



Monthly Overview: Nov 21st 2022 – Jan 13th 2023

**New FVS members:
52**

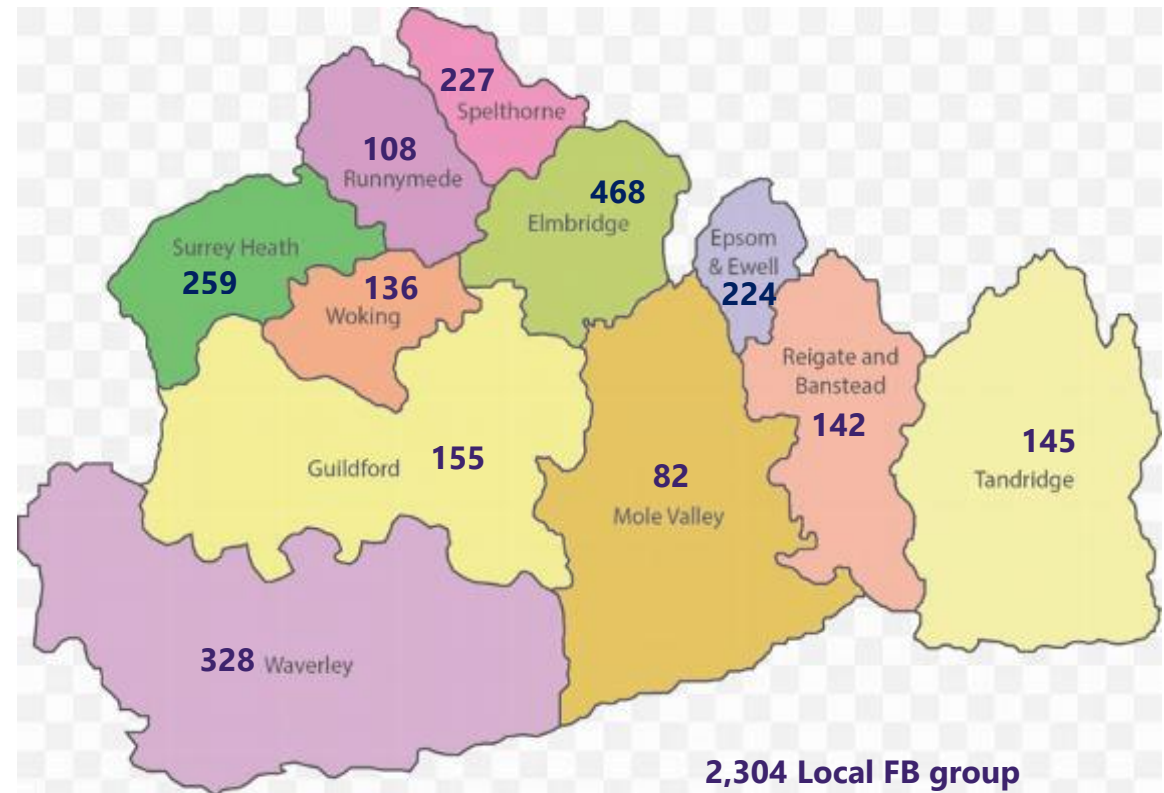
Facebook page likes: 2,837
Facebook closed parent group members: 819
Combined local Facebook group membership: 2,304
Twitter followers: 1,887

**Members who
attended an event: 72**

**If you have a suggestion
to make to the FVS Team
then use our new
suggestion box ...**

This suggestion box is for any comments and suggestions you feel can help us as an organisation to improve and work more efficiently and effectively. Use the below link to send in a suggestion.

[FVS Suggestion Box Survey \(surveymonkey.co.uk\)](https://surveymonkey.co.uk)



**2,304 Local FB group
membership**

What we have heard

Schools treating children in ways that are disrespectful and discriminatory

Difficulty accessing assessments for ND and waiting lists

Parents feeling bad as others don't understand their parenting style

Parents don't find information so easily available and are very glad to have FVS to rely on.

Parents feel isolated and stressed

Communication problems

Parents need parents to talk to!

My house is freezing, I love my cosy Tuesdays at Heroes

Parents are not being supported when transitioning to Secondary School. They just don't know which schools to choose.

Lack of Caseworkers

One of the biggest regrets of my whole life is sending my son to school. The damage was enormous.

Very little and sometimes no psychiatrists available for medication review

Interestingly our nursery SENCO told me that she had heard of nurseries just saying they have 'no space' instead of providing.

Quotes from some of the FVS events

Wellbeing events quotes

'I really enjoyed the event. It was good to socialise with other local SEN parents.'

'I would definitely be interested in attending more events like this.'

'I so enjoyed the session and meeting some new faces.'

'It was well organised, friendly and Rosie made us feel very comfortable.'

'After a very challenging week it really helped me feel more grounded and rested.'

'Having a planned event to attend enabled me to have some time out for myself to relax, really enjoyed the peace and calm.'

'It was well organised and everything seemed to have been thought out and catered for.'

'It helped me to do something for myself which I never do.'

'The yoga helped my stress levels, I need to do more of this in order to look after myself as have neglected to do so for too long.'

years of psychotherapy nearly sorted in 3 hours"

16+ group monthly Zoom session quotes

'The WhatsApp group has been really helpful and has pushed me to get the transition team on board.'

'The WhatsApp group is there when you need help right away.'

'The specific groups that Family Voice run are really helpful.'

'We've applied to the halow project. I'm hopeful. That's a result of the [16+ group] FVS talk which I came to.'

'We're preparing for transition to adulthood and realising there's a lot to think about and prepare for.'

'I've learnt quite a lot from this group and the WhatsApp group is really helpful.'

'We're thinking a lot about wills and trust, it's finding the headspace for it. I'm lacking the confidence that everything's going to be alright.'

'There's no transition service for health, so I'm not sure what will happen.'

'We were told by CAMHS that they couldn't adapt anything for my son as they had to treat everyone the same.'

'We've had a social care assessment from the Transitions Team and it was actually good. They seem to be offering quite a lot of respite for us. I was pleasantly surprised. She seemed to really get it. The whole thing was positive. Previous experiences have been negative.'

'It's not knowing the processes - and making sure everything's done on time.'

'Theoretically, adult services should be based around what a person wants.'

'I've said I'm unwilling and unable to look after my son at home once he finishes college. He needs a peer group at a residential placement so that he can be more independent.'

'I'm ready for my life back.'

'We were given 3 ½ hours per week respite with Crossroads, but it stopped because of Covid. We're back to it now, but it's limited to just 10 sessions and then it stops. I don't know why.'

'If you have a child you're lucky to get any respite care.'

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

In trying to work out the root of my child's intense school anxiety I asked about the staff who support her, and in relation to one member of staff my daughter said, 'She is cruel. Why is she working in a school, she should be working in a prison'

I love going to horse therapy, it is much better than going to school. Why can't every school have horses?

I can't revise. It's impossible.

In describing school my child uses one word – **horrible**.

I don't want to talk about school (and lays face down on the floor (flopping))

Anecdote – Two non-verbal children of different ages have formed a relationship in the playground. X who is interested in insects, found a worm and gave it to Y as a present. This demonstrates subtle communication and care between peers.

Having someone to listen to me really helps me

I don't want to go to school: I am tired of being told what to do all the time.



Parent Carer Quotes

'CAMHS didn't do anything, I had a child in crisis, suicide attempts, it was very difficult.'

Families don't know what they don't know.

My daughter did well in her SATs but she was stressed. When she went to high school it all went pear-shaped. She then went to a PRU, it was a lifeline until she got a specialist placement. But we're not suddenly out of the water, she has good days and bad days.

Even when it's over the experience s{of the SEN system) stays with you.

To get anything you need to send numerous emails and often submit formal complaints as well

My child's specialist school assure me that they understand PDA but in the next breath refuse to let my child have any voice when it comes to support plans arguing that they are the experts. The ignorance and intransigence displayed in this and other comments they make is so profound it is difficult to know how to start a conversation with them.

Thank you for all the work you are putting in to help parents of young people with SEN.

I might (join you for the Wellness event) but would probably just cry into my coffee!

My PDA daughter (now year 10) is at a mainstream secondary and they have been brilliant. She had half a term of no school (except a robotics after school club) and then half a term of random lessons she could cope with, then a year of 60% attendance and she dropped German, history and RS and now managing about 80% attendance and she can leave at 1pm every Friday. We haven't got an EHCP but the school have been flexible and listened to us.

Family Voice Surrey Monthly Overview

'We had a huge struggle getting school to accept my daughter had any issues, because she was masking. Support was only put in place once she stopped attending school. The placement broke down. The trauma caused by being out of school, you can't fix that overnight.'

'My son's been having sessions with Mind Jam for about a year and he really enjoys it.'

One of my sons doesn't go out of the house. The likelihood of him engaging with anyone is very remote.

The years when things went wrong in mainstream were horrendous and the support just wasn't there. I was unprepared for the hostility, professionals just didn't want us. Children with SEND are bad for business, they wanted us gone.

Even in a special school, some of their understanding of issues like masking is bizarre.

Signposting is all very well but there comes a point when we don't need signposting we need help.

We have an EOTAS package from Surrey. It's an ongoing battle really, with paperwork, funding and bureaucracy.

We wish the authorities knew the affect they have on the family due to they way SEND children and families are treated and not listened to, they are not following the law and it's us who suffer in the long run and society as a whole

We had a targeted youth support worker who was very nice but not experienced enough to actually help.

My son won't engage with counselling. CAMHS have written him off.

We've just got an EHCP approved, we're on the 3rd or 4th referral to CAMHS. My son just cannot focus and is on constant high alert. Also he has massive anxiety. He says to me constantly 'what's wrong with me?'

Family Voice Surrey Monthly Overview

**I should trust my instincts
(didn't ask permission)**

Signposting
is of limited
help, it gives
you a to-do
list.

If a child displays obviously in lots
of settings they get help sooner.

**ADHD is just a
difference. My son
says it's a disorder.**

The school is supposed to be
recruiting for a 1:1 but can't
find one. So now they've
emailed me suggesting a
specialist school. They can't do
that.

School doesn't know
what they're doing and
are causing more stress
than is necessary

The hounding by attendance officers was
unbelievable bullying – they wanted us to
deregister. I have had to have a very thick skin. If I
get fines and a criminal record, my children's
education comes first. I'm glad those days are
over. I feel sorry for people coming up behind
with special needs kids.



My son was 6 when I
stopped sending him to
school. He has very complex
needs.'

Social services are
crap and don't care
about families

My child's school have been great with
the EHCP process and are really helpful
and cooperating/listening to us which
has made it so much easier for us and
for my child

"There needs to be a lot more
funding allocated for special needs
not only for specialist schools but for
mainstream so they can identify early
and start early intervention, waiting
over 4 years for OT is not on!"

Events held this month*

		
22 nd Nov	Conversation with Sam Harris from Neurodive	21
29 th Nov	FASD Group	0
29 th Nov	Transition to secondary school	8
1 st Dec	Yoga for wellbeing - in person	8
5 th Dec	16+ group - General Chat	5
6 th Dec	Well-being and Mindfulness session IN PERSON EVENT	15
13 th Dec	PDA Group	8
14 th Dec	School Anxiety Group	7

* 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
Community Equipment meeting	<p>There was an update on a new online (searchable) catalogue has been launched to help residents access the right equipment and technology to suit their needs, helping them stay well at home and therefore less likely to be admitted to hospital.</p> <p>There is a lot of equipment and technology available to help make daily life easier for people who are struggling with everyday tasks at home. New technology or small changes to around the home can make the difference between living independently and needing someone to help. The new Home Equipment Finder has been developed to make it easier for residents to find information and give them, their families and carers options to hire or purchase equipment which suits their needs and help in making the right choices on the type of support they need.</p> <p>Residents can search via health need, room in the house or type of equipment to find practical solutions to fit their needs, from grab rails to help overcome physical barriers, to smart technology to help my daily life easier</p>

Family Voice Surrey Monthly Overview

	<p>There was also updated us that Millbrook Healthcare as your local provider of either Wheelchair Services or NHS Approved Repairs, will now operate under the name Ross Care. This appears to be a re branding decision</p>
<p>The Role of the Case Officer</p>	<p>We are just about to Launch the Role of the Case Officer Quantitative Data Survey and we really want to hear from as many families as possible about their experiences. This will allow us to create an action card with key recommendations so please share take a moment to complete to it for us over the coming weeks so it is truly reflective</p>
<p>Transport</p>	<p>We are continuing our discussions with the transport team and hope to be able to publish the response to our action card and the agreed recommendations in February. We are also working with them on a parent guide which we hope will be available by the end of this term. We were also pleased that transport is now going to feature in all KST letters. We gave feedback on the wording and we are pleased with the final version.</p>
<p>Autism</p>	<p>There is lots of activity happening within the autism strategy. We are delighted to be involved in an event called 'Behind the Mask' this event is for mainstream school leaders and is about understanding, identifying and supporting autistic girls (including those who identify as female and those assigned female at birth) who mask in mainstream schools. We will be running a workshop about the importance of listening and believing parent carers of autistic girls. All the workshops are being run by those with lived experience. The event sold out in less than a week and now has a waiting list for a follow up one so we are delighted it has had such an incredible response. If you would like to share your experience or if there are things that you as a parent carer of an autistic female would love schools to know please do email Leanne – leanne.h@familyvoice.org to help shape this important workshop. Thank you to those of you who have already emailed it has been an incredible response and will be so useful in developing the workshop.</p>
<p>EBSNA</p>	<p>We are pleased that there is a lot of activity happening with EBSNA and an increasing desire and interest in improving the experience for CYP and their families. Training is being delivered to schools by Educational Psychologists, they are keen to ensure the lived experience is reflected in this so they will coming along to one of the EBSNA groups to talk to parent carers – more details from Lucy will follow. There is also some other work being developed including a support plan, graduated response and local offer information, they will again be coming along to an EBSNA group to get feedback to ensure it is really reflective of the lived experience. Feedback will also be sought from children and young people.</p>

Meetings attended

Project	Information
Project	Information
Health	Children's Community Health recommissioning meeting
EWMH	FVS and EWMH Leadership meeting
Social Care	FVS and CWD meeting
Health	Monthly Surrey MHST IG meeting
Health	DCO Health meeting
Social Care	SE19 Joint SEND Strategic conversation
Health	Keyworker Lead Panel Meetings and interviews
Health	Community Equipment Meeting
EWMH	Comms SBN Meeting
EWMH	Mindworks Prototype review meeting
Social Care	CWD Working Together meeting
Health	Voice + VCSE Alliance meeting
PCF's	3 rd Sector AN Network meeting
EWMH	EWMH CYP EMWH & Suicide Prevention meeting
EBSNA	EBSNA Planning meeting
Autism	PDA Meeting
Transport	Transport action card meeting
Transport	Select Committee Meeting
EHCP Processes	Annual Review recording
PFA	PFA Program meeting
Autism	Autistic Girls masking event meeting
Autism	AAA Monthly Operations meeting
EHCP Processes	Mainstream Banding
Autism	Autistic Burnout/masking meeting
Inclusion	Ordinarily Available Meeting

EBSNA	EBSNA Training meeting
	3 rd Sector Additional Needs Meeting
	Surrey Safeguarding Children Partnership
Inclusion	Inclusion and Additional needs Steering Group
	Additional Needs and Disability Partnership Board
	Partnership Action Card meeting
PCF's	South East Regional NNPCF meeting
PCF's	SE19 Joint SEND Strategic Conversation

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 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

Family Voice Surrey Monthly Overview

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
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