
FVP Interim Report

January to March
2023

FVP Parent Representatives

Introduction

This is the fourth and final 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. The focus on the impact of the cost of living continues and an analysis of the end of year survey will be included in brief.

FVP has a new team of 5 parent representatives who between them cover 35 hours of work; mostly meeting attendance, information stands and document reviews. One parent rep focusses on sign posting as the numbers seeking support have increased greatly. 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 0 Fathers, 24 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 21 opportunities enabled 436 adults and 32 children people to get involved at some level.

Participation/Engagement/Involvement January to March 2023

Headlines

- 1) 51 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) 266 parent carers have participated across 3 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) Parent carers reported the ages of their children/ young people as between 2 to 25.
- 5) 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.
- 6) Evidence is both qualitative and quantitative in nature.
- 7) Ethnicity has been self-reported as; White British, Gypsy or Irish Traveller, Roma, Any Other White background, Any Other Mixed or Multiple Ethnic Background, Indian, Pakistani, Chinese, African, Black British, Any Other Ethnicities

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 one sessions taking place attended by 7 new parent carers. The session covered creating your own resilience toolkit. The SENDIASS and EPS hub have taken place in this 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	11	3

Table.1 Numbers of adults and children receiving food

Of the households where data is held over 50% report having an adult with a disability most of which relate to mental health. Where provided the following are reasons for seeking support:

The cost of Living is really affecting me
Yet to receive salary to get some stuff for myself
I been without job a while and I had some bills not paid for December, just need some extra help while sorting out bills.
the reason why I request this support is because only one other member of the family work
No money
Sometimes its hard for me to get to a shop so these donations are very helpful and received with gratitude
Cost of living
Cost of Living
Cost of Living
I can't pay all my bills and still manage shopping
Cost of Living
Cost of Living
I find it expensive to use taxis to the shops I also find my pension doesn't go very far its paid monthly
Money doesn't stretch far enough

Coming through time and again across the quarterly reports 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.

Hybrid Workshops

1 virtual and 2 hybrid workshops have been 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 (Creating your own HeartMath Resilience Toolkit)	10/1/23	7	Mental wellbeing coaching
ICB	Sendiass P/C hub	26/1/23	3	Signposting and support
ICB	Sendiass P/C hub	9/3/23	4	Signposting and support

Table. 2 Attendance Information

CETR Attendance

There have been 14 CETR sessions in this quarter covered by 3 Experts by Experience (EbE). March was the busiest month with 5 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 30 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.

<i>I have an 8 year old son with Autism and I would like support with short breaks /trips</i>
<i>Parent Carer who has a 4 year old boy who in the process of having an EHCP put in place would like help with applying for a primary school for her son to start in September</i>
<i>Parent carer has a 17 yr old with Autism and a 15 yr old waiting for diagnosis for autism and an eating disorder she would like support/signposting with how to get a quicker diagnosis for her 15 yr old and</i>

<p>can CAMS neuro get a quicker diagnosis.</p>
<p>*** called asking for food support , I sent her the food support link.</p>
<p>*** has asked for food support and I have sent her the food support link 2 children</p>
<p>We have a child here at ***** and mum has concerns regarding ADHD and his behaviour. An EHA has been completed and we are just waiting to move to the next step. We have implemented things here at pre-school which seem to slightly help and have tried to support mum to mirror these at home but she says they don't work. I wondered if you have or know of any drop in sessions she could attend to give her extra support at home while we wait for Early help support.</p>
<p>Lady has called about her daughter who is self harming she goes to **** and was seeing CAMHS, her education is suffering and she would like signposting and support to help her daughter.</p>
<p>Daughter turned 16, PIP been incontact asking daughter to make application/ talk on phone. Daughter does not understand, no-one has explained about appointeeship. Call after 2pm as mum works</p>
<p>good afternoon my name is ***** i am a parent of *****whom is 14 yrs of age he has several additional needs and has been threw alot if difficult truma threw his life up untill recently he attended ***** , and had a full ehcp and also is under early help team , i have made contact with you to see if i could find out weather provide any events supervised in the school holidays period , one of ***** trumas is he was attacked ***** by 6 youths his first time out in the community hes has not been out in that area for 9 months he will only go out in out of areas unless supervised , i am looking for clubs that he will be able to attend to help build his confidence and get him back out in the community , i am a single parent that does no drive, but hopefully there are some close by , just seeing what options there are for him please feel free to email me</p>
<p>Hi I'm looking for activities for my daughter. I am homeschooling and would like some support around this . Kind regards</p>
<p>Hi my 14 year old daughter is currently at an eating disorder unit but I am wondering where I can look for home help when she is discharged as I work part time diagnosed with LCH in her spine four year ago and CRMO in her clavicle she is under ***** hospital. She was diagnosed with PTSD, anxiety and anorexia and is under CAMH. She is waiting for an ASD assessment. Thank you</p>
<p>***** would like to speak to Asta ,because has spoken to her in the past about being evicted from the house she has been living in.She has an autistic child. ***** has contacted us first time on 30/09/2022 and now she called us because she hasn't received any support anywhere and is being evicted from the second house too.</p>
<p>***** would like to know who to contact as son is 4 years old with an EHCPin place and school have said he can no longer have one to one as there is no money. the one to one was already set to start very soon but they have oulled out of it so she needs help</p>
<p>Lady called she has a 5 year old autisitc boy who is falling behind at mainstream school she would like advice please on whether to keep him at the school or apply to send him to a specialist school</p>
<p>***** was brought here by someone from the Aiming High group, asking to join the group as well. I spoke with her and her daughter has just been diagnosed with Autism. I asked her to sign up to our mailing list as well, explained a bit about what we do, and gave her a leaflet with contact details..</p>
<p>Ive known ***** - **** is autistic. I have forwarded email to ***** outlining an outline of key points to do with an EHCP review that has been applied for which was supported by his current school. School requested, Medeshamsede. This has been declined and then appealed which the decision has been upheld. SENDIASS are also involved. Would like any advice going forward and would like to meet or talk to discuss.</p>
<p>**** attends our craft group and I have spoken to her before about what we do. Her 11 year old son has ASD is about to move up to secondary school (finds out on 1/3). He is currently at ***** , but since they changed their SENCO she feels he's having no support and despite her reaching out to the new one she has heard nothing back. She is currently completing the SIGNET course and she wants to speak to someone about what happens next and what she can do to support her son.</p>
<p>****, age 8, male, learning difficulties and speech delay, **** School year 3 Short Break like some support with my child. Some activities taking him out and about to meet children with same problems.</p>

Her son is waiting for ASD assesment . He goes to Ormiston Bushfield Acadamy at the moment, but since junior school had SEND issues. Since starting secondary school his behaviour took very bad turn , he had 4 suspensions , disciplinary meetings. School and Senco are not looking into SEND but puting all to the behaviour issues. Mum needs some advice because they have been waiting for ASD assesment for a really long time , have no official diagnosis and she thinks that school isn't very helpful.

Lady would like any information on any challenging behaviour courses in the peterborough area and parenting skills class course for an undiagnosed 13 yr old with challenging behaviour

I've been passed your message through various sectors I am asking for some help or support to help me with my daughter or maybe some knowledge on things that can be put into place.

I am looking for a Ukranian translator who can help to faciliate a meeting between us as a school and a parent of a child with additional needs. SENDIASS suggested you may be able to help.

7 year old daughter showing signs of autism, but also masking at school. Younger son been diagnosed. Had opportunity for diagnosis but parents in denial, then COVID came. Now trying to write up for EHCP and wants to discuss it with someone please, Daughter currently in class with only 20 others and has good TA, plus Family support worker visits home. Calm in class but comes home and has meltdown, uses ear defenders. Good verbally as far as copies phrases in the correct context but doesn't really seem to understand (so says 'that horse is galloping' but wouldn't be able to say what galloping is) often hates wearing clothing or will only wear certain textures, but again, none of this comes out at school. Please can we chat to mum about it and the application for EHCP? Thanks

I work within the 0-25 Disability services of Children social care. I have a couple pf parents that are struggling with behaviour management for their children with additional needs. I was wondering if there is any support your services can give to them.

Mum has phoned us because she and her two kids have moved to Peterborough from ***** in February this year. Her son , age 12, has Autism and Down syndrome he is not at school at the moment. Mum would like to find a place for her son in a special school. Spoke to social worker about it a month ago but haven't heard anything back . She would like an advice and support with many things because she is single parent , she is not driving and her husband has died too.

Mum has phoned her 12 year old with a diagnosis of Autism is being bullied at school and would like some advice as she doesn't feel the school is being supportive enough mum can hardly speak English and I have asked Asta to phone her and she has said yes this is fine (lady has already called about herself as she is suffering from depression).UPDATED 31/03/2023. Had a phone call from ***** , they have contacted us on the behalf of ***** in the past and were checking if anybody have spoken to ****. I was told that mom would like to move her son to the school that is closer to them but schools nearest to them say that they can not take him becausee there are no spaces. **** needs an advice on how to object that and prove that her soon should be given a place in one of those schools.

Mum has called asking for advice/signposting for her 8 yr old son diagnosed with Autism she has just called CAMHS and they have advised to call us, he goes to St Michaels school and she doesn't feel he is getting on very well he is running around at school during the day and says his education is suffering.

Needs a support with her child's EHCP plan.

Good morning,

I was told to get in contact by my mother who has been in discussion with *****regarding your services and my son *****.

My son was born at 28wks and has numerous disabilities. He has hemiplegic cerebral palsy as well as being certified blind or severely visually impaired. I have separated from my husband and we are co-parenting however me and my partner are his main carers. So many professionals are involved in his care and keeping track of the appointments has been very challenging, especially as we both work full time. At the moment, he does not have a nursery place or care setting and my mother cares for him 5 days a week. I have not been able to find a local nursery that has capacity to take him or is suitable for his needs. I am getting assistance through a family worker but this still has not been progressed despite me and my mother repeatedly asking all involved professionals for support with this.

My partner is considering dropping out of work entirely to become a carer for ***** even if a nursery place is eventually found, to be available to take him to his appointments and care for him on the days he is not in nursery. I have an appointment with a family worker to complete **** application for DLA,

but after that I am not sure what, if anything, we may be entitled to to support us further. Any assistance or advice would be keenly appreciated.

Mum has contacted us because her daughter has been diagnosed with ADHD, she has couple more children and her partner's 2 children sometimes is staying with them too. She needs an advice on housing . She mentiond that she doesn't quite qualify for the 3 bedroom house but said that she needs it a lot because her daughter with ADHD has to share the room with her sister and things get really tense because of it.

Fig. 3 Parent Carer Concerns

Of the parent carers requesting support ethnicity (self-declared) puts those seeking support in this quarter at 50%. This would appear to show that parent carers from seldom heard communities are still trusting FVP more as a source of signposting and support, and are more willing to raise concerns and issues.

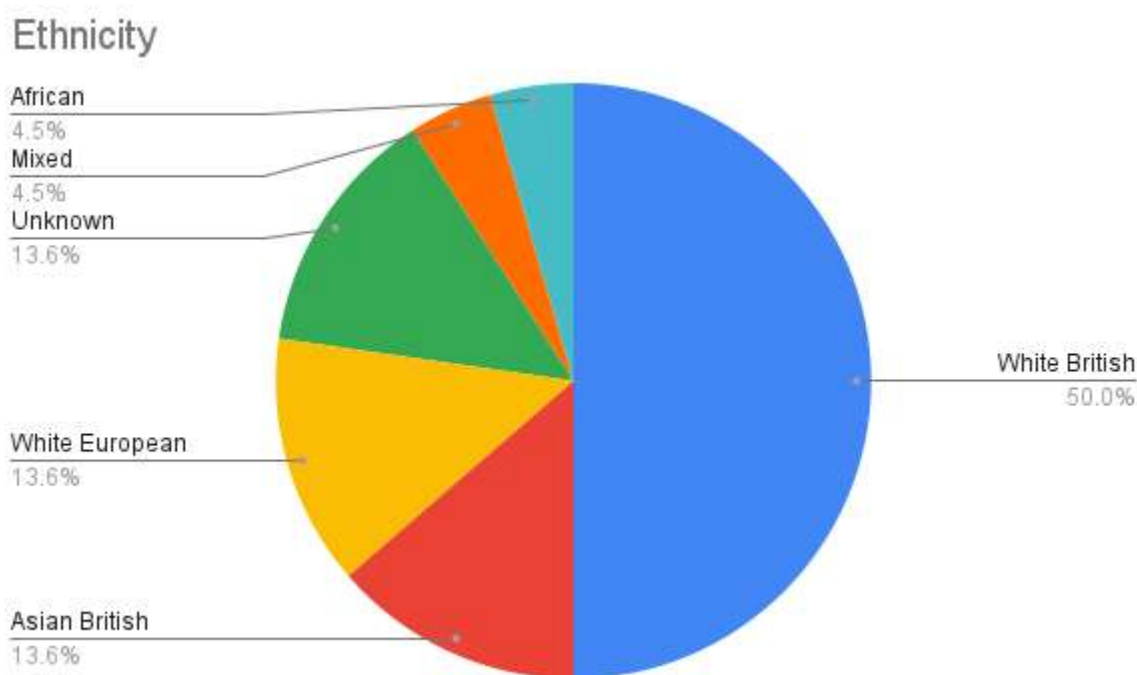


Fig. 1 Ethnicity of parents seeking support

Wellbeing and Family Based Activities

Funding	Family Based Event/Activity	Date	No. of Adults	No. of Children	Purpose/ Outcome
DEFRA	Community Cafe	4-Jan-23	28	5	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	4-Jan-23	11	8	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	7-Jan-23	11	4	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	9-Jan-23	8	6	Decreasing isolation, community cohesion, mental well-being

DEFRA	Community Cafe	11-Jan-23	36	6	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	11-Jan-23	12	8	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	14-Jan-23	11	6	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	16-Jan-23	10	6	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	18-Jan-23	26	2	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	18-Jan-23	12	9	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	23-Jan-23	7	3	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	25/01/2023	35	3	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	25-Jan-23	13	0	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	1-Feb-23	34	8	Decreasing isolation, community cohesion, mental well-being
PCC	Community Litter Pick and Meal	4-Feb-23	4	3	Decreasing isolation, community cohesion, mental well-being
DEFRA	Community Cafe	8-Feb-23	36	1	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	8-Feb-23	16	2	Decreasing isolation, community cohesion, mental well-being
PCC/ ICB	Activity World	10-Feb-23	20	32	Decreasing isolation, community cohesion, mental well-being
Waitrose	Community Cafe	15-Feb-23	34	6	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	15-Feb-23	11	4	Decreasing isolation, community cohesion, mental well-being
Waitrose	Community Cafe	22-Feb-23	32	3	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	22-Feb-23	21	8	Decreasing isolation, community cohesion, mental well-being
Waitrose	Community Cafe	1-Mar-23	30	4	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	1-Mar-23	13	6	Decreasing isolation, community cohesion, mental well-being
PCC	Community Litter Pick & Meal	4-Mar-23	6	3	Decreasing isolation, community cohesion, mental well-being
Waitrose	Community Cafe	8-Mar-23	22	3	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	8-Mar-23	7	9	Decreasing isolation, community cohesion,

					mental well-being
Waitrose	Community Cafe	15-Mar-23	27	3	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	15-Mar-23	20	11	Decreasing isolation, community cohesion, mental well-being
Waitrose	Community Cafe	22-Mar-23	31	3	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	22-Mar-23	8	3	Decreasing isolation, community cohesion, mental well-being
	Community Cafe	29-Mar-23	35	2	Decreasing isolation, community cohesion, mental well-being
PCC	Warm Hub	29-Mar-23	7	2	Decreasing isolation, community cohesion, mental well-being

Table. 3 Activities and Community Sessions

Schools Data/ SEND

Surveys

During the fourth quarter three surveys have been conducted with 266 responses.

Survey Title	Responses
Annual Survey	244
SEND Transport	10
Your Say	12

Table. 4 Survey Response Numbers

The full analysis of the annual survey in particular is available to view via FVP's website <https://familyvoice.org/surveyreports/>

Your Say Data

The Your Say form was completed by parent carers from the Aiming High Group (AHG) at a session designed to facilitate their engagement. The AHG are primarily mothers who self-identify as British Asian and who CYP with a range of complex needs. Results from their responses to a series of questions about education, health and care are as follows:

Do you have any positive feedback to share about Education	Do you have any neutral or negative feedback to share about Education
Yes, very helpful	My daughter has been out of education this year due to her health.
Doing well in his studies	The lack and slowness for SEN help from PCC have made things very difficult and always rushed
My child has not attended school this year as she is on end of life care	The waiting list for SEN provisions is appalling.
My daughters playschool have helped me	Given label to child, once diagnosed no support

navigate and complete the EHCP application. They have gone above and beyond for my daughter even without 1-1 funding.	afterwards, keep asking myself to do triple p programme have done couple.
She has just started school didn't really need anything yet.	No just very slow .
I don't have any concerns regarding her education as it was medical conditions not affecting her ability in education.	Post 16 is not good
My son doing A levels did well in GCSE eldest daughter going to university.	
Yes until child hits 16	

Table 4. Education Views

Do you have any positive feedback to share about Health Care	Do you have any neutral or negative feedback to share about Health Care
My daughter is end of life care now since EACH have been involved and she has started medication to help her with pain.	Lack of support
Don't really get that much help from health care.	Wheelchair services are crap, waiting time is so long
She is still under care until she is 16 yrs old gets seen 1 time a year with consultants at Peterborough City Hospital and Addenbrookes Hospital.	I think my child was failed by health as last year her health deteriorated but they kept discharging her because they didn't really know what was wrong with her I felt as enough tests were not done.
Yes, excellent	After a week of trying to call finally got through to a customer service agent still received no help.
	Yes no support from SENCO, school. Too late to detect problems with child.
	They are very crap - not giving results, long waits.

Table 5. Health Views

Do you have any positive feedback to share about Social Care?	Do you have any neutral or negative feedback to share about Social Care?
In march 2020 during covid my daughter started getting 2-1 care which has been life changing for her.	Social workers keep changing or leaving
Little Miracles and Family Voice have been so helpful and very supportive.	Yes keep changing social worker or youth workers.
They are very good, very supportive, quite early on too.	
Social care are very good at help	

Table 6. Social Care Views

Any other services you wish to mention?	Any other feedback
Sen support	Louise and Kelly are lovely ☐ so are the other ladies
Family Voice have been brilliant in listening to my views and signposting	Needs help with post 16 young adults working especially disability and employment, help with filling employment forms.
Little Miracles and Family Voice have been so helpful and very supportive.	Family Voice absolutely lovely, loved the help I got from them and the information in need.

She was diagnosed when she was 2 years old and was put on a chemotherapy treatment for 2 years and is currently in remission and has no problems was under community nurses services.	This evening was very good.
Just the NHS, very little support for mental health.	
Family voice and Little Miracles are brilliant with help	

Table. 7 Other feedback

Engagement on Social Media

The Facebook group has not been fully utilised this quarter due to capacity within the PCF team. However more generally social media engagement figures are good.

Channel	March 31 st 2022	Increase in 2023	March 31 st 2023	% Change
Twitter	1244	61	1305	4.90%
Instagram	690	62	752	8.99%
FB Page	2181	638	2819	29.25%
FB Caravan	825	40	865	4.85%
FB Group	526	59	585	11.22%
FB caravan group	231	7	238	3.03%
LinkedIn	180	114	294	63.33%
You Tube	0			

Table 8. Social Media Stats

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 7 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. Table 9 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
37	62	1	12.5	75.5

Table. 9 Breakdown of Time spent at Strategic Meetings Jan to March

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

Table 10. Range of meetings attended

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 now being distributed but capacity within the team is hampering progress. Ideally FVP require a dedicated participation lead for schools.

Annual Survey Themes

Overall there is a general move towards more positive experiences in relation to assessment of need, involvement in SEND services and support for those CYP with needs. However communication is in general still an area requiring improvement. More work is also needed to help parent carers know where to find information to navigate the world of SEND, which would decrease some stress.

SEND at a strategic level is working well, operationally for individual parent carers some work is still required to improve participation in particular. It also appears that more issues for families occur at setting or service specific levels as opposed to organisational levels in

particular for PCC. Parent carers made the following suggestions/ comments at the end of the annual survey:

<i>More support and more guidance is needed</i>
<i>We need more support as parents to make choices for our young people and the help and support for there transport because the bus pass allowed them to get on the bus 9.30 and they have to go to education in time and how the college if they provide lunch and how safe it is to leave him there for the first time</i>
<i>Give more support where needed to children and there parents.</i>
<i>Communication with parents</i>
<i>Staff at schools to be better trained on conditions such as asd to help more children cope better and be better understood.</i>
<i>Stop using a one size fits all approach and treat child, young people and parents and carers with respect and as individuals.</i>
<i>Employing more people so that there is more support given to family's with diagnosis and not an EHCP.</i>
<i>real interviews need to be done with children and their parents as a 1st course of action, an actual trained human reviewing the child in their current setting will flag up a high percentage of children that just need to be waived through and put in the queue to get the EHCP assessed & written. for example you don't need 3 years and 20 forms to tell that a child who is non-verbal and supposed to have started school 3 months previous is going to need additional help, it should be a formality not an assault course to get this though to an ECHP decision. also, next time please get someone professional to design the survey, if a section being filled out or skipped is dependant on how you answered a previous question then that needs to be build in to the flow of the questions, i.e. "you don't consider yourself a carer" is no then tell them to skip the next 20 questions.</i>
<i>Better communications regarding special schools and how to apply</i>
<i>I believe children should have more access to resources regarding mental health.</i>
<i>More research when you leave the hospital and more support groups advistised as unless you go looking you don't find</i>
<i>Professionals should talk to parents directly when assessments are directly linked to home situations.</i>
<i>Parents need to be made aware of all resources that are available and appointed a key helper so they have someone to turn to when things are difficult. Some people have never experienced autism or similar conditions before and have no idea what to do in certain circumstances. If we didn't have a helpful nursery I don't know what we would have done</i>
<i>Communication needs to be improve between parent and the school and listening to each other to support the child best, and not telling parents things can't be done due to funding or the waiting list is too long so we won't bother</i>
<i>Accept referrals don't make everything a battle, when us parents are already fighting for support from wherever we can get it from</i>
<i>We feel if SEN services can take initiative to include self defensive skills such as karate or some kind of martial art to SEN kids who are able to be physically participate as this will help them to feel protected and also help in many ways.</i>
<i>If we as parents if SEN kids want to train our kids with extra activities such as piano or roller skating for my child it is very difficult to find as no one is trained to so or we are not able find that information. Also, after school facilities for the SEN kids that can help working mothers. We don't know how to get these information.</i>
<i>The ability to be able to contact a department would be helpful, we appreciate these departments are very busy but often time can be saved if requirements are dealt with at instigation.</i>

<i>Different Peterborough health/help services need to communicate more with other workers. To provide the right information.</i>
<i>More investment in support for young people so that they achieve positive outcomes. Waiting for children to fail is unacceptable. Early intervention has been proven to result in better outcomes for children. Peterborough SEN services are very disappointing!</i>
<i>You need to make services easier to access and re look at your specialist settings criteria. Many autistic children are struggling in mainstream. Every day is a challenge for my son and I feel he would thrive if he was around children similar to himself and teachers understood his needs.</i>
<i>Earlier identification.</i>
<i>I think parents should have access to a hub and that links schools and council. I feel there needs to be a bridge between services and schools. schools also need to train staff better to understand the needs of autistic children.</i>
<i>If the possibility of new special needs schools is not an option, then PROPER training of some teachers to deal with autistic children, not just saying they can cope, and then not being able to cope. At the end of the day it's our children who suffer.</i>
<i>Faster process and follow up on the care that is needed</i>
<i>I think the biggest change would be the waiting times for help. My child's school put her issues down to laziness for years and refused to listen to my concerns. Now we are going into the 5th year at primary school still without any answers to what's wrong. It's been 2 years that the school have registered there's difficulties and we're still waiting to be assessed.</i>
<i>The meeting should be more frequent</i>
<i>For once put yourselves in our shoes the struggle is real until you don't see it from our point of view changes will never succeed</i>
<i>Quicker results</i>
<i>Easier support for parents with teens who have mental health/ behavioural needs.</i>
<i>I have called police multiple times about meltdowns at school and taken over 2 years to finally get a social care assessment started</i>
<i>More monitoring and consistency with primary and secondary ensuring schools are all following the same guidelines</i>
<i>More training to notice adhd in girls in primary school</i>
<i>Better training for staff.</i>
<i>Better understanding of the needs of the young people and families. Stop trying to use a one size fits all aproach</i>
<i>It would be great if they visited schools more with parents so they would be able to support and help parents with send who are not knowledgeable in this process.</i>
<i>More joined up working between children's and adult services. Meaningful co-production where more than lip service is paid to experiences and struggles. A better appreciation of 'invisible disabilities' and more inclusion earlier on with 0-25 team, especially in the lead up to transition.</i>
<i>Improvement in picking up problems & acting faster. To sign post help ASAP.</i>
<i>For the EHCP pathway to be easier & more accessible</i>
<i>Early intervention saves money and prevents all sorts of later problems. Invest in young local people, and you will get that invest back and more!</i>
<i>SEN Services in schools needs massively improving.</i>
<i>Better accessible Information for parents and carers, better forums for parents to question schools/health providers actions or lack of without them taking offence or trying to cover up their negligence. Better pathways for children who mask or are not the a typical stereo type for the disorder.....things need to change now! Better access to assessments before leaving primary to ensure we have things in place in secondary so we are able to have more positive</i>

outcomes as young adults for better transitions into adulthood. Ensuring focus is not just for educational purposes as a child who has social skills communication skills has confidence in themselves to attempt jobs will still have a chance to get educated later in their life! As a parent I want my daughter to be comfortable in herself to know she does not have to meet all the so called peer targets in education but just do her best! What is so concerning is who is advocating for those who are unable to understand or navigate this ridiculous maze we call education/healthcare!

Peterborough SEN should increase their support requirements

The ehcp assessment really needs looking into too many children falling through the net. I also think more information needs to be given out and explain what services can help and what they do. I had to find a family support worker myself through Bernardo's. I would have been nice to feel supported after my son had his diagnosis as I felt alone and I was so scared. I was professionally a carer in the community before having to stop working for my children. Too many appointments.

Employ 10 more xxxx as she is the one member of staff who takes the time to answer your calls, emails, help etc. Cannot praise her enough

More access to advice. I am new to this and knowing who to speak to or where to go is the hardest part so far.

Universal access to parenting programme prior to early help.

Access to therapeutic parenting programmes and attachment pathway locally.

For young people to be able to attend any hospital /consultant in the UK for diagnosis or treatment and not be turned down on grounds of funding

Multi agency parents drop in service , advice and signposting.

I think that the staff who get employed to organised EHCP's need to know the law in regards to when they need to assess. They also need to be fully aware of what should and shouldn't be written in an EHCP. They should listen to staff and parents to ensure that the provision is written carefully. If they do not have enough information about certain areas they should actually use the assessment period to get professionals in rather than making up targets themselves. They need to actually put exactly what children need and not what they think.

There needs to be a much more cohesive approach; the system is too fragmented and much time/resource is wasted by having to try to access triage pathways etc and having to discuss the same things over and over again with different agencies. There is also a "it's not our problem" mentality from each agency, trying to pass the responsibility onto one of the other agencies e.g. Education to Health, Health to Education and Social Care etc.

SEN Coordinators should listen to parents so the child's needs are captured and appropriate help and services are documented in the child's EHCP. Schools should be supported to hire more TAs to promote 121 support to children with special needs. No support outside educational setup is provided at the moment even though the service includes Health and Social care.

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SEN support should be for all children with a diagnosis, the experience I have had is that my children are all academically very capable and appear to be coping but have significant difficulty with social and especially emotional health. There is no support available for this. My eldest child has started secondary school unable to have a conversation with an adult and therefore unable to ask for help. Schools and preschools need better training in identifying SEN and what support they can give to children who struggle in these areas not just those who are struggling academically.

<i>they need to help in arranging child need instead of only focused on documentation .</i>
<i>Better coordination between education and social care, greater proactively by social care services</i>
<i>Senco need help to inform teachers of a special needs child, always a challenge for parents, even worse in secondary school my daughter struggled so much and still does.</i>
<i>Once your yp reaches a certain age a parent cater should have help with stepping into adulthood housing etc</i>
<i>Help needs to be more ready available and a quicker, easier process needs to be made. I have been battling for 5 years for help and things are still the same as they were if not worse.</i>
<i>The waiting time for appointments and assessments and time to complete ammed care plans</i>
<i>Should have easy access for people in need. It's a struggle to find the help first of all then it's a challenge to get that help on time.</i>
<i>Should have easy access for people in need. It's a struggle to find the help first of all then it's a challenge to get that help on time.</i>
<i>The system needs to be easier for parents it takes far to long to get your child diagnosed and even when they are the struggle still carries on for parent and child</i>

Seldom Heard Communities

Seldom heard engagement with parent carers and community leaders has continued this year utilising online meetings as detailed below in table 11 and also face to face via some of the sessions mentioned in the first part of this report.

Information and Awareness	Date	Number of Adults	Theme
AHG Get Together	13/2/23	18	Inclusion
SHCF face to face session	02/02/2023	1	Inclusion
SHCF face to face session - Healthwatch	02/03/2023	3	Inclusion

Table. 11 Seldom Heard Engagement

Approx where known 36.2% of the queries coming though from parent carers requesting signposting are from parent carers from local seldom heard communities.

Overall there has been an increase in engagement from parent carers from seldom heard communities:

Ethnic Category	Parent Carer	
	21/22	22/23
White British	196	42
Gypsy or Irish Traveller	2	0
Roma	0	1
Any Other White Background	20	9
White and Black Caribbean	0	0
White and Black African	0	0
White and Asian	0	0
Any Other Mixed or Multiple Ethnic Background	8	1

Indian	8	5
Pakistani	12	5
Bangladeshi	0	0
Chinese	0	2
Any Other Asian Background	0	0
African	7	6
Caribbean	0	0
Black British	1	0
Any Other Black or Caribbean Background	0	0
Arab	0	0
Any Other Ethnic Group	6	0
Rather Not Say	0	0
Unknown	36	71

Table 12. Parent carer self-identified ethnicity

Ethnicity	Overall Parent Carer Numbers	CENSUS 2021	Percentage of engagement from parent carers
White British	238	128353	0.19%
Gypsy or Irish Traveller	2	551	0.36%
Roma	1	938	0.11%
Any Other White Background	29	31562	0.09%
White and Black Caribbean	0	1990	0.00%
White and Black African	0	1627	0.00%
White and Asian	0	2021	0.00%
Any Other Mixed or Multiple Ethnic Background	9	1979	0.45%
Indian	13	7169	0.18%
Pakistani	17	16972	0.10%
Bangladeshi	0	442	0.00%
Chinese	2	990	0.20%
Any Other Asian Background	0	5228	0.00%
African	13	6225	0.21%
Caribbean	0	1419	0.00%
Any Other Black or Caribbean Background	0	1107	0.00%
Arab	0	897	0.00%
Any Other Ethnic Group	6	5023	0.12%

Table 13. Parent carer ethnicity compared with census data

Parent Carer Ethnicity

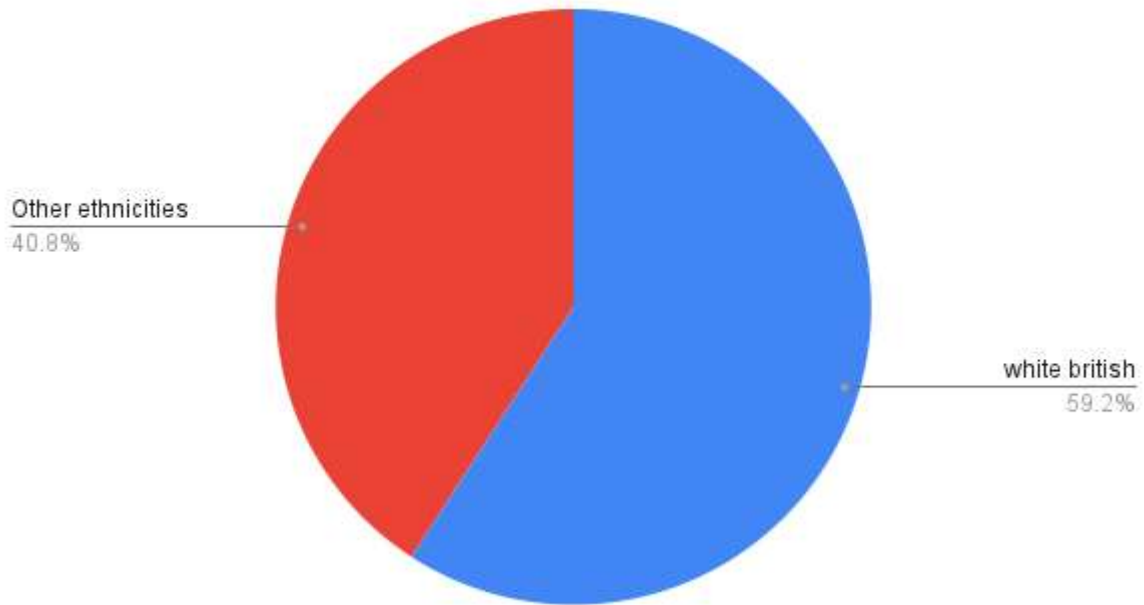


Fig. 2 ethnicity of parent carers engaging in 2022 to 2023

Census data for 2021 demonstrates there is an approximate 60/40 split between residents who identify as White British and then other ethnicities which is matched by the engagement rates of parent carers as seen in fig.2 and tables 12 and 13.

FVP would seek to engage with the following parent carer communities going forwards as well as work towards increasing numbers in general

White and Black Caribbean	0
White and Black African	0
White and Asian	0
Bangladeshi	0
Any other Asian Background	0
Caribbean	0
Any Other Black or Caribbean Background	0
Arab	0

Co-production and Change

Topics of Importance (Tol)

There has been one Tol response produced in the past quarter. The response relates to Preparing for Adulthood (PfA). More work is needed relating to Tol going forwards to keep to timescales and ensure responses are easy to digest and show any real differences being made. Some suggested changes to the Tol process are as follows:

1. Tol should be 'deep dives' into a specific issues and include additional intelligence eg comparisons to statistical neighbours or national findings, case study.
2. Tol to include suggestions and ideas for improvements from parents or other areas.
3. Tol based on emerging trends in other reports
4. 3 – 4 Tol per year

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. Expand the range of opportunities to enable parent participation.
4. Work with partners to help increase understanding of the different levels of participation and embed opportunities for coproduction.
5. Refocus the work of Tol's to close the feedback loop and show further parent carer involvement in the overall process.