



Monthly Overview: January 14th 2023 – February 17th

**New FVS members:
52**

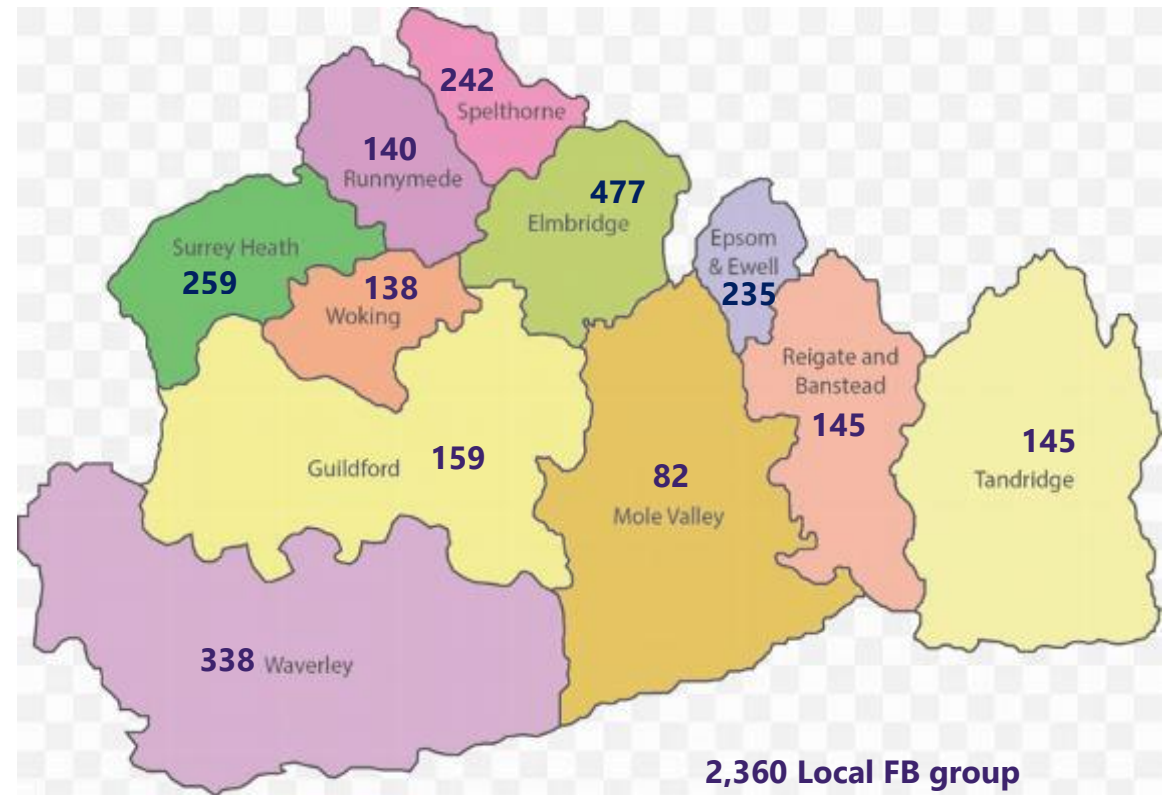
Facebook page likes: 2,887
Facebook closed parent group members: 824
Combined local Facebook group membership: 2,360
Twitter followers: 1,900

**Members who
attended an event:
144**

**Our Winter Survey closes on
Friday 3rd March – please
take a few minutes to
complete it and make your
voice part of the collective
feedback**

Use this link ...

<https://www.surveymonkey.co.uk/r/C562PRD>



**2,360 Local FB group
membership**

Family Voice Surrey Monthly Overview

What we have heard

**Process
first...child
last!**

Impossible to find specialist school that ticks all the boxes 😞

I wasn't offered any support or help; as a parent I don't get help

Should I tell my child about their diagnosis – and how should I tell them?

There's a whole glut of children who are falling between the cracks because they're not disabled enough.

It's taken two years to get anywhere with the Children With Disabilities team. Whatever team you're in you're just pushed from pillar to post and you're left to struggle. I just don't know how to go forward.

We're currently stuck between two teams. I have four children with significant needs. I've been up for two nights. Everyone says we need to be with the Children With Disabilities team. We're left in limbo. We need a significant level of care. We have no social worker.

What about when our children are getting worse, and we're left waiting for support?

FAS (Fetal Alcohol Syndrome) is not recognised, our own social worker doesn't know what it is, so how can they help?

Quotes from some of the FVS events

Autistic Burnout – online talk with Viv Dawes Autistic Advocate 17th January

Parent quotes: “Thank you, very interesting”
“That was brilliant, so comprehensive and useful”
“Really appreciate it and thanks for weaving in your personal journey”



PDA Group Chat – 31st January

Parent quotes:
“I am new to this (PDA) and I don't feel so on my own knowing other parents who understand.”
“How do I meet other Dad's? (SEN/PDA)”

Ponder over a Posy – Well-being Event 31st January

Parent quotes:

‘How wonderful it was to walk into a room that smelt of flowers. It is so important ...only those with SN children understand how tough and lonely it can be. Supporting each other is important and a necessity.’
‘Flowers are always uplifting’
‘As a grandmother with a ‘special’ granddaughter, today was so good to talk to other grannies and to have a social gathering whilst enjoying mindfulness making lovely posies. Such a lovely morning, thank you.’
‘Lovely morning, enjoyed flower arranging. James will enjoy giving to mummy.’
‘Fab idea, thank you Emily. I offer support to parents and carers’ (Early help SCC)

Q – what did you get from today?

A – encouragement, support, advice and laughter

Transition to Secondary School Event January 18th

With Katherine Everett (Education & Inclusion Service Manager for the NE Education and Lifelong Learning Children, Families & Learning SCC)

Points from the meeting:

- Many parents feel the EHCP is not implemented well in school and don't even know how to get this updated or what they are entitled to.
- What are the barriers we need to overcome to implement the EHCP.
- What is the ideal classroom a child can learn in, all of this needs to be in the passport to help the child transition well.
- What sensory support could be put in place?
- Teachers are particularly imaginative of thinking of different ways to engage children who struggle to follow cues.
- Children are not given time to process information.
- ‘Aspire project’ led by Kathrine Everette will be published at the end of the Spring term.

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

A PC told me that her child who is on the spectrum and struggles with now-and-then and with changes responds well to visual cues and the use of cards.
The kid said that he likes cards as "they are easy to understand what happens next and if there is any change."
Shame that the mother had to figure it out herself by trial and error because no professional told her!

The teachers say they understand the damage of masking but then they make us mask all the time, I got told off for crying when I was overwhelmed.

School doesn't cater properly at all for people with learning difficulties and I don't think that's going to be changing any time soon because of the government.

World is not made for people like me!

Child was so happy that they were meeting up with other kids who were 'just like them', in their out of school group.

Anecdote – 'X received a special delivery today (Feb 14th) – she was thrilled!' Children are 7 and 10, not in the same class and both preverbal.



Parent Carer Quotes

What do I do with my son if the school can't have him?

Thanks so much for all the advice and the chat, it was really helpful.

Thank you for the coffee and cake, it was lovely to have a chat and share information. Looking forward to the next one.

The school kept referring us to social services. There are serious safeguarding issues at school, and nobody looks and nobody cares. How can that gap be filled? Nobody cares.



I really appreciate meeting other parents on a similar journey to us, it's good to hear about their experiences and input.

Thanks to the FVS group for info on applying for an EHCP in person rather than through the school as we were told by them not to apply.

We've been refused an assessment [social care] time and time again.

It's great when you have people who are accommodating, I got the McDonalds so he could eat and watch (cinema) as I knew it would keep him still but even explaining that they said no 🙄. Yet let him eat it on the counter of the food.. didn't make sense but sometimes it's not worth stressing yourself over it.

Events held this month*

		
16/1/23	Intensive Interaction & Social Communication with Pam Smith (EH)	18
17/1/23	ADHD/Autism Group in conversation with Viv Dawes Autistic Advocate (SD)	25
18/1/23	Transition to Secondary School Group (NF)	10
25/2/23	In Person Mindfulness event for SEND parent carers (SD)	16
26/1/23	Neurographica: draw yourself happy! (In person event) (LT)	5
26/1/23	Coffee & Chat for Epsom and Ewell Families (AD)	3
27/1/23	FASD Online Chat Group (SD)	6
31/1/23	Mole Valley Health & Well Being Event (LT)	1
31/1/23	Runnymede Health & Well Being Event (EH)	31
31/1/23	Spelthorne in person Health & Well Being Event (LT)	5
31/1/23	PDA Chat Group (DP)	15
8/2/23	School anxiety and Avoidance Monthly Catch Up (LY)	9

* 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	The 'Behind the Mask' event took place on the 22/2 and it was a huge success. It was based entirely on lived experience and over 130 school leaders attended. We are waiting for the feedback and are repeating it in November. We will feedback more over the coming months.
Transport	The recommendations have now been agreed by cabinet which is great news. We are now working closely with transport team to develop the parent guide and ensure the changes happen.

Meetings attended

Project	Information
MULTI Professional Reference Group	
VCSE Alliance Meeting	
CYP EWMH suicide prevention	
Inspection focus group- health interventions and therapies	
Keyworker Lead interviews	
MPRG Service Specification weekly meeting	
SCC Early Years Send and FVS	
Supporting parents workshop	
Short Breaks Retendering meetings	
Inspection focus group- CAMHS	
Keyworker steering group meetings	
FVS and CFLLC quarterly meeting	
FVS and EWMH planning meeting	
CWD monthly catch up call	
Local offer planning meeting	
Surrey Safeguarding partnership meeting	
Social Care (PfA)	Developing a 16+ Social Care assessment + plan meeting
Social Care (PfA)	16+ Social Care assessment + care plan inaugural meeting
EWMH	ND Pathways Monthly meeting
Co-Production	Surrey CC Co-Production Charter meeting
Surrey SEND	Surrey Inclusion and Additional Needs Strategy Planning
Inclusion	Inclusion Steering Group meeting
Inclusion	OAP easy read guide development
EBSNA	Update meeting

Family Voice Surrey Monthly Overview

EHCP processes	Mainstream banding
Inclusion	You said we did
Autism	Behind the mask event
EBSNA	Training update
Autism	Workstream meeting
Early Years	Meeting to discuss working together
Autism	AAA Implementation Board
EHCP Process	Position statement
Transport	Parent Guide
Autism	Children and young people autism partnership board
Autism	AAA Task and finish group
Autism	Demand Avoidance
Inclusion	Co production charter
Inclusion	Partner Action card meeting
EWMH	MHST Deep Dive in-person event.

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

Family Voice Surrey Monthly Overview

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
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