

Speaking up for the families of children & young people with additional needs in Surrey

www.familyvoicesurrey.org

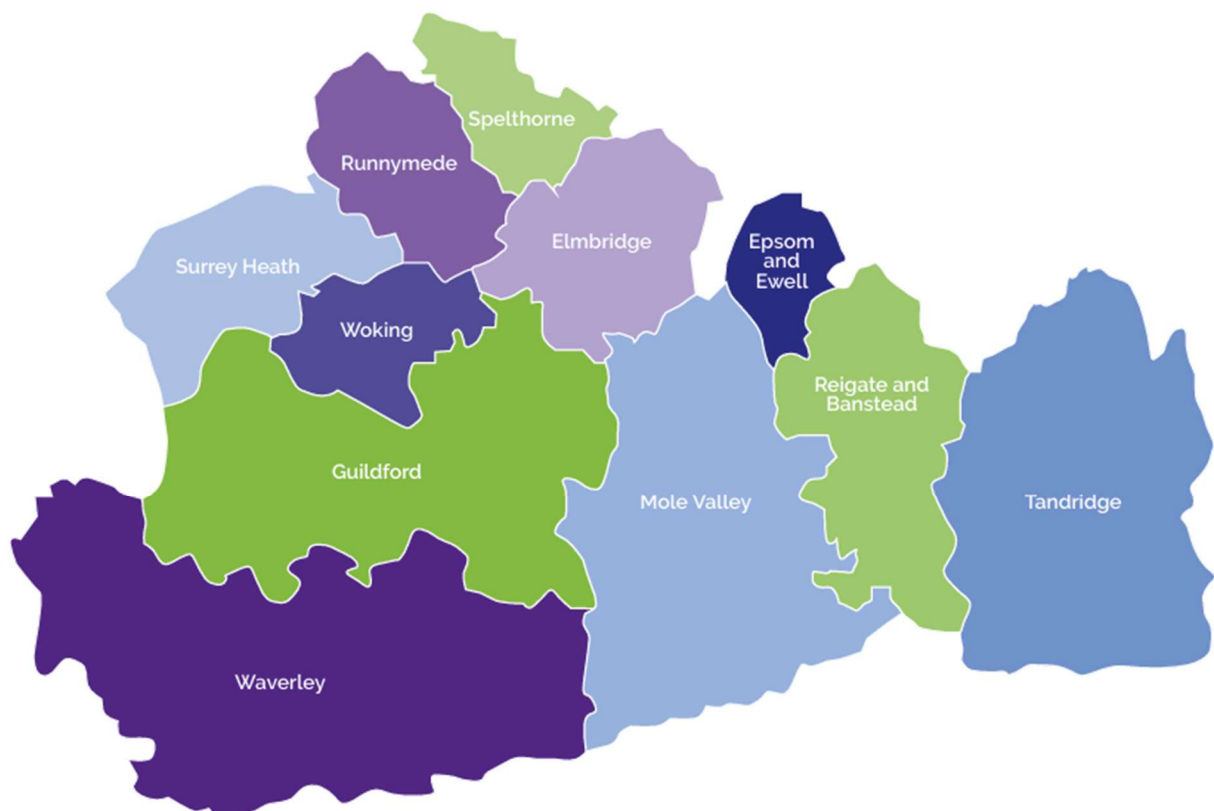
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Family Voice Surrey, CIO

Annual Report 1st April 2023 to 31st March 2024



"If you need a more accessible version of this report, please email contact@familyvoicesurrey.org or call 01372 705708"

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Our Professional Partners



SURREY YOUTH FOCUS

contact For families with disabled children

Chair comments

I hope you and your families are all safe and well. Every year, we reflect on what a year we've had, and this year is no exception. I would like to start by saying a big "thank you" to our members, our team and the Board, for your unwavering determination in working hard for change within the difficult to navigate and often broken SEND system, whilst facing your own personal challenges too.

This report provides a walk through FVS work for this year. I hope you have a few minutes to read about what we have been doing to affect change - please do reach out to us if you have any questions or would like to get involved. We would love to hear from you!

A significant event for families was the Ofsted and Care Quality Commission Surrey's Local Area SEND Inspection in September 2023. The inspection looked at education, health and care services for children with additional needs and disabilities (otherwise known as SEND) in Surrey; to assess their experiences and outcomes. We were pleased that the inspection seemed to emphasize a greater focus on the "lived experience", in reality, our experience is that this area threw up many challenges in ensuring that families were indeed heard.

The outcome of the inspection highlighted the "inconsistent experiences and outcomes for children and young people with special educational needs and/or disabilities (SEND)" but FVS felt that it did not go far enough in shining a light on the extent to which change is required.

It is important to highlight the great work that is going on and, when things go well, the difference made can be life changing; but when things go wrong the consequences can be devastating for families. FVS is frustrated with the lack of progress in truly recognizing the value of lived experience. Whilst you may see many good examples of true co-production within this report, our experience is patchy, and our work frustrated and constrained by time and resource as there is much work to be done.

Despite this we have delivered against the Action Plan of activities committed to in our AGM report last year, plus planning new project work such as Partnerships for Inclusion of Neurodiversity in Schools (PINS) that brings health and education specialists and expert parent carers (through the Parent Carer Forum) into mainstream primary schools to provide whole school support.

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We approach the year ahead with gratitude to our funders, not only for their much-needed financial support but for their approach to partnership and commitment to supporting the parent carer voice as costs rise, budgets are squeezed and anticipated changes to employment legislation come into force. The financial pressures facing many charities such as FVS are set to increase alongside demand for our services. Our focus will be on increasing parent carer participation in all the work that we do, bolstering our reserves, measuring our impact and continuing to understand and bring the voices of parent carers to those who can influence change.

Finally, I would like to take this opportunity to thank the Board who, as volunteers, give their time and skills so generously to further the work of the charity and our members, with a special mention and thanks to Sammy, our outgoing Treasurer, a valued team member with a sharp eye and a clear communicator. In the meantime, whilst we are recruiting, our Treasurer role is covered by Menzies LLP. Please do get in touch if you would like to help us to flourish as a CIO and to continue to make a difference to SEND families across Surrey.

Warmest wishes

Sally

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Who we are and what we do

We champion... the needs and rights of families of children and young people 0-25 years with Special Educational Needs, chronic illness, including mental health conditions, and disabilities living in Surrey.

We are passionate... about improving outcomes for our children & young people and keep this at the heart of everything we co-create, co-produce and do.

Our members and staff are experts... by experience and as such, have a unique understanding of how challenging and rewarding life can be raising a young person with SEND.

We inform, shape and monitor... the development of local services so that they can continually improve and enhance the experience and life opportunities for children and young people, and their parents, families and carers.

We value partnerships... and work alongside Surrey County Council and Local Commissioning Groups as a strategic partner, representing our members' voice when key decisions are being made.

We are NOT... a support group, a protest group and cannot advocate for individuals but... we rely on feedback from parents in order to represent their voice - they tell us their valuable stories.

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Family Voice Mission Statement

Family Voice Surrey's vision is clear: cultivate a diverse and inclusive society where parents and carers feel valued and listened to and all children and young adults with special educational needs and disabilities (SEND) are supported to reach their full potential.

We provide informative guidance to parents and carers of children and young people with additional needs aged 0-25 in Surrey and shine a light on the challenges that SEND families come up against. FVS seeks to break down barriers for children with SEND, by challenging and shaping local decisions, and policies to effect change.

We elevate the voices of SEND families, gather and champion parents and carers' views, and empower them to address assumptions made on behalf of children with additional needs. We represent SEND families in Surrey with authenticity, transparency, and accountability.

Together we're stronger; together, we can make a difference.



Snapshot of the year in Numbers 2023/24



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Family Voice Surrey in the Community

This year our team has offered parent carers an incredible 200+ opportunities to get involved, attend coffee mornings, engage with the Additional Needs & Disabilities (AND) Partnership, receive training and so much more. Our District and Borough Coordinators respond to the needs of their local membership, directly influencing the events and training offered to parent carers. The Participation Team also provides opportunities for parent carers to meet and work with the AND Partnership and for parent carer voices to be heard by decision makers.

We would like to thank FVS members for participating in events including focus groups and workshops, responding to surveys, and most importantly sharing your lived experience and providing feedback. It is vital that we hear from as many families as possible to ensure that we are truly representative so that we can influence change.

Together we're stronger; together, we can make a difference.

"We aren't alone, together we can become a powerful voice!"

"I'd love to attend another Mindful/Pamper event with FVS."

"It's nice that other parent carers understand where I'm coming from."

"Thanks for organising this. Lovely to meet everyone and such a great opportunity to chat in person rather than another Zoom meeting."

"Thanks for arranging this event. It is so good to meet other parents who understand what we are going through."

Here is a small snapshot of the events we held across the year

Woking Spring Chill & Chat	Quarterly Wellness Event, Spelthorne	Guildford Wellbeing event with a Shine Session	Coffee & Cake, Surrey Heath
SEND parent carers Punch Bowl walk and talk, Waverley	SEN Mums Wellbeing Coffee & Catch Up Guildford,	Face to Face Session with the Children with Disabilities Team	School Anxiety – EBSNA training materials for schools
Easter Coffee & Cake, Guildford	Wellbeing Coffee, Cake & Chat, Epsom & Ewell	Cuppa & Chat, Mole Valley	Christmas coffee & chat, Surrey Heath
An Audience with Michael Charles CEO of SinclairLaw- special educational law	Parent carers Walk & Talk at Horsell Common, Woking	Surrey parents of children with PDA – Walk, Talk & Chill	Tandridge in person Action for Carers coffee & chat

"Really nice to meet in person after a long time of Zoom meetings due to Covid."

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“I think the support from fellow parents – which FVS facilitates – is fantastic and is something FVS does well.”

“It was nice to chat with others and share experiences. And to drink coffee & have cake of course!”

“This has reminded me to take time for myself.”

“I would be interested in attending more (face to face events) as we have been so used to online sessions it's good to actually meet up in person.”



Pic 1: Waverley Coordinator, Sara, with Michael Charles CEO of Sinclair Law, March 2024

Pic 2: Woking Coordinator, Di (far left) with parent carers at Woking Coffee morning, October 2023

Pic 3: PDA Walk & Coffee/Chat at Heather Farm, Horsell, March 2024

At FVS we are keen to cater for as wide a range of families and their needs as possible. Get in touch and let us know what events you'd like us to host. We are also working on providing more opportunities for working parents so keep your eyes peeled in 2024-25 for evening and weekend opportunities. You can send us suggestions and feedback here: [FVS Suggestion Box](#)

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Family Voice Surrey Online

Topic based opportunities

As well as local opportunities to meet, we continue to offer topic-based groups which are primarily run online, to be available to our entire membership. These groups continue to be much needed and well attended.

“This is wonderful, I was so lost before coming here, this is the most useful event on ADHD I have been to, when is the next one? I can’t wait to see you all again.”

16+ Group The 16+ group is for Surrey parent carers of young people aged 16-25 with additional needs (as well as parents of those approaching that age), with or without a diagnosis.	PDA group (autistic/avoiding everyday demands) Regular online chat group for parents and carers of children and young people with Pathological Demand Avoidance (PDA)/Autism with demand avoidant traits – with or without a diagnosis.	Transition to Secondary School group The transition to secondary school group is for parents who are thinking about how to prepare their child with additional needs for secondary school, or whose children have support needs as they settle in at secondary school.
FASD Group The FASD Group is for Surrey parent carers of children and young people with Foetal Alcohol Spectrum Disorder (FASD) – with or without a diagnosis.	ADHD/Autism online group The Attention Deficit Hyperactivity Disorder (ADHD)/Autism online group is for Surrey parent carers of neurodiverse children and young people, whether diagnosed or currently awaiting one.	School Anxiety This group is for parent carers of children or young person who struggle with attending school or college, including emotionally based school non-attendance (EBSNA).

To learn more about current groups including how to get involved, please go to our FVS Regular Events web page at www.familyvoicesurrey.org/get-support/fvs-regular-events

Links

“I find your Waverley Facebook group so helpful.”

“I have just been admiring the FVS, very clear and easy-to-navigate, new website.”

“It’s great to see other dads joining more online groups.”

www.familyvoicesurrey.org
www.facebook.com/familyvoicesurrey
www.instagram.com/familyvoicesurrey
www.x.com/fvsurrey
www.linkedin.com/company/family-voice-surrey

Meet your District & Borough Coordinators: www.familyvoicesurrey.org/get-support/we-are-your-voice/

Attend FVS events: www.familyvoicesurrey.org/events-news-projects/calendar/



SEND Local Area Inspection

On Monday 11th September 2023, Ofsted and Care Quality Commission notified Surrey County Council of the start of Surrey's Local Area SEND Inspection. The inspection looked at education, health and care services for children with additional needs and disabilities (otherwise known as SEND) in Surrey, to assess their experiences and outcomes.

This was a challenging process for Family Voice Surrey and we learnt a lot from the outcome. Although we were not sure of the date of the inspection, Family Voice Surrey participated in the mock inspections and worked with Surrey's Additional Needs and Disabilities Partnership to prepare.

Throughout the inspection we were concerned that Inspectors were not hearing the parent carer voice directly from those that are living the experience. We worked hard internally to try and get as much feedback as possible directly to the inspectors and put pressure on both the local authority and inspectors to hear the parent carers' voice.

We were able to take part in a feedback session with inspectors around Alternative Provision during the inspection process, where we used strong evidence from our parent carers to support our statements

During the inspection we also held an online event with our parent carers to collect feedback around their thoughts on the inspection process so far. You can see further information on how we raised the profile of the parent carer voice within the inspection, including a summary presentation that we gave on behalf of our families to the inspectors here: [SEND Local Area Inspection Update & Presentation for Ofsted Inspection - Family Voice](#)

Inspection outcome
The local area partnership's arrangements lead to inconsistent experiences and outcomes for children and young people with special educational needs and/or disabilities (SEND) . The local area partnership must work jointly to make improvements. The next full area SEND inspection will be within approximately 3 years. Ofsted and CQC ask that the local area partnership updates and publishes its strategic plan based on the recommendations set out in this report.

[Surrey](#)

You can view the full inspection report here <https://files.ofsted.gov.uk/v1/file/50233738>

Family Voice Surrey Response to the Inspection Report

The findings of this report go some way to reflecting the feedback we receive from our members, and in representing their experiences. We recognise that whilst positive actions have been implemented to support parent carers across the county, there is still much to be done to improve the lived experience for families of children and young people with SEND in Surrey.

We appreciate the thorough examination carried out during the Area SEND inspection of the Surrey Local Area Partnership. It is evident that there are some commendable aspects of the current system, but there are also notable areas that require attention and improvement. We agree with the four main areas of improvement which

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were identified and are copied directly from the report below. Family Voice Surrey will assist in any way we can to make these improvements achievable.

The partnership board should further develop their strategic evaluation of all partnership projects and interventions in order to improve their ability to monitor at a systemic level the impact of these projects and interventions and their outcomes on children and young people.

Leaders across the partnership should improve communications from SEN case officers and practitioners to parents and carers so that all stakeholders are supported to understand the system and decision-making and feel fully involved in the journey with their child or young person.

Leaders across health, social care and education should ensure that improvements continue in line with their recovery plan in respect of: – reducing waiting times for health assessments; – increasing timeliness and quality of needs assessments; and – increasing timeliness and quality of EHCPs and annual reviews.

Leaders in education should continue to review the breadth and offer of alternative provision in order to inform commissioning so that alternative provision meets children and young people's needs and improves their outcomes.

Surrey Local Area SEND Partnership Improvement Plan & Next Steps

Following the outcome of the inspection and resultant report, the Additional Needs and Disabilities Partnership developed and published the Surrey Local Area SEND Partnership Improvement Plan, January 2024. This outlined the actions that need to be carried out to enable the Partnership to truly know that outcomes had been improved for children and young people with additional needs and disabilities in Surrey.

You can read the full partnership improvement plan here:

www.surreylocaloffer.org.uk/_data/assets/pdf_file/0006/362958/Local-Area-SEND-Strategic-Improvement-Plan.pdf

Parent Carer Feedback Session

In December 2023, following publication of the Surrey SEND Local Area Inspection Report we held an online feedback session to give parent carers the opportunity to feedback their reflections of the report outcome and content.

Parent Carer Coproduction Workshops

In response to the inspection report the Surrey Additional Needs and Disabilities (AND) Partnership worked together to develop an Improvement Plan.

Family Voice Surrey worked with, and as part of, the partnership to offer four workshops in February 2024 for parent carers to attend. These sessions enabled parent carers to give their views and suggestions, directly influencing the plans that were developed, to ensure the partnership makes the right improvements where they are needed.

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MARKETPLACE

FVS 'Empowering Parent Carers' Annual Event

This year's annual event was held at Leatherhead Leisure Centre on Friday 24th November 2023. It was a packed day for parent carers, kicked off by our wonderful keynote speaker, Clare Truman, of Spectrum Space. Clare gave an engaging talk on 'Empowering Families: what we can learn about empowerment from PDAers* and those who care for PDAers**'. To learn more and Clare and Spectrum Space, take a look at their website: spectrumspace.co.uk

The main event of the day was a Q&A session with key members of the Additional Needs & Disabilities (AND) Partnership, including Liz Mills and Julia Katherine. Attendees were invited to ask the panel questions relating to additional needs and disabilities. This was welcomed by families

District & Borough Coordinators ran a 'coffee and chat' area. This was an opportunity for parent carers and professionals to meet the Coordinators from their area. It also gave an opportunity to meet and talk to other parent carers with similar experiences.

SOS!SEN ran three fully booked workshops throughout the day on Tribunal updates**, Emotionally Based School Non Attendance & Education Other Than At School, and Appealing an EHCP**.

In the afternoon members of the AND Partnership and

"Thanks for holding the FVS Annual Event – it was more of a conference with so many organisations and experts there"

Family Voice Surrey hosted 9 breakout tables. These enabled parent carers to speak directly with officers on the following topics:

Early Years. EHCP's. Transport. FVS Trustees. SCC Leadership. Preparation for Adulthood (social care & education). Mindworks/Emotional Wellbeing and Mental Health. Social Care. All Age Autism & Health

*A person with a diagnosis of Pathological Demand Avoidance (PDA), sometimes referred to as 'Persistent Drive for Autonomy'.

ACTION FOR CARERS * ADDITIONAL NEEDS AND DISABILITIES
TRANSFORMATION SCC * ALL AGE AUTISM STRATEGY * ATLAS * JAN GRIFFIN (FASD) * HELEN ARKELL
DYSLEXIA CHARITY *
HOMEFROMHOMECARE.COM * NAS
* SEND ADVICE SURREY * SOS!SEN
LOCAL OFFER * SYNERGY HOLISTIC HEALING * SURREY CHOICES

The Panel

LIZ MILLS - DIRECTOR FOR EDUCATION AND LIFELONG LEARNING * **JULIA KATHERINE** – ASSISTANT DIRECTOR INCLUSION AND ADDITIONAL NEEDS NE * **LIZ BONE** – END TO END REVIEW * **EAMONN GILBERT** – SHORT BREAKS * **MARK KEILLER** – ALTERNATIVE PROVISION * **JENNY BRICKELL** – SOCIAL CARE * **KATHRINE EVERETT** – PREPARATION FOR ADULTHOOD * **CAROL SAVEDRA** – EARLY YEARS * **KERRY CLARKE** – EMWBH/ND

Participation & Coproduction

Family Voice Surrey is a Parent Carer Forum run for parent carers, by parent carers. This enables us to relate to other parent carers, to represent them, and to bring authenticity and lived experience to the work we do as part of the Additional Needs & Disabilities Partnership, and within the wider SEND system.

We use the direct and indirect feedback our parent carers give us to feed into the system. This is taken from emails, survey's, comments on our social media, coffee mornings and the range of other opportunities. Whilst this all helps, as a litmus test, we asked ourselves: *Are parent carers being listened to? Are we making progress to increase parent participation in Surrey?*

We know from parent carer feedback, including during and following the SEND Local Area Inspection, that there is a way to go to answer these questions positively, so we are committed to giving Surrey's parent carers, more opportunities to be 'in the room', to share your lived experience directly to those working in the system. We will be looking at ways to reach out to parent carers who we don't normally hear from too.

Our partners within the Additional Needs & Disabilities Partnership want to hear from you too to help shape and influence the structure of the additional need's pathways.

Here is a flavour of the work we have done in 2023-24, with more opportunities taking place in 2024-25 and beyond.

<p>Children with Disabilities (CWD) Social Care Team, June 2023.</p> <p>This face-to-face event was initiated on the back of feedback we received from parent carers explaining that they are unsure of the criteria for receiving support from the CWD Team. Parent carers were keen to speak directly to decision makers and explain the challenges they are facing with gaining social care support for children with complex needs. Some key themes arose on the day about training for social workers, consistency of criteria, and understanding of Pathological Demand Avoidance (PDA).</p> <p>Following the success of the event the CWD Team committed to holding more events in the future.</p>	<p>Neurodevelopmental (ND) referrals update, February 2024</p> <p>We hosted our first parent carer online engagement event on Neurodiversity and the ND pathway 'pause' in February, in response to the challenges and impact the pause was having on families. Parent carers received a system update from professionals, details of available support from Mindworks Partners, and had the opportunity to hear and share their lived experience directly with Mindworks and NHS professionals. In March an update on ND was published: www.mindworks-surrey.org/talking-points/update-neurodevelopmental-support-children-and-young-people</p>
<p>Action Card Engagement & Participation Group, January 2024.</p> <p>FVS held this online event following feedback from parent carers that they didn't understand the action card process. Following a successful event, we held monthly meetings with parent carers who were interested in helping us adapt the current action card process. These produced some great discussions and suggestions that we turned into actions and recommendations. This work has continued into 2024-25. If you'd like to get involved, please email kate.g@familyvoicesurrey.org or leanne.h@familyvoicesurrey.org</p>	<p>Home to School Transport Event with SCC Transport Team, July 2023.</p> <p>Parent carers joined us online to talk about improvements that have been made to the service over the previous 6 months. We were able to gather feedback, discuss future plans and answer parent carer questions.</p> <p>We were also delighted to share the finalised parent guide which FVS had been working on with the Transport Team. www.familyvoicesurrey.org/2023/06/08/home-to-school-transport-parent-guide/</p>

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Quarterly Quantitative Data Surveys 2023-24

In autumn 2022 we launched our Quarterly Quantitative Data Survey on topics that are affecting our members via quarterly surveys on 'hot topics'. The purpose being to:

- build a substantial body of quantitative data to evidence the scale and nature of issues, and to
- develop solid and actionable recommendations to make things better.

This year we ran the following surveys:

- Quantitative Data Survey – Case Officer
- SEND Transport

Date	Survey	Number completed	Conclusion
May 2023	Short Breaks	231	Family Voice Surrey Short Breaks Survey Results - Family Voice Surrey
July 2023	Attendance, Alternative Provision and Education Other Than at School	247	
October 2023	Home to School Transport	289	https://familyvoicesurrey.org/2024/01/15/home-to-school-transport-survey-findings-action-card-and-la-response/

Action Cards

In 2024 FVS started the Working Action Card Group. The group consists of parent carers and the FVS Participation Team. The purpose is to raise Action Cards with partners in areas of SEND and Health, taking lived experiences to the LA with the aim of helping to improve services and processes. These Actions cards highlight the challenges that parent carers are facing. All recommendations are then sent over to the Partner Action Group, which consists of the Local Authority, Health and other 3rd Sector partners.

This year's Action cards have included the EHCP Process, Send Transport and Case Officers. You can view the full set of Action Cards on our website www.familyvoicesurrey.org/action-cards/

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Participation and Co-production

FVS develops its workplan based on parent carer priorities (gathered from coordinator events, emails and social media input) balanced against priority areas of work identified by SCC leadership and within our work with the AND Partnership Board. Our business plan is based on these priorities and considers capacity and funding opportunities.

Once an area of work is identified, FVS work with our partners to define the nature of the work, identifying meetings and any input that may be required to achieve effective outcomes and influence change. We identify the areas that are not working effectively for families and highlight the areas of strength and the need for impactful collaboration and transparent communication

We proactively raise the frustrations and challenges families encounter with the system and make suggestions on how we could amend policy and procedure to improve the outcomes for Children and Young people and improve the lives of them and their families.

In addition to this project work, FVS sit on a number of boards and staff attend meetings that aim to ensure parent carers are represented. This is a key aspect of our work as a parent carer forum and includes such boards as the Additional Needs and Disabilities board, Schools Forum and the Surrey Safeguarding Children's Partnership.

Meetings attended include

3rd Sector Additional Needs and Disabilities Network	Inclusion and Additional Needs Demand Management Task & Finish Group
AAA Strategy Implementation Board	Keyworker Steering Group
Alternative Provision Focus Group	Mindworks User Voice Engagement Group
Children and Young Peoples Autism Partnership Board	ND Transformation Programme
CWD Strategic Forum	Partnership Action Card Group
CYP EWMH Suicide Prevention Group	Personal Budget Collaboration Group
Direct Payments Steering Group	PfA Programme Board
Early Help Moderation	Regional South East NNPCF Group
Early Years Expansion Planning	SE19 Joint SEND Strategic Conversation
EBSNA Partnership Steering Group	Short Breaks Coproduction Project
EHCP Focus Group	Surrey Additional Needs and Disabilities Partnership Board
EHCP Processes	Surrey Healthy School Steering Group
End to End Review	Team Around the School Steering Group
EWMH Focus Group	User Voice and Engagement Coordination Group
Health Interventions and Therapies Oversight	VOICE/VCSE Alliance User Voice Group

Participation Projects and Workstreams:

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Transport:

During Q3 and Q4 for 23/24 we worked with the Transport team on co-producing a guide specifically designed for parent carers around the process of identifying the need and applying for transport for their children and young people. Using parent carer feedback we identified this process as being daunting and complicated and felt there was a need for specific guidance for this so parents and carers could clearly understand the process. This was published in May 2023.

<https://familyvoicesurrey.org/2023/06/08/home-to-school-transport-parent-guide/>

[Additionally we later co-produced a guide for Post -16 transport.](#)

Family Voice hosted an online Transport Update event for parent carers with key decision makers from the Surrey Home to School Transport Team, to share updates on improvements made to Transport services and to gather feedback on families' experiences and to answer any questions. The Transport survey was shared again with members in October '23 following the transformation work, to determine the impact of improved services and to identify where challenges may remain.

Local Offer:

We supported Surrey County Council in producing a short survey about the Local Offer in June 2023. The purpose of the survey was to capture feedback about how helpful and easy to use the Local Offer is. Using the responses we received, we have been able to work closely with the Local Offer team at Surrey County Council to improve the way parent carers are able to navigate the local offer page.

All Age Autism:

We held our 1st Meeting around healthy eating – this having been identified as a priority by ATLAS and FVS - a working group was established, who's main focus was around raising awareness of the challenges around food linked to Autism to include sensory challenges, ARFID, safe and familiar foods. We will be looking at ways schools could be more flexible in how they support CYP with food related issues and how they can use reasonable adjustments to meet CYP individual needs,

PDA event – on the 11th October the PDA event was delivered to 90 school leaders. This was a full day event with workshops and presentations from those with lived experiences. FVS ran a workshop with 2 PC's who talked about the parent experience of having a CYP with a PDA profile and how schools can work effectively with parents to support the CYP.

Behind the Mask Event – the 2nd event took place on the 28th November '23 and was hugely successful. Leanne Henderson ran a workshop which prompted a lot of thought-provoking questions and comments from parents. Parents and carers also left the event with wider knowledge of the subject and we had a really good response to our request for feedback too – thank you to everyone who came along and contributed.

Alternative Provision and Education Otherwise than at School (EOTAS)

We were notified that a review of the EOTAS policy was being developed, noting the volume of feedback we regularly receive from parent carers. FVS are currently waiting to meet with the review

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team to begin work on the much needed AP Guide for parent carers. The need for a guide initially came out as a recommendation from our survey in July 2023 and we are pleased to see it has now been acknowledged by the team and they welcome our input into its development.

Mindworks:

Throughout the year Family Voice has facilitated parent carer focus groups with Mindworks' User Voice and Engagement Lead. These were designed to capture insights into Mindworks participation and engagement strategy moving forward. We continued to work closely with them to ensure that outcomes align with the ND referrals processes and families' lived experience.

We hosted our first parent carer online engagement event on Neurodiversity and the current ND pathway pause, on 8th February '24. We received an update on the system from professionals, details of available support from Mindworks Partners with parent carers then having the opportunity to share their lived experience directly with Mindworks and NHS professionals. Following this, Mindworks provided an update on the consultation process via schools during the restriction of assessment and referrals via the ND Pathway. The update was shared with schools via the Schools Bulletin.

[Update on the Neurodevelopmental support for children and young people:: Mindworks Surrey \(mindworks-surrey.org\)](https://mindworks-surrey.org)

FVS continues to press for further updates for parent carers particularly on the Right to Choose and the ADHD medication shortage.

Social Care and CWD:

On Tuesday 27th June FVS held a Social Care event with the Children with Disabilities Team at Leatherhead Leisure Centre. The event was arranged following feedback from many families telling us that they felt confused about what criteria the CWD teams used and whether they were able to access them for support. 67 parent carers registered for the event and 27 attended on the day. It was a great session with lots of open and honest conversations and challenge. Some key themes arose on the day around training for social workers, consistency of criteria and PDA understanding.

Following the Family Voice & Children With Disabilities (CWD) Team in person event in June, CWD led a 2nd online session for parent carers in February. The session centered around "The Role of the Social Worker" Over 50 parent Carers signed up for the online event. It was clear from participants how much confusion there was about what help can be accessed, how and why. There was a really useful discussion with the Social Care team on training gaps and many of the professionals agreed to take cases/situations away to look in to. The actions going forward were:

- **How to access Social Care services and support for your child.** Please refer to the attached information, including key roles and responsibilities for the CWD Team. [CWD Family Voice Virtual Event 28.02.2024 Next Steps .pptx](#)
- **Ongoing parent carer engagement opportunities.**
- **Foetal Alcohol Spectrum Disorder (FASD).** Concerns were raised around the lack of awareness and understanding within Surrey CC Social Care and SEND of FASD. Since the



event, Family Voice Surrey spoke with the Designated Social Care Officer for SEND, attended the next Family Voice Surrey FASD Group online meeting on 23rd April.

- **Organisational chart and service map.** Parent carers highlighted the need for a clear visual guide to accessing Social Care support and services, together with routes for escalation processes.
- **Criteria threshold for accessing CWD services.** What if my child does not meet the criteria threshold to access services? Acknowledging those children with complex additional needs and disabilities, who currently do not meet the CWD criteria threshold, and are unable to access support services such as Short Breaks and Personal Budgets.

Keyworker Project:

There have been significant developments in the initiation of this new service in Surrey. Together with , Surrey Youth Focus, Emerge, and Surrey Heartlands, FVS have supported elements such as the recruitment of workforce and coproduction of service operation requirements.

The Keyworker team have been focused on developing the training offer for the workforce, with particular emphasis on learning that will champion person centered planning. This will be part of a thorough induction process as they welcome more team members onboard. Alongside this, the Keyworking Steering Group has been identifying the key elements needed to measure outcomes that will work for the people they support as well as the wider system. Further system development and mobilisation activities took place over the summer.

The service launch took place Autumn 2023 with an initial focus on supporting Children and Young People, (and their families), who are at risk of admission to a Mental Health setting or in crisis, before the expansion of the service criteria more widely.

Shortbreaks:

Our Family Voice Summer '23 Survey focused on the Short Breaks Service. The results of the survey were presented to the Surrey County Council Short Breaks Team along with 4 recommendations which formed the basis for our Short Breaks Action Card. The key recommendation was to re-evaluate the funding for short breaks from March 2024. Short breaks funding has not been increased since 2018. Since then, inflation has risen and the number of children accessing short breaks is approximately 55% against a prediction of 40%. In addition, the number of children with EHCP's is dramatically increasing year on year.

We continued to work closely and build good working relationships with the Short Breaks Team and were given the opportunity to co-produce information sessions which started in early 2024, with a launch event at the Lightbox in Woking. These sessions were well received and are due to carry on until March 2025.

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Plans for 2024/25

Our plans for the year incorporate the Surrey Local Area SEND Partnership Improvement Plan and associated work streams. We continue to focus on ‘reach’, which is a particularly pertinent priority for 2024-25 following the SEND Local Area Inspection report which noted:

‘Parents and carers have access to information, support and guidance provided by the parent and carer forum, Family Voice Surrey (FVS) and SEND Advice Surrey and published online. FVS are involved in key strategic decision-making, such as the All Age Autism Strategy. However, some parents and carers do not know about these services so lack the support they need to understand and navigate the complex system with its very many projects and schemes. This is particularly the case for parents and carers from marginalised groups.’

Surrey Minority Ethnic Forum training for all staff and trustees
Implementation of non-digital alternatives for raising awareness of FVS in local communities
Update and republish the FVS parent carer ‘best trodden paths’ leaflet
Build relationships with schools and community hubs to raise the profile of FVS
Work with local community partners to help build trusted relationships with hard-to-reach families
Launch an improved membership database to include appropriate demographic information
Understand new/different community partners

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Finance

The accounts are prepared, in accordance with Charity Commission guidance CC16, on a Receipts and Payments basis.

The net result for the year to 31st March 2024 is a loss of £33,373 (prior year to 31st March 2023 was a surplus of £34,855). The reserves at 31st March 2024 have decreased as a result, to £125,451, (£158,824 at 31st March 2023).

Income for the year dropped to £194,596 (£216,166 in 22/23) but key funding streaming from National Lottery Grant in 2021 and Surrey County Council remain in place.

Expenditure increased in the year following an inflationary increase in salaries to ensure retention of key service providers. Our expenditure for the year to 31st March 2024 reflected an inflationary increase in service costs across all suppliers and was £227,969. (£181,311 in 2022/23)

As at 31st March 2024, our reserves position remains within our 3-6 month expenditure.

Looking ahead into the year ending 2024/25, income remains consistent, and expenditure appears to be inline with the 2023/24 year. As a result, the reserves position is reducing to the minimum position of 3 months of expenditure. As a result, the strategies for 2025/26 are looking to rectify this position and bolster reserves.


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	CHARITY COMMISSION FOR ENGLAND AND WALES	Charity Name		No (if any)		CC16a
		Family Voice Surrey		1175460		
		Receipts and payments accounts				
		For the period from	Period start date 01/04/2023	To	Period end date 31/03/2024	
Section A Receipts and payments						
		Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
		to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts						
Surrey County Council Grant		85,000	-	-	85,000	85,708
Contact Grant		-	17,500	-	17,500	17,500
National Lottery Grant Yr 2		-	-	-	-	81,500
National Lottery Grant Yr 3		-	81,500	-	81,500	-
CFS Health & Wellbeing Grant Yr 2		-	-	-	-	24,975
Keyworker Project		-	10,350	-	10,350	5,125
Short Breaks Project		-	-	-	-	-
Donations		246	-	-	246	1,358
Sub total (Gross income for AR)		85,246	109,350	-	194,596	216,166
A2 Asset and investment sales, (see table).						
		-	-	-	-	-
		-	-	-	-	-
Sub total		-	-	-	-	-
Total receipts		85,246	109,350	-	194,596	216,166
A3 Payments						
Salaries		94,645	83,673	-	178,318	139,632
Travel and expenses		3,189	2,361	-	5,550	4,607
AGM Annual event		4,614	96	-	4,710	4,810
HR, Consulting, Payroll		4,381	5,672	-	10,053	4,353
Independent examination		2,076	-	-	2,076	1,626
Insurance		1,174	-	-	1,174	1,087
IT Infrastructure		1,105	7,715	-	8,820	8,026
Office equip, furniture etc		-	-	-	-	558
Other event costs		301	1,747	-	2,048	1,631
Telephone, Stationary and Post		1,459	252	-	1,711	3
Recruitment		-	-	-	-	245
Marketing and publicity		1,510	406	-	1,916	3,922
Rent		1,589	8,875	-	10,464	9,509
Subscriptions		150	884	-	1,034	1,034
Training		-	95	-	95	274
Sub total		116,194	111,775	-	227,969	181,311
A4 Asset and investment purchases, (see table)						
		-	-	-	-	-
		-	-	-	-	-
Sub total		-	-	-	-	-
Total payments		116,194	111,775	-	227,969	181,311
Net of receipts/(payments)		- 30,948	- 2,425	-	- 33,373	34,855
A5 Transfers between funds		-	-	-	-	-
A6 Cash funds last year end		88,828	69,996	-	158,824	123,969
Cash funds this year end		57,880	67,571	-	125,451	158,824

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Section B Statement of assets and liabilities at the end of the period				
Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Current Account	57,880	27,571	-
	Deposit Account		40,000	-
		-	-	-
	Total cash funds	57,880	67,571	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
	Details	to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B4 Assets retained for the charity's own use			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Accounts Payable	Mixed	477	
	Credit Card	Mixed	247	
	Net Wages Payable	Unrestricted funds	7,475	
	Pension Liability	Unrestricted funds	2,566	
	Signed by: Sally Allen	31-Jan-2025		
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Independent Examiner’s Report

Report to the trustees/ members of	Family Voice Surrey
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On accounts for the period ended	31 March 2024	Charity no (if any)	1175460
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Set out on pages	21-23
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Responsibilities and
basis of report

I report to the trustees on my examination of the accounts of the above charity (“the Trust”) for the period ended 31 March 2024.

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 (“the Act”).

Independent
examiner's statement

I report in respect of my examination of the Trust’s accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

This report is made solely to the charity’s Trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. My work has been undertaken so that I might state to the charity’s Trustees those matters I am required to state to them in an Independent examiner’s report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charity and the charity’s Trustees as a body, for my work or for this report.

Signed:

DocuSigned by: Janice Matthews 634F24DE92A4471...

Date:

31-Jan-2025

Name:

Janice Matthews

Appendix: Structure and Governance

We are constituted as a membership organisation, with nearly 3,000 members. Membership is open to anyone who is interested in furthering our purpose and who, by applying for membership, has indicated their or its (if a corporate body) agreement to become a member and accept the duty of members. Our constitution is available on request and sets out the rights and responsibilities of our members.

The charity also has a Board of Trustees who manage the affairs of the charity and may, for that purpose, exercise all the powers of the charity. We hold an Annual General Meeting of the members, at which the Trustees present their Annual Report and Accounts. We always welcome new members and details of how to sign up can be found on our website and sign-up leaflets.

We must maintain a minimum of 3 trustees and are always keen to recruit new trustees. We welcome applications from parent carers of children with SEND, as well as people who have experience in the running of small charities, or with finance/treasurer, HR or fundraising skills, and people who have worked in Education, Health or Social Welfare fields, particularly if focused on children and young people with SEND. We also welcome applicants from diverse ethnic, religious or other minority interest groups. The trustee board provides guidance for the charity, ensuring that the operations team develop strategies and activities that will allow Family Voice to meet its objectives and its governance requirements.

While day to day operations are led by the CEO with support from the Business Team as required, strategic decisions are taken as proposals to the trustee board for sign-off. Our constitution sets out the objectives of the charity (as described in the “Introduction” of this report) and the methods for recruitment and appointment of new trustees, and the general running of the charity.

The Trustees have considered Charity Commission guidance on the provision of public benefit. The Trustees believe that FVS provides a public benefit to individuals with a special education need and/or disability, their carers, their families and the local community through the services provided to them. In addition, the services benefit public services by providing support not provided elsewhere. These services add value to the current statutory education, health and social care services, whilst providing value for money.

Major risks as identified by trustees have been reviewed and systems established to manage them. Any organisational risks are identified and discussed as a regular monthly agenda item. All trustees give their time voluntarily and receive no remuneration or other benefits.

We have a Risk Register which is updated and checked on a regular and ongoing basis. Additional policies include: Code of Conduct, Confidentiality, Data Protection, Equal Opportunities, Lone Working, Safeguarding and Data Protection. All have regular annual review dates.

The Trustee Board 2023-2024



Sally Allen (Chair)

Sally was appointed to the Board in Sept 2019 and became our Chair in July 2020. Sally has 30+ years' experience of working within local authority education, housing, social care, and voluntary sector settings undertaking both frontline service delivery and strategic commissioning and Senior Management roles. Sally has experience of living with difference throughout her life – the challenges and gifts that living with an additional need or disability has brought to people closest to her, and to her family as a whole.



Sammy Edginton (Treasurer)

Sammy joined the trustee board in September 2021. She brings a wealth of experience as an accountant, along with direct parent carer experience. Sammy also brings to her role experience in running a small business, recruitment, mental health first aider, counselling and befriending skills.



Sarah Clarke (People Lead)

Sarah, like Sammy, joined the trustee board in September 2021. Much of Sarah's SEND experience comes from her long-term governor of a SEND school. Sarah brings to her role years of experience as a Whitehall civil servant and as a senior HR adviser.



Nicky Brownjohn (Safeguarding Lead)

Nicky joined the trustee board in April 2022. Nicky's SEND experience comes from her work reviewing progress of SEND plans following inspections of Local Authorities. She commits to bringing the SEND family voice to the fore to influence change and provides safeguarding expertise to the team.

The Trustee Board update 2024-25

At the point of publication of the annual report, we would like to share some changes to the current board of trustees.

We are very pleased to share that we have two new trustee board members, Andrew and Deborah.

Andrew Stevens

I am a Parent Carer of two teen Autistic girls, one with an ASD diagnosis and likely PDA (Pathological Demand Avoidance) profile. I have lived experience as an Autistic adult, and a parent of Autistic girls perspectives. Additionally, I have personal experience of the SEND system, and empathy with other parent carers.

Professionally, I have years of experience as an I.T. 3rd line/Backoffice Engineer/Administrator, mostly Wintel, also including ISO standards, cyber security, social media, instant messaging and VoIP social platforms.

I have a passion for making improvements for SEND families and I’m told I’m a good communicator.

Deborah Holden

I'm excited to serve as a Trustee at Family Voice Surrey, bringing with me 20 years of experience in senior leadership roles within the charity sector and currently serving as a CEO. I have a background in building sustainable services and advocating for those in need.

As a parent with lived experience of a child with disabilities, I understand many of the challenges faced by SEND families and am deeply committed to our mission. I’m here to support our team, champion our cause, and help strengthen our voice for the families we serve.

The Trustees, who served during the year and up to the date of this report were as follows:

Trustee Name	Start Date	End Date
Sally Allen	18/06/2019	
Nicola Brownjohn	16/12/2021	11/09/2024
Sammy Edginton	20/09/2021	24/05/2024
Andrew Stevens	15/07/2024	
Debroah Holden	01/10/2024	29/01/2025
Sarah Clarke	20/09/2021	

Thank you and goodbye to Sammy.

We are sad to be bidding farewell to Sammy Edginton. Sammy joined FVS as our treasurer in 2021, bringing her professional accountancy and personal SEND experience to the role as well as her calm, clear communication and financial expertise. We would like to

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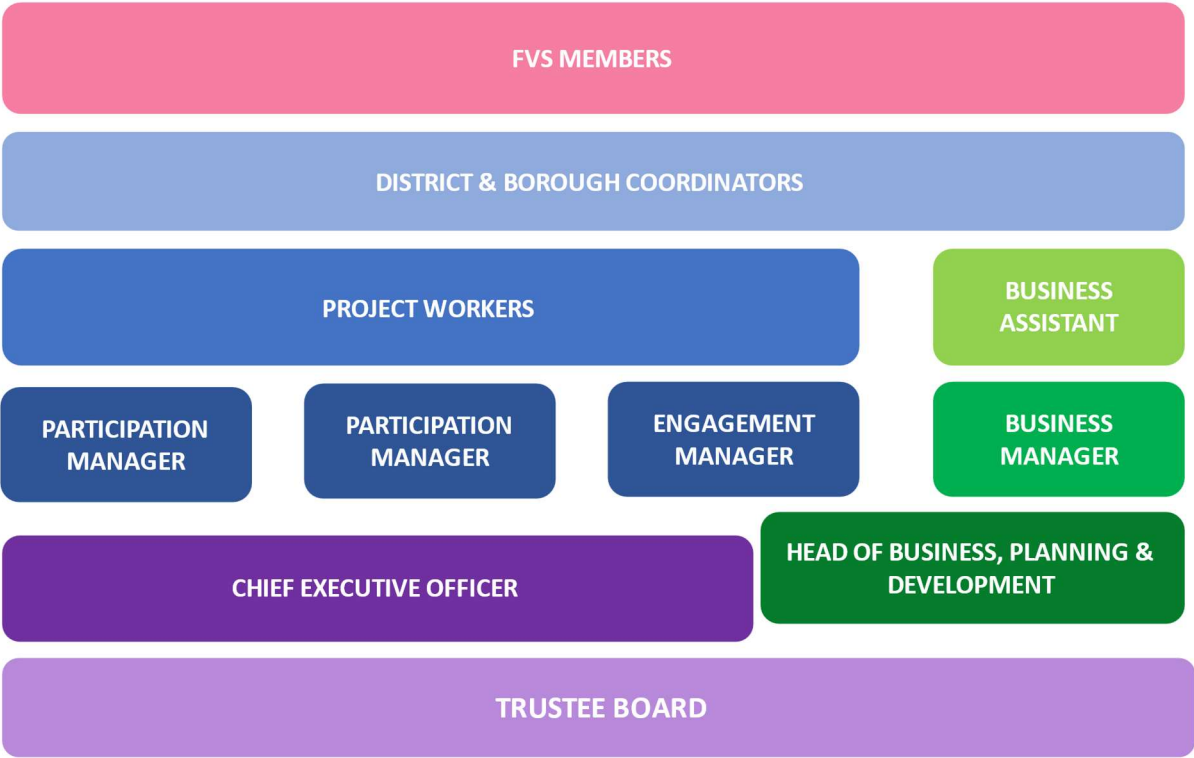
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take this opportunity to thank Sammy for the time and dedication she has given FVS as a volunteer, and we wish her all the best for the future.

Trustee Recruitment:

We continue to actively recruit new Trustees, specifically Trustees that have experience for the Treasurer role and other professions like Safeguarding, but also Trustees that continue to reflect the different needs of children and young people. Please visit our website for more details and the application pack.



The business team (in green) are responsible for day to day business processes and event management. They keep us running!

The operations team (in blue) work in two broad ways: our participation managers work with local area partners to inform them of issues facing parent carers. They are involved in strategic meetings, have input into policy documents and work with our partners in influencing change over a wide range of SEND areas.

Our coordinators work with our members, gathering their stories to be collated as evidence to strengthen the voice of the participation managers, and supporting members in a variety of ways. These include providing a space to talk and get mutual support, organising speaker events and signposting to local organisations where needed.

Acronyms used in this document

ASD	Autistic Spectrum Disorder	LD	Learning Disability
CEO	Chief Executive Officer	NNPCF	National Network of Parent Carer Forums
CYP	Children and Young People	PfA	Preparation for Adulthood
CCG	Clinical Commissioning Group	SPA	Single Point of Access
CHES	Community Health Early Support	SEMH	Social, Emotional & Mental Health
EHCP	Education, Health and Care Plan	SEND	Special Educational Needs and Disability
ESBNA	Emotionally Based School Non-Attendance	SENDCo	Special Educational Needs and Disability Coordinator
FVS	Family Voice Surrey	SCC	Surrey County Council
		SYF	Surrey Youth Focus
FAQ	Frequent Asked Question	UVP	User Voice and Participation
HR	Human Resources		

DCS	Director for Children's Services	SaBP	Surrey and Borders Partnership Trust... deliver the mental health and neurodevelopmental assessment services
DfE/NHSE	Department for Education, NHS England	Schools Forum	A representative body of schools who discuss and make decisions about schools funding. FVS is the SEND representative on the forum
EBSNA	Emotionally Based School Non-Attendance	SEMH	Social, emotional and mental health
EHCP	Education, health and care plan	SEND	Special educational needs and disability
EWMH	Emotional wellbeing and mental health	SSCP	Surrey Safeguarding Children's Partnership
GRT	Gypsy, Roma and Traveller community	SWP	Surrey Wellbeing Partnership
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	SYF	Surrey Youth Focus
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