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# FVP Interim Report

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January to March  
2024

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FVP Parent Representatives

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## Introduction

This is the final quarter report for 2023 to 2024 detailing work of Family Voice Peterborough as the Parent Carer Forum (PCF) funded by Peterborough City Council (PCC). Some work may be funded by more than one grant scheme but the main outcomes sit in this report due to the focus on the PCF. The report will again be structured under the following headings:

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

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

Over the past three months (January 1<sup>st</sup> to March 31<sup>st</sup>) FVP have seen engagement from 5 Fathers, 25 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 50 opportunities enabled 730 adults and 307 children to get involved at some level.

## Participation/Engagement/Involvement January – March 2024

### Headlines

- 1) Over 130 named parents in total have been involved at some level.
- 2) 231 parent carers have participated across 4 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) 5 new fathers have been involved.
- 5) Parent carers reported the ages of their children/ young people as between 2 to 25.
- 6) Participation methods used included; online surveys, case studies, face to face activities, one-to-one telephone or email engagement and parent representation.
- 7) Evidence is both qualitative and quantitative in nature.
- 8) Ethnicity data will be referenced in the full report, we have moved toward categorizing in line with census categories.

## Wellbeing

### Introduction

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

### Food Support and Household Support

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

Support has been provided to a higher number of adults and children compared to previous quarters.

Adults	Children (Total)	Children with SEND
343	107	Unspecified

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

Households provided the following reasons for requiring support.

What challenges do you and your family face currently?	To help us, please expand on any of the above options you have ticked.
Cost of Living	The raising cost of living makes it hard to survive without getting into dept.
Cost of Living	paid house rent, water, light etc.
	N/A
Bills, School/Education, EHCP, Mental Health, Cost of Living, Caring Role, EHCP	I am a single parent of children with additional needs and I find being able to be signposted for support /help and bringing others along who need support/advice.
Health Care, Mental Health, Cost of Living, Caring Role	The person that I bring to the Orton centre is special needs and this is 1 day of the week he really looks forward to and is very important social part of his week.
Mental Health	the problem is about stress
School/Education, EHCP, Mental Health, Caring Role	Try to get EHCP. Managing system etc.
Bills, Housing/Rent, Health Care, Mental Health, Debt, Cost of Living	I am happy with any help given.
Bills, Housing/Rent, Cost of Living	N/A
Bills, Health Care, Benefits, Mental Health, Social Care, Cost of Living	Cost of living , everything is so expensive
Bills, Housing/Rent, Social Care, Cost of Living	N/A

Cost of Living	Cost of living keep going up - pensions no change... yet
Cost of Living	I am working but it is not enough to run the family so I have to come to the food hub/community centre for support.
I am coping ok	N/A
Bills	N/A
	Staying in safe house right now as await for better future
Housing/Rent, Debt, Cost of Living	we are struggling with essentials , money
Benefits, Mental Health, Cost of Living	Attending the hub /Cafe has really helped me to mix with new people and make new friends . It has provided me with lots of useful information.
Bills, Housing/Rent, Benefits, School/Education, Mental Health, Debt, Cost of Living	I have debts with gas and electric. I am carer for my partner who has bad mental health. My son has ADHD. I am currently living with someone on the sofa with my kids due to fleeing DV.

### Signposting/ Support Requests

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

There have been 37 contacts recorded where parent carers new to FVP have requested signposting. Where direct signposting requests have been received it is known that 19% would be considered ethnicities other than 'White British'. The number of parent carers requesting signposting from seldom heard communities in relation to ethnicity is slightly higher in this quarter.

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

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

### **Parental Resilience**

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

- *11, male, adhd/asd, behaviour issues, anger and lack of confidence, Heltwate school . I want some support with my son's behaviour, it's taking a toll on everyday family life. I want to be able to support him but I just don't know how. I'm at my wits end because I feel the years of fighting and still have it.....*

- *female - age 11 - school avoidance - sensory difficulties - mental health - social and emotional difficulties - on pathway for diagnosis of ASD/adhd Any break would be fantastic. This nightmare has been on going for months upon months. It has torn my family apart and I have lost my job of 17 years because of it. To see my daughter not coping with life is heartbreaking and it isn't fair on my young son to see and hear all of the difficulties she faces and causes.*

### **Education/School Attendance**

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

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

### **Managing Behaviour**

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

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

### **Short Breaks and Respite**

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

### **Information and Guidance**

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

## Wellbeing and Family Based Activities

Family Based Event/Activity	Date	Number of Adults	Number of Children
Community cafe	10/01/2024	17	
Community cafe	17/01/2024	14	
Community cafe	24/01/2024	20	
Activity World (19/2/24)	19/02/2024	53	34
Community Cafe 07/02/2024	07/02/2024	31	
Community cafe 14/02/2024	21/02/2024	24	28
Bowling ( 21/02/2024)	22-Feb-24	25	35
Community Meal	23-Feb-24	27	33
Community cafe 28/02/2024	28-Feb-24	36	
Community cafe	6-Mar-24	36	
Community cafe	13-Mar-24	30	3
Community cafe	20/3/24	26	3
Community cafe	27-Mar-24	29	4
Flip Out	23-Mar-24	31	59

Fig. 2 Activities and Community Sessions

This work area is funded via more than one source but all have similar outcomes relating to community cohesion, improved wellbeing and decreased social isolation. Feedback was sought as to what difference the activities make to families and can be seen in table three below.

Has attending any of these activities made a difference to you and your family?	If you answered yes to the previous question, please use the space below to tell us more about what difference has been made to you and your family?
Yes	A place to come where other families have children with needs. Less judgemental people.
Yes	The children, really enjoyed jumping on the trampoline playing around, slide etc. children are happy and smiling, also helps my disabled daughter can try to jump more and more.
Yes	Burn some energy. Have fun. spend time together.
Yes	We got to go places that we cannot normally afford, like Chessington, Hunstanton, we don't drive.
Yes	Opportunity to come to something, we wouldn't often be able to afford. Meeting other parents and get out of the house, let the kids run some energy.
Yes	My daughter looks forward to these days, as they are treats, we cannot afford.

Yes	Great chance to meet new people and get out of the house. My 2 children have such a great time, they really enjoy days out.
Yes	These activities we don't come to much, but grateful to FV provide this.
Yes	Sometimes a struggle to go places with children with additional needs.
Yes	Enjoyed meeting up with other parent. allowed my daughter to let off steam, keep active and socialise
Yes	N/A
Maybe	N/A
Yes	Fun day out for children
Yes	It is sometimes a struggle to get out as a family as I don't drive and few of them have needs
Yes	Connection with others in similar situations
Yes	Reconnect with an old friend. Gives us the space whilst our children play
Yes	N/A
Yes	Kids are enjoying themselves and its very beneficial to children because its not as busy as our children do not like overcrowded places. There is also problem with money because those places are very expensive and unfortunately we do not have that much money
Yes	It get my son out socialising with less people and a quieter environment than what it would normally be

**Fig. 3 Difference made by Activities and Community Sessions**

### General Engagement & Awareness

Information and Awareness	Date	Number of Adults
CDC	24/1/2024	18
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts and Court of Protection 31/01/2024	31/1/24	3
CDC	24/1/2024	18
CDC	28/2/2024	20
Awareness sessions on Wills, Lasting Powers of Attorney, Discretionary Trusts and Court of Protection 31/01/2024	05/03/2024	7

**Fig. 4 Information Stand Data**

Using information sessions and holding information stands continues to be an effective way of engaging with parent carers and raising awareness of not only FVP but all the sources of information and support open to SEND families.



## Schools Data/ SEND

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

Request/ Topic	Work Required
UCL language research - participants needed!	Information Sharing
APPG for SEND Meeting Tuesday 09 January, 2-4pm	Information Sharing
CDC Equality Act training for parents/carers of young children - please share with your members	Information Sharing
Free seminars on Wills, LPA's, Trusts and Court of Protection.	
SENDIASS Manager Interviews	
Stakeholder engagement : call for evidence for young people's mental health review.	Information Sharing
PfA Young Persons Consultation Event in February	Information Sharing
Your SEND Journey Workshop	Work Shop
APP Document Input	Document Review
EPS Feedback	Other
Urgent Care -111-ICB survey engagement	Information Sharing
Seldom Heard Communities - Story for Contact Participation Matters Month	Information Sharing
C&P Learning Disability Improvement Programme - Workshop Invitations	Work Shop
APP Coproduction	Information Sharing
Housing Strategy	Consultation
Autism Acceptance Week Comms	Document Review
SEND Newsletter	Information Gathering
Free Early Years Sharing at the Key	Other
Stakeholder engagement re mental health support and treatment for young people 16 - 25	Information Sharing
Post 16 strategy	Document Review
Family Hub Involvement	Other
All Age Autism Steering Group	Consultation
Working Together - Museum	Coproduction
EHCp Q&A Sessions	Document Review
Letter re LD Improvement Programme Launch - 25.01.2024	Other
Museum Quiet hours programme	Coproduction
Transition in healthcare information	Information Sharing
Involvement in tender evaluation	Meeting Attendance
FVP Views	Consultation

Fig. 5 - 30 requests for FVP involvement (Jan - March)

## Surveys

During the fourth quarter four surveys were conducted with a total of 231 responses.

Survey Title	Responses
Health Inequalities	22
SEND Strategy	9
Annual Survey	188
PfA (Seldom Heard)	12

**Fig. 6 Survey Response Numbers**

Most surveys will have a micro report detailing basic findings and recommendations and may lead to a Topic of Importance (ToI). This is and the survey reports are available via the website. All data from the surveys, but in particular the Annual Survey have been reported on, and can be read via a report placed on FVP's website

<https://familyvoice.org/surveyreports/>

Parent carers have reported less positively about SEND this year compared to previous years across all areas with data showing six key themes:

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
2. Lack of support – managing benefit changes, applying for an EHCNA, mental health management to name a few, support after diagnosis
3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
4. Difficulty in finding Information – you don't know, what you don't know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.

Parent carers when speaking from themselves have shared the comments collated in Fig.7 below.

<b>Please use this space to provide any other information you feel is relevant regarding your experiences with Peterborough SEN services across Education, Health and Social Care</b>
Everything is slow, always a fight and never enough information. People always leaving roles doesn't help.
Although I am not a carer, it's very difficult mentally to work full time and support a child with SEN because of finances and time it's mentally draining
<a href="#">They helped me get my son into a mainstream school</a>
Involve the parents more and listen to what they have to say
As above. A parents SEMH, becomes a strain, when having to constantly fight for our children. Constant big/long paperwork to fill out.

There is not enough money to go round.  
not enough provision/ thought is given to out of school hours care for medically 10omplex children eg no holiday club, after school club etc.

Care is given to one and not another as in not evenly distributed. I am continually astounded that social services especially I think parents talk ti each other so wont know what is available. Had our sons 4 th EHCP and it was first time sw bothered to turn up.

The three services PCC provides are all awful!

Very poor, boring choice of services

Have struggled a lot with continence , fighting for pads as the have a limit per day, child is 16 Years old & still fighting for DFG – the family & hiw they live @ what us not going to make their life difficult us never listened to. The professionals ALWAYS know best. They are not living this life I feel things NEED to change where parents views need to be considered – THEY R THE ONES HAVING TO JUGGLE THEIR LIVES, with jobs, extra bills due to equipment etc m, extra expenses bcos of limit of continence products provided . No DFG – councils way or no way!!

[Been a positive experience](#)

I think the whole system needs looking at especially when they reach 18 you are left on your own to do everything no support or advice what so ever and the gps have no clue

Very long waiting

I don't know if this applies but I do feel strongly that a special needs school should hire teachers trained in special needs and not fresh out of teacher training for mainstream schools. My child's experience has been awful for special school education, partly due to this problem. Finalise my EHC plan and support people who are lone parents with zero support around them to get their child into the right setting. It's exhausting. I don't have enough hours in the day to sort it all, educate, chase adults about trying to get his EHC plan done. Therapy my child and do all the basic parenting stuff too. I get zero breaks. I am up most of the time until 3am and then woken up anytime from 5am. I feel everything is designed to make you give up asking for help. I don't get peterborough. My child gets zero funding yet I am expected to meet the requirements in his EHC plan. Yet a school gets funding. It isn't right. Information needs to be accessible and not just available online as not everyone can use the internet. Home education needs more support. People just feel abandoned. Access to useful resources that will support SEN children would be good.

I had to give up my job because my son isn't in school.

For us to have an appointment regularly with sen services or even on diagnosis to look at child's needs and what support entitled to. I have never had this. I don't really know if we have all support we should have

As above, please please please when parents show concerns please make the process much more quicker. Waiting lists are far too long.

We were repeatedly encouraged by the school to get an autism diagnosis as this was 'the best way to get an EHCP' despite our sons highest needs obviously being social mental and emotional conditions and disabilities, along with physical disadvantages and the autistic traits being less life impacting.

I am just disgusted with the time it is taking it not only affects my child but myself as well, I have been fighting for 9 years for my child

The LA never stick to the EHCP time frame always have to chase them.

Listen to the parents more allow parents to assist

I would have moved if it didn't affect other family members

Carers have no help or support in dealing or learning their children needs

There is no after school provision or wrap around care which affects my work and my ability to progress / choose a career I want. Restricted hours provided by Sen schools means parents/ carers get even less support than their mainstream counterparts.

More support needs to be given to parents of children with sen
The school have been good from the start. I can't fault them
Support for parents and children. We had an OT assessment and they provide support for a couple of weeks then discharge. I know nothing about sensory needs so I have had to do a lit of research. How is that considered support?
Like banging my head against a brick wall when it comes to education
My son has high needs due to autism he struggles to be in social situation and we have to leave he is easily triggered for.meltdown from smells crowds to change in routine
I'm not sure what the LA role is in SEN other than to help with the EHCP process.
My 11 year old is currently excluded still from before Christmas she is receiving no education
I remain actively involved in my daughter's care encouraging her carers to increase the quality of care. This has included making written complaints to PCC during the last 12 months. Particular concerns are diet, exercise and social engagement in evenings and weekends
Everything was excellent and the service and support was good
Hard and invasive.
Very good
Waiting lists are too long, additional funding needs to be provided to adequately resource services
Wait times are unreal. Mental health needs massive improvements and girls in particular, need to be supported more as masking plays a massive role in misdiagnoses'.
My experience with my son at school was diabolical regards to SEN. The education system failed him terribly.

Fig. 7 Parent Carer Experiences

### Strategic attendance

The continued involvement of parent reps in strategic meetings has also been utilised in this quarter.

FVP have a total of 6 parent carers employed as parent reps and they have shared meeting attendance with the CEO and Participation Project Officer.

Number of Sessions	Hours Spent at Meetings	Administration Time (Hours)	Travel Time (Hours)	Total Hours
60	96	37.5	6.5	140

Fig.8 Breakdown of Time spent at Strategic Meetings Jan – March 2024

<b>Meeting Type</b>	<b>Title</b>
Working Group	Pins Early Adopters Forum
Working Group	PfA
Working Group	Clear Hold Build Crime and Cohesion Working Group
Working Group	EHCP Improvement Meeting
Schools Event	Hampton Gardens/Hampton College coffee hub ks4
Working Group	East of England Learning Disabilities and Autism
Working Group	East of England Learning Disabilities & autism
Working Group	PINS Community of practice meeting
Schools Event	Cafe Hub - Hampton college/Hampton gardens
Working Group	Involvement and Participation Network meeting
Working Group	Peterborough SEND Operations group
Individual Meeting with Professional	Individual Meeting with NHS patient experience leads
Strategic Board	Carers programme board
Working Group	Children's and young peoples collaborative
Working Group	PCC - SEND FORUM
Working Group	PINS - Parent Carer Forum Early Adopters Meeting
Forum Team Meeting	East of England Children Palliative Care Forum Meeting
Working Group	Disability Forum
Working Group	Learning Disability Improvement Programme
Working Group	EHCP Improvement
Working Group	MDT EHCP QA session - Theme Post 16
PINS PROJECT MEETING	Pins project Meeting
Schools Event	Schools Offer Session
Strategic Board	Peterborough Early Help Strategy Partnership Group
Workshop	PfA Young Persons Consultation event
Focus Group	Learning Disability Improvement programme, Starting well, Workshop 2
Working Group	PfA Young People's Consultation Prep Meeting
Schools Event	Thomas Moor primary school coffee morning 1
Working Group	East of England Neurodevelopment Disorders Network
Workshop	Next step Parent workshop
Stakeholders Meeting	SENDIASS Stakeholders Meeting
Strategic Board	Learning Disabilities Network
Working Group	PINS
Working Group	Situational Selective Mutism Working Group

Working Group	Widercollabrative meeting
stakeholder meeting	Early support stakeholders meeting
Individual Meeting with Professional	catch up with Graham Lewis healthwatch
Forum Team Meeting	Eastern Region SEND Forum
Strategic Board	Peterborough APP meeting
Strategic Board	Children and Young People Board
Forum Team Meeting	PCC Send Forum
Schools Event	Woodston Primary School
	East of England Learning Disabilities and Autism Share and Webinar
Focus Group	Cyp mental health and wellbeing
Working Group	Peterborough SEND Operations Group
Starbucks coffee morning	Cathedral Square
Individual Meeting with Professional	Meeting AC
Working Group	PINs Steering Group
Queen Elizabeth Carers Forum for Patients	Queen Elizabeth Carers Forum for Patients
Individual Meeting with Professional	Childrens Hospital
Individual Meeting with Professional	Carers Group (Eastern Region Hospitals)
Strategic Board	P'boro APP Meeting
Individual Meeting with Professional	Catch up - Alex Warwick - CPFT Physical Needs Review
Working Group	Adult MHLDA Co production and Collaboration
Forum Team Meeting	Wheelchair User Forum
Coffee Morning	Julaybib Coffee Morning
Forum Team Meeting	Disability Forum
Strategic Board	Carers program board
	East of England Learning Disabilities and Autism Share & Learn Webinar
Working Group	PCC SEND comms

**Fig.9 – Meeting List**

As seen in fig.9 the team have been involved in meetings relating to SEND operations, EHCp improvements and Preparing for Adulthood through to the Maternity and Children's Collaborative. Health meetings have covered physical health and mental health from provision to commissioning.

### Schools Work

School Sessions	Date	Number of adults
Ormiston Meadows Academy (	17/1/24	6
Woodston Coffee Morning	18/1/24	3
Peakirk-cum-glinton coffee morning 3	22/1/24	5
Northborough (third)	5/2/24	1
St Thomas Moore	12/2/24	0
All Saints (fifth)	26/2/24	6
Eye Primary School	4/3/24	1
Hampton Gardens School	18/3/24	4
Hampton Gardens School	20/3/24	10
Hampton Gardens School	25/3/24	4

Fig. 10 School Meetings Data

Provide details of any themes mentioned by parent carers if applicable (this could be specific issues, what difference the session has made, support required etc).	How many people did you speak to?
ongoing border issues	4
only one parent turned up - he was after hep after his son has lost his Grandmother and has started showing aggressive behaviours towards his sibling.	
another one was a member of staff who is a parent carer - children attend a different Peterborough school - she filled out online request form	2

Fig. 11 School Meeting Information snapshot

## 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).

For FVP engagement as of 31<sup>st</sup> March 2024 sits at approx. 70% White British and 30% Other Ethnic Backgrounds.

Ethnicity at March 31 <sup>st</sup> 2024	
White British	466
Gypsy or Irish Traveller	5
Roma	2

Any Other White Background	34
White and Black Caribbean	0
White and Black African	1
White and Asian	0
Any Other Mixed or Multiple Ethnic Background	8
Indian	20
Pakistani	63
Bangladeshi	1
Chinese	3
Any Other Asian Background	11
African	33
Caribbean	2
Black British	3
Any Other Black or Caribbean Background	0
Arab	4
Any Other Ethnic Group	9
Total (Incl. White British)	665
Total (Excl. White British)	199
Percentage of parent carers who self-identify in categories other than White British.	29.92%

**Fig. 12 Ethnicity Breakdown of Known Parent Carers where recorded**

Seldom Heard Sessions	Date	Number of Adults
Gladstone Family and Children Centre - Julyabib project Muslim mums SEND Group 10/01/24	10/1/24	7
Julyabib	6/3/24	6

**Fig. 13 Seldom Heard Sessions**

During the past quarter FVP have continued engagement with the Aiming High Group and Julyabib group in particular who have provided a range of views of local SEND services. The following was provided specifically for the Annual SEND survey report:

- Schools postponing or/and not recognising that the child needs assessment. Not believing to the parent if the child behaves well and/or academically performing well. There were also cases where child had to fell behind academically in order school started to notice parents concerns.
- long waits for assessment and apparently according to Karen Chopping the parenting course was cancelled a year ago but SENCO's were not aware of that.



- Long waiting lists for speech therapy and occupational therapy for children resulting them being falling behind academically and socially
- Disability social workers are not being helpful especially for older children
- Schools are not following ehcps and not providing 1to1 for children who desperately needs it due to not enough funding or other resources
- No support for parent after diagnosis of autism/adhd or parents are not aware there's some support available
- Home occupational therapist are not taking into account family's need when providing home conversions for disabled children resulting families to fund themselves
- Wheelchair services are absolutely disgraceful. Every single family who had to use them has a complaint about them.
- Potential racism during the assessment process

*".....I can safely say that unfortunately there is no actual help or support available to parents of SEND kids in Peterborough."*

*".....SENDias that they are just LA's tick box and very much in favour of schools rather than parent"*

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

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

1. Parental blame – for example being seen as a burden, drain on resources, negative and part of the problem, being made to do parenting courses that are not appropriate to SEND, parenting courses make parents feel they are at fault.
2. Lack of support –managing benefit changes, applying for an EHCNA, mental health management to name a few, support after diagnosis
3. Lack of involvement in decision making, support planning and areas of EHCp outcome monitoring.
4. Difficulty in finding Information – you don't know, what you don't know!
5. Lengthy waiting times - Waiting too long for access to assessments and access to therapies and other forms of support once assessed.
6. Preparing for Adulthood – Not knowing what entitlement may be for access to services, having to self-refer to the 0-25 team, lack of access to transitions officers, impact of benefit changes, '5' day offer and other matters.

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

Due to a number of changes at PCC the Tol responses have been delayed.

### Coproduction

Continued coproduction has occurred in relation to the Accelerated Progress Plan (APP) and the Autism Strategy Pathway.

There have been changes to the requirement of completing a parenting program as part of the referral process for a Neurodevelopmental Assessment.

What is the difference?

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

## **Recommendations/ Forward Plans**

- SEND Communication be considered as a priority for strategic leaders, with a refocus on the SEND Strategy and Action Plan.
- key support initiatives be delivered by the LA/ Health
  - Face to Face befriending (Peer to peer support)
  - Benefits Advice and Support (DLA to PIP)
  - Independent Support (EHCp process)
  - SEND Navigators (support) to find information to help parent carers
  - Development of a resource for new SEND households (Welcome to Your SEND Journey)
- Ongoing opportunities for parent carers to shared their lived experiences directly strategic leaders
- A group to be set up for various group leaders to work with FVP to bring forward the lived experience of the SEND community
- Look at how third sector groups, and front line SEND charities can be funded or supported to gain funding to work directly in providing parent carers with support