
FVP Interim ICB Monitoring Report

April – Nov 2023

FVP Parent Representatives

Introduction

In previous years funds for FVP from the ICB and PCC were combined under an s256 agreement, with all reporting being combined. This financial year is different with ICB funding being paid direct to FVP. Funds to FVP have thus far covered core work, health inequalities work and EbE engagement. This report will reference all three areas and cover the following areas of engagement and PCF work:

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

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.

Since 1st April 2023 FVP have seen engagement from 22 Fathers, 174 Mothers. Of those who have engaged with FVP in this period 195 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 122 opportunities enabled 2980 people (adults & children) to get involved at some level.

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 XX known households as well as attendees at the FVP café and food hub. Of those known:

Adults	Children (Total)	Children with SEND

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."*

Cost of Living Impact

The ongoing cost of living situation is also impacting parent carer wellbeing and consequently the ability to care for CYP with SEND. Feedback forms have elicited the following concerns relating to cost of living:

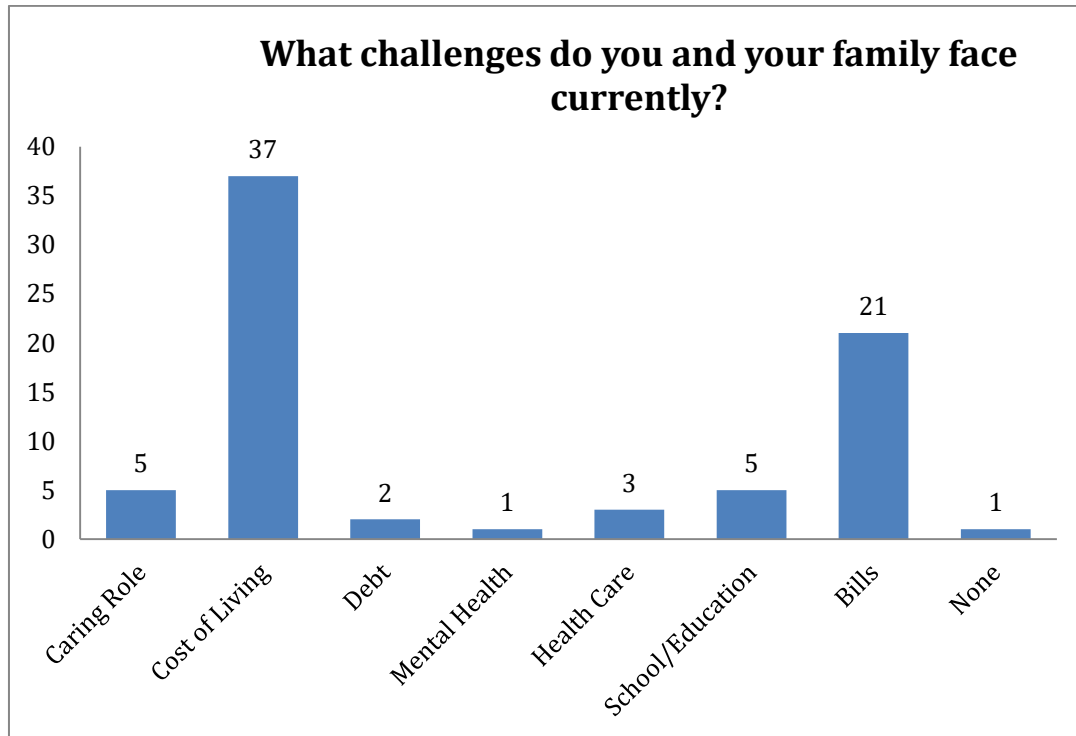


Fig. 2 Parent Carer Concerns

Further Details on Concerns
Disability is a challenge and hard to live with. As a single special needs mother it can be so lonely and hard work. Can be a struggle on a daily basis
David has had to give up work to care for me so we have not much money for food and I am really depressed as he is not in work.
Rising bills ill health everything so expensive
Struggling getting veg and fruit
At the moment cost of living is high and my family and many other families are affected by it
Money to struggling families
My daughter is 19 yrs old and when she is 20 her child benefit and tax credit will stop I am not sure what to do
Hard to buy things these days so expensive
Cost of living affecting living standards
We area a 2 working family but a low income family with medical mental health needs
Food is too much money bills are huge

need a job
Dentistry
School are being judgemental and not helpful and making us look like the bad parents
general price rises
Children not receiving adequate support to meet their send needs and or disabilities parents left in a crisis
cost of living has affected us with bills which are very expensive prices are always going up
Cost of living is proving to be hard for everyone it means that even if people can afford it it is very tight
prices all up
mental health
cost of living is really tight I believe it is a challenge to every family
Everything has risen in price and costs more less disposable income for families
Cost of living all prices up is difficult sometimes to manage with leaving little
Things are expensive in every day cost of living on everyone
Cost of living is killing us all
Would like help caring for son
Dealing with autistic ADHD outbursts and aggression also cost of living while a full time home carer and mental health due to the above
still in hostel
Need more money
To give opportunity to get friendly support
My daughters child benefit and child tax will stop in full time education and cannot claim extra benefits
the team provided a nice day out so i am grateful
food and bills you cannot see a doctor anymore it is very hard
Son is due to start reception in September based on pre-school report they don't think they can meet his needs I find this frustrating as he is always wanting to learn something new and I feel like they are not giving a chance to try mainstream school so dreading the start of school

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 147 contacts recorded where parent carers new to FVP have requested signposting. Where direct signposting requests have been received it is known that 60% would be considered 'White British' and seven have self-identified as a father. The number of parent carers requesting signposting from seldom heard communities in relation to ethnicity is higher in this quarter.

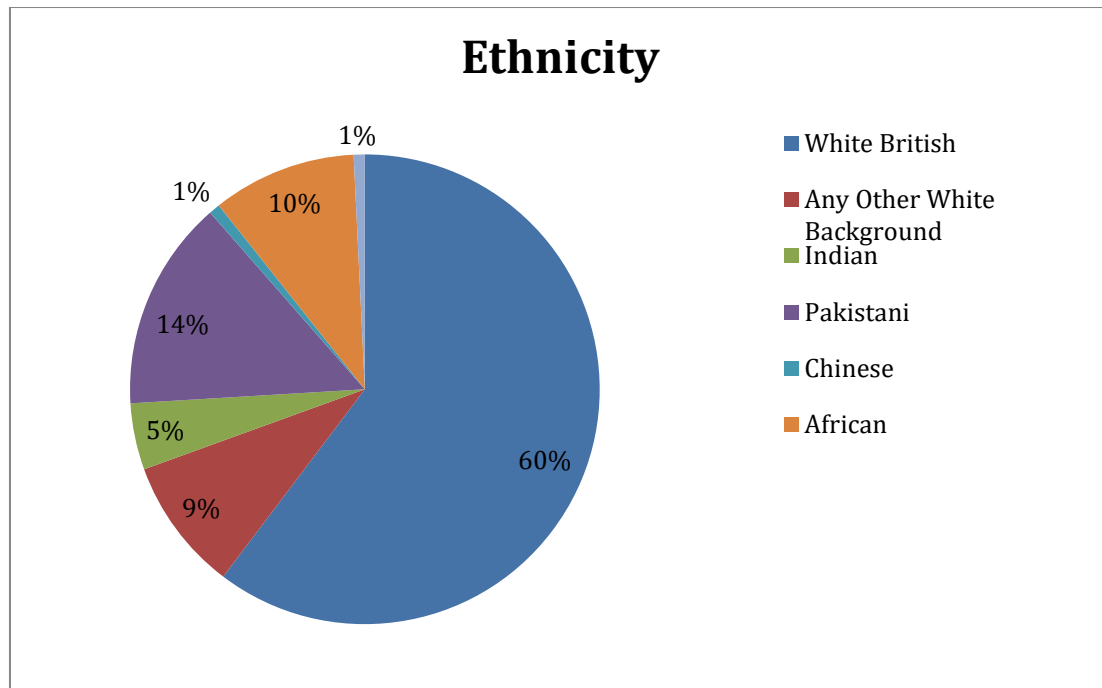


Fig. 3 Household Ethnicity

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

Parental Resilience

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

- *....., age 6, male, Autism Spectrum Disorder, Primary School My husband and I feel under extreme stress. Our youngest son (age 6) was diagnosed with ASD in April and our eldest son (age 9) is waiting for an assessment for ADHD and ASD, due to be in January. We paid privately for both of them, so feel the Early Help Route might not be right for us. We are in desperate need of support but don't know how to access it. We both work, my husband full time and myself 27 hours. I am currently signed off work with high level of anxiety.*

Health Inequalities

Parent carers have started reporting more and more that there are experiencing difficulty accessing health appointments and that when in the health sector feel that they are often judged and not listened to.

- *Experience in A&E terrible, autistic child left for four hours with fractured ankle, had to ask for an ice pack and pain relief. Amazon ward too long wait and no updates given on wait time.*

Rainforest outpatients great. OT, physio, dietetics no real concerns except how desperate they are from mental health teams.... 5 male at ravensthorpe primary school . All as I feel like I'm stuck in a hole with no way out and little help I just need help getting my kids they help they need in school at for them to stay in school forfull days

- *It was absolutely horrific. We had a trip to A&E at Peterborough and the staff treated my child disgracefully, with no accommodations made for his SEND. He had to wait lying on the floor, next to teenage girls discussing their self harm.*
- *No problems except for Wheelchair service. Being not fit for purpose. Slow to answer the phone with a long wait for appts and even longer wait for a new wheelchair. Rude staff on the phone with no updates.*

Accessing Mental Health Services

Accessing Mental Health Issues is still a worry to the parent carers. We have had some reports of children being out of education due to their poor mental health, yet they are unable to find appropriate support for their children. Due to increasing in complaints about accessing Mental as well as other Health Services, we have produced a number of Health Surveys as well as Facebook polls so that we could find out what is the underlying issue(s). We will present the results to PCC and health services in order to show what parent carers are experiencing on a regular bases and how those experiences could be improved.

- *I would really appreciate help with my sons who are both struggling with their mental health issues and I'm not being supported with regards to my sons EHCP and him being out of education is impacting his mental health*
- *..... would like to know who she can reach out to for counselling/support for 9 year old son please. Centre 33 only deal with teenagers, and school currently aren't being much help.*

Information and Guidance

- *10boy awaiting specialist school asd adhd dyspraxia and more. 4 boy starts school September mainstream for the moment, asd adhd (awaiting final paperwork of confirmation) other conditions that are under investigation I need support in all of the above and probably more. I am disabled and now have epilepsy causing serious problems to my memory etc.. Contact me to tell me how best to support myself and sons health, organisations essential basic items*
- *....., daughter Yr 10, out of school, AP, mum doesn't know if daughter has EHCP. She hadn't heard of FVP. Needs support for herself as a carer as well as advice re education.*
- *Dear sir/madam*

I am looking for information on holiday clubs for my 9 year old son who has autism.

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?*** :

I was able to get information I need

I was able to collect information about where to go next and who to contact. Which things need to be done as urgent and which could be left for later. It gave understanding and support

Knowledge of who to contact and what support I can be pushing for for my daughter

Confident in knowing where to find help/ support, that we are here when she needs more info or support.

It's gives me the help of where I can get help for my kids and to know I'm not alone. Sendias, pin point and even parts of your website that can help me

Family Based Activities and Engagement

Activities

Family Based Event/Activity	Number of Adults	Number of Children	Purpose/ Outcome
36 x Community Cafes	694	67	Decreased isolation/ Social Cohesion
Activity World	46	53	Decreased isolation/ Social Cohesion
AHG Ladies/FVP reps meal at Ibrahimi's	19	3	Decreased isolation/ Social Cohesion
Volunteer day of Action	13	0	Decreased isolation/ Social Cohesion
Chessington Coach trip	45	52	Decreased isolation/ Social Cohesion
Activity World	28	53	Decreased isolation/ Social Cohesion
Skegness Coach trip	44	53	Decreased isolation/ Social Cohesion
Hunstanton Coach trip	22	27	Decreased isolation/ Social Cohesion
Easter Eggs 2023	7	0	Decreased isolation/ Social Cohesion
Summer Barbecue	45	36	Decreased isolation/ Social Cohesion
Activity World	30	62	Decreased isolation/ Social Cohesion
AHG Bowling	27	29	Decreased isolation/ Social Cohesion
AHG Pamper Session	4	0	Decreased isolation/ Social Cohesion

Fig. 4 Activities and Community Sessions

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

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!

General Engagement

Engagement Sessions	Date	Numbers
SHCF Face to Face Session	06/04/2023	4
Argo Lounge Coffee Session	19/04/2023	4
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts, Trusts and Court of Protection 12/06/2023	12/06/2023	4
Argo Lounge Coffee Session	21/06/2023	3
Argo Lounge Coffee Session	17/05/2023	4
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts, Trusts and Court of Protection	10/07/2023	3
CDC Stand	20/07/2023	10
CDC Stand	20/09/2023	40
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	11/10/2023	7
Parent Carer Coffee Morning - Starbucks	17/10/2023	4
SEND Training for councillors	24/10/2023	11
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	01/11/2023	5
Gladstone Family and Children Centre- Julaybib project Muslim mums SEND Group	29/11/2023	7

Fig. 5 Information Sessions

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

CCG/ Training	Date	Number of Adults
Emotion Coaching	12/07/2023	6
EPS Parent Carer Hub Session	20/04/2023	2
EPS Parent Carer Hub Session	25/05/2023	2
EPS Parent Carer Hub Session	23/06/2023	1
Sendiass Parent/Carer Hub Sessions	29/06/2023	3
EPS parent/carers HUB sessions	13/07/2023	2
Education provision for children with ASD	15/09/2023	2
Sendias parent/carers hub session	21/09/2023	3

Fig. 6 attendance figures for workshops/ hubs

Surveys

During the first six months of the financial year three surveys have been conducted where health is a theme and these have seen 121 responses.

Survey Title	Responses
Health Appointments	24
Health Inequalities	22
Your Say	75

Fig. 7 Survey Response Numbers

Most surveys will have a micro report detailing basic findings and recommendations. The health specific survey reports are available to view via the survey page of FVPs website. Overall findings from the survey were that:

1. There are perceived health inequalities for SEND households
2. Waiting times are an issue
3. There is a lack of reasonable adjustments being made
4. Even when appointments have been secured the experience of accessing health services is poor.

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 White, English, Welsh, Scottish, Northern Irish or British followed by Pakistani. They have children with range of complex needs and physical disabilities.

Your Child/Young persons Age, Gender and Area of Need	Do you have any positive feedback to share about Health Care	Do you have any neutral or negative feedback to share about Health Care
6, Male, communication and interaction.		Difficulty with getting GP appointments.
9 yrs old Male	Caring	No
19 yrs old	helping a lot to daily routine independence learning	no
7 yrs old male FASD ASD	Trying to get allergy test for celiac disease but was told to watch what he is eating	social worker has been very helpful with sorting out staff to do with his mum and him
my child 5 girl anxiety and speech	again takes a long time to get to see the right person	
4 6 8 Girls	clean	non
6 and 4 both male anxiety sensory and emotional	so so	not a lot of support

Female and male 9 and 5 ASD ADHD Autistic	Medical professionals are very understanding and listen to parents	Waiting lists are too long, limited support once you diagnose parents have to fight for every bit of support its not easily given
Male He has Autism have no understanding of surroundings and danger	no	good
female aged 11 she has autism and problems dealing with emotions and she has mental issues	good	no
male 9 ADHD Autism 4 Male none	no waiting times are poor and support extremely limited	as above
Male 15 PTSD Anxiety self harm depression	Diabetic care is very good in Peterborough the waiting times are quite short so that is a bonus	sometimes its hard to get a referral to a specialist or a different hospital
16 female GDD visual impairment pallative pathway gut dystonia		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
16 female Autism learning difficulties short memory cannot retain information	They were helpful whenever we need	n/a
Autism 17 yrs old Female	Its been good until when covid hit to now then it became very difficult	Very difficult to get an appointment at GP practices
17,15,14,4 2 female and 2 male adhd and autism	Always been helpful in giving advice and writing reports where they can from assessing individual needs of child young person	None
Age 7 male, diagnosed ASD, ARFID and Dyslexia. High anxiety, awaiting ADHD assessment	The dietitians team based in Cambridge are fantastic. Our GP surgery - Wansford are fantastic.	Long waiting lists for assessments and support. Having to chase everything and fight for what your child needs. So many hoops parents have to jump through to even see a paedatrian it is exhausting. No ARFID pathway in Cambridgeshire.
18 female fnd(functional neurological disorder.) Non epileptic seizures. Sensory issues. Need 24hr supervision 11 male Sensory issues Also Care full time for disabled husband	Left to deal with everything on my own	Left to deal with everything on my own
11, female, sensory/ASD/adhd/mental health	Good communication and efficient when you do get appointments	Slow process as lots of people on waiting lists.

4/ female/Autism and development delay	No	Parents are not supported enough to get the right help and the waiting lists are very long
girl autism	Mostly quickly get appointments and reviews with the doctors regularly	
13, male , autism spectrum disorder	Hospital appointment are accessible for us , for example for physiotherapy he waited only 3 weeks from referral date .	Some doctors don't listen , but I think it all depend on personality .
has golden-har syndrome	Always been happy with health care	No
male 21 arthrogryposis, shay male 15 asd and mental health conditions, female 14 mental health, female 2 development delay	Occupational therapists are fantastic while children are school age, when they leave education and become adults its a different ballgame!	No
12 boy autism	No	Yes mental health help is a joke no help for our son. All he has is online calls for self harm.
16- ASD- female 5- ASD- male 2 - No diagnosis	Very pleased with GP services.	Other services such as CAHMS very poor.
9 year old Male with adhd	No	Long waiting lists
9 year boy	No	No
10	The doctor always struggles because he cant communicate so we end up being sent to hospital most times.	Doctors are not massively trained in autism
18 autisma	Once you have their support, it makes such a difference.	Getting someone to listen and help is not easy. You have to grow thick skin, and never give up.
- 10, F. Autism: PDA profile, generalised anxiety, OCD.	Psychiatrist and psychologist do their best to engage our daughter.	Needed to submit a complaint to pals to get anywhere.
28 female Down's syndrome	No	Although annual health checks appointments are made the follow up are not always followed through
6 years old,male, autistic 6years old, male, autistic	No	still waiting for Hebert to be diagnosed. Hugo gets his diagnosis and that was it - you are left to yourself.
5 yrs old, female,Autistic	Not at the moment	Appointment should be given bit quicker. Health care system is very slow.
17/male/global delay & learning disability	No	Never bothered
Age 20, Female, with ADHD and Autism. Needs some living support and supportive education provision.	No	Health care very limited. No regular visitations or significant support

18 Asd and intellectual disability	My positive is that my daughter was diagnosed at the age of 5. So has meant some support started at that point with her needs.	Would say that it's sad to know that the NHS still believe schools over parents and had meant for my daughter that the intellectual disability was not accepted by the professionals until I had battled a year for an educational psychologist and this proved no cognition change six years after being assessed from beginning of primary school. Same with ADHD. I was kept on a waiting list for 10 years, to then only be told that even though my daughter showed it in the QB test, the school however stated that as long as there is routine her attention is ok and just about manageable. Since being in post 16, the routine that special school gave her has somewhat disappeared and has had my daughter and still now going back to behaviours we saw back in primary due to inconsistency and complacency in post 16
Male 19 ADHD ASD TOURETTES	No we've had no involvement since age 14	We've struggled accessing health care & even places like hospital with such long wait in A& E he was still expected to wait & because he couldn't handle the wait he would walk out of appointments and then get discharged as a no show
10 male ASD	Special needs dentist is fantastic	N/a
13yrs, female, anxiety, depression, lung condition	Good health support	Took time to get it initiated
12, male, asd adhd	no	school nurse sent out flu and vaccine consent forms. filled in and returned, school nurse arrived early, did NOT read forms, just assumed it was a yes. its a good job my child refused on the day as we did not consent. who checks? this could have been a deadly decision.
14 female ADHD/Autism	Yes sometimes	Sometimes feels like a battle for your child.
26, male with autism	Accessing annual health check	Difficulty accessing GP service
24, male with autism, learning disability and epilepsy	Accessing annual health check and epilepsy reviews	Difficulty accessing GP services
16 female global developmental delay	No	They don't really know what's wrong with my daughter even though she's on end of life they think she doesn't meet repaite for health needs
Global delay	Free	Delays and not take seriously
19yrs male 11 yrs male and 5 yrs male autism and behaviour	Can get appointments quick	Need to speak to a person not very quick to get back to u no dentists for children with send should be a priority
Male 9 year old deeping st	Brilliant	No

(9) male	Health care is difficult to access at the moment but appreciate all the help they do	Long wait times and issues with contacting gp
Age 7, Male, Diagnosed ARFID, Dyslexia, ASD. High anxiety, awaiting ADHD assessment	General paediatrics team are great	Why isn't there an ARFID pathway in Peterborough, my grandson has a diagnosis but no support, my daughter has to pay privately for this

Fig. 8 Views of Health

Feedback on services is mixed but there are some standout areas:

1. Health services are stretched and waiting times are too long
2. Lack of support/ pathways for ARFID
3. Not enough help with mental health early enough especially where the CYP has a diagnosis of ASD/ ADHD

Seldom Heard Communities

For 2023 to 2024 reporting it was decided to match categories for ethnicity to national census categories from the 2021 Census, to better gauge levels of engagement from groups considered seldom heard based on ethnicity. The Census data for Peterborough shows a population range of approximately 60% White British to 40% Other Ethnic Backgrounds (combined).

Ethnicity				
Category	Adult			
	21/22 (Baseline)	22/23 (New)	23/24 (Re-engaged)	23/24 (New)
White British	220	87	73	68
Gypsy or Irish Traveller	2	0	2	1
Roma	0	1	1	0
Any Other White Background	20	14	0	0
White and Black Caribbean	0	0	0	0
White and Black African	0	0	0	1
White and Asian	0	0	0	0
Any Other Mixed or Multiple Ethnic Background	4	1	1	2
Indian	8	5	3	4
Pakistani	12	12	13	13
Bangladeshi	0	1	0	0
Chinese	0	2	0	1

Any Other Asian Background	0	0	10	2
African	11	10	7	5
Caribbean	1	0	1	0
Black British	0	0	0	3
Any Other Black or Caribbean Background	0	0	0	0
Arab	0	2	1	1
Any Other Ethnic Group	7	0	1	2
Rather Not Say	1	1	0	0
Unknown	13	22	3	81
Total (Incl. White British)	65	48	40	35
Total (Excl. White British)	285	135	113	103
Percentage of parent carers who self-identify in categories other than White British.	438.46%	35.56%	35.40%	33.98%

Fig. 9 Ethnicity Breakdown of Known Parent Carers where recorded

The following are some examples of information and feedback from seldom heard specific activities and meetings.

New Peterborough Faith Based Womens SEND Group (Julaybib 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. 6 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. 7 Community BBQ Pics – Integration

Current Themes/ Parent Carer Concerns

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

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

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

Co-production and Change

Topics of Importance (ToI)

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

Coproduction

Some coproduction has occurred in relation to the development and sharing of a new resource for parent carers called 'Supporting Your Neurodiverse Child' which can be downloaded from the website <https://familyvoice.org/neurodiversity-booklet/>

What is the difference?

From three funding sources a specific outcome was set whereby " *Parent Carers accessing support will feel less isolated and report an increase in their well-being as a result*"

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

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

We have exceeded this target



Recommendations/ Forward Plans

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