

Talking to Parent Carers

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Elmbridge <i>285 members</i>	Vaccinations!! Schools are doing a good job on the return to school and flow testing	School transition places and the lack of contact from case workers. Mental health of children returning to school
Guildford <i>92 FB members</i>	Ladies say they really enjoy the Down's Syndrome Support Group that it is uplifting and a friendly group. The ladies love the self-care groups and enjoy having some time to think of themselves. It was really relaxing and amazing chat afterwards - open and honest.	A lady was having problems getting her son to eat and social services have been threatening to take him away. She felt like no one was there to support her, but rather they were suspicious of her parenting.
Epsom & Ewell <i>111 members</i>	n/a	Confusion regarding what the statutory offer is from Educational Psychology service and how parents can request support (led to contacting EP service to invite them to a coffee morning)
Mole Valley <i>26 FB members</i>	No one currently in post	
Reigate & Banstead <i>73 FB members</i>	Some parents getting prompt response to EHCP assessment requests Some health professionals seem to just 'get' SEND and seamlessly adapt their approach when dealing with children who may be very anxious or need more time. Some schools have been adopting a flexible approach to the COVID lateral flow testing to make sure SEN	lack of school places. Some of this will be addressed by new provision with fox grove etc but nothing coming through for academically able but complex needs children. Case workers not including all details from professionals reports EHCP lacking in detail
Runnymede <i>53 FB members</i>	Getting the kids back to school	Not getting information with regards to placements for key stage transfer placements
Spelthorne <i>73 FB members</i>	ELSA has been positive and supportive in the transition from home to school	Some schools have not made reasonable adjustments to the transition of other children

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	<p>Some schools working to allow reduced timetables to settle children slowly from transitioning from lockdown.</p> <p>Surrey have organised separate taxi and escort due to family shielding at home due to extreme medical vulnerability.</p>	<p>returning to school. (e.g. allowing children to continue to wear tracksuit bottoms and trainers)</p> <p>Don't feel that parental opinion is valued or listened to</p> <p>The child is not at the centre of decisions</p>
<p>Surrey Heath <i>66 FB members</i></p>	No one currently in post	
<p>Tandridge <i>107 FB members</i></p>	Parents who are registered as carers with their GPs are being invited to book a COVID vaccine.	The lack of appropriate secondary school provision for CYP with SEMH needs in Surrey.
<p>Waverley <i>60 FB members</i></p>	No one currently in post	
<p>Woking <i>82 FB members</i></p>	They're glad to get a job, and happy colleges and schools are back.	Mainly the strain at home, not knowing when college would resume. Students struggling with their mental health and wellbeing. Parents finding it challenging and not getting info about carer vaccines, as GP surgery not registering them etc. But most are OK now.

training and events

When?	What?	Who?	How many?
22nd February (Monday 6.30pm - 8.00pm)	'Wellbeing strategies for parents of 16-25 year-olds'	Gretta	8
27th February (Saturday 11.00am)	'Self-care for carers from The Made Up Mum' run	Nicole	8
3rd March (Wednesday 10.30am)	'General chat'	Kim	5
6th March (Saturday 10am)	'Mark Brown talk on sleep problems'	Rachael	15
8th March (Monday 10.30am)	'0-4 Support Group'	Kim	1
10th March (Wednesday 11.00am)	'School anxiety chat' run	Lucy	7
11th March (Thursday 10.30am)	'Support group for Families whose children have Down's Syndrome'	Nicole	6
11th March (Thursday 1.00pm)	'General chat'	Nicole & Di	0
12th March (Friday 11.00am)	'General chat'	Claire W	4
17th March (Wednesday 10.30am)	'General chat'	Kim	5
18th March (Thursday 6.30pm - 8.30pm)	'Dyslexia Awareness' run	Gretta	15
20th March (Saturday 11.30am)	'Curly Hair Project presentation and Q&A'	Di	2 with 6 asking for recording

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: 2234
Facebook closed parent group members: 552
Combined local Facebook group membership: 1038

New FVS members:
101



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.

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

We encourage parents and indeed practitioners and others to use this more formal method of sharing their experience. It allows us to collate thematic information more easily and enables those sharing to tell us whether they prefer to remain anonymous or whether they would like us to share their details with partners. That said, we find that our richest source of information is through face to face events, physical or virtual.

[Tell us your story | family-voice-surrey](https://family-voice-surrey.org.uk)

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.

Education

1. Why are EHCPs in general so out of date?

Dear parent

An EHCP is intended to identify the long term and enduring SEND needs of a young person and will typically contain long term outcomes that the provision of an EHCP will address. The expectation is that when the outcomes identified are achieved the EHCP will be ceased.

The provision of a plan should inform the outcomes to be achieved over an agreed period of time and these outcomes are typically set out over a key stage. Shorter term outcomes such as for a year (sometimes called targets or steps towards the outcomes) will be set by the school and these are reviewed annually. EHCPs are therefore not expected to be amended every year and this is set out in the Code of Practice. However if circumstances have changed significantly and the annual review identifies that the EHCP should be amended then this will be done through the annual review process.

Also a reassessment to inform a revised EHCP is generally only undertaken if the needs of a child or young person has changed significantly

I would advise any parent who feels their child's EHCP requires an amendment or updating to discuss this with their case worker to agree whether it is the description of the young person and their needs which requires updating or has there been a change in their SEND supported by updated medical advice which means the descriptor of need and the provision to be updated.

2. Where are the specialist places for academically able children with send?

We hope to have an answer next month to this question.

3. There is talk of new special school capacity. How has SCC determined what school places are needed?

Part of Surrey's placement sufficiency work is understanding our demand for access to specialist resources and planning for this in advance. We use tools such as demographic forecasting for primary needs for children with additional needs and use this, as well as consulting with key partners, to inform our intentions for expansions or creation of new SEND provision. Surrey take into account local housing developments, population growth, historic data trends and knowledge of children and young people already in the system approaching their transfer. Understanding where the gaps in provision may be help us to define the primary need of new provision and the geographical area.

4. Does Surrey have a strategy for pathological demand avoidance (PDA)?

We hope to have an answer next month to this question.

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.

We have put together a comprehensive training manual which is in its first draft but through up-scaling our new approach we hope that this training for schools will be a key part of helping raise the profile of neurodiversity in this way.

Mental Health/ Neurodiversity

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

The best way to access any help related neurodevelopmental needs is by talking to school staff or a member of the Alliance. We will gradually move away from referrals for ASD/ADHD coming through the SPA as this just leads to a poor experience for families and referrers. Instead, there will be much more in terms of conversation and support from the beginning.

2. How can we access CAMHS faster?

By empowering and enabling families and professionals. There is lots to do to change system culture but our senior system leads are committed to helping us upskill so everyone can respond in some way to emotional health needs. This will allow quicker access to specialist services as the lower level needs can be managed by more services/professionals/families.

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?

The dental practise you refer to isn't a part of CSH Surrey but is at Bourne hall centre in West Ewell. The dental services are run by Virgin care. They are based at Epsom clinic and Leatherhead clinic. Epsom's number is 01372 745 349. They offer all a telephone consultation and then if deemed necessary will conduct a face to face. Please do call them direct if you need anything further.

Questions from our members

Education

1. Dyslexia is increasingly raised as a problem area
 - a. "Dyslexia is a SEN. SCC has a policy not to assess for Dyslexia. SCC has a policy not to detail Dyslexia on EHCP without a written diagnosis." How will children's needs be identified and supported in a timely way if this is the case?
 - b. How can a child or young person be professionally assessed for dyslexia if their parent/ carer cannot afford to pay for this?
2. How are official complaints about the SEND system dealt with and resolved? Is there any external overview of official complaints?
3. How can a parent highlight practice/policy that is inherently discriminatory?

Health

1. Parent carers have said some education settings and GPs were not aware of certain aspects of autism, PDA and that girls may present differently and can get bullied, leading to MH issues. What training is available for health professionals in this area?
2. It can be hard for anyone, but particularly those with SEND to describe symptoms, particularly pain. What training is given to health professionals on this issue?

Care

1. When should there be care input on EHCP?
2. Where can parents get support to learn how to take a step back and encourage independence with children with SEND who do not meet thresholds for social care intervention?

Participation work

Project update

Project	Update
Autism strategy	we launched the children’s autism partnership board which is co-chaired by Benedicte Symcox at FVS and Susan Harris (senior educational psychologist). FVS is the named co-lead in two of the six workstreams: “awareness and understanding of autism” and “education and preparation for adulthood”. The other workstreams have the NAS Surrey branch providing lived experience.
EWMH/CAMHS	We have continued to meet with organisations and staff who will be leading on the new contract and have discussed and provided feedback on future EWMH services. Also promoting engagement events provided by Learning Space where parent carers and young people have been able to feedback and ask questions about the development of the future service and the i-Thrive framework that underpins it.
Inclusion	We sit on the Inclusion Steering Group, in which a broader view of inclusion was discussed (diversity, poverty etc...) as well as SEND. We raised the idea of a school changing to accommodate SEND rather than asking a child to change , to “become normal”. We shared parent experience of inclusion and parent carer hopes for the kind of changes could help CYP with SEND. All agreed that schools were key and should have a forum to discuss was forward, and that FVS should be a part of that discussion.
EHCP processes	We are working with council officers to facilitate communication between the council and those families who have not got a named school for the next stage of their Childs education on their ehcp. Parents came forward with many questions that we’ve put to the council and are currently working on finalising the answers and how best to reassure those families. We have highlighted the need to prepare for a similar but quicker process at the end of March to address the same situation in post 16.
Early Years	We are coming to the end of co-leading the ‘Enabling Families to Thrive’ workstream which has focussed on the availability of community provision and access to information and support. We are now looking at what recommendations can be put forward to the board for future development, including future opportunities for parent carer participation.
Direct Payments	We attend weekly meetings with staff from social care and health services to discuss any issues parents have feedback in relation to Direct Payments. We have continued to be involved in sense checking communication sent out to families to ensure it is clear and provides adequate information, such as that related to PPE, vaccinations and lateral flow tests.
Short Breaks	FVS are aware that there have been some changes and reductions within Short Breaks and will continue to highlight the impact this could have on families, children and young people and the support they can access and receive. We continue to attend the Short Breaks Forum with the Commissioning Team and Short Breaks providers to highlight this feedback from parent carers and families. We also have a planning meeting with SCC to discuss the recent engagement survey, ensuring feedback from this is communicated back to parent carers and considering which areas still need to be highlighted.
Health	We have been linking in with the engagement team at Surrey Heartlands who have led some round table discussion events for parent carers, professionals and wider stakeholders surrounding the future development of Community Health Services. These events have focussed on sessions for parent carers whose CYP have complex needs or have CYP in early years or are of school age. We have attended the events and helped to promote them to ensure parent carers have had the opportunity to feedback their experiences of Community Health Services. This is the first stage of engagement and we will keep parent carers updated of next steps and future involvement.

Meetings attended

- Initial discussion to include parent carer voices to Children's Community Health
- Inclusion Steering Group
- Planning support for the summer with Active Surrey
- Carers Partnership Group
- Children and Young People's Autism Partnership Board
- Family Voice SCC / DCO meeting
- Creating a 3rd sector SEND network with Surrey Youth Focus
- PfA in 2021 planning with Jacquie Burke
- Surrey Appreciative Inquiry and Learning (SAIL) briefing
- Key stage transfer meeting
- User Voice and Innovation EWMH Alliance Meetings with Learning Space
- Early Years Strategy discussion meeting
- Direct Payments weekly catch up meetings
- 0-4 Enabling Families to Thrive workstream meeting
- NNPCF virtual conference meetings

Other

We were invited to sit on the interview panel for some key roles in the world of send at Surrey County council. It was a great opinion too remind any candidates of the importance of parent carer voices in this work, and a joy to meet some truly passionate people. We look forward to working with whoever is appointed.

The Curly Hair Project offer staff training in schools, for GPs and offer parent webinars and were happy to answer more questions. They want more SENCOS to find out about them and asked p/cs and FVS if possible to spread the word.

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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