



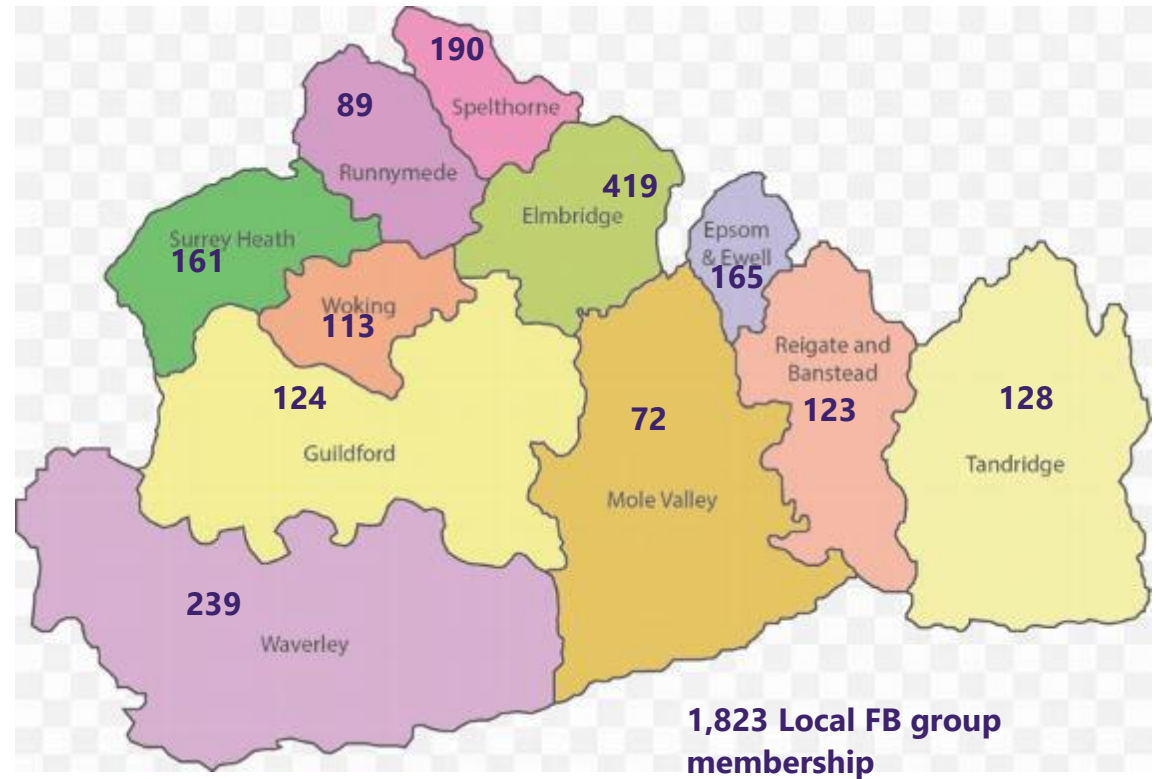
Monthly Overview: March – April 2022

Facebook page followers: 2,576
Facebook closed parent group members: 733
Combined local Facebook group membership: 1,823
Twitter followers: 1,853

Members who attended an event: 149

New FVS members:
40

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

A parent who contacted us to ask for an advocate to enable MH support as her autistic daughter is **attempting suicide** and suffers from an untreated hormonal issue/runs away from home. The mother feels so desperate and that her YP will end up dead.

Conversation with PC about the lack of PAs available. We preferred XXX way back then, but when the holidays come around it's too far away for their school holiday clubs. We use the White Lodge scheme but it's getting stupid, only three days available for the whole of the Easter holidays. 'I've been waiting for respite for ages and I chase regularly.'

Why is there so much duplication in the system? If they are pushed for resources why do they double or triple up on the same tasks such as taking history?

Some advice given included escalating complaints through the system which is something I certainly do. The reality of this means that due to various failings I have to escalate issues on a regular basis which is extremely draining. It also means endless admin, stress and a general feeling of 'self-escalation' which goes a long way to explain the combative nature of SEND parents. This is because we have to do this on top of trying to care for our children who have many needs. **Sadly one can feel more like a manager than a parent.**

A local mum and dad have a boy who is on the spectrum, he displayed all the signs, but the school won't do anything to help him or even to help get him assessed. The mum reached out to me and I suggested to:

- Keep a diary of behaviours and incidents;
- Film the boy when displaying behaviour;
- Speak with and write to the school SenCo listing the incidents, mentioning the video evidence and asking clearly for an assessment of the boy by the EP and an appointment with the EP to discuss an EHCP;
- Ask the GP for a referral to a paediatrician for suspected autism;
- Suggested that she joins the FB group EHCP Experiences Surrey.

I genuinely believe SCC is striving for improvement. However I believe it will take time, a long long time due to the historic mess, enormity of the task and constrains such as finance, staffing, communication issues between departments, inefficient use of IT and lack of a marketing strategy. I actually feel really sorry for people working for SCC when they don't yet see what they have been working so hard on or towards filtering through the system, certainly not in a consistent manor. I think a lot of the staff care a hell of a lot about outcomes and want to make significant improvements but their hands are often tied.

There is a huge lack of support and interaction from CAHMS after initial ADHD consultations.

She has done every single step and has obtained an EHCP!

We heard how there are still such big gaps for those with Downs Syndrome and other disabilities. There is a lack of opportunity and value placed on lives and just in general people are totally unaware of the long abundant lives those with Downs Syndrome can live.

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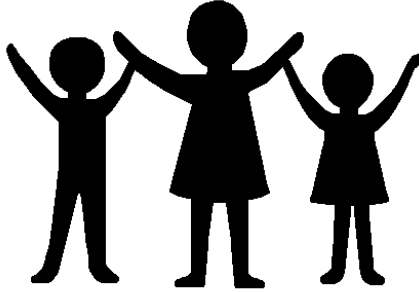
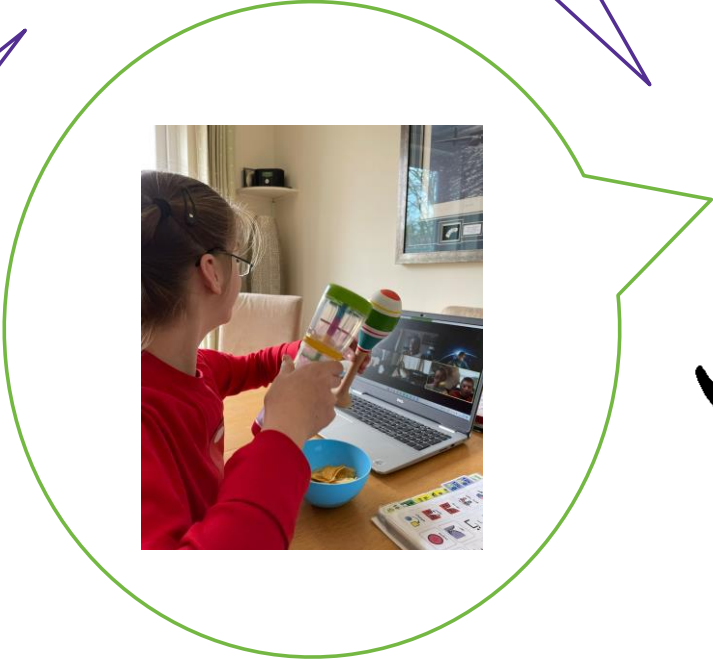
'X' is engaging with an online SCAMMPS event and expressing herself through musical instruments and communicating by using PODD

I am very happy to join the Inclusive Dance, it's such fun! (ADHD child on Surrey Youth Games).

My fidget ring really helps me concentrate in class 😊

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

I like staying in my room



Parent Carer quotes

We find out everything by chance. Why isn't information shared with us automatically?

I have done the Mark Brown's puberty session before, he's very good.

Stay & Play – It was a good session, quite busy. The holiday ones always are as I think people appreciate them more and they're running over the summer too!

When your child is **at crisis point** and you're trying to negotiate this system, it's so, so difficult.

If you don't have access to private reports you are really disadvantaged.

My child is at death's door and we have no support from anywhere

All the support sounds fabulous, but it's so far from my experience that it's concerning.

The PDA presentation (by Harry Thompson) was amazing

Facebook – SCC Transport reform – 'My son's school is 17 miles away. This is the nearest appropriate school that can meet his needs... a 2 hour round trip each way. I wish there was a closer school so I could have the luxury of taking him to and from school. Something us SEN parents miss out on and then hear mainstream parents moaning about doing the school run 😞 if only you knew just how lucky you really are'

My son hasn't attended school at all for Year 11, but an EHCP assessment has been refused.

Thanks for all your advice so far, it's very helpful. That helps a lot and is far more clear than anything else

My child was referred to the Transition Team, but they refused to take him on. I'm nearly **at breaking point**. It's terrible. It's a huge pressure.

My son has no school place for Year 12.

My son was discharged from his social worker at 18. He was also discharged from the CAMHS clinic then. He rarely goes out. I'm now his full-time carer. It's not sustainable. He recently hit me. I can't have a normal life. I've never had a Carer's Assessment.

Stay & Play – Playschemes (White Lodge) are always so oversubscribed. They are full before we even know about it. At least we can come here.

Parents don't have the capacity to process all of the resources and information, we need a professional to help us.





We're just wasting time. It's clear that in 4 months' time my child isn't going to be able to make it into mainstream education.

So happy I don't have to battle the school mornings for a couple weeks

I've had to escalate everything through all of the stages to get support. The system seems more desperate than ever.

My son is on a waiting list for a social care assessment. How can the EHCP be produced if this assessment hasn't been done?

Events

					
22 nd March	Preparing for Adulthood – A Co-Production Session with Surrey CC and parent carers to develop a new brochure for families, young people and professionals	40	4 th April	Dad's Event - Communicating with ND teenagers	22
22 nd March	ASD/ADHD Group	21	6 th April	General Chat	1
23 rd March	Harry Thompson – Journey into a PDA Mind webinar	31	11 th April	16+ group (extended to 13+ for this session): 'Transition to Adult Social Care'	11
24 th March	Mindfulness Parenting	23			

* 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
Alternative Provision	Please keep sending in your questions and experiences around alternative provision and EOTAS so that we can share with the local authority to develop guidance for families around this. You can send them to Leanne – leanne.h@familyvoicesurrey.org
EBSNA	We are delighted to be working with Surrey Youth Focus on the analysis of data of the recent EBSNA survey which we had an overwhelming response. We hope to be able to present this to families along with various teams within the local authority in the very near future. We will then be moving onto the second stage of our survey which is gathering your experiences on EBSNA. More details to follow soon.
EHCP Process	We hope you are finding the bite sized videos useful. EHCP Processes: Role Of A Case Officer , https://www.youtube.com/watch?v=8F51rZ3sGrE

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	<p>We have 2 more that we will be able to share with you soon on the EHCP application and process. We are recording EHCP – the draft plan and annual reviews in April and May. Please do send your comments or questions into us – do the videos match your own experiences? You can email Leanne – leanne.h@familyvoicesurrey.org</p>
SEND Admissions / Key Stage Transfer	<p>We are aware that there are still families who still haven't received a name placement for September. We will continue to work with the admissions team to get updates and track progress on this.</p>
Preparing for Adulthood	<p>Thank you to those of you who inputted into the recent co-production sessions for the development of a new PFA brochure. There will be a further opportunity to feed your views into this in June/July time we will update you once we have the dates.</p> <p>We had a great session in our post 16 group this month where the SEND team came along to speak with families. We are delighted to be welcoming Eamonn Gilbert to talk about vocational pathways to our post 16 group which has been extended to 13+ for this event. It will be on Monday 9th May at 6.30pm please email Gretta – tandrige@familyvoicesurrey.org to book your place.</p>
Short Breaks	<p>Most Short Breaks providers have now opened their summer booking windows, all information can be found on the Short Breaks Visual that is on the FVS facebook page. All providers require a registration process to be completed before bookings can be made so please look at the sign up process to avoid disappointment</p>
Local Offer	<p>The Local Offer continue to update the sections on their website to ensure the information is accurate, useful and easy to understand and navigate. They would love to hear from families about their feedback and what they would like to be included. Please contact kate.g@familyvoicesurrey.org if you would like to be involved</p>
Health	<p>Following the success of the swimming trial in Spelthorne Leisure Centre, they have now started the trial in Sunbury Leisure Centre. Places are very limited so please contact Leanne Rodriguez-Reid with enquires LeanneRodriguez@everyoneactive.com</p>

Meetings attended

Project	Information
Inclusion	Outcomes First Consortium
PFA	Keyworker Project
EHCP Process	SEND Admissions Meeting
Autism	Autism Strategy Meeting
Inclusion	Safety Valve Briefing
EHCP Process	EHCP Video recordings
PFA	Shared Lives Recording
Autism	Education and PFA workstream
Autism	Workstream Lead meeting
EHCP Process	EHCP Paperwork meeting
Autism	Ambitious about Autism meeting
Direct Payments	Direct Payments strategy meeting
Short Breaks	Summer planning email
EWMH	Safety Value Briefing
Social Care	Social Care mapping meeting
Health	Active Surrey training meeting
Direct payments	Co-production reflections workshop
EWMH	ND friendly schools meeting
Local Offer	Website video update meeting
EWMH	ND bi weekly call
Health	Spelthorne Leisure centre swimming meeting
Autism	PBS conversation with Conveners,
FVS & Partners	Regular conversations with Julia Katherine,
Self Evaluation	SEND Strategy Steering Board
FVS & Partners	Safety Valve Agreement Briefing,
EHCP Process	EHCP Safeguarding audit briefing,
EHCP Process	New EHCP template briefing,

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FVS & Partners	Quarterly meeting with elected members
Self Evaluation	Inspection preparation
FVS & Partners	Children’s select committee
FVS & Partners	Interview panel for SE Education & Inclusion Service Manager
FVS & Partners	Dave Hill memorial service

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

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SYF	Surrey Youth Focus	RFID ARFID	Restrictive Food Intake Disorder Avoidant Restrictive Food Intake Disorder
CCHS	Children’s Community Health Service		