

Talking to parent carers

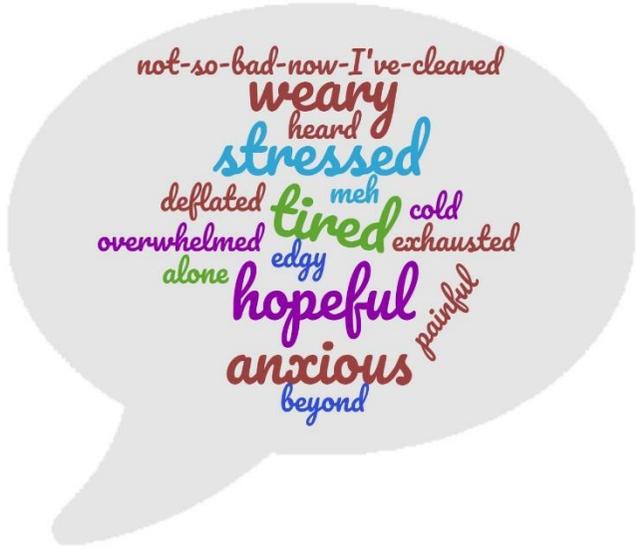
<p>Surrey Heath 66 FB members</p> <p>☹️ 😊</p> <p>No dedicated coordinator here currently</p>	<p>Woking 80 FB members</p> <p>☹️ some families more desperate for support due to lockdown</p> <p>😊 some carers getting used to managing the internet to find support themselves</p>	<p>Runnymede 46 FB members</p> <p>☹️ 😊</p> <p>No dedicated coordinator here currently</p>	<p>Elmbridge 275 members</p> <p>☹️ none 😊 schools being more supportive in this lockdown than last year</p> <p>More regular coffee events please!</p>	<p>Spelthorne 72 FB members</p> <p>☹️ special school placements Home schooling 😊 grateful for FVS 0-4 group Coffee morning has positive impact on 3 parents, linked to Barnados</p>	<p>Epsom 59 members</p> <p>☹️ Parent carers reported SEND case officers not returning calls or emails regularly, when parents want to be 'kept in the loop' even if there is no news yet. 2 Isolation 😊 At Shine and School Avoidance there has been a theme of how important the support group members offer one another is to the confidence and mental health of parent-carers. One parent in School avoidance reported positive support from the Education Welfare Officer, another, very good support from a SENCO who found a temporary educational placement while young person is out of mainstream school.</p>
<p>Waverley 55 FB members</p> <p>☹️ MH concerns for single parents, shielding parents and those whose children struggle with school attendance 😊 parent feedback about Jigsaw's excellent offer post 16 to help with transition into real world.</p>	<p>Guildford 93 FB members</p> <p>☹️ Parents are so burnt out and really need better support for their families 😊</p>	<p>Mole Valley 24 FB members</p> <p>☹️ 😊</p> <p>No dedicated coordinator here currently</p>	<p>Reigate & Banstead 62 FB members</p> <p>☹️ There is a strong and negative theme of disregard in which children and parents are treated by the SEN education system, time wasted, needs ignored, illogical and irrational decisions by case workers. Case workers who seem clueless about SEND Panels that are completely anonymous and unaccountable. Parents are emotionally drained and ground down by the system. 2. Access to school is inconsistent (EHCP) 😊 A SENCO at Rosebery school seems pretty switched on and helpful. Some remote learning provision should be adopted permanently</p>	<p>Tandridge 103 FB members</p> <p>☹️ Lack of timely/ any support from CAHMS Impact of lockdown on parent carers' and CYP mental health 😊 really positive feedback about support from some special schools in lockdown</p>	<p>Training/ Engagement</p> <p>Relax Kids Health and Wellness Community equipment</p> <p>Get togethers</p> <p>1 for families of 0-4 year olds 2 for Down's families 11 general chats 2 for those affected by school anxiety – 1 attended by CAMHS</p> <p>Other</p> <p>FB live most weeks Video interview with Head2Head</p>

what we're hearing

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

Facebook page followers: 2126
 Facebook closed parent group members: 527
 Combined local Facebook group membership: 935

New FVS members:
 76



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.

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

- Themes :
- EHCP process:* how can SCC decide a type of placement that is contrary to the recommendation of parents, teachers and therapists? Why am I already on my 3rd case worker in less than a year?
 - Transport:* Poor communication about post 16 contributions; transport team saying that direct payments can be used for transport to school, concerns of covid safety in crowded taxis with children unable to wear masks
 - After school care:* difficulty in accessing after school care with direct payments, and exclusion of children from after school activities because transport will not flex to accommodate

Answers to your questions

A big thank you to those local area officers and practitioners who have taken the time to send us these answers.

1. Why is the system for personal budget payments so complicated and can it be set out clearly and publicly, to avoid confusion?

Thank you for sharing your concerns about Personal Budgets. We have identified the need to make clearer the criteria for obtaining a personal budget and its use. We are encouraging caseworkers to specify what the personal budget is for in EHCPs to prevent any confusion. Personal budgets can be for Education, Health and Social care and these each have their own different criteria and processes. It is our hope to simplify these over time. A revised Personal Budget policy is being drafted which we will share with FVS before it is finalised.

2. What are the positive lessons being learned from the current covid arrangements?

COVID has presented many challenges as well as opportunities for services and professionals to think creatively and innovatively about how they deliver services. It has also enhanced partnership working between FVS and a range of services and agencies. The commitment to supporting young people has seen the development of virtual assessments, remote learning and innovative processes for ensuring young people receive specialist equipment and support if they need it. Parents have expressed an appreciation of remote learning opportunities.

In addition COVID has enhanced the development of on line tools to support those who are anxious and need access to emotional and wellbeing support. It has escalated a wide range of digital tools to support young people and adults – KOOTH and QWELL All of this work is being supported by the healthy schools approach which embraces all aspects of well-being.

The following are examples of new ways of working in partnership and providing support to individuals which have developed during the COVID pandemic:

- Linking up with the local community fridge initiative and delivering food parcels for local families enabled doorstep youth work to continue and built networks with other organisations.
- Craft packs sent to CYP and photos of their creations posted on the LYP Instagram account. Instagram also popular with CYP accessing gender identity support to share good news/ tips for well-being/ photos.
- “Imagine”- horticultural project for CYP known to criminal system and those NEET.
- Local care home offered grounds to be used for work experience /outside space. “1000 hours outside” initiative recognises impact of fresh air/ space on our mental health.
- DA services sent well-being boxes, including play items that helped the non-abusive parent enjoy interacting with CYP to build confidence and weekly conversations boosted mental health and well-being. Group agreed on value of practitioners working in partnership with parents to help them provide therapy/ support for CYP.
- Older young carers linked in with the Beauty Bank to receive much appreciated beauty supplies.

From whole schools health and wellbeing approach

- There has been a greater overarching focus upon health, wellbeing and their links to achievement and positive outcomes for children and young people.

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- Surrey CC services, directorates, partners, charities and the third sector are working increasingly closely together aiding a graduated approach to meeting the needs of children and young people.
- There has been remote support and training for teachers and school staff relating to bereavement, developing increasingly supportive practices in order to promote joined up working – through the suicide thematic review, and developing universal prevention and targeted support via Surrey Healthy Schools.
- There has been increased use of the School Nursing Chat Health texting service for secondary aged pupils.

3. What is being done to reduce the unacceptably long waiting times for CYP to be assessed for ASD and ADHD?

A number of actions have been taken to address this issue – including the commissioning of a number of specialist providers to support the assessments of those who may have an ASD and or ADHD need. A comprehensive set of arrangements have been implemented which see a significant reduction in those waiting to be assessed month by month and a complete clearing of the waiting list by October 2021. In addition the I THRIVE model is being rolled out as new approach to emotional well-being across the County.

4. How can parents ensure that schools are supporting their children better while waiting for a neurodevelopmental assessment? Schools still say they need a diagnosis first.

Schools and other partners are all being supported to understand the neurodevelopmental pathways which include the provision of support to young people without the need for a diagnosis.

Across the partnership all services are considering what is ordinarily available that schools, parents and families can access to support young people without the need for an assessment.

The L – SPA provides the opportunity for parents to request support and to speak to a professional from a multi-disciplinary team who will sign post and guide parents to access support without a diagnosis or specialist assessment. In addition the local offer web site has been update to ensure it is up to date and parents can self-refer to services.

Schools are at the centre of these developments and training continues though this is often virtual training to COVID. The team developing the Neurodevelopmental pathway are developing tools and guides that will be available in all settings to ensure young people are supported whilst they wait for an assessment. Parents may also wish to refer to the content of the SEN report on the school website as to how they will support all children in their school

5. Where can we find more information on transition/colleges

Information should be available on the local offer website regarding colleges in the local area. The post 16 team are developing a brochure which will set out the different transitions options for young people as they prepare for adulthood. Post Covid the County would like to repeat the road show it undertook in 2020 which enables them to meet a large number of parents and young people. The roadshows allowed the council to demonstrate and discuss with young people and their parents the wide range of options for young people as they transition from children services to adult services.

All colleges in surrey can be found here: [All schools and colleges in Surrey - GOV.UK - Find and compare schools in England \(compare-school-performance.service.gov.uk\)](https://www.gov.uk/find-compare-schools) transition support is also available via [ASC: Surrey Transitions Team | Surrey Local Offer](#)

The link to the Local offer site may be useful for parents, carers and young people: [Preparing for Adulthood | Surrey Local Offer](#)

Questions from our members

SCC Case workers:

1. Staff are still failing to respond to parents' calls/emails and failing to update parents over ongoing issues. What can parents do to move things forward?
2. What are the job priorities of case workers?
3. What are they judged on in the performance of their jobs?
4. Does this impact the way they treat parents?
5. What training do they have in SEND?
6. Why is there such a high turnover of case workers?

Children missing education:

1. None of the school avoidance group reported their children accessing Access2Education which seemed surprising. Is there any guidance as to how to access educational support for your child if they are out of full-time education? Is A2E the best route or are there other options that parents can pursue? Hard to find options on Local Offer page.
2. How many children and young people with SEND are there in Surrey currently with no appropriate educational provision?

Neurodevelopmental issues:

1. Can we have more information on the ASD pathways? Some sessions would be very well attended and in demand!!
2. What is being done to improve access to ADHD assessments, and to provide support to children and young people with ADHD?

Covid/Lockdown:

1. How many people have made the decision to home school (with reduced educational quality) because they were concerned that the taxi bubbles differ to the school bubbles i.e. that going to school posed too big a risk due to transport arrangements?
2. Parents are feeling great expectations to ensure that their SEND children are completing home schooling work, and to "prove" the work that they are doing. What is the council's position on this?

Social Care:

1. What should be in the care section of an EHCP? Seems many people get told if they don't have a social worker this section should be blank. Is this the case?
2. If a child has limited independence skills but has no social worker or social care involvement should there be anything in the care section particularly as they go into post 16?
3. Why does the SCC Transition Team not support disabled young people who have ADHD, while it does support those who have ASD?

Sleep issues:

1. How are our local health services supporting families with sleep? Is it differentiated for children with ASD and ADHD?

Participation work

Project update

Project	Update
Autism strategy	Three workshops were held at the beginning of December to get feedback from autistic people and their families about progress. These were attended by around 50 people each time and FVS acted as one of several facilitators. One of the workshops was dedicated to adults with autism while the other two were open to all and included autistic adults, family members, carers, and professionals. They were very positive events and I'm pleased to say that the feedback provided has already changed the direction in which the strategy will be developed in a good example of people's voices being heard. There is a timeline imposed on the project but we continue to ensure that your voice is at the centre of the process.
Local offer	The local offer review has been paused whilst other work including the Little Help Shop is ongoing.
CAMHS	Alongside the Reigate and Banstead coordinator we invited two Consultant Psychiatrists from SaBP into the USSA support group. This enabled parent carers to have an open discussion about the experiences they and their children have when having difficulties in attending school due to anxiety. This took place on the 13 th of January and parents have subsequently been asked to feedback on any good practice examples from past experience. Some of this feedback will hopefully be used towards a training manual and a video resource. CAMHS will be presenting developments around the new proposed Neurodevelopmental pathway to the team at Family Voice Surrey in February and we hope to have more presentations and sessions focussing on the development of the EWMH support offer for parents over the next few months.
0-4	We have continued to attend the 0-4 Project Board, co-lead on one of the workstreams and attend another workstream which looks at the experiences of families whose children will need to access a greater level of support in order to meet their needs. We have continued to develop the 0-4 support group for parent carers who have children aged 0-4 and will be working on getting guest speakers booked in for the next few months. The aim is that we will be developing case studies from parent carers to highlight experiences at different stages within the early years journey.
school absence	A meeting held with the person in charge of reviewing alternative provision in Surrey was very fruitful. We were able to highlight the experience that you have shared with us, particularly those of you whose children struggle with school attendance due to high anxiety. It was agreed that FVS should be closely involved in the mobilisation of any new strategy and that while this group of children may be small it's crucial to ensure they are not left behind.

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	<p>FVS participated in the formal review by DfE/NHSE of Surrey's progress against their action plan (following the Ofsted revisit in 2019) regarding persistent absence. We were pleased with the transparency of data that officers shared with us and in the meeting. While data shows improvements, we also shared that your experience is not necessarily yet reflecting that positive change. We all agreed that this is an area but continues to require improvement regardless of monitoring by higher authorities.</p>
Direct Payments	<p>We have attended two fortnightly check-in meetings which were also attended by representatives from both Childrens Services and Adult Social Care. This has enabled FVS to quickly highlight any Direct Payments issues raised by parent carers and to also raise any queries in relation to the impact of COVID-19. FVS recommended that additional more detailed comms were sent out via the post to all Direct Payment recipients about the rate change. FAQs and a letter were then co-produced with FVS and were then distributed to all families. FVS helped to host a Direct Payments engagement event for parent carers on the 3rd of December. This was for families who had expressed an interest in being involved in future engagement events in the Direct Payment 2020 survey. The event gave families an additional opportunity to feedback on what had been going well, what areas needed to improve with Direct Payments as well as hearing more about a future engagement opportunity. A date will be planned for an additional engagement event this year.</p>
Short Breaks	<p>The initial Short Breaks Strategic Forum took place which we attended. This is attended by staff from SCC's Commissioning team and representatives from a wide range of Short Breaks providers. This has enabled us to highlight any queries raised by parent carers, the importance of the Short Breaks service for families and any gaps in services. It also enables us to get an update on the impact of COVID19 on these services. We were able to get an update on the recent Short Breaks survey and highlighted the short timeframe that parents had to complete the survey, an extension was put in place for the survey.</p>
Health	<p>We have queried health issues raised by parent carers with the Designated Clinical Officer for SEND. In partnership with the SCC Commissioning team FVS agreed to host the Community Equipment Service Engagement Event. This gave parent carers the opportunity to get feedback from the survey which was undertaken in early 2020. It also gave parent carers another opportunity to feedback on the recent experiences they had had when receiving equipment and the service currently provided by Millbrook Healthcare, who are currently commissioned to provide this service. A summary of the feedback from the 2020 survey has been published and FVS will help to distribute this.</p>

Meetings attended

- SEND systems partnership board
- Surrey Mental Health Summit
- FVS/SCC Escalation process meeting
- NNPCF regional meeting
- Catch up with Liz Mills
- Alternative Provision Strategy meeting
- FVS and the UVP team
- Autism strategy workstream meetings
- Preparation and meeting DfE and NHSE
- Autism Strategic Board (x2)
- Schools Forum induction
- 3 Autism Strategy workshops as facilitators
- Schools Forum
- Autism Strategy post workshop meeting
- Review of EHCP information for Local Offer
- Meeting with Assistant directors for Vulnerable Learners to discuss parent issues
- Parental preference research meeting
- Introduction to Rachael Wardell, new DCS
- Meeting with Appeer
- Catch up with Hayley Connor and Liz Mills
- Quarterly meeting with elected councillors (led by Julie Iles)
- LD & ASD Programme Board
- Preparing an induction programme with SCC for the new Engagement & Coproduction manager
- Several meetings with 0-4 Workstream co-lead from Surrey Youth Focus
- 'Enabling Families to Thrive' 0-4 workstream meetings (x2)
- Direct Payments comms meeting and prep for parent carer feedback sessions
- Local Offer Project Board meeting
- SEMH Project Board meeting
- 'Families who need more help' 0-4 workstream meeting (x2)
- Short Breaks Strategic Forum
- Direct Payments fortnightly meeting with Children's Services and Adult Social Care (x2)
- Direct Payments Quarterly Steering Group Meeting
- 0-4 Project Board Meeting
- Prep meeting for Community Equipment Service Engagement Event

Other!

Interviewing

Surrey County council asked Family Voice Surrey to be a key partner in interviewing, appointing and inducting a new Engagement and Co production Manager. This post has been in place for about 18 months but the person we have been working with has recently been promoted. We welcomed the inclusion of Family Voice to this process as this post is key to true collaboration. The interview panel consisted of FVS operations lead and The SEND transformation programme service manager at SCC. We interviewed four candidates and were unanimous and enthusiastic in the candidate that was appointed. We have more recently worked together on developing an induction programme and look forward to welcoming the new manager in the next couple of weeks.

You said, we did...

Hopefully this will become a regular part of the overview. This month we will focus on one issue that was of great concern to many parents. SCC posted a consultation on Surrey Says about an aspect of SEND funding. This caused a lot of confusion and concern. We clarified our general position regarding the processes we follow about whether we promote a consultation or not: find it [here!](#) We then took the time to discuss and debate the issues as a team, and presented our response to Schools Forum, where we were given the time to verbalise the concerns we had based on many of our members' contributions. We then published our response [here.](#)

Look out for "you said, we did" blog posts on our website...

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	EWMH	Emotional Wellbeing Mental Health