

WORKING TOGETHER FOR BETTER LIVES

for children with disabilities and additional needs

Family Voice Surrey Parent Carer Forum (CIO)



Annual Report
1 April 2024 to 31 March 2025

If you would like this report in a more accessible format,
please email us at contact@familyvoicesurrey.org

Contents



Our Professional Partners	2
Welcome – Chair's Comments	3
Family Voice Surrey Mission Statement	4
Who we are	5
What we do	6-9
Our Year in Numbers 2024/25	10
Key Highlights	11-22
Finance report	23-25
Independent Examiners Report	26
Our Plans for Next Year (2025–26)	27
Appendix: Structure and Governance	28
The Trustee Board 2024-2025	29-31
Acronyms used in this document	32

Our Professional Partners



EVERYTHING WE DO IS GROUNDED IN COLLABORATION, REPRESENTATION, AND INCLUSION.

Welcome - Chair's Comments



Dear Members, Partners and Friends of Family Voice Surrey,

As I reflect on 2024/25, I am filled with gratitude, pride, and a renewed sense of purpose. This has been a year shaped by the strength of our community, Parent Carers, young people, volunteers, professionals and partners, all coming together with dedication, compassion and lived experience to improve the lives of children and young people with additional needs in Surrey.

The year was rich with progress, collaboration and meaningful impact. Our work remained firmly rooted in co-production, and the voices of families continued to guide every conversation, every decision, and every step forward.

Our Year in Review - Amplifying the voices of families for change

Throughout 2024/25, we continued to champion the experiences of Parent Carers, ensuring that family insight influenced key services across education, health and care. Our co-produced projects created real change and strengthened relationships across Surrey's SEND system.

The **Partnerships for Inclusion of Neurodiversity in Schools (PINS)** programme stands out as a highlight. Funded by health partners, the project engaged more than 1,000 Parent Carers and included direct work with 41 schools. These conversations supported practical improvements in inclusion, and Surrey's approach has since been recognised nationally.

Our **Schools Autism Friendly Reviews (SAFR)** project was confirmed for two additional academic years — a testament to the value of its family-led insights and the positive impact it continues to have in schools.

We also delivered two highly successful **Pathological Demand Avoidance (PDA) training** days for education staff, co-produced with autistic young people, parents and professionals. More than 100 professionals attended each session, with overwhelmingly positive feedback. Further sessions, including for social care teams, are planned for the coming year.

Key Achievements

- Improved transparency and guidance through post-16 transport engagement
- Virtual surgeries with the Children with Disabilities team, piloting new ways to support families

- Co-produced personal budget engagement helping shape updated family guidance
- Continued leadership in the All Age Autism Strategy, including PDA resources, eating-support guidance and work around masking
- A central role in the Short Breaks co-production programme, improving booking systems, information and inclusion
- Local Offer Showcase events in Cranleigh, Leatherhead, Ripley and Ewell — reaching communities with less access to local services
- Strong ongoing development of the SAFR programme

None of this would have been possible without our incredible team and volunteers, whose insight and care shine through in every project and partnership.

Leadership & Transition

This year marked an important transition as we said goodbye to our long-standing CEO, Claire Poole, in November 2024. Claire played a key role in our evolution into a Charitable Incorporated Organisation (CIO) and helped steer the organisation through significant growth. We remain deeply grateful for her commitment to families and for the foundations she helped build.

I would like to thank Nicky Brownjohn for her dedicated service as a trustee. Since joining the board in April 2022, Nicky brought valuable SEND and safeguarding expertise that enriched FVS, along with a calm and compassionate presence. Her commitment to keeping families at the centre of every decision strengthened our work at a critical time, and we wish Nicky every success for the future.

In July 2024, we were pleased to welcome Andrew to the Board. As a parent carer to two Autistic teenage girls and an Autistic adult himself, Andrew brings valuable lived experience and insight

into the SEND system. His strong IT and digital background further strengthens our Board's skills. We're delighted to have him with us. We are also grateful to Sammy, our outgoing Treasurer, who kindly stayed on beyond her term to support a smooth transition and handover as Menzies LLP continued to provide professional support.

Emerging Challenges — and Leadership

2024/25 also brought financial pressures. Rising costs, reduced income and the end of several short-term funded roles meant we closed the year with a deficit. We also experienced broader system shifts. Local government reorganisation introduced uncertainty, and although its full implications weren't clear until after March 2025, we were already seeing the effects on partnerships and funding. At the time of writing, there was also uncertainty around the future of our contract with Surrey County Council, our major funder, adding further complexity to an already difficult financial picture.

In response, the Board commissioned an independent review of our operations and finances. This work confirmed that, although our mission, partnerships and impact remain strong, our internal structure needed to evolve to secure long-term sustainability.

After careful consideration of several scenarios, the Trustees made the difficult but necessary decision to pursue a restructure in 2025/26. This decision was taken with great care and with the charity's long-term strength at heart.

We unfortunately had to postpone our Empowering Parent Carers Annual Event, planned for November '24. Although disappointing, this allowed us time

to reflect, ensure transparency, and commit to a broader review of how we stay connected, relevant and truly representative as your Parent Carer Forum.

These decisions were not easy but they were guided by values of integrity, stewardship and our unwavering commitment to families.

Looking Forward

As we close 2024/25, we do so with deep appreciation for the strength and spirit of our community.

The insights and learning from this year have brought us to an important moment. As we enter 2025/26, we are ready to build on our successes through a focused organisational review — one that will help us sharpen our priorities, target our resources where they can have the greatest influence, strengthen our ability to support and represent families across Surrey, and adapt to the changes ahead. We approach this work with optimism, honesty and a genuine commitment to listening, learning and adapting together.

To every parent carer who shared their experience with us, young person, professional partner and funder who have supported us (especially Surrey County Council and the National Lottery) - thank you for your continued support this year, enabling us to continue our important work.

To our staff, volunteers and Trustees: your care and commitment help us move into 2025/26 with renewed purpose and a focus on strengthening positive outcomes for families in Surrey.

Every warm wish

Sally

Family Voice Surrey Mission Statement

Family Voice Surrey aims to build an inclusive community where parents and carers feel heard, and children and young people with SEND can thrive. We offer clear guidance for families of 0-25's with additional needs, highlight the challenges they face, and work to remove barriers by influencing local decisions and policy. We champion the voices of SEND families and represent them with authenticity, transparency, and accountability.

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

Who we are

We are a Charitable Incorporated Organisation (CIO) governed by a Board of Trustees, all of whom are Parent Carers.

You live in Surrey and your child (age 0 – 25) has special educational needs or disability. **We are your voice.**



We champion
your needs and
rights.



We are passionate about
improving outcomes for
your children.



We are experts by
experience because
we are Parent Carers.



We work together with
the local authority to
represent your experience.



We have a say in how local
services work so that they improve
the lives of Surrey families.

We are not a support group or a protest group and we cannot support individuals. But your stories allow us to do our work.



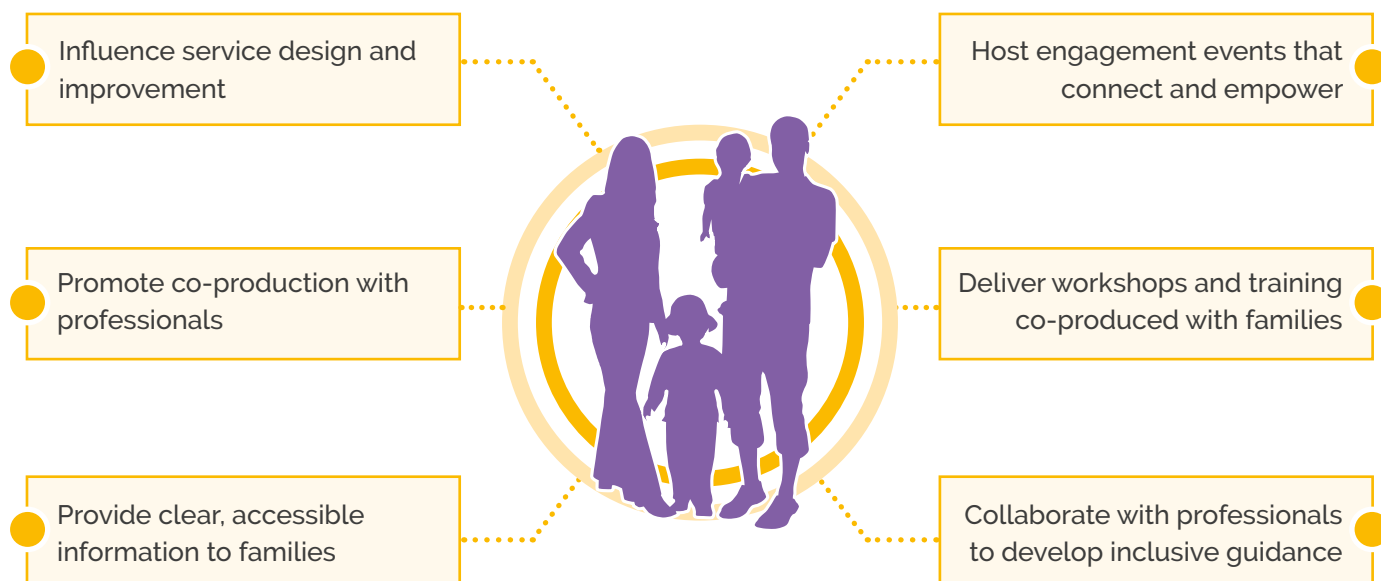
“Thank you” to our members for:

Sharing your experiences through surveys, workshops, events
and for talking to us.

And for joining us as volunteers or staff members.

What we do

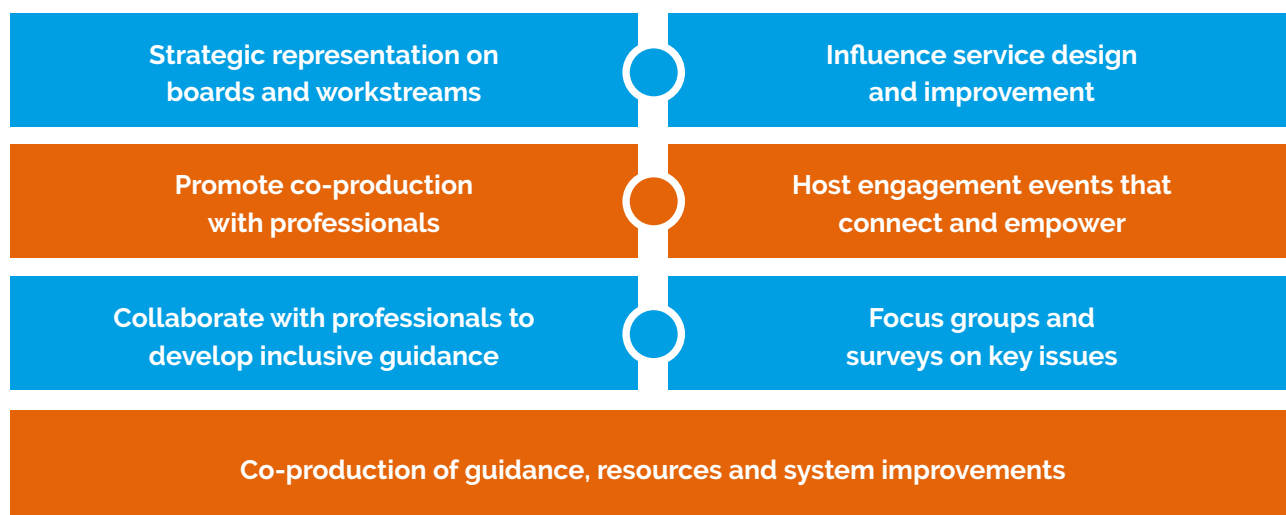
We gather and represent the views and experiences of Parent Carers to:



Our work includes:



How we represent Your Voice – Meetings, Surveys and Panels



Meetings attended

We attended more than 30 strategic and operational meetings, including:

Additional Needs and Disabilities Partnership Board	
Surrey Mental Health Support Team Monitoring & Assurance Group	CYP Mental Health & Suicide Prevention Partnership
EHCP Focus Group	All Age Autism Strategy – PDA Reference Group, Healthy Eating, Masking, Outreach
Action Card Working Group + ToR Review	Keyworker Co-production Governance Group
End to End Review Panels	Short Breaks Co-production Meetings
Autism Outreach Steering Group	Inclusion & Innovation Group
Home to School Transport Monthly Meetings	EBSNA Steering & Partnership Groups
DP Partnership Steering Committee	Nurture Hubs Panels
Inclusion in the Community with 3rd Sector	AAA Education and PFA Workstream
Autism and Healthy Eating Workstreams	AOFS Steering Group
Family Voice Surrey & CFLLC SC Quarterly Meetings	Children & Young People Autism Board

Surveys and Focus Groups

Transport Survey (Nov 2024) — 154 responses; presented to Surrey County Council and Select Committee

Alternative Provision Survey — 86 responses used at a market engagement event for 100+ providers

EHCNA Engagement Sessions — Jan & Feb 2025; helped develop accessible family guidance

Action Cards — Two submitted (Tribunals and ND Pathway); both influenced improvements to process

Common themes – what our members said:

Many parents feel blamed by schools and professionals

Many families still report that it is difficult to get a response from case officers or their managers

School not seeing needs

Provision difficulties leading to Parent Carers not being able to work

Transport difficulties compounded by staff changes

Lack of awareness and understanding of Foetal Alcohol Spectrum Disorder in the area

The challenges around accessing ADHD medication

Lack of support for EBSNA

Supporting our Community

Promote co-production

Provide clear, accessible information to families



Host engagement events that connect and empower – we are stronger together

Events such as coffee mornings, training sessions and showcases

Face-to-Face and Online Engagement (FREE EVENTS)

Coffee mornings and support groups - Over 50 sessions across Surrey. Targeted support for families on issues like EHCPs, education, transitions.

Guest speakers from SOS!SEN, Mindworks, SEND Advice Surrey, SCC

Walk & Talks and wellbeing sessions

Themed workshops (ADHD, transitions, pathological demand avoidance, post-16, EOTAS – we offer parents a chance to learn more about a particular area of SEND, to come together in a supportive environment and to share their experience.

134

Post 16 attendees

139

Autism/ADHD attendees

150

Pathological Demand Avoidance attendees

District and Borough Coordinator Engagement

50+
local engagement
sessions

Throughout the year, our District and Borough Coordinators have played a vital role in bringing support, information, and connection directly into local communities. From Woking to Tandridge, Spelthorne to Epsom and Ewell, coordinators hosted over 50 in-person and online sessions designed to meet the everyday needs of Parent Carers navigating the SEND system.

These events included informal coffee mornings, wellbeing sessions, walks and talks, and themed discussions on key issues such as ADHD, autism, transitions to secondary school, EOTAS, post-16 transport, and personal budgets. We welcomed guest speakers from organisations such as SOS!SEN,

SEND Advice Surrey, Mindworks, and Surrey County Council. Sessions also offered safe spaces to talk about emotional wellbeing, share lived experience, and access practical advice from specialists.

The impact of these events has been wide-reaching — reducing isolation, building confidence, improving access to information, and creating stronger local networks. We are incredibly grateful to our Coordinators for their commitment and creativity in keeping local engagement meaningful, inclusive, and responsive to what families need most.

Facebook and Whatsapp Community Groups

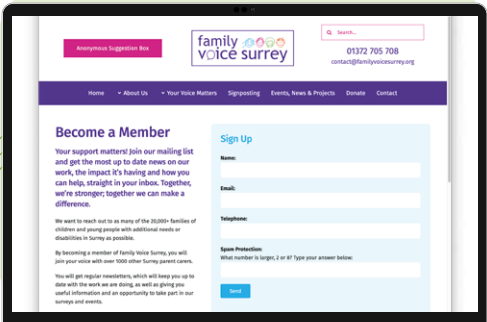
Parent Carers can apply to join our closed online community groups to connect with other Parent Carers, to ask questions and to share information.

126
ESSNA
WhatsApp

100
School Anxiety/
SEN Ideas
WhatsApp

Our website Membership

Our website is a go-to place for Parent Carers to find helpful information, local resources, and updates on what's happening in the community. It's designed to make it easier to get support, stay informed, and feel more connected.



Membership is free and open to all Parent Carers. By joining, you'll receive regular updates, have the chance to share your views through surveys and events, and be the first to hear about opportunities and activities for families.

<https://familyvoicesurrey.org>

Examples of training Delivered

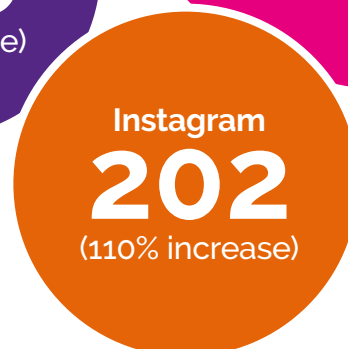
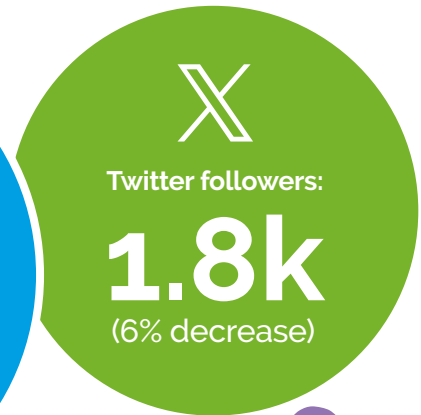
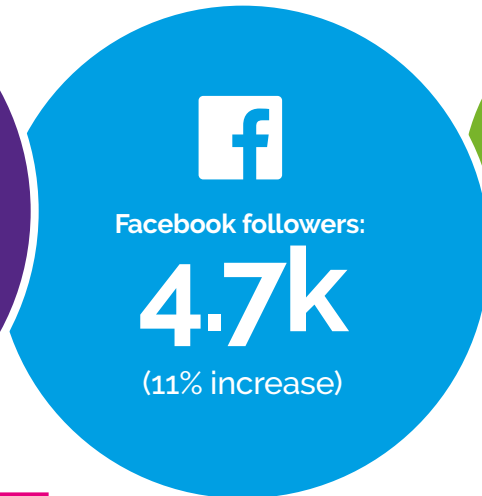
- Cultural Awareness
(May 2024 – Surrey
Minority Ethnic Forum)

Foetal Alcohol
Spectrum Disorder
Training (Sept 2024 –
Road to Foetal Alcohol
Spectrum Disorder)

PDA Training for
Schools (Nov 2023 &
March 2024) — 100+
attendees at each

Upcoming Social Care
PDA Training — May
2025

Our Year in Numbers 2024/25



Key Highlights

Pathological Demand Avoidance (PDA) – Training for Schools and Education Staff

Based on feedback from Parent Carers and young people, the All Age Autism Strategy in collaboration with Family Voice Surrey ran 2 full day in person training sessions for education professionals in Surrey. These events took place in November and March 2024 and had over 100 people in attendance at each and a waiting list. The training was co-produced with those with lived experience and professionals from start to finish.

The event had workshops that were run by parents carers and young people with lived experience and professionals. The events also had key note speakers Eliza Fricker and Julia Daunt Lived experience Authors and Public speakers.

The aim of the training was to raise awareness and to provide ways of working with families and children and young people with a PDA profile. It was designed

to allow those attending to go away with some top tips to be able to immediately put into practice.

The feedback from the training was overwhelmingly positive and a future date has been planned in November 2025.

Some of the feedback received:

Participants overwhelmingly found the training highly relevant to their roles and rated their understanding of pathological demand avoidance (PDA) significantly higher after the session, with average ratings out of 10 increasing:

4.97 out of 10
increasing to
8.55

What you said:

The parent voices & lived experiences absolutely blew me away! Their stories alone were invaluable to hear & learn from, I thank them very much for sharing their struggles & vulnerability.

It was great to hear lived experiences rather than from the perspective of a professional.

The parent talk was so insightful. Especially the 'what do parents need to hear' from staff.

Hearing from those with lived experience - being able to return to school with some 'positive outcome' stories to relay to parents who have a journey ahead of them.

It was a personal experience, of the mother of a daughter with PDA it was very informative and gave an example of coping strategies implemented within a family home, to keep the child and relatives safe.



The feedback on how it would impact their practice:

"To be much more aware of what parents are going through To discuss with school staff why a child might be behaving in certain way and emphasising that a child with PDA needs to have autonomy."

"It was incredible. There is a lot I will change. My understanding and empathy for parents and their children with ASD (PDA). I will listen to parents more, particularly when they tell me how their behaviour is different at home. Earlier intervention, rather than fire fighting. Building of relationships and how as a SENDCo I facilitate those when children exhibit challenging behaviours. Moving my school well-being days to provide a low demand start to the year to build relationships."

"For out students with PDA, I am now much more aware of masking. We have students who are so good with us - very positive experience working with them, and when they don't turn up we think it is 'blip'. What I hadn't realised is the extent to which masking is going on and the effort it may have taken to get them from bed, into the building each day."

"Being more confident to understand and communicate students with PDA and give me knowledge of the strategies that may need to be put in place for them- reasonable adjustments etc."

In addition training on PDA for social workers in the CWD team and wider social care professionals is planned after being identified as a need by Parent Carers and will be delivered over 2 full days in May 2025.

Post 16 Transport Engagement Session

Family Voice Surrey facilitated a parent carer online engagement session in July 2024 with 51 people in attendance. This session was in response to Parent Carers collective feedback of transport application challenges for Post 16. The home to school transport team came along and gave an overview of the changes in their statutory duty at Post 16, answered questions and took feedback.

One of the outcomes from this session was a commitment from the Travel Assistance Team to look at the process and ensure there is more clarity about the information that is needed to demonstrate extenuating circumstances and also to look at the systems ability to upload more than one document as evidence.

Children with Disabilities Team Virtual Panel

We have been working with the CWD team over the last year doing online and in Person events and sessions based on Parent Carer questions and feedback.

One of the suggestions that came out of the engagement sessions, was to run a Parent Carer Surgery with professionals. Therefore, in November 2024, we facilitated a trial parent carer panel as a pilot approach to understanding the barriers and needs of Parent Carers.

We received 11 requests from Parent Carers to meet with a bespoke panel specific to their family's needs. We completed three virtual surgery sessions with Parent Carers. It really highlighted the need for clear, consistent and timely communication and identified how this can resolve situations quickly for families , remove unnecessary delays, ensure accuracy and reduce complaints.

This feedback has been shared and the new approach is looking to be built into the End to End review process.



Personal Budgets Parent Carer Engagement sessions

Family Voice Surrey were part of the Personal Budget working party and subsequently very involved in the co-production of the Personal Budget guide. Working closely with Jo Mcsherrrie, Service Manager for Policy and System Development, we gained valuable feedback and suggestions from Parent Carers on how the process could be adapted and improved for families.

Two, very well attended, Personal Budget Parent Carer sessions were held with Jo on 6th June and 11th July 2024, with approximately 30 Parent Carers at each session. There was a lot of very valuable input and suggestions about the guide with a focus on the importance of legalities, panels and consistency. The guide has now been finalised and a training programme is currently being put together for professionals.



Education, Health and Care Needs Assessment Engagement Sessions

FVS were asked to host some engagement sessions with Parent Carers to gather feedback on the current EHCNA process and to collaborate on new guidance to support Parent Carers through the process. The sessions were held on the 8th January and 6th February 2024 with up to ten people per session.

These sessions were hugely insightful and lots of practical suggestions were shared on how to make the experience easier to navigate. This feedback will be used to create a guidance document that will be available to families and young people to help them to understand and feel more involved in the process from the outset. Further engagement sessions are planned on decision making.



Action Card Engagement Sessions

The Action Card process is a mechanism developed by Surrey County Council to ensure that Parent Carers, young people, and professionals can raise key issues or concerns within the SEND system and formally request a response or action. Each Action Card highlights a specific challenge or systemic barrier, and triggers a structured review and response process by the relevant services. It is intended to be a co-productive tool that drives meaningful service improvement and accountability.

Over the past year, Family Voice Surrey has continued to play an active role in shaping and embedding the Action Card process. We attended monthly meetings of the Action Card Working Party, working alongside Surrey County Council and other partners to review how the process could evolve to better reflect transparency, responsiveness, and joint ownership.

As a result of ongoing feedback and collaborative dialogue, Surrey County Council's Education and Inclusion Service Manager (North East), Katherine Everett, convened a dedicated meeting in July 2024 to agree a revised **Terms of Reference** for the Action Card process. FVS contributed to this review, ensuring the voices of Parent Carers were fully reflected.

2
Action Cards
submitted



Following this, the Family Voice Surrey Action Card Working Party raised two formal Action Cards — one focusing on **Tribunals** and another on the **Neurodevelopmental (ND) Pathway**. These have been submitted through the updated process and are available to view on our website.

Our collaborative work with Surrey County Council and the broader Partnership Action Card group concluded in April 2025 with the agreement of a new, clearer process for raising and responding to Action Cards. This revised approach is now in place, and FVS will continue to monitor its implementation to ensure it remains effective, inclusive, and responsive to the needs of our membership.

Surveys

Alternative Provision Survey

We were approached by Surrey County Council to gather some feedback from Parent Carers on Independent Alternative Provision to feed into a market engagement event and to make providers mindful of the needs families have. We ran a survey to gather this feedback and received 86 responses with detailed information on the providers they had experience of.

This information was pulled together and was presented at an alternative provision market engagement session in early June which was attended by 104 providers. We received feedback to say how helpful this was and we hope the providers will take this into consideration when developing their offer.

You can view the presentation here: [Independent Alternative Provision – What Families Need](#)

86

Alternative Provision survey responses

Transport Survey

FVS ran their annual home to school transport survey in November 2024. We received 154 responses. The findings were analysed and recommendations were formed and presented to the home to school transport team. The findings were also shared with the Select Committee who endorsed our recommendations.

Full findings and recommendations can be found here: [Home to School Transport Survey 2024](#)

154

Transport survey responses

Local Offer Showcases

Throughout 2024 to present we have been working with the Local Offer Team on Showcases in boroughs that often don't have events held at them

The first one was held on October 22nd 2024 in Cranleigh.

The event had a number of services and local community groups attending and FVS and the Local Offer Team planned, advertised and hosted the event. The next one will followed in February 2025 in Leatherhead and we also held ones in Ripley and Ewell.

FVS have a working party on this project, including relevant borough coordinators and a member of the business team

Over 50 Parent Carers attended each event and we had fantastic feedback at each session. There are more planned in 2025 going into 2026.

[illegible]

4

Local Offer
events hosted



Internal Training

In May 2024 the whole of the FVS team completed Cultural Awareness training delivered by SMEF and in September 2024 the team also received training on Foetal Alcohol Syndrome Disorder (FASD) led by Jo Garofalo and Jan from the Road to FASD.

Partnership for Inclusion of Neurodiversity in Schools (PINS)

PINS is a new national Programme that aims to support the education and health needs of neurodiverse children in schools, through partnership approach, working with local authorities and parent carer forums.

The aim of the programme is to enable every child in school to thrive, have a sense of belonging and feel safe.

It is a whole school approach that uses the power of working in partnership with families and professionals to build an inclusive culture, where neurodiversity is a valued strength that adds to the school community. The project ran from 1st April 2024 until March 2025.

The 41 schools in the pilot were situated in the South East and North West of Surrey .

Family Voice Surrey had their own PINS team working on the project and they went into all 41 schools. Meeting with Parent Carers they collaboratively looked at themes and ideas that could build on inclusion within the school.

All parents whose child attended a school taking part in the PINS project were given a link to a

survey where they could share their thoughts and we were delighted to receive over 1000 responses from parents.

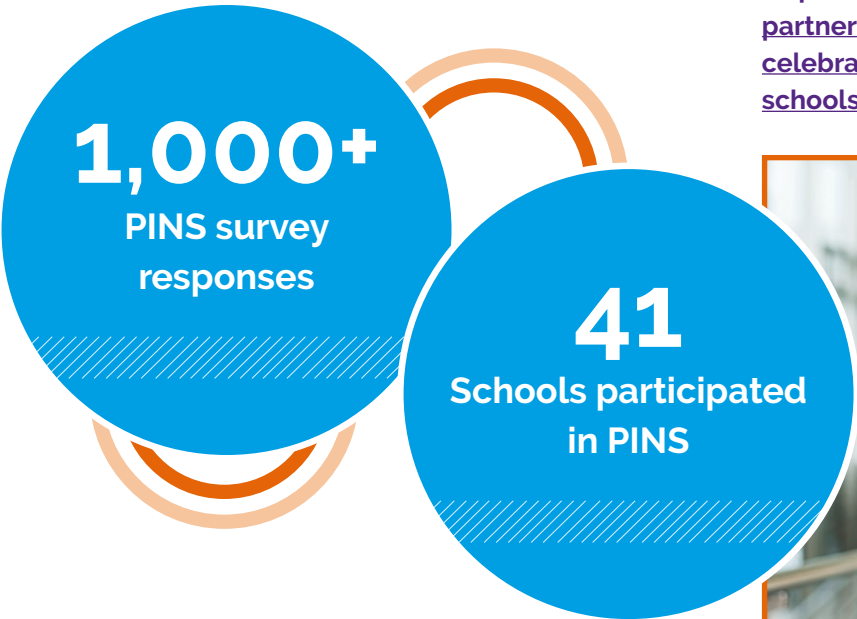
Following the survey results our PINS project workers visited each school to join with the school leadership teams in meeting with Parent Carers to understand what is working well and what opportunities there are.

It was wonderful to meet so many Parent Carers at these sessions and incredibly valuable to listen to their experiences, thoughts and suggestions.

Our team met with the school parents three times and the feedback received enabled us to support them with additional training, building communication and implementing Parent Care Groups to sustain and continue to develop inclusion for neurodiverse children and there families.

This project has been an excellent example of co-production and are delighted that PINS has been signed off for a second year till March 2026. In addition, we are pleased to say that the Surrey PINS team have been recognised Nationally for their execution of project.

<https://news.surreycc.gov.uk/2025/09/25/partnership-for-inclusion-of-neurodiversity-celebrates-the-programmes-expansion-into-70-schools-across-surrey/>



Schools Autism Friendly Reviews (SAFR)

During the academic year a team of young people, Parent Carers and professionals have been conducting reviews of secondary schools to assess how autism friendly they are.

The review starts with a questionnaire designed by young people with 'lived' experience and is sent out to pupils in the school. A questionnaire is also sent out to parents and to the staff team – both teaching and non teaching staff. The aim of the questionnaire is to get an understanding of everyone's views as a starting point.

The questionnaires are then analysed by the young people and Parent Carers and a day is scheduled for a visit by FVS. On the visit Jane Gupta, All Age Autism Strategy Service Manager, spends the whole day at the school observing. The day is split into two for the young people where they spend part of their time in a lesson observing and then run a session with students where they ask questions linked to the survey responses.

A further session is run for parents by a member of the FVS team to gather their views and ask further questions that have come out of the questionnaires.

The information is collated and put into a presentation which is then shared with the school. The presentation contains suggestions of how to further develop the school to become more autism friendly.

These reviews have been hugely successful and it has been extremely rewarding that so many schools embraced the opportunity. Following on from this success it has been agreed that these reviews will continue for another two academic years, with a designated team in place to carry them out. It has been an inspiring project that has been entirely driven and led by autistic young people and Parent Carers. It really highlights how successful collaborative and true co-production can be.



Participation Projects and Workstreams

Transport

Over the last year FVS have been working with the 'home to school' transport team to address issues that Parent Carers have been facing. This year the team took a more robust stance on their policy of transport of under 5's and as a result many families were left in a challenging situation.

Following on from discussions it was agreed that a more relaxed approach to the parameters would be applied this year and that next year,

communication about the eligibility would be shared much earlier. We also gave feedback on proposed changes to policy and have worked hard on co-producing a parent guide to make the process easier to understand.



All Age Autism

Over the last year FVS have continued working and co leading on the All Age Autism Strategy. This has included;

- co-producing a PDA position statement
- running PDA training sessions for education staff
- co-producing a healthy eating document for schools to support children and young people who have eating challenges

We have also supported work that is beginning the process of reviewing pre and post diagnostic information following feedback from Parent Carers. In addition we have started work on co-producing a masking position statement, as well as developing a bank of resources for families, children and young people that enables them to access support and understanding on a range of topics identified by those with 'lived' experience.

Alternative Provision

Following on from our survey conducted in 2023 on Alternative Provision and Education Otherwise Than At School we have been working with the team at Surrey CC to create a guide for Parent Carers on Alternative Provision. Feedback has also been given on the EOTAS position statement.

It is also our intention to offer some engagement sessions to Parent Carers to further develop the guide and to improve the experience for families.

Ordinarily Available

In September 2024 Surrey agreed to do a project on the revision of the Ordinarily Available guidance. Part of this process involved us joining focus groups to look at the current version and make recommendations. The outcome from this led to the decision being made to create a parent guide to support parents with understanding of Ordinarily Available Provision. Some engagement groups with parents are planned for the summer term.

Emotionally Based School Non-Attendance

FVS EBSNA parent carer group have been actively involved in the development of the whole school EBSNA training. Focus groups have taken place to review the training and make suggestions, many of which have been incorporated into the training.

An evaluation of EBSNA work across the county including; progress and challenges took place

in December 2024. FVS fed into this based on the parent carer experience our members have been telling us, as well as from our regular EBSNA parent carer group.

The outcome of this evaluation, which is due in April 2025, will inform next steps for the wider EBSNA work in Surrey.



Education, Health and Care Plan Processes

There has been an End to End Review of SEND services in Surrey. FVS have been attending the EHCP focus group regularly and feeding parent carer experiences into this.

In July 2024 we took part in a multiprofessional 'in person' session to audit some EHCP's as part of the Invision programme which we have previously been involved in. This was a really informative session and very insightful to hear different perspectives.

Surrey CC have commenced work on a parent portal – the aim for this is to be an online system where Parent Carers can; access information on their child's EHCP, see progress, send messages, etc. This is a very welcome plan. There was an initial meeting which Parent Carers were invited to see a demo of the system in its earliest form.

It was a positive session and the attendees gave some valuable feedback and raised some crucial questions. Development of this is ongoing and there will be further opportunities for Parent Carers to input into this as it progresses.

FVS have been asked to review and give feedback on a number of letters that are sent to Parent Carers at different stages of the process. The idea is to make the letters as easy to understand as possible and to ensure they include the right information.

FVS have been asked to support work to improve the process of applying for an EHCNA. Where Parent Carers with relevant experience joined two focus groups in January and February 2025 to give feedback and find solutions. See above for more details.

Mindworks and Neurodevelopmental Pathway

Over the last year Family Voice Surrey have been committed to raising the challenges faced by families during the Neurodevelopmental Pathway pause. We worked tirelessly at identifying opportunities for Parent Carers to be directly involved in informing and shaping of services.

In line with parent carer feedback regarding concerns over the Neurodevelopmental Pathway process and communication to Parent Carers, we

raised an action card on the Neurodevelopmental process which was co-produced with the FVS Action Card Working Group.

As the provision of services and support moves away from a 'medical-led' to a 'needs-led' model around early intervention, we continue to ensure that the 'lived' experience of families is heard and at the heart of any transformation work.



Short Breaks

The Short Break team have been embarked on a 12 month programme of activity, funded by the Department for Education to coproduce improvements to the Short Breaks service.

There were over ten parent engagement sessions and workshops that we attended to discuss challenges and opportunities within the play and leisure short breaks schemes. The sessions were held at a variety of venues across Surrey, alongside some online sessions at different times in the day to ensure that everyone could have an opportunity to get involved.

The Parent Carers that attended helped identify six main areas of focus for the programme.

The workstreams were:

- **Information and communication** – working with the Surrey Local Offer Team to develop the information on the Local Offer in response to changes suggested by families.
- **Booking process** - working with providers looking at the scope for aligned booking windows, standardised registration forms and creating a booking charter.
- **Waiting list** – looking at positive and effective ways to support families on the waiting list while they are waiting to access services.

6 Short Breaks workstreams shaped

- **Networks** – Working with Family Voice Surrey to identify, promote and develop networks as well as the scope and need for new networks to support families.
- **Inclusive practice** – Investigating what we can do to help mainstream providers in supporting Children with additional needs to attend settings. This could be through training and providing advice and support.
- **Building a sustainable service** – Looking at ways we can build the sustainability and resilience of the service in co-production with the providers and parents and carers.

Following the conclusion of the project the Short Breaks team have been reflecting on what short and long term outcomes identified can be implemented into the service going forward.



Networking project

At FVS our project worker, Vanessa Francess, has also been working on a Networking project for the Short Breaks team in order to identify support groups across Surrey, based on need and audience. The project identified gaps in geographical patches and a lack of support groups for some disability sectors. We presented our findings and recommendations to the Short Breaks team and the list of groups can now be found on the 'local offer'.

[Short Breaks Project Work on Parent groups directory](#)

Nurture Hubs

We have been working with Jim Nunns- Assistant Director for inclusion and additional needs Lucy Pearson Senior Project Manager- on the redesign of the primary and secondary nurture centres. This was a very exciting piece of work and we have been delighted to have been able to be an active part of the moderation sessions and complete the parent carer appreciate enquires.

The parent carer sessions were hugely valuable at collating the experience of families who have either had experience of an existing nurture group or a similar type of set up that some schools have developed independently and allowed for learnings to have been incorporated into the next stage.

There are now 18 nurture hubs in Surrey (10 in primary and 8 in secondary) and our hope is that Surrey will have a nurture centre in each district and borough for both primary and secondary schools.



Personal Budgets

Personal budgets and direct payments provide an individual with the means to pay for their own care and support - enabling them to have greater choice and control over the way they access services.

In October 2024 Surrey County Council established a working group comprised of Adult Social Care, Children, Families, Life-Long Learning, Finance, Surrey Heartlands and Family Voice Surrey. The working group explored how the current direct payment and personal budget models can be further developed and improved to enable more people to use personal budgets and direct payments to achieve their aspirations.

Following the mapping out of the current processes, five workstreams were identified to focus on. One of these workstreams was to develop a guide for children, young people and families to further clarify the processes around access to a personal budget.

Family Voice Surrey have been involved in the co-production of this guide and a representative

from the Council worked closely with us whilst ensuring teams in the Council were supporting the developments. The guide includes frequently asked questions which have been discussed at the co-production meetings.

To gain further insight, FVS facilitated two Personal Budget Parent Carer sessions with Jo Mcsherrrie, Service Manager for Policy and System Development which were very well attended.

There was a lot of great input and suggestions about the guide, focussing around the importance of legalities, panels and consistency. Although the guide was due to be finalised in early 2025, it is still under development as engagement sessions with Parent Carers are taking place in order to review progress and discuss next steps.

Once the guidance is signed off the training plan will commence. This will involve a roll out programme that includes a number of professionals to ensure everyone fully understands Personal Budgets.

Key Worker Project

The **Key Worker Project in Surrey** is part of a **national initiative** led by NHS England to provide **intensive, personalised support** to children and young people with **complex needs** — particularly those who are:

- **Autistic** and/or have a **learning disability**
- **At risk of admission to inpatient care**, or
- Already in hospital and need support to **return to the community**

Surrey County Council has been delivering this project in **partnership with Surrey Heartlands Integrated Care Board (ICB)** and local partners such as **Surrey Youth Focus** with a focus on co-production with families and as such we have been supporting the implementation of the Keyworker programme in Surrey over the last year.

We've been working closely with the Key Worker team to spot patterns in the challenges families are facing and to help turn these into opportunities for wider change. The goal is to prevent more families from going through the same issues.

This past quarter, we've focused on sharing what we've learned, highlighting where things get stuck, and helping shape the team's first set of key priorities and measures.



Finance report

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 2025 is a surplus of £166 (prior year to 31st March 2024 was a deficit of £33,373). The reserves at 31st March 2025 have increased as a result to £125,617 (£125,451 at 31st March 2024).

Income for the year increased to £246,332 (£194,596 in 2023/24), with key funding streams from the National Lottery Grant and Surrey County Council remaining in place.

At the end of March 2024, we knew a reduction in expenditure was required due to rising costs and the expected loss of District and Borough funding. Therefore, we incurred upfront HR and consultancy costs during the year to explore the potential for an internal restructure, with the aim of reducing costs in future years. Our expenditure for the year to 31st March 2025 reflects inflationary increases in service costs across all suppliers, in addition to these upfront HR and consultancy costs, resulting in total expenses of £246,166 (£227,969 in 2023/24).

As at 31st March 2025, our reserves position remains within our 3–6 month expenditure policy.

Looking ahead to the year ending 2025/26, there is an expected reduction in income due to the loss of District and Borough funding. However, because of the measures taken during the current year, expenditure is expected to decrease further. As a result, the reserves position is progressively being built towards six months' worth of expenditure.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name	No (if any)
Family Voice Surrey	1175460

Receipts and payments accounts

For the period from	Period start date	To	Period end date
	01/04/2024		31/03/2025

CC16a

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Surrey County Council Grant	- #	104,236	-	104,236	85,000
Surrey County Council - PINS Project	-	40,000	-	40,000	-
Contact Grant	-	17,500	-	17,500	17,500
National Lottery Grant Yr 3	-	-	-	-	81,500
National Lottery Grant Yr 4	-	81,500	-	81,500	-
CFS Health & Wellbeing Grant Yr 2	-	-	-	-	-
Keyworker Project	-	2,400	-	2,400	10,350
Short Breaks Project	-	-	-	-	-
Donations	60	42	-	102	246
Interest	594	-	-	594	-
Sub total (Gross income for AR)	654	245,678	-	246,332	194,596

A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	654	245,678	-	246,332	194,596

A3 Payments

Salaries	32,078	149,481	-	181,559	178,318
Travel and expenses	-	4,526	-	4,526	5,550
AGM Annual event	-	3,738	-	3,738	4,710
HR, Consulting, Payroll	11,872	13,927	-	25,799	10,053
Independent examination	-	-	-	-	2,076
Insurance	989	313	-	1,302	1,174
IT Infrastructure	1,339	10,728	-	12,067	8,820
Office equip, furniture etc	-	-	-	-	-
Other event costs	-	2,522	-	2,522	2,048
Telephone, Stationary and Post	143	128	-	271	1,711
Recruitment	-	-	-	-	-
Marketing and publicity	874	984	-	1,858	1,916
Rent	349	10,755	-	11,104	10,464
Subscriptions	170	650	-	820	1,034
Training	-	600	-	600	95
Sub total	47,814	198,352	-	246,166	227,969

A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	47,814	198,352	-	246,166	227,969

Net of receipts/(payments)	- 47,160	47,326	-	166	- 33,373
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	57,880	67,571	-	125,451	158,824
Cash funds this year end	10,720	114,897	-	125,617	125,451

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	10,126	39,897	-
	Deposit Account	594	75,000	-
		-	-	-
	Total cash funds	10,720	114,897	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details			
		-	-	-
		-	-	-
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 asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
B5 Liabilities	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
	Credit Card	Unrestricted	75	
	Credit Card	Restricted	116	
	Pension Liability	Restricted	623	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature Signed by:	Print Name	Date of approval	
	Sally Allen B81D794006A9476...	Sally Allen	29-Jan-2026	

Independent examiner's report on the accounts

**Report to the trustees/
members of**

Family Voice Surrey

**On accounts for the
period ended**

31 March 2025

**Charity no
(if any)**

1175460

Set out on pages

23 - 25

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31 March 2025.

**Responsibilities and
basis of report**

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").

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.

**Independent examiner's
statement**

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:

29-Jan-2026

Name:

Janice Matthews

**Relevant professional
qualification(s) or body
(if any):**

FCA

Address:

Menzies LLP, Magna House, 18-32 London Road
Staines-Upon-Thames, Surrey
TW18 4BP

Our Plans for Next Year (2025-26)



1 Strengthen Representation and Inclusion

- Complete PCF structure review
- Broaden engagement across communities
- Maintain localised and hybrid events



2 Influence System Change Through Co-production

- Finalise guides on Education, Health and Care Needs Assessment, Personal Budgets, Alternative Provision
- Continue co-designing the parent portal
- Engage with Action Card reform
- Education, Health and Care Plan Process Reform



3 Support Inclusive Education

- Deliver Year 2 of Partnership for Neurodiversity in Schools
- Expand School Autism Friendly Review
- Support nurture hubs and the reduction of school-based anxiety



4 Monitor and Respond to Reform

- Track local government restructure
- Respond to national SEND policy changes
- Embed family voice in all strategic forums attended



5 Mental Health, ND and Early Help

- Deliver social care Pathological Demand Avoidance training
- Advance Neurodevelopmental pathway redesign (subject to funding being available)
- Local Offer Showcase



6 Secure Long-term Sustainability

- Family Voice Surrey Review Implementation
- Diversify income streams
- Maintain strong governance and compliance

Appendix: Structure and Governance

We are constituted as a membership organisation, with over 3,200 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 Surrey 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 2024-2025

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.



Andrew Stevens, (Trustee)

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.



Sarah Clarke (People Lead)

Sarah 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.



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 Trustee Board update 2024-25



We would like to acknowledge Debbie Holden, who joined the Board during the year. Although her term as a trustee was brief, she brought valuable senior leadership experience from the charity sector and meaningful lived experience as a parent of a child with disabilities. Debbie moved on to further develop her career, and we are grateful for the commitment she showed to strengthening the voice of SEND families during her time with us.

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	
Sammy Edginton	20/09/2021	24/05/2024
Sarah Clarke	20/09/2021	
Nicky Brownjohn	16/12/2021	11/09/2024
Andrew Stevens	15/07/2024	
Debroah Holden	01/10/2024	29/01/2025
Amie Stace	28/07/2025	





FAMILY VOICE SURREY MEMBERS

11 DISTRICT & BOROUGH COORDINATORS

PROJECT WORKERS

BUSINESS ASSISTANT

PARTICIPATION MANAGER

PARTICIPATION MANAGER

ENGAGEMENT MANAGER

BUSINESS MANAGER

CHIEF EXECUTIVE OFFICER

HEAD OF BUSINESS PLANNING & DEVELOPMENT

TRUSTEE BOARD

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



Work with us to improve the future of children with disabilities or additional needs. We can't achieve this without your support.

Join us and add your voice to ours. Together, we're stronger.

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Leatherhead
Surrey
KT22 7LT

Charity number: 1175460

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www.facebook.com/familyvoicesurrey



[@FVSurrey](https://twitter.com/FVSurrey)