



Monthly Overview: May - June 2021

Facebook page followers: 2416
Facebook closed parent group members: 562
Combined local Facebook group membership: 1239
Twitter followers: 1776

Members who attended an event: 131

New FVS members: 25

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



At the greatest time of need, we have been failed, doors closing in us, signposted to places that bounce us back and back. It's been exhausting, relentless and heartbreaking.

In a discussion on self-compassion, the group leader suggested that as parent carers we need to put our oxygen mask on before putting the mask on our children and the group members said they sometimes feel that 'there is no oxygen mask'. This illustrates how desperate some families feel.

These kind of meetings have been fantastic over the last 18 months because we've all been through this. It's the same story we're hearing. We've been through the same trauma

A group member asked if everyone had heard the story 'welcome to Holland' (about thinking you were off to Italy as a parent, but as a parent of a child with additional needs you were on a different journey, going to Holland), but that when your child has a PDA profile 'it's not Holland, it's Beirut'. Parents opened up about how hard it is when your child is struggling so much that they might hit out or be 'explosive' using the analogy of family life being like 'walking through a landmine field and waiting for the bomb to go off at any point'.

Monthly Overview May - June 2021

Parents are proud of their children for....

I'm proud of my daughter being able to do certain things more independently and love how her language is coming along xxx I'm proud the way my oldest son is going after his dream as a formula one driver and how he's just doing so well with his attitude in school, I'm proud that my middle son is working so hard on his Timestables and I'm proud of proud youngest son for working hard at his writing and doing extremely well in reading. So proud of them for working hard and just being who they are x

I'm proud of them for all the many times this year I've had to say something disappointing to them and they have managed to adjust to all the many Covid limitations.

By being full of love and smiles every day

My son got the head teachers award for "managing friendship problems" he was able to go and tell his teacher "I am frustrated" when another child took a toy off him! Super proud mummy!!!

My youngest received an excellence in English. For a kid that's dyslexic that makes me very proud 😊

Making a good choice when asked to, even though he finds this very difficult

Got star of the day for phonics and spelling he really struggles with reading and phonics x

He's been bullied lots for his Tourette's tics but is still smiling like a pro.

She isn't giving up in spite of her health making her rethink everything

She is working hard overcoming her school phobia and being around lots of people.

helped younger kids at school through a difficult day

My son managed to use his words to tell me why he was so upset/angry yesterday instead of going into full blown meltdown and I couldn't be prouder of the progress he is making in voicing his emotions



My housebound autistic young man went for a job interview!

(My daughter) went on a hardcore hike (in the pushchair!) in Scotland 🇬🇧 and didn't mind that it rained a bit.

I was super proud of (my son) for saying no to having the timer on for his times tables test and he aced his gold badge first time 😊 the timer sets of his anxiety massively but he used his voice to do it his way x

Talking to parent carers

	GOOD NEWS	BAD NEWS
Elmbridge <i>309 members</i>		
Guildford <i>105 FB members</i>	Many parents who felt so alone feel like through the Shine course they have friends they can speak to now. Also this month there was the general feeling that we are helping people so much more to cope with their circumstances and get answers to their problems. Coping strategies.	<ul style="list-style-type: none"> Some people are still struggling with the CAMH services. They wait years to get an appointment for their children and then only get 3 appointments. Some parents are still struggling with how badly their children with PDA are supported in school. Their children are super anxious and struggling to attend school and the school wont acknowledge the problem. Parents who have children who are severely disabled have no support especially single parents outside of the school hours, they are constant carers. They are exhausted and need so much more support. I spoke to a parent who has not been able to get their child to return to school since the beginning of the pandemic.
Epsom & Ewell <i>126 members</i>	<ul style="list-style-type: none"> Gratitude for the groups we offer that enable parent-parent support Evidence of a parent carers feeling very supported by particular services: Ockley area - despite CAMHS waiting list, parent reported 'a great advocate from CAMHS'. She obviously felt that she and her child were being held in mind and kept safe, even though potential treatment might take time. Another family had a very positive view of the Youth Club in Farnham that they were introduced to by the Family Crisis Intervention Service. 	<ul style="list-style-type: none"> Parents reported a wide range of professionals being involved with very different ideas and that they didn't always know everyone's role and didn't always feel supported when reaching out for help. Ultimately the parents shared a mistrust of professionals and one talked about a Team around the family (TAF) meeting in which they said there were 'all of these different professionals and you don't know who to trust'.
Mole Valley <i>38 FB members</i>		Lack of support in schools, requiring EHCP assessment, but then schools not supportive of that process
Reigate & Banstead <i>91 FB members</i>	When schools react to the cause of the problems and not just focus on the symptoms progress can be made	<ul style="list-style-type: none"> Some early help professionals seem to have limited understanding of the EHCP process or ASD or mental health and thus sometimes offer misleading or potentially damaging advice. Misinformation re referrals for ASD assessment – schools saying they can't do it – GP's saying it's better coming from school as they see the issues. Hard to contact case workers and many staff changed Attendance code problems !!! Sorry to keep saying it but it's a big issue Problems with inclusion service
Runnymede <i>67 FB members</i>	So many excited parents, looking forward to their new school placements in September. Many of them have not been able to see their new schools but are excited nonetheless.	Several parents have been promised school placements but then have been told to look again as that place has now gone or the school is now full. Also, many people are told this on a Friday so spend the weekend worrying about it. Or are told (in 2 cases) on the Thursday evening and their caseworkers don't work on a Friday – so again they are left to worry until Monday.
Spelthorne <i>76 FB members</i>	Message of thanks from members who have been through key stage transfer process and feel that FVS have helped influence this process.	Covid restrictions still impacting things at school and being used as an excuse rather than actually taking action eg swimming lessons, sports days, school trips
Surrey Heath		

82 FB members		
Tandridge 122 FB members	Parents were very interested to learn about the possibilities of EOTAS	At our ADHD Zoom event for the 16+ group, we heard that many young people with ADHD stop taking their medication at 18, even though their ADHD is still there and they still need the meds. These young people are then discharged from the ADHD service. If they later decide (as many do) that they would like to resume taking ADHD meds, a new referral is required and the waiting list for this through adult services is 3-4 years. What can be done to eliminate this waiting list, so that all young people with ADHD can have access to the medication that they need?
Waverley 125 FB members		The main concern in Waverley was concerning a special school where several significant changes are happening including many experienced SEN teachers leaving.
Woking 92 FB members	I was so honoured that parents shared and were very appreciative of FVS and all the events and groups. A few parents emailed to say thank you and how beneficial the PDA group was for them.	Parent fighting the LEA or other agencies in the system and not getting support with education when out of school and college.





Even better if...

Team Around the Family (TAF)

- As a professional, remember that parent carers cannot be expected to know the process, professional roles etc and that this should be clearly communicated.
- There is a need to review the TAF meetings to ensure that parents feel safe.
 - SCC should seek parents' views on these meetings (including parents who decline to attend and why this is?)
 - Young people should be invited to these meetings or their views sought.
 - If parents don't feel safe then it is likely young people would not either.
- Wouldn't it be incredible if children and young people were so central to Surrey's processes that they were enabled to attend their own planning meetings, annual reviews etc or if professionals routinely sought a meaningful way for their voice to be heard! It seems that children and young people avoiding school are communicating very clearly that placements don't meet their needs when they do not attend, but this is not being meaningfully explored.

Monthly Overview May - June 2021

Events

					
18th May 8.00pm	'The SEND Trainer webinar'	38* 22	8th June	'Shine Women Empowerment/Self-Care Session'	8
18th May	'Shine Women Empowerment/Self-Care Session'	8	9th June	'General Chat'	1
19th May	'General Chat'	1	9th June	'School anxiety chat'	16
20th May	'Acceptance and Commitment Therapy'	11	10th June	'What's next when school is finished?'	8
20th May 7pm	'Acceptance and Commitment Therapy'	2	11th June	'General Chat'	3
24th May 6.30pm	'16+ Group'	10	14th June	'General Chat'	5
24th May	'0-4 Support Group'	0	15th June	'Shine Women Empowerment/Self-Care Session'	8
25th May-	'Shine Women Empowerment/Self-Care Session'	8	17th June	'Downs Syndrome Parent Carer Group'	3
26th May	'General Chat'	2	17th June	'PDA Group'	12
28th May	'General Chat and Catch up'	3			

* 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.

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

Autism Assessments

- We've received glowing praise for the Healios service, from pre-assessment, through the assessment itself and post diagnosis support. A Parent also told us that the report was fast tracked to support their child's EHCP timeline.

Young Carers

- Siblings who are reliant on the support from Young Carers are being sent letters to say that their 2 years of support is coming to an end and being discharged. It appears that the impact of low level support is not recognised enough and many families are distraught at the loss.

3 Short Breaks/Respite

- Parents are telling us of the devastating impact that closure of some schemes have had on their children. Barnados' "Moving Forward" scheme, LinkAble in Surrey Heath and Disability Challengers after school clubs are particularly missed. The loss of Freemantles summer club is causing a great deal of anxiety.
- There is still confusion about whether direct payments can be used to pay for short breaks play and youth schemes.

EHCP

- In a case where a child is traumatised by school, and this is recognised by all, parents are being advised by the inclusion service to send them to school for the purpose of gathering evidence for an EHCP. That this is putting the child at risk seems to be an acceptable if unfortunate necessity and is causing understandable distress for the family.
- We continue to receive stories from parents about the difficulty in reaching case workers, not being notified when a case worker leaves, some children having no allocated case worker despite being at the late stage of the EHCP process.

Another known issue was raised again this month: SCC refusing to accept a private OT report for an OHCP, yet unable to do their own. These stories are aggravated by poor communication throughout the process and often result in a tribunal process.

Family Centres

- Families describe kind and well intentioned support workers whose understanding of the SEND system is inadequate.

Your questions

Your questions last month were wide ranging and require considered responses. We are also aware that a number of questions from the last few months have yet to be answered. So Benedicte Symcox will be working this month to get answers to all these questions and these will be sent to you in a separate email this month, and published on our website. Thank you so much for your patience.

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

Please see the document (NEXT STEPS – Transition Guide Booklet) also attached to our monthly overview website post for more details about this. [June FVS Monthly overview for Surrey \(familyvoicesurrey.org\)](https://familyvoicesurrey.org)

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

Attendance codes are determined national by central government. There is currently no such plan, but FVS wanted to share the following resource for your information which should help during conversations with schools or GPs:

[School attendance guidance \(publishing.service.gov.uk\)](https://publishing.service.gov.uk)

Code I: Illness (not medical or dental appointments) Schools should advise parents to notify them on the first day the child is unable to attend due to illness. Schools should authorise absences due to illness unless they have genuine cause for concern about the veracity of an illness. If the authenticity of illness is in doubt, schools can request parents to provide medical evidence to support illness. Schools can record the absence as unauthorised if not satisfied of the authenticity of the illness but should advise parents of their intention. Schools are advised not to request medical evidence unnecessarily. Medical evidence can take the form of prescriptions, appointment cards, etc. rather than doctors' notes.

[Not Fine in School - School Refusal, School Attendance](#)

Participation work

Project update

Project	Update
Transport	We have been working closely with the SEND transport team and are delighted to have Chris McShee – Travel assistance manager attending our event on 22 nd July. The customer journey is being worked on and we hope to be able to share with members for feedback soon. We are also pleased to hear that transport applications have been processed much earlier this year and we have some data that we are happy to share in this months newsletter.
Autism Strategy	The Autism strategy is progressing well and the final plan is due to be published on 8/9 it will then start its implementation. There are three objectives that will be focused on in each workstream over the first year – further objectives will then be rolled out over the following years. We will be sharing progress with members regularly and seeking feedback as the implementation rolls out. Once the plan is published we will share the link.
PFA	We were delighted to have so many members join our event on PFA – Eamonn Gilbert, Steve Hook and Hannah Futter joined us to tell us about the PFA transformation program and to answer questions. There was some excellent questions asked and it created a very meaningful conversation. Unfortunately we realised that 1 hour was not enough time to answer all the questions asked so we have taken all unanswered questions back to Eamonn, Steve and Hannah and once we get a response we will make the Q&A's available to all members. The PFA team are keen to attend sessions regularly so we will arrange another date soon. Please do send us your feedback it is really beneficial we will feed this back to Surrey and it will help shape future events.
Local Offer	We arranged for six Family Voice Surrey coordinators to attend a workshop with Surrey County Council where the initial new website for the Local Offer was presented. This enabled us to provide feedback on what we liked or did not like, thoughts on the graphics and where we answered questions related to where we would go to search for specific information. Later in the year the coordinators will have the opportunity to be involved in more deep dive exercises as the new website develops.
EWMH/CAMHS	We helped to facilitate a workshop with eight parents which focussed on the new website for the new EWMH service which launches in September. We were all given the opportunity to feedback on what aspects we liked or did not like, the images used, areas such as stories, news articles. Following on from the workshop parents were asked to feedback any further comments from themselves or their child/young person. The group will be consulted again once the site has developed further.
Direct Payments	We will be looking for parent carers with lived experience who would like to contribute to co-producing a Direct Payment Strategy. We continue to highlight the main areas that need further development and attention such as issues relating to flexibility and communication.

Meetings attended

Inclusion Steering Group	Sight for Surrey intro to FVS
Autism Workstream Leads Meeting	Carers Partnership Group
LRT and FVS meeting	UVP meeting about appropriate terminology
Preparing for Adulthood Transformation Programme Board	EWMH website scoping
Children and Young People's Autism Partnership Board	Launch of "The Surrey Story"
SEND Transport update meeting	How to answer parents' questions
Graduated Response update meeting	Pathways-ed.. alternative provision
Responding to Parents Concerns	SSCP Engagement and communication group
Prep for Adulthood: Comms and Engagement Working Group	CYP Autism Partnership Board
Family Voice SCC / DCO meeting	iTHRIVE workshop
Meeting the Transition team	Overworld: gaming for autism
Miniland,,, alternative provision and short breaks	Surrey 3 rd Sector SEND Network
The Children's Social Care Review – "The Case for Change" online learning session	Surrey Charities forum
NNPCF SE regional meeting	Surrey Family Help Hub workshop
3 rd sector operational network	LD & ASD programme board
0-4 SEND Project Board	EWMH website development and parent carer session
Dental neglect webinar	Impact of Covid on disabled people's activity levels webinar
Direct Payments partner meeting	Adolescent neglect webinar
Short Breaks strategic review	SYF listening to families
CwD needs assessment results	Local Offer website meeting
Understanding patient data workshop	Early Years Strategy Forum

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		