be continuing to offer Zoom meetings for parents to get together online during April, May and June. It is likely that some Zoom support groups will continue, even when face-to-face meetings resume.

The **Parents of Children Group** meets fortnightly, alternating Monday evenings at 8.00 pm and Wednesday mornings at 10.00 am. **Please note the time change for the morning meeting.** The next meetings are:

Monday 12th April 8.00 pm
Wednesday 28th April 10.00 am
Monday 10th May 8.00 pm
Wednesday 26th May 10.00 am
Monday 7th June 8.00 pm
Wednesday 23rd June 10.00 am

To go on the mailing list to receive the Zoom links for these meetings, please email Emma Phillpotts at support@nassurreybranch.org

The **Parents of Adults Group** also meets fortnightly alternating Friday afternoons and Wednesday evenings. The next meetings are:

Friday 9th April 2.00 pm
Wednesday 21st April 7.30 pm
Friday 7th May 2.00 pm
Wednesday 19th May 7.30 pm
Friday 4th June 2.00 pm
Wednesday 16th June 7.30 pm

To go on the mailing list to receive the Zoom links for these meetings, please email Hilary Dyce at hilarydyce@yahoo.co.uk

We also have a group for **Parents of housebound autistic people**. This group meets every 4 weeks on Tuesday evenings. The next meetings are:

Tuesday 6th April 8.00 pm
Tuesday 4th May 8.00 pm
Tuesday 1st June 8.00 pm

To go on the mailing list to receive the Zoom links for these meetings, please email Emma Ellis at events@nassurreybranch.org

We have started a support group for **parents of children and young people with Pathological Demand Avoidance (PDA)**. This group meets on the final Thursday evening of the month. The next meetings are on :

Thursday 29th April 8.00 pm
Thursday 27th May 8.00 pm

To go on the mailing list to receive the Zoom links for these meetings, please email Sara Truman at nas@mugsy.org

How can you support the National Autistic Society Surrey Branch?

The Surrey Branch was founded in 1995 to support parents in the Surrey area. For many years we have run parent support groups around Surrey and held talks by professionals. We have also run a number of conferences in the past.

As the Branch is run entirely by volunteers, we focus on signposting families to funded services and on supporting parents through our newsletter and forum, as well as organising events around Surrey that provide practical and emotional support. Two members of the committee have also been actively involved in the development of the All Age Autism Strategy.

Many of the committee members have been involved for a long time and are now seeking to reduce or end their role, so we need to bring on board people who can help us to get the word out about what we offer, including developing our social media presence.

We need a range of people with different skills who can learn more by shadowing and supporting the committee member/s currently carrying out that role. Roles that we urgently need to fill are:

- Social Media Officer – to develop our presence on Twitter and post content onto our Facebook page and Wordpress website.
- Publicity Officer – to keep publications and flyers up to date.
- Admin and Events - Helping a committee member with admin and organising online webinars
- Joining a rota of volunteers to support Emma Phillpotts with the Parents of Children online support group. We'd particularly like to hear from you if you have experience of going through the EHCP process as this is something that is coming up a lot in these sessions.

Could you give a few hours a month to the branch to support the work that we do?

Could you find out if you could run a stand at your schools summer fair to publicise the work that we do, along with a committee member to offer support and resources.

If you can help, please email Carol Teunon at NASSurreyBranch@nas.org.uk

Planned Parent Support Groups Leatherhead & Lower Kingswood

There has been some interest in the new Leatherhead support group, with most interest so far in an evening rather than a daytime meeting. We are also looking at starting a coffee morning in Lower Kingswood on either a Wednesday or a Friday morning. This coffee morning would start up in September, when children return to school (subject to COVID restrictions being lifted).

Please contact Carol Teunon at NASSurreyBranch@nas.org.uk saying which venue you are interested in. Also include which days and times you would be available for the Leatherhead group and which day out of Wednesday and Friday you would prefer for the Lower Kingswood coffee morning.

World Autism Awareness Week

World Autism Awareness Week is taking place from 29th March - 4th April.

Take a look at the range of suggestions about how you can take part and show you're supporting this event on the NAS website <https://www.autism.org.uk/get-involved/raise-money/world-autism-awareness-week>

- **Download the World Autism Awareness Week background for your video calls.** It's available in both calm and vivid colours.
- **Tell your followers about World Autism Awareness Week** – download shareable social media assets to help raise awareness online.
- **Hold a quiz night** – adding autism questions to a quiz is a great way to help your friends, family or colleagues learn about autism while having some fun in lockdown: <https://bit.ly/3feG8rg>
- **Read-up on autism** – expand your knowledge of autism by checking out some of the website resources.

Please note that our Executive Function talk for World Autism Awareness Week on 1st April is **sold out** – see page 6 for other forthcoming talks.

If activities aren't for you, you can still help by donating to the NAS Surrey Branch: <https://www.justgiving.com/fundraising/nassurreybranch>

Surrey All Age Autism Strategy

The last stage of public consultation on Surrey's All Age Autism Strategy was completed in March, and the final version of the Strategy Framework will be published in April, with the complete Strategy being published in July.

Autistic people, parents/family carers and others interested are invited to contribute to the ongoing development of the strategy. You can be involved with as little, or as much, of the Strategy as you wish – it is likely that commitments will be for a couple of hours every month, with the opportunity to contribute to specific working groups of your choice, linked to the 6 Strategy workstreams. They are:

1. Awareness and understanding of autism in the community
2. Information and navigation to live an active life
3. Education and Preparation for Adulthood
4. Health and Social Care Support
5. Housing and Independent Living
6. Employment

To be involved, email autismstrategy@surreycc.gov.uk for more information.

There is also a reference group for autistic adults being run by Surrey Autism Partnership Board to gather their views about the strategy. See page 15 for details.

Thank you to St Nicolas Church Guildford

Our thanks go to St Nicolas Church in Guildford for their donation of £190.75. The donation was used to cover the costs of printing and posting the last issue of the branch newsletter to those members who are not able to receive it via email.

Branch Webinar on Education and Health & Care Plans (EHCPs)

We are hosting two live webinars in May on EHCPs delivered by Tanya Williams, founder of www.senadvice.com. Tanya is an SEN advocate and SOS!SEN volunteer, who worked for over 20 years as a litigation lawyer, and is also a mum to two young people with neurodiverse conditions.

The events are free, but spaces are limited, so please only book if you are able to attend. You can book one or both events.

The EHCP Process - Wednesday 5th May 2021, 7pm to 9pm

- the EHCP process
- criteria for assessment
- statutory timescales
- gathering evidence and who should contribute
- issuing of an EHCP

To book for 5th May, go to Eventbrite <https://www.eventbrite.co.uk/e/autism-and-the-ehcp-education-health-and-care-plans-process-registration-147395290281>

The Contents of an EHCP - Tuesday 18th May, 7pm to 9pm

- what an EHCP looks like
- what each section should contain
- what to be wary of
- how to get a good EHCP

To book for 18th May, go to Eventbrite: <https://www.eventbrite.co.uk/e/the-ehcp-education-health-and-care-plans-contents-registration-147813591431>

There will be a chance for questions, but please note that Tanya can't provide detailed advice on individual EHCPs.

We hope to provide a recording of the webinars, which will be available for 30 days to registered delegates.

Family Voice Surrey Free Online Events

Family Voice Surrey (FVS) champions the needs and rights of SEND families in Surrey with children or young adults up to the age of 25 who have special educational needs (SEND), chronic illnesses, including mental health conditions, or disabilities. They are hosting **two talks by Dr Chloe Farahar** (an autistic academic) in April:

Fri 16th April, 12 noon - Fostering a positive Autistic identity for wellbeing. Dr Farahar will discuss the importance of moving away from a pathologised, medical "culture of autism" to the positive Autistic identity found via Autistic culture. Email diana.p@familyvoicesurrey.org for more details and zoom login

Fri 30th April, 12 noon - Why Autistic people need Autistic identity, culture, community, and space for better mental wellbeing. In this one-hour session Dr Chloe Farahar critically discusses the evidence for the use of CBT with Autistic people and asks attendees to consider the wellbeing of Autistic people and not how to change Autistic experience. Email diana.p@familyvoicesurrey.org for details and zoom login.

The Curly Hair Project

The Curly Hair Project (CHP) is a social enterprise that supports autistic people and those around them, founded by autistic author Alis Rowe. Alis uses animated films, comic strips and diagrams to make the books, webinars and e-courses interesting and easy to understand. NAS Surrey Branch Chair Carol Teunon recent interviewed Alis Rowe about how she set up CHP which you can read on our website

<https://nassurreybranch.org/curly-hair-project/>

Members of NAS Surrey Branch can get a 10% discount off Curly Hair Project

webinars, e-courses and books. Resources are used by GPs, psychologists, speech and language therapists and teaching professionals. The webinars really show what it is like to be autistic, from the inside, and are therefore extremely helpful for autistic adults and parents of autistic children. They focus on strategies that help. If members of Surrey Branch use the code NASSURREY, they will be able to access the 10% discount.

There are a range of webinars available in April and May. Most of them last for an hour and you receive access to a recording for a week afterwards.

- Meltdowns and Shutdowns Thursday 8th April at 7.30 pm
- Understanding Masking Wednesday 14th April at 8 pm
- Autism and Executive Function Thursday 15th April at 7.30 pm
- **New webinar for children!** Managing anxiety as an autistic child Saturday 17th April at 10 am. This is a practical webinar for young people aged approximately 6-16 years to help them understand more about their anxiety.
- Understanding what it's like to be autistic Tuesday 20th April at 8 pm.
- ASD and eating Monday 10th May at 8 pm

For more details and to book see:

<https://thegirlwiththecurlyhair.co.uk/services/events/>

If you need any help with accessing the discount please email

NASSurreyBranch@nas.org.uk

Group for Autistic and Neurodiverse Girls - Appeer CIC

Appeer Community Interest Company was set up to benefit autistic and neurodiverse girls and women and those around them. They will be running events for younger girls aged 7 -12 and teens aged 13-17, as well as parents/carers, from April. The Surrey Branch are partially subsidising the online groups for younger girls.

Sessions for younger girls include a Star Wars session, a pizza bomb bake session, a dogs-based session and more. For details and to book go to:

<https://www.appeer.org.uk/7-12-years-old-girls>

Sessions for autistic teen girls aged 13-17 include sessions on art, cooking and more. Details can be found here: <https://www.appeer.org.uk/teens>

Support for parents/carers and women in due course can be found via the website too. Please email jo@appeer.org.uk with any queries.

Talk Report: Introduction to Pathological Demand Avoidance (PDA)

Clare Truman spoke to the NAS Surrey Branch about PDA in March 2021. This is a summary of her talk.

Clare provides distance learning education programmes for children and young people with autism spectrum disorders who find it difficult to access school-based learning. Most of the students have Pathological Demand Avoidance (PDA). Clare also provides consultancy and training in autism and/or PDA for schools and other professionals, or families. She has been teaching for 13 years and specialising in autism for 10 years, and has an autistic brother.

Clare started with a definition of PDA which is increasingly – but not universally – accepted as a behaviour profile seen in some individuals on the autism spectrum. It is characterised by an overwhelming need to avoid or resist the ordinary demands of life. It has also been described as an anxiety-driven need to remain in control.

People with PDA may appear to be sociable but need help to develop social understanding. They may have excessive mood swings and impulsivity, enjoy role play and pretend games, and have obsessive behaviour which often focusses on people.

There are different kinds of demands, all of which can cause extreme anxiety in someone with PDA. For instance:

- Direct demands – “Brush your hair”
- Subtle demands – “It’s 8.30” (implies ‘time to put your coat on and go to school’)
- Silent demands – e.g. the pressure to respond to a question or comment
- Self-imposed demands – wanting to do an activity but not being able to

Strategies to Help

Parents and others wanting to help someone with PDA need to try to reduce the demands on them, in order to reduce the anxiety. The PDA Society has a useful word to remind people of the 5 key strategies they recommend – PANDA – which stands for:

- P – Pick battles (or prioritise demands)
- A – Anxiety management
- N – Negotiation and collaboration
- D – Disguise and manage demands
- A – Adaptation

Pick battles – try to list all the demands that might be put on the PDA child/young person in a day, and rank them in order of importance, e.g., not hurting siblings would be a high priority, finishing a drawing might be a low priority. By concentrating on the highest priority demands and leaving the others, the overall level of anxiety should be reduced. It can also help to depersonalise demands when you can, so it is not you insisting that they don’t hurt their siblings, it is the law that says you mustn’t hurt people.

The PDA person may be more anxious on some days than others, so when they are extremely anxious keep demands to a minimum, but when they are more relaxed they may be able to tolerate more demands.

Anxiety management – try to balance the day so that in between demands there are relaxing activities to reduce the PDA person’s stress levels. Don’t make the relaxing activities a reward for completing a challenging task, as it can be counter-productive if the person needs to do the relaxing activity before he can complete the task. It can

Talk Report: Introduction to PDA /cont'd

help to make an anxiety management plan, by making a list of the "triggers" that cause anxiety and the warning signs that show when the person is getting anxious or stressed, and having plans ready for avoiding or managing the triggers and reducing stresses when you see the warning signs.

Negotiation and collaboration – where possible, involve the PDA person in decisions. Only do this with things that you are willing and able to negotiate about. If siblings might feel left out, you could involve them by getting the non-PDA child/ren to choose 2 out of several options, then getting the PDA child to choose between those 2 options. Where possible, see potential issues as challenges that the PDA child could help you solve e.g., instead of saying "put the shopping in the bag," say "I don't know if I can fit all the shopping in the bag."

Disguise and manage demands – use low demand phrases as much as possible, for instance, instead of saying "Let's go out" say "I'd quite like to go out".

Adaptation – try to adapt what you say or how you do things to keep demands low; often using humour can help to diffuse a tense situation or to teach skills. Sometimes a challenge can work to achieve a task e.g., "can you put your shoes on in 20 seconds?" (NB this won't work if the person doesn't like challenges or would not be able to do it in 20 seconds or if winning and losing is a trigger for stress/anxiety.) Try to use the person's interests where you can - would it encourage a child to eat if their plate had their favourite character on it and instead of saying "eat up your dinner" you say, "I wonder when you will be able to see X on the plate". Offering choice can be helpful, so perhaps have a choice of 2 toothpastes to encourage teeth brushing.

Rewards can be counterproductive for PDA people, as receiving one highlights that they've complied with a demand, increasing the sense of demand.

Clare is often asked how families can manage the situation if there are different rules at home for the PDA child as opposed to their neurotypical sibling. Wherever possible, try to allow all the siblings the flexibility that you have to give the PDA child. For example, if the PDA child cannot cope with the demands of sitting at the table to eat so is allowed to eat elsewhere, you could allow the siblings to do the same. Where you can't do that, can you give rewards or privileges to the non-PDA sibling to compensate them for the fact that there are different rules for the PDA child. Don't panic if the neurotypical siblings show signs of anger, jealousy, anxiety, sadness or guilt. These feelings are normal and will pass.

Clare's website is: <https://spectrumspace.co.uk> and other useful resources include:

- NAS page on PDA: <http://www.autism.org.uk/about/what-is/pda.aspx>
- The PDA Society: <https://www.pdasociety.org.uk/>
- Google: Phil Christie PDA
- The PDA Resource www.thepdaresource.com
- Dr Ross Greene's challenging behaviour website: www.livesinthebalance.org
- YouTube channel: Chloemejustme
- Sally Cat's guide to PDA <http://www.sallycatpda.co.uk/>
- Julia Daunt's Blog <https://memyselfandpda.com/>
- Steph's Two Girls Blog <https://www.stephstwogirls.co.uk/>

Family Voice Surrey SEND Support Groups

The Surrey parent participation group, Family Voice Surrey, runs support groups for parents and carers of children and young people with any sort of Special Education Needs or Disabilities. These are currently online.

Mon 26th April 6.30pm - 8.00pm – Support Group for parents of 16 – 25 year olds

The focus for April is **transitions to employment** with expert advice from Christina Earl of Surrey Choices. Email gretta.s@familyvoicesurrey.org for details and joining information.

Tues 27th April 10.30am Support Group for parent carers of children aged 0-4

The group is for families who have a child with any disability or additional needs either diagnosed or undiagnosed. They will be joined by Home Start East Surrey Team. Email kim.b@familyvoicesurrey.org for more details and zoom login

Check out the FVS website for additional dates.

<https://www.familyvoicesurrey.org/single-post/spring-and-summer-dates-for-your-diary>

New School Places for Children with Autism in Surrey

Freemantles School expansion

Surrey County Council is proposing that Freemantles School in Woking be permanently expanded to accommodate a total of 270 pupils by providing an additional 72 places in Years 7 - 14. The main point of intake will remain at Reception year. The expansion will utilise space on the school's current site. Overall, the new accommodation will be provided for 135 additional permanent places, which takes into account the current temporary bulge classes moving through the school.

Numbers at the expanded school will grow incrementally, but will take into account the additional pupils already attending the school in the temporary bulge classes. It is expected that the expanded school will reach its new full capacity of 270 by September 2028.

You can have your say about the expansion on the Surrey CC website. The closing date for feedback is 19th April

<https://www.surreysays.co.uk/csf/proposal-to-expand-freemantles-school/>

Woodfield Secondary School Merstham expansion

Woodfield Secondary School, Merstham, is a community special educational needs school which provides secondary education to children and young people aged 11-19 years with Moderate Learning Difficulties (known locally in Surrey as Learning and Additional Needs (LAN)).

Surrey County Council is proposing that Woodfield Secondary School is expanded by 60 places in total across National Curriculum Years 7-11. This expansion is to provide an additional 50 places (10 places per year group) for children who have Moderate Learning difficulties and a further 10 places in the school's flexi-teach provision, which are to be made permanent. It is proposed that the additional places will start to come online from September 2021 and that the project delivery and handover of the expanded school site will be completed by September 2022.

New School Places for Children with Autism in Surrey / Cont'd

Fox Grove School Leatherhead - Update

There is now a website for the new Fox Grove school in Leatherhead.

<https://www.foxgroveschool.co.uk/index.asp>

Marie O'Rourke has been confirmed as Fox Grove's first head teacher. For the last 15 years, Marie has been teaching at Linden Bridge school in Worcester Park.

Fox Grove School is an all-through special free school in Leatherhead, Surrey, due to open in the academic year 2021/22 in a purpose-built school building. There were further details about the school in the last newsletter or you can find details on their new website.

Fourth Cullum Centre at Howard of Effingham School

A fourth Cullum Centre for autistic children is being developed within The Howard of Effingham School near Leatherhead. It will be a specialist autism facility for 20 pupils and include sensory, social and learning gardens. It will be built as part of the redevelopment of the school on a new site.

There has been a lot of local opposition due to concerns over the number of homes that are part of the scheme, and accessibility and transport issues. There is now a need for an additional 110 enabling homes for the scheme to go ahead, due to the increasing costs. This therefore needs to go back to planning. The plan is for the new Howard School to be ready for opening in September 2023.

Action for Carers Free Online Talks

Action for Carers runs a range of talks and support groups relevant to carers, and there are some coming up which may be of specific interest to parents/carers of an autistic child or adult.

Wills, Trusts and Lasting Power of Attorney led by Steve Howells, Rethink

- 19th April, 7.00 - 8.30 pm
- 12th May, 10.30 – 12 pm – with a focus on related mental health issues.
- 8th June, 1 pm – 2.30 pm

Education Health and Care Plans 28 April, 12.30-2pm led by Paul Baker, Transition Manager, Surrey CC. Support to know where to start applying for an EHCP and what you need to include in an application.

Autism Workshop: Coping with Anxiety 26 May, 10.30am-12 pm led by Dr Mark Brown, Special Help 4 Special Needs. Mark will explore issues relating to having additional needs and anxiety, obsessive behaviour, how it impacts on everyone in the family and interventions to reduce the consequences of anxiousness.

There is also a new **carers of adults with learning difficulties and autism support group** running on the fourth Tuesday of each month from 7.30 pm – 9pm. The next meetings are on 27th April, 25th May and 22nd June.

Action for Carers also run Mindfulness courses for adults. They have a five-week course starting on 26th May and regular drop-in sessions on Tuesdays at 4 pm. To book for any event please go to: <https://www.actionforcarers.org.uk/events/>

NAS Stepping up for Autism courses

As part of the new offer and launching at the end of April (see below), professionals from the NAS Surrey Service are introducing Stepping up for Autism courses for parents and carers. These are 8-session courses for parents and carers who live in Surrey. Sessions include: .

- What is Autism?
- Parent & Child Wellbeing
- Communication
- Visual Supports
- Managing Behaviour
- Understanding Behaviour
- Sensory Differences
- Supporting Social Skills

A range of dates, times and formats (Zoom and Face to Face) will be available to choose from. Please contact the new NAS service on 01483 521 744 or email surrey.familysupport@nas.org.uk to book your place.

NAS Surrey Service Joins New Alliance To Transform Emotional Wellbeing And Mental Health Support in Surrey

A new contract to provide children and young people with greater support around emotional wellbeing and mental health has been won by a new alliance of organisations, including the NAS Surrey Service, the professionals based in Godalming (a different organisation to the volunteer-run NAS Surrey branch).

The Emotional Wellbeing & Mental Health alliance brings together NHS clinical expertise with local and national third sector organisations who have proven track records in delivering services to children and young people. Support will be available earlier without the need for a formal diagnosis for children and young people with neurodevelopmental needs, including those who are autistic or have ADHD.

NAS London & South East Resource Centres will be working in the new alliance which will offer services for children, young people and families in Surrey from April 2021. The NAS family support service will grow to include 9 new members of staff, who will deliver a range of services for parents and carers, children and young people.

Surrey User Voice and Participation Team

Surrey's User Voice and Participation (UVP) Team is designed to help children and young people, their parents and carers, to share their views and opinions about the services they use. It offers:

- Participation groups
- 1-2-1 sessions
- Phone calls and messaging
- Online through social media

UVP also provides an advocacy service for children, young people, parents and carers who need support accessing or communicating with services.

<https://www.surreycc.gov.uk/social-care-and-health/children-in-care/user-voice>

There is also a YouTube channel for UVP at:

https://www.youtube.com/channel/UC_tkwqy3H6s0WvbssyGBW3Q

RESEARCH REQUESTS

Edinburgh Napier University Augmented Reality Research

This research is concerned with investigating and designing a tool to help people with autism to manage stress. The survey is being run by Dr John McGowan and Dr Iain McGregor from the School of Computing at Edinburgh Napier University.

This is the first part of a larger project exploring the role that augmented reality technology could play for people on the autism spectrum. A mobile application could monitor data from body movement and use audio-visual technology to manage stress. This initial survey is designed to identify things that might create stress within people with autism. <https://bit.ly/3w1DfQE>

Conversational Techniques to Improve Memory in Children

The Department of Psychology & School of Health Sciences at City, University of London is looking for parents of children with a diagnosis of autism spectrum disorder aged 7-11 years to take part in a remote study. The research aims to compare and explore the benefits of using two conversational techniques suggested to improve memory and communication skills in children with autism.

This is an opportunity for parents to receive online communication training with an autism researcher, and a report summary of your child's research test results. The study will involve parents using the new technique during 5 minute daily conversations with their child for 20 weeks, and keeping a record of their progress. A researcher will complete brief, remote cognitive assessments with your child at the start and end of the study using video software.

All involvement in this study will be done remotely and participant information will be kept completely anonymous. Parents are free to withdraw from the study at any time.

Parents and children must:

- Have access to the internet and a digital device (e.g. smart phone, tablet or computer)
- Not be taking part in another research study

Children must also be:

- 7-11 years
- Diagnosed with autism spectrum disorder
- Have minimal or no language or intellectual disabilities

This study has been reviewed by, and received ethics clearance through the Psychology Committee, City, University of London (Application ID: ETH1920-0682).

For more information about this study, or to volunteer for this study, please contact: Gemma Ryan (School of Health Sciences) at 07340 109163 or Email: gemma.ryan@city.ac.uk

York University Sibling Relationships Survey

The Psychology in Education Research Centre at the University of York is seeking parents and children to take part in a project. The research is to find out more about the relationship between autistic children/adolescents' (10-19) and their neurotypical siblings (5-19) and how they affect autistic children's/adolescents' feelings. After completing each survey, you will be provided with two extra survey links for your children's participation with 15 questions about sibling relationships that are the same questions you would answer in the parent's survey and it is expected to take less than 5 minutes to complete.

The information that you share will help scientists and specialists to understand the effects of the relationships between siblings on children's feelings in order to develop better treatments and approaches to prevent any negative consequences resulting from problems with sibling relationships.

If you are willing to participate in this project, this would involve completing two online surveys at two-time points in a 12 months period. It is expected that the first survey will take approximately 20 minutes to complete. After completing the first survey, you will be asked: "Are you willing to answer 3 more questions (open-ended) about your children's sibling relationships?". We would be pleased to hear from you if you could take some time and answer those 3 questions about the relationships between your children. For details, contact researcher: Emre Deniz, email: emre.deniz@york.ac.uk

Social Media Use in Autistic Young People

Researchers at Canterbury Christ Church University are studying social media use in young people, and want to hear from you. They are looking to discover more about young people's opinions on the benefits and downsides of social media as well as how its use impacts on making friends and overall wellbeing.

The researchers are seeking young people aged 16-19 who have a diagnosis of autism or Asperger Syndrome who are English speaking and have access to a computer or mobile device.

If you would like to take part, this will involve completing a short anonymous online questionnaire about your use of social media and your social life. The questionnaire takes about 15 minutes to complete. Anyone taking part will be entered into a prize draw to win a £50 shopping voucher.

https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_0j0ucO22rOV0EBf

'As I Am' Charity

With the draft Surrey All-Age Autism Strategy Framework being published recently, you might also want to take a look at the Autistica webinar that contains an interview with Adam Harris from the Irish Autism Charity **As I Am** *How can we move towards an autism-friendly world?*

<https://www.youtube.com/watch?v=QDWpykMPxQ8>

This Irish charity has worked on a number of areas that are a focus on the autism strategy including understanding autism and educating the wider community.

<https://www.youtube.com/watch?v=nkBTMKRS9tE>

INFORMATION FOR ADULTS, YOUNG PEOPLE AND THEIR FAMILIES

Surrey All Age Autism Strategy

The last stage of public consultation on Surrey's All Age Autism Strategy was completed in March, and the final version of the Strategy Framework will be published in April, with the complete Strategy being published in July.

Autistic people can continue to be involved in the development of the strategy via the Reference Group (see below). Parents/family/carers and others can also contribute. *Please see page 5 for more details*

Autism Partnership Board Reference Group

This is a group for autistic adults living in Surrey, who do not have a Surrey County Council Adult Social Care package. The groups alternate between afternoon and evening meetings. Members can take part in the Reference Group by talking in the meetings, writing in the chat, or by email outside the meeting.

The meetings are run by Surrey County Council and the next meetings are on:

- Monday 10th May at 7pm
- Monday 14th June at 2 pm

Meetings are currently via Zoom and members are able to choose whether to have their camera on.

A wide range of topics are discussed including employment, housing, health, and issues group members want to raise themselves.

Views from the group will be shared at the Surrey Autism Partnership Board. This will help to shape the new All-Age Autism Strategy and how it is implemented.

To ask to join the group please contact:

Imogen Osborne, Engagement and Partnership Officer.
Phone/text: 07929 863582
Email: imogen.osborne@surreycc.gov.uk

Discount on Curly Hair Project Webinars, e-Courses and Books

The Curly Hair Project material is suitable for autistic people as well as parents and professionals. You get access to the webinar for a week afterwards.

The courses can be useful so that you feel that you are not alone, particularly if you are newly diagnosed.

Alis Rowe, the autistic woman who founded The Curly Hair Project, has recently provided the Branch with an interview about how she set up CHP which you can read on our website <https://nassurreybranch.org/curly-hair-project/>

Please see page 7 for details of discounts available for members of NAS Surrey Branch.

About NAS Surrey Branch

NAS Surrey Branch is a volunteer-run, support group for the parents of autistic children and adults and is part of the National Autistic Society. It's FREE to join (although a small donation is appreciated) and we have around 2,000 members in and around Surrey.

We hold regular support group meetings, organise social events and special interest groups (currently online) and represent parents in meetings with health, education and social services.

We host an active online forum and produce this email newsletter every two months. To join, go to www.nassurreybranch.org or email NASSurreyBranch@nas.org.uk to request a membership form.

If you are a member of the National Autistic Society at national level, you can nominate us to receive part of your subscription by emailing supportercare@nas.org.uk.

The National Autistic Society works for autistic people and runs a wide range of services such as schools, clubs and adult centres. It has over 20,000 members and 100 branches and works in partnership with more than 50 local autism societies.

The NAS exists **to transform lives** by being a trusted source of support and practical advice for autistic people and their families at key stages in life and **change attitudes** by working with businesses, policymakers, autism professionals and the public to reduce isolation and open up opportunities in society as a whole.

As the NAS approaches its 60th birthday it faces the challenge of reduced funding due to COVID 19. By joining the NAS, you can help boost funds, as well as providing additional information for you and your family.

The individual member price is £26 for card payment/£24 for direct debit
The joint member price is £32 for card payment/£30 for direct debit

Joint membership allows two adults living in the same household to take advantage of publications discounts and to vote in elections for the NAS' Council of Members. It also gives family members a chance to be involved and to show their support.

Parents often take out joint membership with an autistic child who is over 18.

**National Autistic Society, 393 City Rd, London EC1V 1NG www.autism.org.uk.
Registered charity, number 269425. Company limited by guarantee number 1205298.**

The NAS Surrey Branch is part of the National Autistic Society - Registered charity, number 269425. Company limited by guarantee number 1205298.

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