
FVP Interim Report

April – June 2023

FVP Parent Representatives

Introduction

As with all previous PCC grant reporting in line with the reporting format introduced in the last financial year, to match annual reporting requirements this report will be set out in sections that match predicted outcomes. The report will also have a final statement detailing potential recommendations and ways forward. The only difference for this financial year is that this report will no longer contain a section on work relating specifically to health funding. Previously PCC and Health funds were combined which is no longer the case. The report will be set out 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 and wider support.

Work has moved consistently back to face to face methods with some online participation via survey completion. This has also been possible through grant funding from Peterborough City Council, Cambridgeshire and Peterborough Integrated Care System, The Department for Education (DfE) and The National Lottery (tNL) amongst other funding sources.

Over the past three months (April 1st to June 31st) FVP have seen engagement from 6 Fathers, 55 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 20 opportunities enabled 308 people to get involved at some level.

Participation/Engagement/Involvement April – June 2023

Headlines

- 1) 133 named parents in total have been involved at some level.
- 2) 30 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) 6 new fathers have been involved.
- 5) Parent carers reported the ages of their children/ young people as between 2 to 25.
- 6) Participation methods used included; online surveys, 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

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. This means some information may appear in more than one monitoring report.

Joint funded work streams relating to areas such as food support and access to signposting has been included here due to their overall impact on mental 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.

Support has been provided to 2 known households as well as attendees at the FVP café and food hub. Of those known:

Adults	Children (Total)	Children with SEND
2	5	1

Fig.1 Numbers of adults and children receiving food

Both households report having low income levels, and struggling to manage in particular with school holiday periods.



Kerry, who volunteers at FVP after asking for help for herself and her son, said:
*"Even the cheapest food is going up a lot so coming here is really helpful.
"I'm helping by giving other people the courage to come and to talk, and to collect food as well."*

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. Families are seeking support across a broader range of areas, and these are related to much more than education.

There have been 38 contacts recorded where parent carers new to FVP have requested signposting. Where direct signposting requests have been received it is known that 30 would be considered 'White British' and one has self-identified as a father. The number of parent carers requesting signposting from seldom heard communities in relation to ethnicity is lower this quarter but this is already changing as this report is being written and in the next quarter figures will be different.

From these and other contacts with parent carers the team of parent representatives at FVP have identified the following themes:

Health, MH and Education

1. Parents difficulty accessing MH, services for their children either via GP or support from school
2. (..... even threatening a parent with fines as failing to recognise anxiety (maybe be burnout) GP refusing to refer to CAMHS, school will only recognise if CAMHS involved, GP refuses to help.)
3. Focus on suspensions/ exclusions by schools, sometimes many in a day and 'punishment' for responses in line with their disability. A push by schools to permanently exclude more challenging children, even sending parents info for other schools (!)
4. No notice to parents for reducing timetables, including pre school provision.
5. Schools not taking into account child's wishes (they love their school, friends, etc) and not working with the child where the child is at.
6. Schools fobbing off parents by not doing the things they should be doing, hoping parents do not know any better. Adding to parent's tensions, then as always parent's blamed for complaining.
7. Lack of resilience/ tiredness in parents newly diagnosed children, needing breaks, help with understanding their children, how to adapt and needing more support/ advice.
8. Some pre-schools/ nurseries much better than others- more training needed at a younger level.
9. Lack of special school places, parents willing to try new provisions being proposed, but if they don't work preferring special school options.

Lessening resilience of children/ teenagers with other needs, worsening MH, lack of support schools/ GP's, self harm and not addressing stress when there is previous history.

1. Lack of understanding/ empathy by GP's of what Autism and MH is (sorry to put in same sentence but this is coming up a lot at mo), and how this is severely impacting children and their families. Lack of diagnoses and a reluctance by GP's to refer to various places, assessments etc adding to the issues.
2. Difficulties accessing Sendiass (Aware of new changes to team which should help going forwards)

Food Support

1. mainly for more specialised foods that they cannot access because of cost of living crisis.

Housing and Homelessness

1. Threats of evictions as rents being out up, it is very difficult for any parent in that position with children with additional needs having the uncertainty of so many variables adding to already tense situations. Working parents too, struggling on top of the challenges they already have.
2. Families with children disabilities, especially ASD/ ADHD, etc needing own bedrooms

Single Parents

1. Feeling lonely and isolated, across cultures.

Activities for disabled children and families

1. Very much called for, especially for 'no judgement'
2. Parents diagnosed/ identifying as ASD, starting to see this come through more ... that there challenges are being ignored by various services (eg schools, education, health that maybe involved.)

DLA- PIP

1. Parents often worried for this transition, seems daunting, needing support to do these.

Parent's Resilience

1. Lack of breaks, constant tiredness, pushbacks from school and health services, lack of resources

From feedback gathered in relation to the signposting being offered it is clear the service is appreciated. Examples of responses received to the questions; *What difference has your contact with FVP made to you?* And *What did you do after your contact with Family Voice for example feel confident to contact organisations when you require?* :

Knowing
where to go for
support

Family voice has given me support, good advice and also sign posted me to get further support, also been to events with my children which are lovely so can meet up with other families and carers so can then give each other support

Someone understanding, something to try, (initial suggestion worked but then passed back to originating issue ...(following today's call more suggestions to try)

Felt more confident to speak to other people for help , for example sen at school

Continued with the course of action I had already put in motion

Wellbeing and Family Based Activities

Funding	Family Based Event/Activity	Date	Number of Adults	Number of Children	Purpose/ Outcome
	Easter Eggs 2023	03/04/2023	7	0	
	Community Cafe	5/4/23	19	3	Decreased isolation/ Social Cohesion
	Community Cafe	12/4/23	25	9	Decreased isolation/ Social Cohesion
	Community Cafe	19/4/23	24	2	Decreased isolation/ Social Cohesion
	Litterpick	1/4/23	7	7	Decreased isolation/ Social Cohesion
	Community Cafe	26/4/23	19	2	Decreased isolation/ Social Cohesion
	Community Cafe	03/05/2023	14	2	Decreased isolation/ Social Cohesion
	Litterpick	06/05/2023	11	11	Decreased isolation/ Social Cohesion
	Summer Barbecue	06/05/2023	45	36	Decreased isolation/ Social Cohesion
	Community Cafe	10/05/2023	22	2	Decreased isolation/ Social Cohesion
	Community Cafe	17/05/2023	21	2	Decreased isolation/ Social Cohesion
	AHG Pamper Session	18/5/23	5		Improved Mental Wellbeing
	Community Cafe	24/05/23	18	1	Decreased isolation/ Social Cohesion
	Activity World	26/05/23	30	62	Decreased isolation/ Social Cohesion
	Community Cafe	31/05/23	16	1	Decreased isolation/ Social Cohesion
	Litterpick	03/06/23	6	0	Decreased isolation/ Social Cohesion
	AHG Bowling	01/06/23	27	29	Improved Mental Wellbeing
	Community Cafe	07/06/2023	27	2	Decreased isolation/ Social Cohesion
	Community Cafe	14/06/2023	21	1	Decreased isolation/ Social Cohesion
	Community Cafe	21/06/2023	22	2	Decreased isolation/ Social Cohesion
	Community Cafe	28/06/2023	23	3	Decreased isolation/ Social Cohesion

Fig. 2 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.

The community centre has given us a great base for our craft club and by attending I now feel more confident plus have made new friends.

The day made a difference in the sense that she spent the rest of the day outside and learning to wait in queue.

Had a great time at the pamper session where there was a light lunch and snacks provided to suit both veg and non veg. over all the session was so relaxing,i was given some great beauty advice and lots of freebies to take home! I cant wait for the next session!

It brought a lot of joy and happiness



General Engagement

Place of Information Stand	Date	Number of People Spoken to	Number of Parent Carers
Asda Information Stand	4/4/23	150	8
Easter Sport Hurt at Central Park	8/4/23		
Lime Orton Family Day	8/4/23	19	16
Asda Information Stand	13/4/23		
Coop Food & Supermarket, Orton Shopping Centre	16/5/23	70	5
Central library	23/5/23	50	10
CDC	25/5/23		6

Fig. 3 Information Stand Data

To support the work of FVP and raise awareness of what support and services are available the team hold a variety of information stands, 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.

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 request 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	Work Required
Children and Young People's Guide	Coproduction	Coproduction of a new resource for SEND Families
Community Short Breaks parent/carer consultation	Consultation	Recommissioning for the Community Short Breaks offer in Peterborough – sharing of information with Parent Carers
ADOS information leaflet for parents	Consultation	Review of information leaflets and letters to parents regards ADOS
SAMS interviews	Other	Request to join interview panel
Annual Survey Review	Other	Request to review annual FVP survey with 0-25 team
Carers week celebration Saturday 10th June	Other	Take part in attending the event and share the information
CPFT website	Other	Request to test the CPFT website translate button to see whether it is possible to find the information in different languages
Social Care Review	Document Review	As you know it was reported to us that an external agency had been commissioned to carry out reviews of people who access social care. This was due to the back log that had occurred due to the pandemic. Could you please read and let me have any thoughts or questions
SEND training for councillors	Other	Deliver SEND training to cllrs.
Workshop for Parents and YP		Share flyer for upcoming free workshop on internships
Community of Practice Involvement	Meeting Attendance	Deliver presentation at community of practice meeting about who FVP is
SEND Newsletter	Information Sharing	The SEND newsletter aimed at families is due to go out in June with a deadline of 7th June for content to be sent. Request for articles
Draft Carers Strategy	Consultation	Views on carers strategy.
Service user Feedback Design (CPFT)	Other	CPFT are hoping to get some feedback from the parent carers about our services to inform our transformation.

		Request to provide some feedback and codesign the questionnaires
PfA Document Feedback	Document Review	Review of draft guide for PfA as there have been lots of changes due to qualification changes nationally.
Postcard Feedback	Document Review	<p>SEND Information Hub posters and postcards update</p> <p>So what I would like from the group is as follows please:</p> <ul style="list-style-type: none"> • What should the wording be? • Are the photos suitable? • Are the organisations listed on the postcard the correct ones? • Should the information include logos for health and Family Voice as well as the council? • The plan is to produce posters, postcards and business cards. Also a tablecloth and a pull up banner. Is there anything else we should consider?
"Feedback on post 16 education offer 24-25" with you.	Document Review	Review of post 16 document
Home & Community Support Parent Carer Rep on Evaluation Panel	Consultation	Tender involvement – question from PCC would it still be an option to have a parent carer rep on the evaluation panel using these timelines?
SENDIASS Interviews	Meeting Attendance	Parent rep on interview panel form new SEDIASS lead
Hydrotherapy - call for evidence	Other	Seek evidence regards Hydrotherapy as EHCp provision
MHST - Review	Consultation	The MHST programme is considering potential future enhancements to the MHST offer, including the range of children and young people's mental health and emotional wellbeing needs which are supported. Views are being sought.
CYP Mental Health Board ToR	Coproduction	Review of ToR
Feedback wanted: Wheelchair User Forum posters	Document Review	<p>What do you think?</p> <p>The idea is that posters will not be dated by having meeting dates on it.</p> <p>We know it needs info on where to find out more information: the phone number, email, website (the QR codes are designed for people to use with their smartphones and connect to the websites, but we know not everyone has these!)</p>
Home & Community Service User Panel	Information Sharing	<p>The SUN Network are working with Cambs County Council on the retender of Homecare provision locally.</p> <p>There are three work strands and The SUN Network are hoping to support 8 people to be involved in each strand.</p> <p>The strands are:</p> <ul style="list-style-type: none"> • Mental health

		<ul style="list-style-type: none"> • Complex learning disabilities • Generic care 65+ <p>Share details</p>
Parent Carer views on PfA experience	Consultation	Tasked by PCC to gather views of 18-25 year old on what is working, and what isn't working, with services, across education, transport, housing, health, social care, etc to be used when OFSTED visit in
Travel training Resource and launch working group	Document Review	Provide feedback on the final version of our Travel Training Manual.
Afternoon Tea	Other	Invite to session at Lime Orton Academy
Children's LD health needs assessment	Meeting Attendance	I am working with the ICB on a population-level health needs assessment, looking specifically at the health needs of children with a learning disability. This is to support some of the wider system work.
SEND Focus Week	Work Shop	SEND focus week where we deliver a week of workshops dedicated to families and professionals providing support around specific areas.
Review of PfA strategy slides	Document Review	Review slide deck
situational / selective mutism pathway - Peterborough working party	Meeting Attendance	Involvement in new work programme relating to situational mutism
PfA Document Feedback	Document Review	Provide feedback on new quick access guide
Mystery Shop - CPFT website	Other	Search for and provide feedback on the parent carer pages of the CPFT website
Changing place survey	Other	Complete a survey about the current provision for accessible toilets at CDC

Fig. 4 - 34 requests for FVP involvement (April – June)

Surveys

During the first quarter seven surveys have been conducted with 185 responses.

Survey Title	Responses
Transport Strategy	30

Fig. 5 Survey Response Numbers

Most surveys will have a micro report detailing basic findings and recommendations. The transport strategy feedback survey is available to view via the survey page of FVPs website. Overall findings from the survey were:

Overall, the strategy was viewed positively with respondents showing that the proposed changes would make a difference to their families. There are still some concerns reflected in the wider comments, which would

match with the other data gathered in previous surveys. These relate to communication, responding to concerns/complains appropriately and transport provider training, especially in relation to neurodiversity. The underlying issues need to be resolved so that the children with SEND as well as their families can have a more positive experience.

There is some scepticism amongst the respondents whether the proposed changes will be carried through, which is concerning. This may be because either parent carers have had a previous bad experience with the service or due to wider issues with SEND services overall.

Your Say Forms

A form called 'Your Say' is used to gather more general anonymised feedback regards services relating to Education, Health and Social Care. These forms have predominantly been completed by parents who self-describe as Pakistani British. They have children with range of complex needs and physical disabilities.

Do you have any positive feedback to share about Education	Do you have any neutral or negative feedback to share about Education
the senco team at stanground academy are supportive	Not enough resources for children with SEN. No flexibility in the way children learn.
Really helpful amazing	he needs laptop as subjects on line
helpful and manners	things take too long to get done
I think they do the best they can with the time and money they have	Make sure people are being safe
yes at the moment I think everything is working well but also ongoing training should always be considered	No regards into parents concerns say one thing and do another
My son is happy in his education	More training and funding should be allocated to charity and organisation support education
My sons SEND school provides safe, engaging environment which ahs caused him to thrive develop communicate is amazing . My daughters school has given support but a lot more work compared to my sons	The lack of funding to the school is limited and the waiting times are hugely disruptive
yes everything is good	Mainstream needs to provide more and better support in students and parents
We are very supported by the boys education providers who ensure regular reviews they do not receive any addition funding for this	When adults teachers leave school this should be communicated to parents arguments over leaving 5 mins early one day a week when website states one dismissal time and admin team refuse to allow him to leave Things like this show should be handled better than threatening parents with part time time tables
yes school - marshfields mainly a brilliant school	The SENDCO has 6 hours each week that is not enough time for all the SEND children within the school They need

	more funding more hours to help support our children
Schools sometimes do young carers programmes at their school or nurturing programmes	Sometimes there is a lot of a wait for special needs places or schools are quick to say that they cannot meet need
My daughter does not attend school due to her change in health but she loves swimming/hydropool so she attends 4 times week in school to use the hydropool	16 yr old currently doing GCSE's but has not had someone in person to read exam questions 14 yr old is struggling with emotions less time in classes
Pleased with how far he has done well in school	Only possibly some kids been placed in the wrong settings
School always helped her	school does not want to help to get a EHCP plan as child is 2 yrs behind everyone in his class
My daughter struggled a lot at mainstream school but since she started at a special needs school she has improved a lot	
It is a good way to teach children	
Education have been very understanding and have accommodated for my daughters needs	

Fig.6 Views of Education

Do you have any positive feedback to share about Health Care	Do you have any neutral or negative feedback to share about Health Care
helping a lot to daily routine independence learning	Difficulty with getting GP appointments.
Well I think the health care sector is striving hard to meet the needs of patients and service users but more support should be allocated	not a lot of support
Medical professionals are very understanding and listen to parents	Staffing level and work pressure is affecting the sector and patients
Diabetic care is very good in Peterborough the waiting times are quite short so that is a bonus	Waiting lists are too long, limited support once you diagnose parents have to fight for every bit of support its not easily given
They were helpful whenever we need	sometimes its hard to get a referral to a specialist or a different hospital
	I am very frustrated when it comes to health care all professionals are saying different things and in the meantime my daughter is in a lot of pain not sleeping hurting herself and crying because of pain
	Very difficult to get an appointment at GP practices
	Trying to get allergy test for celiac disease but was told to watch what he is eating
	again takes a long time to get to see the right person
	Its been good until when covid hit to now then it became very difficult
	no waiting times are poor and support extremely limited

Fig. 7 Views of Health

Do you have any positive feedback to share about Social Care?	Do you have any neutral or negative feedback to share about Social Care?
They are really helpful	Things have been very hard and I felt in the dark a lot of the time
very satisfied and helpful	EHCP process is long and difficult
Social care is working hard to provide standard care and supporting vulnerable people in all areas. I think they are doing amazing work	Previously being told you don't meet the threshold Domestic violence from your child is serious and mentally draining and challenging as a single parent
yes I get help always when I need it	If social worker is going to stop working with child needs to give notice
Social care is all fine my daughter is 2;1 care 24 hours	Would like a social carer for 16 year old
Currently got youth workers for 14 year old really good help	
social worker has been very helpful with sorting out staff to do with his mum and him	

Fig. 8 Views of Social Care

Any other services you wish to mention?	Any other feedback
Not really I am happy with everything	Really good service and helpful
we are happy with everything	satisfied and helpful
Family Voice has done some lovely work	Thank you for everything you do for us
Family voice provide a hugely valuable space for parents and carers	Good thank you
Social services are very stretched especially when it comes to occupational needs assessments	As a parent its hard to adapt to a neurodiverse child you have to change your parenting style having charities to talk to for support is so supportive to me . When you have school refusal you fell very isolated.
More activities to do in half term holidays	I am happy with all currently
The SEN team are brilliant big shout out to the EHCP team and educational psychology team as well wonderful work	

Fig. 9 General Views

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

1. Health services are stretched and waiting times are too long
2. Funding for schools impacts on provision
3. Overall the feedback is more positive, despite issues and concerns.

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 5 parent carers employed as parent reps and they share 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
40	62	18.5	0	80.5

Fig.10 Breakdown of Time spent at Strategic Meetings Apr-Jun

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

The following section of this report contains direct contributions from the parent rep team and Forum Coordinator. Work to establish the schools offer to local settings is under way and two meetings have taken place.

School Sessions	Date	Number of adults
Beeches Coffee morning	16/5/23	5
Newborough Coffee morning	23/5/23	7
Lime Orton Academy	June	8

Fig. 11 School Meetings

Further information can be found in this table regards progress of the offer so far.

Setting	School Offer Requested/ Purchased	Meetings Occurred/ To Take Place	Number of Parents engaged with	Outcomes for parent carers	Funded directly (fee) or via PCC grant
Northborough	Coffee Mornings	1	5	Parents were able to self-refer to short breaks and SENDIASS	Funded by PCC
Peakirk-cum-Glinton	yes - coffee mornings	First Coffee morning 18/09/2023			Funded by PCC
Werrington Primary		Dates to be confirmed in September			Funded by PCC
Orton Wistow,	Coffee mornings	First meeting			Fee secured for

Nene Valley and Woodston Primary schools		will take place 19/09/2023			coffee and signposting sessions
Ken Stimpson	SEN Information Report	Awaiting the dates suitable for the SENCO			Fee secured for SEN information review
West Town Primary School		Attended their Summer Fair	10	Parents of newly diagnosed children needed more information on the services available	
All Saints Primary School	yes - coffee mornings	2	7	Self Referral to incontinence services for 3 families; families have been referred to the relevant services	Funded by PCC
Eye Primary School					Funded by PCC

Fig. 12 School Offer Record

General themes from Schools engagement

- Lack of Family Voice awareness from school staff and some SENCOs.
- Awareness of the support available with SEN reports, signposting, building the bridge between parent carers and professionals.
- Awareness of parent support that Family Voice offers through trips, signposting, parent carer hub sessions and training.
- Lack of awareness of how engagement with parent carers can help them to improve the services and, in turn, outcomes for their children and young people.

Barriers

There have been certain barriers that we had to overcome in order to improve the engagement with SENCOs. Because school office staff were unaware of FVP they were not always passing the information (meaning our leaflets) to the relevant people and can be very reluctant to share the information (e.g., who the SENCo is). This has proven to be the main barrier to engage with schools, however it became apparent that the more face-to-face contact we have, it then changes people's perspective. This led to changing the way Parent Reps engage with schools in order to improve the outcomes.

Outcomes/ Difference

All Saint's primary school – case study

Family Voice Representatives had 2 coffee mornings at All Saint's school with another 4 dotted throughout the next Academic Year. The demographics of this schools is very diverse, with a lot of families classed as Seldom Heard – this provided us with an excellent opportunity to engage with them as they may not have gone to an event in a different setting. Although the setting is very welcoming to their parent carers, due to the language and other barriers, they struggle to engage with some of them. The SENCo also felt that a lot of them could benefit from some external services, however she was unsure of what other help was available to the parent carers and how to access it.

It is important to note, that some of the Seldom Heard parents, albeit a little disconnected at first, have found our coffee mornings very useful and continued to engage with FVP during the next coffee morning. The increase in confidence means that they will not only feel less isolated, but will be able to join FVP at other activities, access the help they need through other services, which, in turn, will improve outcomes for their children and families and them a voice that could help shape current and future services.

Narrative on issues/ themes mentioned

- Little knowledge of NHS funded nappies/pull ups for children with SEND as parents are currently paying for them. All Saints have made 3 referrals since our first meeting. This will help parent carers access the right size nappies/pull-ups and will alleviate some of their financial burden that comes with sourcing their own nappies.
- Parents struggling with sleep patterns for their children and are unaware of any help available to them
- Parents with worries about the SALT services available to those children who are currently awaiting diagnoses.
- In order for parent carers to feel less isolated and more informed, FVP has shared a copy of SEND newsletter which gives information on groups, activities, trips and support over the summer holidays

What difference FVP coffee mornings made to schools (Feedback from SENCOs):

Working with Family Voice has been very important for our school over the last academic year. It has provided opportunities for parents to know there is a network of people they can talk to and ask questions to; we have learnt lots as a school community about the resources

and services that are just at our doorstep. Online courses have also increased the confidence of parents. I look forward to working with them more in the future!

Giving the parents a contact and highlighting that they can access support for their children. The parents gave very positive feedback to school staff about the session. Thank you very much.

Creating a space for parents to meet others, share worries, questions, being aware of specialist services having someone to answer questions SENCO/school cannot.

As you can see from the feedback above, SENCOs value our input and they feel we make a difference to their parent carers. SENCOs have highlighted how difficult it is to know the information that parent carers so desperately need, whether it is about what their children and their families are entitled to, where to go and seek help and support when the need arises, or what are other services available to them (e.g. carer's assessments, nappies, day opportunities for their children, family breaks etc). This information can sometimes be hard to find and as SENCOs feel already overwhelmed with their busy roles, they welcome us to their schools to provide the necessary information and help their parent carers.

What difference FVP coffee mornings made to Parent Carers (Parents verbal feedback):

My English is not very good, and I worry people don't understand me and that's why I don't speak a lot. Thank you for making me feel better about it, being patient and listening to me. I will speak with SENDIASS and use the DLA guide you told me about. If I need more information, I know who to call. Thank you for that.

I didn't know that there were other services available for my child, like short breaks, direct payments and many other organisations that can provide my child with some other activities during the weekends and school holidays. I didn't even know that the 0-25 Disability Team existed! My head is buzzing with all the new information you have given to us.

As can be seen from the information above, parent carers are not always aware about the services available to their children and families. They often feel 'stuck' in their own world and feel as if no one cares about them. They feel very empowered when finding out the information about different services and always tell us they wish they knew about it sooner. Parent carers feel more empowered to seek the help they need; they have better knowledge about their entitlement and feel relieved that the services they thought do not exist are actually available to them.

Lime Orton Academy - Afternoon Tea Report

There were 8 parents present. Most were busy catching up with each other.

I asked the family liaison for any issues that may have been noticing more than others, with the details below being provided:

Support

Families not getting the support they need,- Social Services, especially respite is very challenging to achieve.

Services

Across the board services are full to capacity

Direct Payments

Families need someone who can do the work that they can entrust their children to.

Biggest stand out, Transition and support around transition for their students, LA having final say where their students will go.

Positive story For the first time ever, this year one of their students has been accepted for 'SENSE' , normally a real challenge.

Lime Academy has a new parent group called 'Parent Voice', feeding back to the school re. their experiences.. I have asked if they have anything coming through as in any themes that they could share with us re. any general issues that would be worth knowing.asked me about what we do at FVP. I shared the various roles FVP has locally and providing parent's views for feeding into decision making by LA.

General Feedback from a family worker with a local charity

She is noticing lots of issues with children reception/ Yr 1 who are way behind their normal development. Teachers saying it's like they are doing the work of nursery and pre-schools, lack of communication skills, toileting issues, etc, things normally seen with younger children, impacts of Covid.

Seeing 4 year olds learning from 2 year old.

Classes being split into 3 to give more attention, however needs more staff, TA's and premises.Educating staff.

YR6 SEMH issues, usual things that occur like body development have not been around each other and missed in that development.

Example of son, age 15, really stressed, normal development environment in peer group missed.

Staff need educating for better understanding.

....., **Family support worker**

Would like to connect with, Peterborough Muslim Women's SEND group.

Punjabi community, cannot access translation on PCC website as many are illiterate.

Positive Feedback

..... parent, daughter 5 ½ yrs, complex needs. Had lots of praise for the services involved, including disability social worker, neuro disability team, hospice- support call and breaks .Her wellbeing team at her GP surgery are good, 'they make all the difference' they call her and arrange a check in every 6 weeks, offer of a phone call or visit... *she did add that she often feels guilty as she knows other parents don't have this level of support.*

Face to Face Sessions

Information and Awareness	Date	Number of Adults
SHCF Face to Face Session	6/4/23	4
Argo Lounge Coffee Session	19/4/23	4
Argo Lounge Coffee Session	17/05/2023	4
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts, Trusts and Court of Protection 12/06/2023	12/6/23	4
Argo Lounge Coffee Session	21/6/23	3

Fig. 13 Coffee and Information Sessions

Attendance at coffee meetings and themed sessions has been low, but they are well received and have resulted in parents following up with signposting requests.

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	199	54	34	15
Gypsy or Irish Traveller	2	0	1	1
Roma	0	1	1	0
Any Other White Background	20	10	0	0
White and Black Caribbean	0	0	0	0
White and Black African	0	0	0	0
White and Asian	0	0	0	0
Any Other Mixed or Multiple Ethnic Background	8	1	2	1
Indian	8	5	2	0
Pakistani	12	7	9	2
Bangladeshi	0	0	0	0
Chinese	0	2	0	0
Any Other Asian Background	0	0	5	0

African	7	6	2	3
Caribbean	0	0	0	0
Black British	1	0	1	0
Any Other Black or Caribbean Background	0	0	0	0
Arab	0	1	1	0
Any Other Ethnic Group	6	0	1	0
Rather Not Say	0	0	0	0
Unknown	40	67	8	38
Total (Incl. White British)	263	33	25	7
Total (Excl. White British)	64	87	59	22
Percentage of parent carers who self-identify in categories other than White British.	24.33%	37.93%	42.37%	31.82%

Fig. 14 Ethnicity Breakdown of Known Parent Carers where recorded

New Peterborough Faith Based Womens SEND Group (not Aiming High Group)

I was made very welcome, baked a lovely cake, and they helped me with parking.

Number of parents 5 including &

Caring together had been invited but couldn't attend this session.

Discussions

From the outset the ladies clearly shared a sincere love of their faith, shared respect, and how important it is in their family lives- this was a natural part of the conversation, rather than educating me... how important the Quoran is to them, and shared a story how a young ASD boy was able to recite the Quoran despite his many difficulties/ SEN needs, they felt that was amazing.

The ladies group explained how difficult it can be to come together and discuss disability issues as often it's taboo within families and friends. They are a mixed cultural group, and a couple have converted to Islam. One lady was recently bereaved and was just about holding things together for her children.

Group Lead Themes

1. I mentioned The Aiming High Group to *She would like to have their group shared by Aiming high*
2. had applied for a job with a charity, citing flexible working hours, when it came to the interview, that had changed somewhat. She has no family support. She felt as if she may be being discriminated against as it simply wasn't possible to do the hours

stated. She has 15 yrs experience and this was a basic admin role. They offered her a volunteer position.

Children's Issues/ Challenges and Signposting

1., 3 children, aged between 7 and 17. Youngest complex needs, Spina Bifida, ASD, hydrocephalus (?) Marfan syndrome, food issues, suddenly stopped all food including things they like; 11 yr old, suspected ASD, anxious about school and going to secondary- Hampton College- I suggested contacting Senco for a chat ahead of the school year to talk through concerns and raise the possibility of ASD..
2. concerns Autism and puberty in the future, possible PDA. Suggested PDA website for info and strategies. (When PDA was mentioned a few parents raised that as a possibility with their children)
3.has 5 children/ young people aged between 25 and 4. Four girls and one boy. One daughter has Epilepsy. Son has Microcephaly and is non-verbal with global development delay, mental age 12-18 months. Genetic, skips generations, possibly toxin/ Zika virus although feels more genetic. Family also experiencing grief due to close family bereavement. *would like to find other parents/ carers locally with children with microcephaly.*
4.son is 14, at Kings School. He is hyperactive. School put her son into isolation, no support. Global delay with ASD traits. Wanting to move schools, has spoken with Jack Hunt, I suggested contacting Sendiass. Son wants to move schools, very unhappy at Kings. *Would like info on holiday activities, he likes archery.*
5., child Yr 1, ASD. She was previously a TA, 17 yrs, Queen Katherine, left as no allowance to fit in with childcare. Annual Review, March, all ok in mainstream, was non- verbal, now communicating, now learning Quoran. Asked me about home educating, EHE and EOTAS,PB's, signposted to Fb groups to find out more and to come back to us if any more info.

General Concerns Arising from Meeting

1. More info EHCP's *The group would like a talk specifically about EHCP's*
2. *Kings School not catering for ethnicity, disability/ SEN* (..... shared that a child/ family she knows is having a good experience)
3. *Concerns across the group re. Autism and puberty- a lot of fears and worries,* (I shared that everything isn't necessarily bad or negative though it's a good idea to prepare for puberty with their children as can occur early in children ASD)
4. *Much concern across group re. sex education in schools, unhappy with sex education - too much, too soon, for children- too young.* Feeling lack of balance in this area of children's education.
5. *PDA mentioned by 3 parents and frustration Peterborough not diagnosing-* More help needed for parents to manage challenges, challenging behaviour, and their own wellbeing. I directed to PDA society website/ Fb group... info re PDA- clearer to see if that is their child or not - plus lots of info and strategies that may help either way.
6. *Autism Diagnosis- then what? Lack of support and info eg a young girl age 7, no support service* A talk/ meeting could be helpful. I said that for younger children there is a more joined up approach for the early years children.

Actions

1. Signposting relevant parent enquiries from meeting
2. For FVP to attend the next meeting.

AHG Bowling Session

Themes	Details	Outcomes
<p>Little to no knowledge about short breaks and other activities for children with SEND, especially during the school holidays. 2 families needed some help from SENDIASS and they were very happy to have them present on the day as they find the face-to-face engagement far easier and do not feel very comfortable speaking on the phone/emailing.</p> <p>One particular family, with very limited English, were unaware that their son was on an illegal part time table. Their child is attending a special school 1 hour a day, which starts after the other children leave the school. Information was given to parent carers about available offers, however they were extremely cautious when social services were mentioned, thinking that the only reason for the involvement from the services if the child's needs are not being met at home or there is a safeguarding issue.</p>	<p>30 parent carers attended and the team has spoken to every parent carer. Ongoing support needed from SENDIASS which has been arranged on the day.</p>	<p>Expanding our reach with Seldom Heard Families</p>

Fig. 15 Themes from Bowling Sessions

Other work as detailed in this report has taken place to include community leaders as well as parent carers from seldom heard communities together, by way of community based trips, activities and events such as a community barbeque that took place in May.



Fig. 16 Community BBQ Pics – Integration

Current Themes/ Parent Carer Concerns

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

1. Transport concerns – will the strategy really make a difference?
2. Lack of funding leading to poor education – SEND children not welcome in settings.
3. Increased waiting times to access health care.
4. Parent carers still feeling there is not enough information for them and their CYP in relation to SEND.
5. Decreased parent carer resilience; parent carers reporting being tired, stressed and overwhelmed much of the time.
6. Stresses on households relating to financial pressures due to the ongoing cost of living concerns.
7. Positive experiences do occur, but there is often the view that it is a fight to get to that point.

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 not been any Topics of Importance (ToI) yet. Two responses have now been received from the last quarter of the last financial year (PfA and Resilience) which can now be downloaded from FVP website.

Coproduction

Some coproduction has occurred in relation to development of the transport strategy, work relating to the Accelerated Progress Plan and a variety of documents relating to Preparing for Adulthood.

What is the difference?

We have seen increased take up and positive feedback from the schools offer work, with 10 schools signed up so far. One SENCO said about what difference the offer makes:

“Creating a space for parents to meet others, share worries, questions, being aware of specialist services having someone to answer questions SENCO/school cannot.”

When asked what difference the trips and sign posting had made to families two responded with:

“more confident to speak to other people for help , for example SEN at school”

“The day made a difference in the sense that she spent the rest of the day outside and learning to wait in queue.”

Parents and settings report differences on individual levels relating increased awareness of support, confidence in managing situations and changes in the behaviour of their CYP as result of all FVP have on offer.

Recommendations/ Forward Plans

1. Complete a ToI relating to educational experience and health waiting times
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.