



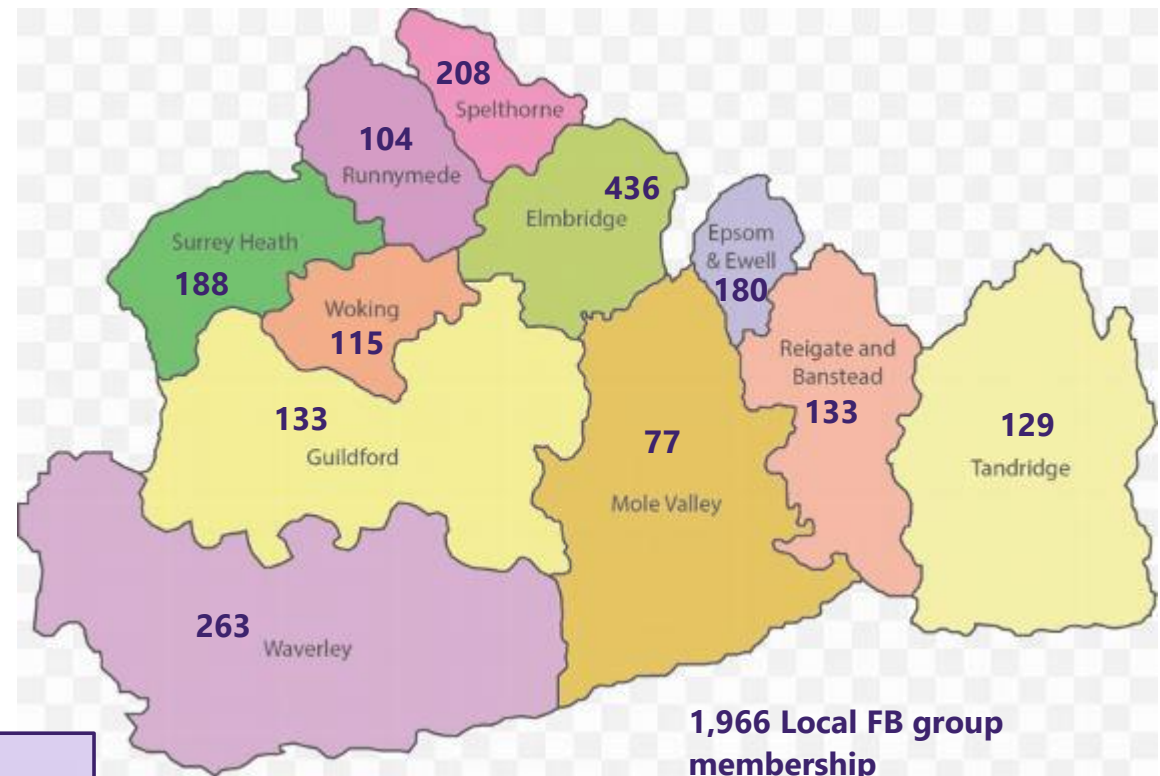
Monthly Overview: May-June 2022

Facebook page followers: 2,699
 Facebook closed parent group members: 755
 Combined local Facebook group membership: 1,966
 Twitter followers: 1,865

Members who attended an event: 123

New FVS members: 132

In one word tell us how you're feeling: this mood picture is fed back to partners and has been really powerful in conveying the impact of services and support



1,966 Local FB group membership

When one word is not enough

"I can't put how I feel in one word unless I'm using one word to describe the people and the system they work in"
 "... The system causing me to potentially losing my job car and home.... What word shall I use for that?"

What we have heard

If I could improve my child's world right now I would reduce CAMHS wait lists.

My 8 year-old talks about how different she is and not wanting to be alive.

I don't know how much to keep trying things and what things to try. We're waiting for CAMHS, we're paying privately for counselling.

It seems to me that so many conditions overlap and yet none of the services do due to the way they are structured and funded.

Hearing the difference in your [*NEST and KITE*] approach to what so many kids are getting....surely there has to be something better.

My neurodiverse daughter has been asked to leave her prep school. We're struggling to find a school.

My son hit Year 6 then could not cope in school. Then finally he was not able to attend school at all. I can't actually see him attending anything that looks like school.

I've had a letter from SCC asking me to apply for transport for next year, but we're on travel allowance. I have spoken to the case worker and they said it was in error, but now they are saying they're not sure?! We have been trying to resolve this since March but the case worker says SCC won't get back to them.

Any transitions should surely just be based on changed needs, not birthdays.
No one wants cliff edges.

The biggest help on Monday was when the TA came to the office to collect my Daughter as she was late, we had a chat, I explained what my daughter's worries were, the TA looked really surprised.

If I could improve my child's world right now I would reduce the Occupational Therapists wait lists and have more schools with high coin units.

My ASD son is very reluctant to go to school, his Primary School don't make any adjustments for him that work, but they say they're doing enough. All of the expectation is on him to find the resilience to go in. I'm now looking at Secondary schools, and am very worried. I'm finding this a really useful group.

My son has a learning disability and couldn't access the mental health support which was offered.

My child's school recently sent a report for this academic year listing her attendance as just over 50% and making comments on issues such as engagement and attitude to learning. She hasn't set foot in the school for well over a year. Do they really think she's been all that time or are these reports just copied and pasted?

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Because my writing is neat, my school doesn't believe I can be dyslexic. Reading is so hard for me and I feel embarrassed having to keep asking for help in front of my friends so I don't ask anymore.

My school say they understand autism but I don't think they do. They talk to me very slowly which is humiliating. Because of my ADHD, when they speak so slowly, I lose track of what they are saying. Then they expect an answer right away. I don't think they understand what processing difficulty is.

I think being in a quiet, safe environment helps. The parents know they can relax and that rubs off on the children too.

I feel that grown-ups in school boss me around.

When I say: - let's go out for a break - my teacher says no! - I don't like it.

I actually like school now, it's really good.

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

The little girl engaged and held my hand today - The mum said she was really astonished as 'x' will only let mum touch her. (*context: using intensive interaction with a pre verbal toddler*)



Parent Carer Quotes

It was very valuable to be able to actually speak with someone at CAMHS, to hear their points and to put our own views across.

Regarding experience of specialist placement after mainstream placement breakdown....It's like benign neglect. They're not going to punish us but they're not helping us. My daughter feels ignored and lost.

I have 2 children with ASD, the youngest is in Year 5. She did go through an awful phase of struggling to get to school. She's doing OK at the moment but it goes in phases. School says she's OK but my concern is secondary school as she's really struggling at primary level. I've applied for an EHCP assessment. I'm trying to avert a disaster that is waiting to happen.

My child would like to be more independent, but doesn't realise how much support she still needs to keep her safe.

It seems that your child has to be on the point of committing suicide to get any help!

In the talk today I learned more about EOTAS and whilst my child is struggling in mainstream school, it's good to hear about other models and ways of meeting our children's needs and feeling that there are options. It's always so useful to hear about the experiences of other parents, their empathy and sharing of resources. It makes the hard days feel less lonely.

I am bullied constantly by parents who see me in the street struggling with my child because they just don't understand what it is like!

I thought the Clare Truman talk was a really enjoyable session and also very useful. She was a very knowledgeable and approachable speaker. I liked the short presentation as I find it hard to carve out time for longer presentations. It was a very practical session and I'm sure parents caters went away with a few ideas to try at home which always feels very positive! I don't think there would have been a way to improve the session as the short presentation accommodated lots of time for questions to be answered and the group to discuss. I continue to value FVS and the free opportunities for learning and support alongside the role of the organisation in helping parent-careers have a collective voice.

My 14 year old has been unable to access services offered as they weren't suitable.

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I have 2 school avoiders from the same primary school. My eldest has dyslexia and PDA. She completely shut down last Easter. Gradually more and more she couldn't cope. School removed class from the equation. She can enter the classroom but she can't sit and learn there. She now has no access to her friends except at breaktime. She wanted to continue at school to be with her friends but she can't do it. The inclusion lady came to our house and threatened us last week. We didn't know she was coming. We have requested emergency alternative provision as she's been out of school for a year. My youngest was refusing school before my eldest. She was struggling before lockdown. We asked school for help, they gave her a folder of mind-mapping techniques.

I'm always worried about placement breakdown.

I now have a draft EHCP for my son and I'm so bored. Every day's a bit challenging.

My child's primary school are amazing!

The service that Clare offers sounds perfect for children like ours.

Thank you so much for running the neurographica session. I could see how the technique could have a real impact, finding solutions, clarity, and a bit of de-stress! I would enjoy a short series of sessions on a weekly basis perhaps.

School are just ignoring the trauma my child has experienced and expect my child to carry on without any issues.

We're going to need an LSA to deliver Clare's resources. I want to have my own life again. I'm just there as an accessory to my son. He is now engaging with some formal learning with his tutor, I never thought we'd get to that point. When he started she just watched him playing.

This was my first 16+ session with FVS as timings with work just haven't allowed me. It was a really friendly and informative session. It is always really helpful to be able to speak directly with the professionals running the services to understand how the system works so our expectations are not unrealistic. I often find as parent of a child with SEN that unless you end up speaking to the right people you are in unknown territory not even sure which questions to ask. It was really good to hear other parents share their experiences and hear their tips and advice as well as Dr Ferreira-Ley.

Thank you for the neurographica talk today. I couldn't find any particular shapes in my picture and could only find two energy lines, but at the end I realised they were cutting a path through the middle of the chaos, and that I can make it from one side to the other!

My 18 year old son was under the eating disorder service in Epsom for over a year with ARFID, but they can't refer him to the adult ED service because they are not commissioned to treat ARFID. We only have the GP, he gets no help with his ARFID. [He] has ASD, ADHD PDA traits and the ARFID. He is verbally very abusive to me, has been stuck at home for over a year and has stopped taking his anti-depressants. I am struggling with coping with his behaviour. His GP has referred him to the adult mental health team but she said he most likely will not be seen. He will stop eating to punish me and refused to see the GP today. He is up most of the night playing computer games and is not able to regulate his mood/emotions and takes all his frustration out on me.

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My child had a complete crash and burn at secondary school. They're now at a special school. They're constantly disappointed by the day at school. They say they'd rather be dead. They go to school then need days off to recover. We're so torn between saying s*d it with school and just sitting at home. But they really need peers and friends, which they've not found at special school.

Anything to do with Autism or neurodiversity feels like it is side-lined automatically.

Every session [with FVS] I attend there is something of interest and help.

There's no emotional support for children with epilepsy.

I went to my MP Jeremy Hunt and just got back a load of rubbish. He was sucking up to me, sent me a consent form and said he'd help but in the end it was just box ticking to say he'd helped someone when all he did was pass on the dismissive response I'd already had. He didn't challenge on my behalf what he was told. What was the point? I felt worse for speaking to him.

The opportunity to understand a bit more about the transition to adult services (I knew nothing about this so was very helpful). The way in which we were encouraged to ask questions and in which these were answered, thoughtfully and honestly.

You can wait a year for therapy, you get 5 or 6 sessions, then you're discharged. It breaks the child's trust, it's not enough time.





No one's given me any support.

ASD comes under education and social care. If you go down the EHCP pathway it's a nightmare. Social care won't offer any kind of care. So a whole group of kids is shoved to the side because they're autistic and not seen as a whole person. You're blocked at all avenues.

It's good to hear about the big picture but as a parent it's not good enough. My son is 18, he's been underweight for so many years, he's gone a bit strange, he's stopped taking antidepressants. I really am struggling. I want my son to be healthy. If you can't get your child to eat it's so awful.

After over a year of being out of school and not being able to attend fulltime for many years before that, my daughter is in the early stages of settling into her new school, and it is going better than I could have wished for. The school are following her lead entirely, listening to her and me as her parent which is allowing her to feel safe and secure and letting her decide when she is ready for the next stage. It is an extremely slow and gradual process but last week she made a friend and I am literally over the moon! Her school are fully committed to allowing her all the time she needs to get it right. All schools and professionals could learn so much about this approach when supporting children with Autism and emotionally based school nonattendance.

Events held this month*

					
17 th May	Intensive Interaction & Social Communication with Pam Smith	24	1st June	General Chat	1
23 rd May	Surrey County Councils Inclusive Apprenticeship Project	14	3 rd June	FB Live Interview with Surrey County Council and Inclusive Apprenticeships!	n/a
24 th May	ADHD/ASD Group	12	7 th June	Laura Kerbey - NEST	13
25 th May	Restrictive Food Intake Group	5	8 th June	School anxiety and Avoidance Monthly Catch Up	12
27 th May	FB Live <i>Benedicte talks to one of our members about her departure from FVS</i>	n/a	13 th June	16+ group Mental Health	18
27 th May	Neurographica: draw yourself happy!	12	14 th June	Downs Syndrome Group	3
			16 th June	Surrey Choices Supported Internships	9
			17 th June	FB Live Interview with Rachael Hurton from Synergy Dance	n/a

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

Participation work

Project update

Project	Update
Transport	<p>Following the recent home to school transport consultation the new policy has now been published and can be accessed via the following link.</p> <p>https://www.surreycc.gov.uk/schools-and-learning/schools/transport</p> <p>Whilst we are concerned about how some aspects of the new policy will affect families particularly around the changes to post 16, solo transport and the introduction of collection points, we are however pleased that mileage will now be calculated using road routes rather than as the crow flies which will be a welcome change to those who receive a travel allowance. We</p>

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	<p>are also pleased that some consideration has been taken about families' experience should transport be stopped. Family Voice Surrey are now working closely with the transport team on developing a parent guide which we will share with members as soon as it is available. If you have any questions about the new policy you can contact travel.assistance@surreycc.gov.uk</p> <p>If you have any comments or feedback you can contact Leanne leanne.h@familyvoicesurrey.org who will share this with the transport team.</p>
<p>EHCP Process</p>	<p>We hope you are finding the bite sized videos useful.</p> <p>EHCP Processes: The Role of the Case Officer - https://youtu.be/dOsYvBAUes8 EHCP Processes: The Governance Board - https://www.youtube.com/watch?v=OgdmPdTe4g8 EHCP Processes: Preparing for Adulthood and post 16 - https://www.youtube.com/watch?v=8F51rZ3sGrE EHCP Processes: The Application - https://youtu.be/SQZjLJ79QPE</p> <p>We will also have EHCP – the draft plan and the plan ready soon. Our next recordings will be on annual reviews and tribunals. Please do send your comments or questions into us – do the videos match your own experiences? You can email Leanne – leanne.h@familyvoicesurrey.org</p> <p>FVS have taken part in the first round of audits to assess the quality of EHCP plans in Surrey, we hope to update you on the outcomes of this soon, these will now happen on a termly cycle.</p>
<p>Health</p>	<p>Following the successful training of the Surrey Youth team coaches last month, Active Surrey have asked us to support them training their Club4 HAF (Holiday Activity and Food) team coaches. This will consist of them going through the training material written by Kate and Lara, followed by a Q and A with Benedicte on 23rd June. This will be a wonderful support not only for coaches but for young people with additional needs and their families.</p>
<p>Social Care</p>	<p>The Social Care Mapping process has now been completed and feedback obtained. This is in the process of being signed off so that we are able to share with all families and begin a deep dive into what each service offer and eventually our aim is to establish where the gaps are.</p>

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Preparing for Adulthood	The PFA event is going to be held at Brooklands College on the 15 th October so please save the date! More details to follow.
Short Breaks	<p>The next Short Breaks session is scheduled for the 22nd June. The session is aimed at speaking to families and users of the short breaks scheme to explain the outcomes that have come out of the process so far and listen to how they would like them implemented. FVS are attending and would be love as may parent carers to be involved as possible.</p> <p>If you would like to attend or know of a young person or parent that would be interested then please contact Kate on kate.g@familyvoicesurrey.org</p>
Local Offer	<p>Surrey County Council want to know more about your experience with Local Services. They have produced a short survey for parent carers to complete. Your feedback will help inform and shape SEND strategy and improve local services for children with additional needs and as a thank you for your time and thoughts you will be in with a chance of winning two gold Merlin passes. The link can be found below-</p> <p>Parents' Voices Matter survey - Surrey County Council - Citizen Space (surreysays.co.uk)</p>

Meetings attended

Project	Information
NNPCF SEND	Response to Green paper
Direct payments	Direct payment policy review
Social Care	Mapping meeting
EWMH	ND friendly schools x2
Local offer	Third party sector planning
EWMH	MHST team meeting
EWMH	Emerge meeting
EWMH	FVS and Mindworks monthly meeting
Short Breaks	Outcome meeting
EWMH	Crisis card planning

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Health	SABP care plans feedback
Health	Childrens Health website- Amy Brett- Scheider
Health	Spelthorne leisure centre meeting
Health	Tim Bates GP meeting
Inclusion	FVS and Send Advice Surrey
EHCP Processes	Send Admissions and FVS meeting
Inclusion	SEMH meeting
PfA	PfA Event group
Autism	AAAS Implementation Board
Inclusion	NNPCF Response to the Green Paper
Inclusion	SEMH Steering Group
Inclusion	SCC FVS Green Paper Meeting
Autism	AAAS Strategy Meeting
Transport	Parent Guide Meeting
Inclusion	Inclusion Steering Group
Autism	Children and Young People Autism Partnership Board
Inclusion	Ordinarily Available Meeting
Inclusion	Team Around The School meeting
EBSNA	EBSNA meeting
Inclusion	Inclusion mock Inspection
EHCP Process	New Paperwork Meeting
Strategic	Carers Partnership Board
Strategic	Green paper Consultation Joint Response
Diversity	Reaching out to the GRT community
Strategic	CFLLC Select Committee chair 1/4ly meeting
Autism	PBS guiding coalition
Strategic	Regular catch up with SCC operational lead
Mindworks	SABP Care Plans discussion
Mindworks	FVS and EWMH planning
Strategic	Surrey Healthy Schools Steering Group

Social care	CwD monthly catch up
Strategic	Mock Inspection meetings

Glossary

AAAS	All age autism Strategy	MHST	Mental health support teams
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 life long learning committee	NNPCF	National network of parent carer forums
CwD	Children with Disabilities social care team	PBS	Positive Behaviour support
DA	Domestic abuse	PfA	Preparation for Adulthood
DCO	Designated Clinical Officer	RFID / ARFID	Restrictive Food Intake Disorder / Avoidant Restrictive Food Intake Disorder
DCS	Director for Children’s Services	SaBP	Surrey and Borders Partnership Trust... deliver the mental health and neurodevelopmental assessment services
DfE/NHSE	Department for Education, NHS England	Schools Forum	A representative body of schools who discuss and make decisions about schools funding. FVS is the SEND representative on the forum
EBSNA	Emotionally Based School Non-Attendance	SEMH	Social, emotional and mental health
EHCP	Education, health and care plan	SEND	Special educational needs and disability
EWMH	Emotional wellbeing and mental health	SSCP	Surrey Safeguarding Children’s Partnership
GRT	Gypsy, Roma and Traveller community	SWP	Surrey Wellbeing 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	SYF	Surrey Youth Focus

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Local Offer	Most often used to refer to the website that gives information on SEND provision in Surrey	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
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