



## Monthly Overview: March - April 2021

Facebook page followers: 2299  
Facebook closed parent group members: 556  
Combined local Facebook group membership: 1069  
Twitter followers: 1746

New FVS members:  
37

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*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*

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### Talking to parent carers

	😊	😞
<b>Elmbridge</b> <i>285 members</i>	Covered by the wider team	
<b>Guildford</b> <i>97 FB members</i>	Potential PDA support group starting up as well as a group of ladies wanting to meet in person	That parents are still struggling so much to get the help they need; professionals and parents around them to believe the struggles they are having with their children and then waiting sometimes years for appointments and then having to fight to get an EHCP.
<b>Epsom &amp; Ewell</b> <i>113 members</i>	Positive stories about an outstanding local SENCO and receiving an EHCP well within timeframes. A parent said 'Surrey can't be faulted on this'	When diagnosis for ASD is such a lengthy process, EHCPs may come before the diagnosis. This is fantastic if this means individualised support can be put in place more quickly, but hard when a new school type of school provision is necessary, as potentially suitable schools will not consider a young person without a diagnosis (primary need may be considered SEMH rather than ASD). Y
<b>Mole Valley</b> <i>28 FB members</i>	Covered by the wider team	
<b>Reigate &amp; Banstead</b> <i>78 FB members</i>	Once professionals take a child's needs seriously very good plans and strategies can be put in place.	Assumption that in inclusion strategies 'cure' a child's needs and can be removed once things are stable. This is very damaging and actually makes children feel less safe and supported. One parent reports getting a refusal to assess decision on grounds that her child has no diagnosis.
<b>Runnymede</b> <i>55 FB members</i>	Covered by the wider team	

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Spelthorne 72 FB members	Continued positive impact for families connecting through Zoom.	People experiencing discrimination in rented housing due to having disabled children. One estate agent referred to their policy on "not allowing pets".
Surrey Heath 67 FB members	Covered by the wider team	
Tandridge 114 FB members	That schools and colleges are now fully open.	The increased need for mental health support for children and young people.
Waverley 62 FB members	No one currently in post	
Woking 87 FB members	Back to school seems to be going okay.	Lack of recognition of autism/late recognition. Also more info required for girls generally, who are on the spectrum. Any groups for teen Autistic girls/YP., and Autistic / ND teen LGBTQ+ groups?

## Events

					
15/3	Eliza Fricker talk on PDA	5	30/3	Laura Kerbey PDA session	17+12*
20/3	Curly Hair Project Event coffee morning event	4	30/3	0 – 4 Focus Group	1
22/3	Self Care Talk coffee morning	11	31/3	Zoom Coffee Morning	6
22/3	16+ Support Group Zoom on mental health, with Benedicte Symcox	8	7/4	Coffee Morning	2
25/3	Self care	7	7/4 & 14/4	WEA talk on ADHD (2 week course)	14
26/3	Coffee morning	1	14/4	USSA monthly chat session	10
27/3	Mark Brown Anxiety talk	14+9*	15/4	PDA Group coffee Catchup	11
29/3	WEA Talk on navigating the SEND system	11	16/4	Chloe Farahar - Positive Autistic identity	12

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

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*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.*

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

## Mental Health

- Mental health needs not met and leading to child missing education for 2 years
- Mental health needs not acknowledged by school unless CAMHS is involved. GP advice ignored
- Children with SEND or mental health needs who were not given access to school during lockdown now struggling with school attendance
- A need for an attendance code that acknowledges anxiety as a reason for absence. This would make early identification much easier
- Schools normalising meltdown behaviour as a consequence of lockdown, and minimising the needs of autistic children

## EHCP

- EHCP process going beyond timescales with accounts of very adversarial experience, parents feeling “intimidated and bullied” when they make an appeal, frustrated at the need to go to tribunal when it seems that the available evidence has not been read.
- No action on an annual review after a year in spite of agreement that a different setting is required
- Young person feeling ignored in their preference of post 16 options
- Concern at the proposal to remove boarding provision at Sunnydown school
- Lack of communication from case workers to families in the key stage transfer process, both while waiting for a placement to be named and if the placement feels wrong. Several stories express frustration and dismay that their voice is not being heard.
- Where relationships have broken down, there is fear that schools have a powerful say in decisions and parents are disempowered

## Other

- Lack of speed and support following exclusion, and frustration at alternative provision that is unsuitable to a child’s SEND
- Surrey Young Carers are having to remove support from some families (due to capacity?) and this is causing huge distress
- Housing needs – councils not recognising the impact of SEND when looking at applications (Spelthorne and Runnymede)

## 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

From last month 😊 Does Surrey have a strategy for pathological demand avoidance (PDA)?

Further to your enquiry regarding the provision of specialist placements for those with Pathological Demand Avoidance (PDA), children and young people with demand avoidant profiles usually have a diagnosis of Autism.

In Surrey we have a position statement regarding PDA which is being updated.

In summary we would expect any school who is meeting the needs of a young person with autism to understand, adapt and differentiate the delivery of the curriculum and the learning environment to include those with anxiety based demand avoidant profiles. Therefore, some young people are supported in a mainstream setting and some in a specialist settings according to their individual needs.

Surrey schools are able to seek support from the Educational Psychologist service and the Autism Outreach service if they require advice and support to meet the needs of children and young people with autism and demand avoidant profiles.

I hope this information is helpful and you find it useful

1. Dyslexia is increasingly raised as a problem area

a. "Dyslexia is a SEN. SCC has a policy not to assess for Dyslexia.." How will children's needs be identified and supported in a timely way if this is the case?

The Surrey County Council policy for dyslexia was published some time ago and is currently being updated. The current policy ( on our website) does however define our understanding of dyslexia at this time and best practice in assessment and intervention. The policy states that :

Teachers should be able to identify, at a young age, children who may have a dyslexic profile and who may be finding it harder than others to learn to read, write and spell. Teachers should be able to identify areas in which children and young people are struggling and to understand that this may be due to dyslexia

and that

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The local authority will provide support to develop quality school-based identification, intervention and monitoring of the provision for pupils with dyslexia. Access to this support will be through school staff training and collaborative working within the consultation process offered by specialist teachers and educational psychologists

It may be that there is some confusion about the phrase 'not to assess for dyslexia' where the focus is on assessment for diagnosis. Whilst the assessment process may indicate that the child has dyslexia, specific learning difficulties or difficulties in learning to read and write the focus of the assessment must be for teaching/intervention so that the child can acquire the skills they are struggling with.

Whilst diagnoses can be important for a number of reasons they are not an access route to resource in and of themselves, or barrier to receiving the right support at the right time. Schools follow a graduated support offer in line with the child's identified needs.

"SCC has a policy not to detail Dyslexia on EHCP without a written diagnosis"

I haven't seen this however we would expect the plan to describe the child's identified needs irrespective of diagnosis – the diagnosis does not describe the particular challenges

b. How can a child or young person be professionally assessed for dyslexia if their parent/ carer cannot afford to pay for this?

When a child or young person is not making expected progress in their literacy skills teachers are best placed to complete an accurate school-based assessment in order to inform an appropriate intervention. These assessments measure reading accuracy, reading fluency, reading comprehension, spelling, and writing and will identify the specific areas of literacy that need improving. Additional assessments are sometimes completed by specialist teachers and/or educational psychologists

Assessment over time and monitoring of the child or young person's response to teaching is now accepted as the most effective way of identifying literacy difficulties<sup>2</sup>, informing intervention and determining the rate of progress.

2. How are official complaints about the SEND system dealt with and resolved? Is there any external overview of official complaints?

A formal complaint goes through "Be Heard" who would then decide which team is best placed to respond e.g. if it is about Transport or tribunals or Key Stage transfer admissions or about Vulnerable Learners' service. Our preference is for issues that parents are concerned about to be resolved as

quickly as possible without the need for a formal complaint. So we encourage parents to liaise with their case officer or escalate to the senior case manager for a way to resolve problems quickly. (please see leaflet attached for more info).



Tell us what you  
think about our Educa

The Customer Service Team whilst not independent of the Council, is an impartial service. Should a full review of concerns raised be required at stage 2, the team is tasked with balancing the original complaint and the Service's initial response at Stage 1 against the relevant procedures and associated guidance to determine if any further action is needed on the part of the Council. The team liaises with the families and also with the Services involved to complete the response.

### 3. How can a parent highlight practice/policy that is inherently discriminatory?

Families can submit their concerns through the online link [Children's social care, education and SEND complaints - Surrey County Council \(surreycc.gov.uk\)](https://www.surreycc.gov.uk). The Customer Relations Team would review the most appropriate route to take this forward. In these instances, it is likely the issue will be raised with the appropriate member of the Senior Leadership Team. The Customer Relations Team will act as a single point of contact for the family.

Health: we will chase answers and add them to next month's overview

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?

We make every effort not to repeat questions that have been answered previously, but this one slipped through the net 😊 Find the answer [here](#).

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?

The service you describe is quite specific, so there are only limited instances of this exact offer or something similar to it being provided. We have however highlighted below a few services/sources of information that may be of use in building a sense of knowledge and so reassurance to feel able to step back.

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- The [preparing for adulthood section of the Local Offer website](#) provides detailed information and support services for young people moving into adulthood.
- [National Autistic Society - Transition Support Service](#), provide a Transition Support Helpline which offers advice and support to young autistic people and their families on making the transition from school, further or higher education to adult life. The helpline number is 0808 800 0027.
- [Contact](#) have a section regarding [Preparing for adult life | Contact](#) which may be helpful to refer to. It is “young person friendly”, so you might like to also refer them to this.
- The [Preparing for Adulthood website](#) provides knowledge and support to families and young people, so they can ensure young people with SEN and disabilities achieve paid work, independent living, good health and community inclusion as they move into adulthood.
- The [Council For Disabled Children’s Transition Information Network](#) is a further source of information and good practice for disabled young people, families and professionals.

All of the above have been found using the [Local Offer Directory](#), we would highlight this as an invaluable tool for all parent/carers to use to find the details of services and support.

## Questions from our members

1. Lots of families are contacting us about KS transfers as they do not have placements and have had no information. Who should they contact if the caseworker is not providing information?
2. When SEND Case Officers are allocated an adopted or fostered child or young person to support, how much and for how long do they liaise with the Post-Adoption Support team and the Virtual School?
3. My child's social worker shows little understanding of their SEND. How can I ask to work with someone more suitable to assess their need?

## Participation work

### Project update

Project	Update
Autism strategy	FVS is the named co-lead on two of the workstreams developing and then implementing the strategy: Education & Preparation for Adulthood and Awareness, Understanding and Information. We will be working with coordinators to gather feedback from parents that will then feed into all the workstreams. We continue to work closely with NAS Surrey branch who provide the lived experience lead on the other workstreams.
Transport	We have posted a call for families embarking on the SEND transport journey to work with us as case studies to monitor and shape the "customer journey" while working closely with SCC.
Inclusion	We have begun working with SCC to clarify what families should expect from mainstream schools and will be looking for experience that will then feed in to the work on inclusion.
EHCP processes	Work this month focussed on giving information to key stage transfer families who do not have a named placements. We collaborated on a "FAQ" leaflet that all such families should have received. We have asked families to contact us if they have not received it.
Early Years	FVS co-lead on one workstream "Enabling Families to thrive and achieve their full potential" and are involved in feeding back recommendations to the board.  The early years graduated response team have joined the FVS 0-4 group twice to talk to parents directly and to answer any questions parents have.
Direct Payments	The initial Terms of Reference Group on Direct Payments has discontinued. To ensure this is truly coproduced it was felt that this group should be led by an independent organisation. This piece of work will now be directed by the Surrey Coalition of Disabled People and we will be meeting with them to look at how parent carers' voices and feedback can be included in the new group.
Local Offer	Using the consultation feedback Surrey County Council are working on a 'beta' version of a new Local Offer website. In June Family Voice will be involved in feeding back on the initial version and ensuring a wider group of parent carers have the opportunity to

	feedback during the early stages of development. Following this more detailed ‘user testing’ will take place, with a view to the new Local Offer being in place by the end of the year.
Social Care	FVS are working with officers to find way to develop links with CWD team staff/area coordinators to better inform parents of existing services and support and also to inform the social care teams of parent experience with and without support.
Short Breaks	A new Short Breaks Directory is being compiled. The importance of parents knowing as soon as possible what will be offer for the summer was highlighted. FVS will work with commissioning to ensure feedback from the recent survey is given to parent carers and will continue to highlight any gaps in the current offer for families.
Children’s Community Health Service	Several coordinators attended the round tables to give feedback on parent experience of the community health service.

## Other Activity

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Surrey Heartlands asked us to comment on a leaflet designed for patients referred to their rapid diagnostic service. We were pleased to highlight Send issues that could make their work more accessible.

## Our wish list

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SEND is a huge world and we will never be able to do everything we would like. Here you’ll find details of things we have had to say no to...

*Surrey County Council and its Health CCG Partners are recommissioning the Community Equipment Service, for implementation in April 2022. The commissioners are looking to form the following group, Surrey CES Recommissioning – Service User and Carer Group. The group will be relatively small, containing representation from Surrey Coalition x2, Family Voice x1, Action for Carers x1 and Age UK x1.*

While we did not have the capacity to meet this request, we signposted the team to someone we felt would offer representation of parent carers.

## Meetings attended

<p>ASD Workstream Lead meeting x2          Preparing for Adulthood Meeting          FVS/SCC DCO Meeting          SEND Transformation SEMH project board meeting          SEND Systems Partnership board          Children's autism partnership board          Feedback from families to SCC RE proposal to close boarding at Sunnydown          Transforming the Surrey system for CYP EWMH workshop          SSCP Engagement and Communication Sub Group          Inclusion steering group          Inclusion and EHCP processes discussions          Transport discussion          PfA comms &amp; engagement working group          Direct payments catch-up x2          Direct Payments reference group          CwD catch-up x3          Short breaks research findings          Short Breaks Strategic forum          0-4 SEND project board          Early Years strategy steering group</p>	<p>NNPCF AGM          NNPCF input into the SEND Review          SE19 NNPCF regional meeting          Input to "SEND in Surrey" Impower research          Partner interview panel for AD SEND posts          Collaboration with Surrey Youth Focus          Collaboration with Healthwatch x2          Quarterly meeting with elected members of Surrey County Council          Catch up with Liz Mills, Director Education, Lifelong Learning and Culture          Introduction to communications &amp; engagement at SCC          Headteacher meeting to discuss inclusion          Alternative provision discussion          Local Offer Project Board x2          Early Years workstream meeting x2          Early years/autism scoping meeting          3<sup>rd</sup> sector safeguarding meeting          Surrey Safeguarding Partnership meeting          Community Health Services discussion          CSPA/LSPA meeting          SWP Alliance user voice update</p>
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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
CwD	Children with disabilities social care team	SWP	Surrey Wellbeing Partnership