



Monthly Overview: October & November 2022

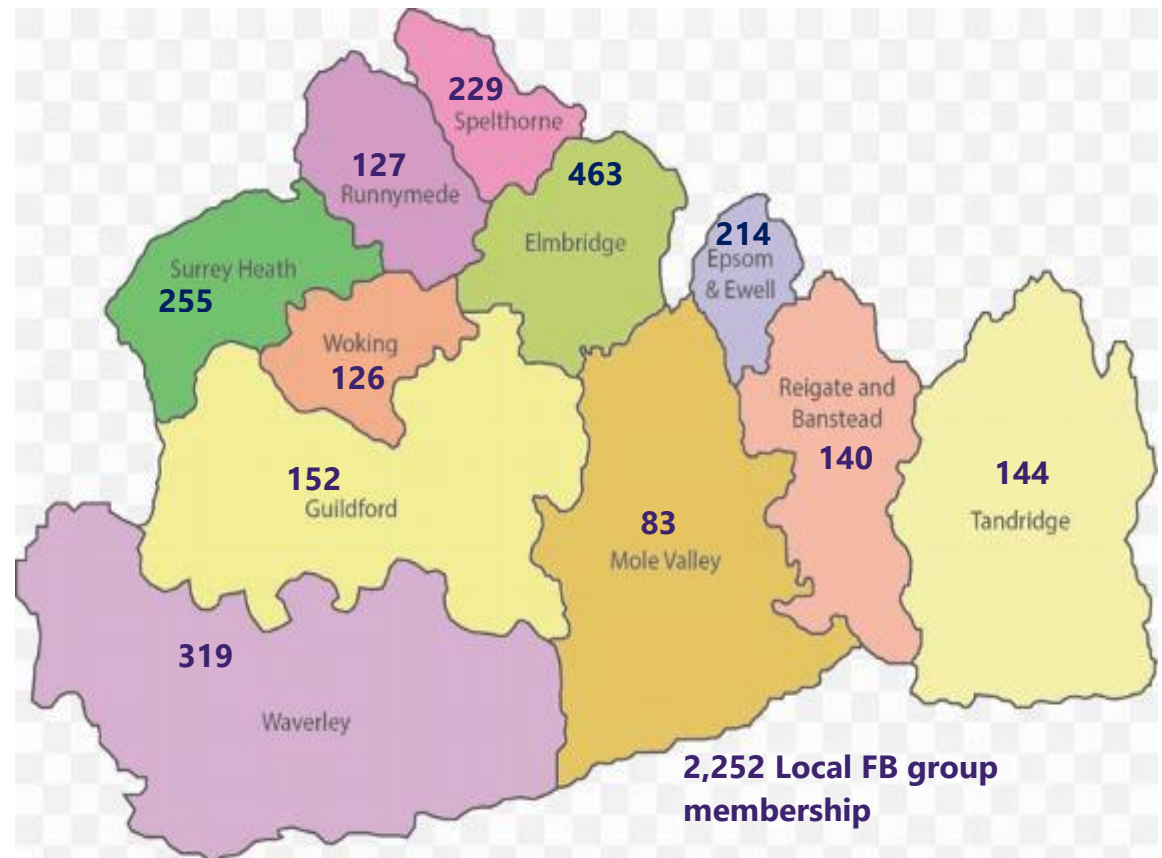
Facebook page likes: 2,767
Facebook closed parent group members: 808
Combined local Facebook group membership: 2,252
Twitter followers: 1,881

Members who attended an event: 47

New FVS members:
162

If you attended our Annual Event this year either virtually, in person or both we would welcome your feedback via this quick survey. Your thoughts will help us improve our offering for next year 😊

<https://www.surveymonkey.co.uk/r/7RXFJLG>



FVS Annual Event & AGM
14th - 18th November

What we have heard

There is no real way of seeing the scale of this problem as there is no attendance code for EBSNA. If the local and national government wanted to do this they could. A new code was brought in for COVID pretty much overnight. I'll believe they take it seriously when I see a code for it.

Do you have any other comments about the session or about the FVS 16+ group emails?

'Someone I know in this group says she is in a few support groups and the FVS post 16 group is definitely the most useful for gaining information. I think it is really useful but I have no comparison.'

I found the discussion on the WhatsApp group recently about Universal Credit tiers helpful

I've got a 13 year-old who's autistic, but CAMHS won't diagnose her. Transition was a disaster. In Year 8 she had 50% attendance, Year 9 nothing. We've just got the draft EHCP, I don't know how to name a provision. She can't get into the school building, nothing has overcome what is almost a phobia of school. All education has become a no no!

What did you enjoy about the Surrey Choices session?

'It was very useful and informative. It's good to know that Surrey Choices cater for different levels of readiness to work and they seem to be very well connected and professional. The only thing I would have liked to hear from them but didn't really was a deliberate effort to forge friendships via shared activities with a view to creating a peer group necessary for people to combat loneliness and thrive. It sounded as if the social side was an optional extra if you were sociable enough to join whatever activity in the first place. I have no faith whatsoever in adult social care ever funding anything, not because we are not in need, but because of the people, whose children are in obvious need, who are shockingly turned away from adult social services with no reasonable explanation why. So my heart literally sank when I heard the route in to Surrey Choices, if the EHCP has expired (which Surrey generally try to do by 19 apparently) was via adult social care i.e. a door slammed in the face. Anyway there is hope. DWP fund Surrey Choices (currently) What joy!'

'The Surrey Choices presentation was very interesting and Louise Hayes was very knowledgeable and easy to listen to. The slides were also very useful.'

I have two children, the eldest is 17, is ASD, is transgender, fell apart in secondary, is now doing really well with Surrey Choices. School isn't for everyone. My 10 year-old is also ASD and was out of school for 1 ½ years. She's now started at Aurora and it's amazing, totally at her pace, a totally bespoke programme with a 1:1. The trauma she'd had prior was so extreme that's what was needed.

How helpful do you find the FVS 16+ group emails?

'I find the email very useful and the reminders especially!'

'Very useful when we get talk PowerPoints sent through from the sessions. Obviously emailed links to the sessions are required.'

After my son being unauthorized for an entire year, school was being misled by the local authority. They said if you produce a consultant letter mentioning anxiety we'll authorize it. They've plucked this out of thin air, it's a punitive requirement. The LGO says once 15 days absence is up, the duty of provision is on the local authority. So why is Surrey still getting away with pushing things back to schools?

Family Voice Surrey Monthly Overview

Mum, what special school am I going to go to next year? All my friends at school know where they are going to next year, why can't I know? I am worried.

I can't even talk to anyone or see anyone or go out anywhere if I feel ill.

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

No one understands me!



Parent Carer Quotes

I have yesterday attended the movie night. (Burview Hall) The hall is very nice and clean and they have sensory room if any kid get uncomfortable. Most people attended were adults with needs. We were the youngest. Would be nice to see some familiar faces, but I wanted to try as we do not go cinema due to his needs. This is great alternative. Screen is huge and is not so noisy as cinema. It only cost £4, as she took me and my daughter as young career. I would pay £21 in cinema.

It's frustrating that little things can't be put in place that will make such a difference to children.

When schools say absence is unauthorized then it makes it even harder to get provision. Surrey inclusion officers tell schools to record EBSNA absence as unauthorized.

Early intervention makes such a big difference

There's a high number of people in the criminal justice system who have additional needs.

The last time I drove my son to school he was headbutting the dashboard so hard that he left a mark.

The inclusion officers' task seems to be to lump everything back onto the school. Schools are caught in no-mans land with the local authority giving no support.

I wish my child's potential wasn't limited by the system that tries to put them in a box

He (*child*) would never have looked at that bird if you (*me*) hadn't reinforced your language with sign

Family Voice Surrey Monthly Overview

My son is 4, he is in reception mainstream school he has an EHCP. He is there only 3h but he cannot settle. I saw other school with high coin but only covers 3h morning in separate room where my son already is. Other schools are too far, I am very disappointed by system, not with school. Special needs kids are being ignored and invisible and so is their parents.

We've not had much success with the virtual school.

The only way you get adult social care support is if you throw your child out, and I'm not prepared to do that.

My daughter puzzles people as she's academically quite bright but her needs are very complex, they don't know what to do.

I don't like the phrase EBSNA – it implies the child is not enough.

An internship was offered but there isn't really much choice or effort put into making sure it matches with what the young person wants to do.

My 4yr old son started reception in September after a long-winded fight with SCC. His EHCP deems his needs as CSCN but currently attending a LAN school in Leatherhead. The mainstream school my son was going to attend because his sister is there were massively overwhelmed by the challenges he would face if attending their school and the amount of support he would require.





I always knew my son wasn't going to attend a mainstream setting, but it was a case of finding a more appropriate setting for his needs.

Mainstream schools with COIN units usually only cover morning hours and to find a unit that takes from 4-11yrs are in short supply.

Totally agree [with the article by the Independent titled "Schools need more specialist help for primary-age children with additional needs"]. But this has been an issue for years my daughter is now 26 and nothing has change. I feel it has got harder for parents.

I'm concerned by parents whose children so obviously need adult social care being turned away so am concerned that adult social care will never be there to fund anything at all.

Events held this month*

					
18th October	ADHD/ASD chat	11	9th November	School Anxiety Group	9
1st November	Neurographica - Draw yourself happy! <i>In Person Event</i>	6	9th November	Transition to secondary school	6
7th November	16+ group - Pathways to Employment	10	10th November	Neurographica - Draw yourself happy! <i>In Person Event</i>	5

* 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
Autism Strategy	Within the Autism Strategy we are planning an event in February 2023 for professionals and in particular schools to raise awareness of masking in autistic girls. There is also work happening to raise more awareness and understanding of CYP with a PDA profile.
EHCP Process	We have recently given feedback on new paperwork that is being rolled out for annual reviews. We hope the new format will make the process a lot clearer and ensure key information is included. We are planning to do a recording on this in the very near future.
SEND Transport	Our survey which closes on the 25 th November has had over 250 responses, we will be using the data from this survey to work with the transport team to ensure the stressful experience that many parent carers had this year is not repeated. There is also a lesson learned review happening withing the local authority and this will be presented to the select committee in December. We have fed into this review with the parent carer experience that we have been hearing, and we hope that the steps that we have asked for to improve the service will be actioned as a result of the review. We will update our parent carer members as this progresses.

Family Voice Surrey Monthly Overview

Quantitative data project	<p>It was lovely to see so many Parent Carers at our event last week and speak to them about their journey and frustrations. What became very clear is the challenges they face around communications, especially with their Case Officers. We heard lots of examples of where case workers had left, gone on maternity leave or even long-term absence and nobody had informed the Parent Carer, resulting in confusion, frustration and unnecessary delays.</p> <p>As a result, I think it would be a good topic for our next Quantitative Data Survey. This is due out in January so if you have any ideas or thoughts about questions to be include, please email myself or Lucy before the end of the year Kate.g@familyvoicesurrey.org</p>
Mindworks	<p>As you will be aware from last month’s update a new school-based needs system has been put into place to help understand a child's needs as early as possible and get them the right support at the earliest opportunity.</p> <p>Anna Dawson, FVS Coordinator, attended Surrey’s Neurodevelopmental service meeting which focused on how the new schools’-based system for referrals is going. It was launched on 31st October with the aim of assessing needs and getting parent carers help to meet their child’s ND needs whilst waiting for or without having to wait for a diagnosis. Early feedback suggests that SENDCos are making lots of referrals and finding it an easy system to use.</p> <p>If you are a parent carer who has been through this new system (i.e., a needs referral has been done by the school since 31 October), we’d love to hear from you. How has it worked out for you, do you have any concerns or feedback about this way of getting your child’s needs met? More information on the new way to request help https://www.mindworks-surrey.org/our-services/neurodevelopmental-services/support-families</p>

Meetings attended

Project	Information
Short Breaks	Short breaks evaluation and moderation sessions
Health	LDA Keyworker project meeting X3
Health	Better start transformation board
EWMH	Mindworks and Family Voice monthly Meeting
EWMH	SEMH focus group SCC

Health	Healthy schools Steering group
EWMH	Time for Parents Meeting with Surrey Youth Focus
Health	Health inequality call with DCO's
Social Care	Social Care Mapping meeting
Health	School based offer meeting with Rebecca Scarth
EWMH	Suicide prevention meeting
Local Offer	Tina Cambell Family Centre meeting
EBSNA	Task and Finish group: Training and Resources
Autism	All Age Autism Strategy Focus Group
EHCP Process	KST Meeting
SEND Transport	Lessons Learnt Review Meeting
EBSNA	Action Card discussion
Alternative Provision	Alternative Provision Focus Group
Autism	AAA Workstream Meeting
Autism	Autistic Girls event planning meeting
Autism	AAA Monthly Operational Meeting
Autism	PDA Discussion
Autism	AAA Implementation Board
Communication	Family Voice and CFLLC SC Quarterly Meeting
Autism	CYP Autism Partnership Board
Transport	Transport 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

Family Voice Surrey Monthly Overview

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	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 – they 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
FASD	Foetal Alcohol Spectrum Disorder	SWP	Surrey Wellbeing Partnership
GRT	Gypsy, Roma and Traveller community	SYF	Surrey Youth Focus
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	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
Local Offer	Most often used to refer to the website that gives information on SEND provision in Surrey		