

40 Talking to parent carers

<p>Surrey Heath 66 FB members</p> <p>☹️ 😊</p>	<p>Woking 81 FB members</p> <p>☹️ Parents being overstretched and no time for themselves in the day as working or home educating schedule is hard, especially with more than one child at different stages and ages.</p> <p>😊 parent carers saying they are thankful for FVS, also 2 mums that Nicole knew from school saying how helpful, chatty and supportive she is.</p>	<p>Runnymede 48 FB members</p> <p>☹️ 😊</p>	<p>Elmbridge 283 members</p> <p>☹️ The lack of school places and advice/knowledge for transitioning kids</p> <p>😊 'FVS have kept us sane with the coffee chats and talks, it is so good to connect and talk to other SEND parents with no judgement - we really appreciate all you do!'</p>	<p>Spelthorne 72 FB members</p> <p>☹️ Fed up of the "let's wait and see" attitude</p> <p>No-one is taking responsibility for supporting families</p> <p>Parents often feel in limbo between the mainstream and SEND</p> <p>community and that they don't have a place in either group 😊 Hard to find</p>	<p>Epsom & Ewell 111 members</p> <p>☹️ • CAMHS not supporting a YP with Anxiety/ Depression due to ASD and mild learning disability (will be in a tell us your story) • College not supporting with EHCP request • Families waiting for OT mentioned in emails regarding OT talk and in Q and A at OT talk • Families uncertain what to do while waiting for diagnoses ASD/ ADHD/ DCD (Dyspraxia)</p> <p>😊 FVS being sought as an organisation that can support local families and services Parents positive about both events this month</p>
<p>Waverley 60 FB members</p> <p>☹️ PDA support, lack of recognition leading to lack of support / appropriate interventions Lack of local SEND accessible sport and social clubs</p> <p>😊 NHS services not affected by covid. Consultant, physio, MRI, X-ray, paediatrician appointments have stepped up to covid challenge and passed with flying colours. Alternative phone / online appointments / hospital appointment with covid measures. No delays whatsoever. What a shining example of what could be achieved!</p>	<p>Guildford 92 FB members</p> <p>☹️ To please give parents better support who are changing to special school. Please also give parents who have children with special needs support who are sick themselves</p> <p>😊 So great to have the online support of family voice and be able to chat with other adults</p>	<p>Mole Valley 25 FB members</p> <p>☹️ One member from my 'actual' meetings messaged me via another attendee looking for a SEND friendly playground (she has three SEND children under 6 years) BS recommended Thames Valley Playground – she was delighted to find somewhere as other parents have been commenting that her children get 'too close' when at the playground and its been stressing her out, she hasn't been looking forward to the outdoor time that she usually enjoys. She also really needed someone to listen to her.</p>	<p>Reigate & Banstead 66 FB members</p> <p>☹️ 😊 On those occasions where professionals focus their attention on the needs of the child and the family rather than their own organisational processes, the outcomes can be very positive and the sense of distrust and animosity starts to dissipate surprisingly quickly.</p>	<p>Tandridge 104 FB members</p> <p>☹️ Many parents are feeling exhausted from the pressures of supporting their children with home learning.</p> <p>😊 Some parents who are registered as carers have received their first COVID vaccine.</p>	<p>Training/ Engagement Get togethers Other</p> <p>17 Events/Talks with 164 attendees in total.</p> <p>We held a variety of talks from: - Mark Brown, Richard Semmens, SEN Tutor, Dean Beadle, CAMHS, SiBs</p> <p>Topics included: - Downs Support, Dyspraxia, Anxiety, 0-4 support, puberty & neurodiversity plus coffee and catch ups with our members</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: 2217
Facebook closed parent group members: 539
Combined local Facebook group membership: 1008

New FVS members:
89



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 :

Transport : post 16 transport should be means tested . Some families cannot afford any contribution at all. Families continue to be concerned about the risk of covid due to the lack of social distancing in taxis.

Health : equipment that has been agreed as necessary for a child is not made available and families are signposted to charities. families would like more flexibility to use available direct payments when needed

EHCP: how can a child access after school provision if they have transport provided by the council? This raises the issues of inclusion and equity. Another family wrote of being asked to provide a diagnosis before a need could be added to a plan.

Mental health : we heard a good news story of a young adult being supported in a timely and effective way by community mental health services in the South West

Adulthood : a family told us that navigating Universal Credit for their young person is proving difficult, with little apparent understanding of SEND.

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.

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?

We are working on this issue as we are committed to providing good customer care to our parents and carers. All caseworkers are expected to maintain contact with the parent and carers and we have standards we expect to be adhered to emails to be responded to within 48 hours and telephone calls to be responded to within 24 hours. We are aware that there has been a technical hiccup which means some caseworker calls have been redirected to the incorrect number. IT are in the process of remedying this.

I suggest if parents do not receive a response within the expected timescales and this is not because the caseworker is on leave or unwell they should escalate to the senior case worker in each quadrant.

2. What are the job priorities of case workers?

Case workers have a number of competing priorities as they are involved in all activities and tasks in relation to EHCNA and the maintenance of finalised EHCPS

Priorities will differ according to the time of the year at this moment we are all focused on the completing tasks for the KST 2021 cohort in readiness for the 15th February deadline

In the spring and summer terms we are often focussed on the completion of annual reviews to support next year's transitions

3. What are they judged on in the performance of their jobs?

All staff have regular supervision and an annual appraisal the details of which are confidential to that member of staff.

4. Does this impact the way they treat parents?

We expect all parents to be treated politely and respectfully

5. What training do they have in SEND?

Many of our SEND caseworkers are very experienced and come into the role from other LAs. All SEND caseworkers receive training in a variety of areas including; customer care, safeguarding, confident conversations, GDPR. In addition, staff attend regular webinars which are specific to their role such as working with parents which was delivered by BS from FVS.

In addition, we have taken the decision to develop a qualified SEND workforce and have commissioned accredited SEND courses/ qualifications from IPSEA and NASEN. Over time we expect all of our caseworkers to either have these qualifications or to be in the process of acquiring these qualifications.

6. Why is there such a high turnover of case workers?

There are a number of reasons for the turnover of caseworkers.

Monthly Overview 16th January- 15th February 2021

- following a major restructuring there have been many vacancies in the team and these were filled with agency staff these posts have now been filled with permanent staff
- When we have a pressure in the system we will take on additional staff which for expediency may be agency staff they will then leave when a task is completed
- Staff are promoted or take up secondment opportunities which may result in a change of caseworker
- We may have to manage out staff if they are not meeting our standards
- Staff leave for a variety of reasons

In our quadrants we now have a stable work force who we are investing in through a variety of training

The key issue here is the communication with parents and carers about changes and the handover between case workers which we are happy to work with FVS to improve as necessary.

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.

If a child is on the roll of a school they are expected to access learning and support via their school.

There are many children accessing A2E who have anxiety as the key reason for not attending school

If FVS is aware of a child being out of school who is not on a school roll they should contact their area Inclusion Manager in the first instance

2. How many children and young people with SEND are there in Surrey currently with no appropriate educational provision?

This question is ambiguous and it would be helpful if could clarify what is being requested –

However, I am able to state that we have 37 children who have no education provision

We have 183 that are supported by A2E

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?

The neurodevelopmental pathway has revised how families will receive support and a range of training and support information is being developed by partners

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?

I am unable to be specific about whether parents made the decision to EHE due to transport issues I can confirm 657 new requests to EHE have been received since September 2020

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?

It is acknowledged that many parents have found home schooling challenging and as in all parenting situations we can only support parents to do the best they can. I am not sure what parents are being asked to prove and to whom.

FVS: please see our February newsletter for survey which will allow you to give more detail about your experience of lockdown and home schooling so that we can better inform council partners.

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?

We are working with social care to develop a response for parents who do not have an allocated social worker – in those cases we would expect parents to access information available on the local offer website or if they require support to contact the LSPA or the Surrey Family Help Hub (formerly the Little Help Shop)

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?

We have been in touch with the relevant teams and will have answers to these two questions next month.

Sleep issues:

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

The advice given to parents is the same in the first instance and if identified with additional needs would be sign posted to the Surrey Local Offer website as well. Each child and family are offered support according to individual need. If the sleep issue is extreme and directly related to ASD and dependant on identified need the OT or Physio services may need to take it forward e.g. Lycra suits.

Questions from our members

Education

1. Why are EHCPs in general so out of date?
2. Where are the specialist places for academically able children with send?
3. There is talk of new special school capacity. How has SCC determined what school places are needed?
4. Does Surrey have a strategy for pathological demand avoidance (PDA)?
5. How can the system ensure that neurodiverse young people in mainstream are not discriminated against when they cannot meet strict behaviour guidelines? For example, if they are disorganised/ inattentive due to dyspraxia and/or ADHD and have detentions/ behaviour points for forgetting books etc.

Mental Health/ Neurodiversity

1. How can CYP access an assessment for ADHD, and what support is available for them once diagnosed?
2. How can we access CAMHS faster?

Health

1. The NHS special needs dentistry team in Epsom are only taking emergencies and urgent care because of COVID. When will normal services resume, and has there been provision put in place to deal with the additional time and treatment that many children young people with send will require as a result of the reduced service?

Participation work

Project update

Project	Update
Autism strategy	Work on developing the strategy continues with involvement of family voice and NAS at the heart of the work. We have agreed to co-chair a new board that will support drive an inform the strategy from the perspective of children and their parents and carers. this is to be called the children's autism partnership board.
CAMHS	We were joined by a Consultant Psychiatrist from SaBP and the Associate Director for Children and Families Services who spoke to FVS about the new neurodevelopmental model to gain feedback. We have been meeting with organisations and staff who will be leading on the new contract for EWMH services which is due to start in April, continuing to feedback parent carer views, highlighting the importance of parent carers being kept informed about the new service and promoting opportunities for parents to engage in discussions about the new service and what children, young people and families need.
Inclusion	A new group called the Inclusion Steering Group has been set up. This group aims to bring together the whole system approach to inclusion our role is of course to ensure that the lived experience of parents carers informs that approach.
transport	Surrey County Council is re-examining the SEND transport system, in particularly the experience of parents in navigating the system. We now planning how best to work together to ensure that parent carers experience informs any change to give than you system its best chance of success.
Surrey Family Help Hub	Surrey have developed a new online site designed for families to quickly access help on a variety of issues. As this is a BETA site the focus whilst this is trialled is for families to access support related to behaviour. We have attended a meeting to discuss the current status of the project and have been encouraging parent carers to access the site and provide feedback on the site via a link online. All feedback entries will be entered into a prize draw to win a £100 Amazon voucher. Surrey's Family Help Hub
Direct Payments	We have continued to attend regular meetings to obtain information and feedback issues raised by families who use Direct Payments. This has been mainly focussing recently on the roll out of the vaccination and regular lateral flow testing for PA's, ensuring comms are clear, highlighting any queries or difficulties parent carers have reported. We have also attended the new Terms of Reference Meeting for Direct Payments where we will continue to highlight areas for development and improvement.
Short Breaks	We have continued to attend the Short Breaks Forum with a range of Short Breaks providers and the Commissioning Team at Surrey County Council. We will be working with Surrey to ensure the feedback from the recent consultation for parent carers is feedback to parents and will consider whether there are any gaps in the feedback that the consultation has not highlighted and what future engagement may be needed. We continue to highlight the vital role that Short Breaks plays in the lives of children, young people and their families, ensuring good accessibility and in highlighting any areas for development.
Health	Surrey County Council appointed a second designated clinical officer (DCO), Paula Vyze, to join Andrea Ferns. we look forward to working with them both on a range of send issues, with initial emphasis on how information from practitioners' assessments is translated into EHCPs. We have met with an engagement officer for Community Health Services and will be looking at increasing engagement opportunities for parent carers to feedback on their experiences of Community Health Services.

Meetings attended

- SEND Systems Partnership Board
- Setting up Children's Autism Partnership Board (FVS as co-chair)
- Briefing MPs on SEND issues
- Children's Select committee – witness on transition item
- NNPCF South East Regional meeting
- Introduction to senior officer in PfA space
- Inclusion steering group
- Strategy discussion about new neuro-developmental model
- Surrey Equity, Diversity and Inclusion workshop
- Head2Head interviews
- ASD strategic board
- UVP team, FVS and Learning Space
- Introductory meeting with AD for schools, Jane Winterbone
- Interview with Surrey press RE ASD diagnoses [Surrey adults face 'unacceptable' wait of over a year for autism assessment - Surrey Live \(getsurrey.co.uk\)](#)
- SEND transport meeting
- Direct Payments Reference Group
- Direct Payments weekly catch-up meetings x 3
- Introductory meeting with new DCO, Paula Vyze
- Meetings with 0-4 Workstream co-lead from Surrey Youth Focus
- Meeting re; Surrey's Family Help Hub
- Monthly meeting with SCC and DCO
- SaBP discussion/meeting with FVS re; new neurodevelopmental model
- 0-4 project board meeting
- Meeting with Engagement Officer for Community Health Care Services
- Short Breaks Strategy Forum
- 'Enabling Families to Thrive' 0-4 workstream meeting

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