



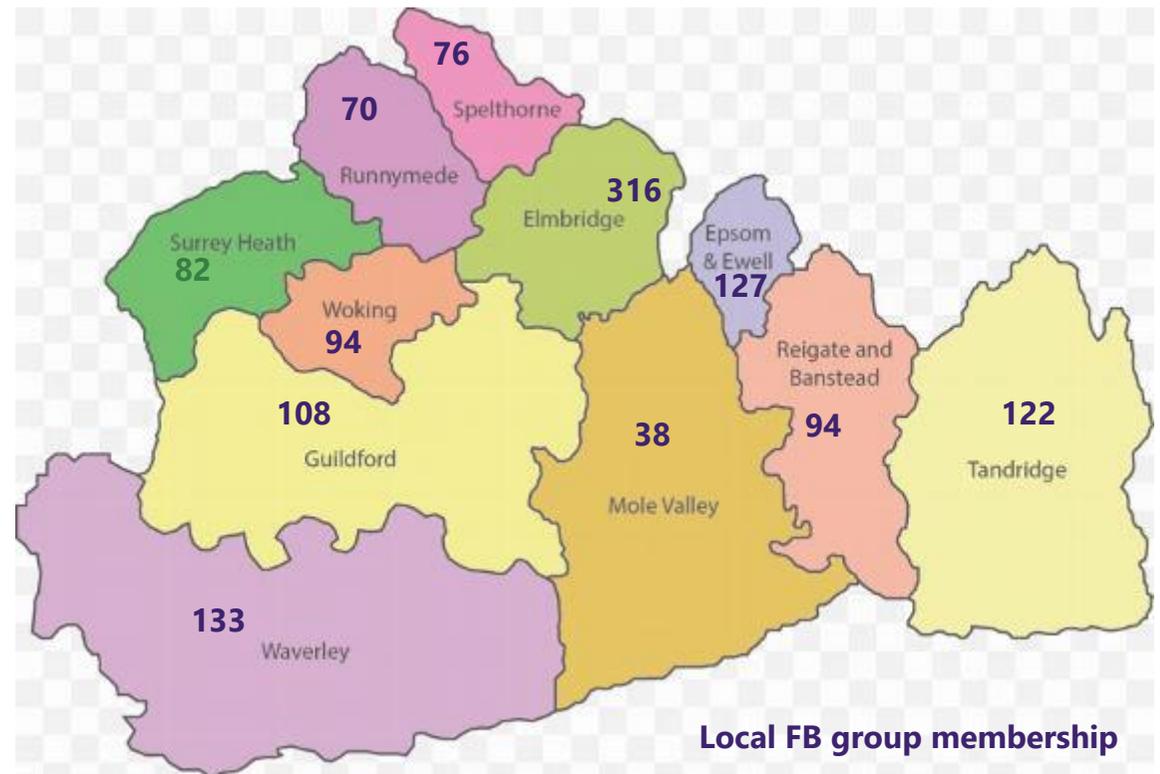
Monthly Overview: June - July 2021

Facebook page followers: 2484
 Facebook closed parent group members: 583
 Combined local Facebook group membership: 1260
 Twitter followers: 1794

Members who attended an event:
 135

New FVS members:
 31

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



Local FB group membership

What we have heard

16+ and the Transition team
Very helpful to parent carers.
Many had never heard of the transitions service though they should have via school SENCO's etc.
Clearly a gap in the service for those without ASD diagnosis. What about those who most likely have ASD but are not diagnosed?

RFID
Happy to find families that understand

ADHD Soli Lazarus
Powerpoint presentation for an hour and people submitted questions in the chat box.
Parent carers liked the speaker, liked the positivity, encouragement. Range of examples relevant to all age groups – not just young children. Asked for: Teenage ND brain; sleep issues; family issues – unsupportive/unaccepting wider family, sibling issues.

PDA
We discussed school placements.

Getting a Diagnosis in Surrey?

Schools feel unhelpful and obtrusive. We heard several stories of parent blaming.

We discussed schools and strategies that are helpful. *

We promoted self-care and tell us your story/LA feedback. Also discussed breaks and clubs in the local area.

Parents mentioned they were thankful for the opportunity to meet and for the group.

**See "What helps families"*

PDA talk
Powerpoint presentation and Q&A afterwards.
Talk was well received by the audience.
Many real-life examples as Clare used to teach (now does teaching online). Recommended books and websites for information.

One teacher/SEN parent found it inspiring and many ideas to use at school.
All PCs who gave feedback said Clare was a good speaker.

Downs syndrome
The main question people want to know is, is supported Living for them?

School anxiety
All agreed that there is little understanding of what Inclusion officers do
There are a severe shortage of school places for children who cannot manage school and in essence none in the maintained sector for those who need a complete mainstream curriculum but cannot cope in mainstream.

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Guildford hangout

People found it beneficial to meet local parents

One parent wanted to be a parent rep. Parents are still struggling to get the right support.

One cannot get their child into school and has no support with this

Several parents struggling to get an EHCP for a child who already has a diagnosis.

In the private schools there doesn't seem to be as many children with a diagnosis and this seems quite strange.

Louise Cheetham Bridge Flexi school

"Great and helpful session."

There was a range of answers from people needing funding for part-time help at home to people needing support on how to help their anxious children.

A lot of parents really needed support again with the EHCP process and getting what is stated in the EHCP, but also some of them need help getting their EHCP updated.

What was helpful was one parent needed help getting their child out of their room who had been stuck in their room for over a year and there was hope to help people out of that situation.

General chats

Parents really appreciate downtime and time in a social environment. They feel isolated.

Good to chat about holidays/Covid travel and getting an appropriate school place.

Talking about school provision and how satisfied people were/what experiences people had.

YP in hospital schooling but no further offer

Good to hear how others got places.

The best places were given to those who went to tribunal and had judicial reviews.

Parents unhappy at the process.

Free school meals – question re how support will happen over Summer hols (already followed up)

Discussion around health funding for EHCP where need is mental health
Difficulty around accessing CAMHS. Positive experience of using new Surrey youth mental health phoneline

'Radical acceptance' that life will be different for our neurodiverse children discussed

What helps families with anxious or demand avoidant children?

Helpful approaches for a PDA profile of autism

Conventional support strategies, including those often recommended for ASD, are often ineffective and counter-productive with a PDA profile. In place of structure, routine, firm boundaries, praise, rewards/consequences, is a person-centred approach based on negotiation, collaboration and flexibility.

The PDA PANDA symbolises the need to tailor the environment to meet needs and our P A N D A mnemonic is a simple reminder of helpful approaches.

For more information please visit www.pdasociety.org.uk

Pick battles

- Minimise rules
- Enable some choice & control
- Explain reasons
- Accept that some things can't be done

Anxiety management

- Reduce uncertainty
- Recognise underlying anxiety & social/sensory challenges
- Think ahead
- Treat meltdowns as panic attacks: support throughout & move on

Negotiation & collaboration

- Keep calm
- Proactively collaborate & negotiate to solve challenges
- Fairness & trust are central

Disguise & manage demands

- Word & position requests indirectly
- Constantly monitor tolerance for demands & match demands accordingly
- Doing things together helps

Adaptation

- Try humour, distraction, novelty & roleplay
- Be flexible
- Have a Plan B
- Allow plenty of time

Pick battles
Anxiety management
Negotiation & collaboration
Disguise & manage demands
Adaptation

See the person
Explore interests
Engage positively

© PDA Society 2019

Parent carers found this graphic from [the PDA Society](http://thePDA Society) really helpful. They would like more schools to use it in staff training.

[Harry Thompson](#) has helped many parents understand their child and find more appropriate responses.

Don't pressure the person, try not to dictate but rather collaborate.

Take time for yourself, accept that you need some respite and space to breathe and manage your own anxiety

Don't take things personally! Swearing and outbursts are an expression of anxiety.

We heard very good things about how Papillon School was handling their child. The small classes were very helpful.

Parents would like to find the "perfect school" but it is really down to each school, parent and child. The dynamics are so varied that you need to visit and build relationships so that the child's needs can be met.

Events

					
21/06 evening	16+ group With SCC Transition team	19 (4men)	1/07	Louise Cheetham of Network Interventions and the Bridge Flexi School	12
22/06	Shine course	6	5/07	Soli Lazarus, founder Yellow Sun ADHD Hub	11
23/06	General chat	3	6/07	PDA group	4
23/06	General chat	3	7/07	General chat	3
24/03	Guildford meet and greet	5	8/07	Downs Syndrome Parent Carer Group	2
25/06	General chat	2	13/07	PDA talk	18
28/06	Q&A with Cerebra – Services, Sleep, Legal and more	5	13/07	Coffee and chat	1
28/06	Is your child with SEND age 13 – 25? With SCC officers	31 (5men)	14/07	GDD group	1
29/06	Talk on restrictive food intake	6	15/07	Guildford Zoom hangout	3

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

Best thing I have noticed about FVS events is the helpful exchange of information

Excellent presentation. Clearly illustrated by realistic hands-on experience. Learned a lot and references are useful.
Parent comment following PDA Talk with Clare Truman

Surrey doesn't care about families like us.

Thanks – very interesting

Why have I been rejected for the EHCP assessment when I already have a diagnosis?

It was good to chat

Please pass my thanks onto Clare. It was amazing and such an insight into PDA which I wasn't fully aware of. I'm going back to my school (and my parenting skills!) with lots of good ideas.
A SEND parent/carer who is also a teacher.

'Very Inspirational'

Concerned about the lack of adult services for ARFID

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.

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

Short Breaks/Respite

- In line with what we have heard at get togethers, families are telling us of the impact that Short Breaks closures are having and how area boundaries have caused confusion and loss of support.

Early Identification

- One family told us of their frustration in how to meet their child's needs. What had seemed to be hearing impairment might be auditory processing. School are struggling to find the appropriate intervention and the family is desperately seeking support at home. The process of identifying their child's needs is very slow.

Participation work

Project update

Project	Update
Social Care	Please see our newsletter for an update from the Children with Disabilities team We are embarking on an exciting piece of work to develop a direct payments strategy. The need for true co-design has been acknowledged and we are pleased to be part of a group that includes Surrey Coalition for Disabled People https://surreycoalition.org.uk/ and Surrey Independent Living Council https://www.surreyilc.org.uk/home . If you would like to be involved, please contact benedicte.s@familyvoicesurrey.org
Communication & Information	A new Local Offer website is being developed and SCC are looking for parent carers to test it. Please contact
EWMH	We have worked with the new EWMH service to help design a website that meets the needs of families, and supported an initial workshop. Follow up work is continuing and those interested should contact Lucy.y@familyvoicesurrey.org
Short Breaks	The service is in the midst of a strategic review and keen to hear from parent carers about their experience and need. You may be asked to fill out a survey by providers but you can also let us know your experiences at tell us your story
Transport	Travel Assistance Manager – Chris Mcshee at Surrey County Council attended one of our events on 22 nd July and gave a fantastic presentation on the developments that they have been working on and answered members questions. Chris is hoping to attend events regularly and bring different colleagues from different areas of transport along to answer questions. We are delighted to be able to share the slides that Chris presented at the event, as you will see there has been a significant improvement in applications processed in comparison to last year. We are delighted to learn that Surrey transport have listened to feedback, they have agreed that Parent carers and young people need a one point of contact rather than being passed from one department to another. As of the 1 st July there is now a designated email address for a SEND transport queries which will cover both application and transport delivery queries. travel.assistance@surreycc.gov.uk
PFA	We have been working with the PFA team, and there are plans in place to hold an event at a Surrey college after October half term, keep an eye out for more information on this soon! Following on from our event that we hosted in June we are delighted

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	<p>to say Eamonn Gilbert - Assistant Director SEND & LAC Commissioning and Steve Hook - Assistant Director for Learning Disabilities, Autism and Transition will be attending another event on the 13th September. We also hope to be able to circulate the questions that we ran out of time to answer in the June event very soon.</p>
Autism	<p>The Autism Strategy is at a very exciting point in its development. The strategy has been worked on by professionals in a vast number of fields who are all committed to taking the views of autistic people and parent carers that came out of the consultation and making things better for them. The most important thing to highlight is that the strategy has been developed alongside and in co-production with those with lived experiences. Every workstream has representatives from autistic people and parent carers. The strategy is due to be published in early September and the implementation plans will begin to be rolled out. The strategy is being rolled out over five years, and to ensure it is successful and really meets the needs of autistic people in the Surrey community it will be focusing on set objectives for each workstream in the first year. These will be evaluated by gathering feedback from those experiencing it and adjusted accordingly, and then rolled out more widely. I am delighted to say that Tom Moore Senior Commissioning Manager - County Autism Lead is coming along to an event on the 7th October at 10.30 to talk all about the Autism Strategy and its roll out and answer parent carer questions. Please contact Sara to book onto this event waverley@familyvoicesurrey.org</p>
EHCP Processes	<p>We are delighted to be working on some webinars with Surrey looking at the role of a case officer and the EHCP process. We are hoping to gather questions from parent carers that you would like answered. They will not be able to answer personal questions but are happy to answer more general questions about the role and the process. If you have any questions, please do send them to Leanne leanne.h@familyvoicesurrey.org</p>

Meetings attended

LD & ASD program board	Surrey Safeguarding Children Partnership Board
Partner interviews for AD roles	FVS/ SEND Advice Surrey
Quarterly meeting with elected members	SEMH questionnaire design
SEMH project board	Early Years Strategy
Schools Forum	Summit Meeting on School Exclusion
SEND Systems Partnership	Comms and Engagement Group
Hidden Disabilities Sunflower conversations	Meeting with CHES team
Team Around the school stakeholder meeting	Inclusion Steering Group
Play and Leisure Consortium	Leaders Round Table
Short Breaks Strategic Forum	Autism Strategy Workstream Meeting
	Team Around The School 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

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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
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