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# FVP Interim Report

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October to  
December 2023

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FVP Parent Representatives

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## Introduction

This is the third quarter report detailing work of Family Voice Peterborough as the Parent Carer Forum (PCF) funded by Peterborough City Council (PCC). Some work may be funded by more than one grant scheme but the main outcomes sit in this report due to the focus on the PCF. The report will again be structured under the following headings:

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

There is some crossover between areas, with work often having the potential to fall in more than one section. The ongoing impact of the cost of living crisis, the separation between Peterborough and Cambridgeshire shared services and other local and national concerns have an effect on Family Voice Peterborough (FVP) and the work of the Parent Carer Forum (PCF) as well as the beneficiaries to the wider charity primarily Parent Carers. This reporting period has been quite busy with respect of general parent participation, wider support and school based engagement.

Over the past three months (October 1<sup>st</sup> to December 31<sup>st</sup>) FVP have seen engagement from 11 Fathers, 79 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 through completion of surveys to attendance at a variety of face to face activities. Wider engagement across 34 opportunities enabled 596 adults and 346 children to get involved at some level.

## Participation/Engagement/Involvement July – September 2023

### Headlines

- 1) 122 named parents in total have been involved at some level.
- 2) 22 parent carers have participated across 1 online survey.
- 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) 11 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, case studies, face to face activities, one-to-one telephone or email engagement and parent representation.
- 7) Evidence is both qualitative and quantitative in nature.
- 8) Ethnicity data will be referenced in the full report, we have moved toward categorizing in line with census categories.

# Wellbeing

## Introduction

As with previous reporting periods work is funded from a combination of funding sources which have similar outcomes in relation to participation, wellbeing and engagement from seldom heard communities.

## Food Support

Food/ Financial support continues to be an identified need, especially in relation to access to healthier food choices such as fruit and vegetables and funds to shop for every day essentials. Having access to food and support to manage the stresses associated with the extra costs of providing care to CYP with needs leads to improved mental wellbeing for the parent carers. As a result they are more likely to engage with participation activities.

Support has been provided to 75 known households through the provision of Hampers in the month of December.

Adults	Children (Total)	Children with SEND
156	184	93

**Fig.1 Numbers of adults and children receiving food**

Households provided the following reasons for requiring support.

<b>How is the current cost of living crisis affecting you and your family?</b>
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 Kayla 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 that's been condemned 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. struggling with money.
Struggling money wise
Found more difficult
I have a lot of stuff to pay off plus it's really hard with all these 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 pantries, 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 it's 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 Kyle 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 without 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 council 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 diesel for the car for appointments

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.

A lot

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 choose 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 can't have heating on as can't afford it have to use less electricity as I need it over night for CPAP machine and can barely afford 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

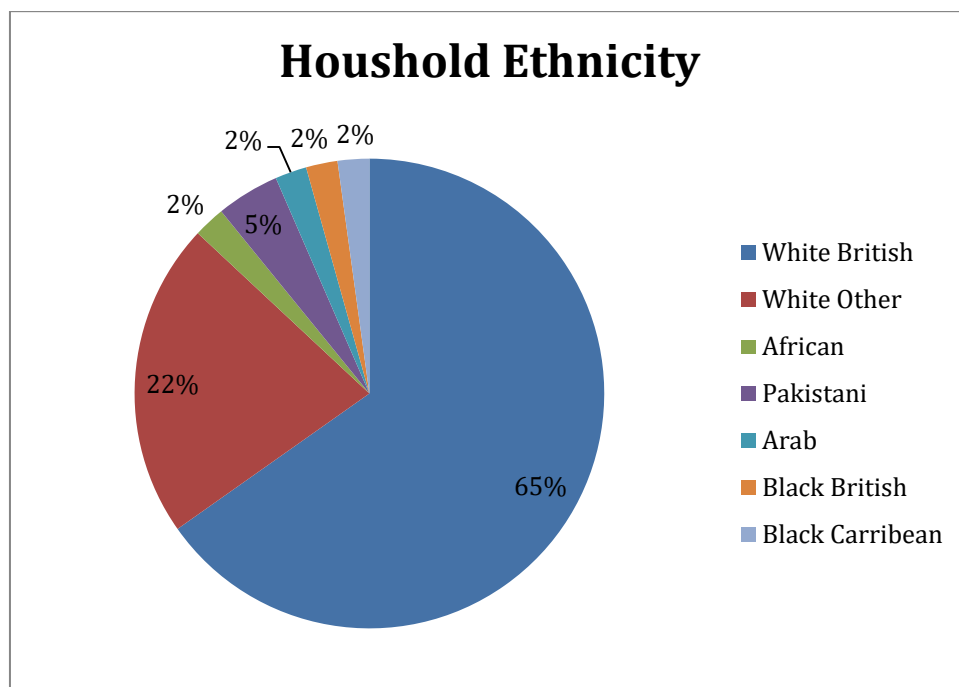
Food and bills are so expensive

Money just doesn't stretch far enough

## Signposting/ Support Requests

The needs of those requesting signposting and support have changed and it appears more than signposting is required, especially due to a change in the complexity of signposting support requests on average initial contact calls are now taking approximately 45 minutes. Families are seeking support across a broader range of areas, and these are related to much more than education. To manage demand and work on enabling more of the team to support with signposting work a lead parent rep has been developing a signposting pack which will be available via our website in due course.

There have been 51 contacts recorded where parent carers new to FVP have requested signposting. Where direct signposting requests have been received it is known that 65% would be considered 'White British'. The number of parent carers requesting signposting from seldom heard communities in relation to ethnicity is slightly lower in this quarter.



**Fig. 2 Self-Reported Household Ethnicity**

The preferred form of contact is via the website contact form. Parent carers are also reporting as having heard of FVP from a range of sources which seems to show work to raise awareness of FVP more generally is working.

From these and other contacts with parent carers the team of parent representatives at FVP have identified the same themes as the previous quarter with the addition of short breaks:

### **Parental Resilience**

Over the past few months, we have been seeing a sizable decrease in parental resilience. Parent carers facing a lot of daily pressures: from school attendance, getting their children help they need, accessing diagnoses to financial pressures to keep their family going. Those pressures increase significantly when families are caring for more than one child with SEND

- *My husband and I feel under extreme stress. Our youngest son (age 6) was diagnosed with ASD in April and our eldest son (age 9) is waiting for an assessment*

for ADHD and ASD, due to be in January. We paid privately for both of them, so feel the Early Help Route might not be right for us. We are in desperate need of support but don't know how to access it. We both work, my husband full time and myself 27 hours. \*I am currently signed off work with high level of anxiety.

- I'm at my wits end because I feel the years of fighting and still have it.....

## Education/School Attendance

Parent carers have reported more issues with communication with settings, lack of support for their CYP's SEN needs in school, having to 'fight' for support and feeling that mental health needs are being neglected. School avoidance is on the increase based on the signposting calls being received relating to being out of education.

- Mum would like to speak as soon as possible. Mum has been suggested to speak to us by occupational therapist and other organisations she had to deal with . Her daughter has EHA at school , communication with school is very poor, even though she had a lot of meetings with school mum feels she is being lied to. At the moment her daughter has been assessed by occupational therapist and really struggling at school. She has no diagnosis yet but they are looking into Sensory processing disorder and Neurodevelopmental disorder .... 5 male at ravensthorpe primary school . All as I feel like I'm stuck in a hole with no way out and little help I just need help getting my kids they help they need in school at for them to stay in school for full days
- 14 yrs old Autistic, diabetes type 1, eating disorder ARFID, sensory sensitivity, anxiety. Home educated, not wanting to meet other people or make friends or socialize, over stimulated in public places Any information on what I can do in Peterborough while home educating my daughter, anything she can take part in without pressurising and very low demand, volunteering.
- 13. Male. ADHD and Autism. Home educated, Education/ Health or Social Care Advice, Answering questions. Guidance and advice on what support there is for my son and myself. I am a single mother and struggling

## Accessing Health Services

Accessing Mental Health, Health Assessments and Health Services more generally have become a concern reported on more.

- Age 7, male, Autism/Dyslexia/ARFID diagnosed, high anxiety and awaiting ADHD assessment I recently put in a parental request for an EHCNA and it has been refused by the local authority, looking to consider mediation or appeal and would appreciate advice. I have had advice from Sendiass but I feel a bit like they are giving me information but sitting on the fence too much..... would like to know who she can reach out to for counselling/support for 9 year old son please. Centre 33 only deal with teenagers, and school currently aren't being much help.
- .... 16 yrs old Female, .... She has dyslexia and she is suffering in her studies, she is quite behind and she has anxiety issues, she has developed a rash all over her body.

## Short Breaks and Respite

- Assessing some night support for my son



- *Short Break I need with applying for PIP and DSA*
- *Mum has a 25 yr old son with Autism and she would like advice on things to do for him, activities, groups and anything else on offer, she has found where she lives in Wellingborough its not very good in terms of activities etc.*
- *.....he has languages delay needs more help with that as well he got problems with walking disbalanced problems with feeding very choice with food also help with short breaks if we can get some sports lessons for my child and me swimming for my son and me will be great*

### Information and Guidance

- *Signposting ,education/health or social care advise Advise and support for ..... to have a personal development opportunity to improve her life and independence*
- *Age 13. Male. ADHD and Autism. Help with answering questions. Guidance and advice on what support there is for my son and myself. I am a single mother and struggling*
- *Son, 13 out of school, EHE, SEMH, Mum needs advice re educatuion and getting an ND assessment*

### Wellbeing and Family Based Activities

Family Based Event/Activity	Date	Number of Adults	Number of Children
Community Cafe	4/10/23	22	2
Litterpick	7/10/23	2	0
Community Cafe	11/10/23	22	2
Community Cafe	18/10/23	23	2
Community Cafe	25/10/23	18	0
Activity World	27/10/23	46	53
Community Cafe	1/11/23	14	0
Community Cafe	8/11/23	21	0
Community Cafe	15/11/23	16	0
Community Cafe	22/11/23	21	1
Community Cafe	29/11/23	17	0
AHG Ladies/FVP reps meal at Ibrahimi's	30/11/2023	19	3
Community Cafe	6/12/23	21	
Community Cafe	13/12/23	20	
Hampers	19/12/23	144	193
Activity World	20/23/23	42	87
Community Cafe	20/12/23	19	

**Fig. 3 Activities and Community Sessions**

This work area is funded via more than one source but all have similar outcomes relating to community cohesion, improved wellbeing and decreased social isolation. The numbers

reported in the next two images are from a full six month analysis but can be applied here, with some increase.

Parent Carers accessing this support will feel less isolated and report an increase in their well-being as a result

- ▶ Our outcome was to increase Parent Carer Wellbeing by 50%
- ▶ We have delivered a range of activities and trips including wellbeing sessions for parent carers.
- ▶ On average 90% of parent carers self-reported feeling included and supported.

We have exceeded this target



Increase in the number of and participation in community events and fun days

- ▶ Our outcome was to hold 24 community events over the two year life of the grant with a view to include themed sessions and faith groups .
- ▶ Between March 2022 and September 2023, we have held 23 family/community events. We have seen attendance at these of 1252 people (children and adults), as evidenced by attendance records.
- ▶ So far 1025 people (children and adults), have participated as as evidenced by attendance records.

We are **on target** to achieve this

## General Engagement & Awareness

Information and Awareness	Date	Number of Adults
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	11/10/23	7
Parent Carer Coffee Morning - Starbucks	17/10/23	4
SEND Training for councillors	24/10/23	11
Zebedee Shoes, 45 Oundle Road. Pe2 9PB	24/10/2023	25
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	1/11/23	5
Orton Library	7/11/23	30
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	13/11/23	13
Parent Carer Coffee Morning - Starbucks	21/11/23	3
Lush Peterborough	25/11/23	20
Lush Peterborough	26/11/23	
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	29/11/23	7

**Fig. 4 Information Stand Data**

Using information sessions and holding information stands continues to be an effective way of engaging with parent carers and raising awareness of not only FVP but all the sources of information and support open to SEND families. This can be demonstrated by the general increases in the numbers engaging via social media following face to face contact with 89 new follows on Facebook alone.

## **Schools Data/ SEND**

Work for the Parent Carer Forum can take place in the form of parent reps attending meetings, schools offer and engagement work, more general engagement and awareness raising and provision of parent participation opportunities. FVP also receive numerous requests for involvement in a range of areas from document review to information dissemination. Requests come from a variety of service areas and providers; CPFT, Cambridgeshire and Peterborough Integrated Care System, Peterborough City Council, The Eastern Region Parent Carer Forum to name a few. The requests received so far are in the following table.

Request/ Topic	Work Required
Keep Your Head Website	Consultation
Work on Transitions	Other
Research involvement	Other
C&P Community Services Review	Consultation
PALS Activity	Other
School Coffee Morning (Jack Hunt)	
LO Social Media Messaging	Other
ED Services	Information

	Sharing
Early help Services	Meeting Attendance
Learning Disability and Autism Strategic transformation Partnership board	Meeting Attendance
Embedding users voices into the Children and young people's JSNA	Information Gathering
Patient experience - translation of surveys	Information Gathering
Action from last PFA Steering group for June 23 to be chased	Information Sharing
HOS SEND Interviews / Head of SAMS Interviews	Meeting Attendance
Autism Pathway Development Workshop (Autism Strategy) - Next steps Proposal	Document Review
Sleep Right Service Decommissioning	Information Sharing
APP Action Point	Consultation
Partnerships for Inclusion of Neurodiversity in Schools (PINS) Initial Delivery Plan	Coproduction
Parent carer involvement	Meeting Attendance
Early Support Stakeholders Request	Meeting Attendance
Effective Practice Examples	Other
Engagement in the LDA Improvement Programme	Coproduction
joint local area SEND inspection	Consultation

**Fig. 5 - 23 requests for FVP involvement (Oct - Dec)**

## Surveys

During the third quarter one survey has been conducted with 22 responses.

Survey Title	Responses
Health Inequalities	22

**Fig. 6 Survey Response Numbers**

Most surveys will have a micro report detailing basic findings and recommendations. A Topic of Importance has been launched as a result of this survey. This is and the survey report are available via the website.

## Your Say Form Questions

During this quarter 50 'Your Say' forms have been completed leading to a range of views on Education, Health and Care being expressed. Ethnicity as self-reported by those completing the forms is shown in fig. 7 below:

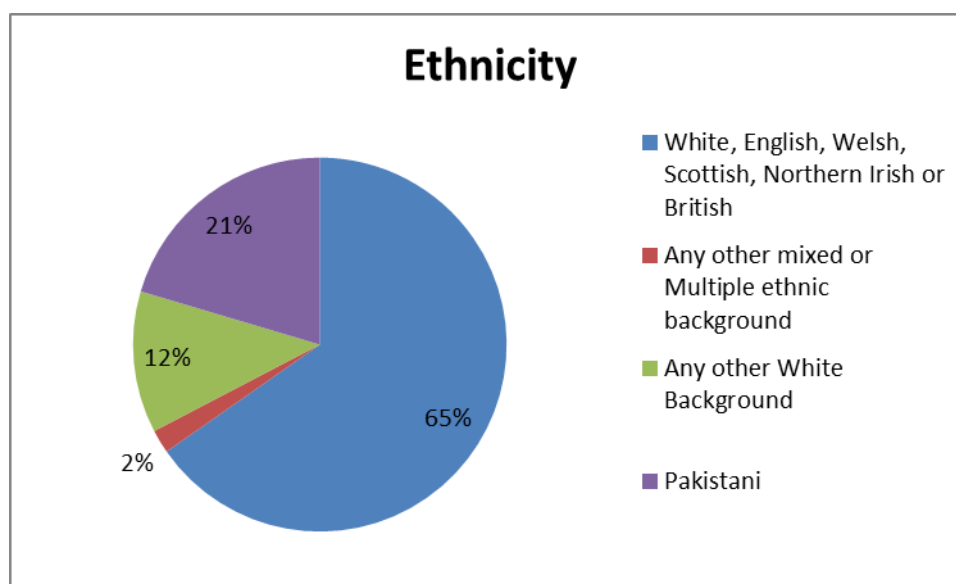


Fig. 7 Self-reported ethnicity

<b>Do you have any feedback to share about Education (positive or negative?)</b>	
<b>Working Well</b>	<b>Even Better If</b>
Improving by sharing information and making transitions easier for students she's has senco and one to one	More understanding needed and education on needs Early help needs to be more consistent regular meetings to ensure effective communication between parent carers and staff
Not particularly, Teachers try their best but it feels like at my sons school they don't really understand his needs even though they think they do.	Just not fast with diagnoses
Since starting secondary school, my daughter has refused school quite a bit. Her current school have been supportive in the way of good communication, forming good relationships with myself and setting up groups to aid my daughter.	It feels like support is only put when they have a legal obligation to do this i.e. a professionals report eith recommendations otherwise they say it isn't available or an option. I have asked several times for my son to have access to the sensory room and I am told it is only for children with an EHCP. I have put in a parental request for an EHCNA which was recently declined so looking to appeal.
Her mainstream school is really helping her with her development	The process of Early Help/support/official diagnosis
Transitions to specialist placement was done gradually which allowed tome to settle back into education	EHCP process takes to long, it should be easier for parents to get support for kids. It can be very overwhelming at times
My child is happy and progressing at school	The waiting time to find specialist placements
Yes ,they are trying their best to support	Waiting times for assessments are long
Yes, educational psychologists were a brilliant tool	Not this year is good

for gaining a ehcp.	
Already filled this in but forgot to screenshot thankyou page	The ehcp paperwork never gets sent and the next one comes round and you still haven't had it! Maybe this year it'll get sent!!
Yes this year he started medeshamstede academy secondary class and his teacher is amazing. My son is willing to do his work.	Parents should be listened to. They are the voice of their child.
Tommy is thriving since starting school. We're very happy.	LA are absolutely disgraceful.
Both children attend specialist settings. Both have been good. Especially with my daughter who recently returned to education after autistic burnout/home education	Teacher should have proper understanding of teaching. Not everyone has a same level of understanding of education. Especially SEN children.
Brilliant with my boy	Never had support for his needs
we are one of the lucky families where my child has the correct placement.	Despite promises, local authority have failed to provide any educational opportunity. Liaison with GAPS has been carried out by us.
A supportive Senco is worth their weight in gold. An unsupportive Senco should reconsider their career choices.	Where do I start? Been in the 'system' for a very long time. My daughter is still in Education but we are still facing challenges although we have had EHCp for many years and it's predecessor; the statement. I would summarise our negatives by saying that we are still fighting and it's taken a toll on parent health. It's very hard to fight a system that will not move forward and think holistically about the YP needs. We are still stuck with the unknown of which is also having an impact on my YP
Assistant SENDCO did everything she could.	After my son got moved to a special school he had no education and was left in a room alone then was excluded and left with no education so was then put in a PRU who couldn't meet need then at home again then put in college when he was vulnerable to older mainstreamed students at age 14 & led him to smoking cannabis
They have great school and teachers, always helpful. Ormiston meadow academy !	Took a long time to get it
Educational opportunity being provided by GAPS (TCHC)	special/ extra needs school- still does not understand child's needs properly. seems very unprofessional, very un-equipped and more focused on playing games rather than educating and setting up for future.
Thinking of a positive is hard when it's been a very rocky journey. My daughter had a one to one TA in primary school. Although only qualified as a level 1 TA she went above and beyond for my daughter and then went on to help other children in the class that were being missed with SEN. She grew up with Autism in the family so was able to identify what was needed very quick	He no problems So far
No my son had a managed move to a special school for autism in year 5	Yes it's so hard when you feel like the school doesn't help your child.
His school listens majority of the time	certain settings are to be avoided for young

	people with disabilities. EHCP process is very poor. Having an EHCP allowed this individual to stay in education until the age of 25. However, despite achieving targets and having new ones set, the document was only updated once in 6 years!!! The EHCP was not updated when the individual left education despite several communications and strenuous effort from the family. very neagive experience with EHCP process.
We received home tutoring	Certain settings have been very negative towards individual and prevented progress especially New Stamford College
No always a ongoing battle	One to one attention required
Yes! We love their school Ormiston Meadow Academy. Was big help for us. The teachers are fantastic!	No communication no parent courses that learn sign lang or learning more about conditions etc adhd or why they do things need more info or update on things
certain staff in certain settings were supportive and allowed this individual to thrive	No correspondence from school nurse in regards to continued issues
Certain staff in certain settings have been very supportive and allowed individual to thrive	More funding needs to go into schools, more resources for children with additional needs, more support with childcare
Easy location	
Friendly staff good info need more training as teachers can be young not have children themselves transport staff can be lazy had heart problem's on one bus dont give children time dont let them hold bag or nappys they just want a easy child no problems sit still	
Its grest	
Teachers do the best they can with what they have available to them	

Fig.8 Educational Experience

<b>Do you have any feedback to share about Health Care (positive or negative?)</b>	
<b>Working Well</b>	<b>Even Better If</b>
Always been helpful in giving advice and writing reports where they can from assessing individual needs of child young person	Long waiting lists for assessments and support. Having to chase everything and fight for what your child needs. So many hoops parents have to jump through to even see a paedatrian it is exhausting. No ARFID pathway in Cambridgeshire.
The dietitians team based in Cambridge are fantastic. Our GP surgery - Wansford are fantastic.	Left to deal with everything on my own
Left to deal with everything on my own	Slow process as lots of people on waiting lists.
Good communication and efficient when you do get appointments	Parents are not supported enough to get the right help and the waiting lists are very long
Mostly quickly get appointments and reviews with the doctors regularly	Some doctors don't listen , but I think it all depend on personality .

Hospital appointment are accessible for us , for example for physiotherapy he waited only 3 weeks from referral date .	Yes mental health help is a joke no help for our son. All he has is online calls for self harm.
Always been happy with health care	Other services such as CAHMS very poor.
Occupational therapists are fantastic while children are school age, when they leave education and become adults its a different ballgame!	Long waiting lists
Very pleased with GP services.	Doctors are not massively trained in autism
The doctor always struggles because he cant communicate so we end up being sent to hospital most times.	Getting someone to listen and help is not easy. You have to grow thick skin, and never give up.
Once you have their support, it makes such a difference.	Needed to submit a complaint to pals to get anywhere.
Psychiatrist and psychologist do their best to engage our daughter.	Although annual health checks appointments are made the follow up are not always followed through
My positive is that my daughter was diagnosed at the age of 5. So has meant some support started at that point with her needs.	still waiting for Hebert to be diagnosed. Hugo gets his diagnosis and that was it - you are left to yourself.
Special needs dentist is fantastic	Appointment should be given bit quicker. Health care system is very slow.
Good health support	Never bothered
Accessing annual health check	Health care very limited. No regular visitations or significant support
Accessing annual health check and epilepsy reviews	Would say that it's sad to know that the NHS still believe schools over parents and had meant for my daughter that the intellectual disability was not accepted by the professionals until I had battled a year for an educational psychologist and this proved no cognition change six years after being assessed from beginning of primary school. Same with ADHD. I was kept on a waiting list for 10 years, to then only be told that even though my daughter showed it in the QB test, the school however stated that as long as there is routine her attention is ok and just about manageable. Since being in post 16, the routine that special school gave her has somewhat disappeared and has had my daughter and still now going back to behaviours we saw back in primary due to inconsistency and complacency in post 16
Can get appointments quick	We've struggled accessing health care & even places like hospital with such long wait in A& E he was still expected to wait & because he couldn't handle the wait he would walk out of appointments and then get discharged as a no show
Brilliant	No we've had no involvement since age 14
Health care is difficult to access at the moment but appricate all the help they do	Took time to get it initiated



General paediatrics team are great	school nurse sent out flu and vaccine consent forms. filled in and returned, school nurse arrived early, did NOT read forms, just assumed it was a yes. its a good job my child refused on the day as we did not consent. who checks? this could have been a deadly decision.
	Sometimes feels like a battle for your child.
	After diagnosis for Hugo we were left by ourselves really. Id twin boys and one had his diagnosis and one still waiting
	Difficulty accessing GP service
	Difficulty accessing GP services
	They don't really know what's wrong with my daughter even though she's on end of life they think she doesn't meet repaite for health needs
	Delays and not take seriously
	Need to speak to a person not very quick to get back to u no dentists for children with send should be a priority
	Long wait times and issues with contacting gp
	Why isn't there an ARFID pathway in Peterborough, my grandson has a diagnosis but no support, my daughter has to pay privately for this

Fig.9 Health Experience

<b>Do you have any feedback to share about Social Care (positive or negative?)</b>	
<b>Working Well</b>	<b>Even Better If</b>
Recent contact has proved to be more effective than a few years back when we needed support so that's	Left to deal with everything on my own
Have regular cin meeting which helps all work together to support a plan	When in urgent need with mental health, a few years back, I was told my social services that I didn't 'qualify' for support.
Thorough, fair and accurate assessment under section 17. Awarded respite care.	Sometimes not another social worker not available when on holiday or sick so can struggle at them times
Now that I am poorly they are trying to help more because being my daughters only main carer I am now unable to take care of her in the em way I used to.	Never supported even in time of need
Positive been very helpful	Slow to arrange disabled fundinh
Package meets individual's needs and is changed as appropriate. Some social workers are very supportive.	Cannot access any social care help as they seem to need school/education approval and as my children are both "fine in school" it seems we do not meet criteria
Most social workers have been supportive and obtained appropriate package which has been changed to meet needs.	I am very pleased that my daughter now lives in supported living. It has relieved me of a huge burden enabling me to rebuild my life (I'm a single mum and my daughter was violent towards me

	when living with me until 2020), and has enabled her to grow in confidence with greater independence. But the standard of care isn't as good as I would like and for the last 3+ years I have had to make repeated requests for the care providers to improve the quality of my daughter's diet, encourage physical activities and help her engage in interesting activities in evenings and at weekends. I have been driven to making formal complaints to social services to address this. The situation is better but still not good enough. Without my support nothing would happen. As we have no other family this does not bode well for the future.
Social care has been great with us helping us with our daughter respite. She is getting the right level of care at the moment	Tried to get respite but they kept moving the goal posts so I gave up. I have spoken with other parents who were given it without the process I was subject to. Totally unfair and stressful.
	The provider they commissioned to cover our respite hours can't meet our needs.
	Support is very basic, unimaginative and difficult to access
	It was the year of assessment for two hours week that was really quite stressful due to the high turn around of social workers in that time.
	We've had no social care involvement although we were crying out for help the last few years
	Lack of continuity as social worker keeps changing
	Lack of approved 1:1 provisions only day care which doesn't meet needs. Some social workers have an agenda and can prevent progress
	Limited options for overnight respite and 1:1 support. Poor service from social worker Nicolae Manulescu caused problems some of which are still having an impact randomly several years on
	Long delay no impact or effective
	Very pushy

Fig. 10 Care Experience

Feedback on services is mixed but three main areas that stand out are:

1. Health services are stretched, waiting times are too long and accessing GP's are a strong concern.
2. Funding for schools impacts on provision
3. Difficulty in accessing social care support.

<b>Any other services you wish to mention?</b>
Charities and parent carer forums do amazing job in supporting families
Sendiass are a great support but because they are employed by the local authority sometimes it can feel like they are sitting on the fence and trying to be neutral when my opinion is they should only be concerned about support the parent to get the child what they need.
When had a key worker to support family was very useful as could support with meeting and school
Charities are helpful regarding accession the knowledge , I like zoom or personal meetings , get together and sharing information,signposting .
Family Voice are brilliant advocates for families and their children
Sendiass is a great support.
Charities are doing really good, atleast putting smile on the children and parents by giving them chance to get together. Family voice is highly recommended.
School learning support
Circles are fantastic with the role they have been in our lives.
Children's dietitians are great, supporting my grandson because the eating disorder don't have a treatment for him

**Fig. 11 Any Other Services**

<b>Any other feedback</b>
Pinpoint and family voice have been a fantastic source of support and information. IPSEA website is amazing. Social media esp. Facebook groups have been where I have learnt most.
Citizens advice are extremely hard to contact in regards to finding support finically now I have become unemployed after 17years due to my daughters needs!
Respite care should be easier to get and we should be able to use it how parents wish. Respite is for the parent especially when your on your own. Felt judged and made to feel bad for asking for a break from 24hr care.....
Family voice is incredibly doing good. Keep it up as you are helping people in so many different ways. Thank you for that.
Apart from being isolated at home most of the time, I try to be optimistic and positive about the future
Always fighting to get things put in place for my daughter.
Really appreciate all that family voice do

**Fig. 12 Other Feedback**

### Strategic attendance

Through the ongoing use of the online form 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 a total of 7 parent carers employed as parent reps and they have shared meeting attendance with the Forum Coordinator, CEO and Participation Project Officer.

Number of Sessions	Hours Spent at Meetings	Administration Time (Hours)	Travel Time (Hours)	Total Hours
39	68.5	35.5	2.5	106.5

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

Type of Meeting	Name/ Title of meeting etc attended
Working Group	Peterborough APP meeting
Working Group	Travel training and launch working group
Working Group	PfA Independant living working group
Strategic Board	NHSE & ERPCF Lunch and Learn
Working Group	PfA young peoples consultation working group
Strategic Board	SENDIASS Steering Group
Focus Group	Respite & Young People Breaks With Autism & Asperges
Strategic Board	Wider Collaborative - Community of Practice
Strategic Board	Co-Production Collaborative- Mental health
Schools Event	PCC SEND Forum
Forum Team Meeting	Eastern Region SEND Forum
Panel	Health watch summit
Strategic Board	Children, young peoples and families Co-production Collaborative
Strategic Board	Children and Young Peoples Mental Health and Well-being board
Strategic Board	APP Performance and Risk meeting
Focus Group	Parent Toolkit for new starters 2024 meeting
Individual Meeting with Professional	Transition Nurse introduction with FVP
Moderation meeting	Community short breaks moderation
Working Group	EHCP Improvement meeting
Strategic Board	Peterborough SEND operations group
Working Group	Children & Young People's Mental Health and Wellbeing
Training opportunity	Healthy Parent Carers Peterborough
Working Group	AP/Inclusion strategy working group - initial meeting
Strategic Board	PCC SEND FORUM
Strategic Board	Children's and young people board
Working Group	ERPCF CATCHUP
Strategic Board	EHCP improvement meeting?SEND Strategy 12 people in attendance
Strategic Board	Adult co-production Collaborative Mental Health, learning disabilities

	Carers Programme Board
Working Group	East of England Neurodevelopmental disorders network
Working Group	PfA Independent Living
Operations Group	SEND Operations Group
Julaybib Project (SEND Muslim Mums)	Julaybib Coffee Morning
Workshop	Mental Health, Learning Disability & Autism Partnership & VCSE Workshop
Working Group	PfA Employment Group
Working Group	Carers Programme Board
Working Group	Carers Programme Board
Working Group	Situational Mutism (Framework Termly Group)
	East of England Learning Disabilities and Autism Share & Learn Webinar

**Fig.14 – Meeting List**

As seen in fig.14 the team have been involved in meetings relating to SEND operations, EHCp improvements and Preparing for Adulthood through to Maternity and Children’s Collaborative. Health meetings have covered physical health and mental health from provision to commissioning.

### Schools Work

<b>School Sessions</b>	<b>Date</b>	<b>Number of adults</b>
<b>Nene Valley Primary</b>	<b>10/10/23</b>	<b>1</b>
<b>Orton Wistow Primary</b>	<b>17/10/23</b>	<b>5</b>
<b>Lime Academy @Tesco</b>	<b>14/10/23</b>	<b>12</b>
<b>Peakirk-cum glinton</b>	<b>6/11/23</b>	<b>5</b>
<b>Woodston Primary</b>	<b>8/11/23</b>	<b>6</b>
<b>All Saints Primary</b>	<b>20/11/23</b>	<b>14</b>
<b>Parent Carer Coffee Morning</b>	<b>21/11/23</b>	<b>3</b>
<b>Northborough (third)</b>	<b>23/11/23</b>	<b>1</b>
<b>Eye Primary School</b>	<b>11/12/23</b>	<b>3</b>

**Fig. 13 School Meetings Data**

Provide details of any themes mentioned by parent carers if applicable (this could be specific issues, what difference the session has made, support required etc).	Have you had contact with any parent carers from the following list at the session being reported on?Any	How many people did you speak to?	other comments?
Parenting courses before formal diagnosis Delay with any support after formal diagnosis - feeling of just 'being left to it' Linc/Cambes referral processes	Polish, Romanian, Somali, Syrian, African, Indian, and Pakistani communities, Fathers and male relatives and carers of disabled children.	5	Parenting courses before formal diagnosis Delay with any support after formal diagnosis - feeling of just 'being left to it' Linc/Cambes referral processes
Parent Carers really struggling with multiple issues & children, long waits.	Families experiencing domestic abuse/substance misuse, Home educated children., Families with a disabled adult parent carer and particularly all those with learning disabilities or mental health issues.	3	Parent Carers really struggling with multiple issues & children, long waits.
Delay of support after a diagnosis	Polish, Romanian, Somali, Syrian, African, Indian, and Pakistani communities	4	Delay of support after a diagnosis
Difficulties finding an NHS Dentist / struggling to get a Doctors appointment / wheelchair services.	Very low-income families or families whose income drops suddenly due to a change in circumstances, self-employed., Families with a disabled adult parent carer and particularly all those with learning disabilities or mental health issues., Rare conditions – children with rare condition, family lacking support network/information, Families with limited literacy skills	6	Difficulties finding an NHS Dentist / struggling to get a Doctors appointment / wheelchair services.
A Parent said after doing the Triple P's Parenting course she felt demoralised. None of the Parents knew about the Parent Carer's Assessment. Secondary School was a talking point and some mums showed concerns about it especially one that hasn't had a diagnosis yet for her Daughter.	Very low-income families or families whose income drops suddenly due to a change in circumstances, self-employed.	5	A Parent said after doing the Triple P's Parenting course she felt demoralised. None of the Parents knew about the Parent Carer's Assessment. Secondary School was a talking point and some mums showed concerns about it especially one that hasn't had a diagnosis yet for her Daughter.

Border issues with referrals Headteacher not responding to emails with reference to referrals	Fathers and male relatives and carers of disabled children.	5	Border issues with referrals Headteacher not responding to emails with reference to referrals
Lack of support from school Direct payments	Polish, Romanian, Somali, Syrian, African, Indian, and Pakistani communities, Families with limited literacy skills	11	Lack of support from school Direct payments
One family was concern son wasn't getting enough support at school and have a meeting with the chair of Governors on Thursday and needed some reassurance.	Fathers and male relatives and carers of disabled children.	2	One family was concern son wasn't getting enough support at school and have a meeting with the chair of Governors on Thursday and needed some reassurance.
Border issues for referrals - Louise is aware and raising the issue with health and LA	Parents who are borderline Lincs/cambridgeshire	2	Border issues for referrals - Louise is aware and raising the issue with health and LA
Attended Orton Wistow A Parent said after doing the Triple P's Parenting course she felt demoralised. None of the Parents knew about the Parent Carer's Assessment. Secondary School was a talking point and some mums showed concerns about it especially one that hasn't had a diagnosis yet for her Daughter.	Very low-income families or families whose income drops suddenly due to a change in circumstances, self-employed.	5	Attended Orton Wistow A Parent said after doing the Triple P's Parenting course she felt demoralised. None of the Parents knew about the Parent Carer's Assessment. Secondary School was a talking point and some mums showed concerns about it especially one that hasn't had a diagnosis yet for her Daughter.
SENCO frustrated with waiting times for referral's School have set up a SEND Class for the 6 SEND children in one year as luckily they had capacity as shortage in that year.	Very low-income families or families whose income drops suddenly due to a change in circumstances, self-employed.	4	SENCO frustrated with waiting times for referral's School have set up a SEND Class for the 6 SEND children in one year as luckily they had capacity as shortage in that year.
Wanted to know about activities available in local area	Families experiencing domestic abuse/substance misuse, Very young or new parent/carers	3	Wanted to know about activities available in local area

**Fig. 14 School Meeting Information**

## Seldom Heard Communities

For 2023 to 2024 reporting it was decided to match categories for ethnicity to national census categories from the 2021 Census, to better gauge levels of engagement from groups considered seldom heard based on ethnicity. The Census data for Peterborough shows a

population range of approximately 60% White British to 40% Other Ethnic Backgrounds (combined).

Ethnicity				
Category	Adult			
	21/22 (Baseline)	22/23 (New)	23/24 (Re- engaged)	23/24 (New)
White British	220	87	73	68
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	13
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	81
Total (Incl. White British)	65	48	40	35
Total (Excl. White British)	285	135	113	103
Percentage of parent carers who self-identify in categories other than White British.	438.46%	35.56%	35.40%	33.98%

**Fig. 15 Ethnicity Breakdown of Known Parent Carers where recorded**

FVP have been attending sessions held by the Julyabib group and have arranged an outing for the Aiming High Group (AHG) with a view to hearing what the parent at both want, providing access to sign posting and working to bring the groups together.



At a session specifically for the AHG the parents were asked what has or would help them in their time caring for a CYP with SEND, which led to the following comments:



Seldom Heard Sessions	Date	Number of Adults
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	11/10/23	7
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	1/11/23	5
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	29/11/23	7
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	13/11/23	13
AHG Ladies/FVP reps meal at Ibrahimi's	30/11/2023	19

**Fig. 16 Seldom Heard Sessions**

## **Current Themes/ Parent Carer Concerns**

The current themes being raised by parent carers and the parent rep team include:

1. Accessing education
2. Accessing health
3. Parental resilience
4. CYP mental health and wellbeing.

These themes can be identified via signposting contact, completion of surveys and feedback forms and conversations with parents at a range of activities and events.

## **Co-production and Change**

### Topics of Importance

There have been Tol's submitted relating to educational inclusion and health inequalities. Responses are still outstanding.

### Coproduction

Continued coproduction has occurred in relation to the Accelerated Progress Plan (APP) and work is about to commence on updating the Autism Strategy Pathway.

Initial discussions have also taken place regards development of a resource for parent carers now termed 'welcome to your SEND journey'.

### What is the difference?

1. There is an increase in the numbers of Seldom Heard parent carers engaging.
2. More parent carers are reporting an increase in wellbeing after participating in FVP activities.

## **Recommendations/ Forward Plans**

1. Work continues to engage with a wider more diverse section of the parent carer community locally.
2. To work with PCC and Health Partners to explore solutions to themes raised through parent carer concerns
3. To explore better ways of establishing outcomes and impact from the work of FVP.
4. To develop a toolkit of sorts with a range of information, advice and guidance to help parent carers navigate the SEND world