FAMILY VOICE SURREY

England & Wales · Charity number 1175460

Details

Status	Registered
Legal form	CIO
Registered	2017-10-30
Register	View on the Charity Commission register

Contact

Address	Family Voice Surrey Connect House Kingston Road Leatherhead KT22 7LT
Phone	01372705708
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Website	www.familyvoicesurrey.org

Activities

Objects: TO RELIEVE THE NEEDS OF CHILDREN AND YOUNG PEOPLE AGED 0-25 YEARS IN SURREY AND SURROUNDING AREAS WITH DISABILITIES AND/OR ADDITIONAL NEEDS, INCLUDING THEIR PARENTS, FAMILIES AND CARERS AND TO ASSIST IN IMPROVING THEIR QUALITY OF LIFE AND PROMOTING THEIR INCLUSION IN THEIR LOCAL COMMUNITIES AND TO HELP AND SUPPORT THEM TO REACH THEIR FULL POTENTIAL AS INDIVIDUALS AND MEMBERS OF SOCIETY FOR THE PUBLIC BENEFIT BY; A) FACILITATING EFFECTIVE DIALOGUE AND COMMUNICATION BETWEEN CHILDREN AND YOUNG PEOPLE AND THEIR PARENTS, FAMILIES, AND CARERS AND HEALTH, EDUCATION, DISABILITY AND SOCIAL CARE SERVICE COMMISSIONERS AND SERVICE PROVIDERS; B) WORKING IN PARTNERSHIP TO INFORM, SHAPE AND MONITOR THE DEVELOPMENT OF LOCAL SERVICES SO THAT THEY CONTINUALLY IMPROVE AND ENHANCE THE EXPERIENCE AND LIFE OPPORTUNITIES FOR SUCH CHILDREN AND YOUNG PEOPLE, AND THEIR PARENTS, FAMILIES AND CARERS;C) PROMOTING AND IMPLEMENTING CO-PRODUCTION IN DECISION MAKING AND PLANNING FOR FUTURE SERVICE PROVISION, SO THAT THE CHILDREN AND YOUNG PEOPLE, AND THEIR PARENTS, FAMILIES AND CARERS ARE AT THE CENTRE OF IMPROVEMENTS IN SERVICES.

Activities: To relieve the needs of children and young people aged 0-25 yrs in Surrey & surrounding areas with disabilities &/or additional needs, including their parents, families & carers & to assist in improving their quality of life & promoting their inclusion in their local communities & to help and support them to reach their full individuals & members of society for the public benefit.

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Classification

- **How:** Provides Advocacy/advice/information, Acts As An Umbrella Or Resource Body, Other Charitable Activities
- **What:** Disability, Economic/community Development/employment
- **Who:** Children/young People, People With Disabilities

Geography

- Surrey

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£246,332	£246,166	-	-
2024-03-31	£194,596	£227,969	-	-
2023-03-31	£216,166	£181,311	-	-
2022-03-31	£219,097	£164,649	-	-
2021-03-31	£140,343	£137,947	-	-

Trustees

Name	Role	Appointed
Sally Allen	Chair	2019-06-18
Sarah Clarke		2021-09-20

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Accounts

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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**

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Our Professional Partners

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

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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

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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.

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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.

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What we do

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

- Influence service design and improvement
- Host engagement events that connect and empower
- Promote co-production with professionals
- Deliver workshops and training co-produced with families
- Provide clear, accessible information to families
- Collaborate with professionals to develop inclusive guidance



Our work includes:

- Strategic representation on boards and workstreams
- Events such as coffee mornings, training sessions and showcases
- Focus groups and surveys on key issues
- Co-production of guidance, resources and system improvements

How we represent Your Voice – Meetings, Surveys and Panels

- Strategic representation on boards and workstreams
- Influence service design and improvement
- Promote co-production with professionals
- Host engagement events that connect and empower
- Collaborate with professionals to develop inclusive guidance
- Focus groups and surveys on key issues
- Co-production of guidance, resources and system improvements

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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

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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
- Lack of awareness and understanding of Foetal Alcohol Spectrum Disorder in the area
- Transport difficulties compounded by staff changes
- Provision difficulties leading to Parent Carers not being able to work
- The challenges around accessing ADHD medication
- Lack of support for EBSNA

Supporting our Community

- **Promote co-production**
- **Host engagement events that connect and empower – we are stronger together**
- **Provide clear, accessible information to families**
- **Events such as coffee mornings, training sessions and showcases**

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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

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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

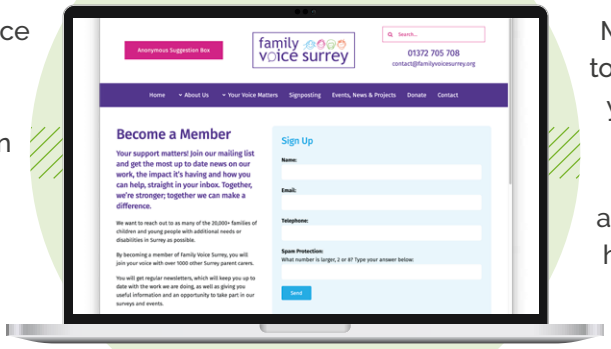
126
ESSNA WhatsApp

100
School Anxiety/ SEN Ideas WhatsApp

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

Our website

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

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

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Our Year in Numbers 2024/25

FVS Members:
3,200
(7% increase)

Facebook followers:
4.7k
(11% increase)

Twitter followers:
1.8k
(6% decrease)





11
local private Facebook groups
with a total of
3,313 members
(10% increase)

1,164
Members voices collected through surveys

LinkedIn
119
(8% increase)

Instagram
202
(110% increase)

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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.

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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.

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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 Mcsherrie, 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.



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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.

2
Action Cards submitted



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.

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.

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Surveys

Alternative Provision Survey

86
Alternative Provision survey responses

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**

Transport Survey

154
Transport survey responses

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**

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.



4
Local Offer events hosted

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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/

1,000+
PINS survey responses

41
Schools participated in PINS



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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.

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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.



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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 childs 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.



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Short Breaks

6
Short Breaks workstreams shaped

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.
- **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

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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 Mcsherrie, 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.

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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.











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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**

CC16a

Receipts and payments accounts

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

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

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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, Staitonary 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**

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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	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

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds 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	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	Print Name	Date of approval
	Signed by: Sally Allen B81D794006A9476...	Sally Allen	29-Jan-2026

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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		

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 2025.

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		

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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

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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.



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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.

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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	









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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.





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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

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family voice surrey



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.

Family Voice Surrey
Connect House
Kingston Road
Leatherhead
Surrey
KT22 7LT

Charity number: 1175460
Tel: 01372 705708
Email: contact@familyvoicesurrey.org
Website: www.familyvoicesurrey.org

www.facebook.com/familyvoicesurrey
@FVSurrey

FAMILY VOICE SURREY

England & Wales - Charity number 1175460

Accounts

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Speaking up for the families of children & young people with additional needs in Surrey
www.familyvoicesurrey.org
contact@familyvoicesurrey.org
T: 01372 705708

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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Page 26-29: Our Trustees Our Family Tree

Page 30: Acronyms used in this document

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Speaking up for the families of children & young people with additional needs in Surrey
www.familyvoicesurrey.org
contact@familyvoicesurrey.org
T: 01372 705708

Our Professional Partners

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.

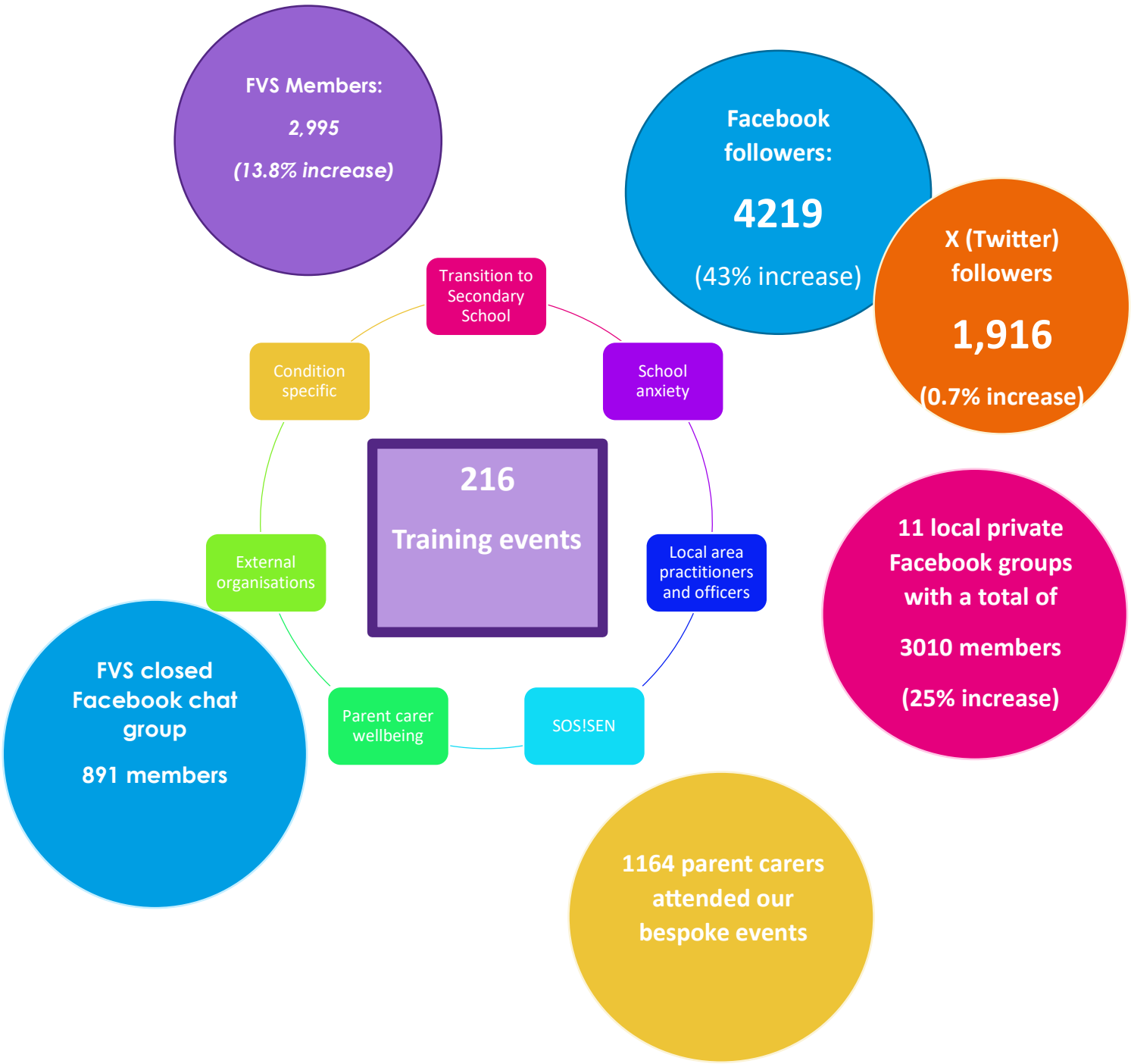
We elevate the voices of SEND families, gather and champion parents and carers' views, and empower them to address assumptions made on behalf of children with additional needs. We represent SEND families in Surrey with authenticity, transparency, and accountability.

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

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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 Health
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 attended 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/

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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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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'.*

MARKETPLACE

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

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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.

Children with Disabilities (CWD) Social Care Team, June 2023. 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). Following the success of the event the CWD Team committed to holding more events in the future.	**Neurodevelopmental (ND) referrals update, February 2024** 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
Action Card Engagement & Participation Group, January 2024. 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	**Home to School Transport Event with SCC Transport Team, July 2023.** 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. 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/

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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 Neorodiversity 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)

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

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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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Speaking up for the families of children & young people with additional needs in Surrey
www.familyvoicesurrey.org
contact@familyvoicesurrey.org
T: 01372 705708

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)
Family Voice Surrey	1175460

Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	01/04/2023		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	Restricted funds	Endowment funds
		to nearest £	to nearest £	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

	Details	Unrestricted funds	Restricted funds	Endowment funds
		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	
	Sally Allen	Signed by: Sally Allen B81D794006A9476...	31-Jan-2025	

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Independent Examiner's Report

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

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").

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: 31-Jan-2025

Name: Janice Matthews

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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.

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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.

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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

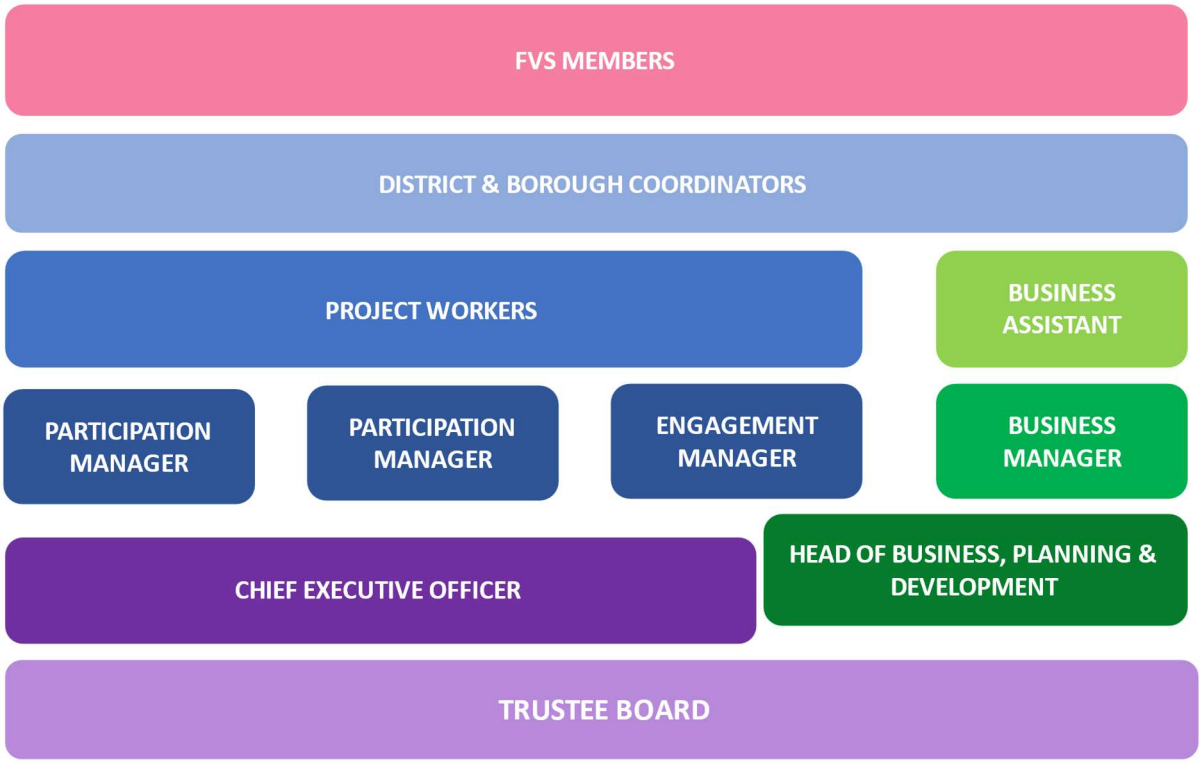
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take this opportunity to thank Sammy for the time and dedication she has given FVS as a volunteer, and we wish her all the best for the future.

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.

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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.

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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

FAMILY VOICE SURREY

England & Wales - Charity number 1175460

Accounts

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family voice surrey

WORKING TOGETHER FOR BETTER LIVES

for children with disabilities and additional needs

Annual Report 1st April 2022 to 31st March 2023





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

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Our Partners and funders

Surrey Additional Needs and Disabilities Partnership

SURREY COUNTY COUNCIL

COMMUNITY FUND

Community Foundation for Surrey

Together we can

contact For families with disabled children

NHS Surrey Heartlands

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Chair comments... Sally Allen



I would like to begin my report by saying a big "thank you" to everyone who has generously gifted their voice and experience so that we can continue our important work to bring about positive change for Surrey SEND families.

Your voice is a valuable gift and to be heard is a positive step towards better understanding.

A recent conversation with another parent carer reminded me of the importance of our work around participation "Until I joined FVS there were many times when I have felt that no one was listening – it has been a very frustrating, stressful and very lonely experience."

This report covers one of the most challenging periods for children, young people, parents, and carers in the UK. With services fully opened up, working at full stretch and with national funding cuts, families have been greatly impacted whilst themselves facing sharp increases in the cost of living and, supporting children and young people struggling with anxiety and mental health issues often experiencing isolation themselves.

2022/23 saw a steady increase in our work, with more families contacting FVS with a wide range of increasingly complex needs. With membership increasing by 13%, Facebook group membership up by 32%, 811 parent carers attending bespoke events, 76 training events delivered and 24 discussion or support groups covering a range of subjects taking place it certainly has been an exceptionally busy year for our dedicated team of FVS staff. We were delighted that following a successful recruitment drive Claire Poole, our Interim CEO became our permanent CEO, providing the continuity, experience, and vision to bring us into the next phase of our journey.

In our last report we pledged to focus on bringing the lived experience to the heart of decision-making and to be a full partner in the development of Surrey's new Inclusion and Additional Needs Partnership Strategy.

In this report we set out how we delivered on this commitment by, as a key member of the Additional Needs and Disabilities (AN&D) Partnership Board, representing the user voice of parent carers on a Board which comprises Education, Health, Social Care and our third sector and user voice partners. We ensure the views and needs of parent carers are heard at the earliest point. A co-produced strategic plan in January 2023 identified 7 priorities of work, a key priority being co-production.

True participation and co-production means an equal role in delivery not just design. FVS worked with families and key partners to offer learning opportunities such as the 'Behind the Mask' event as part of the implementation of the All-Age Autism strategy. Over 130 school leaders attended to learn more about the phenomenon of "masking" often seen in girls with autism, and which creates a significant barrier to identifying and meeting their needs. The stories highlighted how much professionals had to learn from people with different perspectives - particularly people with lived experience.

We have also invited expert speakers to present to our community groups dependent on members' requests and have worked closely with Local Area partners so that parent carers can find information about services and feedback their own experiences, which in turn provides valuable information on how we can remove the barriers to positive change.

So looking ahead we at FVS recognise that there is so much more work to be done in bringing co-production to life by embedding it as a "way of doing" in all of our work with partners and in engaging with people from different backgrounds and with different life experiences. At FVS we are keen to listen to unheard perspectives and to make space for the voices of people whose perspectives are often ignored or unheard.

It is vital that we allow services, policymakers and organisations to get a variety of viewpoints from people representing the diversity of our parent carers in Surrey. So looking ahead we will be working hard to ensure a more open co-production process, with more people with a range of lived experience involved from the start. Please do join us if you are not already a member, tell us your story and experience or become a Trustee!! There are so many ways that you can get involved – the more people, the more opportunity for families to benefit.

In delivering my final Annual Report for FVS, as I end my term as Chair of the Board, I wish to pay special thanks to the wonderful, dedicated and committed team at FVS. I would like to record our heartfelt appreciation for their hard work and dedication including our volunteers; our Board of Trustees who generously donate their time and wisdom, to ensure the safe and secure running of FVS. Also, a special mention to our supporters, partners, and funders, without whom we could not continue with our vital work in bringing about positive change for families in Surrey.

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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 additional needs and disability.

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...



which starts with our parent carers and their families. Their feedback enables us to share their lived experiences into the Additional Needs and Disabilities Partnership Board as a strategic partner. Therefore, 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 parent carers in order to represent their voice - they tell us their valuable stories.

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 people with additional needs and disabilities (AN&D) 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 AN&D families come up against. FVS break down barriers for children with AN&D, by challenging and shaping local decisions, and policies to effect change.

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

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

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Snapshot of the year in Numbers 2022/23

FVS Members:
2,914
(13% increase)

Facebook followers:
2,941
(8% increase)

Twitter followers:
1,903
(3% increase)



- Anxiety
- Self care
- Condition specific
- Local area practitioners and officers
- SEND law and processes
- External organisations
- Mindworks professionals

76
training events
(27% increase)

811
Parent carers attended our bespoke events

11
local private Facebook groups
with a total of
2,413 members
(32% increase)

Over **24**
discussion/ support groups.
Some meeting 9 times in the year

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Engagement with Parent carers - Events overview & experts in the field

Our District and Borough Coordinators were asked to host one online event one month and one in person event the following month as part of our COVID recovery plan. Our members asked us to maintain the online groups that were such a lifeline during lockdown and that support their participation when their children's needs make accessing in person events impossible.

We invite expert speakers to present to our community groups dependent on the members' requests, and also work closely with Local Area partners to allow parents to get information about their services and feedback their own experiences, thus informing the services directly of their effectiveness.

Our events have two aims: to inform and train parents, and to hear their experiences. The following quotes give a flavour of what we have heard this year.

> *As always, I found it very helpful and great to speak to people in a similar situation and I thought it was great how you got everyone involved.*

> *The opportunity to understand a bit more about the transition to adult services (I knew nothing about this so was very helpful). The way in which we were encouraged to ask questions and in which these were answered, thoughtfully and honestly.*

> *This was my first 16+ session with FVS as timings with work just haven't allowed me. It was a really friendly and informative session. It is always really helpful to be able to speak directly with the professionals running the services to understand how the system works so our expectations are not unrealistic. I often find as parent of a child with SEN that unless you end up speaking to the right people you are in unknown territory not even sure which questions to ask. It was really good to hear other parents share their experiences and hear their tips and advice as well as Dr Ferreira-Ley.*

> *Thank you for the Neurographica talk today. I couldn't find any particular shapes in my picture and could only find two energy lines, but at the end I realised they were cutting a path through the middle of the chaos, and that I can make it from one side to the other!*

> *Thank you for trying to educate the educators.*

Some coordinators have also taken responsibility for topic-based groups which are run online to be available county wide. These groups have been instrumental in the growing membership of FVS.

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Top 3 Topics of Events attended in 2022/23

ADHD / ASD group

Run by our Waverley and Woking Coordinators, this is monthly online peer to peer group for parent carers of children and young people with neurodiverse conditions. These are our best attended events across the year and include a combination of parent training and support, as well as an opportunity to gather experience that is then fed back to the Participation team for use in projects such as the "Implementation of the All Age Autism Strategy".

School Anxiety

Following the success of a course developed by FVS in partnership with the Recovery College and Surrey County Council's UVP team in 2020, the Reigate & Banstead and Tandridge Coordinators have now been running a group for these families for the last 3 years. This group has been instrumental in informing the AN&D Partnership and other professionals of the impact of this problem on the whole family, and how parents would like to see it addressed.

The group offers peer to peer support and understanding from parents who have experienced the problem, training from experts and multiple opportunities for parents to share their experience with decision makers.

The topic of school anxiety and persistent school absence has now been recognised as a national concern throughout the world of education and SEND.

Neurographica

Neurographica is a new method of self-discovery and management of life situations through fun and simple drawing. These sessions run by our Spelthorne Coordinator have been extremely well received and FVS has responded by hosting further session as our members tell us that they benefit hugely from them. This form of drawing can help improve emotional response to life challenges and can provide instant stress relief. Neurographica has also been scientifically proven to stimulate neuroplasticity.

As an organisation run by staff with lived experience of SEND, we make every effort to balance our offer to members between support and training and ensuring that we give members a variety of opportunities to share their experience of services in Surrey. These events are a good demonstration of how we aim to strike that balance.

Ponder over a Posy – In person Well-being Event

> *When you spend a lot of your time focusing on someone else, you may feel as if you have no time for yourself. But looking after your own wellbeing is important for you and for them. - Mind*

Our Runnymede coordinator invited AN&D parent carers and their children to an in-person well-being event on 31 January.

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Our members used cut flowers and foliage provided by FVS, as a stimulus for conversation. The relaxed atmosphere and unstructured session allowed parent carers to feel comfortable working on their posies whilst chatting with new people and sharing their stories. A two-year-old child joined in using a colander to poke flowers through, which he thoroughly enjoyed.

Parent carers also had the opportunity to chat with Lori Hilson (from the Early Help team) whilst sitting (rather than standing and talking formally), who also enjoyed making her posy.

Parent carers and children were encouraged to use the paper tablecloth and pens to doodle and leave feedback.



Mindfulness

Waverley's coordinator held a wellbeing event with Emma Martin Mindfulness in Godalming in January.

Emma discussed mindfulness techniques and affirmations and demonstrated the application of them and concluded with a short talk on meditation then a guided meditation session.



Yoga

In December our Tandridge coordinator organised a free yoga wellbeing event for parent carers. This event was very well received.

> *The yoga helped my stress levels, I need to do more of this in order to look after myself as I've neglected to do so for far too long. Years of psychotherapy nearly sorted in three hours!*

Our ability to fund such events is reliant on a variety of funding opportunities and we would like to thank Community Foundation for Surrey for their support in sourcing funders and helping charities such as FVS link with the appropriate channels.

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Engagement with Partners

Surrey Schools SEND event

We were invited to attend the Surrey Schools SEND conference, enabling us to reach SENDCos across the county, and to give them information about the importance of parent carer voice and support. Our coordinator for Epsom and Ewell, spoke to SENDCos about the forthcoming training about recognising autism in girls, and to organisations including as Learning Space, Eikon, REMA and the Family Information Service, about supporting children and families with AN&D.

These are great opportunities for us to raise awareness of the issues, frustrations and experiences that parent carers share with us and to connect with organisations providing SEND services and support.

Preparing for Adulthood event

We were delighted to meet many families at the very well attended Preparing for Adulthood event held in Weybridge in October. Those who attended got lots of valuable information and the opportunity to speak to key people at the local authority. The event also saw the launch of the new Preparing for Adulthood brochure which has been codesigned with young people, parents and professionals.
This brochure was the result of a long collaborative project including FVS, the PfA team at SCC and of course and most importantly parent carers themselves. We are really pleased with how it has turned out and know it will be an extremely useful tool for families and young people.

Behind the Mask event

This event was hosted as part of the implementation of the All Age Autism Strategy and was entirely based on lived experience. Over 130 school leaders attended to learn more about the phenomenon of "masking" often seen in girls with autism, and which creates a significant barrier to identifying and meeting their needs.

Thank you so much. Both as a deputy head and father of an autistic girl I found the whole experience really useful and the morning, in particular, very emotional.

Best training day I have attended in some time. Co-production excellent and added powerful insights and learning. Great structure today that aided learning (loved the modelling of breaks!). Lovely blend of content and presentation style e.g. art exhibition, workshops etc.

The insights given from the perspective of parents and CYP with lived experiences - this was the most authentic insight I could have had.

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Annual event

The theme of our annual event this year was Primary to Secondary School Transition.

Our last two annual events were held virtually, due to Covid restrictions. This year, with restrictions being lifted we were able to offer a hybrid event that allowed us to offer our members the best of both worlds. Monday to Thursday saw online live and pre-recorded guest speaker presentations and Q&A sessions.

The recordings of the event can be found on our YouTube channel at **https://bit.ly/3ujRF1R** allowing parent carers to revisit the speakers anytime they need support.

Or scan the QR code

Dr Kathryn Hollins, Consultant Parent, Child and Family Psychiatrist and Psychotherapist, SABP.	**Tips for managing the Primary to Secondary Transition**
Hugo Metcalfe, Psychologist, The Happy Mind Tribe	**Parent Carer Mental Health**
Rachael Wardell, Executive Director, Children, Families and Lifelong Learning, SCC.	**What to expect if you are a parent with a child with additional needs or disability transitioning from primary to secondary**
Kenny Wheeler, Inclusion Lead, Schools Alliance for Excellence.	**Managing transition from primary to secondary with schools**
Conrad Benefield, Senior Commissioning Officer, SCC.	**Short breaks - what parent carriers can access for their children**
Michael Pipe, Helping Families Early Lead, C-SPA, SCC.	**Local Offer**
Katherine Everett, Education and Inclusion Service Manager NE, SCC. Emily Gaunt NE Deputy Lead for Specialist Teachers for Inclusive Practise, SCC.	**Transition from primary to secondary**
Dr Rebecca Scarth, Consultant Clinical Psychologist and School Based Need Lead, Mindworks, SABP.	**Mindworks, SABP. The school based offer**
Karen Munns, National Autistic Society, Surrey Branch.	**What is available for parents through NAS in Surrey**
Gerry Hughes, Head of Business Support & Surrey School Transport & Assessment team, SCC. Cheryl Knight, Travel Choices Lead, Surrey Choices.	**Home to school transport and independent travel training**
Jo Dilworth, APPEER.	**What is available for girls and their families through APPEER**
Claire Galvin, Action for Carers.	**Support for parent carers with children transitioning to secondary school**
Sarah Palmer, SEND Lawyer and Expert, Children's Legal Practise.	**Reasonable adjustments and legal rights**
Farran Leach, Active Surrey.	**Staying active and healthy during periods of transition**

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We hosted an in-person session on Friday at Eastwood Leisure Centre in Woking and had the pleasure of hosting four fantastic guest speakers:

Award winner and author Yvonne Newbold of Newbold Hope discussed ways to support anxiety driven behaviour challenges.

SEN lawyer and expert Sarah Palmer from The Children's Legal Practice, talking about reasonable adjustments and legal rights.

Dean Beadle, an autistic speaker talked about his experience of being autistic with a touch of comedic brilliance and humour.

Rachael Wardell, Executive Director, Children, Families and Lifelong Learning, at Surrey County Council spoke about what to expect during the primary to secondary transition.

As always we also hosted a 'marketplace' which gave parent carers the opportunity to speak to a variety of organisations and charities providing information about the support services that they provide.



Gathering information - capturing real life experiences

Our Coordinator for Reigate & Banstead approached the team with an idea for gathering qualitative and quantitative data 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.

In autumn 2022 we launched our Quarterly Quantitative Data Survey. Our first topic was chosen based on the high volume of correspondence we were receiving from parent carers regarding challenges they were encountering with the home to school transport service in the run up to the new academic year.

In total 290 parent carers responded to the survey and we were asked to present our findings along with an overview of what we had been hearing from families at the Select Committee meeting on the 15th December 2022. SCC also presented the findings of their own review they had conducted in light of the challenges.

FVS made 12 recommendations to address the issues families had faced with transport and we were pleased to learn that the select committee endorsed all of our recommendations.

This is a wonderful example of how the collective and powerful voice of parent carers can make a huge difference.

Quarterly Surveys for 2022-23

Date	Survey	Number completed
October 2022	Home to School Transport	290
February 2023	The Role of the SEND Case Officer	500

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Supporting Navigation of the System

Our members often ask us for support in navigating various aspects of the SEND system. This year, the FVS team have worked in various ways to respond to this:

Helpful guides

Everyone Matters - representing children with a severe or profound learning disability.

FVS worked on this project following feedback from parents of children with severe or profound learning disabilities who felt FVS did not represent their children and their experience well enough. During the project we consulted a number of families with a child with severe or profound learning disabilities in order to better understand the challenges they face, their views on how Surrey County Council (SCC) can better meet their needs and how FVS can better represent them.

The following extract taken from the last paragraph of the report summarises our role in ensuring that the voice of parent carers of children and young people with a severe or profound earning disability is heard.

> *I am convinced that FVS could play a really important role in highlighting the particular needs of children with severe and profound learning disabilities. I am also convinced that this is a group that needs as many allies as possible and far more representation in order to achieve a society where everyone is valued.*

We will be using this report to ensure that these families are heard in all of our work and sharing it with those who have the ability to effect change in the areas identified.

***We will do some testing in 2023-24 to ensure we are embedding this in the work we are doing*.**

> *Hello, I was really heartened to receive this report and to hear about the time you have put into putting together the testimonials.*
> *They really do all reflect our experience and fears and concerns as a family and whilst my daughter has had her needs met at school and by respite, I know that there is such a lack of understanding and consequently investment in provision for our children. I am following with great interest any developments and discussions and changes that take place as a result of this piece of work.*
> *With kind regards (mother of a non-speaking 15 year old daughter)"*

The Crisis Card

Following a meeting and idea from a parent, whose daughter tragically took her own life last year, we have been working with the Mindworks (formally CAMHS Child and Mental Health Services) team and Emerge (a local charity that supports young people who have arrived in hospital as a result of suicidal ideation or attempts) to produce a Crisis Card that would be put into all hospitals and GP surgeries in Surrey. This card fits in a wallet and gives local contact information to crisis services, allowing parents to have quick access to phone numbers that can help them at a moment of crisis.

This project was triggered within our "action card" system described on the next page, and is an example of how this system will allow us to effect change.

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Mindworks Surrey

Crisis line for support during a mental health crisis

0800 915 4644 – For children, young people and parents. Open 24/7

Neurodevelopmental helpline for parents of children with ADHD and autism

0300 222 5755 – Open 5pm to 11pm every day

Scan me to visit our website

www.mindworks-surrey.org

Action Cards

Surrey County Council is keen to ensure that lived experience is at the heart of its decision making. One of the ways in which this has been done successfully is the introduction of "Action Cards". As such, FVS has just introduced its version of Action Cards that line up with existing systems, while being independent and focused on parent carer experience. We started with 3 action cards and the aim is to ensure that a concrete outcome is achieved. These action cards are posted on our website when they are published, as soon as the outcome measures have been agreed. We then publish updates every quarter, at a minimum. The topics of the first three cards were as follows:

Action Card 1: EBSNA (Emotionally Based School Non-Attendance)

Desired Outcome:

- To understand what educational options are currently available for these children.
- To see SCC's plan for specialist provision that includes an equitable range of academic teaching and qualifications.
- To see how SCC's sufficiency plan accounts for these children.

Action Card 2: Communication

Desired Outcome:

- When communication is made about a child, parents are copied in wherever possible, unless there is a safeguarding concern.

Action Card 3: Suicidal crisis support

Desired Outcome:

- A card including crisis services sized to fit into a wallet so that the young person, parent, teachers etc have easy access to support should the next crisis occur.

You said – We did

In April 2022 we introduced 'You said – We did', taking the questions you have been asking to Surrey County Council and Partners for a formal response.

The questions you are asking are really varied including Post 18 ARFID service, Tourette's, Blue Badge Scheme and Free school meals. Additionally, there are also some common themes, that we see throughout our work at FVS, including Transport, EHCP's, EBSNA and Mental Health.

To read all of the questions and responses visit
https://familyvoicesurrey.org/your-voice-matters/you-said-we-did/

This continues to be a regular communication with our members, so please keep the questions coming. You can email your questions to **contact@familyvoicesurrey.org** or complete the online form using this link **https://familyvoicesurrey.org/your-voice-matters/tell-us-your-story/**

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Participation and Co-production with local area partners and the 3rd sector

We plan our work based on feedback from parent carers collected through surveys, data, events, emails, and social media.

We actively participate in various external meetings, representing our members on important boards like the Additional Needs and Disabilities Board, Schools Forum, and Surrey Safeguarding Children's Partnership. In 2022-23 we attended well over 250 external meetings.

Our collaborative approach with partners involves holding each other accountable and working together to overcome challenges that get in the way of positive outcomes for families. This feeds into our work and planning.

In January 2023, the Surrey Additional Needs and Disabilities Partnership published a strategy outlining goals until 2026, known as the Surrey Inclusion and Additional Needs Partnership Strategy. This strategy focuses on seven key areas: Co-production, early intervention, inclusion in education and the community, joint commissioning, preparing for adulthood, systems and practice, and leadership, accountability, and governance.

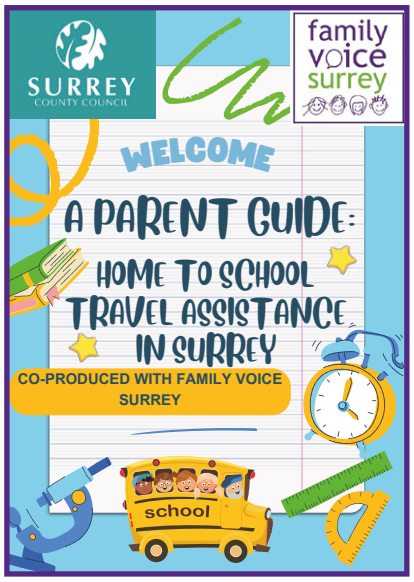
FVS actively contributes to the improvement efforts related to these priorities and plays a crucial role in monitoring progress and action plans. Looking ahead to 2024, we will maintain our role as an equal partner on the Additional Needs and Disabilities Partnership Board, influencing strategic objectives and providing essential feedback as the Surrey parent carer forum. Our ongoing input is vital in shaping and implementing the strategic improvement plan in response to the recently published Ofsted and CQC Report.

Meetings attended include

- 3rd Sector Additional Needs and Disabilities Network
- Additional Needs and Disabilities Partnership Board
- All Age Autism Strategy Implementation Board
- Alternative Provision Parent Guide Planning
- Best Start for Surrey Transformation Board
- Children and Young People Autism Partnership Board
- Children with Disabilities (CwD) Strategic Forum
- Children, Families, Lifelong Learning and Culture Select Committee
- Childrens Community Health recommissioning
- Coproduction Charter
- Education, Health and Care Plans Focus Group
- Emotional Wellbeing and Mental Health (EWMH) Focus Group
- Emotionally Based School Non Attendance (EBSNA) Working Group
- Healthwatch Surrey
- Home to School Transport (H2ST) Customer Journey Review
- Inclusion Steering Group
- Learning Disability and Autism (LDA) Keyworker Project
- Lessons Learnt Review
- Local Offer planning
- Mainstream Banding Public Consultation
- Mental Health Support Team (MHST) Deep Dive in-person event
- Mindworks Reference Group
- Neurodevelopmental (ND) Reference Group
- Ordinarily Available Provision Easy Read workshop
- Partnership Action Cards
- Preparation for Adulthood Transformation Board
- Schools Alliance for Excellence (SAfE)
- Schools Forum
- SEND Advice Surrey (SENDIAS) Steering Group
- Smooth Transitions Planning
- Social Care Mapping
- Social Emotional Mental Health (SEMH) Steering Group
- South East Region National Network of Parent Carer Forums
- Surrey Healthy Schools Steering Group
- Surrey Safeguarding Children Partnership
- Team Around the School Steering Group
- Voluntary, Community and Social Enterprises Alliance (VCSE)

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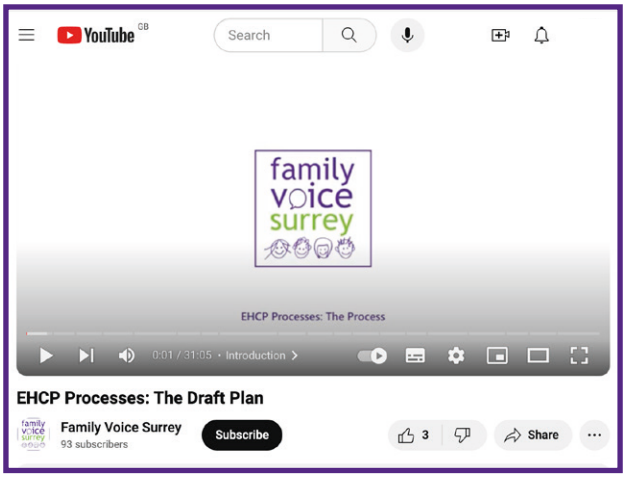
Here is a taster of what we have been doing over the past 12 months



We worked with the home to school transport team at Surrey County Council to develop a co-produced parent guide which details the process for accessing travel assistance for your child or young person from eligibility right through to delivery. You can read the guide here: **https://familyvoicesurrey.org/wp-content/uploads/2023/06/H2ST-FVS-Parent-Guide-Final-24.5.23.pdf**

EHCP Processes: The Draft Plan and The Plan.
https://www.youtube.com/watch?v=a1YQdF_-Ggs

FVS produced another EHCP Processes bite sized video, this time on EHCP Processes: The Draft Plan and The Plan, with the SEND team at Surrey County Council.



We would love to hear your feedback of these videos and your own experiences of draft and final plans as part of the EHCP process. If you have any further questions after watching the video, please do send them to **leanne.h@familyvoicesurrey.org** and we will do our best to get them answered.

We were delighted to be invited to the Surrey Leisure Operators Forum to give a presentation about the SEND swimming trial we supported Spelthorne Leisure Centre to set up. The Leisure Centre managers were very keen to learn more about how they could include this into their swim schedules. We discussed the challenges involved and how they could initiate the trial at their leisure centres.

A fantastic outcome of this project has been Eastwood Leisure Centre commencing SEN swimming sessions on Sunday mornings from January 2023, with a swimming teacher who has worked in Freemantle's! They have also started a SEN casual swim session on a Wednesday afternoon after school.

Surrey's Local Offer team, Family Voice Surrey and Surrey County Council collaborated on a visual guide to Children's Services in Surrey.

This document has been created to raise awareness and understanding of what support is available from Children's Services, in a quick and easy to understand way.

"At Family Voice Surrey, we have often heard from parent carers that they need an easy way to understand the support offered by children's services in Surrey. We wanted a quick guide that everyone could read and easily understand. We contacted Surrey County Council's Local Offer team to propose this, and they immediately agreed that it would be a good idea. As the work progressed it became obvious, we would need other staff at Surrey County Council to help us. We are delighted with what we have produced, and we hope you find it helpful."

This collaborative working helped the document to evolve; after initial meetings, simplifying the wording and length. A draft version was reviewed by parent carers at Family Voice Surrey and their extremely helpful comments were incorporated into the final document.

If you feel the support described in the document isn't applicable to your families' circumstances and you feel you 'fall through the gaps of the support available' then please let us know by contacting **kate.g@familyvoicesurrey.org**

You can read more about the work we have been doing by reading our Monthly Overviews here: **https://familyvoicesurrey.org/monthly-overviews/**

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Plans for 2023/24

Planning a Parent Carer Forum year is always a delicate balance between our passion to represent parent carer voices and the practicalities of finite time and resources.

Our priorities for the next year have been put together following feedback from parent carers on the areas that they would like to see us focus on (via surveys), parent carer experience (your stories), our collaborative work with the Additional Needs and Disabilities Partnership, 3rd Sector and other key partners alongside our own business planning, involving all staff.

Thank you to everyone who has taken the time to help us plan for the year ahead.



Our key plans for the year are:

- Increase membership and reach
- Ensure a wider range of additional needs and disabilities are represented
- Roll out face-to-face events in our local community
- Improve meaningful engagement and co-production with parent carers (Steering Group) AND Partnership Plan - improvement plan includes better opportunities for Co-production
- Increase collaboration with the 3rd Sector
- Co-create FVS Equality, Diversity & Inclusion Strategy
- Launch FVS Engagement & Communication Strategy
- Pilot quadrant-based events with partners
- Build connections with organisations and schools
- Launch new website
- Trustee recruitment
- Continue Organisational appraisal and business planning
- Learning Disability and Autism (LDA) Keyworker Project

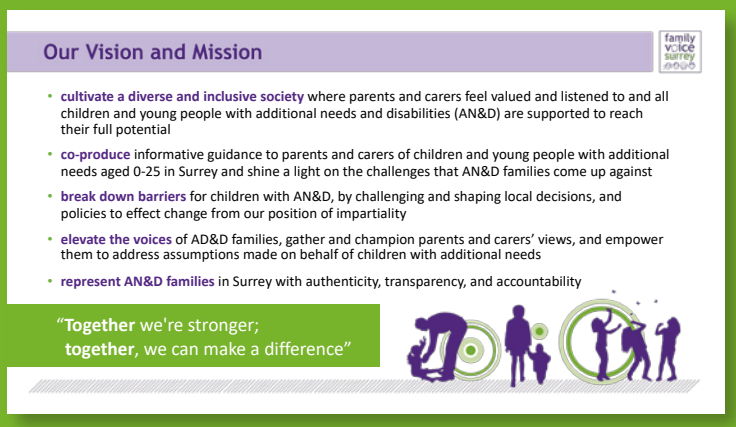
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Participation Work:

- Children with Disabilities Social Care event
- Community Health Recommissioning
- Smooth Transitions Pilot
- Emotional Based School Non-Attendance Training
- EHCP Processes – Recovery Plan
- ND Pathway
- PfA Social Care and Education
- Transition Autism Pilot
- Home to School Transport review

Our focus is to engage with our community and facilitate positive connections between parent carers and decision-makers in Surrey. We're happy to report that decision-makers appreciate this effort. Our annual event in November 2023, entitled "Empowering Parent Carers," was crucial in advancing this priority.





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Finance report

Family Voice Surrey Treasurers Report for the year ended 31st March 2023.

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 2023 is a surplus of £34,855 (prior year to 31st March 2022 was a surplus of £54,448). The reserves as at 31st March 2023 have increased as a result, to £158,824 (£123,969 at 31st March 2022).

Income for the year has remained static at £216,166 (2021/2022 £219,097) in line with the award of a National Lottery Grant in 2021.

Expenditure increased following the award of this grant to maintain service delivery. Our expenditure for the year to 31st March 2023 remained in line with expectations and was £181,311 (2021/22 £164,649).

Our reserves position remains within our 3-6 month expenditure policy.

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	To	Period end date
	01/04/2022		31/03/2023

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	85,708	-	-	85,708	85,016
Contact Grant	-	17,500	-	17,500	17,500
National Lottery Grant Yr 1	-		-	-	81,500
National Lottery Grant Yr 2	-	81,500	-	81,500	-
CFS Health & Wellbeing Grant Yr 1	-		-	-	24,975
CFS Health & Wellbeing Grant Yr 2	-	24,975	-	24,975	-
Keyworker Project	-	5,125	-	5,125	-
Donations	1,358		-	1,358	106
CFS Grant	-	-	-	-	10,000
***Sub total** (Gross income for AR)*	87,066	129,100	-	216,166	219,097

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A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	**87,066**	**129,100**	-	**216,166**	**219,097**
A3 Payments					
Salaries	**45,013**	**94,620**	-	**139,632**	**127,283**
Travel and expenses	**4,377**	**230**	-	**4,607**	**2,490**
AGM Annual event	**4,810**	-	-	**4,810**	**2,072**
HR, Consulting, Payroll	**1,110**	**3,243**	-	**4,353**	**3,929**
Independent examination	-	**1,626**	-	**1,626**	**1,020**
Insurance	**1,087**	-	-	**1,087**	**630**
IT Infrastructure	**4,187**	**3,839**	-	**8,026**	**12,830**
Office equip, furniture etc	**558**	-	-	**558**	-
Other event costs	**527**	**1,104**	-	**1,631**	**2,053**
Telephone, Stationary and Post	- **3**	-	-	- **3**	**2,022**
Recruitment	**245**	-	-	**245**	-
Marketing and publicity	**3,922**	-		**3,922**	**1,407**
Rent	**848**	**8,661**	-	**9,509**	**8,010**
Subscriptions	**534**	**500**	-	**1,034**	**520**
Training	-	**274**	-	**274**	**383**
Sub total	**67,215**	**114,096**	-	**181,311**	**164,649**
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	**67,215**	**114,096**	-	**181,311**	**164,649**
Net of receipts/ (payments)	**19,851**	**15,004**	-	**34,855**	**54,448**
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	**68,977**	**54,992**	-	**123,969**	**69,521**
Cash funds this year end	**88,828**	**69,996**	-	**158,824**	**123,969**

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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	Cash at bank	88,828	69,996	-
		-	-	-
		-	-	-
	Total cash funds	**88,828**	**69,996**	**-**
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds 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	Zoom	Unrestricted funds	1,779	17/4/23
	Microsoft	Unrestricted funds	141	17/4/23
	Mailchimp	Unrestricted funds	68	17/4/23
			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
	DocuSigned by: S. Allen B81D794006A9476...	Sally Allen	23-Jan-2024

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Independent examiner's report on the accounts

Report to the trustees/ members of	Family Voice Surrey		
On accounts for the period ended	31 March 2023	**Charity no (if any)**	1175460
Set out on pages	18-20		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31 March 2023.

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:**	23-Jan-2024
Name:	Janice Matthews		

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Appendix: Structure and Governance

We are constituted as a membership organisation. 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 acceptance of 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 particularly if with children with AN&D. In particular, we welcome applicants from diverse ethnic, religious or other minority interest groups. The trustee board provide steer for the charity, ensuring that operations team develop strategies and activities that will allow Family Voice to meet its objectives.

While day to day operations are led by the CEO with guidance from Head of Business, Planning and Development and Business and Engagement Manager 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 an additional 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 received 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.



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family voice surrey

FVS MEMBERS

11 DISTRICT & BOROUGH COORDINATORS

PARTICIPATION OFFICER | 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 participation team (in blue) work with local area partners to inform them of issues facing parent carers. They are involved in strategic meetings, have input into some policy documents, work with partners on messaging, all in a wide range of areas pertaining to SEND.

Our coordinators work with our members, gathering their stories to be collated as evidence to strengthen the voice of the participation team 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.





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The Trustee Board 2022-2023

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. 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.

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Acronyms used in this document

ADHD	Attention deficit hyperactivity disorder	**MHST**	Mental Health Support Teams
AN&D	Additional Needs and Disabilities	**ND**	Neurodevelopmental
ARFID	Avoidant/restrictive food intake disorder	**NNPCF**	National Network of Parent Carer Forums
ASD	Autistic Spectrum Disorder	**PfA**	Preparing for Adulthood
CAMHS	Child and Adolescent Mental Health Services	**Q&A**	Questions and answers
CEO	Chief Executive Officer	**SABP**	Surrey and Borders Partnership
CYP	Children and Young People	**SAfE**	Schools Alliance for Excellence
C-SPA	Children's Single Point of Access	**SCC**	Surrey County Council
EHCP	Education, Health and Care Plan	**SEMH**	Social, Emotional & Mental Health
ESBNA	Emotionally Based School Non-Attendance	**SEN**	Special Educational Needs
EWMH	Emotional Wellbeing and Mental Health	**SEND**	Special Educational Needs and Disability
FVS	Family Voice Surrey	**SENDCo**	Special Educational Needs and Disability Coordinator
LD	Learning disability	**SENDIAS**	Special Educational Needs and Disabilities Information Advice and Support Service
LDA	Learning disability and Autism		

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family voice surrey

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.



Family Voice Surrey
Connect House
Kingston Road
Leatherhead
Surrey
KT22 7LT

Charity number: 1175460
Tel: 01372 705708
Email: contact@familyvoicesurrey.org
Website: www.familyvoicesurrey.org

www.facebook.com/familyvoicesurrey
@FVSurrey

FAMILY VOICE SURREY

England & Wales - Charity number 1175460

Accounts

WORKING TOGETHER FOR BETTER LIVES

for children with disabilities or additional needs

family voice surrey







Family Voice Surrey, CIO

Annual Report

1st April 2021
to 31st March 2022

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

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The Trustee Board

This year saw some significant changes to our trustee board, including the departure of Simon Morley and Karen Lettington in November 2021.

We are so pleased to have welcomed two new trustees to the board, Sammy Edginton and Sarah Clarke, in September 2021. You can read more about our new trustees and our continuing chair, Sally Allen, below.



Simon Morley (Treasurer)

Simon joined FVS in 2017 and became a hugely valued member of the board. His calm yet uncompromising approach to the mission of the parent carer provided a sure compass and he was always committed to supporting all FVS staff. Simon initially joined the board as treasurer but subsequently also took on the role of chair of trustees while we worked to find new trustees.

He provided valuable mentorship and support to the incoming CEO Benedicte Symcox, and was instrumental in the organisation's ability to navigate a period of turbulence and change.

We would like to take this opportunity to thank Simon for the time and dedication he gave to FVS for the five years he was with us, and wish him the best in his next adventures.



Karen Lettington

Karen joined FVS as a trustee in 2019 and was always a strong voice in favour of inclusion, sharing her story at our annual event that year. Hers is a powerful story of advocacy and the power of true inclusion, but also one that demonstrates how a parent carer can change the outcome for their children by advocating strongly for them.

Karen drove the board and the organisation to do better at every turn, and was the key person to drive us to examine the accessibility of our work. We must be accessible to all if we are an organisation representing those with additional needs! Thanks to her, we make sure to create an "easy read" version of our annual report, and work hard to make all other reports simple to read.

Karen's other commitments have led to her resignation from the FVS board this year and we wish her wonderful things for the future.



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 (Lead People)

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

Chair Comments... Sally Allen



This has been another year of change, of challenges and social upheaval for many people as we try to get to grips with what "opening up" looks like for us as individuals and our families.

Whilst parents, carers, communities and our public and third sector have all worked hard to support children through the pandemic, and many children and young people have benefited from this support and have coped with navigating the challenge, there are many of our families, children and young people whose wellbeing has been negatively impacted, with change being felt more acutely by some than others and the prospect of opening up and re-joining society proving challenging and to some unimaginable.

As we emerge from the pandemic, the stark fact is that systemic inequalities continue to exist alongside new complexities which have the potential to lead to further isolation or disadvantage for many SEND families.

I am immensely proud of our team, at Family Voice Surrey who have not only ensured that the vital lifeline of regular, friendly contact, connecting with people who understand and have access to resources and information that might unlock hope continues, but have also developed a blended offer with face-to-face opportunities alongside live online sessions and bite sized videos on special topics requested by our members. With a strong focus on parental wellbeing, the team continue to do everything they can to nourish and encourage families through some tricky times with information and peer support and have focused on the opportunities that can arise out of difficult times. As parent carers too and well used to adaptive parenting, our team bring valuable insight and skills to their important work in bringing about effective, positive change for SEND families.

There are many highlights of the year which are the essence of FVS and the reason for its continuing success.

- A 5 year National Lottery Grant and 3 year funding agreement from Surrey County Council signify the importance of our work here at FVS and are testimony to the strong management and positive outcomes that FVS can deliver.
- As the "voice of SEND families in Surrey" we are focused on listening and understanding. This year our planning involved a more detailed understanding from our members, partners and staff of where they think our focus should be and how well we are doing as an organisation. Thank you to everyone who gave up their time in helping us to plan. Our plans have a clear focus on building on our strengths, delivering better outcomes for SEND families, making the case for change and building a truly diverse and inclusive organisation with SEND families at the heart of everything it does.
- Transitioning new members onto the Board as we continue to strengthen our direction and Governance. The recruitment of new Board Members Sammy and Sarah following a successful on-going advertising campaign enabled us to say our "goodbyes" to outgoing Trustees Simon Morley (Treasurer and former Chair) and Karen Lettington, with confidence that their legacy of good governance will continue to go from strength to strength. I would like to thank Simon in particular for his unswerving investment and commitment to families and FVS values, his calm and balanced approach – everything done with gentle kindness and Karen for her uncompromising challenge and vital perspective. It is a privilege to be volunteering alongside Sammy and Sarah and with growing interest in the role and potential new trustees in the pipeline with the support of a talented and committed Board I'm excited to see what opportunities we can create in 22/23 - maybe just maybe you can be part of our journey too!

- Stand out quotes and Member stories help us to keep pace of the important issue that need celebrating or fixing. Member quotes often sum things up perfectly "On those occasions where professionals focus their attention on the needs of the child and the family rather than their own organisational processes, the outcomes can be very positive, and the sense of distrust and animosity starts to dissipate surprisingly quickly." Our members are our barometers - we continue to work with Heath and Social care colleagues to improve their response to vital services such as transport and in monitoring the effectiveness of new services such as Mindworks.



At the time of writing this report I also reflect on other important changes with gratitude and hope. In July 22 we said sadly "goodbye" to Benedicte Symcox our CEO and former Board Member. Benedicte has been the familiar and reassuring face of FVS for over 6 years both as Member, Board Member and CEO. Benedicte's magic blend of being "parent first" to three amazing young people with varying special educational needs, and abilities, creativity and skilled relationship management have been a real asset to our members and have significantly contributed to FVS growth and the strong position that we now find ourselves in an as organisation.

Benedicte's extensive knowledge and experience of navigating complex systems and relationships alongside her overriding ethos of valuing the importance of respectful relationships has enabled families and FVS as an organisation to move forward with increased confidence that our members are seen as equal partners within SEND transformation. We all recognise that there is still much work to be done - never afraid to respectfully challenge and push for transparency we look forward to continuing to hear from and work with Benedicte as a FVS member.



I am delighted to welcome Claire Poole as Interim CEO for initially a 6-month period whilst we recruit to the permanent role. Claire has been associated with FVS since 2015, working closely with Benedicte and the FVS team to keep us all on track as Head of Business, Planning & Development.

Claire brings valuable skills and perspective to the role with lived experience of being a looked after child as well as a carer and parent carer, an ability to question, maintain balance and perspective plus a keen eye on the detail whilst successfully juggling competing priorities.

Looking to the future I am confident and excited to see that FVS is gathering strength in its journey to bring about positive change for SEND families through its amplified voice, growing membership and focus on "family first".



Priorities for the Year

1. ***Staff Welfare***: develop a robust appraisal and support system for staff, to include appropriate training and mental health support.
2. ***Membership:*** build membership and increase diversity; offer training and information events for parent carers; continue to use Facebook live as a means of engagement; provide opportunities for parent carers to meet with council officers and practitioners.
3. ***Annual event:*** "Early Years" a virtual event focussing on conception to school age.
4. ***Financial stability:*** diversify funding; develop stronger commissioning relationship with SCC.
5. ***Participation:*** embed and improve our project approach; ensure that all participation work is evidence driven based on engagement work.
6. ***Webinars:*** build on the success of the Preparation for Adulthood annual event and develop videos with speakers to address parent carer issues.
7. ***Engagement:*** build on the parent training programme begun in the pandemic; develop tools to ensure that parent carer stories are heard and used in participation work.
8. ***Organisational appraisal and business planning:*** how are we doing? What do we want to achieve?
9. ***Partnership:*** increased collaboration with the 3rd sector.

Highlights of the year

Work to influence decision making in Surrey includes:

1. **Early Years Event**: building on the success of the 2020 virtual annual event, we took our attention to the beginning of life and early childhood. We welcomed a plethora of practitioners from the local area, external speakers and spoke to families for several months ahead of the events to gather all the questions and issues that are relevant to these families.
2. **Local Offer Redesign:** we supported and continue to support the Local Offer team to ensure that language used on the local offer website is appropriate and helpful for parent carers.
3. **Swimming for Children with Additional Needs:** we worked in close partnership with Spelthorne Leisure Centre to pilot a swimming course for children with additional needs. This was hugely successful and is being rolled out to other leisure centres of the same franchise.
4. **Preparation for Adulthood event** in coproduction with SCC: this event was led by SCC officers, but co-hosted with FVS and was the first hybrid event since the start of the pandemic.
5. We began an ongoing project to develop **EHCP bitesized videos** with officers to demystify the EHCP process, governance panels and other decision making processes. These are available on our YouTube channel.
6. We supported Health colleagues in their **Digital Navigator project,** ensuring that the experiences of disabled children and carers were appropriately represented.
7. **Emotionally Based School Non Attendance:** we ran a survey that has lifted this serious issue to the top of the agenda in the council's SEND thinking.
8. **Board Recruitment:** we ran a successful recruitment campaign in conjunction with our Local Council for Voluntary Services which meant we were able to strengthen our skills base and welcome two new members onto the Board this year.

Family Voice Surrey in Numbers 2021/22

FVS Members:
2,713
(17% increase)

Facebook followers
2,576
(30% increase)

2,363
Facebook likes
(25% increase)

Average reach via Facebook page
769
(260% increase)

60
training events

- Anxiety
- Self care
- Condition specific
- Local area practitioners and officers
- SEND law and processes
- External organisations
- CAMHS professionals

11 local private Facebook groups, total membership:
1,823
(75% increase)

Twitter followers
1,853
3% increase



Facebook Parent/carer chat group members:
733
(37% increase)

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.

Organisational appraisal

Vision

- A society that allows families whose children have additional needs to be heard.
- A society in which ALL children thrive and are supported to achieve their dreams.
- A society that celebrates difference and diversity.
- A society that breaks down the barriers faced by children and young people with special educational needs and disabilities.

Mission

- Family Voice Surrey aims to bring about positive change for young people with additional needs by:
- Giving families a strong collective voice.
- Being a professional, parent carer led organisation.
- Ensuring parent carers are valued as equal partners within the local authority.
- Supporting parent carers to understand their rights and choices.

Values

- **We are an organisation that is:**
- Respectful - even if we don't agree
- Supportive - even if we don't understand
- Positive - even when we challenge each other
- Equitable - being flexible and prepapred to adjust if needed
- Committed - even when positive change seems slow
- Engaged - we listen to ALL points of view

A priority area this year was staff welfare, and we quickly realised that a broader approach was necessary. As an organisation that regularly champions co-production with system partners, it was important for us to use the same approach internally. As a result, this year saw a number of workshops to review the purpose of the parent carer forum, those aspects of our work that were most important to us, how we evidence the stories we hear and how we support our staff.

Co-production is a slow and sometimes painful process but it focusses on ensuring that every voice is heard. One of the central ideas that we explored was the need for constant self-evaluation and improvement, and that we should never assume that this work is finished.

As part of this process, it was important to include our members, so we ran our first "FVS satisfaction survey", the report of which can be found https://www.familyvoicesurrey.org/single-post/2021-statisfaction-survey

Covid has had an impact on us all, and one area identified was the need for FVS staff to be equipped to support parent carers in mental distress. As a result, we offered all staff "mental health first aid" training and gave all staff a wellbeing day in December 2021 in recognition of the importance of looking after our own mental health. This created a little space for a much-needed pause and re-group.

Partnership

Julia Katherine, Assistant Director for Inclusion and Additional Needs at Surrey County Council

"Here in Surrey we are working hard to transform services to improve the experience that families have of the special educational needs system and to improve the outcomes children and young people with additional needs can expect to achieve."



"We recognise that we still have room to learn and improve, and so the role of Family Voice Surrey is crucial to our aims. As our parent carer forum, Family Voice Surrey helps us to hear the voices of parents and carers (including those voices that are seldom heard), to better understand the lived experience of families with a child with additional needs. As a partnership, we continue on our improvement journey, together, with the ambition of embedding a culture of coproduction that recognises the value that parent carers bring.

Over the past year, Family Voice Surrey have ensured that we collectively keep families at the front and centre of our discussions and decisions. We were delighted with the response to our parent carer survey and we've really enjoyed the opportunities we have had to improve communication through the Facebook live sessions, and publishing 'you said, we did' responses to the action cards that have been raised with us. We have further developed the guidance on the local offer website www.surreylocaloffer.org.uk/ in response to feedback so that parents have the information they need to make informed choices.

One example of a change we have made in response to feedback is in the language we use. Families have told us that they prefer us to talk about 'additional needs and disabilities' rather than special needs, wherever possible. This is why we are proposing that our new plan setting out our future priorities will be called the Inclusion and Additional Needs Strategy. We will be working with Family Voice Surrey to ensure there are continued opportunities for parents carers to contribute to this work, to help us get it right for all of our children and young people.

Thank you to everyone who has contributed their experiences and time to make positive changes!"



2021: Vaccinations and Hope

As we started a new financial year, our children were once again not sitting exams. Many were still at home for fear of catching Covid and either risking their health and lives or that of their loved ones. Regulations were still changing rapidly, but there was for the first time an end in sight, thanks to the vaccination program. In the event, most regulations were to be brought to an end in mid July 2021.

Our community of children with additional needs were at the forefront of much confusion regarding vaccination: was the vaccine safe for children, maybe necessary for the most vulnerable? Were unpaid carers eligible at the same time as professional carers? When would teachers be vaccinated? All these questions and more fed into a time of enormous uncertainty after a year that had proved exhausting for all, but unimaginably more so for those families who include someone with additional needs, disability or illness.

Staff and Changing Workload

Family Voice Surrey continued its work "as normal". We had become accustomed to recruiting staff virtually and worked hard to maintain our ethos of a safe and nurturing workplace. Team working has always been important, but challenging as we all work remotely. Staff meetings are essential but can also be difficult to arrange around the various responsibilities of parent carers whose children are of varying ages and needs.

Our two new participation managers, Leanne Henderson and Kate Goode, rose to the challenge of getting to know the FVS team without ever having met in person. But, also the multitude of local area officers and practitioners, never hesitating to ensure that parent carer voices and views are heard in each and every meeting they attended.

We welcomed four new district and borough coordinators: Shannon Thomas, Jenni Williams, Emily Hazell and Sara Draycott. They successfully built online communities and slowly ventured back into the community as the pandemic allowed. Coordinators are closer in many ways to parent carers than the rest of the team, and they were invaluable in taking the "temperature" of our community through the year.

Jenni subsequently changed role to become a project worker and has worked to support the Local Offer project as well as an exciting project with Emily to ensure that we are hearing the voices of the most severely disabled children in Surrey.

Funding

FVS has matured significantly as an organisation in the last few years, and as such, it has become increasingly important to secure sustainable funding. We are pleased to announce that this year we secured:

- A three year grant agreement with Surrey County Council.
- Funding from The National Lottery Community Fund towards core costs for 5 years.
- We continue to work with other funding bodies, in particular Community Foundation Surrey, to diversify our funding streams.

This combination of funding sources and the longevity of the agreements has given us a strong basis on which we can make longer term plans for the organisation. Trustees have taken this opportunity with enthusiasm and have hosted a series of business planning workshops with all FVS staff to co-produce this long term plan that will help the whole organisation move forward and work to improve the lives of parent carers throughout Surrey.

Please see the finance section for further details of our income and expenditure.

Funding continued

£12,500

allowed us to increase staff hours to engage more frequently with parent carers, and to spend more time working with partners in the local authority and health services to convey what we were hearing. We also purchased 2 laptops, some Facebook training and Zoom licenses to reach families more effectively.

£5,000

supported the expanding need of our coordinator project. We focussed these funds in areas where we had the best resources and could have the best impact at the time. These were the districts and boroughs of Epsom and Ewell, Guildford, Tandridge, and Woking.

£7784

ensured that all staff were equipped with functioning laptops (a year of virtual working had taken its toll on equipment!). Importantly, this grant allowed us to support staff with a range of emotional wellbeing support. As they have been on the front line of traumatic stories, that support has become ever more necessary and we were grateful to Pears for allowing us to provide training and a First Aid Mental Health workshop.

My personal laptop was failing, resulting in disrupted connections during meetings, battery failures and microphone failures. Our work is primarily about communication and relationships, and this was increasingly difficult to achieve. The new laptop came in the nick of time and I have been able to continue working successfully. I also feel happier with a separate work machine given the sensitive nature of the work I do with partners.

I'm really looking forward to the first aid mental health course because many of the parent carers we speak to are in some crisis and I look forward to having more strategies to support them and build my own resilience.



Engagement with members and other parent carers

Events

We host an average of 8 online events a month for parent carers. Throughout the pandemic, our members have told us that they particularly appreciate groups organised by need, though we remain open to change dependent on what our members need. This year, as well as for location based groups, we hosted events for the following groups:

- School Anxiety, 16+, 19+
- Pathological Demand
- Avoidance (PDA)
- Downs Syndrome
- Early Years
- Global Development Delay
- Avoidant/Restrictive Food Intake Disorder

Event feedback

Thank you for being my safe space.

I really enjoyed the NeuroGraphica session yesterday.

FVS has really made a positive difference. I felt very comfortable talking with Lara who clearly understood.

As parent of SEND children it's easy to feel alone with all the battles to get our kids all the support they need. I really appreciate all the support I've received, especially Sara. Thank you.

I have to say thank you for all of you, because I get so many advice and support. And just the feeling that you are not alone is great!

Expert speakers

We invite expert speakers to present to these groups dependent on the members' requests, and also work closely with Local Area partners to allow parents to get information about their services and feedback their own experiences, thus informing the services directly of their effectiveness.
Our events have two aims: to inform and train parents, and to hear their experiences. The following quotes give a flavour of what we have heard this year.

My child still has no school placement. SCC talked about a learning package at home, but I have no update.

Very good service from Surrey continence team – they called ME! to check the products were still ok for my child.

I am a single mother with two SEND children and I am struggling to juggle care and job because I have little support.

Surrey doesn't care about families like us.

Social workers don't know what services are available.

Fantastic support from speech and language this term, we have been given an assisted learning device for our child, funded by the service, that we didn't even ask for!

Annual Event: Early Years

Our annual event this year focussed on the Early Years and we worked closely with partners across the system to provide a wide ranging set of speakers, both from within the system and external speakers. It was a week long, virtual event. The recordings of the event can be found on our YouTube channel at https://bit.ly/3sFbYTq or use the QR code HERE ► allowing parent carers to revisit the speakers anytime they need support.

Liz Mills (SCC)	Trudy Mills (Children's Community Health)	Pippa Gray Kat Link (SCC Early Years)	Dr Kathryn Hollins (Emotional Wellbeing)	Frida Metcalfe (Surrey Libraries)
Michael Pipe (Local Offer)	Angela Wheeler (Occupational Therapy)	Yvonne Newbold (yvonnenewbold.com)	Jackie O'Kelly (Family Support Consultant)	Carol Hodges (Home Start)
Jenny Helyer Lucy Ross (Speech & Language)	Dr Mark Brown (Special Help 4 Special Needs)	Lisa Trend (SEES)	Fran Beale (Family Support Worker)	Jo Neville (Health Visitor)
Sarah Jordan (Community Nursing)	Jane Gupta (Early Years SEND)			



Social media

Our Facebook engagement was increased during this week with approximately 1,400 members viewing, commenting and reacting to posts. The value of a virtual event is that all the recordings continue to be available to our members and viewing figures continue to grow throughout the year.

> *Great event lots of interesting and informative speakers.*

> *Great to have the chance to watch the event when convenient.*

> *I liked the free flowing discussions.*

> I liked the variety of speakers.

Surveys, focus groups, reports

FVS Surveys this year included:

- Lockdown SEND family experiences - April 2021
- FVS Satisfaction Survey - June 2021
- Emotionally Based School Non-Attendance - December 2021
- Safer Gaming Workshop feedback - January 2022

Focus groups include our engagement work, but we also work with partners to support parent participation, for example:

- **Children's Community Health Roundtables** FVS supported Health partners in their review of the service with a view to recommissioning
- **Preparation for Adulthood** SCC officers wanted input from our members to plan a new PfA leaflet for families
- **SEND Transport** SCC transport team joined a group of families to answer their questions about SEND transport
- Services such as the Transition Team, Healthwatch, Short Breaks team, join our regular groups when they are seeking parent carer experience, or if we have asked them to come and talk in response to parent carer requests.

Reports are produced once surveys have been analysed, as a result of parent discussions or as part of our participation work:

FVS Satisfaction Survey

Emotionally Based School Non-Attendance Survey

Everyone matters: representing children with severe or profound disability

> Wouldn't it be incredible if children and young people were so central to Surrey's processes that they were enabled to attend their own planning meetings, annual review etc or if professionals routinely sought a meaningful way for their voice to be heard? It seems that children and young people avoiding school are communicating very clearly that placements don't meet their needs when they do not attend, but this is not being meaningfully explored.



What We Heard

We Heard	We Did
EHCP Processes are complicated and lacking in transparency.	In partnership with SCC SEND teams, FVS created a series of bite sized videos explaining each stage of the process.
Children who suffer from school anxiety are forgotten and ignored – there is no specialist provision.	FVS ran a survey which received 370+ responses. We then worked with Surrey Youth Focus to produce an analysis. This has galvanised the system into realising the extent and severity of this issue.
Long waiting times for neurodevelopmental assessments and confusion around the process of assessment and diagnosis. Schools are still requesting diagnosis before providing support.	FVS has worked with Mindworks to improve information about the new ND service, and works within the Autism Strategy to highlight these issues and ensure they remain at the forefront of discussion.
Many stories of parent carers unable to contact the SCC Transport team.	FVS worked with SCC to help resolve many individual issues. Our focus has been on encouraging SCC to improve their response to parents.
It's too difficult to access specialist mental health support.	FVS has worked with the new Mindworks service to help families understand what the service offers, and what it hopes to do in future. We've hosted various leaders in the service in videos that help inform parent carers about each part of what is a very complex service.
Communication continues to be the most quoted concern, particularly with caseworkers. Parents often tell us of the lack of transparency in the system and have many questions.	FVS has developed relationships with SCC and now has a named person who is tasked with answering our questions. These are then published on our website.
Sometimes, FVS is contacted by several parents about a particular school.	This year, FVS has worked to improve relationships with schools. Such schools have welcomed us in to talk to their SEND parents and Inclusion staff about the forum. In this way, we aim to help each party understand the complexities of the system and refresh their relationship.
There are not enough short breaks spaces, and it's hard to know what is available and when to book.	FVS worked with the Short Breaks team to provide a clear organogram of all the providers available for Summer 2022, with the links and booking dates. This was prepared ahead of the easter holidays.

Continued over /...

We Heard	We Did
Parents don't feel supported in the transition from primary to secondary school.	FVS is focussing the 2022 annual event on the transition from primary to secondary school.
There is huge confusion about the transition to adulthood - in areas of education, health, care, housing, employment etc.	FVS now host a group for parents of children 16+ where we bring parents and officers/practitioners together. FVS has made representation to the Short Breaks team to consider an offer for 18-25 year olds FVS was involved in the development of the new EHCP template, which includes a different template for 14+ focussing on Preparation for Adulthood issues.

On those occasions where professionals focus their attention on the needs of the child and the family rather than their own organisational processes, the outcomes can be very positive and the sense of distrust and animosity starts to dissipate surprisingly quickly.

What our children say

This year, we started asking parent carers to tell us what their children have to say about their lives. The following quotes are examples of what we hear:

I love playing guitar: it makes me feel so relaxed.

My fidget ring really helps me concentrate in class.

'X' is engaging with an online SCAMMPS event and expressing herself through musical instruments and communicating by using PODD (Pragmatic Organisation Dynamic Display).

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



I want to go to school and one to be found for me as soon as possible. I need friends and that is the way I want to live my life.

Other children bully me because I am slow with my learning.

Keeping in touch and being transparent

We have now been producing a monthly overview and newsletter for 17 months which gives us ongoing information about what parent carers are saying, and also how our participation work is progressing. Two additional benefits of this transparency became clear in early 2022: we provided a summary report of parent carer issues to inform the Joint Strategic Needs Assessment (JSNA) and Surrey County Council's self-evaluation. In each case, our report was received with gratitude and respect and considered with the seriousness that we would expect from any evidence gathering process.

The Swimming Project

In November 2021, we received a flurry of comments from parent carers expressing sadness and frustration at the lack of swimming lessons for their children.

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

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

Those parents who could afford it were finding 1:1 lessons, but even those were few and far between, and significantly more costly than a swimming course at the leisure centre.

FVS approached Everyone Active leisure centre in Spelthorne and proposed a pilot. Lessons would be offered at a comparable price to mainstream courses, with classes of 6. Parents would be allowed by the poolside or in the water, and the class would be run by a qualified teacher. The pilot started in February 2022.

> *Our kids need different things to neurotypical kids. Like, for example, my son requires me to be on the side of the pool or he won't go in. Little things like that make a huge difference.*

The two classes sold out in a matter of hours and there is already a waitlist for both classes. Following a successful trial of the SEND swimming in Spelthorne, the class has been made permanent and runs as a 10 week course. We are now implementing the trial in Sunbury with the families who were on the waiting list. On the back of the successful swimming course, Spelthorne will be trialling a trampoline course for children with additional needs, starting in March.

Parent Carers found the courses very beneficial for their SEND kids. Our courses are unique in Spelthorne and adjacent boroughs, as there are no other swimming lessons exclusively for SEND children. We are setting a trend locally!

> *You don't know how many doors I had slammed in my face... it is not easy finding any activity for S (autistic). Actually, when you told me that there was this swimming class for children with special needs, my heart opened up in joy. I was super happy, and in fact I signed him up straight away!!!*

> *Fantastic news! It would be incredibly helpful to get into the pool with N to help build his confidence. Thank you so much for organising this!*

> *I guess I am super happy about this wonderful initiative for children with disabilities.*

Participation and Co-production with local area partners and the 3rd sector

Family Voice Surrey's overall workplan is developed from feedback from parent carers, by business planning and in partnership with SCC colleagues, based on the priorities identified by listening to parent carers as well as those priorities determined by council officers.

Once an area of work is identified with SCC, we meet to decide on the nature of the participation work, the outcomes we are aiming to influence and what meetings we may be required to attend.

In addition, FVS sits on a number of boards and attends meetings that aim to ensure representation of parent carers at a system level. These include the SEND System Partnership Board, Schools Forum and the Carers Partnership Board. We also meet regularly with senior leaders within education, health, care and adult services as well as elected members of the council and third sector organisations.

Meetings attended include:

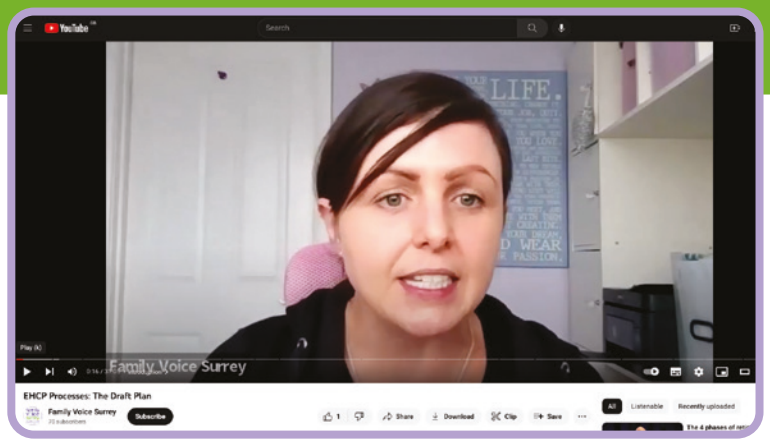
- SEND Systems Partnership
- Schools Forum
- LD & ASD Programme Board
- Short Breaks Strategic Planning Groups
- ASD Strategic Board and related groups
- Regular meetings with Designated Clinical Officers
- Preparation and implementation of the new Mindworks service
- Children's Community Health meetings
- SEMH Project Board
- Inclusion steering group
- NNPCF regional meetings
- Local Offer Project Board
- 0-4 Workstream meetings
- Carers Partnership Group
- Direct Payments meetings
- Quarterly meetings with elected members of SCC
- Monthly meetings with senior council officers
- Monthly meetings with SEND Advice Surrey, UVP team, Surrey Youth Focus

Attending meetings is an important part of our work. FVS remains committed to being an active participant and takes responsibility for being part of effective meetings to ensure that the parent carer voice is heard. Meetings if successfully run can help people to feel included, trusted, and that they are important contributors to the table and ultimately positive outcomes for our Members.



Project work

We developed a workplan based on parent carer feedback and in collaboration with SCC and Health partners:



EHCP Processes

- **To improve understanding of the role of case officers**
- **To highlight parent carer issues to the system and help resolve them**

We embarked on a long project to create bitesized videos with SCC officers explaining the various aspects of the EHCP process. These can be found on our YouTube channel at: https://bit.ly/3DotJLP

We also met regularly with SEND teams and ensured they were aware of ongoing issues.

Inclusion

- **To support true inclusion for CYP with additional needs.**
- **To aid transparency and communication in the SEND Transformation Programme.**

This became a large project, including a pilot "Team Around the School" working to develop an "Ordinarily Available" offer, inputting in, to what is considered an "Autism Friendly" school and others.

Work to highlight the plight of children whose anxiety around school prevents attendance became increasingly important and we chose to create a new project half way through the year to manage the workload.

Autism Strategy

- **To represent the voice of parent carers in the development and implementation of the strategy.**

The strategy was published in September 2021 after a very encouraging process of co-production. Implementation has included FVS in two work streams.

We also began co-chairing a newly formed Children and Young People's Autism Partnership Board to mirror the existing adult board.

Preparation for Adulthood

- **To support the development and implementation of the preparing for adulthood transformation programme.**
- **To represent the voice of parent carers in the transformation work.**

FVS were involved in the strategic planning of this work and hosted a number of focus groups. We also co-hosted an event for young people and their families. We are currently supporting work to produce a family guide to post 16 and PfA.

Our 16+ and 19+ groups offered a space for parents to share experience and knowledge and we offered training based on their needs. This included supported housing providers, Transition Team officers and others.

Early Years

- **To host a multi-disciplinary annual event informing families and practitioners about SEND in the 0-6 age group**

This week long virtual event was prepared after speaking to parent carers to find out what would most have helped them in the early years of their child's life. We welcomed speakers from the following organisations and services, and the full playlist of the event's videos can be found here: https://www.youtube.com/channel/UC1Plh3UFcWkgeMCyFNgEmqA/videos

Surrey Libraries; Home Start; Shooting Star Hospice; Dr Mark Brown; Yvonne Newbold; Surrey Local Offer; Contact "Money Matters"; Children and Family Health Surrey; SEND Advisors; CHES; SCC Early Years; Early Years SEND team; Dr Kathryn Hollins; Early Years in the health system and two multi-disciplinary talks on a range of topics chosen by parents.

SEND Transport

- **To monitor and support a refreshed transport service**

2021 transport issues were complicated by the pandemic, a shortage of HGV drivers meaning that taxi drivers changed career, together with a fuel crisis. The impact on SEND families was considerable and FVS provided significant support to families who were unable to reach the SCC transport team. And we continue to work with the council's team to improve communications and will also be helping produce a parent guide to SEND transport in the coming year.

We provided parent carer feedback during a consultation reviewing the current Home to School transport policy.

Emotional Wellbeing and Mental Health

- **To support the development of a strong website**
- **To ensure the voice of parent carers is heard by the Mindworks service**
- **To monitor and support the new service with 3rd sector, schools and local area partners**

FVS has worked hard to help the new service understand parent carer issues, and to help parent carers understand how the service aims to work. Part of that has been a series of videos with providers, while continuing to work strategically with partners.

We supported the new service to work with a group of parents on the design of the new name and website of the service, all the while helping officers understand that a focus on branding might be received with little enthusiasm by families who were desperate for clinical support.

Social Care

- **To clarify the purpose and criteria of the CwD team**
- **To participate in the development and implementation of a Direct Payments strategy**
- **To develop understanding of Early Help**

The world of social care and additional needs is complex and often confusing for families. In an effort to improve communication and transparency, FVS worked with partners at SCC to map that system. This work proved beneficial not only for parent carers, but also for those who work within the system and we look forward to diving deeper into each of the services on offer.

Short Breaks

- **To represent the voice of parent carers in the development of short breaks**
- **To work with the 3rd sector to hear all parent carer voices**

The short breaks offer in Surrey has been the subject of a strategic review this year. While being involved in this process, FVS also highlighted the need for clarity of offer and booking for Summer 2022 in order that families use the service fully. We were pleased to contribute to an organogram explaining clearly what short breaks would be available and how and when families should book.

Health	
	• To represent the voice of parent carers in the development and implementation of the community health redesign • To collaborate with Healthwatch • To represent the experience of parent carers in the health system

We have worked with a range of health colleagues to ensure that parent carer experience is represented. This included work on the Digital Navigator project, continuing health care guidance input, sexual assault recovery group work, children's community health focus groups and wheelchair services feedback from parent carers.

In considering the wider determinants of health, we worked in collaboration with Active Surrey to provide training to sports coaches ahead of the Surrey Youth Games. We also collaborated with "Everyone Active" leisure centre (see "swimming project" above).

Communication and Information	
	• To support an improved digital information service • To develop a dynamic FAQ system for parent carers • To support the development of the Single Point of Access

Surrey's Local Offer website has been redesigned in the last year, and we have supported the team by providing some testing of the site by parent carers as well as working with SCC colleagues to ensure content was appropriate for parent carers in tone and language.

"Goodbye" from Benedicte Symcox, CEO



"I've had the immense privilege of leading Family Voice Surrey for the last three years. I've been supported by a phenomenal group of parent carers who work with me at FVS, but also members who've taken the time to share their experience so that we can, together, help practitioners and council officers understand the complexities of life when your child has additional needs.

I'd like to give special thanks to a number of people who have helped me along this rollercoaster of experience! Simon Morley and Sally Allen as chairs were hugely supportive and provided great mentorship whenever I needed it. Claire Poole, Emma Hambleton and Rachael Foley have been with me through this journey and been great friends as well as colleagues. To all my other colleagues, at FVS and throughout the SEND system in Surrey, I'd like to give my enormous thanks and great affection. There is no doubt that I will miss spending time with people who genuinely want to improve the lives of families like mine.

It's time for me to move onto other things – becoming a grandmother is a life event of seismic proportions! And I'm excited to see FVS continue to build effective and collaborative partnerships that ensure parent carer voices are heard and placed at the centre of decisions that affect them and their children.

I leave this organisation with huge optimism. The relationships we have built in the last few years allow the parent carer forum to challenge the system when needed, and our engagement with members means that we have the evidence to back those challenges up. In turn, this has allowed us to secure sustainable funding which allows us to plan for the future.

So as I move on to grandmotherhood and other adventures, I will continue as a member of FVS, and look forward to seeing the organisation grow from strength to strength."

Plans for 2022-2023

Our plans for the next year have been put together following feedback from parent carers on the areas that they would like to see us focus on (via surveys), parent carer experience (your stories), our work with partners on change projects and our own business planning, involving all staff.

Thank you to everyone who has taken the time to help us plan for the year ahead. For this year's report we have provided more detail to honour the comprehensive feedback that we have received. The long list of projects is prioritised 1-3. 1 = within the first 6 months, 2 = within 6 – 8 months, 3 = 8 - 12 months and into 23/24. As we progress these projects we will continue to learn and be open to review and adapting within the changing SEND environment.

You have told us we need to:	We are planning to:

Increase awareness of Family Voice Surrey

Outcome: Families have a strong collective voice

Reach more families	• Launch a new website (1) • FVS Engagement and Communication Strategy (3) • FVS Equality, Diversity and Inclusion Strategy (3) • Review FVS volunteer role (parent carer groups led by volunteers, refreshed job description) (1) • Continue to review use of social media, online presence in line with FVS Member requirements - exploring opportunities to collaborate with neighbouring parent carer forums (1) • FVS Satisfaction survey to include questions about whether individual parent carers feel treated and valued as equal partners in their child's support (2) • FVS Satisfaction survey to be run annually with members and publicised widely (2) • Set up a communications working group - member reps, staff and other vol org/PCF reps to aid with the development of Engagement and Communications Strategy (2)
Reach out to schools throughout the county	• Build relationships with 12 schools through SENDCo network, quadrant based to include a special school, primary and secondary school in each (1) • Develop a team of volunteers to work with coordinators as school reps (1)
Create a short video explaining our role	• A "Guide to FVS" to be produced that explains our mission, vision and values to partners and Surrey families (3)

You have told us we need to:	We are planning to:
Work with faith groups and 3rd sector organisations to reach more diverse communities	• Continue with Trustee recruitment campaign in order to increase skills and diversity of Board members (1) • Identify further funding opportunities for targeted project work around parent carer engagement (3)

Engagement

Outcome: parent carers are supported to understand their rights and choices

Continue to work with parent groups to offer training and information, paying particular attention to the needs of working parents	• Workplan to include "parent well-being" project. Parent Carer Care Packages to be explored (1) • Offer training to parents from experts in their field and SCC/CCG professionals (1)
Inform members about navigating SEND processes	• Annual event will be focused on the transition to secondary school (1) • Produce an "After Schools Clubs" leaflet to include short breaks offer for September 22 intake of children (1) • Co-produce videos with SCC to explain the EHCP processes (1)
Re-instate face to face meetings when possible	• Risk assessments are in place and we are beginning to open up to the SEND community where possible including the AGM (1)
Improve links with charities and other 3rd sector organisations	• Continue to build good working relationships with 3rd sector including continuing with FVS representation at the 3rd Sector SEND Network (1)

Participation

Outcome: parent carers are valued as equal partners within the LA and Health

Continue to bring the lived experience to the heart of decision-making	• Represent the voice of parent carers in the transformation work (1) • All project work will champion the importance of coproduction at an individual level. (1) • To be a full partner in the development of Surrey's new SEND Strategy (1) • Grow our effective partnership to include Health partners and include them in our grant agreement (1)

Plans for 2022-2023

You have told us we need to:	We are planning to:
Challenge assumptions that do not line up with parent carer experience	• Improve understanding of EHCP Processes via videos (1) • Develop SEND admission guidance for parents (1) • Participate in the audit of EHCPs termly (1) • Support the development and implementation of the preparing for adulthood transformation programme (1) • Support an improved communication and case management service for SEND transport (1) • Work with SCC on a parent guide to SEND transport (1) • Monitor and support the new service with 3rd sector, schools and local area partners (2) • Participate in the development and implementation of a Direct Payments strategy – including a consultation summer 2022 (1) • Deep dives into each of the areas of social care related to SEND (1) • Increase visibility of progress and feedback - "you said, we did" and action cards (1)
Make sure we share a wide range of parent carer experience	• Work with the 3rd sector to hear all parent carer voices in the development of the short breaks offer (2) • Explore the feasibility of anonymous comments/ suggestions via new FVS website (1)

Outcome: FVS is a professional, parent carer led organisation

Train and inform professionals	• Recruit permanent CEO role (1) • FVS Personal Development Plans – includes trustee development and risk planning (1) • Continue organisational appraisal and business planning to include staff and testing with families (1)
Alongside our training offer we will offer opportunities for professionals to learn from parent carers to improve their practice and benefit families	• Primary to Secondary Transition annual event (1)

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 2022 is a surplus of £54,448 (prior year to 31st March 2021 was a surplus of £2,397). The reserves at 31st March 2022 have increased as a result, to £123,969 (£69,521 at 31st March 2021).

Income for the year was £219,097 (2020/2021 £140,343). This was due to the award of a National Lottery Grant at the beginning of the financial year.

Expenditure increased following the award of this grant to maintain service delivery. Our expenditure for the year to 31st March 2022 was £164,649 (2020/21 £137,946).

Our reserves position remains within our 3-6 month expenditure policy.

Since the end of the year, we have reintroduced face to face support and events to combine with the existing online offer.

Finance report

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

CHARITY COMMISSION FOR ENGLAND AND WALES

Family Voice Surrey	1175460	CC16a

Receipts and payments accounts

For the period from	Period start date 01/04/2021	To	Period end date 31/03/2022

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 Period to the nearest £
A1 Receipts					
Surrey County Council Grant	85,016	-	-	85,016	83,000
Contact		17,500	-	17,500	15,000
Contact Discretionary		-		-	5,000
2022 National Lottery Grant		81,500	-	81,500	
CFS Grant		10,000	-	10,000	1,620
CFS Health & Wellbeing/Covid 19		24,975	-	24,975	5,000
Pears		-	-	-	7,784
SCC Covid 19		-		-	12,506
Mole Valley Covid 19				-	10,000
Donations	26	80		106	105
Other income			-	-	328
			-	-	-
***Sub total**(Gross income for AR)*	85,042	134,055	-	219,097	140,343
A2 Asset and investment sales, (see table).					
				-	
				-	- 0
Sub total	-0	- 0	-0	-0	-0
Total receipts	85,042	134,055	- 0	219,097	140,343

A3 Payments

Salaries	63,628	63,655	-	127,283	92,942
Travel and expenses	674	1,816	-	2,490	2,295
PfA event	2,072	-		2,072	4,081
Other events / meetings	848	1,205	-	2,053	1,870
Training	59	324	-	383	6,259
Marketing and Publicity	106	1,301		1,407	
IT/Infrastructure & computer assets	9,068	3,762	-	12,830	10,467
Rent	188	7,822	-	8,010	11,039
Telephone, Stationary and Post	1,936	86	-	2,022	499
HR, payroll, consulting, recruitment		3,929	-	3,929	5,540
Subscriptions	20	500	-	520	900
Seldom Heard				-	108
Other				-	375
Insurance	630		-	630	611
Independent Examination	1020	-	-	1,020	960
Sub total	80,249	84,400	-	164,649	137,946
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	80,249	84,400	- 0	164,649	137,946
Net of receipts/(payments)	4,793	49,655	-	54,448	2,397
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	64,184	5,337	-	69,521	67,124
Cash funds this year end	68,977	54,992	-	123,969	69,521

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	Cash at Bank	68,977	54,992	-
		-	-	-
		-	-	-
	Total cash funds	68,977	54,992	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds 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)
B3 Assets retained for the charity's own use				

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Zoom	General	1,727	01 April 2022
	Orb X	General	3,922	01 April 2022
	SCA	General	762	01 April 2022

	Signature	Print Name	Date of approval
Signed on behalf of all the trustees		Sammy Edginton	12-Jan-2023

Independent examiner's report on the accounts

Report to the trustees/ members of	Family Voice Surrey		
On accounts for the period ended	31 March 2022	**Charity no (if any)**	1175460
Set out on pages	26-27		

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 2022.

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.

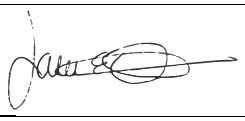
Independent examiner's statement

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:		**Date:**	13-Jan-2023
Name:	Janice Matthews		

Appendix: Structure and Governance

We are constituted as a membership organisation, now with over 2700 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 acceptance of 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.

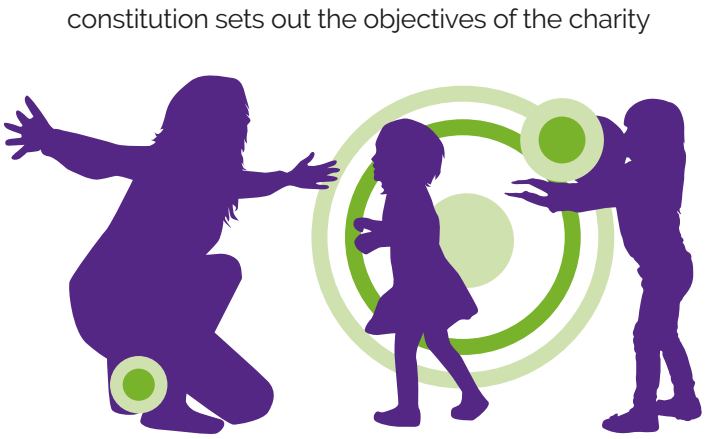
We must maintain a minimum of 3 trustees and are always keen to recruit new trustees. We welcome applications from parent carers of children with SEND, as well as people who have experience in the running of small charities, or with finance/ treasurer, HR or fundraising skills, and people who have worked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

While day to day operations are led by the CEO with guidance from head of business planning and development and business and engagement manager 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 received 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.





FVS 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 support and support services 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 some policy documents, work with partners on messaging, all in a wide range of areas pertaining to SEND.

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
FAQ	Frequent Asked Questions	**UVP**	User Voice and Participation
HR	Human Resources		

Notes

Notes

Notes

family voice surrey

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.





Family Voice Surrey
Connect House
Kingston Road
Leatherhead
Surrey
KT22 7LT

Charity number: 1175460
Tel: 01372 705708
Email: contact@familyvoicesurrey.org
Website: www.familyvoicesurrey.org

www.facebook.com/familyvoicesurrey
@FVSurrey

FAMILY VOICE SURREY

England & Wales - Charity number 1175460

Accounts

WORKING TOGETHER FOR BETTER LIVES

for children with disabilities or additional needs

family voice surrey







Family Voice Surrey, CIO

Annual Report

1st April 2020
to 31st March 2021

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

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The Trustee Board



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.

As an experienced Programme Manager her passion lies in bringing people together who have a wide range of experience, skills and perspectives and harnessing that knowledge and expertise to bring about positive change. Working with a passionate team of people who have different perspectives is one of the most enjoyable and rewarding aspects of her role. Sally feels blessed to have experienced 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.



Simon Morley (Treasurer)

Simon joined the then FVS steering committee as Treasurer in June 2017, and was a founding charity trustee when we became a Charitable Incorporated Organisation (CIO) in November 2017. He is a qualified accountant with broad commercial experience, and a post graduate degree in Charity Finance and Administration, and has served in similar roles in a number of other charities. Simon has two sons, one of whom has special educational needs and disability.



Karen Lettington

Karen has taught in a special school as a class teacher and worked in three mainstream school as a SENCO. Currently she is completing an MA in SEND. She is dyslexic and also has a son with SEND. Karen hopes that with both her professional and personal experiences she can help implement improvements for children and young people in the county.

In addition, two new Trustees were appointed on 20th September 2021, being Sarah Clarke and Samantha Edginton.

Chair Comments... Sally Allen

Looking back on 2019-20, who could have predicted the events which started to unfold just as the financial year came to an end?

Who could have predicted the pain, the challenges and the scale of our learning and re-affirmation of our values, the things that matter and that we hold dear ?

I truly believe that the lived experiences of our parent carer Members and fantastic staff team placed us in a strong position. Our collective skills and the learning gained as parent carers set us in good stead to provide a strong and flexible response to the challenges of the pandemic.

As families united by the wonderful gifts and learning that our children bring....

> ...we are used to spending hours on creating plans that get dashed or don't get implemented properly, or at all, are able to respond to the unexpected and frequently at last the minute, we continue to learn with our children and young people how to navigate an extremely complicated and sometimes scary world. .....and just when we think we have got our degree in "autism" and have got things straight , we wake up to a whole new set of challenges.

I am proud to say that FVS has performed well during the year. Thanks to our fantastic Treasurer (and previous Chair) , Simon Morley, Benedicte Symcox, our CEO and Claire Poole, Head of Business, Planning & Development, we entered into the pandemic with a healthy level of reserves and prospects of additional support from our partners and new sponsors. This allowed us to respond and to move quickly from being reactive to proactive, focusing on the things that families told us that really mattered to them.

Particular highlights of the year for me are:

- The truly collaborative work that went into the production of Surrey's All-Age Autism Strategy, with the people most impacted involved every step of the way.
- Our work with SCC to ensure that our partnership and support for families is sustainable and relevant by working together to co-produce and agree a 3 year Partnership and Grant Agreement.
- The creative workshops conducted on Zoom - where the voice of parent carers helped to shape our vision and values and to prioritise where our focus should be, and of course our Annual Event which attracted over 4000 views!

Despite the additional personal challenges faced by many of our staff and families as the pandemic unfolded we continued to put parent carers and their children's voices and experience at the heart of everything we do.

Importantly we continued to raise the profile of vital issues, never reluctant to have sometimes challenging conversations with our strategic partners. I want to particularly thank the families who contacted us about their experiences of the Key Stage transfer process so that we could try to find answers to their questions and ensure that their voices were heard. We continue to work to ensure positive change for our children.

As we develop as an organisation it is vital that we develop our offer too - ensuring that we are truly representative of the voices of our diverse community in Surrey is our top priority.

Looking ahead I will continue on working with our awesome Chief Exec, Benedicte and FVS team and Board in reaching out to new Members and strengthening the Board. I am confident that we can further diversify our skills and knowledge to provide a truly representative collective voice for Surrey families that continues to bring about positive change.

Priorities for the Year

1. **Annual event "Preparation for adulthood"**
2. **Continue to build on Effective Partnership work with SCC** and secure a long-term agreement to allow for strategic planning
3. **Continue to develop the Coordinator Project** and ensure that Coordinators are heard in participation work
4. **Training program for parents** from experts in their field and SCC/CCG professionals
5. ***Deliver the USSA course to more parents*** This was not possible due to the pandemic
6. ***Launch our new website*** Unforeseen circumstances have pushed this into the next year
7. **Trustee recruitment** – strengthen and diversify the board
8. **Collaborate with SCC on the following workstreams:**
   - SEND transport
   - Local Offer
   - Development of autism strategy
   - ***Development of early years strategy*** Early years worked changed dramatically as the health system addressed the pandemic, but we did several pieces of work in this field
   - CAMHS re-procurement and mobilisation
   - Direct Payments
   - Review of Social Care services for SEND children
   - School Absence
   - EHCP processes
   - Returning to School from Lockdown
   - ***Development and mobilisation of the Learner SPA*** This became a part of a larger communication and information project that includes the Local Offer
9. **Organisational appraisal** – review the charity's aims and business processes
10. **Membership** – increase diversity and reach so that membership is representative of SEND parent voices.

Highlights of the year

Work to influence decision making in Surrey includes:

1. **Development of the All-Age Autism strategy:** FVS led a strong representation of lived experience that influenced the development of the strategy at every stage and continues to influence its implementation
2. **Preparation for Adulthood:** our virtual annual event took place over a week and leaves a legacy of relevant and informative videos for parents, young people and professional to refer to on YouTube and Facebook
3. **Covid response:** we moved to a fully virtual offer, but have been able to support members through this difficult time and seen an increase in membership
4. **Direct Payments:** FVS championed the needs of parents through changes to DP rates at the height of the lockdown
5. **Short Breaks:** While FVS continued to be a strong part of the strategic review of short breaks, our role this year was to highlight the importance of this service in a year when most schemes were closed or severely curtailed
6. **Ofsted processes:** Department for Education (DfE) and NHS England (NHSE) visited in Dec 20 to review SCC progress on the original visit. FVS represented parent carer voices to ensure lived experience was considered alongside the statistics.

Family Voice Surrey in Numbers 2020/21

FVS Members:
2,308
(25% increase)

Facebook followers
1,974
(27% increase)

1,894
Facebook likes

average reach via Facebook page
210

38+
training events

- Anxiety
- Self care
- Condition specific
- Anxiety
- SEND law and processes
- External organisations
- CAMHS professionals

11 local private Facebook groups, total membership:
1,038
(128% increase)

1,800
Twitter followers
9% increase



Facebook Parent/carer chat group members:
533
(40% increase)

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.

Organisational appraisal

Vision

- A society that allows families whose children have additional needs to be heard.
- A society in which ALL children thrive and are supported to achieve their dreams.
- A society that celebrates difference and diversity.
- A society that breaks down the barriers faced by children and young people with special educational needs and disabilities.

Mission

- Family Voice Surrey aims to bring about positive change for young people with additional needs by:
- Giving families a strong collective voice.
- Being a professional, parent carer led organisation.
- Ensuring parent carers are valued as equal partners within the local authority.
- Supporting parent carers to understand their rights and choices.

Values

- **We are an organisation that is:**
- Respectful - even if we don't agree
- Supportive - even if we don't understand
- Positive - even when we challenge each other
- Equitable - being flexible and prepapred to adjust if needed
- Committed - even when positive change seems slow
- Engaged - we listen to ALL points of view

As is right for any charity, we took time this year to re-examine our vision and develop a mission and a set of values that guide all of our work.

Please see the finance section for further details of our income and expenditure.

Partnership

Word from Liz Mills, Director of Children, Families, Lifelong Learning and Culture, Surrey County Council

I'd like to start by acknowledging that the last year has been incredibly challenging for families, the pandemic has brought stress, uncertainty and anxiety. For many, a connection with their community was lost, perhaps at a time, when they needed it most. Children and young people have had to cope with a huge amount of change, especially those unable to attend their education setting in lockdown and then having to adapt again when restrictions were lifted.



Family Voice Surrey have been instrumental in helping us understand the changing needs of families and carers in Surrey. Only by listening and acting upon the child's and family/ carer's voice, are we able to put into place more effective arrangements for our families and carers and improve the outcomes for children and young people.

At Surrey County Council, our ambition continues to be that we root the child at the heart of everything, as a result we have adopted Surrey Youth Focus's Time for Kids principles to remind us all, no matter how busy we are, to think about what is best for the child or young person. I've seen the change in meeting culture, when we adopt these principles at the start of each meeting. This one small change can help with our collective outcomes and make us really reflect on what we can do to help children and young people thrive.

Family Voice Surrey give us valuable insight into the reality of the families of carers of children with special educational needs and disabilities. They have been proactive in using their voice for families of Surrey through their contribution and presentations to select committees, involvement in our SEND Partnership Board and the Schools Forum. They have helped to coproduce the All-Age Autism Strategy; this was an important piece of coproduction work, ensuring those with lived experience were at the core of this strategy development.

I look forward to the next 12 months, we will continue to build on our partnership work with a focus on the next stage of our SEND strategy. Working closely with Family Voice Surrey, we will co-produce this with children, young people and their families and carers in Surrey, keeping their voice central to all that we do.



2020: The Year of the Pandemic

Within three weeks of starting a new financial year, we were in the midst of a pandemic, with the knowledge that our members' families were likely to be among the most severely impacted. As the world adjusted to the kind of isolation our members have lived with for years, much if not all the essential support they had disappeared. While some children continued with school, many were too vulnerable, or schools could not accommodate their needs.

At FVS, we swiftly moved to a solely online presence and considered what we could do to render support to families while also keeping them informed of the almost daily changes. This was facilitated by weekly meetings with an assistant director in the lifelong learning directorate. Through these meetings, we were able to raise issues we heard from parents (the need to continue paying PAs (personal assistants) was a key decision informed by parent carers) and take key decisions back to parent carers via our Facebook group.



Staff and Changing Workload

It is of utmost importance to note in this report the phenomenal response of FVS staff to this extraordinary situation. While all being parent carers themselves, they not only adapted to home schooling like all other parents, but found the strength and creativity to reach out to other parent carers and immediately provide more opportunity for engagement and participation.

It was more important than ever to ensure that the lived experience of our members was heard and conveyed to our partners within the local authority and health systems. Our children and young people suddenly lost all the support and routine that allows them to get through each day. Many parents were struggling to access PPE, medicines and the therapies that keep their children well and we heard from others who were desperately trying to source the one food that their child was able to eat as our whole society was reeling from an unknown situation.

We quickly understood that we were in a position to provide support as well as be the conduit by which our partners could hear from families and get important messages to them. A weekly team meeting via Zoom allowed us to support staff amidst this traumatic time, and coordinators responded to parent carers' isolation by creating Zoom events on a weekly basis.

Simultaneously, health and local authority partners came together in an unprecedented way and we were invited as a critical member of many groups to ensure that any response was meeting the need of families. This resulted in a greatly increased demand for FVS participation.

Funding

In order to meet this new demand across both our engagement work with families and participation with partners, we became very agile in applying for grants made available to organisations responding to the Covid crisis. Our financial report below will give further details, but this section gives an indication of our response and the support we were able to source to ensure an appropriate response to families.

Who we are and what we do

£12,500

allowed us to increase staff hours to engage more frequently with parent carers, and to spend more time working with partners in the local authority and health services to convey what we were hearing. We also purchased 2 laptops, some Facebook training and Zoom licenses to reach families more effectively.

£5,000

supported the expanding need of our coordinator project. We focussed these funds in areas where we had the best resources and could have the best impact at the time. These were the districts and boroughs of Epsom and Ewell, Guildford, Tandridge, and Woking.

£7784

ensured that all staff were equipped with functioning laptops (a year of virtual working had taken its toll on equipment!). Importantly, this grant allowed us to support staff with a range of emotional wellbeing support. As they have been on the front line of traumatic stories, that support has become ever more necessary and we were grateful to Pears for allowing us to provide training and a First Aid Mental Health workshop.

My personal laptop was failing, resulting in disrupted connections during meetings, battery failures and microphone failures. Our work is primarily about communication and relationships, and this was increasingly difficult to achieve. The new laptop came in the nick of time and I have been able to continue working successfully. I also feel happier with a separate work machine given the sensitive nature of the work I do with partners.

I'm really looking forward to the first aid mental health course because many of the parent carers we speak to are in some crisis and I look forward to having more strategies to support them and build my own resilience.



Engagement with members and other parent carers

Events

Zoom has allowed FVS to host far more training events for parent carers as travel and childcare issues do not need the same kind of management. Our team of coordinators has adapted to provide Surrey-wide events while still providing a local point of contact for parents through private borough-based FB groups.

Coordinators respond to the needs of their local membership which has led to a wide range of events being offered, including:

> *It was very helpful to have the space to be with other parents and feel less alone with things. I really appreciated it. Thank you for organising it, and for the resource links.*

Anxiety Support

- School anxiety chat: monthly group for affected parents
- SABP School Anxiety talk
- Lynne Davis School Anxiety workshop
- WEA Helping Your Child Manage Stress and Anxiety workshop
- Mark Brown talk on anxiety

Self-care

- 'Self-care for carers from The Made Up Mum'
- 'Wellbeing strategies for parents of 16-25 year-olds'
- Shine development course for women

> I love Dean's sense of humour and passion about neurodiversity. The biggest credit to this session is that my husband was absolutely transfixed the entire time and said "I could listen to him all night" and he NEVER engages with stuff like this. Dean gave me a lot to think about and I have taken a lot away from the talk

Navigating SEND

- WEA 'Navigating your way through SEND'
- SEND law talk Eleanor Wright, SOSSEN
- Send Advice Surrey

Condition-specific training

> *Just wanted to reach out and thank you personally. Not just for your suggestions of help personally. But also being an amazing person getting all these meetings and help out there. Wish I would have got involved sooner.*

ADHD awareness

- Max Green Event ADHD
- Dean Beadle ASD and Anxiety
- Jo Purdey, ADHD UK

ASD issues including PDA

- Curly Hair Project presentation and Q&A
- Self-harm & neurodiversity talk, Dr Mark Brown
- Laura Kerbey PDA talk
- WEA Understanding Your Child's Autism workshop
- Dyspraxia (Developmental Coordination disorder), Autism and ADHD

Dyslexia awareness

- Dyslexia awareness talk Claire Harvey, Helen Arkell Centre
- Dyslexia Awareness discussion

Sleep

- Mark Brown talk on sleep problems
- Sleep Specialist

Expert Parenting Programme

- Expert Parenting Programme part 1&2 Gail Bedding & Grainne Saunders

Other speakers

- Moves Matter
- Positive Autism Support and Training
- Bridge Flexi School
- Blue Badge
- Healthwatch
- Relax Kids
- Qwell
- Active Surrey
- Surrey Young Carers

> ***"The resources mentioned such as youtube channels, books, etc as well as the powerpoint itself are so useful."***

As the year progressed, we adjusted to our members changing needs. Rather than geographic groups, parents told us they wanted to meet with others in similar circumstances. We launched a group for parents of children with Down's syndrome and those whose children are 0-4 years old. Moving into 2021, this has grown and we currently have the following groups meeting once a month each:

- Early years
- Post 16
- Global Developmental Delay
- Avoidant or restrictive food intake
- Single parents
- Downs syndrome
- School anxiety

Surveys, focus groups, reports

FVS Surveys this year included:

SEND Transport	June 20
Experiences of Covid	June 20
EHCPs	July 20
Direct Payments	July 20
SEND Transport	Feb 21
Return to school	March 21

Focus groups include our engagement work, but we also work with partners to support parent participation, for example:

Autism strategy workshops: FVS supported the multi-systems team by facilitating some of the group discussions

Community Equipment: FVS hosted local authority partners to inform parent carers of the progress made following a previous survey

Reports are produced once surveys have been analysed, as a result of parent discussions or as part of our participation work:

- **School Anxiety and Avoidance Group: Parents experiences of things that have helped**
- **Transport survey**

Keeping in touch and being transparent

The pandemic spurred us to address a long-standing issue: how and what should we communicate to parents? This year saw the establishment of a monthly newsletter and as the country went into lockdown, we started using Facebook to "talk" to our members, live, on a weekly basis. This was so popular that it has continued and is now a platform through which we invite officers, practitioners, school leaders and 3rd sector organisations working in the sphere of additional needs and young people.

In November, we launched our Monthly Overview which is published on our website and summarises all our activity. It allows our members and partners to see how often we speak to parent carers, updates on our projects and questions that are particularly prevalent in our community that month.

Participation and Co-production with local area partners and the 3rd sector

Meetings attended include:

- SEND Systems Partnership
- Schools Forum
- LD & ASD Programme Board
- Short Breaks Strategic Planning Groups
- ASD Strategic Board and related groups
- Regular meetings with Designated Clinical Officers
- Preparation and Implementation of the new EWMH service meetings
- Children's Community Health meetings
- SEMH Project Board
- Inclusion steering group
- NNPCF regional meetings
- Local Offer Project Board
- 0-4 Workstream meetings
- Carers Partnership Group
- Direct Payments meetings
- Quarterly meetings with elected members of SCC
- Monthly meetings with senior council officers
- Monthly meetings with SEND Advice Surrey, UVP team, Surrey Youth Focus

Early years

Families have told us that navigating the system with a young child is daunting. We shared concerns that early intervention cannot work if needs are not correctly identified, and that many of our families were identifying issues before the 24 month check and having to wait months for support. Working in partnership with the health system and other partners in the local area, a pilot was set up to identify and support families of children below 18 months. FVS sat on the interview panel for the post and worked with the team to monitor the progress of the project. Families have been very happy with the service and we hope to see it rolled out across Surrey.





> What we really appreciated was the balanced perspective provided by Family Voice – for families who were proactive to find out about support as well as harder to reach communities who typically did not have a strong voice. It has hugely increased our confidence to do things differently by having the support from Family Voice reps. Community Health Early Support has been a small, new, innovative team that has been created during a unique time.
>
> ***Service Lead for Community Health Early Support (CHES)***

Autism Strategy

Ahead of a national all age autism strategy, SCC led a multi-system group to develop such a strategy for Surrey. At the heart of the work was to be the lived experience of autistic people and their families. FVS worked in partnership with NAS (National Autistic Society) to ensure the voices of parent carers would be heard in every aspect of this work. We worked to ensure the survey met the needs of parent carers, and SCC saw one of its highest response rates: over 1000, of which 2/3 were from parent carers.

FVS led a strong belief that autistic people and their families should and must be heard throughout the process, so three workshops were organised in December. The feedback received led to real change in the previous direction of the strategy, leading to a document that has truly been co-produced with families and autistic people themselves. We look forward to working with all relevant parties on the implementation of the strategy.

EHCP Processes

FVS routinely inform local authority partners of the issues faced by parents during the EHCP process. This year we worked with officers to improve the information provided on the Local Offer website in collaboration with SEND Advice Surrey

> *Raised awareness of the parent perspective. Developing trust between FVS and vulnerable services. Training for our caseworkers to support them with the difficult conversations.*
> **AD Vulnerable Learners**

Key stage transfers

In February 2021, SCC identified 150 families who would not receive a named school for their child's key stage transfer. We worked with them to develop a strategy to reassure and inform those families. Coordinators collected questions from parent carers which were collated into a set of FAQs. FVS worked with SCC to make sure that the answers were family friendly, and the resulting document was sent to all families affected.



SEND Transport

September 2020 saw a huge number of families experiencing problems with the SEND Transport service. FVS gathered a large number of stories that we shared with relevant teams. A FAQ document was subsequently published and while not all issues were resolved, communications were improved. We continued to work with the team to ensure parent carers' experience was central to the development of a new system and are hopeful that 2021 will see a visible difference.



Preparation for Adulthood

Our first online event focused on preparation for adulthood. We hosted 10 guest speakers both from the local authority and independent experts. Their presentations were pre-recorded but followed up with live question and answer sessions held on our Facebook page. On Facebook, we have had a total of 3,124 views of the presentations and Live Q&As. The Live Q&As were much more popular with nearly double the number of the presentation views. On our YouTube channel we have had 818 views of the same recordings. That's a total viewing count of 3,942. The 2019-2020 FVS annual report and yearly update has gained 260 views to date. That's over 4,000 viewings by March 21.

> *I found the FVS Preparation for Adulthood event extremely useful. I am now aware as to what options may be available to my son in the future*

Emotional Wellbeing & Mental Health

We have been meeting with organisations and staff who will be leading on the new contract for EWMH services (starting in April 2021), continuing to feedback parent carer views, highlighting the importance of parent carers being kept informed about the new service and promoting opportunities for parents to engage in discussions about the new service and what children, young people and families need. FVS also facilitated a number of workshops to allow the new service to introduce itself and various aspects of the new model, and for practitioners to hear directly from parent carers.

Short Breaks

Summer 2020 saw dramatic changes in the provision and demand for Short Breaks. Vulnerable families did not feel able to use services that might put them at risk, and providers were forced to reduce their capacity to keep everyone safe. Many short breaks are run by 3rd sector organisations, and these felt the financial implications keenly with many closures happening as a result. It was therefore imperative to keep the system aware of the desperate need there is for a comprehensive short breaks service, and that making any commissioning decisions based on 2020 would be a serious mistake. We have been strong advocates for families of children with a very broad range of additional need in our input to the strategic review, highlighting the lack of provision for high functioning autistic children and young people, and children under 6, among others.





Children with Disabilities social care team



The Children with Disabilities Service at Surrey County Council continues to build its relationship with Family Voice Surrey. Collaborating with Claire Littlewood, Participation Manager, on a range of improvements has helped us to 'think family' and bring our decision making back to the impact on the children we support.

Family Voice Surrey is a supportive and knowledgeable resource that we are lucky to call on to support our work. We also value the challenge and scrutiny they can provide – this is a key part of developing a collaborative approach to the families we support in Surrey. Some of the ways that Family Voice Surrey have worked with and supported our service during 2020-2021 are:

- **Supporting commissioning reviews to ensure we have the right provision in Surrey for children and families.**
- **Reviewing our Disability Resource Panel and financial process**
- **Reviewing our approaches to partnership working and communications**
- **Reviewing threshold and eligibility processes and documentation**
- **Meeting with Service Managers to develop relationships and offer support and challenge.**

Over the next year we hope to strengthen our relationship with Family Voice Surrey and our community by working collaboratively on our communication with children and families. We also hope to develop local links with the Family Voice events that align with our four quadrants. We hope this will improve understanding or our service and who we work with. We will also be working more closely with our Transition Team on the Pathway to Adulthood initiative we hope that this will improve outcome for young people and support parents through the transition from children's to adult services.

Service Manager – Children with Disabilities - SW/SE

Inspections

In December 2020, SCC, Health Partners, schools and FVS met with DfE /NHSE representatives to review the councils progress on their action plan following the 2019 Ofsted review.

FVS had built relationships with Schools Alliance for Excellence (SAfE), CAMHS, SEND Advice Surrey (SAS) and the User Voice and Participation team (UVP) to consolidate the body of evidence that we have with regards to children who experience barriers to school attendance. This report was submitted to the inspectors and considered in the meeting. DfE thanked FVS for clearly representing parent carer voices and also determined that formal monitoring is no longer necessary. We agreed as a partnership that this should not be seen as a reason to stop efforts to support children for whom school attendance is very difficult and FVS has incorporated "school attendance difficulties" into its "business as usual" workplan.

Direct Payments

This is an ongoing project at FVS, and summer 2020 proved to be particularly challenging. We represented parent carers' fears of losing valuable PAs if they could not pay them through lockdown with the result that SCC made the decision that families should continue paying them despite any inability to work due to Covid 19. At the same time, a review of pay rate was ongoing, with different communication strategies in adults and children's services meant that our members received conflicting advice. We worked through the summer and into the autumn to help the council's team send clear guidelines including contact details so that families could ask individual questions.

April - September 2021

The new financial year has already been extremely busy and included the following highlights:

- We have secured a 3 year grant agreement with Surrey County Council
- We welcomed 4 new members of staff and 2 new trustees to our team
- We secured 5 year funding from the National Lottery to support our core services
- We ran our first satisfaction survey to find out what our members and partners wanted from us
- We are strengthening our project work in partnership with the local authority and health systems





Plans for 2021 - 2022

Our plans for the next year include:

1. Annual event focused on Early Years (0-6)
2. Grow our effective partnership to include Health partners and include them in our grant agreement
3. Develop a team of volunteers to work with coordinators as school reps
4. Offer training to parents from experts in their field and SCC/CCG professionals
5. Ensure FVS staff are well trained and supported in their roles
6. Develop a sustainable and diverse funding strategy
7. Update our website
8. Develop links with schools to reach more parent carers
9. Collaborate with local area partners on the following work plan

Plans for 2021 - 2022

EHCP Processes	• To improve understanding of the role of case officers • To highlight parent carer issues to the system and help resolve them
Inclusion	• To support true inclusion for CYP with additional needs • To aid transparency and communication in the SEND Transformation Program
Autism Strategy	• To represent the voice of parent carers in the development and implementation of the strategy
Preparation for Adulthood	• To support the development and implementation of the preparing for adulthood transformation program. • To represent the voice of parent carers in the transformation work.
Early Years	• To host a multi-disciplinary annual event informing families and practitioners about SEND in the 0-6
SEND Transport	• To monitor and support a refreshed transport service
Emotional Wellbeing and Mental Health	• To support the development of a strong website • To ensure the voice of parent carers is heard by the service • To monitor and support the new service with 3rd sector, schools and local area partners
Social Care	• To clarify the purpose and criteria of the CwD team • To participate in the development and implementation of a Direct Payments strategy • To develop understanding of Early Help
Short Breaks	• To represent the voice of parent carers in the development of short breaks • To work with the 3rd sector to hear all parent carer voices
Health	• To represent the voice of parent carers in the development and implementation of the community health redesign • To collaborate with Healthwatch • To represent the experience of parent carers in the health system
Communication and Information	• To support an improved digital information service • To develop a dynamic FAQ system for parent carers • To support the development of the SPA

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 2021 is a surplus of £2,396 (prior year to 31st March 2019 was a deficit of £10,170). The reserves at 31st March 2021 have increased slightly as a result, to £69,520 (£67,125 at 31/3/20).

Income for the year was £140,343 (2019/20 £100,734). This was partly caused by an increase in new funds to support the organisation through the covid crisis which was approximately £27.6k. and Pears DCM funding of £7.7k.

Expenditure increased, partly to support the additional work bought on by the covid crisis, partly to enable the transition of the organisation to effectively work throughout the crisis (for example, our move to 'home-working', and additional spending on wellbeing and training to enable our staff to cope effectively with the increasingly distressed position of many of our members due to the covid crisis). Our expenditure for the year to 31st March 2021 was £137,947 (2019/20 £110,904).

Our reserves position is within our 3-6 month expenditure policy.

Since the end of the year we have won some new grants, the most significant being a 5 year National Lottery grant amounting to £81.5k per year, and mentioned in the main Trustee report.

This increase in our annual revenue (and consequent expenditure) will require us to increase our reserve levels accordingly.





Finance report

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

CHARITY COMMISSION FOR ENGLAND AND WALES

Family Voice Surrey	1175460	CC16a

Receipts and payments accounts

For the period from	Period start date 01/04/2020	To	Period end date 31/03/2021

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 Period to the nearest £
A1 Receipts					
			-	-	
Surrey County Council Grant	83,000		-	83,000	83,000
Contact		15,000	-	15,000	15,000
Contact Discretionary		5,000		5,000	
CFS (R&B)		1,620		1,620	
CFS Covid19 (E&E, GU, TA, WO)		5,000		5,000	
Pears		7,784		7,784	
SCC/Covid19		12,506		12,506	
Mole Valley Covid19		10,000		10,000	
Elmbridge BC					2,000
Donations	30	75	-	105	513
Other income	328		-	328	221
	-	-	-	-	-
Sub total(Gross income for AR)	83,358	56,985	-	140,343	100,734
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-

Total receipts	**83,358**	**56,985**	**-**	**140,343**	**100,734**
A3 Payments					
Salaries	**66,440**	**26,503**	**-**	**92,942**	**70,344**
Travel and expenses	**897**	**1,398**	**-**	**2,295**	**8,405**
PfA event	**81**	**4,000**		**4,081**	**11,048**
Other events / meetings	**440**	**1,430**	**-**	**1,870**	
Training	**413**	**5,846**	**-**	**6,259**	**810**
Marketing and Publicity					**546**
IT/Infrastructure & computer assets	**2,345**	**8,122**	**-**	**10,467**	**3,537**
Rent	**3,161**	**7,878**	**-**	**11,039**	**9,182**
Telephone, Stationary and Post	**499**		**-**	**499**	**1,351**
Other office costs			**-**	**-**	
HR, payroll, consulting, recruitment	**5,540**		**-**	**5,540**	**3,021**
Subsctiptions	**900**		**-**	**900**	**1,215**
Seldom Heard		**108**		**108**	
Other	**375**			**375**	
Insurance	**611**		**-**	**611**	**545**
Independent Examination	**960**	**-**	**-**	**960**	**900**
Sub total	**82,663**	**55,284**	**-**	**137,947**	**110,904**
	-	**-**	**-**	**-**	
	-	**-**	**-**	**-**	
Sub total	**-**	**-**	**-**	**-**	**-**
Total payments	**82,663**	**55,284**	**-**	**137,947**	**110,904**
Net of receipts/(payments)	**695**	**1,701**	**-**	**2,396**	**-10,170**
A5 Transfers between funds			**-**	**-**	**-**
A6 Cash funds last year end	**63,488**	**3,636**	**-**	**67,124**	**77,295**
Cash funds this year end	**64,183**	**5,337**	**-**	**69,520**	**67,125**

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	Cash at Bank	64,183	5,337	-
		-	-	-
		-	-	-
	Total cash funds	64,183	5,337	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets				-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities	Microsoft	General	91.20	01 April 2021

	Signature	Print Name	Date of approval
Treasurer	DocuSigned by: Sally Allen B81D794006A9476...	Sally Allen	16-Nov-2021

Independent examiner's report on the accounts

Section A *Independent Examiner's Report*

Report to the trustees/ members of	Family Voice Surrey		
On accounts for the period ended	31 March 2021	**Charity no (if any)**	1175460
Set out on pages	20 - 22		

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the period ended 31 March 2021.

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:**	16-Nov-2021

Name:	Janice Matthews
Relevant professional qualification(s) or body (if any):	FCA
Address:	Menzies LLP, Centrum House, 36 Station Road
	Egham, Surrey
	TW20 9LF

Appendix: Structure and Governance

We are constituted as a membership organisation, now with over 2400 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 acceptance of 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.

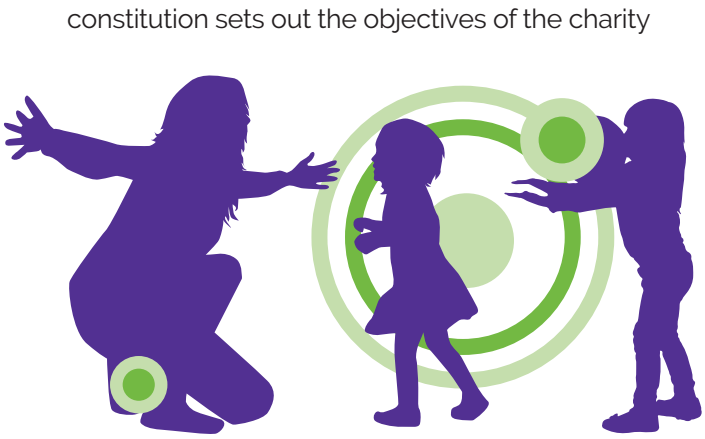
We must maintain a minimum of 3 trustees and are always keen to recruit new trustees. We welcome applications from parent carers of children with SEND, as well as people who have experience in the running of small charities, or with finance/treasurer, HR or fundraising skills, and people who have worked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

While day to day operations are led by the CEO with guidance from Head of Business Planning and Development and Business and Engagement Manager 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.

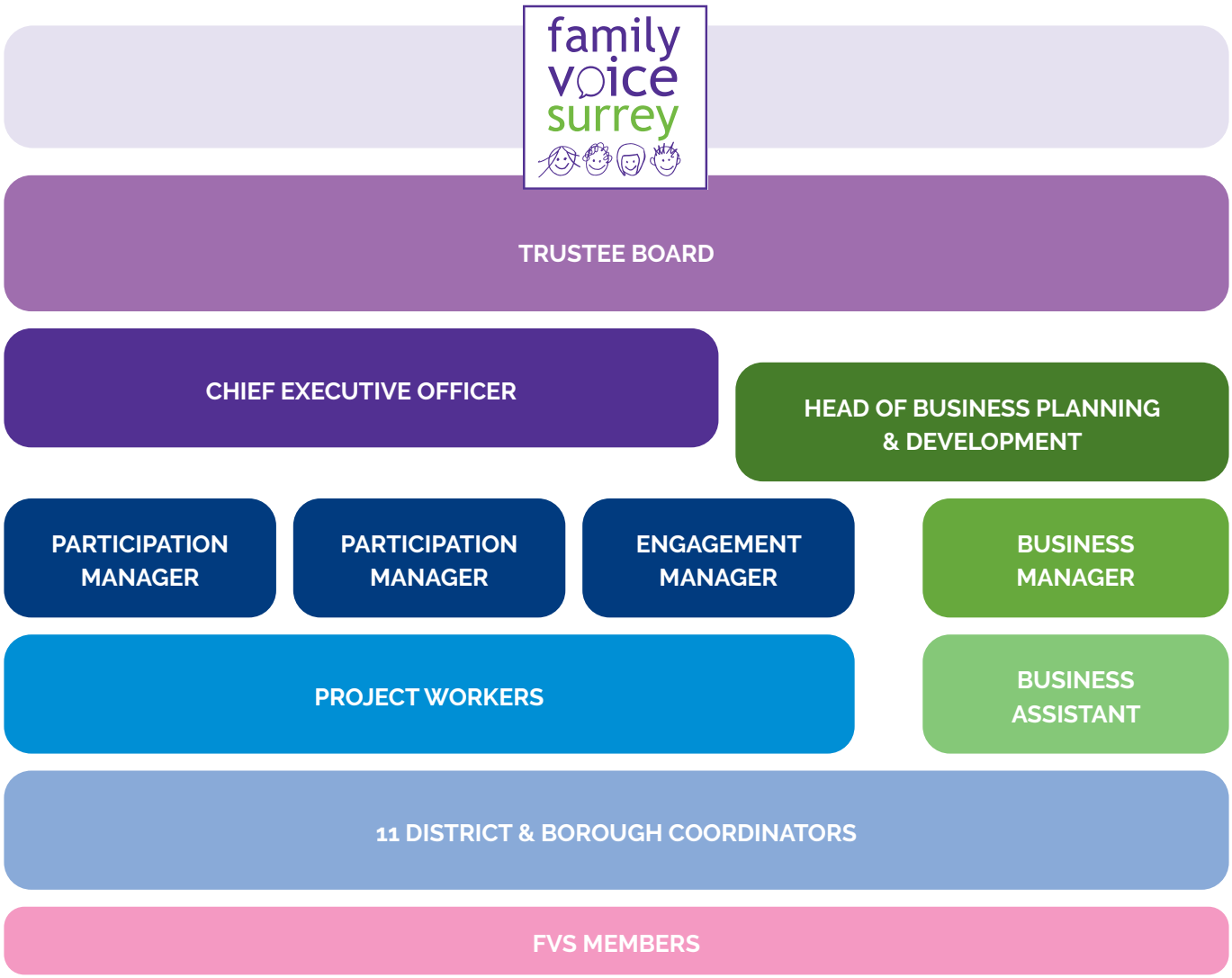
The Trustees have considered Charity Commission guidance on the provision of public benefit. The Trustees believe that FVS provides a public benefit to individuals with a special education need and/or disability, their carers, their families and the local community through the services provided to them. 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 business support 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 some policy documents, work with partners on messaging, all in a wide range of areas pertaining to SEND.

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.



family voice surrey

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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KT22 7LT

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