



# Monthly Overview: Nov & Dec 2021 and Jan 2022

## What we have heard

Group	
Post 16	Speakers: Ginny Willis & Sans Souci Home Care, FOC. Parents said that they found this event interesting and useful. Some said that they would contact Ginny Willis for advice regarding transitions.
Post 19	General chat, no speaker. Main discussion was around supported living. Parents are very grateful for the opportunity to connect with each other via this group.
School Anxiety	Speaker: Eliza Fricker, Missing the Mark, on PDA and school anxiety This speaker was very well-received and the presentation was followed by a lengthy Q&A about school anxiety
PDA	Went very well – parents said they preferred it to some online/facebook groups. Another said they'd help a mum who is new to the process, Mum said she felt heard and appreciated others who understood #the situation.
Early Years	This was a fun and enjoyable session for families to experience Rhymetime, a service provided by Surrey Libraries. This has been slowly reintroduced since July 2021 (COVID). A recorded version of a previous Rhymetime for children with additional needs will be shared by Surrey Libraries and LH to disseminate. The session was also attended by members of Horley Library who are currently developing a similar session for children with additional needs. (CPD session)
Dad's Event	The majority would like a regular event with more focused topics. Most were grateful for an opportunity for Dads to get together. One said they would like to meet in person when the opportunity arises. "But I feel my son is not 'extreme' enough for much of what was discussed to be relevant to me." As far as future events, a parent suggested: "How to get extra help at schools, and how to encourage your child past the "I don't care" attitude and to try harder with school/homework."

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### Transport

Battle to secure.  
Contracts changing with no notice and no new taxi company secured.  
Parents being left to transport children to school

### Short Breaks

Day breaks are too few and far between, also can be difficult to book

### EBSNA

(Emotional Based School Non Attendance)

Bright children, particularly girls, missing chunks of education,  
Many reports of children and young people damaged by the school system and that these impacts/traumas continue throughout life

### PfA

Parent reported that her son was assessed while at specialist secondary where he was very supported and felt safe and this was used to inform support at college and as a result his needs were significantly underestimated and placement broke down.

### Covid

parents unable to visit settings both education and supported living

### Mindworks

parents told that anxiety is part of ASD so cannot be helped  
waiting list for both ND and MH  
crisis line problems

### Health

Parents with NICU experience talk of having a lot of paperwork and little support  
Lack of support in spite of known and common condition

### Early Years

Parents concerned about social media

### Supported Living

Parents report a gap in the supported living market for those who are able to live independently – cooking, working/volunteering etc, but also need high support

### EHCP Processes

parents being forced to appeal ridiculous decisions where often the case worker clearly concurs with this  
Case officer didn't turn up to emergency annual review  
Need to threaten legal action to secure provision.  
Families with money are the only ones who can go to court  
No caseworker for 6 months  
7 appeals and Surrey are not obeying Judge's orders  
Recognition that it is a Government under-funding issue

## Parent Carer Quotes

*PDA - Parent said how she found chatting with other parents very therapeutic. She also said Oatlands School in Weybridge had been very good with her 5-year-old daughter since she had been diagnosed with PDA.*

### *School Anxiety*

*'Our GP won't sign my child off as there's no diagnosis of anxiety.'*

*'My son's been out of education since last March. It's been hard. He's had no professional involved with him since he's been out of school.'*

*'I'm just on my own as my son doesn't want to go out.'*

*'I feel very bruised about what happened to my son.'*

*"It was really lovely to be in the company of a 'room' full of people who just all get it! Thank you"*

### *SEND and Everyone Active (Spelthorne)*

*"Our kids need different things to neurotypical kids. Like, for example, my son requires me to be on the side of the pool. Without me there, he won't go in. Little things like that make a huge difference. I know each kid will have different needs, so this would need to be taken into account by the leisure centre."*

### *SEND and Everyone Active (Spelthorne)*

*"I have been trying to get my daughter back in to 1:1 swimming lessons with me in the pool since Challengers had to stop hers a year ago"*

*"We used to go there (Spelthorne pool), but the centre staff had a go at me for sitting by the poolside, so we left. As an autistic person myself, confrontation is really frightening for me, so it put me off straight away. We have never been back since."*

### *Supported Living*

*'The supported living settings that we've looked at are not very secure. They won't lock their doors, even at night.'*

*'I'm really concerned that we're not going to find a house for my young person to move on to.'*

*'On paper some of the providers look amazing but some of them are enormous.'*

*'Providers saw my son in college where he was managing really well, but when he was taken out of that it was very different.'*

*'We haven't managed to heal from what happened in supported living yet.'*

*"Sans Soucie have always been very good."*

*'I don't want my son to live miles and miles away.'*

*'We should have fought harder but we just didn't know how things should be.'*

*'Our young people are so precious to us.'*

### *Health*

*My daughter's school placement broke down a while ago and she scarcely is able to leave the house. I was very worried as she had been unable to access a COVID vaccine and I was unable to get any help through the online booking system, the standard number or by turning up at walk in sites. I had the most amazing experience when contacting Eva Bangova at NHS Surrey Heartlands having got her number via the NAS Surrey branch forum - she was so helpful! She arranged for my daughter to be seen at the closest centre*

*(which don't usually see her age group), let everyone there know her needs in advance and when we got there the doctor came out to the car to give the vaccine as they were expecting her, Everyone from the car park attendees throughout were so helpful.*

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## What Parent Carers are asking

1. Assessments that are done as children move to post 16 need to be forward thinking and not over depend on independence shown in very supported specialist settings at secondary.
2. Sorry but yet again: Plans for provision for academically capable ASD children? Thinking of those capable of a full range of GCSE options but unable to cope in mainstream there is currently ZERO provision that I know of in the maintained sector.
3. There are always questions about: Do we know if there is a written EOTAS policy at present. If so, can we see it please and signpost parents to it. With so little school provision (see point in Autism Strategy) this is a growing question.
4. Can a school refer to A2E or does it have to be LA? Can children without EHCP access it? Can a parent refer if a school refuses to?
5. What can a parent do if a child would benefit from Surrey Online School but school refuses to pay?
6. Lot of confusion about Mindworks and referrals seem to be in chaos. Parents unclear on where a referral goes to when GP/School make a referral.
7. How does a parent moving in to an area get prescribing of medications from CAMHS transferred.
8. Families referred to PRU are unsure what this is and there is little guidance. Is it possible for FVS to have some guidance ot give out to parents on this.



"I don't like writing because I am not good at it."  
'I don't want to go to school'  
"Other children bully me because I am slow with my learning"  
"All the children at school call me weird"  
"No one at school likes me"  
"The teacher locked us in a classroom today"  
"I want to go to school and one to be found for me as soon as possible. I need friends and that is the way I want to live my life"

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## FVS Events\*

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

					
<b>23rd November</b>	Enhancing your well-being - for carers	18	<b>16th December</b>	General Chat - Christmas attire encouraged!	4
<b>25th November</b>	Meet Emily Chalk, Caseworker at Duncan Lewis Solicitors	5	<b>16th December</b>	19+ chat group	5
<b>1st December</b>	General Chat	5	<b>5th January</b>	General Chat	7
<b>2nd December</b>	Early Years event with Guest Speaker, Dr Kathryn Hollins	5	<b>12th January</b>	School Anxiety Chat	22
<b>6th December</b>	Dads Chat	13	<b>13th January</b>	PDA chat	8
<b>8th December</b>	School Anxiety Chat	19	<b>14th January</b>	Rhyme time for children with additional needs and/or disability	4 Families
<b>13th December</b>	16+ Group	16			

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## Participation work

Project	Update
EHCP	FVS and the NAS have been involved in the interviewing of a new role at Surrey – Autism Lead this person is going to work directly within the Autism Strategy in ensuring the strategy is implemented and is delivering all that it has promised. Once they are settled in their new post we hope to be able to introduce them to all our members later this year.
Alternative Provision	We are pleased to be working with Surrey in developing some parent guidance on Alternative Provision and EOTAS (Education Other Than At School). Please do keep sending in any questions you have about this and any experiences you would be happy to share these will be invaluable in developing this. Please send to Leanne – <a href="mailto:leanne.h@familyvoicesurrey.org">leanne.h@familyvoicesurrey.org</a>
EBSNA	We have been blown away by the response to our survey, please do complete this if you have a child experiencing school anxiety it will stay open until the 11/2 we will then analyse these results and commence our next stage which is gathering families' experiences. Your input really will make a huge impact on the work that is happening in this area. <a href="https://www.surveymonkey.co.uk/r/HVTG77R">https://www.surveymonkey.co.uk/r/HVTG77R</a>
EHCP Process	We are very excited to announce that we have now recorded the first 2 of the series of videos we are producing with Surrey where the questions that you sent in will be answered. We will be developing an FAQ document to go alongside this and will welcome your feedback and further questions once they are published. We are also working on the next few videos which will continue to roll out over the next few months. Once the videos are published we will let you all know.
SEND Admissions/Key stage transfer	We are aware that the Key Stage transfer deadline of February the 15th is looming, and historically this has been very challenging for families particularly those who don't receive the placement they had hoped for or don't receive a placement at all only type. We are meeting regularly with the SEND admissions team and hope to assist with communication to families. If you are experiencing difficulties with this please do email Leanne – <a href="mailto:leanne.h@familyvoicesurrey.org">leanne.h@familyvoicesurrey.org</a> .
Early Years	Our Early Years group meets monthly and is for families with children with additional needs between the ages of 0-6. We meet the second Friday of the month at 11am online. If you would like to join or find out more please do email Emily – <a href="mailto:runnymede@familyvoicesurrey.org">runnymede@familyvoicesurrey.org</a>
Preparing for Adulthood	Family Voice are working with Surrey in producing a new brochure that will cover all families and young people need to know about Preparing for Adulthood. We are also looking forward to the PFA team joining us on some Facebook Lives over the next few months.

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Short Breaks	Awaiting next meeting date to discuss the findings from the feedback stages. Meeting arranged with SCC to understand what is available for families this summer
Mindworks	We are working with Jess Thom and her team to alleviate the confusion families are finding with Mindworks and focus on communication to families about Mindworks can currently offer.
Direct Payments	Attending monthly strategy meetings. FVS facilitating a session for families to feedback the challenges/benefits of using Direct Payments.
Local Offer	We have been working with the SCC to review and rewrite sections of the Local Offer website, including the EHCP section. These sections are now live and we are discussing what sections we will support with next.

### Meetings attended this month

Project	Information
Health	Health inequalities design and transformation workstream
Health	Birth to school partnership meeting
EWMH	CYP Advisory group meeting
EWMH	Responding to sudden and unexpected death of a pupil
EWMH	ND weekly meeting
Direct payments	One council direct payments strategy
Early Years	Better start transformation board
Direct payments	Learning disability partnership board
EWMH	Communication planning meeting
PFA	PFA Comms and Engagement Group
PFA	PFA Transformation Board
Autism	Children and Young Peoples Autism Board
Alternative Provision	Discussion around strategy
Inclusion	Meeting with ICS Joint Strategic Commissioning Conveners & Family Voices Surrey

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CEO	Schools Forum
Direct Payments	One Council Direct Payments Strategy - core/community group
CEO	Co-production; Self Evaluation Framework
CEO	Learning Disability Partnership Board
CEO	LD & ASD Programme Board
CEO	IAN AD monthly catch up

### 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

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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		