



Monthly Overview: July-Sept 2022

Facebook page followers: 3,002
Facebook closed parent group members: 762
Combined local Facebook group membership: 2,125
Twitter followers: 1,873

Members who attended an event: 68

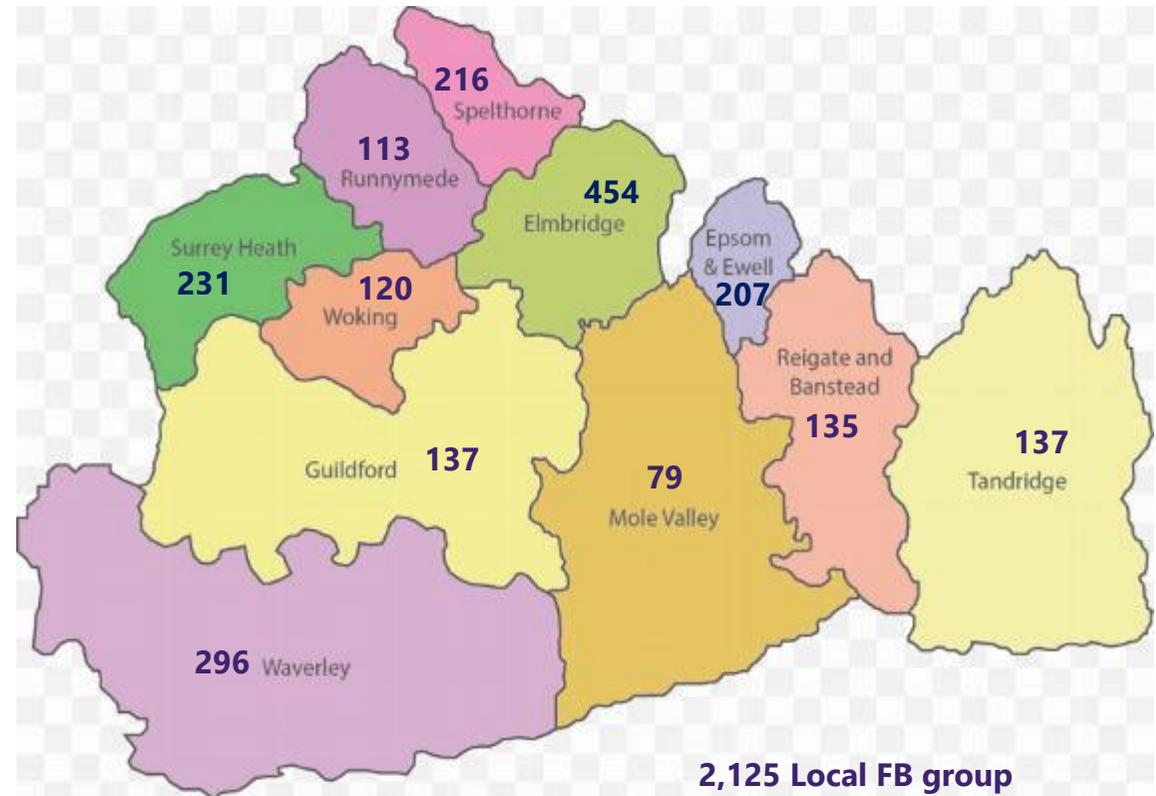
New FVS members:
31



FVS Annual Event & AGM
14th - 18th November

Book your ticket now (limited number available) for our annual event in November using this link

<https://www.familyvoicesurrey.org/annual-event-2022>



2,125 Local FB group membership

Family Voice Surrey Monthly Overview

What we have heard

Apparently Autism is not a learning disability but a neuro diverse condition so despite me once being advised a learning disability is a mental disability under mental health act, it seems now there is total inequality of help for those with autism with no physical issues.

It seems like all the help in Surrey is geared towards Autism.

Enrichment activities need to be a part of the curriculum.

Sadly many children who need one do not have an EHCP in primary school.

Why is education geared towards academics and not wellbeing first? It's all about results, doesn't matter if the child is not coping.

It depends who I speak to at school, it depends how kind they are.

Heathrow is engaging on an employability programme for adults with ND conditions.

Monthly ADHD/ASD group online meeting with Jo Purdey of ADHD Surrey. Jo is launching the Neurodiverse Group in September providing support for children and adults with ADHD. Offering Lego Therapy training courses for parent carers with the aim to improve social communication. Working with Surrey Police to develop a training programme focused on ADHD and the criminal justice system (1 in 4 people in police custody have ADHD). 30-40% of prison population has ADHD. Encouraging people to take responsibility for their actions and increase their understanding of themselves.

Why do so many families still not know about the Call to Evidence for the Downs Syndrome Act?

ADHD Foundation has discovered that although schools are attending training courses on ADHD, they are not then adhering to what they have learnt (in Surrey).

How can {schools} be all inclusive when there is insufficient school funding to do so?

I can't seem to find any clubs where I can leave my children who have SEND needs and my children who are neurotypical together. Everything is separate.

Primary schools are actively discouraging EHCP applications, parents are pushed back at every stage.

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Another reason why I'm struggling is nursery just rang to say he (SEND son) cannot go at all next week - they cannot meet his needs.

My main point about nurseries is private nurseries are not able to cope with children with additional needs - we are on our second but moving to an out of borough specialist nursery. Nursery no1 had no idea how to help kids with additional needs even though their Surrey profile said "has SEN experience".

They actually neglected my son by leaving him in a highchair for hours at the age of 2.

The Surrey graduated SEND team are shocking.

The second nursery I do believe have done lots and tried really hard, but my son needs specialist provision.

However, he isn't actually that bad but we have no choice.

Surrey also do not have any provision - 3 nurseries in whole of Surrey but how many schools there are!

Early intervention will save the council money in long run and do best by these kids but it is simply not there.

Primary Schools need to link with Secondary Schools much more than they do now - if they did then I'm sure there would be less distress for the students.

I asked my child's mainstream secondary for a provision map and they had no idea what it was!

(Talking about Truant Officer of old now being called Inclusion Officer) "Hopefully, with the positive spin on the job role name that will have a positive impact, as in understanding of why a child may not be in school and work with parents and specialists, but if they do what they always did and just automatically fine the parents, then it's pointless".

There doesn't seem to be any school that suits my child's needs. They don't fit into mainstream, and they are not disabled enough for a SEND school.

Also, the issue with primaries can be that a child will manage fine in a small primary setting but a large mainstream secondary is a whole other world and is overwhelming.

For me, it is about wanting to clarify things for others and warn and make sure accurate info is going to be included in any new material produced. I hope those SCC personnel responsible for putting the new leaflet together, will indeed take on board comments and info submitted in the meeting and double check that what they inform is indeed or will be correct. (in ref to the PfA booklet)

I disclosed my significant mental health history to the professionals involved with us. It was used against me and I was told time and again that my parenting was to blame for my children's behaviours. They are both autistic. No amount of parenting will stop that from being the case. I desperately needed support. Of course, this only made my mental health worse. I dread to think how parents with learning difficulties or whose first language is not English cope.

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During my SATS I asked my teacher for a break after sitting there for a while and they wouldn't allow it, I found that really hard.

I love the guitar course. I feel good when I play. Sometimes, I am shy because other children are better than me and I am not good enough.

I don't trust them. They promise things to you but do different things when you are not around.

Surrey Choices has been great!

I don't even need any help.

I'm nervous about Year 7, I'm unsure what to expect.

The enrolment at the college was awful and they didn't have a clue about how to assist me in the process – a shambles. They wasted a lot of my time.

The food at the summer club doesn't taste good. There are strange things like sweetcorn in pasta sauce.

***“Young person's voice/communication”
(verbal, physical movement, Makaton, Pecs, PODD, eye gaze etc)***



Parent Carer Quotes

I've had to give up work to support the children's appointments and travel. I've had my hand forced and have to rely on benefits.

I thoroughly enjoyed the Neurographica session this morning. Lara was clear and engaging and guided us through the process with ease. I felt relaxed by the end of the session and would recommend it as a mindfulness tool and a chance to reflect.

A maintained specialist school has offered my daughter a waking day (residential) placement. Surrey has offer me a day placement for the same school. The school have said they cannot meet needs as a day pupil. How can Surrey offer something to me that it has not been offered to them? is this lawful?

It was useful to have participants who have older teenagers than mine, who could provide 'me' with advice and info.

Are the holidays over yet?

My D has a language disorder and ASC. The unit head and SENCO were  (I guess I know her learning style better) but they both left and this year there will be new people. I also home-school her in parallel as I feel the school system doesn't support neurodiverse learning. So she has private tutors. I have given up on the school system (mainstream) and will not send her to a SEN school. So goal for now is to supplement the education at home until secondary and she matures a bit more.

It's been so nice not to do the anxiety filled school run.

Why is the process so difficult? The case officer seems useless.

My child with a Dx of autism, just won't be able to manage without the additional support an EHCP will provide and why should I have to go through a tribunal or extra time and finances for Surrey to consider an EHCP assessment? In the long run not accessing education affects families and society as a whole – causing more distress and inequality.

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There should be time made to appeal and get concessionary places in taxis accepted or rejected in plenty of time. The policy is stressful enough anyway without working parents or parents with younger siblings needing dropping to school being able to plan their situation ahead of the school year. I believe SCC are only considering concessionary taxi spaces at end of September but weren't all school places known by end of March? SCC's slowness deciding on any certainty, favourable or otherwise causes undue additional stress. Do you need to give notice at work so you can take your child to school? Don't know. Do you need to find and book a child minder to take your younger child to school? Don't know. Are you able to apply for that job to stop you going into poverty during the cost of living crisis? Don't know. Could SCC get a move on with the admin side of things please?

What kind of legal stand point do parents have when their children are unable to attend school? It seems they either have to be in school or you are forced to sign them off by the GP, but no support and nothing else in place to help our children, who are struggling to go to school.

How can a young person get help if they don't meet the criteria for the 'children with disabilities' team (excluding being on board with their 'local' family team of Children's services)?

The school holiday – Could be worse, could be better

DLA have lost my forms, I didn't make copies and I don't have the energy to do it all again.

I wish there were more services for my child to access, my child has severe learning difficulties.

Explain in Plain English, what the process is to appeal a panel's decision?

My child is very anxious because we still don't have a school place for September.

My daughter is at home doing nothing, a school has offered a residential placement to meet her needs. Surrey have offered a day placement with a condition on transport, but a day placement has not been offered by a school.

When are we going to hear about school transport for September?

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There seem to be a lack of adult therapists that have experience helping parents of children on the spectrum deal with emotions.

I feel sorry for those who rely on transport to get their kids to and from school. Thankfully we are just waiting for the money to drive ours in.

My son has started college today, we only received EHCP but I have never been informed about this.

My son was diagnosed with ASD in 2021. We got a draft EHCP in May this year. He's 16.

In 2021 AR the case worker agreed to refer to the transition team. In 2022 Annual review it was noted that I requested the social services to be involved. In June this year I was told that it would be done the very same day.....still waiting.

My experience has been that despite asking for a social care assessment in Y10 and Y11 via the Annual review this was not actioned. I email them directly to be told our case worker needs to refer. It needs to be clearer the pathway to social care referral, the assessment criteria and most of all what Social Services can do for our young people

The local offer has previously referred to talking about transition phase i.e. post-16, from year 9 EHCP review meetings but if child been out of school and very behind with education, not possible to think what future may hold and in practice at reviews, you rarely get the subject broached or representatives from education, health and social care, as also depends if those personnel actually involved with a family.

Too many of our cyp's just can't access the help they need and family's under great strain because however hard parents try, if cyp doesn't engage with help offered which tends to be online through partner agencies, they and the family get no help.

If you don't meet CWD team you get put with ordinary local family Children's social services team and they just go through the generic motions of dealing with your family in a child protection and safeguarding manner and if neither of these an issue, it doesn't help!

Sadly although I managed to have a social care assessment I was immediately told we would not qualify. I have been asking for a referral to the Transition team for over a year and have not yet been successful. The booklet looks good and will be a useful tool.

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Events held this month*

					
19 th July	ADHD/ASD Group with Jo Purdey (ADHD Surrey)	8	5 th Sept	16+ group (extended to 13+ for this session): Preparing for Adulthood booklet	13
20 th July	Dads' discussion with Dr Mark Brown Sibling harmony for ND children 5-11 years	15	7 th Sept	General coffee & chat	1
10 th Aug	Transition to Secondary School	9	8 th Sept	Consultation with Adults with Downs Syndrome and their families	0
11 th Aug	Neurographica - Draw yourself happy!	5 (40 sent video)	13 th Sept	PDA online group chat	8
18 th Aug	Consultation with Adults with Downs Syndrome and their families	0	14 th Sept	School anxiety and Avoidance Monthly Catch Up	6
18 th Aug	PDA online group chat	2	15 th Sept	Neurographica - Draw yourself happy!	1 (25 sent video)
23 rd Aug	ADHD/ASD chat	0			

* Where registered members have not been able to attend (usually due to caring responsibilities), they often have access to recordings or slides.

Participation work

Meetings attended

Project	Information
EWMH	MindWorks reference group
Health	DCO Health Meeting
EWMH	Rebecca Scarth schools offer update meeting
Short Breaks	Surrey Youth Focus call
EWMH	School Anxiety group
Health	CWD Strategic forum
Transport	Meeting with the team regarding issues
Autism	Children & Young People Autism Board
Autism	PDA meeting to discuss work in this area
EHCP Processes	Meeting to discuss videos
Health/Inclusion	DCO Meeting

Glossary

AAAS	All age autism Strategy	MHST	Mental health support teams
AP/Alternative Provision	Education not provided in a school. Includes A2E, hospital school, virtual school, PRU, home tutors and more	ND	Neurodevelopmental
CCHS	Children’s Community Health Service	NEET	Not in education, employment or training
CFLLC	Children, families and lifelong learning committee	NNPCF	National network of parent carer forums
CwD	Children with Disabilities social care team	PBS	Positive Behaviour support
DA	Domestic abuse	PDA	Pathological demand avoidance

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DCO	Designated Clinical Officer	PfA	Preparation for Adulthood
DCS	Director for Children's Services	RFID / ARFID	Restrictive Food Intake Disorder / Avoidant Restrictive Food Intake Disorder
DfE/NHSE	Department for Education, NHS England	SaBP	Surrey and Borders Partnership Trust... deliver the mental health and neurodevelopmental assessment services
EBSNA	Emotionally Based School Non-Attendance	Schools Forum	A representative body of schools who discuss and make decisions about schools funding. FVS is the SEND representative on the forum
EHCP	Education, health and care plan	SEMH	Social, emotional and mental health
EWMH	Emotional wellbeing and mental health	SEND	Special educational needs and disability
GRT	Gypsy, Roma and Traveller community	SSCP	Surrey Safeguarding Children's Partnership
LD & ASD programme board	Discuss is a broad range of issues affecting children, young people and adults with learning disabilities and or autism spectrum disorders	SWP	Surrey Wellbeing Partnership
Local Offer	Most often used to refer to the website that gives information on SEND provision in Surrey	SYF	Surrey Youth Focus
		UVP	User voice and participation team. A SCC team that specialises in hearing the voice of young people in care, using CAMHS and with SEND