



Newsletter

Welcome to the August/September issue of Surrey News

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Please note – there are no Branch talks in August or October.

We celebrated the 20th anniversary of the NAS Surrey Branch in style at our AGM in Woking July – almost 20 years to the day since the first Branch meeting in Farnham on 4th July 1995.

Our speaker for the evening, Dean Beadle gave a touching and highly entertaining talk about growing up with an ASD. The quote I particularly liked was that he said that the word 'inappropriate' has followed him throughout his life – but, he asked, how are people on the spectrum supposed to know that they are being 'inappropriate' if they don't understand what appropriate is?

You should have a copy of the 2014/15 annual report included with this newsletter – please do get in touch if you have suggestions for other activities we can consider for next year.

We seem to have ironed the bugs out of our new web site and will endeavour to keep it up to date. Most of the images on the site at present are library shots – but we would like to include pictures of real people. So if you fancy being famous, please send us a photo of yourself or your family that we can use on the site. We will ask anyone who submits a picture to complete a photo permission form.

Emma

Emma Whitfield
Chair (volunteer)

**NAS Surrey Branch
Tel: 07423 435 413**

General Email: info@nassurreybranch.org

Web site: www.nassurreybranch.org

Twitter: [@NASSurreyBranch](https://twitter.com/NASSurreyBranch)

Donations: www.justgiving.com/nassurreybranch

NAS Surrey Branch Contacts

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trenamans@talktalk.net

Parents of Girls' Group

Rachel Pearson 01483 727378
racheldpearson@gmail.com

Fathers' Group:

Martin Trenaman 01737 360069
trenamans@talktalk.net

Parents of Adults' Group

Hilary Dyce 01276 66032
hilarydyce@yahoo.co.uk

Fundraising

Sarah Mason 07973 379131
slmason78@gmail.com

Other Useful Contacts

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

NAS web site: www.autism.org.uk. For personalised information go to www.autism.org.uk/signpost.aspx

NAS Helpline: Tel: 0808 800 4104 (10am – 4pm), or email autismhelpline@nas.org.uk (replies within 14 working days)

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

Education Support

NAS Education Rights: 0808 800 4102

Surrey Parent Partnership: 01737 737300

<http://www.surreyparentpartnership.org.uk/>

SOS!SEN charity to support statementing, tel: 020 8538 3731, Web: www.sossen.org.uk

Family Support & Representation

NAS Family Support worker - for families with at least one child in mainstream education

Tessa.emery@nas.org.uk, tel: 07436 261163.

NAS Parent-to-Parent line 0808 800 4106

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

Family Voice Surrey

www.familyvoicesurrey.org

Local parent programmes

Early Bird (parents of under 5s) / **Cygnets**

(parents of children aged 5 – 18). Vicky Jones training@linden-bridge.surrey.sch.uk
Tel: 07747 595 155

Redhill CAMHS group for parents of children with ASDs, tel: 01737-287002

Activities for children and young people

NAS Resource Centre, Godalming Tel: 01483 521743

SEResourceCentres@nas.org.uk

interAKtive, Epsom-based charity for children with ASDs and other communication 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 learning disabilities/ASDs tel: 01483-519690, email:

employability@surreychoices.com

Benefits advice

Carers Support <http://www.carers.org/carers>

NAS Tips page – via autism.org.uk

Cerebra DLA guide: 0800 328 1159

About NAS Surrey Branch

The Surrey Branch of the NAS is a volunteer-run parent-to-parent support group for families in Surrey affected by Autism Spectrum Disorders. It's FREE to join (although a small donation is appreciated) and we have around 1,500 members. The branch holds regular meetings and organises social events, local coffee mornings and special interest groups, and represents parents in meetings with health, education and social services. We host an active Yahoo! online forum, and produce this newsletter every two months. To join, email emma@mugsy.org for a membership form.

If you are a member of the NAS at national level, you can nominate us as your branch by emailing supportercare@nas.org.uk, which means we receive a percentage of your annual subscription.

*We're part of **The National Autistic Society**, a national charity founded by parents in 1962 which runs a wide range of services such as schools, clubs and adult centres. It has over 20,000 members, 100 branches and works in partnership with more than 50 local autism societies. The NAS exists to champion the rights and interests of all people with autistic spectrum disorders and to ensure that they and their families receive quality services appropriate to their needs. **National Autistic Society, 393 City Rd, London EC1V 1NG www.autism.org.uk. The National Autistic Society is a registered charity, number 269425. Company limited by guarantee number 1205298.***

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Last chance to book for the NAS Surrey Conference!

A reminder that booking for the NAS Surrey Branch conference "Anxiety and Anger in Autism" closes on September 11th. The conference is being held at the University of Surrey in Guildford on Saturday 3rd October, and there are only a few places left.

Don't miss this opportunity to hear speakers such as Wenn (formerly Wendy) Lawson - psychologist, author and person with Aspergers; Consultant Psychiatrist Dr Raja Mukherjee, Freemantles School teacher Vanessa Oldham, Occupational Therapist Caroline Winfield and Bettina Stott from the NAS ASSIST service.

For details and to download a booking form, please go to: <http://www.nassurreybranch.org/conference.html> or contact Sara Truman, email: conference@mugsy.org tel: 07989 315609.

NAS Surrey Branch Ten Pin Bowling event in October

We have booked exclusive use of the ten-pin bowling centre at Pine Ridge Golf Club in Frimley for members of NAS Surrey Branch from **2.00pm – 3.00pm on Sunday 18th October 2015**. The event is designed to let families and youngsters with ASDs meet one another in a relaxed and fun environment.

There are six lanes and we will allocate five or six players per lane, so you may be put with other members.

Please note, children remain the responsibility of their accompanying parents/carers at all times. PLACES MUST BE BOOKED IN ADVANCE by completing the enclosed booking form and sending it with a cheque with a suggested donation of £3.50 per head.

If you need further information, please contact Sarah Mead 01483-454245 sarah_mead@hotmail.co.uk

Findings from our CAMHS mini survey

In June, we were invited to present to the CAMHS Strategy Board as part of a half-day meeting of commissioners and key decision-makers. CAMHS is currently being re-commissioned in Surrey and it was encouraging to see that the topic of supporting youngsters with autism was prominent on the agenda.

In order to give the commissioners as clear a picture as possible of what families that include someone with an ASD who has been referred to CAMHS experience, we conducted a mini online survey and received over 100 responses within a week. The findings from the survey appear below.

The breakdown by age of the child / children that people were responding about was:

- 5% under 5
- 49% aged 5 – 10
- 34% aged 10 - 14
- 12% over 14s.

Over 50% had visited CAMHS in the last year; around 30% over two years ago and over 11% were still awaiting an appointment at the time of the survey.

We asked about referral routes and people told us that their young person was referred by:

- 44% GP
- 22% Paediatrician
- 2% Primary Mental Health Worker
- 18% School or college
- 14% Others (including specialist behavioural nurse, LD team and social workers)

We asked how long people had waited between referral and first appointment:

- 38% said one to three months
- 28% said three to six months
- 8% said six to nine months
- 11% said over nine months.

Over 10% of children had had emergency referrals and less than 5% had had an appointment in under four weeks.

Several of those who responded had had their children seen by more than one professional, with virtually all saying that the professionals had included a psychiatrist (49%) or clinical psychologist (47%).

We asked whether the service offered was appropriate for the young people who had been referred: 39% said yes and 61% said no.

We shared some of the positive comments from members with the Strategy Board...

- “Helpful for my daughter to talk about her anxiety and OCD”
- “Psychiatrist prescribed anti-depressants. Clinical psychologist provided CBT. Family therapist offered family sessions”.
- “Very professional and helped us through very difficult times in schooling”
- “We currently receive a better service. 3 years ago....we could not get past tier 2”.
- “Referral to psychiatrist, medication, regular ongoing CAMHS appointments”
- “No further action but can re refer if needed.”

... and some of the larger number of negative comments:

- “Offered CBT... he said it was unlikely to help due to her ASD. After that he seemed at a loss”
- “Different Dr each time, no consistency, no pre-reading of notes”
- “Consultant had no information - didn't know what we were there for”
- “Only wanted to meet with me and my husband, not our child”
- “Discharged following assessment.. suggested going to A&E”
- “Refused support as he has an ASD diagnosis therefore not CAMHS remit!”

Findings from CAMHS mini survey /cont'd

- "It was far too late"
- "The wait (3 months +) for appointments was unbearably long"
- "We were given the feeling we were not important enough"
- "No understanding of ASD or PDA"
- "We were told that little help could be given as he's non-verbal.... Now making progress and I'm very satisfied."

We asked parents what the outcome had been of their child's referral.

Replies included:

- Diagnosis
- Still attending / ongoing
- Medication
- Decrease in symptoms
- No progress made
- Signed off / discharged / closed case
- Child refused to go back / parents decided not to go back
- Never got there / refused referral
- Added to another waiting list
- 'Happy son happy parents' (play therapy)

The final question asked whether the child / children were still under CAMHS:

- 39% said yes
- 61% said no.

The meeting included a presentation from Sarah Wild, head of Limpsfield Grange school, about supporting girls with autism; feedback from an independent consultant on approaches to working with children with ASD and discussion about a planned PDA conference in Surrey.

We will continue to meet with the CAMHS commissioners and represent the views of families in Surrey.

Forthcoming Talks & meetings

Thursday 17th Sept GUILDFORD
The Guildford Institute, Ward Street
(off North Street), Guildford GU1
4LH.

For map, go to
<http://tinyurl.com/ln55yvg>

Amanda Hitchcock, Elective Home Education Adviser at Surrey County Council will talk about educating children at home.

Amanda will explain what parents need to know about home education, especially if the child has special needs. Her talk will include looking at what the law says about home educating, and the role of the local authority.

There will be **no branch meeting in October** as we are holding our conference on 3rd October.

Our **November** meeting in Woking will focus on how Occupational Therapy can help children with ASDs (date TBC). This may be of interest to educational professionals working with children with ASDs as well as parents.

If there are topics you would particularly like us to cover in our next **Redhill meeting in February**, please email emma@mugsy.org and let me know, as attendance at our last couple of meetings has been very low, so we would like to ensure that we are covering the topics that are of interest to you .

Dads' Group meeting

The next meeting of the Dad's Group will be on the evening on Friday 18th September. Contact Martin Trenaman for details: trenamans@talktalk.net

Have your say on SEND services in Surrey

Family Voice Surrey is the official forum representing families of children and young people with special educational needs or disabilities (SEND) in Surrey. The forum, which is run by volunteer parents, is conducting a survey to find out what parents in Surrey think about services for children and young people up to age 25 with SEND.

It is really important that as many parents as possible respond to the survey, to be sure that the views gathered are representative. We all tend to speak up at times when we are struggling to get the help we need or when we meet obstacles, but it is vital for a survey like this that all parents respond – those who are happy with the help their child is getting, as well as those who are having problems.

Family Voice Surrey say that they always try to be balanced and accurate when expressing views on behalf of families in meetings with health and local authority representatives, talking about what is going well with services as well as highlighting problems.

Family Voice want to get a big enough response to their survey to give the evidence to confirm or challenge these views in future. Please take five minutes to complete a short survey and tell us what you really think about SEND services in Surrey. How does the Local Authority live up to its claims? What have your experiences of various aspects of SEND been like? How satisfied are you?

If you are the parent or carer of a child or young person under 25 living in the Surrey County Council area please complete the survey via this link: <https://www.surveymonkey.com/r/satisfactionautumn2015> or to find out more, go to the Family Voice Surrey web site www.familyvoicesurrey.org/

Young man from Molesey wins Employment Award

In April, the NAS Surrey Branch presented this year's NAS 'Undiscovered Workforce' Special Recognition Award to Joseph Cross at the *Making a Difference* awards in Dorking, run by Surrey Choices EmployAbility. The branch presents the award to an individual on the autism spectrum who has shown outstanding initiative, determination or achievement in their efforts to get a job or in their work activities.

Joseph is a great example of someone who has used his strengths to make a success of what was originally an unpaid work placement in the restaurant at Kingston University. The management were so impressed with his conscientiousness and initiative, that they offered him a paid role before he had even completed his unpaid placement. Joseph's mother, Rebecca Canter, said, "Joseph's dad and I are so proud. I would love all the parents of children on the spectrum to hear about Joseph, and feel more positive about the future."

Equality Act Inquiry

The House of Lords is conducting an inquiry into the impact of the Equality Act 2010 on people with disabilities. Written evidence is invited on questions such as whether the Equality Act is effective in preventing disability discrimination and whether reasonable adjustments are being made when required. The closing date for submitting your views is 4th September 2015.

You can find information about the inquiry here:

<http://www.parliament.uk/documents/lords-committees/equality-act/call-for-evidence.pdf>

An Easy Read version is available here:

<http://www.parliament.uk/documents/lords-committees/equality-act/Call-for-Evidence-EasyRead.pdf>

Talk to Healthwatch on 3rd August in Guildford

Healthwatch Surrey is an independent organisation that gives Surrey residents a voice to help improve and shape health and social care services. It is planning a series of events called 'Voice It', which will give members of the public an opportunity to come and talk to Healthwatch representatives about their experience of using health or social care services.

The first of the 'Voice It' events is being held at Astolat, Coniers Way, Burpham, Guildford, GU4 7HL on **Monday 3rd August, from 2.00 – 3.30pm**. There is free parking on site, and light refreshments will be provided. If you would like to go along, please email Vanda Green: vanda.green@healthwatchsurrey.co.uk or call 0303 303 0023. You can also use these contact details if you would like to give your views about health or social care services but are unable to attend the meeting.

Healthwatch is hosting an online 'live chat' specifically about mental health services on Tuesday 18th August from 5.30 – 7.30 p.m. To join in go to their Facebook page: <https://www.facebook.com/healthwatchsurrey>

For more information about Healthwatch go to <http://www.healthwatchsurrey.co.uk/>

'Fast Facts' from SILC

Surrey Independent Living Council (SILC) produces a series of information sheets that are useful for anyone trying to find out more about managing their own care. Topics include:

- Understanding Direct Payments
- Buying from agencies and care providers
- Employing a personal assistant
- Helping you plan your support
- Understanding pooled Budgets

For details go to http://www.surreyilc.org.uk/fast_facts/

News for Adults

Activities for young adults with LDs

Welmede is a company which provides care and support and runs a scheme called *Your Time*. The scheme has five summer activities days in August for young people with learning disabilities aged 18 – 25. These are:

- Bowling and Laser Quest in Woking on 7th August
- A Music and Motors Barbecue in Kingston on 16th August
- A trip to Portsmouth on 22nd August
- A trip to the South Bank summer festival in London on 26th August
- A trip to the London Mela celebration of Asian music and culture on 30th August.

They also run a club for young adults on Friday evenings in New Malden, called NX Generation, plus a range of other outings for adults with LDs of all ages. For details go to: <http://www.welmede.org.uk/YourTime/Listings.aspx?catid=2> or contact the Your Time team: email yourtime@welmede.org.uk tel: 0193 2 567666.

Social Group for people with LDs

Surrey Choices is a company owned by Surrey County Council which provides social care services for people with learning disabilities or other needs.

On 7th August, Surrey Choices is running a social evening for people with learning disabilities at their day centre in Redhill, which they have called 'Speed Dating'. The event will run from 7.00 – 10.00pm and the cost is £5 per person. Food and drink will be available to buy at the event and places must be booked in advance.

For more details contact Surrey Choices on 01483 806806 or email info@surreychoices.com.

NAS Surrey Branch Calendar AUGUST – OCTOBER 2015

Our local support group meetings, talks and activities are a great place to meet other people - please always phone/email ahead of time to make sure meetings are still on before you go. For up to date news and events, go to our web site www.nassurreybranch.org

August

Thursday 6th 7.30pm Weybridge
PARENTS OF ADULTS GROUP
Hilary Dyce 01276 66032
Hilarydyce@yahoo.co.uk

September

Weds 2nd 7.30pm Farnham
PARENTS OF ADULTS GROUP
Hilary Dyce 01276 66032
Hilarydyce@yahoo.co.uk

Weds 9th 10.00am Oxted
SUPPORT GROUP
Lisa Sawyer 01883 371090
lisamsawyer@yahoo.co.uk

Monday 14th 9.15am Frensham
SUPPORT GROUP
Christine Malik 07941 121395
christinemalik@btinternet.com

Monday 14th 10.00am Woking
PARENTS OF GIRLS GROUP
Rachel Pearson 01483 727378
racheldpearson@gmail.com

Weds 16th 10.00am Woking
SUPPORT GROUP
Sarah Norris 07543 920917
sarah4ian@ntlworld.com

Thurs 17th 9.15am Chertsey
SUPPORT GROUP
Emma Whitfield 07423 435413
emma@mugsy.org

Thurs 17th 7.45 for 8.00pm
Talk by Amanda Hitchcock on Home
Education – contact Emma Whitfield
emma@mugsy.org

Friday 18th – evening, location TBC
DADS' GROUP
Martin Trenaman trenamans@talktalk.net

Friday 25th 10.00am Guildford
SUPPORT GROUP
Sara Truman 01483 822630
nas@mugsy.org

Tues 29th 10.00am Walton-on-Thames
SUPPORT GROUP
Tessa Patel 01932 886578
madinthepark@gmail.com

October

Saturday 3rd
NAS Surrey Conference 'Anxiety and
Anger in Autism'
BOOKING ESSENTIAL
Sara Truman 07989 315609
conference@mugsy.org

Weds 7th 7.30pm Camberley
PARENTS OF ADULTS GROUP
Hilary Dyce 01276 66032
Hilarydyce@yahoo.co.uk

Weds 7th 8.00pm Weybridge
PUB SOCIAL MEETING
Hand & Spear, Weybridge
Emma Whitfield 07423 435413
emma@mugsy.org

Thurs 8th 10.00am Dorking
SUPPORT GROUP
Sarah Mason 07973 379131
slmason78@gmail.com

Friday 9th 10.00am Haslemere
SUPPORT GROUP
Fiona Bowring 07729 024040
timandfiona@btinternet.com

Friday 9th 1.30pm Hinchley Wood
SUPPORT GROUP
Emma Whitfield 07423 435413
emma@mugsy.org

Weds 14th 10.00am Redhill
SUPPORT GROUP
Helen Ruffhead 01737 212043
h.ruffhead@ntlworld.com

Weds 14th 10.00am Guildford
PARENTS OF GIRLS GROUP
Rachel Pearson 01483 727378
racheldpearson@gmail.com

Friday 16th 10.00am Woking
SUPPORT GROUP
Sarah Norris 07543 920917
sarah4ian@ntlworld.com

Sun 18th 2.00 – 3.00pm
Bowling at Pine Ridge, Frimley
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Sarah Mead 01483-454245
sarah_mead@hotmail.co.uk
