



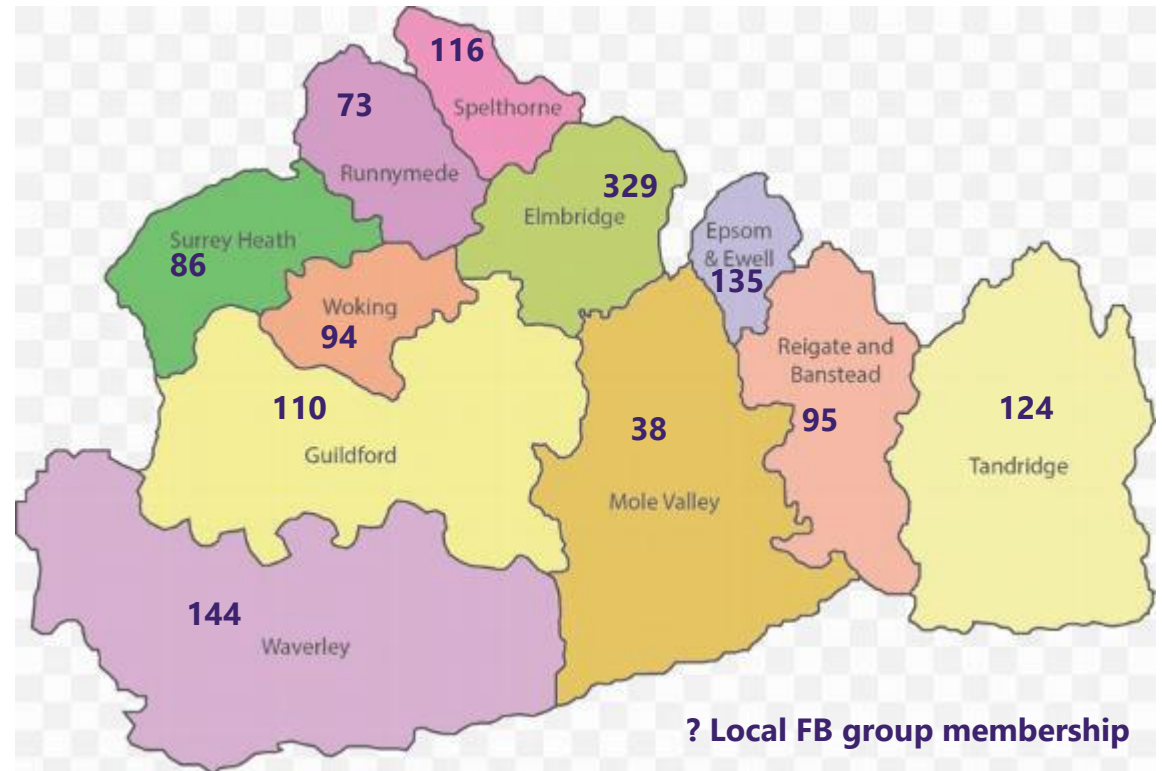
Monthly Overview: July, August and September 2021

Facebook page followers: 2556
Facebook closed parent group members: 641
Combined local Facebook group membership: 1376
Twitter followers: 1811

Members who attended an event: 125

New FVS members: 64

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



What we have heard

Action for Carers

Parent Carers asked questions including: how to obtain ADHD medication if you have a private diagnosis - A4C have an expert in this area called Nicole.

GP Carers Prescription.

Helped can be given with Tribunals for DLA/benefits.

An Event Report is being produced and copies of Powerpoint available for members that wish to have a copy.

When we are meeting in person again, we will explore the opportunity of pairing up with A4C when they hold their local coffee mornings.

Transport

If a child is unable to attend school due to delay in transport allocation, what are the legal ramifications? Is that child listed as absent until transport is arranged?

General chats

Enjoyed the chance to chat, finds these chats a good way to meet people

School anxiety

Lots of ongoing chat in the WhatsApp group. Several cases where panels are making decisions which contradict all advice from professionals. As ever lack of recognition of issues until crisis is hit.

PfA talk

Parents have no idea what is available for each stage of the process and it is so much looking for yourself which is confusing and time consuming, we need an easy read flow chart to see what is out there.

A parent is struggling to get an EHCP for her child who is now past 18, it seems much harder to get it at this stage, but she needs it to get the help she needs.

Downs Syndrome

Parents of children with Downs Syndrome are really concerned that they are slipping through the system once their children reach the age of 18. They cannot access any of the services like day centres, respite, etc without a Social Worker, but social services won't help their children because they say they are too well. Unless children are severely disabled, parents cannot get the help they need. This is really a problem, and it is also very draining on the parents who constantly have to fight to get the help they need for their children. Other than that, we discussed many different issues, and it was a very helpful session to the parents. The parents said they liked it because it was relaxed.

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“I had to educate the school in what they had to do.”

There are very few weekend activities for SEND toddlers

Social workers don't know what services are available

I'd like to thank Waverley Family Voice for all the help and advice. As parents of SEND children it's easy to feel alone with all the battles to get our kids all the support they need. I really appreciate all the support I've received, especially Sara. Thank you.

Using Access to Education has been very positive for the child, once everything was in place it is working well.

applying for senior schools and have emailed 3 schools about SEN friendly school visits but only 1 has replied

Very good service from Surrey continence team - they called ME, to check the products were still ok for my child! +++++

I love my new teacher because she doesn't shout at me”

I am a single mother with two SEND children and I am struggling to juggle care and job because I have little support.

Zoom calls are really working -



“I have to say thank you for all of you, because I get so many advice and support. And just the feeling that you are not alone is great!”

Restrictive Food Intake
not enough support for children and it takes so long to see a specialist



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Events

					
19th July	'16+ Group' evening	12	18th Aug	'General coffee and chat'	3
21st July	'General Chat'	4	20th Aug	'New school placement chat'	0
22nd July	'Family Voice Chat with SEND Transport'	5+7*	24th Aug	'Talk on restrictive food'	3
27th July	'Day in the Life of ...'	7	1st Sep	'General Chat'	1 dad
27th July	'Discussion group on restrictive food intake'	5	3 rd Sep	FB Live: accessible sport	95
28th July	'General Chat'	4	6th Sep	'Global Developmental Delay - Drop in	0
30th July	FB Live chat with Sabrina from ATLAS	66	7th Sep	'General Chat'	1
4 th Aug	'General coffee and chat'	0	8th Sep	'School Anxiety Chat'	16
6th August	'Q&A with Rachael Wardell – DCS FB live '	359	13th Sep	'PFA event with Eamonn Gilbert and Steve Hook'	22
10th Aug	'PDA Group – with Laura Kerbey- PAST' evening	10	14th Sep	PDA group chat and intro to Mindjam'	7
11th Aug	'Network Interventions and the Bridge Flexi School'	5	15th Sep	'General Chat'	0
			16th Sep	'Meet Action for Carers'	6+4*

* 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
Early Years	<p>FVS are very excited to be running their annual event on Early Years. It will run throughout the week commencing 15th November, and it will have a range of different events with speakers who will be doing presentations, discussions and Q&A'S. The event will be running virtually so they hope many of you will be able to join them for as much or as little as you can. They want to ensure that they are covering the topics that really matter to families, so if there is anything specific around early years that you would love to find out more about please do let them know and FVS will do their best to put it in there, or if there are any questions about early years you would love to have answered please email Leanne - leanne.h@familyvoicesurrey.org.</p> <p>We are delighted to be re starting our monthly 0-4 group which will be hosted by Jenny – Mole Valley Coordinator and Emily – Runnymede coordinator and Leanne – Participation Manager will be supporting the group. More details will follow soon and we look forward to seeing you there.</p>
Transport	<p>FVS are currently working with the Surrey SEND transport department to bring parent carer experiences to the attention of the team and offer feedback on the systems and processes currently in place. We are aware that many of you have had real difficulties with communication from the transport team and we have been working hard to try and get the problems solved. We will be working with them to try and find new ways to ensure this improves significantly for future cohorts. The more voices they have the more impact they have so they would love to hear from you if:</p> <ul style="list-style-type: none"> • You have recently applied for transport • Your child or young person is about to start using transport for the first time • You have been using transport for a few years • You are about to apply for transport. <p>If you would be happy to share your experience which would be anonymised please do get in touch with Leanne leanne.h@familyvoicesurrey.org</p>

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PFA	<p>We had our follow on virtual coffee morning on the 16th September where Eamonn Gilbert- Assistant Director SEND & LAC Commissioning and Steve Hooke Assistant Director for Learning Disabilities, Autism and Transition will be coming along to update you on the Preparing for Adulthood program and answering any questions.</p> <p>We are very excited to be involved in an event that is being planned. It is going to be held at East Surrey College on the morning of Saturday 6th November 2021, there will be a range of speakers and stalls with information on preparing for adulthood. We really hope many of you can come along, more details will be following soon. As part of the event we are hoping to hold a panel type discussion to cover some of the areas that are of most interest and importance to young people and their families so if you have something that you would really like to hear more about please do get in touch with Leanne – Leanne.h@familyvoicesurrey.org.</p>
Autism	<p>The strategy has been published this month and we are really excited to tell you more about it. We are holding an event on the 7th October at 10.30am. We have currently got Tom Moore Senior Commissioning Manager, County Autism Lead Surrey County Council and Christina Earl - Head of Innovation and Business Development at Surrey Choices who is co leading on the employment workstream coming along to tell us more about the strategy and to answer any questions. If you would like to book a place please do get in contact with Sara - waverley@familyvoicesurrey.org</p>
EHCP Processes	<p>FVS are planning some webinars with Surrey and they are keen to ensure they are centred around what is important to families, so they would love to hear from you with any questions you may have about:</p> <ul style="list-style-type: none"> • The Role of a SEND Case Officer? • The EHCP Process? <p>FVS will not be able to answer any personal questions, so please keep them general and email them to Leanne - leanne.h@familyvoicesurrey.org</p> <p>Thank you so much to all of you who posted questions on the Facebook page please do add more if you think of them it will remain open until the end of September so the more the merrier!</p>

Meetings attended

Alternative Provision Strategy Update Meeting	Surrey Safeguarding partnership
Comms and Engagement Working Group	Short Breaks Strategic Forum
Workstream Leads Meeting	EWMH Alliance website
Webinar Planning	ND Pathway transformation
Annual Event Planning	Directors catch up
Community Equipment Group	SEND Advice Surrey catch up
National Autism and Disability strategy partner discussion	Short Breaks Strategic Review: Transitions workstream
ASD workstream planning	ASD Strategic Board
SSCP Engagement and Communications group	Surrey Heartlands patient voice committee design
School anxiety collaboration	Autism interventions offer
Working with parents/carers of children with SEND in the Early Years	CwD leadership meeting
Introduction to new assistant directors	Early Years meeting with National Autistic Society
DCO catch up	Disabled Facilities Grant meeting with Cerebra
Literacy Practice	Learning Disability Partnership Board
Introduction to newly elected members	CCHS: Health inequalities
Local Offer catch up	PfA Transformation Board
EWMH planning	Invision training
Carers partnership group	SEND Network planning
LSPA catch up	Wheelchair services issues discussion
SYF catch up	Children and Youth Charities CEO meeting
Health digital navigator	Inclusion steering group

Glossary

SEND	special educational needs and disability	Schools forum	A representative body of schools who discuss and make decisions about schools funding. FVS is the SEND representative on the forum
NNPCF	National network of parent carer forums	EHCP	Education, health and care plan
Alternative Provision	Education not provided in a school. Includes A2E, hospital school, virtual school, PRU, home tutors and more	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	DCS	Director for Children's Services
DfE/NHSE	Department for Education, NHS England	SaBP	Surrey and Borders Partnership Trust... deliver the mental health and neurodevelopmental assessment services
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	DA	Domestic abuse
SEMH	Social, emotional and mental health	DCO	Designated Clinical Officer
CwD	Children with disabilities social care team	SWP	Surrey Wellbeing Partnership
NEET	Not in education, employment or training	SSCP	Surrey Safeguarding Children's Partnership
SYF	Surrey Youth Focus	RFID ARFID	Restrictive Food Intake Disorder Avoidant Restrictive Food Intake Disorder
CChS	Children's Community Health Service		