
FVP Interim Report

October to
December

FVP Parent Representatives

Introduction

This is the third quarter grant monitoring report for the financial year period 2022 to 2023. As with all previous reports in this financial year and the last the reporting format has been changed to demonstrate full year reporting requirements. The report is designed to demonstrate work conducted against different funding streams. The report will be set out under the following headings:

- CAMHs Work
- SEND Data and Schools Work
- Seldom Heard Communities
- Co-production and Change

As with previous reports there is cross over between the areas detailed above and some work easily falls in more than one theme so the report may reflect this. There has also again been a focus on the impact on the cost of living crisis the country has been facing as this is where parent carers are seeking support. The nature of the work of the PCF in particular is that it is intended to be parent carer led so if parent carers are focussing on daily living then that is what the PCF will report.

FVP have also seen some organisational change due to the needs of the workforce changing, many of whom are themselves parent carers which has led to increased capacity concerns for a small team. Work has commenced to increase the parent rep team in particular and look to develop a slightly different working structure to afford some stability and consistency. This is also happening against a backdrop of LA/ Health changes which makes maintaining key relationships between the PCF and Strategic Partners vital to ensure that SEND really does remain everybody's business and coproduction doesn't fall beside the wayside. Pressure in the system as a whole makes it harder work without any issues and this has been acknowledged on all sides.

FVP has continued to utilise a hybrid model of working to meet the needs of the PCF, wider charity and various beneficiaries. The use of virtual working, face to face working, allocation of tickets & passes, trips & activities and schools engagement have all enabled wider parent participation. This has also been possible through grant funding from Peterborough City Council, Cambridgeshire and Peterborough Clinical Commissioning Group (CPCCG), The Department for Education (DfE) and The National Lottery (tNL) amongst other funding sources.

Since the last quarterly report FVP have seen engagement from 6 Fathers, 46 Mothers, who are new to FVP, on an individual basis where details are known whose ethnicity ranges from White British to Pakistani British, African and/ or Central & Eastern European. Further participation has occurred across a range of areas from online zoom sessions, through completion of surveys. Wider engagement across 42 opportunities enabled 544 adults and 103 children people to get involved at some level.

Participation/Engagement/Involvement October to December 2022

Headlines

- 1) 82 new or returning known parents in total have been involved at some level (due to changes in data gathering methods it is not possible to separate data further to include their CYP.
- 2) 51 parent carers have participated across 2 online surveys.
- 3) Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
 - a) Autism Spectrum Disorder
 - b) Attention Deficit and Hyperactivity Disorder
 - c) On the Neurodevelopmental Diagnostic Pathway
 - d) Varying degrees of Learning Disabilities and Difficulties
 - e) Global Developmental Delay
 - f) Genetic Disorders
 - g) Downs Syndrome
 - h) Cerebral Palsy
 - i) Spina Bifida
 - j) Achondroplasia
 - k) Social, Emotional and Mental Health Needs, including Eating Disorders and Anxiety Disorders.
- 4) 6 new fathers have been involved.
- 5) Parent carers reported the ages of their children/ young people as between 2 to 25.
- 6) Participation methods used included; online surveys, seldom heard group sessions, one-to-one telephone or email engagement, face to face contact via trips/ activities and parent representation.
- 7) Evidence is both qualitative and quantitative in nature.
- 8) Ethnicity has been self-reported as; White British, Asian, Gambian, Lithuanian, Polish, African, Portuguese, Latvia, Indian, Pakistani and White European.

CAMHs Transformation/ Parent Carer Mental Wellbeing/ Online Support

Introduction

Some of this work is funded via more than one source especially where the grants have similar outcomes. The funding split can include one grant covering the cost of items for example and another grant covering the cost of staffing and volunteers to administer the work.

The mental wellbeing/ resilience building workshop has been run again, with two sessions taking place attended by 5 new parent carers. The sessions covered improving sleep and self-care to improve mental wellbeing. Plans are in place to set up again the SENDIASS and EPS parent carer hubs to commence in the next quarter.

Food Support

Food support continues to be an identified need, with support being provided to 4 new households:

Adults	Children (Total)	Children with SEND
21	34	10

Fig.1 Numbers of adults and children receiving food

Of the households where data is held over 63% report having an adult with a disability most of which relate to mental health.

Where provided the following are reasons for seeking support:

<i>Due to the price of food scoring sky high feel like going round in circles and struggling at this moment in time getting payed monthly after weekly is has a Hugh affect making it hard to afford food</i>
<i>Had hard year in house some time take Stoke seizures after have my baby at 29 weeks high blood pressure pre-eclampsia , fall behind bills to be paid</i>
<i>Just had £300 stolen we had saved for Christmas.</i>
<i>My autistic son never stops eating and is never full. I am struggling to keep enough food in for him with the rising costs of everything</i>
<i>Cost of living. Boiler has broken so using more electric on little fan heaters</i>
<i>we are a family with low income,even though we are on universal credit, it all went on bills</i>
<i>due to increased housing costs</i>
<i>We are from Ukraine and do not have any payments from the government yet</i>
<i>Struggling</i>
<i>i am currently pregnant with a couple of weeks left till baby arrives I am facing difficulties with the cost of living having gone up drastically. I am struggling paying towards life costs especially gas and electric. All my pay goes on rent and priority bills. I work part time and I am classed as disabled with income from personal independence payment support. My main support needed is baby's essitanil items, and help with children's itesms, food and gas.</i>

I have got my big bits all sorted from a baby bank in Ely but as it's far away I'm unable to travel there again for things I need.

I've searched market place and haven't come across anything cheap or in my budget so far. baby essential items, nappies, wipes, milk creams, bath washes etc or storage drawers or units or anything suitable for new born baby.

Getting universal credit and not have money to buy food not enough

Coming through from such comments is the impact on mental wellbeing that is happening through parenting, providing care over and above the parenting, trying to support the household in general and meeting the extra costs often associated with having a disability. It is recognised that everyone is currently being affected by the cost of living but for FVP it is important to also raise this concern as it costs more to raise a child with a disability under 'normal circumstances' so families as a result of the cost of living are being doubly impacted.

Virtual Workshops

2 virtual workshop held in this quarter directly related to this funded area has taken place. The table below shows which workshops took place and the attendance rates.

Funding	CCG/ Training	Date	Number of Adults	Purpose
ICB	Mental Wellbeing (Improving sleep, feeling calmer more easily, with HeartMath)	18/10/22	2	Mental wellbeing coaching
ICB	Mental Wellbeing(Looking after you ,a Focus on Self Care, Using Heart Math)	22/11/22	3	Mental wellbeing coaching

Fig. 2 Attendance Information

CETR Attendance

There have been 21 CETR sessions in this quarter covered by 3 Experts by Experience (EbE). October was the busiest month with 11 sessions included a couple of days with more than one at the same time.

All admin support for the workshops and CETR's is conducted by the office manager who also oversees all other work funded by the grant programme. The office manager role is funded directly by this grant programme. The costs with the workshops relate to trainers fees, administration and any parent carer expenses. Other grant programmes may pay for staff time of other team members involved.

Signposting/ Support Requests

There have been 22 contacts recorded where parent carers new to FVP have requested signposting. As with the previous quarter the themes remain the same: how to access an EHCp, support to manage behaviours that challenge, support with food, housing concerns and maintaining a good level of education, resilience/ emotional wellbeing and PfA.

Education/ Health or Social Care Advice. I need my son to be assessed as the schools he is been to are not helpful. i need help to try and understand what is going on with my child, why is he not able to be in school and behave, concentrate, focus, have a normal conversation, play with other children, etc I want my son to have support in school and outside school

Has a 16 yr old daughter diagnosed with Asd who hasn't received an education for over 2 years now, has been advised she will not be receiving any even though the law states every child has to have one until 18 yrs, concerned for her daughter and upset that the responsibility falls on her, would like advice please.

My son is on the send register, he is in year 6. We are currently going through the process of at EHC plan but we only had draught meeting last week.
I'm really struggling on deciding on a secondary school that will be best for him and was wondering if I could talk to someone to get some advice on it? Please

Mum is struggling with her 6 yr old son who has a diagnosis of Autism he is becoming violent and is needing advice /signposting with regards to respite options available also advice with toilet training and any activities/trips available - (I have emailed a welcome letter that includes a link for "Your say" whereby completing certain surveys, activity passes can be issued)

Amber, 4 months old, female, medical and health Education/ Health or Social Care Advice Maybe support after surgery

(male, 12, autistic) (male, 10, young carer) (female, 7, autistic, possible ADHD, developmental delay, home educated, in need of EHCP for specialist education) Education/ Health or Social Care Advice Need help to apply for DLA and EHCP

looking at options for respite care and breaks away. Has a (17 or 19 year old) son who needs a hoist and they are finding it more difficult to find places that can accept them all or for him to have a few days away while the parents have some quality time with their younger children. They have been to places with adaptations before, like caravans, but often the hoists are more like ones that old people use to help themselves rather than parents helping a teen.

6 year old son has ECHP and attends mainstream school. At recent SCHP review school advised they will not be able to provide for his needs much longer and they need to look at getting him placed elsewhere. They have reached out to a few schools, such as Heltwate, to be told they cannot even speak with the school for another year as there is just so much interest and such a large waiting list. They do not know what else to do.

Son reaching adulthood and mum worried about what happens next re care. Been told if she wants to continue having a say in his care she will need a deputyship, but she wants to check this is the case and that nothing further will be needed to be actioned by her. Is very concerned someone else who does not know her son will step in and take over. Told her about the SeNi online meeting next week but she hates zoom and technology, but said if uploaded to youtube afterwards she would like to watch then.

he family of a child with an EHCP have asked me to help them to find out more about specialist provision in the city. Mum's English is limited and she struggles to engage with any support groups due to lack of confidence/community access. I have contacted SENDIASS on her behalf and await their response, but I know they are struggling with capacity. Is anyone within FV that can help to support this family please?

10 years old Education/ Health or Social Care Advice We need an advise on some of health issues around his autism

Son, age 11. Has complex medical needs, (had a kidney transplant, has diabetes, visually and hearing impaired). Moved from cardiff where was doing well, despite school attendance being as low as 15% at one stage, due to home school visits and support. Took Peterborough 4 months to create draft EHCP after receiving it from Cardiff, but it was not correct, and did not offer the right support. Had issues withand son ended up in Beeches which is not offering him the correct care or support (mum being told to attend every lunch to see to his medical needs but cannot and he has ended up in hospital due to this). Mum understandably very fed up.

Can you please help me source larger nappies for my special needs son ? He is nearly 9 has autism and a global developmental delay and is full time in nappies . I have tired a few place on line but can't find anything suitable . I would be grateful for any advice thank you

.... is a parent carer of a 4 yr old and is asking for help/support in filling out the disability living allowance forms she would like a phone call rather than email please

.....is a 15 years old girl whop currently attends Arthur Mellows village collage (year 11). She has been struggling in the school since year 9, her attendance is very low. She struggles with mental health issues, has severe anxiety and also struggles with hear learning (2 years beind in 2019), suspected ADHD. School is not supportive at all, mum is at her wit's end. Whenattends school she struggles a lot and they send her home but if she doesn't attend they are threathening with fines. Senco told mum 'we are not a baby sitting service' and refuse to provide any support. Mum is at her wits end, doesn't know what to do and how she can help her daughter. is also a young carer for her sister with autism, who currently attend Medehamstede.
..... boy 18 Help with bus to college If you ever get any gluten or lactose free food please thank you
To see what benefits and a short break can get Male age 15
...has Autism he is 5yr Thorpe Primary School Education/ Health or Social Care Advice Advice/guidance
Adhd autism Food support, any support offered
Education/ Health or Social Care Advice Provide me information about work for my son
.... has downs and receives money for 2 carers plus respite. They have only recently started him on respite, so are a little unsure what is available etc, but also they want to check the direct payments his carer's should be receiving as they seem to be getting a lot of money paid into his account, but the carers are still on £12.60 an hour which they've been on for a couple of years and they're not sure if they should have had a pay rise by now. I have messaged PCVS to see if they can confirm any rates, but if you happen to know please can you call her and let her know, plus maybe speak to her about respite as well? Thanks
.....called asking for food support help I emailed the food support link.

Fig. 3 Parent Carer Concerns

Of the parent carers requesting support ethnicity (self-declared) places White British overall slightly in the minority. This would appear to show that parent carers from seldom heard communities are trusting FVP more as a source of signposting and support, and are more willing to raise concerns and issues.

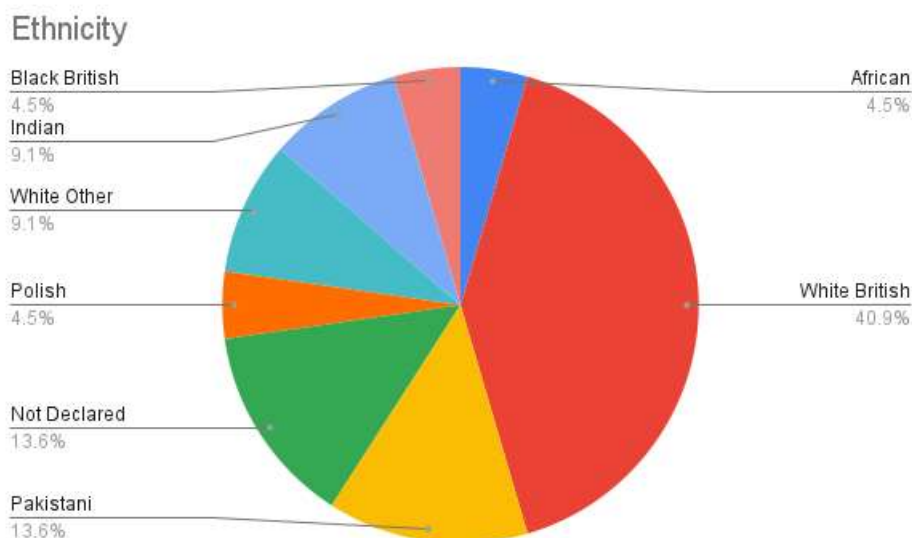


Fig. 4 Ethnicity of parents seeking support

Wellbeing and Family Based Activities

Funding	Family Based Event/Activity	Date	No. of Adults	No. of Children	Purpose/ Outcome
DEFRA	Litter Pick	1/10/22	6		Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	5/10/22	9		Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	12/10/22	11		Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	19/10/22	19		Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	26/10/22	13	12	Decreasing isolation, community cohesion, mental well-being
Lottery	Lush Event	26/10/22	7	17	Decreasing isolation, community cohesion, mental well-being
PCC	Halloween Goody Bags	31/10/22	7		Decreasing isolation, community cohesion, mental well-being
PCC	Halloween Party	28/10/22	16	36	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	2/11/22	16		Decreasing isolation, community cohesion, mental well-being
DEFRA	Litter Pick & Meal	5/11/22	5		Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	9/11/22	22		Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	16/11/22	24		Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	21/11/22	3	1	Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	23/11/22	7	4	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	23/11/22	25		Decreasing isolation, community cohesion, mental well-being
Lottery	Carers Right Day	24/11/22	10		Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	26/11/22	4	4	Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	28/11/22	7	7	Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	30/11/22	7	4	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	30/11/22	21		Decreasing isolation, community cohesion, mental well-being
DEFRA	Litter Pick	03/12/2022	8	4	Decreasing isolation, community cohesion, mental well-being

PCC	Warm hub	05/12/2022	5	4	Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	07/12/2022	19	3	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	07/12/2022	26		Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	10/12/22	25	16	Decreasing isolation, community cohesion, mental well-being
PCC	Warm hub	12/12/22	9	3	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	14/12/22	35		Decreasing isolation, community cohesion, mental well-being
PCC/ICB	Christmas party	20/12/2022	46	68	Decreasing isolation, community cohesion, mental well-being
PCC/Longueville	Christmas hampers	19/12/22-23/12/22	89		Decreasing isolation, community cohesion, mental well-being

Fig. 5 Activities and Community Sessions

Warm Hub and Hampers

An addition to the work of FVP is to function as a 'Warm Hub' funded by the government household support programme administered by PCC. Although core funding for this work is through PCC and also a Parish Council supplementary grant the work is detailed here due to the impact it is having on parental mental wellbeing.

How many adults are there in your household	How many children are there in your household	How many CYP in your household with SEND (0-25)
130	172	67

Fig. 6 Numbers receiving hampers

An extra activity conducted during the month of December included the distribution of hampers to households in need where there was a child/ young person with SEND and/ or an adult with their own needs. Fig. 6 shows how many individuals were supported through this scheme, and Fig. 7 shows the breakdown of SEND across households.

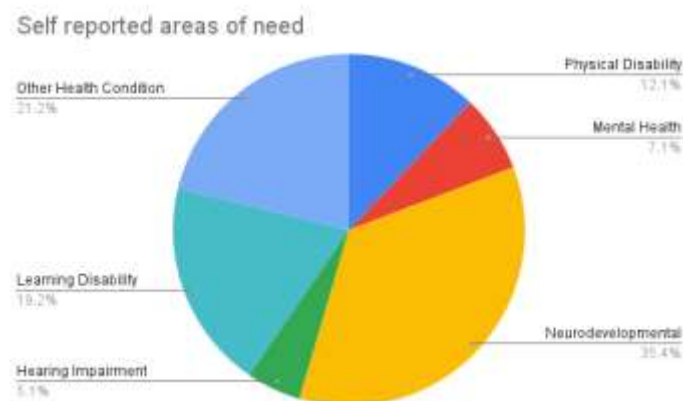


Fig. 7 Areas of need of CYP/ adults

How is the current cost of living crisis affecting you and your family?	Please provide details about your wider household (i.e Ethnicity, Economic Status, Marital Status, Disability/ Health Needs)	Please provide any further details which you feel may be relevant.
Everything has got so expensive, and the necessities are becoming luxuries	I'm white, disabled with mobility issues, and chronic pain, single, on benefits	
Everything is so expensive, and I have trouble juggling the household finances, while still managing the school runs, and feeding everyone. And now electric costs are spiralling roo	White, on benefits, cohabiting, I'm not disabled, but 2 of the kids have needs,	
My husband is unable to work due to disability, and our finances are so stretched.	White, on benefits, married, husband has a broken back and kidney failure, caused by a workplace accident. He is trying to figure out how to manage working now.	
I'm homeless and struggling to manage as I only get 184 pounds per month. It goes nowhere!!	White British, unemployed on benefits, single, mental health issues due to CPTSD.	
Money doesn't go as far as it used to, and I'm really struggling to prioritise bills, food, and baby goods	White British, unemployed, single, mental health problems.	I'm currently 5 months pregnant with my child
Restricting times and how long putting heating on because of cost, after bills paid we have not much left over at all.		
Struggling for food and bills being a low income family	Single parent household	
Struggling with bills and shopping, unable to heat home	White British - one person household	
Has a big impact on us as not sure how we going to pay everything with limited income		
Struggling	Epilepsy	We have been struggling so.much since loosing ... and having is inquest on going is making it hard
Money doesn't seem to go very far, and what we're once necessities, are now luxuries.	White British, on a pension, ßingle, I have COPD, diabetes, heart failure, blood cancer, mobility problems.	
Struggling with food and electricity with high rent		
I have had no income for 4 months and am being evicted	Landlord is responsible	
Like many, I am trying not to put the heating on and buying extra blankets. It means I cannot afford to buy a lot of meat and expensive food items so diet is not so good. We have cut out treats/activities and life has become quite boring without outings.	British/English single mum working part time and on some benefits. I am also immunosuppressed so illness can be a major issue from time to time. I suffer with psoriasis, lichen sclerosis, osteoarthritis. Both children in full time education.	
Less money to do activities and family time		
Arrears in gas and electric	British, single, working part time, anxiety and depression	

No money, sleepless night and upped antidepressants!	I am married, suffer with fibromyalgia, was diagnosed with breast cancer again in March, had a Breast removed in April, and have just recovered from an operation on my eye where I had a cyst removed in October. Both my husband and I work as much as we can whilst caring for the children. I work as much as I can as does my husband but with increasing prices, it would not matter if they added hours to a day.... We both work so are not helped a lot.... But we do what we can when we can.... I'll keep going until I Break....	
It's crippling us especially with cost of gas and electricity and food price rise I'm really worried about getting through winter		
Having to keep the house warm to prevent ellie having hypos and cost of food and petrol . We use more electricity as dad never leaves the house due to mentle health		
Choosing cheaper vegetables than going for high priced food items,using cycle or for commutation instead of using car.	Indian,middle class	
Expensive	Down syndrome	
Badly. I am struggling so bad with food and bills	I myself have autism dyslexia and dyspraxia	
A great deal. The cost of gas and electricity and food		I have adhd too
It's very hard financially.		
We have to be careful how much electricity and gas we use but as both disabled this is difficult.	White British, unemployed due to long term sickness, married, restricted mobility and mental health	
We are struggling to keep our home warm for our girls, put decent meals on the table or have decent snacks for addy with autism and food sensitivities. We also had our £300 Christmas savings stolen so now are struggling to divide the one income to provide a Christmas for the girls		
We are struggling to heat our house as we use our conservatory as a front room but can't afford heating.My children don't even have one Xmas present.Food is getting so expensive	Married both me & my husband are cardiac patients	
Very very hard		
Very badly	Black British. Only 1 adult working.	
Very difficulty living	Economic	
Food fuel heating days out	I'm disabled kidney disease child dyslexic British	
We cannot afford for us both to go to	N/a	My son has allergies to milk

<p>work due to the childcare costs so therefore we have one wage and some benefits(uc) this is helping us get by but we are struggling with bills and many times having to not put heating on as we cant afford the high costs of gas/electric.</p> <p>There is higher costs in food shopping due to my son being allergic to milk too.</p> <p>My daughter had many heart surgeries so i had to stay off work to look after her first but now she is ok but this took its toll on increasing debts and then the cost of living going up has added to this.</p>		<p>so we have to buy alternative options for him which costs alot and food therefor is costing alot for us to meet his needs.</p>
Really struggling. Currently 32 weeks pregnant and still working. Suffer from health conditions myself.		
Struggling for gas and food	NA	
It is hit our family very hard we've recently lost my dad he passed away due to heart failure my Mum is not in the best of health and is a struggle to heat the house and put food on the table Christmas has become very stressful every day is stressful	<p>... widow Susan is disabled</p> <p>... is divorced I'm a survivor of domestic violence</p> <p>We're all Christians</p>	If there is any help with school uniform and shoes
We are struggling with bills food and everyday living		
It's affecting us badly, feeling very cold at night.	N/A	I suffer with hypermobility and my joints ache when it's cold.
Less activities, less celebrations, higher bills		
Trying to juggle, coping	White British, benefits, single mum, one special needs child	No
The cost of fuel is expensive and as I use my car for work it is difficult to make ends meet. We like to eat healthilly but this is increasingly difficult.	We are british, we are a same sex couple with one child. I am the main one to work in the household.	My annual income £19,000
Struggling with energy bill		
Struggling with bills and food.		Single mother
Struggling to pay bills, rent and childcare.	Married, No recourse to public funds	We are new in the country and working hard to settle with our family. Childcare is expensive especially when we have twins in the family.
Energy bills and food stuff re on the rise.		
Struggling with Energy bills at the moment		
Mainly its affected our ability to heat the house and do normal food shops.		

In financial distress wife is disabled waiting 14 weeks for pip to be awarded.	Married, disabled white british	My wife is wheelchair bound and neither of us drive.
Cost of living is really affecting me as my energy bills are extortionate! It's a choice between heat or eat at times! It's a major stress.	Ethnicity is mixed white and Asian and I'm single.	Suffered from domestic abuse from ex-partner, single mum with 2 young children
Low income family. The whole family only rely on husband's income as a chef in a takeaway.	The applicant is Chinese, married, living with partner, on working tax credit, housing benefit. Her child receives DLA due to disability which comes to her account. Unemployed since 2011, because of high childcare cost, maternity leaves, also language barriers but currently learning English. Her son who is aged 11 has autism and requires her care.	
yes massively affecting us	White British Heterosexual Mental health difficulties	
It's worrying me. I get state pension and then the money is gone again.	State pension, single, white British	
Living crisis is making it hard to cover everyday costs	We are a non married working family, I am a registered carer and ethan gets PIP for autism	
Can't afford to live, can't afford my rent. It's either pay my rent or buy food		
My husband is self employed taxi driver with cost of living gone so high we are finding it really hard to keep head above water. Bills so expensive work is really quiet		
Single mum working many jobs trying to support the family	Chinese. low income. mental health issues	
We are very concerned, but fortunate to have a wood burner. Still we wait till we really NEED the heat to put it on. Christmas is scaled way back. Presents are of the need variety (like shampoo) rather than the "want/frivolous" type...	Happily married, husband works. I have health and physical problems and suffer from anxiety. Daughter goes to Peterborough college studying IT. She needed a computer upgrade at home which cost £3,000 this year. So that's another reason things are tight now.	

Fig.8 Details of households and reasons for support linked to cost of living.

Further details relating to the households supported looked at benefits, ethnicity, gender and age, the details of which are shown in fig 9 to 11 below. A factor to note is that when comparing the overall number of those recorded as White British or other ethnicities then the majority of those receiving support are other ethnicities at a total of 63.01%

Age Range Percentages

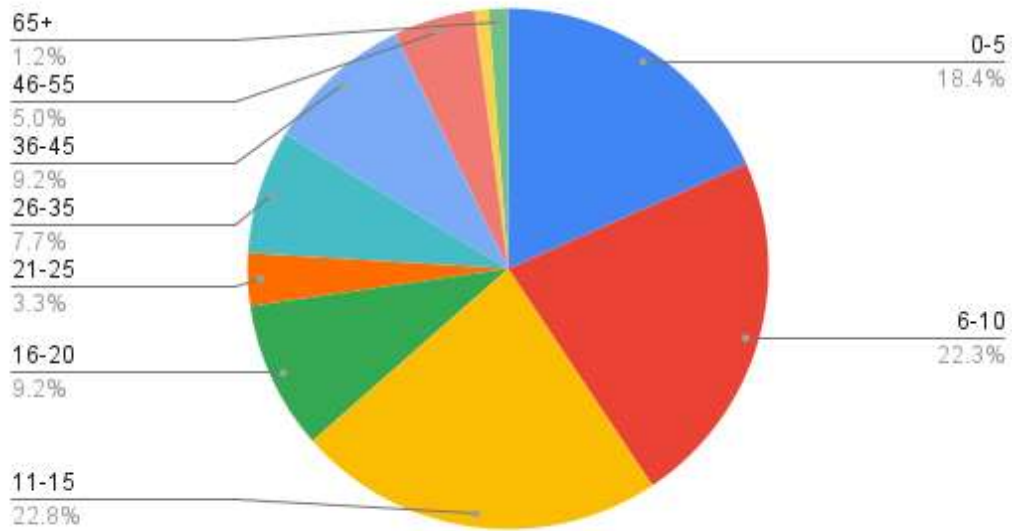


Fig.9 Household ages where declared

Gender

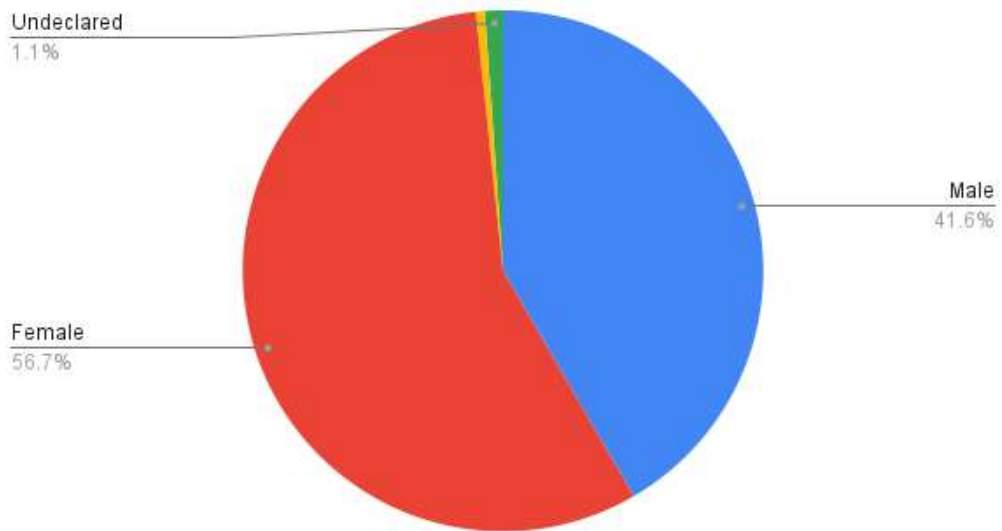


Fig.10 Household genders where declared

Household Ethnicity	
Ethnicity	Numbers
White British	146
Gypsy or Irish Traveller	13
Roma	1
Any Other White Background	3
White and Black Caribbean	0
White and Black African	0
White and Asian	3
Any Other Mixed or Multiple Ethnic Background	0
Indian	7
Pakistani	9
Bangladeshi	4
Chinese	6
Any Other Asian Background	4
African	31
Caribbean	0
Black British	6
Any Other Black or Caribbean Background	0
Arab	5
Any Other Ethnic Group	0
Rather Not Say	0

Fig.11 Household Ethnicity

Schools Data/ SEND

Surveys

During the third quarter two surveys have been conducted with 51 responses.

Survey Title	Responses
Therapies/ Wheelchairs	21
Digital Access	30

Fig. 12 Survey Response Numbers

Both surveys have their own micro reports and are available for view via FVP's website <https://familyvoice.org/surveyreports/>

Engagement on Social Media

The Facebook group has not been fully utilised this quarter due to capacity within the PCF team.

Strategic attendance

Through the ongoing use of the online forum used for parent representatives to report on strategic meetings attended, it has been easier to demonstrate time invested and work/actions as a result of the meetings attended

FVP have had a total of 3 parent carers have been attending meetings either through volunteering their time or as casual workers. As a result of low parent rep numbers a recruitment campaign has been initiated to help. Fig.13 shows the number of meetings attended where reports have been completed.

Number of Sessions	Hours Spent at Meetings	Administration Time (Hours)	Travel Time (Hours)	Total Hours
33	40.5	0	15.5	56

Fig.13 Breakdown of Time spent at Strategic Meetings Oct - Dec

Meetings attended included:

Children with Disabilities Operational Group
Celebrate next steps and moving on' cease to maintain working group
Peterborough SEND Operations group
EHCP Improvement Meeting
5 day offer
SEND Health Advisory Group
Adult Co-production Collaborative
Carers conference steering group
PCC SEND Forum
CYPMHW
SENDIASS Stakeholder Group
Short Breaks Innovation Bid - Inclusive Services Programme
East of England Eating Disorders Network Webinar- Keeping Myself Safe – Dr Madeleine Tatham, Consultant Clinical Psychologist
PCC SEND Communications
Discussion re: parents info for YC Project
Carer Assessment Workshop (Carer Strategy Refresh)
CWD Operational Group
PCC SEND Strategy 2nd Session (Parent Carers)
#AAP Local offer 18-25 year old consults with parents

EHCP Improvement Meeting
Pboro APP Working Group
APP work - Follow up Post 16 survey
Children & Young People's Board Meeting
PCC SEND Forum

Fig.15 Range of meetings attended

Schools Work

Workshops, Focus Groups and School Sessions	Date	Number of adults
Lime Academy Orton Open Evening	17/10/22	4

Fig. 16 Schools Work

The schools work needs better focus, and is still slow in some areas. A guide to the programme has been produced and is ready to distribute but capacity within the team is hampering progress. Ideally FVP require a dedicated participation lead for schools.

Preparing for Adulthood Task and Finish Group

The session was attended by 6 parents, 4 came in person and 2 dialed in virtually. They all had children with EHCPs from the age of 14 to 21 with variety of needs, including Downs Syndrome, ASD, SEMH, Learning disabilities and complex needs. Although their children were at various stages into their PfA journey, each and every single one of them were struggling to get the support they need. What parent carers have told us :

It is a full time job to gather all the information and find out what help is out there and what my son is eligible for.

If my son's social worker is unaware of what options are available for my son then how am I supposed to help him?

What do our parent carers want:

- A clear transition plan with options suitable for their young people, their needs and personal wishes
- Help to consider all post 16 options, rather than being told 1 option without the YP having a say in it
- YP as well as their parents need to be made aware of the limited offer in post 16 education in colleges: not everyone is able/can afford to provide unpaid care for 4-5 days a week
- Help finding employment/internship.
- More information for YP at school to help them understand the importance of PfA and what steps they need to take
- Lack of knowledge about PfA options for parent carers From their child's place of education, whether it is school or college.

Next Steps:

- Inform PCC of the outcomes of this task and finish group
- Attend meetings with PCC, such as Peterborough APP, to see what is being done to alleviate some of those pressures that parent carers and their YP are experiencing and see whether more can be done
- Share our TOI response on PfA with our parent carers and gather their feedback
- Gather all the relevant information in order to answer parent carer's questions
- Feedback to the group about what the response from the LA was and what will be our next steps going forward
- Share all the relevant information as widely as possible to ensure that parent carers are being well informed

Parent carers have also informed that the 0-25 disability team is not widely known, they still view it as an authority to 'take their children away from them' and do not understand the value of it. Those parents who are aware of it say that it is very difficult to get into the system and very often get 'fobbed off'.

Seldom Heard Communities

Seldom heard engagement with parent carers and community leaders has continued this year utilising online meetings as detailed below in fig.17 and also face to face via some of the sessions mentioned in fig.5 in the first part of this report.

Information and Awareness	Date	Number of Adults	Number of Children
SHCF Help & Support Domestic Violence	19/10/22	10	SHCF Help & Support Domestic Violence

Fig. 17 Seldom Heard Engagement

45.3% of the queries coming though from parent carers requesting signposting are from parent carers from local seldom heard communities as are the majority of those engaged through the winter hub and hamper programme at 63.01%.

Since 1st April there have also been 662 new community contacts added to FVP's data recording system. These are a mix of families and community leaders who have engaged across a range of areas including face to face and online.

Co-production and Change

Topics of Importance

There has been one Topics of Importance (ToI)¹ produced since 1st September which covers parent carer resilience. The ToI's produced in the last quarter now have agreed responses²

¹ ToI detail what parent carer concerns are <https://familyvoice.org/toireports/>

² ToI Responses (PfA/ Short Breaks) <https://familyvoice.org/topics-of-importance-response/>

Coproduction

Areas involving coproduction are linked mainly to the CWD group where there is ongoing involvement in the development and review of services for children with disabilities.

FVP also have ongoing involvement in the work relating to Peterborough City Councils Accelerated Progress Plan (APP) which is coproduced via meetings and at SEND boards. FVP have had at any moment in time at least one parent rep included in meetings.

Recommendations/ Forward Plans

1. Conduct a better analysis of work relating to seldom heard parent carers to establish what the reach of FVP is and where improvements may be made.
2. To work collaboratively with PCC partners to establish who is within scope of seldom heard communities and develop plans to increase engagement from parent carers within these communities.
3. Make more use of face to face opportunities to increase engagement and participation of parent carers.
4. Increase capacity with FVP to ensure continued parent participation in the growing number of work streams.
5. Work with partners to help increase understanding of the different levels of participation and embed opportunities for coproduction.