



## Monthly Overview: June-July 2022

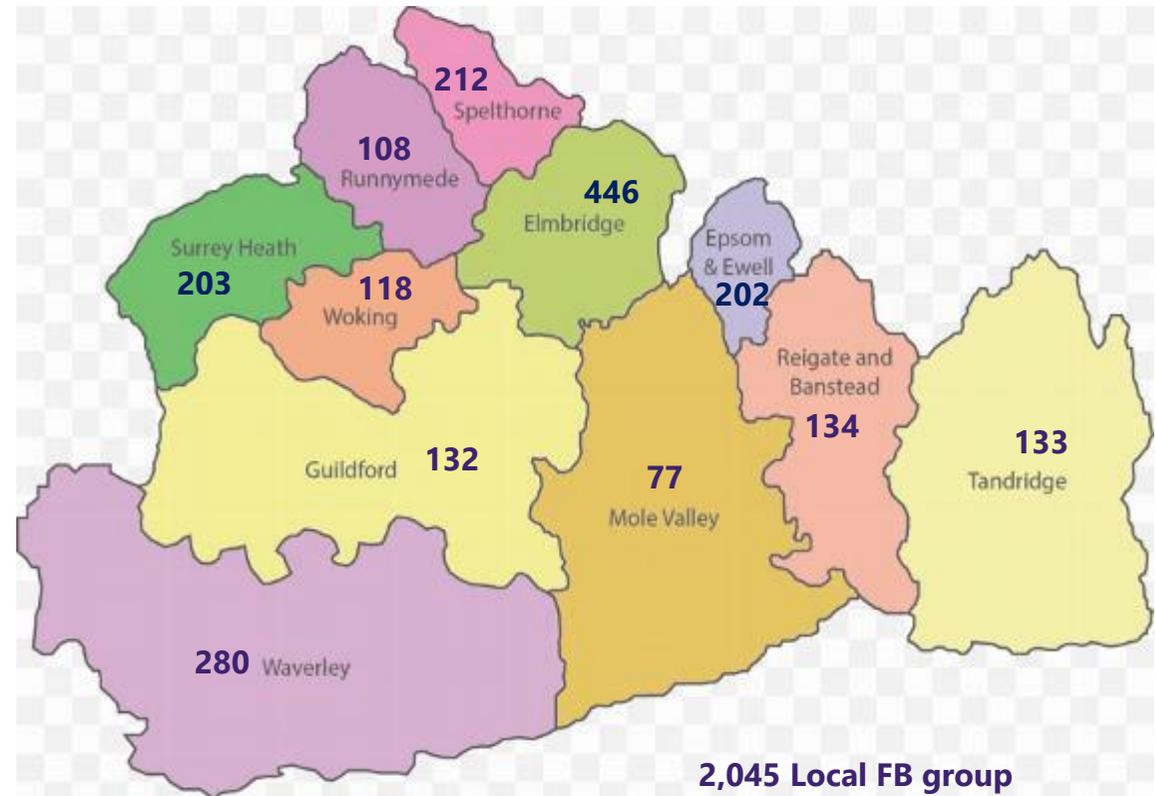
**Facebook page followers: 2,794**  
**Facebook closed parent group members: 760**  
**Combined local Facebook group membership: 2,045**  
**Twitter followers: 1,867**

**Members who  
attended an event:  
94**

**New FVS members:  
66**



All of us at FVS hope you are able to enjoy the Summer break. We will be running a skeleton staff over the next 6 weeks, but if you need to contact us please send us an email to [contact@familyvoicesurrey.org](mailto:contact@familyvoicesurrey.org) or call 01372 705708.



**2,045 Local FB group  
membership**

## What we have heard

My young person has multiple disabilities, he can't talk, but he has no physical disability, but we saw nobody from the transition team until he was 17.

We need to be signposted. Who do we go to? We don't know!

Early Years have SEND clinics very often. Surely the case officers should be able to do that?

My grandson is 20 and he's lived with us for 13 years.

I don't know what the transition team do. I've heard nothing from them. I didn't even know there was a transitions team. They need to be more visible.

It's like a puzzle where all the bits are on the table but there's no picture to follow and you just have to work it out.

**When there is an incident, schools seem to prefer blaming the child with special needs over the other children. This is not fair!**

I trusted her as she was my son's social worker and I thought she knew what to do. She kept reassuring me that she was on top of chasing the EHCP. I had a hell of a shock when I realised she didn't and the EHCP was a year out of date. What was the social worker doing? They wasted a whole year of not dealing with the EHCP or getting resources in place, he could have been getting home tutors in but all the time was wasted.

**The Surrey Youth Games was great fun this afternoon – thank you for posting about it. The kids did everything except the climbing wall and that was only because we ran out of time.**

Advice give is often very boundaried and not informed by specifics of individual situations.

A couple of times I have been told the case worker is the person who should trigger things, like adult social care or surrey choices. I'm not sure if this is directly or via transition team but it would be nice to have a list of what case officers should actually be doing in the grand scheme of things and when.

It's virtually impossible to get support from the CWD\* team.

\*CWD = Children With Disabilities

I spent 20 min yesterday on FVS website and I think that it is one of the most comprehensive and easiest to navigate website there is. Thanks to you guys for making it so easy for people to find information.

## Family Voice Surrey Monthly Overview

The SEND department at my school say I am no longer able to go to my safe place and sometimes I am being excluded for it.

It is tough not being able to access school at the moment because I have been excluded so much, I have really tried my best, but I still can't seem to get it right!

I am scared of the next year teacher: I don't know her, she is new to the school and she might be a zombie.

I love going to gym.

I love using my Ring Fit.

The TA in my class asked me if I had a problem or something!

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

Really liked the support dog that came into school, he was so fluffy and it made me happy.



## Parent Carer Quotes

What will I do when my child is 18, how will I work? There doesn't seem to be much on offer for them during the Summer Holidays?

His school is in London, a 40 minute drive so a bit difficult, his school are fantastic but I wish it was nearer to where we live

Why do we not know about organisations like Surrey Care Trust that are doing amazing work, it is so hard to find the help we need for our children?

Really appreciate the PDA group for comradery and shared experience.

Why do I feel gaslighted and put down by the school?

Why are these (Summer) activities only for Younger SEN Children? Where is the activities for teens, they don't magically stop struggling past 7 or 10.

**It seems such a trauma taking my child to school!**

My son is in reception. He has selective mutism and doesn't talk at school. The whole year has learnt Makaton as standard, which has been hugely important to building his confidence to communicate at school. His class teacher has gone a step further though and taught him to sign the phonics sounds so that he can learn to read and "read aloud" to his teacher. This is what inclusion looks like. 😊

When things are very tough, taking one day at a time. Picking your battles.

## Family Voice Surrey Monthly Overview

I don't know who designed the parent views survey, but it appears to be a tick box exercise rather than seeking parent views. The question about annual reviews is misleading. It asks about the AR meeting, but the meeting is only one part of the AR process and meaningless unless the EHCP is updated and required changes implemented. My eldest had AR in February but absolutely nothing since! The last question is how happy did you feel yesterday scale 0-10. That's the end! No support details for parents who feel 0 on the scale. I'm sorry but that says it all for my experience of Surrey.

"I'm just here today because I'm struggling a bit and wanted a quiet space."  
(Parent with 4 children, 3 with additional needs – all children are in school so she came to the drop in session in Chertsey alone)

Surrey couldn't get them anything in the Borough. I didn't think much of the school, very minimal facilities, so counting on the teaching there'  
(Parent with twins starting infant school in September in Slough).

I am not ok

**These groups keep me sane!**

Got a yes to assess, was gearing up for a fight but so far so good.

Why is it so hard to get support?

My son is in respite this week, I so needed the break, but I don't want to sit at home alone.

Really grateful to have found people who understand.

Things have been going so well and now it's like we have taken a step back again.

## Family Voice Surrey Monthly Overview

My daughter had a terrible year because of COVID. She's sort of doing work experience but nobody's responsible for her.

School caused my child PTSD

There just isn't a school for my child, what am I supposed to do?

Finally feel a shift at the school, they are starting to really get it.

We have waited 2 months for our ASD outreach report, why do things take so long?

My 17 year old has been diagnosed with autism. We have an EHCP but I don't know if it's worth the paper it's written on. He's extremely behind. He hasn't taken any exams. The case worker doesn't get back to me.

My case worker seems to not want to talk to me, they don't communicate what options there are available and parents are left to basically fend for themselves.

Everything about SCC is not fit for purpose.

My caseworker doesn't get back to me and I don't know what's going on.

I've only just started my SEN journey and I feel so over whelmed already.

You're always firefighting, dealing with what's going wrong... never planning, thinking of the next step is often impossible.

# Family Voice Surrey Monthly Overview

## Events held this month\*

					
21 <sup>st</sup> June	ADHD/ASD Group	12	5 <sup>th</sup> July	General Chat	5
23 <sup>rd</sup> June	Restrictive Food Intake Group	6	7 <sup>th</sup> July	Mentoring talk by Surrey Care Trust	20
24 <sup>th</sup> June	Foetal Alcohol Spectrum Disorder Group	4	11 <sup>th</sup> July	16+ group - General Chat	7
24 <sup>th</sup> June	<b>FB Live</b> - Sian Jones and Hannah Jackson from Surrey Care Trust talk about the Mentoring Programs they run across Surrey	n/a	12 <sup>th</sup> July	Downs Syndrome Group chat	2
29 <sup>th</sup> June	PDA group chat	7	13 <sup>th</sup> July	School anxiety and Avoidance Monthly Catch Up	25
			14 <sup>th</sup> July	Preparing for Adulthood event information gathering session	6

\* 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
EBSNA	There is now a working group with many professionals and the 3 <sup>rd</sup> sector, our recent survey has had great influence over the development and direction of this group, there is a lot of work to be done but it is refreshing to see the interest and commitment of Surrey officers to improve things for families experiencing EBSNA.
EHCP Process	We are delighted to be able to share our latest bite sized video – <b>EHCP Processes: The Draft Plan and The Plan.</b> <a href="https://www.youtube.com/watch?v=a1YQdF_-Ggs">https://www.youtube.com/watch?v=a1YQdF_-Ggs</a> Family Voice Surrey have produced a bite sized video on EHCP Processes: The Draft Plan and The Plan with the SEND team at Surrey CC. Kathrine and Jo are answering the questions that you have asked. We would love to hear your feedback of these

## Family Voice Surrey Monthly Overview

	<p>videos and your own experiences of draft and final plans as part of the EHCP process. If you have any further questions after watching the video please do send them in and we will do our best to get them answered. For questions and feedback please email - Leanne Henderson <a href="mailto:leanne.h@familyvoicesurrey.org">leanne.h@familyvoicesurrey.org</a> To share your experience of appealing to the SEND first tier tribunal please fill in a 'Tell Us Your Story' via our website <a href="https://www.familyvoicesurrey.org/tell-us-your-story">https://www.familyvoicesurrey.org/tell-us-your-story</a></p>
<b>Preparing for Adulthood</b>	<p>Save the Date! There will be a preparation for adulthood (PFA) event at Brooklands College on Saturday 15<sup>th</sup> October that we are co-hosting with the PFA team at Surrey. It will be an opportunity to find out more about PFA and hear from a range of speakers and organisations. More details to follow.</p>
<b>Transport</b>	<p>The new policy has now been published. We are working closely with the transport team on developing a parent guide which we hope will be available soon.</p>
<b>MindWorks</b>	<p>The Final copy of the Crisis Card has now been signed off and sent to print by MindWorks. This will be accompanied by a poster and a piece done with Sharren Bridges about her daughter Jen. The distribution of cards will begin with Health Centres and Hospitals in Surrey. We are then looking at schools and places in the community like libraries, coffee shops and sports centres. If anyone has any suggestions or contacts to support the distribution then please get in touch with Kate Goode <a href="mailto:kate.g@familyvoicesurrey.org">kate.g@familyvoicesurrey.org</a>.</p>
<b>Social Care</b>	<p>Having worked with the social care teams to produce the Social Care visual sheet, we have been made aware that some changes are coming in the near future to one of the services and they have asked us to hold fire on sharing currently. Although they are unable to share the details at this time we have asked for timescales, as we believe that families need to understand what is available to them now and if or when these changes come into place, we will amend the information to reflect this.</p>
<b>Health</b>	<p>A little while back Lara (FVS Spelthorne Coordinator) suggested we ask a local Leisure Centre to offer Carers a <b>FREE</b> day to access the facilities to rest, relax and restore. I'm delighted that Spelthorne and Sunbury Leisure Centre loved the idea and signed off a whole weekend in July. We are hoping that we will be able to roll this out to other Everywhere Active leisure centres in Surrey if the weekend is a success.</p>

## Meetings attended

Project	Information
EWMH	Emerge awareness meeting
EWMH	ND friendly schools meeting
Health	Problems with SEND health services
EWMH	FVS and Mindworks meeting
Short Breaks	Short Breaks outcome forum x2
Health	Tim Bates GP introductory meeting
EWMH	Mindworks Crisis card meeting
Local Offer	SEND Inspection meeting
Health	Safeguarding Partnership meeting
Health	HAF training
Social Care	Julia Katherine and FVS meeting
Health	Better start transformation board
Social Care	Time for kids believe meeting
Social Care	DCSO health and social care meeting with Diane Saunders
Social Care	Social Mapping meeting
Direct Payments	Direct Payments training course x2
Health	Child wellbeing meeting Active Surrey
Health	MHST meeting
L'spa	Surrey additional needs and disabilities partnership work stream
EWMH	ND monthly call
PFA	PFA Transformation Board
Transport	Parent Guide development meeting
Autism	Workstream lead meeting
Autism	Monthly meeting with Autism lead
EBSNA	EBSNA Working group

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Inclusion	SCC & FVS liaison meeting
Autism	AAA Education and PFA meeting
Inclusion	Mock Inspection on Inclusion
Early Years	Best Start for Surrey Transformation Board
SEMH	SEMH Steering Group
PFA	PFA Working group
Inclusion	OAP Provision Mapping
Inclusion	Inclusion Steering Group
EHCP Process	EYES Demo
EHCP Process	Video recording meeting
EHCP Process	Interview panel for Senior role in Surrey
Autism	Meeting with Autism Lead and parent
EHCP Process	Mock inspection with East Sussex
Inclusion	TAS Steering Group

### Glossary

<b>AAAS</b>	All age autism Strategy	<b>MHST</b>	Mental health support teams
<b>AP/Alternative Provision</b>	Education not provided in a school. Includes A2E, hospital school, virtual school, PRU, home tutors and more	<b>ND</b>	Neurodevelopmental
<b>CCHS</b>	Children's Community Health Service	<b>NEET</b>	Not in education, employment or training
<b>CFLLC</b>	Children, families and life long learning committee	<b>NNPCF</b>	National network of parent carer forums
<b>CwD</b>	Children with Disabilities social care team	<b>PBS</b>	Positive Behaviour support
<b>DA</b>	Domestic abuse	<b>PfA</b>	Preparation for Adulthood
<b>DCO</b>	Designated Clinical Officer	<b>RFID / ARFID</b>	Restrictive Food Intake Disorder / Avoidant Restrictive Food Intake Disorder

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