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# FVP Interim ICB Monitoring Report

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December 2023 to  
March 2024

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FVP Parent Representatives

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## Introduction

Funds to FVP have thus far covered core work, health inequalities work and EbE engagement. This report will reference all three areas and cover the following areas of engagement and PCF work:

- Parent Carer Wellbeing and Resilience.
- Family Based Activities and Engagement.
- Seldom Heard Communities.
- Co-production and Change.

As mentioned in previous reporting, there is some cross over between grant programmes with FVP whereby some work has taken place that meets the outcomes of more than one grant programme. Staffing may be funded via one grant with activity work being funded by another grant to maximise the number of beneficiaries and stretch how far funds go.

It is important to note that although the decoupling between Peterborough and Cambridgeshire has taken place due to the ICB/ ICS covering the whole area some shared work still occurs which can cause capacity issues for FVP. Other factors still causing concerns relate to the ongoing impact of the cost of living. These two factors 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 and wider support.

At March 31<sup>st</sup> 2024 FVP have seen engagement from 42 Fathers and 351 Mothers. Of those who have engaged overall 366 are new and 266 have re-engaged from previous years. Engagement has occurred via surveys, parent carer hub sessions, trips/ activities and signposting.

Where engagement figures are known 209 parents have taken 3 surveys and 27 parents took one FB Poll. Further data was gathered when parent carers claimed rewards for completing surveys in the form of vouchers. In this instance views on services more generally were gathered from 153 parent carers. More information is in the body of this report.

# Wellbeing

## Food Support

Food support continues to be an identified need, especially in relation to access to healthier food choices such as fruit and vegetables.

Adults	Children (Total)	Children with SEND
343	107	Unspecified

Fig.1 Numbers of adults and children receiving food

## Cost of Living Impact

The ongoing cost of living situation is also impacting parent carer wellbeing and consequently the ability to care for CYP with SEND. Further to data gathered last time, another small scale survey/ feedback form was created to seek views on what challenges are currently being faced

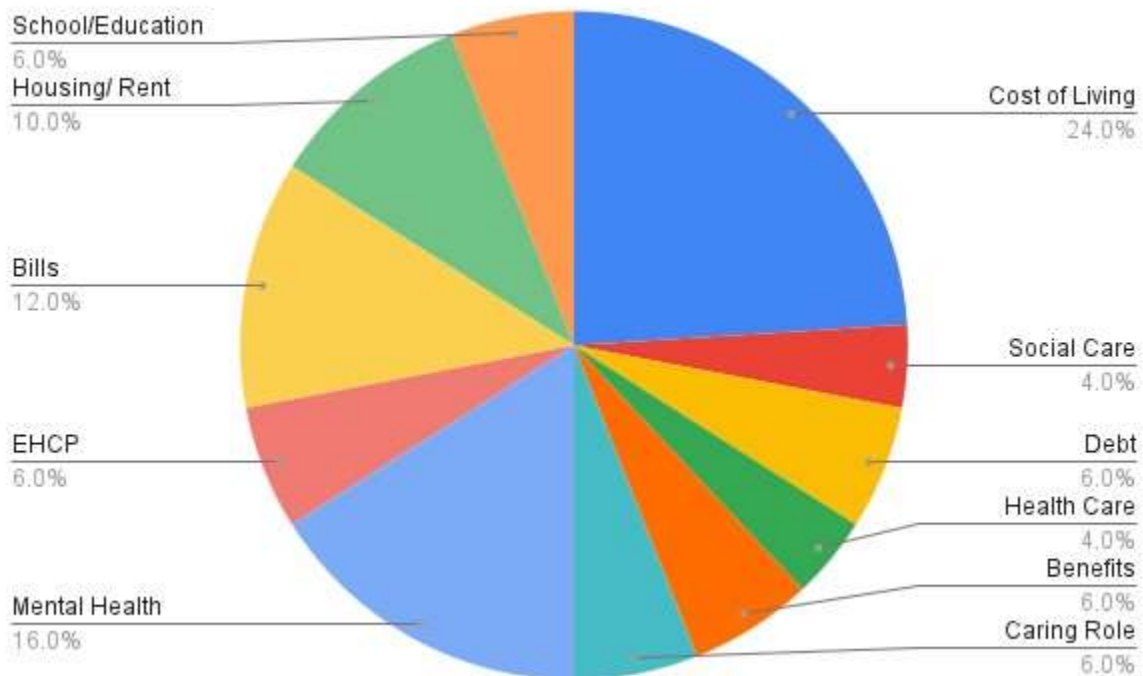


Fig. 2 Parent Carer Concerns

<b>To help us, please expand on any of the above options you have ticked. (If this question is not relevant to you, please put N/A)</b>
The raising cost of living makes it hard to survive without getting into dept.
paid house rent, water, light etc.
N/A
I am a single parent of children with additional needs and I find being able to be signposted for support /help and bringing others along who need support/advice.
The person that I bring to the Orton centre is special needs and this is 1 day of the week he really looks forward to and is very important social part of his week.
the problem is about stress
Try to get EHCP. Managing system etc.
I am happy with any help given.
N/A
Cost of living , everything is so expensive
N/A
Cost of living keep going up - pensions no change... yet
I am working but it is not enough to run the family so I have to come to the food hub/community centre for support.
N/A
N/A
Staying in safe house right now as await for better future
we are struggling with essentials , money
I have debts with gas and electric. I am carer for my partner who has bad mental health. My son has ADHD. I am currently living with someone on the sofa with my kids due to fleeing DV.

**Fig. 3 Household worries**

### 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 63 contacts recorded where parent carers new to FVP have requested signposting. Where direct signposting requests have been received it is known that 19% would be considered ethnicities other than 'White British'. The number of parent carers requesting signposting from seldom heard communities in relation to ethnicity is slightly higher in this quarter.

The preferred form of contact is via the website contact form followed by email. 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 similar themes as the previous quarter with the addition of short breaks:

### **Parental Resilience**

The decrease in Parental Resilience reported in our Annual Survey Report is still evident within signposting contact.

- *11, male, adhd/asd, behaviour issues, anger and lack of confidence, Heltwate school . I want some support with my son's behaviour, it's taking a toll on everyday family life. I want to be able to support him but I just don't know how. I'm at my wits end because I feel the years of fighting and still have it.....*
- *female - age 11 - school avoidance - sensory difficulties - mental health - social and emotional difficulties - on pathway for diagnosis of ASD/adhdAny break would be fantastic. This nightmare has been on going for months upon months. It has torn my family apart and I have lost my job of 17 years because of it. To see my daughter not coping with life is heartbreaking and it isn't fair on my young son to see and hear all of the difficulties she faces and causes.*

### **Education/School Attendance**

Parent carers have reported more issues with communication with settings, and lack of understanding/ support where there are behavioural concerns. School avoidance is on the increase based on the signposting calls being received relating to being out of education.

- *He is being disruptive in class, being silly, shouting out etc then getting isolations and being excluded for behaviour.*
- *7, female, waiting for EHC plan, she is on a part time school timetable at 2 locations. struggling with this. Need support with school and social services - they both have ordered that my daughter needs to go to a school location that requires me to travel all day on buses and wont provide transport or funding for it, struggling with money because i am in debt and the job centre have said that as of April I will be considered as able to work but not making myself available to work and so will stop my benefits. Education/ Health or Social Care Advice*

### **Managing Behaviour**

More parents are reporting concerns over their CYP behaviour and seeking advice and guidance on how to manage/ cope.

- *4 Yr old girl with developmental delay, ASD, hearing impairment. Challenging behaviour (hitting) currently in main stream primary, Help with behaviour management , Guidance on behaviour management*
- *.... worried about sons behaviour. Yr 7, Arthur Mellows School. Currently being referred and going through process for ADHD. SENDCo are not helping as he has no diagnosis yet.*

## Short Breaks and Respite

- *I have 4 children with additional needs ages 4,6,8,9. help with Short Breaks, Help with places that do activities for children with disabilities and holiday places too.*

## Information and Guidance

- *I am looking to see if you could advise on how to explain her condition to her younger sibling, or if there are any groups that her younger sister could attend.*
- *.....I am mainly looking at advise where I can seek legal aid and other help to get Oscar into school.*

## Family Based Activities and Engagement

### Activities

Family Based Event/Activity	Number of Adults	Number of Children	Purpose/ Outcome
13 x Community Cafes	263	38	Decreased isolation/ Social Cohesion
Hampers	144	193	Decreased isolation/ Social Cohesion
Activity World	42	87	Decreased isolation/ Social Cohesion
Activity World (19/2/24)	53	34	Decreased isolation/ Social Cohesion
Bowling ( 21/02/2024)	25	35	Decreased isolation/ Social Cohesion
Community Meal	27	33	Decreased isolation/ Social Cohesion
Flip Out	31	59	Decreased isolation/ Social Cohesion

**Fig. 4 Activities and Community Sessions**

Although some of this work is directly funded via a range of sources, the staffing in relation to administration through to delivery is funded via PCC, Lottery and ICB funding. These activities have led to better community cohesion, an increase in people volunteering including parent carers. Sessions bring people together to make new connections, learn about different communities across Peterborough, receive signposting to direct support services and at times just simply provide the opportunity to sit down and talk to someone.

*Kids are enjoying themselves and its very beneficial to children because its not as busy as our children do not like overcrowded places. There is also problem with money because those places are very expensive and unfortunately we do not have that much money*

*The children, really enjoyed jumping on the trampoline playing around, slide etc. children are happy and smiling, also helps my disabled daughter can try to jump more and more.*

*It get my son out socialising with less people and a quieter environment than what it would normally be*

## General Engagement

Engagement Sessions	Numbers
Gladstone Family and Children Centre - Julyabib project Muslim mums SEND Group	7
Gladstone Family and Children Centre - Julyabib project Muslim mums SEND Group	6
CDC	18
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts and Court of Protection 31/01/2024	3
CDC	18
CDC	20
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts and Court of Protection 31/01/2024	7

**Fig. 5 Information Sessions**

To support the work of FVP and raise awareness of what support and services are available the team hold a variety of information stands and coffee mornings/ afternoons, an outcome of which is increased attendance at the wellbeing activities and also parent carer contact for signposting. Working face to face enables better engagement and awareness. This also increases attendance on workshops and hub sessions.

CCG/ Training	Date	Number of Adults
EPS Parent Carer Hub Session	26/01/2024	3
EPS Parent Carer Hub Session	8/2/24	3

**Fig. 6 attendance figures for workshops/ hubs**

## Surveys

During the last six months of the financial year three surveys have been conducted where health has been mentioned a theme and these have seen 209 responses.

Survey Title	Responses
SEND Strategy	9
Annual Survey	188
PfA (Seldom Heard)	12

**Fig. 7 Survey Response Numbers**

The annual survey presented the widest range of views and concerns of local Parent Carers and the results showed six key themes:

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.

Views specific to health were:

<b>Please use the space below to provide any further information regards your experiences relating to health services</b>
No access to OT
No offer of any sort of help for my daughter s mental health
Health professionals have a lack of understanding of Down Syndrome, despite clear guidance on infections and low threshold for antibiotics.
My son is on 6 waiting lists for different services. Early Help referral was completed in July but I do not feel it has achieved anything and nothing has changed in terms of services coming on board.
Took years to get a diagnosis.
Very difficult to access and lengthy waiting times. Also once accessible seems to be for the shortest time possible.
Great team but under funded and short staffed so always a challenge to have regular appointments.
I had to go back to go several times to instigate referrals and referrals. It's frustrating that notes are not shared or read.
No funding available for FASD diagnosis
Not listened too. I've had to learn I myself, prior my son being diagnosed, to help him.
More funding is needed. They need to see and recognise the further help people with Sen require, rather than us telling and having to fight for everything.
Very happy with physio, ot. Happy to be back with peterborough CCN's.
if mobility support includes wheelchair services theyvare a joke and should be removed of their contract.
Community team at Child Development Centre (City care centre) are vile to say the least as they only do a tick box exercise. They are lovely people who cannot provide my child with the level if service he requires.
I am thankful for all what is but needs more attention face to face, not sending photos to Gp online. Disabled people want to be listened and received some peace of mind from doctors if needed. They may not understand that mommy sent a picture and doctor said "it's fine", they will trust the specialist sometimes more , than mother.
We had not help
GPs/drs don't necessarily understand the basics of autism or how ro deal with an autistic child.
My son is expressing how he wants to end his life and embarking on dangerous behaviour. He has



<p>hs two appointments with CAMHs, on3 as an emergency, but despite this, we have heard nothing further from them or been offered help other than websites to look at.</p>
<p>Identifying diagnosis took a long time over a year, this was a very hard time.</p>
<p>Cahms have been helpful for my daughter, she has had help with her anxiety</p>
<p>Accessibility is terrible. Support never tends to include parents who have no child care so we can't go to meetings. Places are set in remote or inaccessible areas. When your child can't use public transport and the DLA drag their heels to provide mobility it makes getting anywhere impossible and you become house bound. Seeing a therapist once every four to six months, I don't feel is conducive to actually helping them really progress. Someone on the spectrum needs regular visits to engage properly and feel comfortable. This is why things like the dentist are a nightmare. You are told "we can do some warm up appointments" then they are weeks/ months apart. It doesn't work. It feels like we are all being spoon fed a little help, to tick a box. Make information accessible to parents. It's hard for many to get online and do stuff like search for support. Provide one booklet with all of it in. So we have it at hand. GP Surgeries are a nightmare for my child. Regardless of my endless reminders he needs a quiet space. We rarely get it, if we do I am told off by doctors. I have been told by receptionists they just can't do it as doctors have asked them not to provide me with one. My son ends up down the corridor, over stimulated, desperate to leave. By the time he is seen, he is generally unable to settle. It is clear children with autism do well when they are prepared for what's coming, using social stories and pictures. It would be good if clinics etc had photos they could provide parents with, such as the waiting room, the room they will go in, the face of the doctor/nurse they will see. This would help reduce anxiety building up. And possibly make the appointment more successful. I also believe some sort of class for kids on the spectrum where they can rehearse such things would help. Like rehearsing going to the dentist and sitting in the chair. Anything to relieve anxiety and help the appointment be successful</p>
<p>After several appointments with speech therapy that did not seem beneficial to my child who is non verbal with limited understanding we were offered PACT which has been amazing</p>
<p>No help for mental health</p>
<p>The services we have received have all been extremely good but unfortunately time scales for waiting on appointments and then any form of support in the meantime has really made for a really hard impact on my daughter mental well being .</p>
<p>Camhs have supported child and family fantastically.</p>
<p>Our daughter suffers with constipation, which I believe is fairly common alongside autism. She has been prescribed meds for over 2 years now with no GP review.</p>
<p>Audiology is brilliant. ENT has been a poor experience throughout. We had great support in lock down with OT exercises for vertigo.</p>
<p>Waiting lists are far too long. We feel forgotten, still unsure when or if going to get seen. Kids need support as a matter of urgency. My son now has extremely high anxiety levels, on top of he's ASD ,due to a failing system, who. Left him so long to get seen, over 7yrs from when I showed my concerns. CAMHs kept saying they need more information (even though they had loads, and my son was excluded, regular exclusion all the time, also put into a behaviour school. All the school/other professional saw the ASD however CAMHs kept wanting more proof, before going on they long waiting list. Kids mental state worsening due to this.</p>
<p>15 months over due an appointment to follow up in 3 months due to ear problems identified at 3 months but due to his situation appointments have not been regular enough to identify and action issues.</p>

Very difficult to access and lengthy waiting times. Also once accessible seems to be for the shortest time possible.
Great team but under funded and short staffed so always a challenge to have regular appointments.
So needed to be seen in 3 months for a more accurate diagnosis – appointments repeatedly cancelled by NHS and 3-month follow up appointment due Nov 2022 is now scheduled for Feb 2024.
Ophthalmology have been excellent post adoption and he has had an operation that has improved his quality of life.
Our child requires help with SALT and continence support which we are struggling to obtain..
To long a wait it's just not good enough.
No help given nothing explained the systems is failing all special need children and their families
They pass the blame onto school and vice versa
Impossible to get OT involvement to support my child's sensory and regulation needs
There is no specialised therapy for Autistic youth locally. The CBT offered by Camhs does not help autistic people.
The doctors review and never include us only when they have decided what to do.
Too many waiting lists and long waiting or being forgotten
Long waiting lists pointless appointments to be put on more waiting lists they need to listen to the schools more
I have tried to have my son referred to camhs, got told to do the parenting course again, then once completed I had 12 weeks before he could continue with the referral. Applied online for it to be rejected as I need to contact the start to start the whole process again.
Diagnosed and discharged in the same appointment. Waited 2 years for cygnets course.
The problems we have had have been with my child needing audiology help which we have had a lot of problems with, without this help my child is possibly stuck in limbo not being able to achieve what he could if they had helped adequately from the beginning
xxxhas orthotics for.his flat foot however due to sensory needs he struggles.to.wear these
xxx also still see continence for bed time wetting
Been on waiting list for dietary services for 2 years. Given up hope of ever being seen by them. Speecy and language wasn't very productive.
Awful for most part.
Auditory processing difficulties were identified but referral to GOSH refused by local commissioners. Difficulty went undiagnosed.
Long waiting lists, parental exhaustion from having to constantly fight for and chase up support for your child, no timely support provided following diagnosis.
Terrible. I have lost my job of 17 years due to my daughters difficulties and I feel it is a never ending vicious circle! I feel so let down. It is and has effected my life and the people around me for too long with little to no support.
So far I feels listened to and supported
Physio is good .
My son has been refused referrals from the doctor as they said it's for the school to put in even with asking the last school for referrals they refused.

**Fig. 8 Health Experiences**

## 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).

<b>Ethnicity</b>	<b>21/22</b>	<b>22/23</b>	<b>23/24</b>
White British	195	306	466
Gypsy or Irish Traveller	0	2	5
Roma	0	1	2
Any Other White background	22	34	34
White and Black Caribbean	0	0	0
White and Black African	0	0	1
White and Asian	0	0	0
Any Other Mixed or Multiple Ethnic Background	3	5	8
Indian	6	13	20
Pakistani	11	30	63
Bangladeshi	0	1	1
Chinese	0	2	3
Any other Asian Background	16	0	11
African	4	21	33
Caribbean	0	1	2
Black British	1	0	3
Any Other Black or Caribbean Background	1	0	0
Arab	0	2	4
Any Other Ethnicities	0	6	9

**Fig. 9 Ethnicity Breakdown of Known Parent Carers where recorded**

For FVP of those who engaged where individual details are known the overall breakdown of household ethnicity is 70.08% White British and 29.92% Other Ethnicities.

Part of work in this reporting period also focussed on gathering the views of seldom heard parent carers in relation to their community and PfA

<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	She has no job experience but	Health experience is terrible at the	Friendship she is so important	No

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 is looking for part time volunteering.	moment. Doctors are not helpful.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
N/A	N/A	no	N/A	none
My child don't have EHCP plan I have applied but it got rejected so now school is applying one	My goes to school	No	Good	No yet
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	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	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.

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		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.		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
N/a	N/a	N/a	Friends and family help alot	N/a
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.10 PFA experiences**

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

The themes raised before are more or less the same:

1. Positive experiences do occur, but there is often the view that it is a fight to get to that point.
2. Decreased parent carer resilience; pare carers reporting being tired, stressed and overwhelmed much of the time.
3. Stresses on households relating to financial pressures due to the ongoing cost of living concerns.
4. Lack of reasonable adjustments being made by health services which leads to negative experiences.
5. Parent carers still feeling there is not enough information for them and their CYP in relation to SEND.

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 (ToI)

The first health based ToI of this period has been shared with health partners and is awaiting a response. The focus was health inequalities especially for families with CYP who are neurodiverse.

## Coproduction

Some coproduction has occurred in relation to the development of the Autism and Learning Disability Pathways

### What is the difference?

Here is it easier to share the views of parent carers directly rather than make strategic commentary.

<b>What difference has attending the above made to you and your family today? (If this question is not relevant to you, please put N/A)</b>
Lovely to engage with the community
N/A
Opportunity to catch up with family and friends
We feel less isolated and don't struggle as much to feed ourselves and family. Also we can look after ourselves with hygiene products issued and got into less debt as we can afford to pay essential bills.
The person who I bring here supported really enjoys being here as he knows everybody here and has a really good support with them.
The cafe on Wednesdays makes me happy , I can mix with the people in my age . I am please to see them and talk to them.
Meeting other people , talking .
Helps with food and helps a lot.
N/A
meeting family we don't normally get to socialise with
Making new friends.
Gets me out seeing people, gossip+ news etc.
It has provided support to my family and with food and toiletries especially. I have met new people and made friends as well.
Being able to meet with family and friends in a safe space.
Life improvement for my family.
It makes my family feel loved, socialising, making friends, getting to know and be close to people.
A big difference . It has supported me to my family big time
Have social phobia and the cafe has really helped me integrate into the local community-especially as I was new to the are last year .I was also able to access help from Family Voice with form filling.
Made new friends. Got me out of the house, helped me with dog food.

**Fig. 11 Difference Made**

## **Recommendations/ Forward Plans**

1. Further exploration of health concerns and a focus on sharing key sources of information and support (i.e health passports)
2. Work continues to engage with a wider more diverse section of the parent carer community locally.
3. To work with PCC and Health Partners to explore solutions to themes raised through parent carer concerns
4. To explore better ways of establishing outcomes and impact from the work of FVP.