

1<sup>st</sup> April 2023 to 31<sup>st</sup>  
March 2024

# Participation, Engagement and Involvement – Charity and Forum Annual Report



fvp

Family Voice Peterborough

7/9/2024

# Executive Summary

## Purpose

When FVP has reported previously on SEND across Peterborough and the work of the Charity itself, the picture has always been mixed as to how services are experienced at an individual level by Parent Carers and how FVP often work in difficult economic circumstances to help Parent Carers in navigate this system. This past year has been particularly difficult across a range of areas not only due to the economic downturn nationally, but also due the changes across the LA and Health sector strategically with many new professionals now working locally in a system that has officially decoupled from Cambridgeshire in respect of the LA.

At the time of reporting FVP have also seen an increase in demand in the SEND system more generally from engagement work and in particular in discussions with other Third Sector Organisations and Partners across Health, Education and Care at an operational level as well as Professionals from Land Health strategic levels. It has been noted in a range of meetings, contact with Parent Carers and through evidence gathered that there is also more complexity of need within SEND households. Parent Carers often report their own additional health needs, having more than one child/ young person (CYP) with SEND, increased financial pressures, and their CYP have more complex needs.

Any system that sees such changes and external factors alongside an increase in demand and complexity of need from those seeking support is bound to experience pressure. FVP are looking to help raise awareness of how local SEND families are navigating a system that can be complex, confusing and at times traumatic leading to reduced resilience, poor mental wellbeing and a decreased willingness to engage in participation and co-production.

The hope is that this report provides a snapshot of the lived experience of local SEND families from the point of view of Parent Carers to enable discussions with senior LA and Health leads and that those discussions effect change. The intent is not to find fault rather to show how the system is not working from an individual level and seek solutions to make things better at a local level for individual households.

## SECTION ONE

Unlike previous reporting periods which focussed on SEND and Participation across grant funded work streams the intention here is to report on SEND more fundamentally from the lived experience of Parent Carers across Peterborough. The lived experience of Parent Carers has been broken down into four areas to enable evidence to be presented that still matches broad outcomes FVP works towards:

- Parent Carer Wellbeing.
- SEND and Schools Work – Parent Carer Engagement & Views
- Seldom Heard Communities
- Co-production and Change

Core areas of concern impacting parent carers have been identified as:

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
2. Lack of support –managing benefit changes, applying for an EHCNA, mental health management to name a few, support after diagnosis
3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
4. Difficulty in finding Information – you don't know, what you don't know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.
7. Mixed engagement, communication and involvement at setting level, which is more negative as opposed to positive.

## SECTION TWO

The wider work of the charity detailed in section two makes reference to the assets retained for charity use namely the community centre and caravans and explores further the ongoing impact of the current cost of living crisis.

Key Themes:

1. Change in service delivery and review of assets
2. Parent Carer wellbeing
3. Seldom Heard Communities engagement
4. Charity business planning – sustainability, development and marketing.

## Acknowledgements

This report would not be possible without; the level of co-production the forum has achieved between the Local Authority, ICB, Local Health Trusts and Educational Settings and the number of parent cares willing to participate with the forum and afore mentioned partners.

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## **Report Introduction**

Some of the information presented in this report has been presented throughout the past year in a number of micro reports including quarterly monitoring reports and FVP's Annual Survey Comparison Report. As these reports contain a broad range of data which present both quantitative and qualitative evidence of how Parent Carers are experiencing SEND the data presented in this report will be scaled back with reference made to the other reports.

A brief overview of FVP will again be given in this introduction as a means to putting in to context the different functions of FVP as a Charity including the changes as a result economic and political and other ongoing concerns.

## **Forum Context**

The Parent Carer Forum (PCF) function of FVP is integral to charity and has been a function since FVP formed initially as PCF steering group in 2009. FVP is recognised as the Department for Education (DfE) designated parent carer forum for the City of Peterborough and as such is also a member forum of the National Network of Parent Carer Forums (NNPCF). FVP goes through a fairly rigorous process to draw on forum specific money nationally which then enables funds to be accessed locally.

Annually since 2010 FVP have applied for funding from the DfE via Contact (national support partner of parent participation working with NNPCF). The grant value currently stands at £17500 and is paid in two instalments. As part of this process, an MOU is signed by the LA accepting FVP as the designated parents forum. The LA then pays another grant to FVP as a form of top-up funding. This second grant is outside of general commissioning guidelines as it is a unique provider grant. You can only have one parent's forum per authority and this forum must be recognised as a forum by the DfE and a subsequent member of the ERPCF and NNPCF.

The main aims of the PCF element of FVP are to:

1. Continue to support and deliver help advice and guidance around SEND. In particular ensuring co-production and the implementation of the priorities and action plans within the SEND agenda and all other associated strategies.
2. Ensure parent carers are included, heard and enabled to participate in a way which meets their individual needs and requirements.

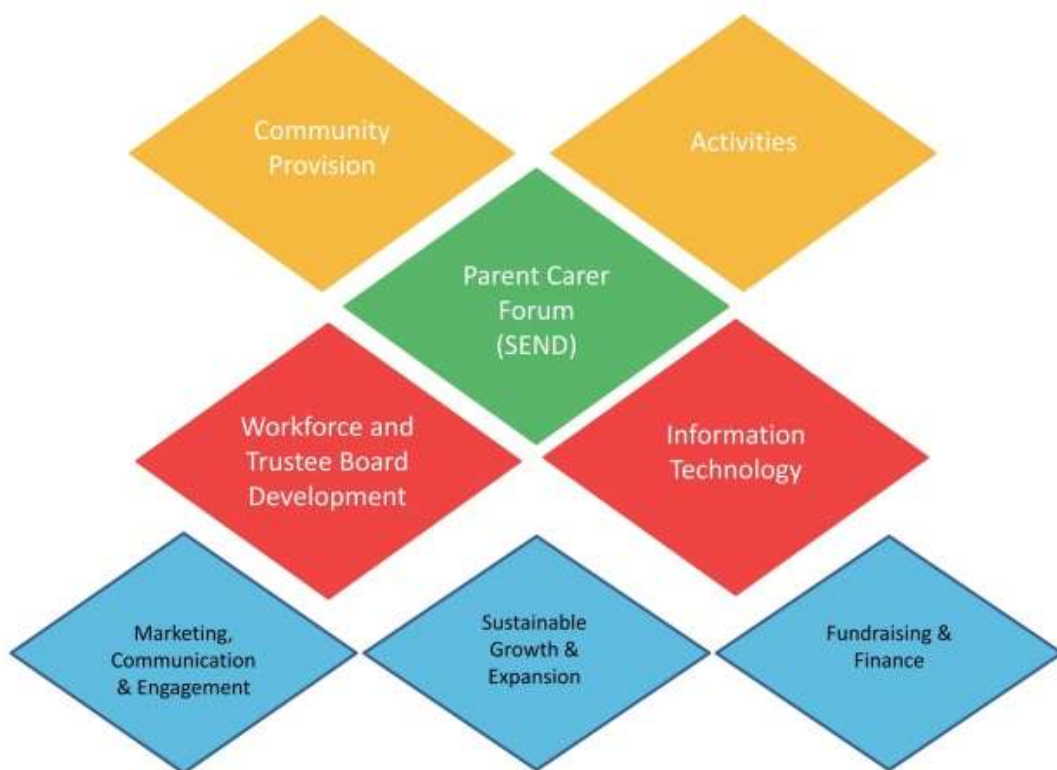
The work of the forum takes place from commissioning through to provision and across the LA and Health sector, with some work falling within the remit of FVP as a forum but outside of the scope of any grant funding. In the past year with some slight changes parent carer views have been gathered via; social media using discussions in a chatroom and online Polls, online surveys, recording of parent carer contact via email and/ or phone. All the information gathered is collated in to reports and fed back to key partners by parent representatives in various meetings.

FVP work the Local Authority and Health to find solutions to concerns raised by parent/carers. This way of working does not deliver instant results and changes that take place may not be easily recognised by individuals.

## Charity Context

FVP current legal status is as a Charitable Incorporated Charity (CIO); registration number: 1171389. FVP's charitable purpose is defined in the following objects *'to relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough in such ways as the trustees shall think fit, in particular by the provision of advice, information, support and advocacy'*. FVP operates under a foundation model where the trustees are the members of the charity and the CIO holds the assets of the charity. FVP have engaged with approx. 304 known parent carers at some level across a range of activities and communication channels. FVP are supported by board of trustees which has gone through immense change in the past year, which has included some major changes towards the end of the financial year as reported in FVP Trustees Annual Report.

The board have set FVP's priorities over the next five years:



## Participation/ Engagement/ Involvement April 2023 to March 2024

### Headlines

1. >300 known parents have been involved at some level via virtual meetings/ events/ online activities/ Facebook Polls and Discussions.
2. >100 professionals have been involved at some level via virtual meetings.
3. 408 parent carers have taken part ( online surveys of Facebook Polls.
4. Parents have self-reported being members/ attendees at; Peterborough District Deaf Children Society (PDDCS), Peterborough Area Down Syndrome Group (PADSG), Little Miracles (LM), National Autistic Society (NAS), Autism Peterborough, Shine, Caring Together and the Aiming High Group (AHG)
5. Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
  - a. ASD, ADHD, (This is the most prevalent condition reported)
  - b. Global Developmental Delay (GDD),
  - c. Foetal alcohol spectrum disorder (FASD)
  - d. Speech, Language and Communication Needs (SLCN),
  - e. Complex Health, Obsessive Compulsive Disorder (OCD),
  - f. Cerebral Palsy (CP),
  - g. Tourette's,
  - h. Learning Disability and Difficulty (LDD),
  - i. Hearing Impairment (HI), Depression, Behavioural Needs,
  - j. Achondroplasia,
  - k. Goldenhar Syndrome,
  - l. Downs Syndrome,
  - m. Hypochondroplasia,
  - n. Health Needs including conditions such as Epilepsy and Type 1 Diabetes
  - o. Spina bifida and Hydrocephalus
  - p. Physical Disabilities
  - q. Anxiety Disorder
6. 22 new fathers have been involved which is an increase on the previous year and 1 father has had regular involvement in person and another via social media.
7. Parent carers reported the ages of their children/ young people as between 2 to 34.
8. Participation methods used included; Coffee Mornings and Afternoons, some community activities where possible, Surveys and feedback forms.
9. Evidence is both qualitative and quantitative in nature.
10. Self-reported ethnicity is overall 64.29% White British and 35.71% Other Ethnicities which match 2021 Census categories.





## **INTRODUCTION**

### **Parent Carer Wellbeing**

Much work of FVP has centred on evidencing the marked decrease in Parent Carer resilience and wellbeing through sign-posting work, engagement at face to face schools sessions and a range of surveys. More recently through such contact it has become clear that Parent Carers have experienced a SEND system that is confusing, complex and difficult to navigate alongside increasingly difficult financial circumstances; Parent Carers are feeling traumatised.

### **SEND Data & Schools Work – Parent Carer Engagement & Views**

This area of work has seen engagement and participation across a number of areas from >300 known individuals. The participation has taken place through a variety of methods including; online polls, online surveys and face to face contact. Engagement with schools has recommenced with 162 parent carers attending 30 sessions. A full report has been produced analysing this work and also reviewing information settings have in terms of their SEND offer <https://familyvoice.org/reports/>

### **Seldom Heard Communities**

Work has continued in this area in relation to general engagement and facilitating participation through face to face events. A community development worker (CDW) has also invested time in outreach work to identify new contacts and groups; the CDW has worked alongside the team of Parent Representatives to reach a wider group of parent carers. Regular attendance has occurred at sessions run by the Julaybib Group in addition to work that has been ongoing with the Aiming High Group.

### **Coproduction and Change**

The use of Topics of Importance (ToI) has continued but as a result of the decoupling between Peterborough City Council (PCC) and Cambridgeshire County Council (CCC) has dropped off in relation to responses to any issues raised via the ToI approach. Co-production has continued in other areas especially in relation to local ASD pathways and LD needs assessment pathways; this has occurred across Health and the Local Authority. In Peterborough specifically work continues with the Accelerated Progress Plan (APP)

### **Data Gathering**

Data to ascertain parent carer views and experiences has been via online surveys, case study work, feedback forms at events and discussions with parents via email or phone.

Number of Sessions				Total Hours				Beneficiaries			
20/21	21/22	22/23	23/24	20/21	21/22	22/23	23/24	20/21	21/22	22/23	23/24
425	683	941	981	1094	1648.5	6224	2497.6	2342	3409	4391	6080

**Fig.2 Comparison across years**

A brief comparison with data from 20/21 to 23/24 shows that there was an overall year on year increase in all areas. This is in part due to moving back to face to face work, and being able to hire out the community centre.

## Overall Data Table

Type of Session	Sessions	Hours	n Time	Travel Time	Total Hours	Parents/
EPP	0	0	0	0	0	0
CB	0	0	0	0	0	0
Wellbeing Training	1	5	2	5	12	5
Parent Carer Hub	5	36	36	0	72	21
Themed Workshops (Open Forum)	1	2	2	0.5	4.5	6
CETR	30	0	0	0	0	30
Information Stands	14	0	0	0	0	905
SHCF - Face to Face	1	4	2	0	6	4
CDC Sessions	8	5	1	1	7	132
Focus Groups	11	20	26	6	52	67
Schools Offer	30	58	87	29	174	162
Coffee/ Breakfast/ Lunch Meeting	8	7.5	14	5	26.5	18
Conference	1	5	10	1	16	57
Facebook Polls	1	0	0	0	0	57
Surveys	8	0	0	0	0	351
Family Based Trips/ Activities	70	0	0	0	0	2569
Strategic Meetings	180	316.5	114	15	445.5	9
Volunteer Support (activities)	2	128.0	0	20	148.0	16
Hall Hire	557	1910.6	1671	0	3581.6	1500
Caravan Hire	53		159		159	171
	981	2497.6	2124	82.5	4704.1	6080

**Fig.3 Overall Engagement Data**

## Wellbeing

### Overall wellbeing activity

There has been some change across the years to how wellbeing support is facilitated in the Parent Carer community locally which has been driven by a combination of charity resourcing and Parent Carer need. Over time signposting, trips & activities and coffee sessions have become increasingly popular.

	Actual Sessions						Actual Hours						Actual Beneficiaries					
	18/19	19/20	20/21	20/22	22/23	23/24	18/19	19/20	20/21	21/22	22/23	23/24	18/19	19/20	20/21	21/22	22/23	23/24
EPP	4	5	1	1	0	0	40	45	7	3	0	0	30	41	6	10		0
CB	4	5	3	1	0	0	25	30	1	4	0	0	21	41	15	6		0
HUB	6	6	3	4	5	5	29	20	6	12	24	72	8	20	4	8		21
CETR	38	39	59	61	36	30	311	279.5	354	305	216	180	28	39	56	61		30
Well Being	0	0	0	4	5	1				12	30	12				17		5
Food/Warm Hub					25	52					300	450					817	1581
Sign Posting					129	150					258	300					129	150
<b>Total</b>	<b>52</b>	<b>55</b>	<b>66</b>	<b>71</b>	<b>200</b>	<b>238</b>	<b>405</b>	<b>374.5</b>	<b>368</b>	<b>336</b>	<b>828</b>	<b>1014</b>	<b>87</b>	<b>141</b>	<b>81</b>	<b>102</b>	<b>946</b>	<b>1787</b>

**Fig.4 Numbers benefitting from Wellbeing Support**

Between 21/22 and 23/24 there was an increase in number of hours worked and number of beneficiaries despite a slight decrease in overall charitable funding. This is different to the previous years 19/20 to 20/21 where there had been a decrease across all areas. The introduction of the sessions looking at parental wellbeing to facilitate their caring of their CYP led in part to the increase in the numbers of parents engaging in sessions as has providing access to support to alleviate the impact of the cost of living.

### Parent Carer Hubs

Previously data was presented to show attendance rates and cancellation/ no show rates as a way of examining trends. This year this has not been continued as the way the hubs run has changed and now set appointment slots are allocated to parent carers based on need and using a first come first served approach to incoming requests. This has resulted in no missed 'appointments'

### Food Support/ Signposting

An initiative FVP started in 2020 to 2021 and that continues to be provided is the provision of food and phone/ email support. This area has proved to have a real impact on Parent Carer wellbeing from alleviating the impact of the ongoing cost of living concerns through to ensure information is provided at the right time in the right way.

Number of Sessions	Number of attendees
<b>52</b>	<b>1581</b>

**Fig.5 Food Support**

Parents	Children
<b>144</b>	<b>193</b>

**Fig: 6 Food Support – Xmas Campaign**

Total Contact	Follow up required			Contact Form
	Phone	In Person	Email	
<b>206</b>	<b>46</b>	<b>25</b>	<b>25</b>	<b>110</b>

**Fig.7 Signposting Direct Contact**

## Household Details

A cursory examination of data held by FVP shows that household demographics are very mixed. Of a sample of 59 households 35 have only one child/ young person with SEND and all households have a minimum of two children/ young people.

All households are in receipt of at least one benefit (including in work benefits) and 34% of households are single parent and 29% have at least one adult Parent Carer with a disability/ health need of their own.

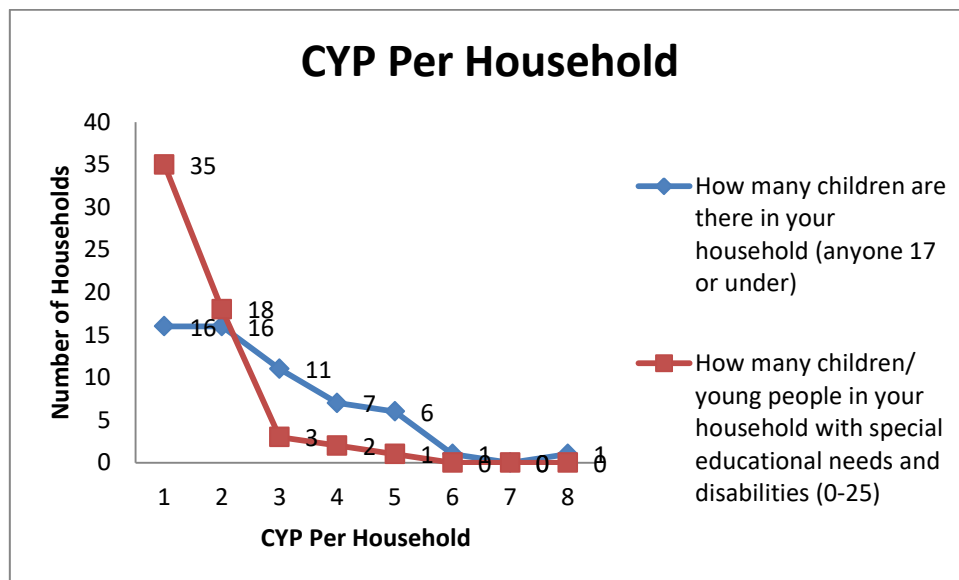


Fig. 8 CYP Per Household

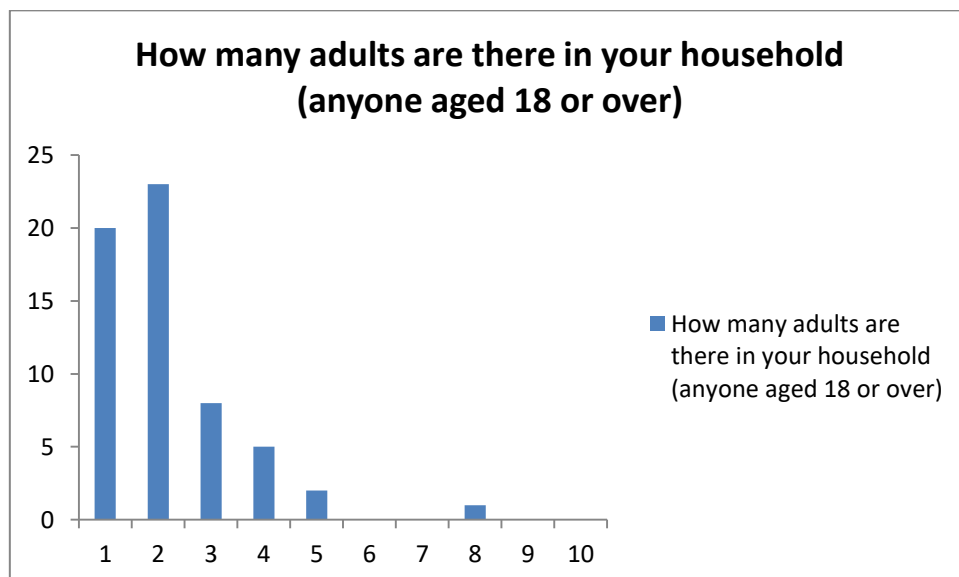


Fig. 10 Adults per Household

## Themes

When parent carers contact FVP for anything during the initial contact they are asked what support they require/ what their concerns are. The following are examples of response themes support may be required.

- Access to short breaks/ respite
- Educational advice
- Advice on how to access social care
- CAMHs and Mental Health
- EHCp assessments
- Early Help access
- Housing Advice
- Access to community provision
- Isolation and social exclusion
- Poor communication between LA and family
- Financial concerns
- Preparing for Adulthood

## **Impact of ability to Care and Mental Wellbeing**

Although unlike in previous years where separate surveys focussing specifically on Parent Carers as carers have not been conducted, questions relating to carers were asked specifically in the Annual SEND Survey. Further to this whenever feedback has been gathered at activities or events Parent Carers have been asked what difference the sessions have made to them and whether their mental wellbeing has been improved as a result.

Some of the key findings of how Parent Carers experience the system currently is:

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
2. Lack of support –managing benefit changes, applying for an EHCNA, mental health management to name a few, support after diagnosis
3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
4. Difficulty in finding Information – you don't know, what you don't know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.

## Parental Requests for Information

- *My 12 year old son is autistic and I'm worried he's not receiving the right education and care in the current setting he is in now.*
- *My son cannot get an appointment to see the EPS Team at school. School find it very difficult to level my son. ASD Diagnosis, age 7. Refuses to participate in most activities at school apart from PE.*

- *I want my child assessed as he is diagnosed with autism and this was done virtually through zoom. I need someone to assess him face to face to see how far globally delayed he is and the other issues we are facing with him at home and school.*
- *My son is having issues at school with regulating his emotions*
- *My child's mental well being, social interaction difficulties, help with her anxiety, high sensory needs and with getting her to attend school.*
- *On advice for getting help for my daughter who's being tested for ASD*
- *I want my child to be assessed by an Educational Psychologist in school as the cognition and learning age in her EHCP is incorrect*
- *Get help.*
- *Son has autism and attends a sen school close to permanent exclusion*
- *Support with advice for echp review process moving school nor meeting their echp ways to support understand off her diagnosis*
- *Would like to talk about my son. He is autistic and very sensitive boy. He is starting to have school anxiety and overthinking about everything.*
- *My daughter recently had be diagnosed with ADHD*
- *My son has a diagnosis of autism. I would like to know of any support available and how schools should support his needs.*
- *Suggested by my son's speech and language therapist- not making progress currently. School have not placed him on sen register yet as want to set some targets first.*
- *My daughter has DiGeorges syndrome and needs a further medical diagnosis for possible Autism as she is falling behind in key skills at school and needs additional support in class. We are currently in the Webster Stratton parenting program as we was told by school we need to complete this before an EP can be sourced.*
- *About support for my daughter whom has mental health difficulties and eating disorders*
- *My daughter had adhd and struggling with mental help*
- *Daughter recently diagx with Crohn's disease. Experiencing a lot of fatigue and pain. Struggling to go to school. We are unsure how to advocate for her - what adaptations to request etc*

### Cost of Living Concerns and Impact

- *It is making daily life very difficult and we are having to make cuts to the household*
- *Very badly*
- *A lot and have recently been dismissed from my job of 17 years due to my daughters difficulties.*
- *Terribly . Struggling more and more financially .*
- *Struggling having to only buy essential items*
- *Massively, i cant afford days out or events like i used to before.*
- *No days out*
- *it's not been good finding things very hard*
- *It's a nightmare can't afford the basics of clothes & food I also have a 4k electric & gas bill on top of paying them £900 a month*
- *We have had to buy Christmas presents for the children secondhand from FB this year. We don't turn the heating on until the evening each day, despite having myself and .... home all day every day.*
- *Badly due to mental health*

- *Badly. After paying the rent there is barely any money left for food shopping yet alone other things we require ie travel to/from doctors appointments, new footwear (desperately needed) new clothing etc*
- *Extremely. I'm on disability benefits but currently working 12 hours. Had to reduce my hours due to disability's but no help or support available. Find it all hard to get in touch with anyone due to anxiety and depression*
- *It's hard*
- *It's very hard to juggle presents and food*
- *Finding keeping up with everything difficult*
- *I am having to find means of getting a cooker thats been contemed and washing machine as broken*
- *Finding very hard to provide food and heating in the colder months*
- *It's very hard for us, me as a mum focusing just on children and eating left overs after them ( which I don't mind actually because this is what mum's should do). We often rely on food banks and borrowing money from friends and family to keep up with regular meals and essentials.*
- *I lost job. stragling with money.*
- *Struggling money wise*
- *Found more difficult*
- *I have alot of stuff to pay off plus its really hard with all this kids by myself as my husband died*
- *Dramatically. My son is on part time. So just school runs costing 200 pound a week. Currently all money seems to go on transport*
- *Lot of prices are gone up so it's quite difficult at the moment to manage .*
- *Have to budget on food*
- *Not receiving enough money I am only get universal credit for myself no other income of £379 a month that all*
- *We are struggling to provide basic necessities and often need support*
- *The cost of food and energy has an impact on us*
- *We have been using food pantry's, have called my energy supplier to lower my bill as couldn't afford it, reducing the amount of times I put the heating on as its too expensive, not going out often due to not having the money, getting second hand clothes*
- *We are currently on a section 21 from our landlord and facing homelessness by the end of the year and this is putting a huge financial strain on me as a single parent as I have to pay for house applications, storage and moving vehicles at a very difficult and already expensive time of year.*
- *Hugely, struggling to pay bills*
- *Not enough money to go around*
- *We are struggling drastically with rising cost of living, struggling to pay bills. Scared to put our heating on due to the cost of gas and electric.*
- *We are really struggling with the worry and growing cost of food and bills this year .*
- *I was looking forward to getting warm home discount so can heat the home when need be. I found out my house isn't in the criteria this year due to square meter age. Food costs are high and he's a growing lad that eats a lot. He's also gone through a very angry stage so I've had a lot broken. Mentally and emotional it's broken me*
- *Losing my wife last year means not only am I grieving but I'm not able to work like I used to as I'm having to care full time for ..... outside of his 2 days allocated college*

*time. Meaning my income is low and bills remain high. Plus food costs. I tend to not heat the house as much as possible and sit in a coat and hat most of the time and Kyle keeps warm himself as isn't cold blooded. Money's tight on top of grief.*

- *My little boy last year was in and out of hospital around Christmas time making it hard for us to enjoy it. This year I wanted him to have the full magical effort which he deserved for his first Christmas and with the cost of living crisis I'm worried that I'm not going to be able to do that for him due to it having much money left to spend on ourselves after paying for everything.*
- *We have had pip removed 18 months ago and children are home schooled due to insufficient care by statutory schools available. Money is very tight and we are being supported by my elderly grandmother at present.*
- *Affecting us mentally and physically*
- *I can't afford to get my son presents for Christmas or decorate my home with a tree ect. I'm struggling with bills, electric and gas. Struggling with food*
- *we struggle day to day and have accepted Christmas wouldn't really happen this year*
- *I am really struggling with daily living so with Christmas coming and having 2 young children in my care , plus a teenage brother living with me after our mum passed away, I'm finding it extremely difficult too be able too make Christmas a good one. I am unable too work due too the cost of childcare and also due too my physical and mental health. So I rely solely on benefits currently with a house that is extortionate. We don't have much family either so I'm struggling massively too even put food on the table now let alone at Christmas. Thank you so much for advertising this amazing offer and hope I will be considered. Thank you*
- *A struggle*
- *It's a big worry I tend to work but it's never enough all the bill add up and we had to put the heating on because it's getting colder and now it's Christmas my mum had not been well and we had to take her to the hospital parking and food can add up the price of food is going up each day*
- *Struggling to get by gas electric food ect*
- *We are finding it very difficult*
- *I'm a single mother and receive ESA due to a medical condition I have. Worrying about money this time of year is depressing, I pay for gas and electric through a meter, sometimes we have to go with out the heating to eat.*
- *Very hard due to a single mother with depression*
- *It has been a struggle with the cost of living and also losing my job due to my own ill health struggling with long covid amongst a few other health conditions*
- *Struggling*
- *Been hospital coulies tax wasn't paid falling before in ot*
- *We are really struggling to be able to heat the house and have regular meals. I feel depressed every day I can't see a way forward*
- *with an extra mouth to feed and no help from anyone its crippling us. were struggling every day with food. heating and desiel for hte car for apptpointments*
- *Dreadful*
- *This year we lost a family member, I lost my job and am now going through the process of trying to get PIP, and my son and daughter have struggled through school.*
- *Alot*
- *Yes badly*
- *Things are very costly and it has not been easy.*



- *Finding the price of food very difficult*
- *Now winter here and we need heating I am feeling it have to chose to eat or heat*
- *Very bad, we are very sad*
- *Very Difficult.*
- *Because of food costs going up and gas/electric bills struggle to afford days out and clothes*
- *Badly we cant have heating on as cant afford it have to use less electricity as i need it over nite for cpap machine an can bearly aford food because prices. I go days without food so kids eat*
- *Very difficult situation*
- *A lot*
- *"It's affecting us a lot as my daughter is on end of life care and my husband had to reduce his hours at work."*
- *By not having money*
- *I struggle to pay for food and clothing for my daughter, especially school uniform and shoes because she is big for her age and is growing very quickly.*
- *We are managing but on a tight budget*
- *cost of energy and everything is very high*
- *Badly not enough money for gas and electric and food*
- *Food and bills are so expensive*
- *Money just doesn't stretch far enough*

## **SEND DATA AND SCHOOLS ENGAGEMENT**

The SEND Data is broken down into themed workshops, focus groups, working with schools and surveys. Most sessions taking place have now done so face to face, as the preferred method for parent carers.

### **Participation and Engagement Sessions**

There have been a total of 22 participation sessions through face to face methods with a total of 152 overall attendees.

<b>Type of Session</b>	<b>Number of Sessions</b>	<b>Number of Parents/ Beneficiaries</b>
Themed Workshops (Open Forum)	1	6
SHCF - Face to Face	1	4
Focus Groups	11	67
Coffee/ Breakfast/ Lunch Meeting	8	18
Conference	1	57
<b>Totals</b>	<b>22</b>	<b>152</b>

**Fig.11 Total number of sessions and attendees across types of work**

## Schools Engagement

There has been a marked increase in schools engagement since the introduction of the schools offer. Coffee mornings/ afternoons are most well received and lead to the broadest engagement rate FVP have seen of late from face to face sessions. Overall there have been 30 sessions with a total of 162 parents in attendance.

School Session	Attendance
Beeches Coffee morning	5
Newborough Coffee morning	7
Northborough Primary	5
All Saints C of E	3
Peakirk-cum-glington	12
Northborough Primary	3
Orton Wistow Primary	9
All Saints Primary	9
Nene Valley Primary	5
Nene Valley Primary	1
Orton Wistow Primary	5
Lime Academy @Tesco	12
Peakirk-cum glinton	5
Woodston Primary	6
All Saints Primary	14
Parent Carer Coffee Morning	3
Northborough (third)	1
Lime Academy Orton	8
Peakirk-cum-glington	5
Lime Academy Orton	8
Woodston Primary	3
Northborough	1
St Thomas Moore	0
All Saints	6
Eye (4/3/24)	1
Hampton Gardens/college 18/03/24	4

**Fig.12 School Session Attendance**

## Online Surveys

<b>Survey</b>	<b>Response Rate</b>
Transport	30
School Attendance and experience 23/24	40
PfA (ToI)	26
Health Appointments	24
Health Inequalities	22
SEND Strategy	9
Annual Survey	188
PfA (Seldom Heard)	12

**Fig.13 Total number of responses per survey conducted**

A number of surveys have been completed and are designed to be anonymous. The surveys do have filter questions so they are completed by parent carers in Peterborough only. It is important for the surveys to be completed by this specific group as the results are intended to inform commissioning in Peterborough relating to SEND services.

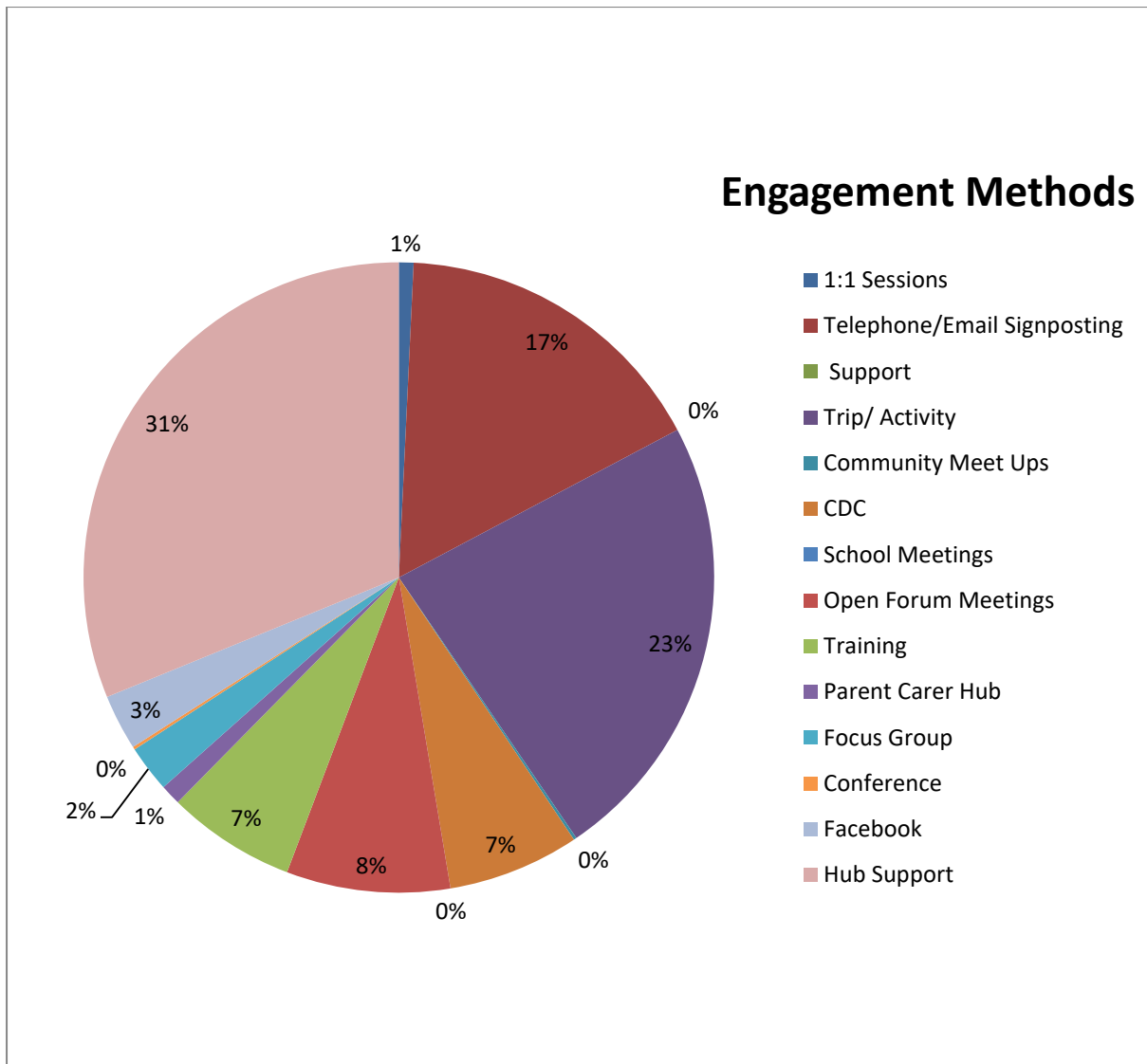
There have been 8 surveys completed in 2023 to 2024 with one directly informing the offer of support to families. There have been a total of 351 responses. The main end of year survey has been reported on in a separate report where the results have been compared to data gathered since 2018. The full comparative report is available via this link on the FVP website. <https://familyvoice.org/wp-content/uploads/files/SurveyReports/SEND%20In%20Peterborough%20&%20Annual%20Survey%20Comparison%20Report%20January%202024.pdf> . The annual survey saw the highest response rate to date at 188 responses.

### Overall Survey Analysis

Although the surveys cover a range of topics some key themes occur across all of them; Information and communication, support, emotional wellbeing and financial concerns. The annual survey in particular shows a distinct negative shift in how local Parent Carers are experiencing the SEND system and any associated services.

### Engagement and Participation Methods

Where parent carer preferred participation and engagement methods can be identified it can be shown that some methods are more popular than others.



**Fig.14 Preferred methods of participation as percentages**

The preference this year has related to support and receiving something for example vouchers for accessing local activities of food. This may be linked to the current focus on financial matters for families linked to the cost of living crisis. Where any engagement has taken place attempts have always been made to establish how SEND is being experienced locally.

### **Demography of those engaging**

FVP also gather data on the ethnicity and gender of the parent carers who participate and the needs of their child (ren). The findings where know are as follows:

Fig. 15 and 16 reflect self-reported ethnicity of the family and parent carer gender. The predominant ethnicity was White British and the predominant gender was Female.

Ethnicity				
Category	Adult			
	21/22	22/23	23/24 (Re-engaged)	23/24 (New)
White British	199	54	34	15
Gypsy or Irish Traveller	2	0	1	1
Roma	0	1	1	0
Any Other White Background	20	10	0	0
White and Black Caribbean	0	0	0	0
White and Black African	0	0	0	0
White and Asian	0	0	0	0
Any Other Mixed or Multiple Ethnic Background	8	1	2	1
Indian	8	5	2	0
Pakistani	12	7	8	2
Bangladeshi	0	0	0	0
Chinese	0	2	0	0
Any Other Asian Background	0	0	5	0
African	7	6	2	3
Caribbean	0	0	0	0
Black British	1	0	1	0
Any Other Black or Caribbean Background	0	0	0	0
Arab	0	1	1	0
Any Other Ethnic Group	6	0	1	0
Rather Not Say	0	0	0	0
Unknown	40	67	8	37

Fig.15 Self-reported familial ethnicity

	Gender							
	Male		Female		Other		Unknown	
	Adult	Child	Adult	Child	Adult	Child	Adult	Child
2021/2022	20	86	298	81	0	2	3	382
2022/2023	16	73	147	52	0	0	4	158
2023/2024	6	21	54	13	0	1	0	25

Fig.16 Self-reported parent carer and CYP gender

Disability	
Physical Disability	11
Mental Health	18
Neurodevelopmental	273
Hearing Impairment	18
Visual Impairment	1
Learning Disability	32
Other Health Condition	122
Unknown	250
No Disability	246

Fig.17 Number of CYP with and without needs per parent carers

The predominant area of needs reported was ASD and a growing number of parents report their CYP as having more than one area of need. Compared to previous years more parents of CYP with complex health, physical disabilities and other needs are also engaging.

### **SELDOM HEARD ENGAGEMENT**

FVP are aware it is harder to identify and work with parent carers from seldom heard communities and that there is general view this relates only to differing communities based on ethnicity. In the past few years some extra guidelines were shared with PCF's nationally as to which groups are considered seldom heard for parent participation purposes. The groups are broken down in to a range of categories not just ethnicity.

Seldom heard communities can also relate to all of the following:

1. Parent carers who are Gay, Lesbian, Bisexual, Transgender, Questioning and other (LGBTQ+)
2. Families experiencing domestic abuse
3. Families experiencing alcohol or substance abuse
4. Families with unsettled ways of life (e.g. former asylum/ recent refugee status)
5. Very low-income families or families whose income drops suddenly due to a change in circumstances, self-employed
6. Rural and geographically isolated families
7. Male Carers
8. Families of home educated children or young people
9. Families of children or young people in alternative provision or out of area settings
10. Families with a disabled adult parent carer and particularly all those with learning disabilities or mental health issues.
11. Families with a disabled parent carer with learning disabilities or mental health issues
12. Parent carers of children and young people with rare conditions, or low incidence disabilities
13. Parent carers of children and young people who are deaf or hearing impaired
14. Parent carers of children and young people who are blind or visually impaired
15. Grandparents, kinship carers, foster carers
16. Adoptive parent carers
17. Refugees or asylum seekers

Work is still required to focus on all areas above, but an external analysis of FVP from and Equality, Diversity and Inclusion (EDI) assessment has shown that overall FVP's workforce is fairly reflective the diversity within Peterborough. Specific work has taken place with two groups over the past year; The Aiming High Group (AHG) and The Julyabib Group.

<b>Topic</b>	<b>Adults</b>	<b>Children</b>
AHG Pamper Session	5	
AHG Bowling	27	29
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	7	
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	5	
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	7	

Gladstone Family and Children Centre- Julyabib project Muslim mums SEND Group	13	
Gladstone Family and Children Centre - Julyabib project Muslim mums SEND Group 10/01/24	7	
PfA Survey (Flip Out)	12	23

**Fig. 18 Seldom Heard Session Attendance**

At some of the sessions above work took place to gather views regarding Preparing for Adulthood (PfA) in particular.

<b>Tell us about your understanding and experience of Education.</b>	<b>Tell us about your understanding and experience of Employment and Getting a Job</b>	<b>Tell us about your understanding and experience of Health.</b>	<b>Tell us about your understanding and experience of Friends/ Relationships/ Communities</b>	<b>Tell us about your understanding and experience of Independent Living</b>
My daughter 16yrs old . Has recently had dyslexia screening, she is struggling a lot in studies but still determined to study further for her future career. She has possible ADHD . She has not any educational plan settings for her yet.	She has no job experience but she is looking for part time volunteering.	Health experience is terrible at the moment. Doctors are not helpful.no	Friendship she is so important	No
No I am trying to make one but they have rejected it now school is applying I hope my child gets it this time	My young child is still in school	No	Good	No
My child does not have ehcp plan	Na	No not aware health services	Na	No
My child has ehcp and is on the track to archive the outcomes	I don't have experience with that yet but as far as I know my child want to continue education after his GCSEs	We haven't get any experience about health check yet for him	It's good to have network support.	He will be living with us at the moment . He is still young and law can change and support can change after few years so than we will be thinking when the time is right
Was to poorly to attend	No completely disable	Yes	Very good	No experience
Not required	Not required at the moment	No	Group session	Not required as yet
My child don't have EHCP plan I have applied but it got rejected so now	My goes to school	No	Good	No yet

school is applying one				
We have had no information of what PFA is and what the Post 16 learning provision is. I would have thought authorities, Gp's or even the schools would at least let parents know when their child is about to reach PFA age and the parent/carer can start looking into options but parents are just left in the lurch. The 5 day offer is very misleading as just reading it parents have the impression that the child or young person will have a provision or education that covers 5 days a week. The title is very misleading and needs looking into	One of the toughest tasks we have had to face so far. Not much information about what is available with regards to support into employment	Gp's seem as if they are basically non existent so we haven't bothered much as everytime you want an appointment there isn't any. I have heard of the annual health checks but not from my Gp but through my own research Never been told about adult health services All that I know about my young adult I have researched myself. It would be very helpful to parents if LA or schools can run PFA sessions for parents when their child is about to start transitioning to adulthood.	My young person has never had/made friends. I don't think she knows any different anyway but if she had the opportunity to get support to know how to make friends that would help	I am quite scared about this topic as I have heard horror stories with adult social care charging for services that they are not providing especially in cases whereby there is little or no mental capacity and the young adult doesn't quite understand what is been explained to them. With the cost of having to apply for Deputyship, PA or LPA, some parent carers cannot afford it and thereby this results in the young person making decisions they fully do not understand or have no mental capacity to deal with
Yes my child has proved in his education	No not yet as still in education	Yes but not as much help	Very good and understandable	No
He has EHCP but I feel there is not enough provision here in pboro	He does not have understanding or capability if this	Have heard but no one spoken to me about them	Not a lot	No

**Fig. 19 Pfa Experience**

Much of the work of FVP demonstrates that engagement has either started or is well underway with range of parent carers including from the groups above, although there is still work to do. This does not mean things wouldn't benefit from a review and potential change.

It has also become clear that engagement works best when:

1. Parents can engage at an activity where their CYP are present
2. Parents prefer to engage at an activity as opposed to a specific topic based focus group

### **COPRODUCTION AND CHANGE**

The use of Topics of Importance (ToI) which FVP introduced a number of years ago has slowed extensively, which may be linked to so many changes in LA staff members and restructuring linked to the decoupling of Cambridgeshire and Peterborough. FVP have produced two ToI which are still awaiting official responses. The ToI's are Education and



Inclusion and Health Inequalities, both of which are still important issues for local families. It should be noted that although there are no official responses they have been discussed at a number of boards and the concerns they raise have been considered in service planning.

The following suggested changes are still being consider in relation to facilitating responses from partners:

1. There should be no more than 3 or 4 Topics of Importance each year
2. ToI's should be 'deep dives' into a specific issues and include additional intelligence eg comparisons to statistical neighbours or national findings, case study.
3. ToI's to include suggestions and ideas for improvements from parents or other areas.
4. FVP data often highlights emerging trends. These emerging trends should be reported as they can indicate the next area for ToI.

### Change and Co-production

Co-production can in some areas be seen as embedded and part of the general practice of working with Peterborough City Council and Cambridgeshire & Peterborough Integrated Care Board and System.

The highest level of coproduction has been achieved in:

1. Services commissioned via the Children with Disability group
2. Work relating to the APP
3. ASD and LD Pathways

Change partly through the work of FVP continuously presenting evidence of concern and the lived experience of local SEND families has occurred to the Early Help Pathway in relation to Neurodevelopmental Assessments. As of April 2024 Parent Carers will no longer be required to take a 'parenting course' before their CYP is considered for assessment where ASD and/ or ADHD are suspected.

### Ongoing Involvement

1. ASD and LD Pathway Work
2. Accelerated Progress Plan
3. SEND Communication
4. Seldom Heard Parent Carer Engagement
5. Preparing for Adulthood

## **ANALYSIS**

**From an analysis of the work completed throughout 2023 to 2024 a number of themes have become apparent:**

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
2. Lack of support –managing benefit changes, applying for an EHCNA, mental health management to name a few, support after diagnosis

3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
4. Difficulty in finding Information – you don't know, what you don't know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.

### Recommendations

The following areas of need identified in the last annual report are still relevant in that parent carers would benefit from the following:

1. Face to face befriending to enable them to receive peer to peer support when they are new to the SEND world, and sign posting to all existing sources of support and information.
2. Benefits advice in relation to appointeeship and the move from DLA to PIP.
3. An Independent support type service to help the parent/ Young Person navigate the initial request for assessment stage of the EHCp process.

These are all short term types of support, some of which are time limited/ time bound. They are intended to be once off activities.

## **SECTION 2 – FAMILY VOICE PETERBOROUGH AS A CHARITY**

*To relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough in such ways as the Trustees shall think fit, in particular by the provision of advice, information, support and advocacy*

## **Chairs Forward**

As Chair of Family Voice Peterborough, I have great pleasure in introducing this report. Since last year, we have again seen changes to the board with members continuing to bring a range of skills and experience, with the newest members joining at the end of 2023. As a Parent Carer and a disabled person, I have been involved with the charity now for several years, as a Parent Carer Rep and now a Trustee. This past year, the centre has been fully open for community groups etc, however due to the economic downturn and cuts to statutory funding, usage has decreased. Despite this, we are confident that even with a decrease in usage, the centre has still been a focus for much needed community cohesion.

The community café which brings local residents together, combats loneliness and provides a centre for support and social networking has continued to be a valuable resource in our local area. The café, which is held every Wednesday morning, continues to grow from strength to strength with increasing numbers of people attending and volunteering. The café also uses the fareshare surplus food to offer to attendees; this weekly food hub has proved very popular and much needed during this cost of living crisis. In addition to this, we provide Christmas hampers for those in need of help, and continue to host litter picking sessions twice a month to create a sense of community pride.

We continued to use the National Lottery bid which is funding staffing costs as well as centre and caravan costs of caravans until 31<sup>st</sup> March 2024. Due to an underspend, in part, because of the delay in recruiting staff, the project has been extended to 30<sup>th</sup> June 2024. We will need to apply for further funding to continue to run the charity after next year. Sadly, the caravans became unviable and had to be sold. Whilst we understand that this is a disappointment to users who relied on it, unfortunately we had no choice.

FVP continue to host community barbeques that involve local people together with the Gambian community. As well as meals at a Turkish restaurant for seldom heard families; play activity sessions for children and families at Activity World, and the supply of vouchers for a trampoline park. These events are well attended and enjoyed by local residents from different communities and the charity. These events created a sense of community cohesion where staff, trustees and volunteers came together to create a wonderful fun and inclusive atmosphere.

Our signposting service has expanded we supported over 200 households and look forward to continuing to support the community.

I look forward to another year of working with Louise, trustees, staff and volunteers

Jason Merrill Chair FVP

## **Trustees**

Jason Merrill – Trustee: April 2023 – October 2023; Chairperson: October 2023 onwards

Tanya Smith – Joined: March 2024

Heather Skibsted – Chairperson: April 2023 – October 2023; Resigned: March 2024

Oluyemisi Anthonia Williams – Resigned: March 2024

Yi White – Resigned: March 2024

Aishat Idris – Joined: December 2023

Maggie Romjom – Joined: December 23; Resigned: January 2024

## **Declarations of Interest**

Heather Skibsted is Ward Councillor (Orton Longueville Ward, Parish Councillor Orton Longueville).

## **Governance and Structure**

Operating Model:	Constitution
Legal Structure:	Charitable Incorporated Organisation
Trusteeship:	<p>(1) Apart from the first charity trustees, every trustee must be appointed [for a term of [three] years] by a resolution passed at a properly convened meeting of the charity trustees.</p> <p>(2) In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.</p> <p>FVP has adopted a safer recruitment policy with associated procedures for the purposes of ensuring any appointed trustees:</p> <ul style="list-style-type: none"><li>• Understand their role within FVP</li><li>• Understand what FVP’s purpose is, who its beneficiaries are where it operates.</li><li>• Are eligible to act as a trustee and meet charity commission requirements and safeguarding requirements I relation to children and vulnerable adults</li><li>• Bring skills and experience to the charity that mean it will continue meeting its purpose</li></ul> <p>(3) New Trustees will be given an initial probation period of six months, which can be extended following a review.</p> <p>(4) Trustees must commit to a minimum of 20 hours a month.</p>

FVP has a small, but growing team of staff and volunteers who have operational responsibility for managing the charity on a day-to-day basis. Due to the size of the charity the trustees still have some operational duties which are being gradually devolved to the staff team via delegation which takes account of governance guidance principle 1.5. The Trustees moved towards using sub-committees chaired by a trustee and attended by other board members and key staff, Finance & Resources, Health, Safety & Safeguarding, Assets, Parent Carer Forum as per their constitution.

FVP works with a number of other third sector organisations as well as acting as a strategic partner of Peterborough City Council in relation to offering collective information, advocacy, support and advice to parent carers which is in line with the purpose of the charity as defined in its objectives. FVP has also started working with a wider partnership of organisations both statutory and third sector as part of the expanding seldom heard communities' work.

### Risk Statement

Risk management has changed this year, with an updated Risk Policy, risk log and use of dedicated time at sub-committees to manage any issues as they arise. The Trustees have also benefitted from some basic risk management training in relation to organisational health and safety. Identified risks relate to:

1. Financial viability of the organisation,
2. Premises Management and Maintenance,
3. Organisational capacity and growth in relation to operational functions,
4. Trustee Board capacity, skills and sustainability,
5. Caravan management, maintenance and sustainability,
6. Health and Safety,
7. External Relationships,
8. Reputation,
9. Staff and HR.

### Assets and Ownership

All assets are under the ownership of the CIO with two trustees signing leases/contracts as required as per the constitution. The assets of the charity at the start of the financial year were the Goldhay Community Centre and two caravans which are sited at Haven Caister and Butlin's Skegness respectively. Both Caravans were sold in November 2023 because they were no longer financially viable, as were unable to rent them out at a rate that would cover the costs of running them. The community centre was transferred to the CIO in February 2020. However, it has been agreed with the Local Authority that the lease can be surrendered and returned to their ownership.

## **Staff 2023 to 2024**

Operational management of the charity is the responsibility of the Chief Executive Officer (CEO). Due to recent changes in the organisation and funding constraints, the Senior Leadership Team (SLT) has been reduced. It now consists of the CEO and an Office Manager. The SLT team between them manage 10 employees. No staff member is remunerated over £50,000 and the staff costs are covered through specific grant funding and income generated from the hire of the premises. The staffing for the charity covers the forum functions of FVP, all administration and management of the assets. All staff received a cost of living pay rise at the start of the new financial year, except the CEO and IT Manager.

The trustees have been made aware of risks associated with being employers, especially as the charity is a relatively small organisation. The trustees have continued to mitigate risk through suitable financial planning, employee support and trustee board development. All has continued to be underpinned by the risk management policy which is reviewed annually. The board continue to seek external advice with respect to employment where required. The board have also had a renewed focus on Equality and Diversity to ensure they are supportive and understanding of the diversity within the workforce.

## **Volunteers 2023 to 2024**

FVP have secured the support of 5 active volunteers, some ad hoc volunteers' courtesy of the Rotary club and volunteers for specific pieces of centre works from the Gambian Community of Peterborough.

The parent rep team has moved from voluntary status to employment with the majority being on term time contracts. We have continued to run a Community Café which is being supported by a lead volunteer and other ad hoc volunteers. This work alone probably equates to over 900 hours of volunteer time.

It has not been possible this year to identify the number of volunteer hours given to the charity due to there being such variation in work conducted, and constant changes to work/volunteering due to personal commitments of the volunteers and changes within the charity itself.

## **Objectives and Activities**

The objects of the CIO are to relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough in such ways as the Trustees shall think fit, in particular by the provision of advice, information, support and advocacy.

The Board of Trustees have paid due regard to statutory guidance PB1, PB2 and PB3 issued by The Charity Commission when planning and undertaking activities in relation to the objects that define the purpose of the charity.

The trustees also look to consider social impact when undertaking work as means to demonstrate value for money and positive benefit to individuals and their families.

## **Social Impact – Regular Reviewed and Identified in Strategic Plans**

Definition: The effect of an activity on the social fabric of the community and well-being of the individuals and families (<https://www.youfirstsupportservices.org.uk/page/social-impact/45/>).

Social impact is also about changes which improve people’s lives and have positive consequences for the wider community.

The following outcomes matrix has been reviewed and amended as necessary over the last year, especially as the charity prepares for the next five years of planning. Much of the plan has been achieved, so now is the right time to start reflecting, reviewing and forward planning accordingly.

Ongoing outcomes/ impact:

Priority	Outcome	Indicator
<p><b>Parents Forum/SEND</b></p> <p>Continuing to support and deliver help advice and guidance around SEND. In particular ensuring co-production and the implementation of the priorities and action plans within the SEND agenda and all other associated strategies.</p> <p>Ensuring parent carers are included, heard and enabled to participate in a way which meets their individual needs and requirements.</p>	<p>All Parent Carers going through the SEND process are empowered to be involved and heard.</p> <p>Increased Parent Carer Representation and participation within the parent carer community.</p> <p>Parent Carers and families demonstrate increased personal and interpersonal resilience.</p> <p>Parents Carers are confident to manage meetings and challenges related to services that their child or charge require.</p>	<p>There will be an Increase in attendance figures at SEND based sessions ie focus groups, on-line forums, training.</p> <p>Using the latest census and SENI2 data FVP will collect data on disability and ethnicity to demonstrate an increase in reaching seldom heard and hard to reach groups.</p> <p>There will be an increase in engagement with more schools with the school offer.</p> <p>More parent carers will engage in training programmes.</p> <p>FVP will see an increase the number of parents attending setting based sessions.</p> <p>Families will self-report being more able to manage crises, or plan to avoid crises.</p>
<p><b>Community Provision</b></p> <p>Goldhay community centre is used to provide families</p>	<p>Parents and carers feel able to contribute to the</p>	<p>There will be an Increase in footfall access services at the</p>



<p>with training and support opportunities, food hubs, social events and activities that enable a diverse range of seldom heard groups to come together and celebrate various aspects of their lives.</p> <p>This has enabled the community space to be utilised for local residents and the wider community to access services and support and allow participation in the wider community, thus decreasing isolation amongst specific groups or those impacted by caring for a child/ young person.</p>	<p>development of community activities and peer support</p> <p>Local Residents and Community Groups are supported to build more cohesive communities and become less isolated</p> <p>Volunteering Opportunities are afforded to the community</p> <p>Carers and families demonstrate increased personal and interpersonal resilience</p> <p>Improved social capital and interaction</p>	<p>community centre</p> <p>There will an increase in regular and private hall hire.</p> <p>Carers and local residents report less social isolation</p> <p>Increased engagement from more diverse user group</p>
<p><b>Activities</b></p> <p>SEND families and local communities have access to affordable and where possible free trips, activities and events.</p> <p>Improved wellbeing and decreased financial stress for parent carers and other community members.</p>	<p>Increased attendance figures, as shown on attendance records</p>	<p>12 activities will have taken place that have included coach trips, hire of local activity places, themed sessions and family based activities provided at the community centre, across Peterborough and to further destinations.</p> <p>Parent carers and other attendees report to FVP that being able to access affordable and/ or free trips and activities leads to improved wellbeing for SEND families.</p>
<p><b>Work Force &amp; Trustee Board Development</b></p> <p>FVP is run by a Board of trustees who have overall responsibility and accountability for ensuring the charity runs according to the legal framework it was set up for.</p>	<p>New volunteering opportunities leading to increased numbers volunteering and gaining new skills</p> <p>Improved Staff capacity</p>	<p>FVP has a workforce in place with capacity to deliver on other aspects of the business plan</p> <p>Increased confidence in ability to return to work/ volunteering after long periods as a carer.</p>

<p>Staff and volunteers are responsible for the daily running of the charity</p> <p>The trustee board has several new members and with this they are bringing fresh ideas, links to the wider community and a renewed commitment to take FVP forwards.</p>	<p>Clear Workforce planning</p> <p>Increased number of parent carers either working with us as volunteers, or looking for volunteering opportunities</p> <p>Increased number of parent carers taking up paid roles as parent representatives.</p>	
<p><b>Information Technology</b></p> <p>FVP will continue to utilise virtual working through our social media platforms</p> <p>will continue to record workshop sessions and ensure they are accessible throughout social media sites to make them more accessible on virtual platforms i.e. YouTube</p> <p>Develop virtual training for parents and carers</p> <p>Look at an on line schools offer</p> <p>Update the website</p>	<p>People will report easy access to FVP media platforms</p> <p>Increased use of FVP YouTube channel to facilitate wider signposting and information sharing</p>	<p>More parent carers accessing what FVP has to offer via online systems, thus FVP make best use of Information technology to facilitate an inclusive way of working that is cost effective and maximises engagement</p> <p>To keep social media platforms and the website live and current.</p>

Outcomes Grid

The next five years will be set out in the forward plan at the end of this report.

For FVP the social impact of the charity relates to activities that result in:

- Improved access to services for children/ young people with disabilities and additional needs.
- Increased parent participation which can include involvement, engagement, information sharing.
- Increased participation from a more diverse group of parent carers.
- Increased empowerment of parent carers leading to more involvement in the services accessed by their children and increased confidence.
- Increase community cohesion and working together.
- Improved relationships between parents and settings.

## Measuring Social Impact – 2023 to 2024

To demonstrate social impact of the charity a range of qualitative and quantitative data is gathered. This is used to measure the outcomes and impact of the work of the charity; Some of the methods include activity/ event feedback, survey results, quotes, numbers in attendance, demographic information, changes to services for children/ young people with disabilities as shown in responses to the Topics of Importance. This past year has also seen FVP continue the changed delivery model, working both face-to-face and online.

1. FVP has seen a new team of parent carers join the Parent Carer Forum (PCF) as parent carer representatives working under term time contracts. This has facilitated an increase in participation and engagement.
2. Through a range of meetings, events, online activities, Facebook Polls and Discussions, 310 parent/carers including 18 fathers have participated in 46 sessions. These provided signposting, support, the opportunity to build new relationships and connections and increase social inclusion.
3. Parent carers, including those from seldom heard groups and local residents fed back that the provision of hampers helped made the festive period more enjoyable and manageable. These worked well as an addition to face-to-face activities. Through the activities 2569 people have benefitted in some way.
4. 53 caravan bookings were secured in the past year leading to 171 people benefitting from a short break. Those who have used the caravan have reported improved wellbeing.
5. There has been a significant drop in use of the centre with 138 sessions equating to 330 hours, compared to the previous financial year where 509 sessions were held, equating to 1281 of activity hours. The usage has enabled increase social inclusion and improved mental health and wellbeing.
6. Signposting support has been offered to 206 parent carers for accessing information relating to SEND services, benefits, mental health services and other areas.
7. Improved communication and information from between the LA and parent carers have occurred as a result of the introduction of the Topics of Importance; the SEND newsletter continues to be produced for parent carers who want to receive it, ongoing EHCp documentation, practices and processes are reviewed in the EHCp improvement group, Parent Participation is actively encouraged at a strategic level using a hybrid method of engagement and participation, provision of food support and other activities there has been a marked increase in overall numbers accessing FVP.

Type of Session	21/22	22/23	23/24	21/22	22/23	23/24	21/22	22/23	23/24
EPP	1	0	0	9	0	0	10	0	0
CB	1	0	0	9	0	0	6	0	0
Wellbeing Training	4	5	1	20	30	12	17	16	5
Parent Carer Hub	4	5	5	16	24	72	8	13	21
Themed Workshops (Open Forum)	6	2	1	51	8	4.5	78	10	6
CETR	61	69	30	305	1035	0	61	69	30
Information Stands	15	17	14	90	92	0	727	680	905
Virtual Sessions (SHCF)	11	6	1	60.5	28	6	149	55	4
CDC Sessions	0	1	8	0	5	7	0	20	132
Focus Groups	6	6	11	16.5	12	52	21	14	67
Schools Offer	2	7	30	11	28	174	5	41	162
Virtual (Coffee/ Breakfast/ Lunch) Meeting	9	0	8	51.5	8	26.5	38	0	18
Conference	0	1	1	0	0	16	0	95	57
Facebook Polls	26		1	0	0	0	399		57
Surveys	12	16	8	0	0	0	267	515	351
Family Based Trips/ Activities	18	93	70	0	Unknown	0	917	2584	2569
Strategic Meetings	296	136	180	645	744	445.5	8	7	9
Volunteer Support	3	4	2	34	367	148	7	42	16
Hall Hire	138	509	557	330	3843	3581.6	574	Unknown	1500
Caravan Hire	70	64	53	0	Unknown	159	117	230	171
<b>TOTALS</b>	<b>683</b>	<b>941</b>	<b>981</b>	<b>1648.5</b>	<b>6224</b>	<b>4704.1</b>	<b>3409</b>	<b>4391</b>	<b>6080</b>

#### Session and Beneficiary Comparison 2021 to 2024

Working face-to-face again and having the centre and caravans until November 2023 open for use has increased access to support and a clear decrease in social isolation.

## Information

1. Training sessions in understanding mental health and wellbeing and understanding behaviour have provided parent carers/ family members with basic skills to self-manage and gain resilience in their caring role.
2. Information stands at various locations across the city, to enable direct contact with FVP. This enables literature to be handed out to members of the public, parent carers to have someone to talk to for signposting. 14 stands and 905 people spoken to.
3. Online and face-to-face sessions based on specific SEND topics have been delivered, supported by BSL interpreters and made available online to increase their reach. The use of interpreters increased accessibility. The topics provided information and support in navigating the SEND system.
4. The ongoing development of an e-news to share messages and opportunities to engage. There are currently over 526 subscribers.
5. Use of social media to enable a wider and more diverse group of beneficiaries to receive information and participate in service change. There has been a marked increase in the audience for all platforms which has increased reach.

## Advocacy (Collective)

1. Online participation sessions, face to face activities and the running of on-line surveys to facilitate parent carers raising concerns/ issues and sharing views with relevant organisations such as Local Authority Commissioning (Social Care and Education) via Topics of Importance.
2. Parent representation enabling parent carers to share concerns and views about disability services with education and social care commissioners.

## Support

1. The provision of tickets and passes introduced in 2020/ 2021 has continued but linked more directly to completion of participation activities. There have also been far more trips and activities included enabling access to areas SEND families in particular may struggle to go to; support here is in the form of coordinating the activities and providing coaches etc.
2. Delivery of festive hampers including food, vouchers and gifts has provided support whereby households can cover the cost of their utilities without having to make a heat or eat choice.
3. A community café have enabled local residents, parent carers and seldom heard community members to have support through peer to peer engagement, a safe space to talk about what is impacting their lives, build friendships, have a warm place to meet and receive wherever possible food provisions.

## Advice

1. Parent Carer Hub sessions have provided direct access to professionals from Education, Carers Support and SEND Partnership.
2. Signposting to a range of services/ support systems/ SEND professionals has occurred for 209 parent carers.

## Community Premises

1. Community engagement has continued to take place using the community café and a number of face-to-face community sessions.

## **Achievements and Performance**

### Family Activities & Parent Carer/ Community Support

#### **Family Activity Opportunities**

- Trips and Activities
  - Parent carers were provided the opportunity to take part in a range of local activities and coach trips. (AT – 1<sup>st</sup> July – September)
  - Some of these were also accessed by parent carers from the Aiming High Group and Seldom Heard Community leaders and their families which led to an increase in diversity and engagement from more families with CYP with very complex health needs.
- Survey Response Vouchers
  - Vouchers are often used as an incentive for completion of surveys, as these are proven to increase participation. Parent carers have also reported valuing the recognition of their participation.
  - Vouchers are available to access Bowling, Activity World, Sacrewell Farm and Key Theatre.
- Parent Carer/ Community Support
  - FVP have also been providing phone line/ email signposting/ face to face support for a range of subjects including; how the move from DLA to PIP works through to how to make a complaint about SEND provision or what would be the best primary school to apply to.
  - Wellbeing, emotional support and information sessions with local services resulted in parent carers receiving direct support.

### Participation and Engagement

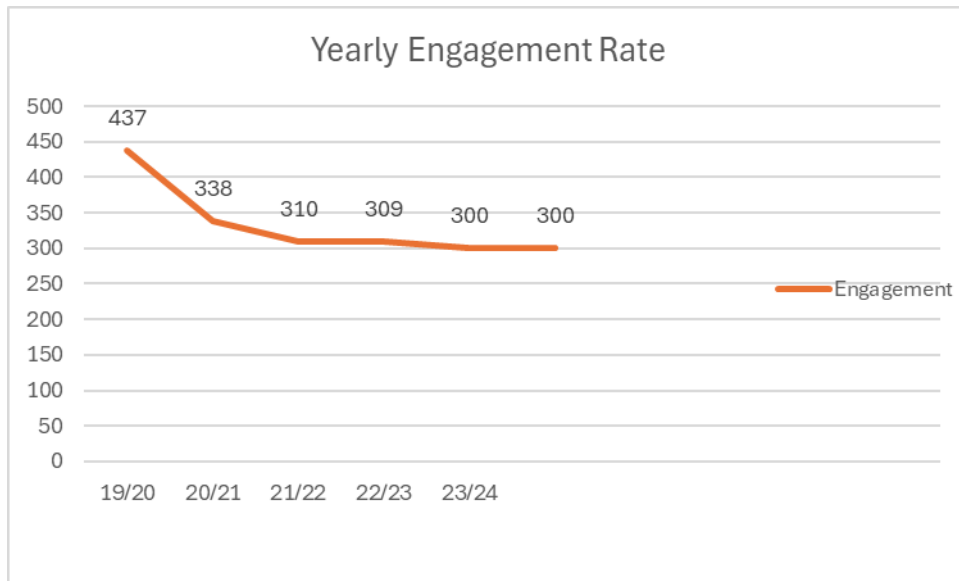
Attendance at a range of participation and engagement sessions has increased this year. The following provides a snapshot of engagements levels:

- Parent Carer Hub – a total of 21 parent carers attended
- 1 Wellbeing Workshops a total of 5 parent carers attended
- 1 Themed Workshops - a total of 6 parent carers attended
- 11 Focus Groups - a total of 67 parent carers attended
- 30 School Based Meetings - a total of 162 parent carers attended

### Parent Participation

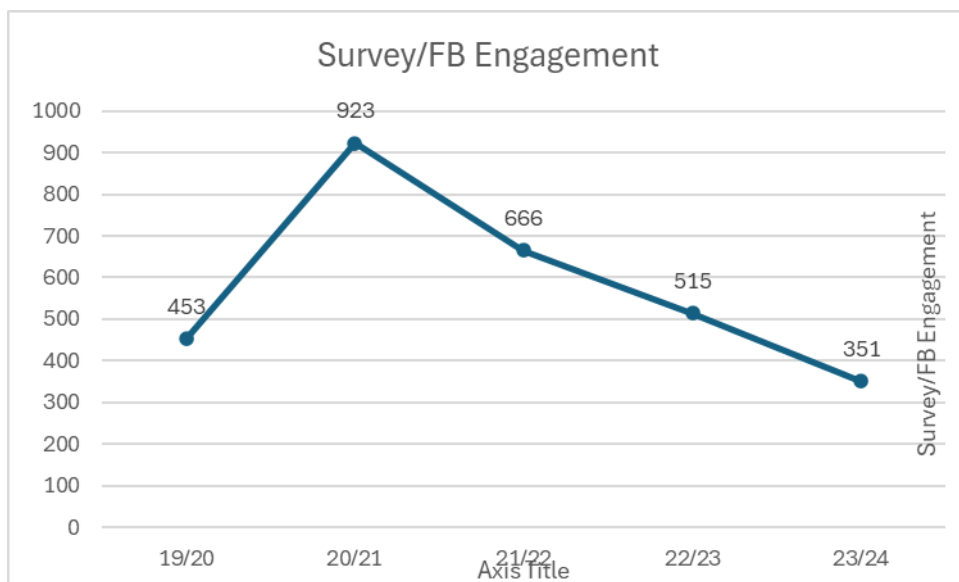
The financial reporting period this relates to, 2023 to 2024, has seen for FVP the level of recorded individual participation dip again, as can be seen in Fi.?, although the drop is

starting to slow down. However what is different is an increase in the number of parent carers re-engaging.



**Overall Engagement Rate**

Online engagement rates have fluctuated across years. In the past year there have been no FB polls used due to having new staff who are not so adept at this function for participation purposes, however the numbers are still relatively high due to the popularity and marketing of the small scale surveys used and in particular the annual survey.



**Engagement via surveys and FB**

There has been continued investment by FVP in helping parent carers understand their “right” to be heard on a personal and collective level in the services accessed by their children and young people especially at face-to-face sessions in educational settings.

Underpinning the Children and Families Act 2014 are the Section 19 Principles whereby Local Authorities have a duty to pay due regard to the views, wishes and feelings of children and young people with SEND and those of their parents and carers and support them to participate fully. The work conducted by FVP has been shared with the Local Authority to help them understand what the views and feelings of parent carers are. This was partly achieved through an ongoing use of themed sessions and newly introduced coffee and signposting sessions.

## Parent Representation

Nine parent carers acting as representatives have attended 180 strategic meetings investing 316.5 hours in terms of administration, travel time and actual meeting attendance.

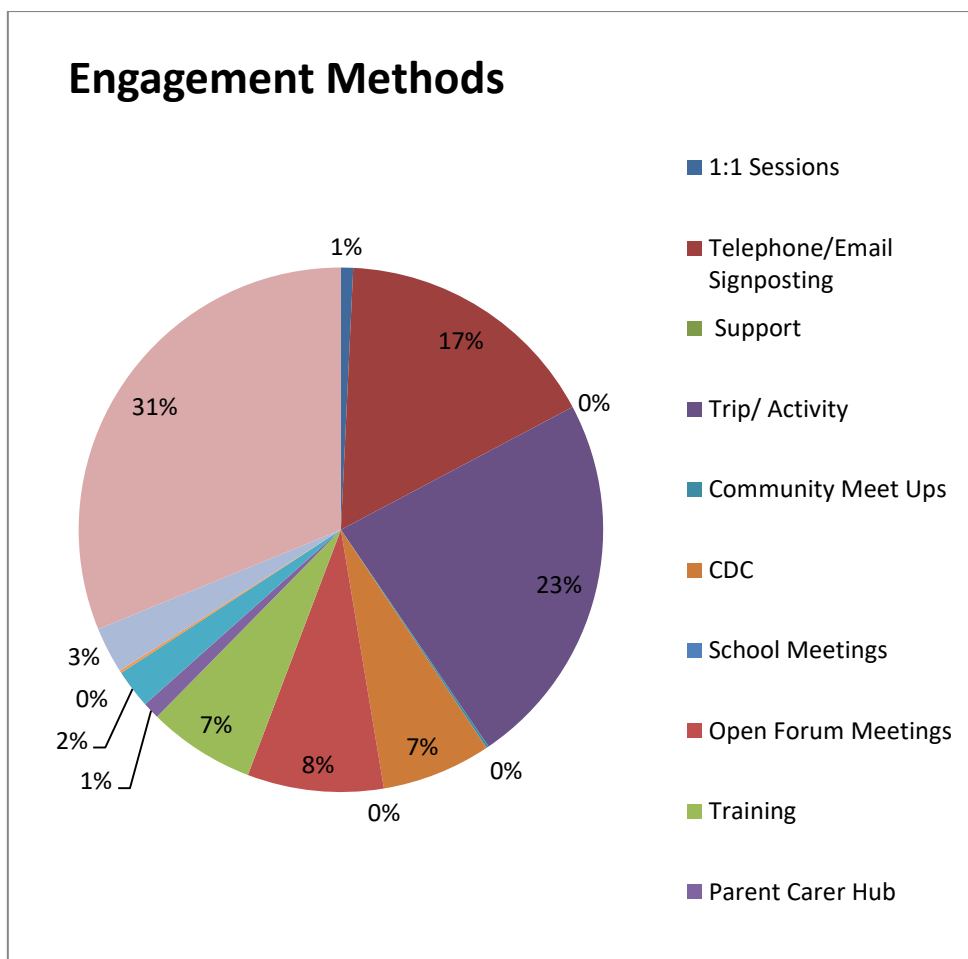
## Preferred Parent Participations Method

FVP have seen 332 parent carers, some of whom have participated more than once.

We have engaged with the following ethnicities over the last 3 years, which demonstrates how representative the organisation and community are.

Category	Ethnicity			
	Adult		23/24 (Re-engaged)	23/24 (New)
	21/22	22/23		
White British	220	87	73	71
Gypsy or Irish Traveller	2	0	2	1
Roma	0	1	1	0
Any Other White Background	20	14	0	0
White and Black Caribbean	0	0	0	0
White and Black African	0	0	0	1
White and Asian	0	0	0	0
Any Other Mixed or Multiple Ethnic Background	4	1	1	2
Indian	8	5	3	4
Pakistani	12	12	13	18
Bangladeshi	0	1	0	0
Chinese	0	2	0	1
Any Other Asian Background	0	0	10	2
African	11	10	7	5
Caribbean	1	0	1	0
Black British	0	0	0	3
Any Other Black or Caribbean Background	0	0	0	0
Arab	0	2	1	1
Any Other Ethnic Group	7	0	1	2
Rather Not Say	1	1	0	0
Unknown	13	22	3	85





### **CHARITY ASSETS (Premises)**

The Goldhay Centre is more than a Community Centre and Offices for FVP; it is a community provision under the terms of the community asset transfer lease. Part of the requirement of taking on the Goldhay Centre under asset transfer was to make it available to local residents and run it as a community centre.

As well as the groups who have hired the centre in the past and those currently hiring the centre, FVP also use the community hall for community activities. FVP have provided a range of sessions which have more recently included a community café and warm hub. The community café was well received and those who attended reported feeling less isolated. The centre is also used to provide events for community leaders and local seldom heard parent carers, as well as being available to hire by other groups and organisations.

The only separation between the community centre side and the FVP office side is the internal dividing door; there is no separation of heating, water, plumbing, electrics, fire safety, utility supply etc. It is impossible to ascertain the costs for the centre as a separate entity and expenditure relates to the building as a whole.

In September 2023, a report and survey were carried out by the LA on the community building in light of new regulations. This report highlighted more works and repairs that were required for the community centre to remain a public building. The cost to upgrade the roof and wiring as well as fireproofing have led to the need to re-evaluate the benefits of remaining responsible for this building as over £300k would be needed over the next 5 years.

In addition, the rising cost of living has meant many groups can no longer rent sessions and the bookings since November 2023 started to decrease; by March 2024 most regular bookings having been cancelled beyond 1<sup>st</sup> April 2024. This meant there would be no sustainability. With new building regulations especially in relation to reaching an energy rating of 'C' as part of central governments Net Zero targets we do not have the money to continue to run a community centre so we asked the LA if we could return the building to them.

The LA have agreed not only to take back the lease but as they value us and the benefit of a PCF so much, they are willing to find us suitable premises with the LA area to ensure the core PCF work is continued.

The decision has been made by our trustee board to give up the lease for the community centre and concentrate on their core role as a PCF.

### **Overall Usage**

Over time there have always been more regular bookings than private bookings. However for 2023 to 2024 hire has significantly decreased with the centre running at 7.25% capacity.

Due to the financial crisis, several users of the Centre have had their funding cut, therefore they are unable to rent the Hall. This has had a significant negative impact on our income.

### **Parent Forum Opportunities**

1. Having the premises has continued to make the forum more accessible to parent carers and provides FVP with more in-house participation and training opportunities. Now it is more established, more effort has gone into the promotion of the activities, training and participation opportunities in the centre leading to an increase in regular engagement with parent/carers at the centre and a decrease in external venue hire costs.
2. FVP staff, parent representatives and parent volunteers are also provided with space and office use to enable them to carry out their duties.
3. Parent carers can attend meetings at the office and seek information, signposting and face to face contact more easily.

### **Community Opportunities**

The centre provides the opportunity for a range of providers of services to access a venue from which they can meet the needs of local residents. It has been beneficial to the local community to be able to set up a new service provided by FVP. Residents say the centre activities enable them to make friends, seek support and feel less lonely.

## **Financial Review**

### **Reserves Statement**

The trustees are continuously working to establish sustainability and good governance for the charity and have developed various policies and procedures including a reserves policy to facilitate this. The policy establishes how reserves levels are set and how these relate to unrestricted funds and such levels will be managed.

The trustees have historically proposed to maintain the charity's free reserves at a level which is at least equivalent to six months operational expenditure and three months as a minimum. This year the reserves have decreased to approximately 6 months equivalent of annual running costs, due to a number of factors including a general increase charity running costs. This policy will require review as the staffing structure changes and operational matters go through further change due to charity growth. It will be an ongoing priority of the Trustees to re-look at this as part of the wider business planning focus.

### **Principle Source of Income**

The principle source of income for FVP remains grant funding which is linked to predefined outcomes. Grants have been allocated by Contact behalf of The Department for Education (DfE) Peterborough City Council (PCC) on behalf of the Integrated Care Board (ICB) and PCC PCVS and The National Lottery. The total grant income equates to 83% of the charity income which is up slightly down from 22/23 by 2%. Income from sources such as hire from assets (rental) and donations/ fundraising (public) has decreased slightly and will be a focus going forwards to try and move further away from reliance on grants.

Much work has also been taking place to secure other less restrictive grant funding that can be used to build in charity sustainability and enable the charity to explore other unrestricted income streams.

### **Fundraising/ Donations/ Legacies/ Consultancy (Public)**

Donations and fundraising have netted £7,700.09 which is a 59% decrease from the previous year. This is an area the Trustees felt to be important to focus in the last Trustees Annual Report. This year, FVP did not secure income from fees for work (consultancy).

Any fundraising is managed under an ethical fundraising policy held by the CIO and as such work relating to joint fundraising falls under this. To demonstrate best practice, the CIO is also self-registered with the Fundraising Regulator.

### **Expenditure**

The majority of the charity expenditure is from restricted funds from grants paid in year. 90% of overall expenditure was from restricted funds. This is down by 8% from 22/23. The majority of core costs fall into restricted funds expenditure with most staffing covered under restricted funds.

The majority of grant expenditure is set against pre-defined outcomes with specific outputs and measured against an outcomes matrix. The DfE grant although for a small amount is a

receipted grant, where every receipt has to be allocated and spending has to be strictly kept within predefined budget. The outcomes match the objects of the charity. Expenditure has been on providing families with access to information, advocacy, support and advice; therefore meeting the objects of the charity.

### **Further Details**

1. Staffing costs have increased to 45% of overall expenditure for the charity. This is up from 37% in 22/23.
2. No employee is remunerated at £60,000 or over.
3. The majority of those employed have been parent carers who volunteer extra time to the charity over their contracted hours of employment. All costs relating to employment are linked to grants.

### Accounts Preparation

In line with the charity's constitution and charity accounting guidelines as defined in CC15d 'charity reporting and accounting: the essentials' the accounts are prepared under an accruals system and the Trustees have taken the decision to secure the services of a suitably qualified accountant to conduct the accounts returns.

### **Trustee Statement**

Because of the financial crisis, it has been felt that the charity still finds itself in unprecedented times as a result of the subsequent and ongoing cost of living crisis, so the Trustees have decided to again produce a more in-depth statement detailing the impact on the charity and its beneficiaries. They strive to keep charity services going, protect the assets to ensure their ongoing availability for charity beneficiaries and work to support the beneficiaries in any ways the trustees feel appropriate has been taken time, effort, resources and staffing in difficult economic circumstances.

Again at the time of writing this annual report, the charity still finds itself in uncertain times, due to a number of factors; climate change/ crisis, rising cost of living, the increase in minimum wage, increasing inflation rate to name a few. The need of the charity beneficiaries is changing, and in some areas increasing, with wider societal concerns impacting on individual mental health and wellbeing. This has all been reflected in the next five year strategy and plan for the charity as a result.

### Services

Services have continued using hybrid and face-to-face methods based on demand. There has been a return to trips and activities which have been well received with requests for more of the same. Food support is still required as a result of the economic impact of the rising cost of living. The community café has seen a marked increase in attendance with some weeks 30 people popping in for hot drink and food if available.

### Assets

There have been greatly increased costs for utilities and we have continued with ongoing repairs to the Centre as needed. Additionally, we replaced the Playhouse

### Staff and Volunteers

It has now become more common for FVP team members to split their time between remote and office based working, and the flexibility to manage this has been enabled the charity to work better in some areas. The team report feeling supported with their needs being balanced well with the needs of the charity. New employees are furnished with a laptop shortly after their start date to enable them to work from home and hot desk at the office. The office layout has also been changed to enable hot desking and better, safer sharing of the space available.

FVP takes full account of Equality, Diversity and Inclusion (EDI) when supporting the team, enabling them to do their roles to the best of their abilities. EDI as well as Health and Safety (H&S) are considered at all levels of the charity, which is important to facilitate the growing team and enable them to continue meeting the needs of the charity beneficiaries.

### Financial Stability

The financial stability of FVP is still an ongoing concern, with most grant funds still being on a year only basis, and revenue from the charity assets being below what would be required to cover their basic running costs. Much work has taken place throughout the past year to stabilise the accounts, move towards generating more revenue from the assets and encourage public donations and team fundraising.

Our Lottery funding ended March 2024, although we were allowed to carry over an underspend to 30<sup>th</sup> June 2024. Although this has helped in the interim it is still short term. Longer term funding, from other sources including assets would enable the charity to have time to work on developing growth and sustainability plans.

### Beneficiaries

FVP have continued to gather information from parent carers as to how they are managing, what factors are impacting their lives and how they are coping in relation to their caring role. Key themes identified impacting families are:

1. Poor mental health and wellbeing including a feeling of isolation.
2. Financial worries.
3. Increased difficulty in identify sources of support
4. Difficulty finding information in relation to SEND and particular concerns around PfA.

## **Forward Plan**

After careful risk assessment and completion of a SWOT analysis which included input from various stakeholders the following areas have been prioritised with five areas highlighted and three others woven throughout:



### **Priority One - Parents Forum/ SEND**

1. Continuing to support and deliver help advice and guidance around SEND. In particular ensuring co-production and the implementation of the priorities and action plans within the SEND agenda and all other associated strategies.
2. Ensuring parent carers are included, heard and enabled to participate in a way which meets their individual needs and requirements.

### **Priority Two - Community Provision:**

1. Goldhay community centre is used to provide families with training and support opportunities, food hubs, social events and activities that enable a diverse range of seldom heard groups to come together and celebrate various aspects of their lives.
2. This has enabled the community space to be utilised for local residents and the wider community to access services and support and allow participation in the wider community, thus decreasing isolation amongst specific groups or those impacted by caring for a child/ young person.

### **Priority Three- Activities**

1. FVP provide coach trips, hire local activity places, hold themed sessions and provide family based activities at the community centre, across Peterborough and to further destinations.
2. FVP know that being able to access affordable and/ or free trips and activities leads to improved wellbeing for SEND families.

### **Priority Four - Work Force and Trustee Board Development:**

1. FVP is run by a Board of trustees who have overall responsibility and accountability for ensuring the charity runs according to the legal framework it was set up for.
2. Staff and volunteers are responsible for the daily running of the.
3. The trustee board has several new members and with this they are bringing fresh ideas, links to the wider community and a renewed commitment to take FVP forwards.

**Priority Five - Information Technology:**

1. FVP has always used virtual platforms such as their Website, Facebook, Twitter YouTube and WhatsApp to reach a wider audience, however much of the engagement work of FVP delivered focussed on face to face work with Parent Carers, their families and the wider community.
2. What covid 19 and the lockdown has shown is that a move to virtual work can be as beneficial as face to face is cost effective and has led to greater engagement from a wider and more diverse cohort of people.