



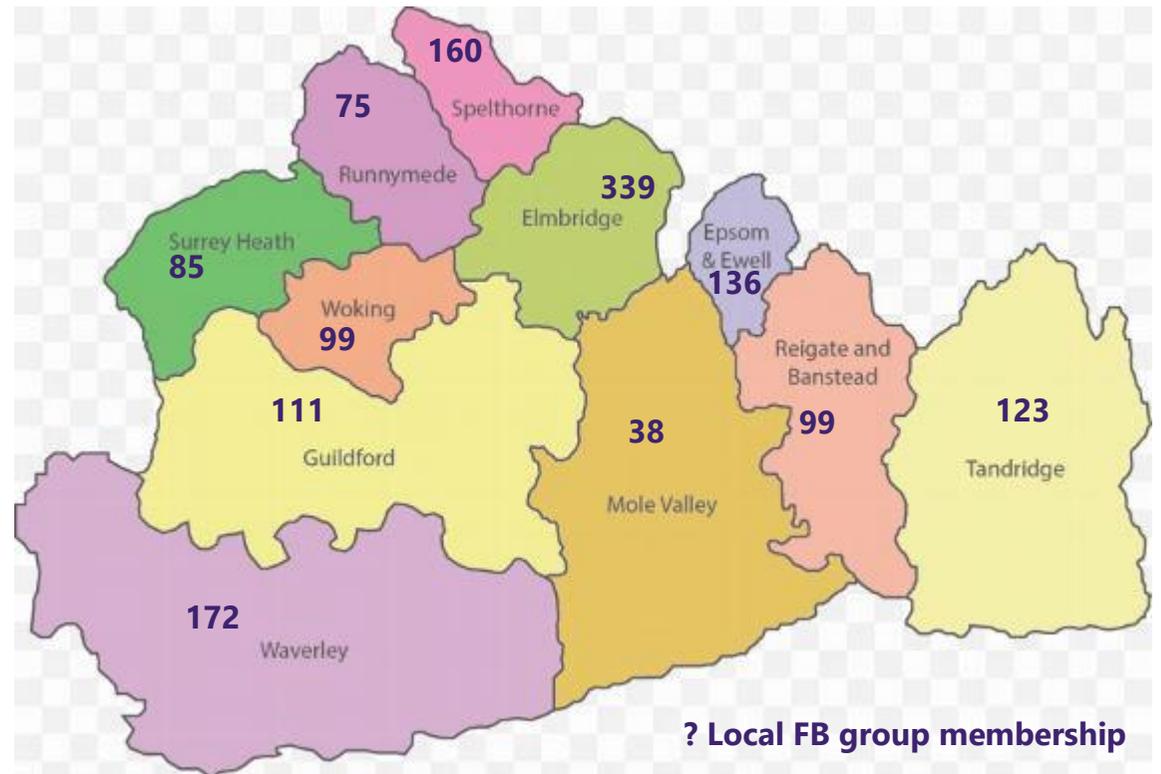
Monthly Overview: September - October 2021

Facebook page followers: 2211
 Facebook closed parent group members: 653
 Combined local Facebook group membership: 1443
 Twitter followers: 1823

Members who attended an event:
 70

New FVS members:
 33

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

When School isn't working...

We have a large group of parents whose children face great barriers to school attendance. 56 parents regularly attend a monthly session and share their experiences.

- A2E is useful, but often too little too late.
- A2E requiring consultant level medical evidence has been found to be unlawful but is still happening
- Delays during the referral process to A2E and then lack of communication means children are left with no provision for weeks or months.
- Inclusion officer telling a parent that she should not be taking work calls during school hours
- Welcome support from an inclusion officer, Lucy Bryant who “fought our corner”

Down's Syndrome

Parents feel very supported through childhood, but the 18th birthday feels like falling off a cliff. They feel a lack of support from social services, transport arrangements are a battle, and colleges don't respond.

EHCP Processes

- We are hearing stories that governance panels make decisions that contradict evidence, with poor if any justification
- We also hear from parents who have been told their case is being heard, but months go by with no news.
- Parents are told that the LA will only consult with 1 parental preference school

16+ Group – Short Breaks

Parents told us that “short breaks” is a confusing term. Many think it just covers respite. We had a lively discussion about the range of short breaks and activities for children and young people. This group highlighted the confusion at this age because there is a mismatch between services. EHCPs last till a young person is 25, but short breaks end at 18, with nothing apparently to fill the gap. Parents describe aht as a “deep dark hole”

Household Emergency Preparedness

Our speaker steered a discussion about how to make your family more resilient to emergencies.
“really helpful and insightful – I'm amazed we have got so far without a plan”

Healthwatch sought feedback about Mindworks

Parents expressed concern over the new service. They are still experiencing huge waiting lists... 2 years for children to be assessed. Children need to be suicidal to get any help at all and even that seems insufficient to access support. Services are not specialized enough for those with autism. Therapists ask questions in a way that makes it impossible for autistic children to give honest answers. Once an ASD diagnosis is given, you are discharged without help. There have been issues of confidentiality, with information sent to the wrong family. Families do not see evidence of early intervention. CAMHS services seem to adopt a wait and see approach that leads to children getting worse, and parents unable to leave their homes. “There is no support and families are completely breaking down”. CPT, ADHD and Stepping Up courses were described as great and extremely helpful. Parents told us that they were unable to get help for children who won't eat until it's “too late”.

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It was a shock that my son's transport timing was being changed for the second time. It seems that no one is hearing us

When can we meet face to face for coffee?

Mother referred by Spelthorne Social Prescriber:
FVS has really made a positive difference. . I felt very comfortable talking with Lara who clearly understood.

We are now on our 4th caseworker. They have all been rubbish. They don't send us what they are supposed to, forget, say they will do it and forget again, over and over. But it is what it is I guess

Spelthorne Social Prescriber:
It is invaluable for us to have an organisation (FVS) that we can refer to with confidence – many thanks

There is a gap for short breaks post 18 because there is nothing. Parents need Surrey to look at that big hole.

My child's updated EHCP is late yet again. SCC couldn't care less about the law, they're a complete joke

Restrictive food intake
I felt this group was really friendly, welcoming and supportive. It was such a relief to share my worries and fears with the group and to hear advice which was hugely helpful.

Some children at school make fun of me because I'm different

I have to self fund online education while I wait for my EHCP appeal because the LA isn't providing anything.

My son is routinely bullied at school about his condition. School is not too effective at curbing this...



My year 7 child still has no school placement. SCC talked about a learning package at home, but I have no update.

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Events

					
20 th Sep	16+ evening group Conrad Benefield SCC: Short Breaks	7	6 th Oct	General chat	3
21 st Sep	Chat on Restrictive food intake	3	7 th Oct	Autism Strategy update with Tom Moore, SCC, Susan Harris, SCC and Christina Earle, Surrey Choices	17+ 7*
23 rd Sep	Guildford meet up	0	8 th Oct	0-4 group	0
24 th Sep	Barbara Paulger SCC: Therapy Services in Surrey	4	8 th Oct	FB live: All Aboard Club	
28 th Sep	Household Emergency Preparedness	6	13 th Oct	School Anxiety group	10
30 th Sep	Emotional Wellbeing and Mental Health Service	9	14 th Oct	Downs Syndrome group	5
	Healthwatch Surrey		14 th Oct	PDA group	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
EHCP Processes	<ul style="list-style-type: none"> We are hoping to start recording the bitesized videos early in December for families on the EHCP process and the role of the case officer We are hoping to hear more about the new Alternative Provision strategy soon and we hope to be able to offer a parent carer perspective to this work.
Inclusion	<ul style="list-style-type: none"> We are involved in the working group for the Team Around The School which will be piloted over the next few months We will be involved in giving feedback on The Ordinarily Available that is being developed We are involved in the Literacy practice guidance We are working on some school anxiety work with Surrey Youth Focus
Autism	<ul style="list-style-type: none"> The strategy has now been published and implementation is underway. FVS will continue to co-lead on the Information, Awareness and Education and PFA workstreams We are working on some new guidance around ABA and other ASD strategies with Surrey
PfA	<ul style="list-style-type: none"> A PFA event is happening on the 6th November at East Surrey College FVS will be facilitating the panel discussion and having a stall
Transport	<ul style="list-style-type: none"> We are meeting regularly with the Service Manager to raise individual concerns if you have any parents experiencing difficulties with transport please ask them to email Leanne.h@familyvoicesurrey.org
EWMH Emotional Wellbeing and Mental Health	<ul style="list-style-type: none"> Mindworks surrey website launched and we are active in our feedback Now agreed to write out to everyone on CAMHS waiting list Paying Google to ensure it is easily found and accessible

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- The Google link will have (includes CAMHS) in brackets under the title on google for 6 months
- Jess Thoms doing Facebook live on 12th and coming to our team meeting on 5th Jan
- There is a Children and young person lead on launch and the team is looking for more young people to support their group- will re advertise this week
- We are starting to understand the school-based aspect and where they are at currently
- Would welcome any feedback people are experiencing in schools when looking for support and if they have used mindworks

Social Care

- Direct Payments have just started to be redesigned. Started Oct 2021. Monthly meetings till March 2022
- Looking to coproduce and get a wide range of input but deadline is very short -March 2022
- needs to look at flexibility, responsibilities, individual need and care of personal assistant

Short Breaks

Short Breaks is Recommissioning currently. Concludes April 2023

- Currently coming to the end of the feedback stage then moving into design workstreams in 2022
- FVS have attended and inputted into all short breaks review meetings
- Looking at factors like- signposting to short breaks, holiday clubs, after school and community-based activities, facilities/locations and fair coverage for families
- Working with gaps in activities with active surrey
- Short Breaks survey results due out imminently

Health

- Digital navigator Project- Will be doing a family feedback on 22nd November
- Agreed supported workstreams with Children's Community Health Service- Health inequalities, transitions, complex and long term needs
- Health inequality meetings commenced last month

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Local Offer

- Currently being redesigned. Working with Sian Lapwood and Michael Pipe to ensure language choice is clear and navigation of system is as easy as possible
- Michael Pipe doing a section on Early Years Event

Meetings attended

SEND Advice Surrey catch up	Transitions Workstream Community Health
SENDIASS steering group	Recommissioning workstream
Monthly catch up with Directors Liz Mills and Hayley Connor	Digital Navigator Patient Engagement
CFLLC Select Committee	Autism Strategy Update
Update on Mindworks website	Active Surrey Physical Activity Network Event
Literacy Practice Meeting	Health Inequalities design and Transformation Workstream
PFA Comms and Engagement working group	Healthwatch collaboration feedback meeting
Preparing for Adulthood Transformation Board	Carers Partnership Group
Inclusion Steering Group	LSPA catch up
Children and Young People's Autism Partnership Board	Wheelchair services update
Early Years Strategy Meeting	Short Breaks Strategic Forum
Autism Approaches Meeting	Children and Youth CEO s meeting
Information and Awareness Workstream	Team Around the School meetings
SSCP	Meeting West Sussex Parent Carer Forum
Children's Community Health service update	CYP Autism Partnership Board
SEND Inspection preparation	Consultation RE social care provision for autistic LAC
Short Breaks Recommissioning conversation	

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Early Years

- Our annual event is coming along really well, we have got some great speakers including:
 - Jane Gupta – Early Years Graduated Response
 - Pippa Gray and Kat Link – Early identification and the EYFS
 - Dr Kathryn Hollins – Parent well being
 - Trudy Mills – Update on Early Years and her role
 - Sally Rogers and Shellan Majid – CHES and Speech and Language
 - Susan Harris – Educational Psychology
 - Jo Neville – Health Visitor
 - Frida Meltcalfe – Surrey Libraries
 - Michael Pipe – Local Offer
 - Carol – Home Start
 - Gail – Contact – Money Matters
 - Yvonne Newbold - TBC
 - Dr Mark Brown – TBC

We have got a mix of presentations and Q&A sessions which we hope will be really successful. It is happening during the week of the 15th November and we encourage you to register here to get all updates

<https://www.eventbrite.co.uk/e/fvs-early-years-event-2021-tickets-159836359855> .

- We have also relaunched our 0-4 group (renamed Early Years Group) which is hosted by Emily and supported by Leanne. It is going to run on the second Friday of the month at 11am and the January one we have got someone from Surrey libraries coming along to do a SEN rhyme time!

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		