

What we have heard

ASD I have a 10-year-old daughter and I'm currently having a battle with getting help with a diagnosis. I have completed forms for ADHD and ASD screening and I've been told that I meet all 4 categories, but I don't get enough points from her school for the screening to be put through. I had a meeting with the SenCo: they basically turned around and said that she isn't ASD and, even if the school were to change the forms later on, they would not put her through for screening as they feel she isn't showing signs of being ASD. They basically said that I need to put more structure in place and help her to manage her outburst and find ways of substituting her behaviours and said her hormones have a lot to do with it as she started her periods when she was 9.

Short Breaks

Parents with children who need more support feel like there are not many after school activities where they can leave their children on their own especially in the 16+ age group. They really want to be able to do this, but it is not always possible if activities they attend do not have enough volunteers/safe spaces to keep their children from running off.

EBSNA

Emotional Based School Non Attendance

My daughter went into a mental health crisis a year ago, has been unable to attend school since last Easter and has just been diagnosed with ADHD. We're now applying for an EHCP.

Supported Living

'We've had no respite since the end of August.'
'There seems to be a scarcity of places.'

Covid

My son really struggled with lockdown and withdrew from education but now he's back in the education system and it's a massive relief.'

Health

My son was under the eating disorder clinic. Lockdown had a very bad effect on his eating. He's severely underweight. He should have been hospitalised but as he has ASD they said it would be too traumatic. He was discharged from the clinic. Now he's 18 and the adult service doesn't treat ARFID so our GP couldn't refer him anywhere.

Early Years

We are in Woking and have recently moved to this area. We are coming to this group because we can't find anything similar in our area.

School Places

Yesterday, after a long anxious wait, we found out what school our beautiful boy will be attending. Fortunately he was given a place at our first choice school, which is a huge relief to our family and he will likely be there until he is 19. I cannot express how happy this has made me. He is absolutely thriving at his current specialist nursery and I know he will be in the best school to help him. His future is so bright and beautiful.

PfA

Parents who have children in the 16+ age group also have a lot of anxiety of what will happen with their children after they leave school. They need a lot more assurance and support of what's next and what colleges would be best for them to attend. It just seems like a massive grey area.

Event feedback

Group	
Could it be Autism with Appeer	Very well received event with interest from people unable to attend the event but wishing to receive recording
16+ General chat – discussed lack of post 18 ARFID service, difficulties accessing ADHD support, mental health issues	‘It was good to chat to people to keep informed about what could happen when things don’t go quite to plan and for people to get advice from each other and the co-ordinators on how issues could perhaps be tackled.’
19+ General chat – discussed difficulties with finding appropriate supported living settings	‘It’s been a real blessing to find this group and to hear other people’s experiences’ ‘It’s so refreshing to speak to people who understand what you’re talking about’
Safer Gaming Workshop	The Workgroup generated a lot of interest and several new FVS members were signed up “Absolutely amazing! Attended the whole thing. More of this would be most welcome.” “This was all very helpful and could probably do with hearing it all again.”
ADHD/ASD Group	Good response for the Group and well attended. Some people who joined were new to FVS so signed up as members and flagged to their local FB Group. Lots of lively discussion. Signposted one parent to NAS for Autism counselling. A couple of parents wanted input on how to direct schools to support their children. Especially when they do not already have an EHCP.
PDA Group	EDGE talked about their supported employment service for the 15+ age group. Following their presentation, lively discussion took place between parent carers talking about how to obtain diagnosis and contrast between Introverted PDA and Extroverted PDA. A Parent was in the group and has immense experience, and was very much in the flow, speaking very eloquently. She was misdiagnosed herself growing up and had a lot to say which really helped the PCs in the, they could relate and felt heard.

Parent Carer quotes

I feel exhausted. Nobody helps me

My son's very upset, he doesn't want to go to school, he's crying at night and in the morning, but school say he loves it there.

I don't think we can carry on as we are.

There is not much going on for children with special needs in this area.

We had our annual review and the Local Authority have asked me to put together what we'd want in an EOTAS package but at the same time they are blocking what I want to put in it.

My 14 year-old came out of mainstream at Secondary, he's in a special school but they don't understand him, he can't manage to go in every day.

It's a strange situation because I want to stay informed and connected but currently there are no issues. My son's EHCP is up to date, his case officer attended his annual review and the sun is shining at the moment. This made me feel little bit sheepish when introducing myself and my situation. I felt like I was gate crashing the party and whilst no one would wish bad times on anyone they perhaps don't want to hear it's all okay from where I'm standing whilst that is clearly not their experience.

My son has been out of school more than he's been in school.

Some days I think school might just work eventually – but how long will it take to work?

I've had to give up work, I don't know what to do next.

My son was OK at Primary, with support through an EHCP, but at Secondary he's finding it hard, he has anxiety and paranoia.

It was good to chat to people to keep informed about what could happen when things don't go quite to plan and for people to get advice from each other and the co-ordinators on how issues could perhaps be tackled.

Ever since he was at preschool my son didn't want to go.

My son's on a reduced timetable but he's not accessing any education.

What Parent Carers are asking

Post 16: There are still many areas in Surrey where there are no after school activities for children in the 16+ age group to attend and many parents have to travel for one hour one way to take their children to after school activities. Some of the clubs are really unhelpful, they are offered really late at night during the week and its very hard for kids to attend something that they get home from at 9pm at night. Parents would like more youth clubs on Friday nights that are safe for their teenagers and young adults to attend, maybe in a school hall or something. They would like to be able to drop them off so their kids can gain more independence and parents can also have a break from having to attend another activity with their child. It would be nice if there were more dance groups and swimming classes for kids in Guildford. Parents definitely need more weekend activities that their children can attend so they are not sitting on ipads all weekend.

Inclusion: What is the correct procedure if a parent thinks their child should get Surrey Online School and the school is deflecting the question or says no?

Should all children with persistent attendance issues, say more than 6 months, related to anxiety be on the SEN register?

When should Surrey Online school be offered?

Autism Strategy: Parents are still asking repeatedly about specialist provision for academically able children. Is this in SCC's sufficiency plan?

A2E: Who can refer to A2E is this the school or LA or can either do it?

EHCP: Are SENCO's being told to update EHCPs? Parent was told this by a SENCO. What measures are in place to monitor this?

School places: Will FVS or SCC be running sessions to support parents who are unhappy at the named school in their child's key stage transfer?

FVS answer: *We do not have the expertise to advise parents on appeal processes but are always happy to signpost parents. In our remit as the parent carer forum, we are able to feed experiences back to the local authority. If you would like to share your story about key stage transfer, or your need for help to navigate next steps, please contact leanne.h@familyvoicesurrey.org*

PfA: Why does Surrey have no post-18 ARFID service and what is being/can be done to rectify this situation?

EOTAS: How do parents put EOTAS packages together when children and YP are unable to leave the house?

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I love dancing at Synergy Teen Dance SEN group on a Saturday!

My learning is deteriorating. I am losing brain cells. All my teachers either leave or move to a different class.

From a child who, since September, has had three different form teachers and two teaching assistants in a SEN specialist school. The current form teacher, who only joined in October, is leaving on February 25, only two weeks after announcing it to class. Very unsettling.

School is very boring

My daughter loves horse therapy and it was the one thing that got her out of the house.

I love doing after school activities with special children like me

“Our children’s voice”



Events

					
17th January	16+ Group	2	27th January	19+ chat group	6
19th January	General coffee, Global Developmental Delay and chat	2	2nd February	General Chat	3
24th January	Could it be Autism? Appeer talk	13	7th February	16+ Group	6
24th January	Safer Gaming Workshop for SEND Parent Carers	24	9th February	School Anxiety Chat	19
25th January	Restrictive Food Intake Group	8	11th February	PDA Group chat	13
27th January	ADHD/Autism Group	9			

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

Participation work

Project update

Project	Update
Autism	The All Age Autism Strategy is having a launch event during World Autism Acceptance week. It is going to be held during the week of the 28th March online. More details will follow shortly.
Alternative Provision	Please keep sending in your questions and experiences around alternative provision and EOTAS so that we can share with the local authority to develop guidance for families around this. You can send them to Leann – leanne.h@familyvoicesurrey.org
EBSNA	We have now closed our survey and had an astonishing 366 responses! Thank you to everyone who took the time to complete this. We will now spend time analysing the data and once complete we will share this with you and let you know the next steps for this work.
EHCP Process	We have now recorded 3 of our bitesized videos – the first 2 are now live and can be accessed: https://www.youtube.com/watch?v=OgdmPdTe4g8 https://www.youtube.com/watch?v=8F51rZ3sGrE The role of the case officer will be available shortly. We are continuing our recordings over the next few months and will update you as and when they become available. Please do let us know your thoughts and whether it matches your experience or if you have any questions and the SEND team will answer them.
SEND Admissions/Key stage transfer	We are aware that some families have not yet received a named placement, we have been working with the admissions team and those families should be receiving a letter with an update and a phone call from the SEND team by the 4 th March.
Preparing for Adulthood	Surrey County Council is in the process of developing a new Preparing for Adulthood brochure, to provide families and Carers, young people with additional needs and disabilities, and staff with a resource that outlines the pathway for transitioning into adulthood . Surrey CC are hosting co-production sessions to ensure the brochure is designed collaboratively, and that we receive feedback throughout the development process. More information can be found here: https://www.familyvoicesurrey.org/single-post/new-preparing-for-adulthood-brochure
Transport	<u>Transport Consultation Surrey CC</u> We were notified by Surrey CC on Friday 18 th that they were opening a consultation on the current Transport policy from Tuesday 21 st February to 31 st March 2022. This is the link to complete the consultation and for more information: https://www.surreysays.co.uk/csf/h2s/ We appreciate this will have come as quite a shock and understand there will be many mixed views and emotions. We are committed to working with Surrey CC to ensure that they understand the impact this has on families. Family Voice Surrey will have the opportunity to feed parental comments back to Surrey CC officers and possibly elected members when the time comes, so we would be grateful for any stories from parent carers about the

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	<p>impact these changes may have on them. Please do send feedback/comments to: Leanne - leanne.h@familyvoicesurrey.org and we will ensure this is fed back to Surrey.</p>
Short Breaks	<p>We are working with the short breaks team and the 13 providers to understand what they can offer over the summer break for children and the dates that their booking windows open. This will be on our website next month so keep an eye out.</p>
Health	<p>We are delighted that the SEN swimming class trial starts this week at Spelthorne Leisure Centre. The two classes sold out in a matter of hours and there is already a waitlist for both classes. At the end of the 6 week course we will update you on the next steps and are hopes to role it out to other leisure centres in Surrey. Spelthorne have just signed off a trampoline course for Children with additional needs that will be starting in March.</p>

Meetings attended

Project	Information
Health	Learning Disability Partnership Board
EWMH	EWMH Leadership meeting
Direct Payments	Direct Payments working group
Health	Active Surrey Training meeting x2
Direct payments	Direct Payments strategy planning meeting
Health	CWD resources budget meeting
Short Breaks	Short Breaks planning meeting
Health	Spelthorne Leisure centre swimming trial implementation meeting
Social Care	New starters network meeting-SYF
Health	SYF planning meeting
EWMH	ND weekly calls
Health	Time for Kids meeting
Health	Building family strengths forum
EWMH	ADHD/ASD coordinator event
Social Care	Social care planning meeting
Local offer	Local Offer website review meeting
EHCP Processes	SEND Admissions Meeting
Inclusion	Team Around The School Steering Group
Preparation for Adulthood	PFA Comms and Engagement Group
Preparation for Adulthood	PFA Transformation Board
Autism Strategy	AAA Education and PFA Workstream
Autism Strategy	AAA Awareness and Information Workstream
Inclusion	SEMH Steering Group
EBSNA	Update Meeting
Autism Strategy	Event Working Group
EHCP Processes	EHCP Recordings

Transport	Consultation Meeting
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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
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		