



Monthly Overview: April - May 2021

Facebook page followers: 2370
Facebook closed parent group members: 562
Combined local Facebook group membership: 1207
Twitter followers: 1757

Members who
attended an event:
103

New FVS members:
49

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

One member asked me to thank Family Voice Surrey for all their work with SCC on the Key Stage Transfer process. They felt that although they have not had the best treatment from Surrey that FVS have been supportive and they knew we were working hard on behalf of families.



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Talking to parent carers

	GOOD NEWS	BAD NEWS
Elmbridge <i>307 members</i>	covered by the wider team	
Guildford <i>102 FB members</i>	I've been talking to different people via Facebook and asking them if they would like to bring FV to their schools seems positive. Also parents would like to gather their Downs teens to young adults to try and build friendships for them. It is so helpful to have a lovely support network where people can share advice with each other and support each other. You also find out about many other great charities where you can get support for your child.	
Epsom & Ewell <i>125 members</i>	<ul style="list-style-type: none"> Families have reported great support from the FVS groups on offer. One family reported excellent support from their Paediatrician around their child's extended absence from school. 	The continuing punitive response to children being too anxious for school. Families require support and viable options to get children back to education in a timely manner (see Education question below).
Mole Valley <i>36 FB members</i>	covered by the wider team	
Reigate & Banstead <i>86 FB members</i>	Some positive stories of good impact once early help is involved.	<ul style="list-style-type: none"> Inconsistency of support that is put in place when a child is struggling, a matter of chance whether a school calls in early help or outreach etc. Parents being put off applying for an EHCP before key stage transfer and getting told to see how things go at the next stage – even when the child has been struggling for some time. Some are told they will have to wait until things go very wrong before applying for an EHCP. Many reports LA Professionals reports being very vague and unhelpful Concerns that the Local Authority message is the EHCP's should not go beyond 18 I was concerned to hear a SCC professional express the attitude that it is cheating or underhand to use measures such as putting in place a disabled persons trust to ensure protection of benefit entitlement for the young person as well as protecting them in general. I felt this displayed a failure to comprehend the vulnerability of SEN young people and worry for how this translates into the way that professional may deal with families. Attendance code problems
Runnymede <i>65 FB members</i>	covered by the wider team	
Spelthorne		Still 2 families who have not been given any update on Key Stage Transfer

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76 FB members		One family going through school exclusion with little help or support whilst child is out of placement. One family not receiving support to move and still being met with discrimination from private landlords requesting a whole years rent up front which would then not be reimbursed by Universal Credit.
Surrey Heath 78 FB members	covered by the wider team	
Tandridge 119 FB members	Parents are pleased about the targeted groups that we are hosting, eg 16+, single parents.	The transition from CAMHS to adult mental health services is very difficult and in some cases this means that vulnerable young people are left with no support at all.
Waverley 121 FB members	covered by the wider team	
Woking 92 FB members	More parents are aware of the rights for their kids/EHCP and are accessing the FVS groups and finding them helpful	

Events

					
21/4	General chat	6	1/5	SEN Single Parents group	3
22/4	Laura Kerbey on ADHD	14	5/5	Surrey Ed Psych Q&A	12
22/4	Down's syndrome support group	2	11/5-22/6	Shine Women empowerment ant self care	10
23/4	Generall chat	3	12/5	General chat	5
26/4	16+ support group	8	12/5	School anxiety chat	7
27/4	0=4 support group	1	13/5	Down's syndrome support group	2
29/4	General chat	0	13/5	PDA group	12
30/4	Autistic Wellbeing	22	14/5	General chat	4 + 2*

* Where registered members have not been able to attend (usually due to caring responsibilities, they often have access to recordings or slides.

Tell us your Story: We respond to each story and signpost where relevant. When issues are repeated, we feed those back to relevant leads in SCC and health, and will be using this overview document to inform you of progress.

13 Stories received through formal channels. This is separate to the general feedback received via our coffee mornings, events, and Facebook contact with parents.

Mental Health

- Psychiatrist turnover is too high and causes harm. But a thumbs up for Dr, Phil Ferreira-Lay
- Child left without appropriate assessment for 2 years due to poor communication between SENDCo and CAMHS, and parent not being included in communications.

EHCP

- The complexity of conditions involving chronic fatigue and ongoing misunderstandings throughout the system that increase the pressure on young people

School Concerns

We were contacted by 10 parents with concerns about one school. We collated the themes of concerns and are working to ensure that the matters are resolved to the families' satisfaction.

Answers to your questions

It has been a busy month and we have had some staff take annual leave at FVS. This has left us with a little lag, so the answers to parent questions asked in April will be a little delayed. We will update you as soon as we can. Thank you for your patience! But others from May are coming in fast 😊

Specialist provision for the academically able

Many parents would like to know what Surrey Maintained Special schools cater for Academically average to above average children (who need a full curriculum including separate science subjects, languages, humanities) when these children cannot manage in mainstream despite all inclusion efforts.

With reference to the previous question is there any provision in the plan to increase special school places for these children?

Re ASD/COIN for more academically able young people who will be taking GCSEs, Cabinet has already approved the following expansions under the SEND Capital Programme:

- 1. Betchwood Vale Academy (180 places NCY3-NCY14) delivered by DfE - new special Free School*
- 2. New ASD/COIN special Free school, west of county (200 places NCY0-NCY14), sponsor/s and site/s to be confirmed*
- 3. Limpsfield Grange (40 places NCY12-14)*
- 4. Three Rivers Academy secondary SEN Unit (30 places NCY7-NCY11)*

Property and I are exploring a number of other options for additional mainstream secondary SEN units specifically for ASD/COIN with providers and the DfE after half term.

I'm also meeting with all ASD/COIN special school headteachers at the end of June to look at sufficiency modelling over the next 10 years, so any views from Family Voice would be very much welcomed prior to that.

Questions from our members

School anxiety

1. Are there any plans to add an attendance code for anxiety or SEN related absence?

Parent carers whose children have school anxiety aren't all offered option of referral to A2E or St Peter's Hospital School. This has been due to Sencos not being aware of these options. Some families have become aware of them only via other FVS families. These services also appear to be very oversubscribed.

2. How is Surrey responding to the need for these placements?
3. How does this need relate to lack of access to CAMHS (due to the long waiting list) to support anxiety, or late diagnosis for ASD leading to inappropriate support in school ultimately escalating to school avoidance?
4. How is this issue being addressed systemically by education and health?

When a child or young person is out of school due to anxiety, families have experienced the LA as punitive. Standardised letters about attendance lack any understanding of the very real struggles families go through when a child is too anxious to attend school. Team around the Family/ Child meetings have also been experienced as meeting needs of professionals not families (the antithesis of what a TAF meeting should be) for example making a parent feel outnumbered by unknown professionals and not prioritising attendance of medical staff who know the young person best.

5. What are Attendance Officers and SEN officers doing to understand better the needs of children and the reasons why the school environment might be problematic and causing distress? And are they working together to improve this?

Egress

Parent carers have been expressing distrust about the use of Egress - because emails and documents do not stay available permanently, this has been seen as a means of being less than transparent about communication. To encourage greater trust, might it be possible to warn parents that documents are only available short term, so that they know to download or print off reports?

NEETs with SEND

Parents whose young people are not accessing education or employment do not know where to find information and advice. Where can they find this?

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Finance and Benefits

Where can parents find information on finances and benefits for their young people when they reach 18 years old?

Where can young people SEND accessible information about finance and benefits?

Growing up

What offer does Surrey have for young people with SEND over 19 years old to socialise and develop work skills?

Participation work

Project update

Project	Update
Preparation for Adulthood	We have been working with Surrey on the Preparing for Adulthood Strategy and will be organising a virtual coffee morning with parent carers to give an update on this work and an opportunity to ask any questions. There is also a young person engagement group that is commencing soon.
Transport	As Part of the work Surrey are doing to improve the way transport is managed Surrey have been putting in place many steps to make the process smoother for parent carers. They are keen for our feedback so more to follow on this soon.
Autism Strategy	Work on the Autism strategy continues and as we move closer to the implementation, we will be asking for regular feedback from parent carers to get an idea of what is working and what is not this will feed into the strategy over the five year rollout.
Early Years	FVS have continued to hold a monthly group for parent carers who have a child aged between 0-4 and invite different professionals into these groups to offer advice and support to parent carers. Home Start attended last month's session. We will be looking at how to structure these sessions going forward and will be asking parent carers what they feel will be most beneficial. We continue to attend the 0-4 SEND board feeding back on recommendations and have also attended the newly formed Early Years Strategy Steering Group to highlight the importance of parent carer voices being included within the strategy's development.
CAMHS/EWMH	FVS continue to meet with Learning Space who are leading on user voice and engagement to ensure parent carers are kept up to date with communication and are informed of development opportunities and events to discuss future services and ideas for change. They are currently working on the development of video resources where children, young people and parent carers can offer tips on what works well and strategies for positive interventions.
Short Breaks	FVS are working with the commissioning team to ensure engagement with parent carers continues and that parent carers are asked what they would like future services to look like. FVS continue to highlight the importance of short breaks for children, young people and their families, the impact any changes can have on families and gaps in provision.
Children's Community Health Service	We will be talking to the engagement team about the round table events and looking at what the next steps will be to ensure parent carer voices remain throughout the process of redesigning services. We have met with Healthwatch Surrey to discuss our work and plan to meet with them regularly to collaborate on key areas of work.

Meetings attended

<p>Family Voice DCO SCC Meeting ASD Strategy Workstream Leads SAIL (Surrey Appreciative Enquiry) Preparing for Adulthood Comms & Engagement Preparing for Adulthood Transformation Board Meeting about SEND Transport ASD Awareness, Understanding and Information Workstream Integrated Care Systems – what they mean for SEND and parent carer forums Education and Preparing For Adulthood Strand Leads Meeting</p>	<p>SEND 0-4 Project Board Monthly FVS/DCO/SCC meeting Healthwatch/FVS meeting SAIL briefing South East Regional NNPCF meeting Short Breaks Strategic Forum Qwell discussion and comms meeting SEMH Project Board meeting</p>
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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

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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		