



Monthly Overview: October - November 2021

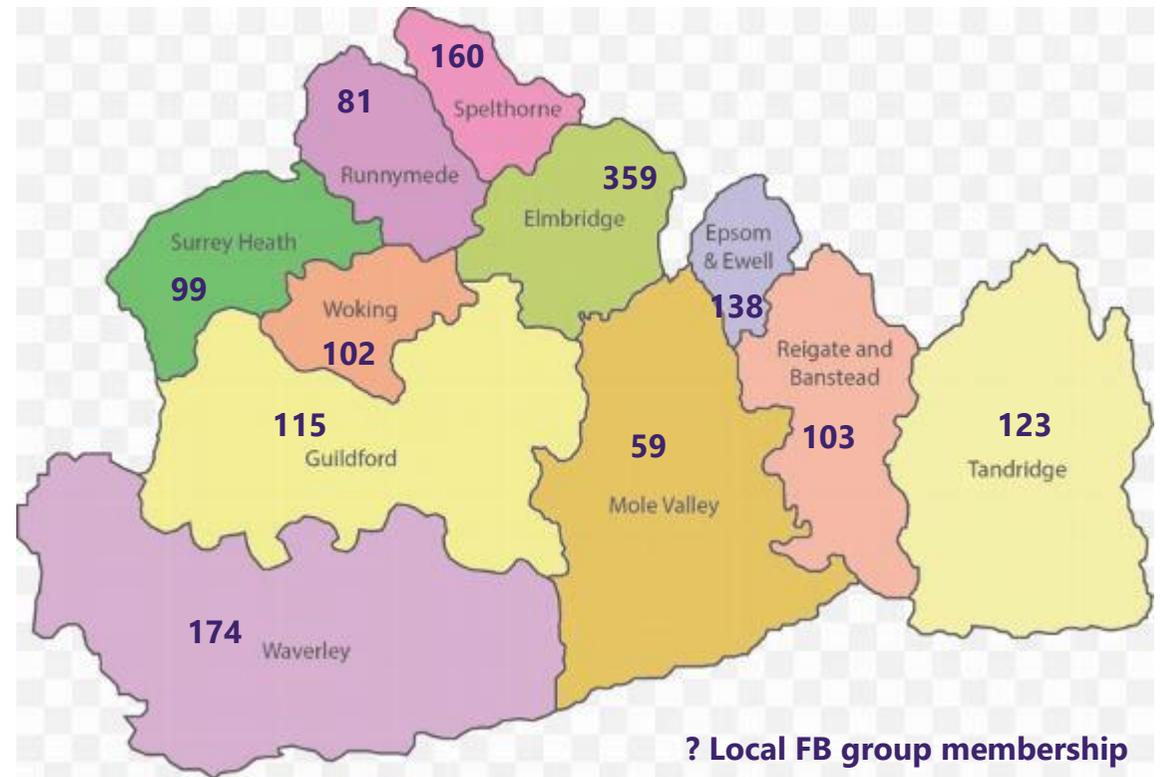
Facebook page followers: 2293
Facebook closed parent group members: 695
Combined local Facebook group membership: 1529
Twitter followers: 1831

Members who attended an event: 81

New FVS members: 23

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

Restrictive food intake	All members want to send a letter to their MP re lack of funds for ARFID. Whatsapp group set up and going well. To join contact shannon.t@familyvoicesurrey.org
PFA Event (SCC/FVS/Surrey Choices)	<ul style="list-style-type: none"> • Where is the support for academically young people with mental health needs? • Parents shared concerns about the vulnerability of young people with SEND to drugs
Tribunal Stories	<ul style="list-style-type: none"> • LA conceded before Tribunal and awarded fulltime DIRECT 1-1 for a child who is in year 6 but the provision stated that it was only while at PRIMARY SCHOOL which obviously is useless to the child going to senior school in September. They have gone back and its been changed to while in a MAIN STREAM setting. No explanation as to why these words are being used and obviously is causing parents unnecessary stress. • The LA postponed a tribunal 24 hours before it was meant to go ahead and changed witnesses and reports last minute – this has detrimentally affected the parent who has been building up to this for a very long time
Inclusion	<ul style="list-style-type: none"> • Parents ask who holds the LA accountable when parents are scapegoated for failure of schools to recognise SEN and support children resulting in school placements breaking down and children out of school because there is no suitable provision? • Lot of questions around role of inclusion officer following some recent job adverts for SCC inclusion officers. • Families whose children do not have firm diagnoses (ASD) are not able to access help for severe anxiety in their children. School attendance becomes impossible, and alternative provision seems unachievable. • Systems are not able to respond to co-morbidity or the possibility of more than one person in a household with additional need • Gender dysphoria is an increasingly important and difficult topic raised by our families and is leading to exclusion
EHCP Processes	<ul style="list-style-type: none"> • SEND caseworkers not responding to calls or emails. SE quadrant is well known, but we hear of this throughout the county. • Annual review paperwork takes months to arrive, if at all. • Parents are struggling to access EHCP level support for post 16 students
Transport	<ul style="list-style-type: none"> • Parents are still unclear about disabled bus passes and whether these can be used to get to college/school • The transition from school to college is not planned for well enough with families, leading to mistakes and excessive stress • We heard another positive story from a parent who requested the travel allowance rather than a taxi. Good customer support.

<p>Primary to Secondary Transition</p> <p>Stories from a group of parents whose children are in year 7 and 8</p>	<ul style="list-style-type: none"> • Many parents are still not being supported very well from the transition from primary to Secondary. • Parents have to fight to be heard and many schools disregard all the hard work the primary schools have already put in place for children going into Secondary Schools. • Secondary Schools seem unchanging in their approach – this is the way we have done it for 25 years and this is the way we will do it. Secondary Schools need to be more willing to support children, listen to the voice of the parents and change their practices, if need be, to support a child better. Parents should not feel they need to give threats to make the school change, but secondary schools should be more willing to change and be more open minded and listen to the parents. • Secondary Schools should do their homework better and read all the paperwork regarding new SEND children coming into their schools and then put proper plans in place for those children and discuss the plans with the parents so that the parents know what is going on with their children. • Secondary schools need to be better at communicating with the parents about what is going on with their SEND children. Its not good enough to communicate about a major issue 2 days after it has happened. Some Send children are kicked to the side and now have low grades because of the lack of support given at the Secondary School. They seriously lack motivation and have no reason to try. • Also some children who really need an EHCP cannot seem to get the school to help them – give them advice and to support them in this process. • Some children that were doing really well in a primary school setting are now school refusing in Secondary because of a lack of support.
<p>Early Years</p>	<ul style="list-style-type: none"> • Family centres don't seem equipped to deal with children with developmental needs or disabilities. Sensory rooms are great, but it makes parents feel excluded if that's the only part of the service they are able to access. • If you are not eligible for Portage or for whatever reason you don't get it, who is the support/ what service helps you with schools, information etc? Health visitors fade in and out • Parents are seeking information and support – FVS annual event will hopefully address some issues
<p>Mindworks</p>	<ul style="list-style-type: none"> • Out of Hours Service for Mindworks Surrey – parent reaction: “We reached crisis point last night (again) and this time I bit the bullet and called the crisis team. The nurse was fabulous and this morning the same advice team have come back to me and actioned more things in a few minutes than we’ve been able to achieve in 6 years. Finally seems a bit more joined up. They have a record of everything that we’ve asked for and that hasn’t been done over the years and are finally saying they need to act!” <p>Two weeks later:</p> <p>"Since then nothing else has happened, despite repeated pleas to the social care and CAMHS mental health teams. I even called the crisis team at midnight on Saturday to be told that there was nobody who could help as they finished at 10pm. Could I take my daughter to A&E instead?"</p> <p>"Do they literally have any idea what some of us are dealing with in our homes?"</p>

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<p>Transition</p> <p>Comments from parents in the 16+ and 19+ groups</p>	<ul style="list-style-type: none"> • There is a tendency for schools to be over positive in written reports at transition so the next setting is often ill prepared for the real needs of the young person. This is a particularly big issue when young people leave education, lose their EHCPs and enter adult social care. • The “emergency planning” was a very useful session and whilst a lot of it was common sense it made me realise that whilst I may be prepared for many emergencies I have made no effort, except in the case of fire, to teach either of my children what to do in case of emergency. They are growing up and I really need to prepare them both so I should start imparting some information and the sooner the better! • Felt it was vital to make contact with other parents in my position, invaluable moral support. • Hearing from people ahead of you helps you plan and mentally prepare for what needs doing next. It’s valuable information to allow you to take a pragmatic approach to finding solutions to future problems. • Perhaps people need some sort of event around mental health, transition to adulthood, the difference between having a breakdown as a child / young adult, support, rights, the difficulties with fluctuating capacity, how to plan for someone who is usually mentally all there (and perhaps doesn’t want to give power of attorney as they think they are independent and can cope) and then loses it periodically and finds themselves in hospital (briefly without capacity), who to call in a crisis e.g. suicidal thoughts, cutting wrists? Who is there in an actual emergency, when ‘you are on our waiting list come back later’ is not enough?
<p>Therapies</p>	<ul style="list-style-type: none"> • Lack of Occupational Therapists is being felt by both schools and parents and causing huge distress.
<p>Parent Wellbeing</p>	<ul style="list-style-type: none"> • The event was received well and people were engaged during the session. Parents afterwards were all talking about how effective Neurographica was to help them relax and de-stress, as well as overcoming their worries. In general, people would be happy to have a session every month and one lady was so impressed that she said she would look into courses to become an instructor herself. • I have a “good” story to share that I have personally experienced it myself. I have been enjoying a concessionary charge to access the leisure centre in Staines (Spelthorne Everyone Active) as a Carer even when I go on my own. Most leisure centres/swimming pools only offer concessions to carers when they accompany the person they care for. I love going swimming on my own to recharge my batteries and be ready to take care of my disabled child. • Many attendees to Nicola Reekie (PDA Space)’s workshop said thanks, that it was helpful. Just seeing Parent carers setting aside that time and trying a few of Nicola’s suggestions seemed to help with calmness in the group overall. There were a lot of positive responses. One parent was quite upset but another group member was responding to their concerns then the speaker did more calming techniques to finish. One person said they were off to write down a ‘Happy List’ there and then.

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New school Placement going really well! First meeting, felt very welcomed, felt my concerns with my son were taken seriously and felt good knowing there are people who understand

School using EHCP funding for whole class not intended child. What's the point in fighting for support if no one is help accountable?

Thank you for being my safe space

It's a battle to get my child to school

How do we overcome non-SEND parents' stigma? I'm too scared to go anywhere with my child'

SEND families are an easy target for bullying or be taken for bad behaviour'

Thanks for Thursday, it was so good to have you there. Feel free to contact me at any point

What does it take to get an EHCP?

Where do I get a diagnosis?

Short Breaks at White Lodge saved my life, I honestly wouldn't be alive now if it hadn't been for them

How do we get the EP to come into the school?

Fantastic support from Speech and Language this term, we have been given an assisted learning device for our child, funded by the service, that we didn't even ask for!

I really enjoyed the (NeuroGraphica) session yesterday. I choose this quote because it is so nice to allow parents/carers to have a break.

I love playing guitar: it makes me feel so relaxed.

There seems to be absolutely no mental health crisis support available for young people once they're 18

It is very difficult to negotiate with people to get my child's needs accurately recorded

I struggle with other students in the class. They're not as able as me, or have 'odd' habits which distract me

Transport has been approved for my child but it's not yet been arranged

The more you're seen to manage at home, the more you're left

My son's started at Nescot and it's going really well, it's surpassed all my expectations



Events

					
18th Oct pm	'16+ Group'	6 (1 ♂)	10th Nov	'School Anxiety Chat'	10
19th Oct	'Neurographica: draw yourself happy!'	6	11 th Nov	19+ group	9 (3 ♂)
22nd Oct	SEND Advice line Q&A'	0	12th Nov	'FB live - Benedicte chats to Jess from Mindworks'	
28th Oct	'Chat on Restrictive Food Intake'	6	15th Nov	'16+ Group Emergency Planning'	11 (1 ♂)
3rd Nov	'General Chat'	6	17th Nov	'General Chat'	4
5th Nov	'FB live - Q&A with Rachael Wardell'		18 th Nov	St Cuthbert's primary school	10
6th Nov	'Preparing for Adulthood at East Surrey College'		23rd Nov	Nicola Reekie "Enhancing your wellbeing"	13

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

Useful Information

<p>Runnymede Police</p>	<ul style="list-style-type: none">  Textphone service on 18000, you can also use our 999 emergency text service https://www.relayuk.bt.com/  Pegasus card scheme - We encourage anyone who has speech or communication difficulties to join our Pegasus card scheme, which could save you time and help you in an emergency. Visit https://surrey.police.uk/Pegasus for more information.  InterpreterNow - We've partnered with @Interpreter_Now to provide a British Sign Language Video Relay Service that puts BSL users in immediate contact with an online interpreter - https://interpreternow.co.uk/  Herbert Protocol - a form that carers, family or friends of a vulnerable person, or the person themselves can fill in. It contains a list of information to help the police if the person goes missing. For more information visit: https://www.surrey.police.uk/notices/af/herbert-protocol/
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Participation work

Project update

Project	Update
SEND Transport	<ul style="list-style-type: none"> Continuing to meet regularly with the SEND transport team to address ongoing issues, please do email Leanne leanne.h@familyvoicesurrey.org with any difficulties or feedback (good and bad) about SEND Transport Continuing to work with SEND Transport on communication and providing relevant and accessible information
Autism	<ul style="list-style-type: none"> The Autism Strategy is now in its implementation stage, we are co-leading on two workstreams which are: Information, Awareness and Understanding and Education and Preparing for Adulthood. We will be having regular meetings and seeking regular feedback from families.
Early Years	<ul style="list-style-type: none"> We were delighted to bring you our annual event this year it was focusing on early years during the week of the 15th November. See the newsletter for more details. Our next Early Years group will be on Thursday 2nd December at 11am and we are delighted to welcome Dr Kathryn Hollins who was a huge part of our event – she has offered to come back and talk to families and answer questions on parent well being in the early years. Please do book your space by emailing Emily – runnymede@familyvoicesurrey.org and we look forward to seeing you there! Our January Early Years group will be on Friday 14th January 2022 at 11am and we are so excited to have Surrey Libraries joining us for a very special rhyme time tailored to babies and children with additional needs. To book your place please email Emily – runnymede@familyvoicesurrey.org
Alternative Provision and Emotionally Based School Non-Attendance (EBSNA)	<ul style="list-style-type: none"> We will be working with Surrey CC to understand what their alternative provision strategy means for families, and working on ways to ensure information is accessible to families. We are working on some projects around emotionally based school non-attendance (EBSNA) and we will be working with Surrey and health along with Surrey Youth Focus to get a better understanding of the size of this cohort of children and bring the lived family experiences to ensure it is at the heart of this work.
EHCP Processes	<ul style="list-style-type: none"> We are continuing to plan our webinars and will start recording them in December so we hope to start rolling these out over the coming months. We will be meeting regularly with the SEND admissions team ahead of the key stage transfers in February, we hope this will enable us to keep abreast of challenges and support communication to families.
Inclusion	<ul style="list-style-type: none"> We continue to feed into the inclusion work happening across Surrey and ensure that the parent carer voice is at the heart of everything that we do – your stories really do allow us to continue to work this way.

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	<ul style="list-style-type: none"> • We are involved in the Team Around the School which is being piloted in Spelthorne and will gradually roll out across Surrey over the next year. We hope to be able to provide further information for families soon. • We will be working on the development of the Ordinarily Available guidance – this is going to be a document primarily for families to understand what support should be available in school and the different stages that support looks like. • We are also working with Surrey on developing some best literacy practice guidance for families to understand what support is available to their child who maybe struggling with literacy.
Preparing for Adulthood	<ul style="list-style-type: none"> • We were delighted to attend the event at East Surrey College on the 6th November, it was great to meet in person and it was well attended with a large range of stall holders and panel discussions. • We will be working with the PFA team on developing a brochure of comprehensive guidance for young people with the aim of it being given to them during a year 9 annual review and continuing with them from there. It is one of the ways they are looking to improve the communication and trying to make everything clear and less confusing as. • The PFA team have agreed to join our Facebook lives on a regular basis – more details will follow as to when the first one will be.
Health	<ul style="list-style-type: none"> • Andrew Smart from Surrey Heartlands asked us to arrange a focus group for Parent Carers to help them better understand how they might use digital technology to improve the care they offer to Surrey residents. Participation was excellent and Surrey Heartland have taken away all points raised to look into further to see how they can be incorporated into the programme. Once it is ready to be trialled, they are going to come back to the focus group to ask them to see how they think it works. It really is a great example of collaboration at its best!
Social Care: Direct Payments	<ul style="list-style-type: none"> • The Direct payments policy is being re-evaluated. The aim is for it to be concluded by March 2022. Kate is attending the monthly meetings and all aspects are being reviewed. SCC is keen to gain feedback directly from families that already use Direct payments to understand their first hand lived experiences and how they would like it to be improved. If you or any of the families you speak to use or have used Direct payments then please ask them to get in touch with Kate. kate.g@familyvoicesurrey.org

Kate provided support to the CCG in revision of the policy for the assessment and delivery of Children and Young People’s Continuing Care. While the CCG would always want to ensure full stakeholder engagement, and as far as possible co-production when writing policy, the input of Family Voice for a parent and carers view was particularly important for this document as sensitive issues such as provision and arrangements for end of life care need described accurately but compassionately.

Kate kindly reviewed the draft policy and provided helpful feedback and met with the Senior Commissioner writing the policy to assist with clarifications. The policy reads as a more accessible and empathetic document as a result and is now ready for governance processes for approval. It will be made available via Local Offer shortly.

Gavin Spiller, NHS Surrey Heartlands Clinical Commissioning Group

Meetings attended

Project	Meeting	Project	Meeting
SEND Transport	Meeting with Service Manager	Core	CFLLC select committee RE SEND Transformation
PFA	Comms and Engagement	Core	West Sussex Parent Carer Forum
PFA	Event at East Surrey College	Core	SENCO update meeting
Autism	Autism Strategy Event	Core	High Sheriff
PFA	PFA Programme Board	Core	SEND Transformation catch up
Inclusion	SEMH Steering Group	Core	SEND Transformation Board
Autism	Autism Strategy: Information, Understanding and Awareness Workstream	Core	Rachael Wardell
EBSNA	EBSNA meeting	Core	SIASS steering group
Health	Health and inequalities design transformation workstream	Core	Strategic Conveners
EWMH	ND pathway weekly meetings	Core	SEND Partnership Board
	Select Committee with Jim Nunn	Health	Meeting with OT
Health	Digital Navigator Workstream	EWMH	Mindworks Leadership Team planning meeting
Direct Payments	Direct Payments strategy group	Inclusion/Health	SEMH 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	EBSNA	Emotionally based school non attendance
Strategic Conveners	Three new roles within the NHS, but working within SCC: Driving the implementation of a single commissioning service in your respective area (Mental Health, Children and Learning Disabilities) the focus, and challenge, will be to drive collaborative working with our partners to develop long-term collective commissioning strategies that provide integrated services that are sustainable, cost effective and deliver positive outcomes."		