FVP Interim Report

April – June 2024

FVP Parent Representatives

Introduction

The report will cover four main areas of work to match grant based outcomes, and will finish with a recommendations section.

- Mental Health and 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 past quarter has seen a shift back to more traditional methods of engagement such as coffee mornings, schools sessions, family based activities and information stands; all of which are face to face. Parent carers have consistently reported they prefer face to face methods and often seek to engage at sessions where they may be some form of benefit, with family based activities proving the most popular.

Core areas of concern identified via contact with parent carers are; cost of living impact, short breaks and coping during school holiday periods, accessing assessments of child and young person (CYP) need, health appointment/ assessment waiting times, poor mental health and wellbeing and educational support/ emotionally based school avoidance (EBSA).

Over the past three months (April 1st to June 31st) FVP have seen engagement from 5 Fathers, 16 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 online surveys with 481 parent carers sharing their experiences. Wider engagement across 38 opportunities enabled 359 people to get involved at some level.

Participation/Engagement/Involvement April – June 2024

Headlines

- 1) 124 named parents in total have been involved at some level (due to changes in data gathering methods it is not possible to separate data further to include their CYP.
- 2) 481 parent carers have participated across 2 online surveys.
- 3) Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
 - a) Autism Spectrum Disorder
 - b) Attention Deficit and Hyperactivity Disorder
 - c) On the Neurodevelopmental Diagnostic Pathway
 - d) Varying degrees of Learning Disabilities and Difficulties
 - e) Global Developmental Delay
 - f) Genetic Disorders
 - g) Downs Syndrome
 - h) Cerebral Palsy
 - i) Spina Bifida
 - j) Achondroplasia
 - k) Social, Emotional and Mental Health Needs, including Eating Disorders and Anxiety Disorders.
- 4) 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, Facebook discussions and polls, case studies, virtual seldom heard group sessions, one-to-one telephone or email engagement and parent representation.
- 7) Evidence is both qualitative and quantitative in nature.
- 8) Ethnicity has been self-reported as; White British, Gypsy or Irish Traveller, Roma, Any Other White background, White and Black African, Indian, Pakistani, Any other Asian Background, African and Black British.
- 9) Some parents have chosen the 'Rather not say' option when asked to self-declare their ethnicity.

Household Details

Parent Carer Data				
April May June				
Male	0	0	5	
Female	0	3	13	
Other	0	0	0	
New	0	34	47	
Returning	4	19	30	

CYP Data (Self-declared by Parent Carers)				
April May June				
CYP No Needs	0	5	10	
CYP Needs Unknown	5	11	3	
CYP Needs 0 10 11				

Where known 46% of households state they are single and 43% report an adult in the household having a disability or health need. This would suggest need within the household more generally. Further to this 24% report some reliance on benefits from Universal Credit through to DLA and/or PIP.

Mental Health and Wellbeing

Food Support

Food support continues to be an identified need, but

Support has been provided to 6 households where full details are known:

Adults	Children (Total)	Children with SEND		
9	114	8		

Fig.1 Numbers of adults and children receiving food

Of these households 1/3 report having an adult with a disability the majority of which relate to mental health needs.

Generally reasons for requiring support are linked to low wages, benefit changes or unexpected bills.

Reasons for food support

- 1. Every month I have to spend lots of money for my kids when I go Asda
- 2. I need the help due to the cost of living and having a short fall in wage due to taking on more hours and recieving less entitlements from UC
- 3. Struggling with finances

- 4. Short on money and need to get food
- 5. I have been struggling this month with unexpected bills etc coming out
- 6. My business is not doing well and I cant afford to pay me anything at all, was only £645 anyway. I am transitioning from WTC to UC and they have advised me my Carers allowance will not be paid in addition to the UC but deducted from the UC matched WTC/UC amount (instead of paid in addition to WTC as before). I just don't know how I am going to manage.

Hubs and Workshops

Four hubs and one session focusing on Challenging Behaviour have taken place, which has led to 10 parent carers receiving direct support from services.

CCG/ Training	Date	Number of Adults	Purpose
EPS	26/4/24	2	Support/ Signposting
EPS	23/5/24	2	Support/ Signposting
SENDIASS	13/6/24	3	Support/ Signposting
CB Workshop	17/6/24	2	Support/ Signposting
EPS	27/6/24	3	Support/ Signposting

Fig. 2 Attendance Information

Signposting/ Support Requests

There have been 36 requests for sign posting this quarter with themes ranging from CYP out of school to households struggling financially.

How was contact made	Where did the person hear about us?	Ethnicity	Area of Concern
In Person	school		Parent carer wellbeing, special school placement request
Contact Form (Website)	Caring Together		Support for working parent
Contact Form (Direct Form)			Housing
Contact Form (Direct Form)	Peterborough Council Website.		Benefits advice, housing, short breaks, parental mental health and wellbeing
Contact Form (Direct Form)		Pakistani	Holiday support and short breaks
Email			Financial concerns, debt, utilities concerns
Contact Form (Website)	Mental health support team		School concerns
Contact Form (Website)	NHS		General ASD support
Email	Julyabib		EHCp processes

Phone			Meeting attendance, concern over annual review
Phone			Parental and CYP mental health, parent carer rights in care system
Phone	knows about us from other parents, contacted us before		out of school, seeking special school placement
Phone	Next steps course	White, English, Welsh, Scottish, Northern Irish or British	
Contact Form (Direct Form)	Child's nursery	White, English, Welsh, Scottish, Northern Irish or British	Just support for family, and advice Education/ Health or Social Care Advice,
Contact Form (Direct Form)	referral via caring together	Rather Not Say	Parents would like to have some information and advise about support available to them. currently their son is still attending a special school in Lincolnshire. please contact as soon as possible
Contact Form (Direct Form)	Occupational therapy		Help with education and help with assessments and doctors
In Person	Cygnets Pre- school coffee morning		Seeking ADHD diagnosis
In Person	Cygnets Pre- school coffee morning		Short breaks
Contact Form (Direct Form)	Been a member for long time	White, English, Welsh, Scottish, Northern Irish or British	social anxiety, eating disorder ,Education/ Health or Social Care Advice, Advice/ help groups to do with mental health and eating disorders,
Contact Form (Direct Form)	Through school coffee morning	White, English, Welsh, Scottish, Northern Irish or British	Behavioural support
Phone	school referral		EBSA
In Person	FVP		EBSA
PINS	PINS Survey		Lack of support in school
PINS	PINS Survey		seeking neurodevelopmental assessment
PINS	PINS Survey		Not enough school support
PINS	PINS Survey		seeking dyslexia diagnosis
PINS	PINS Survey		Lack of school support
PINS	PINS Survey		Lack of school support and mental

			wellbeing of CYP
PINS	PINS Survey		Lack of assessment, support for needs on school
PINS	PINS Survey		Support to seek neurodevelopmental assessments
Contact Form (Direct Form)	FVP/ Liz	White, English, Welsh, Scottish, Northern Irish or British	Mental Health support, Education/ Health or Social Care Advice, Appropriate services information and advice, Phone,
Contact Form (Direct Form)	Peterborough city council website, SENDIASS page	Indian	Sensory support, SALT, hyperactivity, short breaks, after school, advice on how to deal with the situation when SEN support provided in the school is questionable and have concerns,I need support on all the four topics given here,We want your advice and guidance how to go about further,
Phone	Facebook		Short breaks and CYP emotional support
Contact Form (Direct Form)	Facebook	Pakistani	Parental mental wellbeing concerns, neurodevelopmental assessment support
Contact Form (Direct Form)	Daughters Primary School	White, English, Welsh, Scottish, Northern Irish or British	Challenging behaviours, ASD diagnosis support, making a complaint
Phone		Fig. 2 Cian mosting data	General advice after CYP has received diagnosis

Fig. 3 Sign posting data

Wellbeing and Family Based Activities

Family Based Event/Activity	Date	Number of Adults	Number of Children	Purpose/ Outcome
Community Cafe	3/4/24	5	17	Decreased isolation/ Social Cohesion
Community Cafe	10/4/24	23	4	Decreased isolation/ Social Cohesion
Community Cafe	17/4/24	26	3	Decreased isolation/ Social Cohesion
Community Cafe	24/4/24	32	3	Decreased isolation/ Social Cohesion
Community Cafe	1/5/24	27		Decreased isolation/ forward planning/ parent participation
Community BBQ	4/5/24	50	56	Decreased isolation/ Social Cohesion
Community Cafe	8/5/24	24	2	Decreased isolation/ Social Cohesion
Community Cafe	15/5/24	0	0	Decreased isolation/ Social Cohesion
Community Cafe	22/5/24	37	1	Decreased isolation/ Social Cohesion
Community Cafe	29/5/24	34	4	Social Cohesion
Activity World	29/5/24	20	49	Increased Emotional Wellbeing/ Sign

				posting
CTM Garden Day	4/6/24	24	0	Decreased isolation/ Social Cohesion
Community Cafe	5/6/24	30		Parent Participation/ Inclusion
Community Cafe	12/6/24	17		Decreased isolation/ Social Cohesion
Carers Rights week meal	13/6/24	9	0	Decreased isolation/ Social Cohesion
Community cafe	19/6/24	25		Decreased isolation/ Social Cohesion
Community cafe 26/06/24)	26/6/24	37		Decreased isolation/ Social Cohesion

Fig. 4 Activities and Community Sessions

At the Carers Meal parent carers were asked to state what difference the activity made to them. The comments provided show the importance to the parent carers of having time for themselves and their own mental wellbeing.

- It would be nice to meet other parents
- Having someone to talk to
- Less isolation and better mental health
- Less loneliness and better mental health
- *I will get chance to learn more so that I can help my son more*
- Meeting other parents who are glung through the same issues and don't feel alone and supportive with each other.
- To talk to other people who understand the difficulties trying to get support and advice to battle the system
- To have more knowledge to use as a tool to advocate for the children
- Social
- Meet people and get a chance to share adivce
- Meeting different people, listening to other people's ideas, swapping ideas
- Being able to speak to others in the same position
- Connect with other parents
- Meet other Parent Carers/support
- I can eat my food in peace
- Meeting new people

Schools Data/ SEND

Surveys

During the first quarter two surveys have been conducted with 486 responses.

Survey Title	Responses
Your Say	59
PINS Survey	427

Fig. 5 Survey Response Numbers

Generally surveys would have their own micro report, however on this occasion the 'Your Say' data is recorded below and the PINS survey is still live so full reporting cannot be conducted yet.

Your Say



Fig. 6 Word Cloud of Parent carer concerns - Your Say Responses

In the Your Say survey parents are asked to provide positive and neutral/negative experiences of Education, Health and Social Care

Do you have any positive feedback to share about Education	Do you have any neutral or negative feedback to share about Education
He getting help he needs so far	Had to pull son out to home educate him due to school not having funding to provide 1 to 1 support he needed
Getting better	Constantly giving detentions instead of supporting his needs
18yr old been very good support, 14yr old not enough support	Not enough support
My daughter is in a specialist setting at marshfields and this environment has been very positive for her and she is in	Very slow feedback from school

Education Experiences

classes that are small enough for her to cope with and has made friends for the first time in all her school years and is comfortable with going to school now.	
5 year old doing well in mainstream and well supported by his school and teacher.	Her previous setting primary school Southfields Peterborough was awful and I had to fight them every step of the way. They did not help me with applying for a SEN secondary school or help with the process or transition at all.
My daughter attends a specialist setting and they have been amazing with her and she has really came out of her shell. She has made friends for the first time and this is beautiful to see.	Oldest child has struggled at times with regard to social skills which are often neglected due to her being academically bright.
is well looked after at lime academy orton	Southfields primary school were awful and not supportive throughout the whole process of an EHCP, or applying for a specialist secondary school setting and tell you false information with regards to interventions that don't actually take place
Special school was amazing	The ehcp system is terrible in Peterborough, not enough special school places in Peterborough
The nursery have been exceptional in supporting with this via positive modelling	Mainstream did not manage ASD successfully
Nursery are exceptional in supporting with speech	Not enough life skills alot of focus on academics
TA's are very helpful	Everything is always a battle
Online work for children which is good as we can check on our phones the progress	Yes trying to get Ehcp support is horrendous
Online eduction which they get children to do at home on the phone so we can check progress	School system for children with special needs not helped enough
Free childcare available from 9 months for working parents	Cleaner place to play
The SEND department is very good and the school is very caring towards children.	Her school have small hub where she receives support from fimmillar group off staff in her relaxed program and combines outside activities and play to her learning and with small numbers of children
Mainstream school tries to accommodate but consistency often missed	Need to have a better way to deal with bullying.
Not really	Yes wasn't able to meet my sons needs
Yes . Everyone who works with my child very helpful	Inconsistent support, largely due to absence of some kind but contingency plans often poor due to lack of experience and understanding of how to work with individual children to meet needs. Lack of consistency results in lack of progress, change in behaviours and impacts emotional wellbeing
	I would say rather neutral, but previous year was perfect this school year he is not doing so well, because of change class and teacher which we really not approved. Continuing with previous class and teach will bring continuing progress. This is stopped.
He is attending Heltwate School.	Neutral will be he is on a journey to be supported fully in school
im happy with everything	i am happy as my child doesnt need a education plan and is in mainstream school
Very good	I feel they do not want to Persue Ehcp etc Destiny failed Sats and only then would they listen it was a four year battle
Have managed to get Ehcp for Corey with your support still	Not enough support for kids with ehcps

trying with destiny		
Yes specialist provision give good individual learning programs for my child who is now being more independent and joing in new activities experiences	Not enough help in school	
Amazing help given at Peterborough college,adhered to the EHCP jn every way		
Yes, education have put in for ehcp to help support		
Fig. 7 Educational Experience		

Health Experiences

Do you have any positive feedback to share about Health Care	Do you have any neutral or negative feedback to share about Health Care		
Good health plan	Parking at city care centre not good, long wait lists		
Well done for recognising needs of children	To long await to be seen for ASD assments		
Good support when eventually seen	Health care rubbish		
Long, long, long delays!	Better in the past, more recently need prompts most of the time		
Awaiting	feel children in need should not be pushed to adult services once over 26		
special needs dentist will always see him the same week if asked	Have to fight for everything		
They've done their best with limited resources	GP surgeries need to improve a lot, not enough done to diagnose people, better pain management for people in pain.		
Health visiting team have been very supportive	Long waits not taken seriously		
Health visiting team are great	Need more accurate needs assessments rather than fitting provision to meet local available resources		
Yes really positive	Sometimes doctors just send you home without any tests an stuff		
Health care is better than education but I'm worried as mine is post 16 & going to have to use adult services	Gettting GP appointments in school hours, having to take child to my appointments is very difficult		
Always a struggle	There is not shared information between health care professionals so it can be carry on or continue with help. They pretend to share information but in practice they can't see everything.		
Excellent service with hard working staff	Im happy with the service		
My doctors is very good can get appointments when I need them.	System I feel is broken		
He is healthy	Quick to dismiss parents concerns		
GP has not idea and barely know how to deal with this type of child. Difficult to get refer to see specialist. Very long time for waiting foe any help.	Very slow with appointments		
Yes . When ever I need some help I always get it.	Yes ,that don't help as they should,special for kids like my son nonverbal.		
Health care has always be fabulous since birth			
Daughter appointment are in good time			
Good health care			
	1		

Social Care Experience

Do you have any positive feedback to share about Social Care?	Do you have any neutral or negative feedback to share about Social Care?		
18yr old, quick referral after turned 18 and got help/support	Short breaks funding was so so long to get arranged. Due to delay, after delay after delay took us more than 6 months from start to finish.		
Now it's in place, it works really well	Don't listen		
They've listened when challenged	Not enough resources social workers not paid enough		
Actually yes finally managed to secure 8 hours a month for my daughter to grow her independence	Support takes to long to come into place		
Not enough help for parents with children who have autism	Can be difficult to communicate to		
The social worker regularly meets at our house and calls to discuss child's progress and how she is she is understanding and allows time to play with her and transition time well	It's a long and arduous process		
My social worker is very good always there when I need her.	You have to be out of a job & claiming benefits & then you will get help and support, not if your working v hard paying your way, making ends meet and trying your best to work when your child is on holiday and there is no holiday clubs suitable for your child because of needs and social care - not interested - will be if you sent them in with the same clothes all week or not changed underwear.		
Social worker are pro active searching for right support and help	Always have to fight		
Unfortunately I have never met the criteria so can't comment but thresh hold much be very high	Don't help unless you have done something wrong		
	No negative at this time.		
	It's hard to get some help when you need it . Waiting times are long		
	System broken		

Fig. 9 Social Carel Experience

Two new questions have been added to the form this year and the answers are as follows:

Please use the space to tell us what you need right now and how you like to interact with school and services.	Please tell us what support services you feel are missing or that you need for your child/ family.		
Early help assessment	Family support within school		
I would like the sensor team to monitor my son learning	Learning support for my son		
Support for my sons (both) to access help in school. So they can avoid detentions.	Support to help in home as I am a disabled single mum		
More support and help for 14yr old , just diagnosed eating disorder needing help and support	Emergency respite help or support for mental health crisis		
Quicker paperwork completed been waiting ages	Senco quicker response		
ehcp to be accepted, school are very good with interacting with me now	Respite funding		

Schools need to respond to emails. Have a senco assigned even if your child is not diagnosed but has an ehcp plan in placs	Everything. I have no support	
I like to interact with services that provide sessions for SEN children and families of SEN because you feel comfortable in the space and activities with others that u feta tans and make no judgements. It helps you feel less alone.	I feel that families do struggle mentally with the load of being a SEN parent and get lonely. Maybe a parent SEN	
Support for parents. I'm exhausted and feel unsupported	More parental support as above	
Parent groups/counselling for SEN parents to come and mix and share concerns and feel accepted	SEN parent groups	
Respite	Ehcp ASD assments	
Support and guidance from EHCP to everything and information and guidance to move forward Including mental health	One to one	
Support with anxiety going to school and in school coping mechanisms of staying in 6 hours at school and being happy	No support for anxiety	
Consistency, understanding, flexibility, joined up working	Short breaks providers	
Noting at present, I like the face to face interaction	Behaviour support	
Nothing at present	Behaviour management	
Moving into 6th form awaiting the new changes. Transition to adulthood is a minefield	Ok at the moment	
Post 16 lack of services & places in peterborough	Social places/needs clubs for holidays & help towards it	
Get Ehcp and school sorted	Support fighting for Ehcp to be completed	
Better trained staff to educate and help children with special needs. More support and help for parents.	My child has autism and Im struggling to get the help and support he needs to lead an independent life, his quality of life depends on the help he gets now. I'm physically and mentally drained due my own health and I'm expected to learn everything so I can fight for the help he should be given by the school and other services.	
Have things for kids to go to for cheap	More actives for kids	
Have more things for kids to do in holidays	More cheap family events	
Events	More regular check up on baby development	
We do need more support with her challenging behaviour and mood changes waiting for adhd assessment more from school and therapy more advice on this and what to do to divert and what to do in difficult situations	Support worker	
Schools need to be able to be contacted alot easier as sometimes it's very hard to get in contact with the school.	Support will be from school I feel he is not well supported in area of learning	
Consistent support	I need more help in school holidays	

We have quite big problem with our son as he refuse to go to school. There is probably problem in his class but either school either class did not inform us so we do not know what is happening.More things for kids to doMore support for kids special needs.Family voice education otMore activity kids to doMore specific training for autism adhd coursesim happy with everythingSomeone to listenSchools should have cheap trips for kidsRespiteNeed more support with childrenplaces to meetI need destiny's Ehcp I need to find a therapist in Peterborough who deals with ptsd in childrensocial worker visits every 10 days and see daughter in specialist schoolI need support with my daughter currently hardlyImage: State Stat	I need an educational plan for him and an OT	I think that will be great to know who we should ask if there is a problem and also we found out that school has big impact on everything. You have no choice no power to ask and request things will heal your child. In practice they doing what they want and it is not always in our child best interest. Any type of intervention they treat like interfere in school plan.
go to school. There is probably problem in his class but either school either class did not inform us so we do not know what is happening.More things for kids to doMore support for kids special needs.Family voice education otMore activity kids to doMore specific training for autism adhd coursesim happy with everythingSomeone to listenSchools should have cheap trips for kidsRespiteNeed more support with childrenplaces to meetI need destiny's Ehcp I need to find a therapist in Peterborough who deals with ptsd in childrenSocial worker visits every 10 days and see daughter in specialist schoolI need support with my daughter currently hardlyImage: State Sta	In school holidays it's hard time with my children	I need support as single mum with kids SEN.
More activity kids to doMore specific training for autism adhd coursesim happy with everythingSomeone to listenSchools should have cheap trips for kidsRespiteNeed more support with childrenplaces to meetI need destiny's EhcpI neet to find a therapist in Peterborough who deals with ptsd in childrenSchool email daily social worker visits every 10 days and see daughter in specialist schoolI need to find a therapist in Peterborough who dealsI need support with my daughter currently hardlyI need to find a therapist in Peterborough who deals	We have quite big problem with our son as he refuse to go to school. There is probably problem in his class but either school either class did not inform us so we do not know what is happening.	
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If yyyySchools should have cheap trips for kidsRespiteNeed more support with childrenplaces to meetI need destiny's Ehcpplaces to meetI need to find a therapist in Peterborough who deals with ptsd in childrenset of the set of the	More activity kids to do	More specific training for autism adhd courses
Need more support with childrenplaces to meetI need destiny's EhcpI need to find a therapist in Peterborough who deals with ptsd in childrenSchool email daily social worker visits every 10 days and see daughter in specialist schoolI need support with my daughter currently hardly	im happy with everything	Someone to listen
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I need to find a therapist in Peterborough who deals with ptsd in children School email daily social worker visits every 10 days and see daughter in specialist school I need support with my daughter currently hardly	Need more support with children	places to meet
and see daughter in specialist school I need support with my daughter currently hardly	I need destiny's Ehcp I need to find a therapist in Peterborough who deals with ptsd in children	
	School email daily social worker visits every 10 days and see daughter in specialist school	
attending school	I need support with my daughter currently hardly attending school	
Email, and need help with tommy attending full time	Email, and need help with tommy attending full time	
Help with activities for children	Help with activities for children	

Fig. 10 Support provided and required

Any other services you wish to mention?	Any other feedback
Speech and language have gone above and beyond to support my son providing us with plenty resources to help him in his speech and understanding his emotions	enough help with services
LA and DFG - family of children in need not considered at all.	If there is a real need- you won't get anything - if your playing the system & claiming benefits you will get everything
Family voice have always helped me Thankyou	Thank you so much
With all services you have to fight and know your rights and law to be helped	Parents struggling and fighting the system to get basic help not good enough.
More things for kids to do for cheap	More cheap things for kids to do
Hope they do more actives in holidays	
Nursing services, I wish my son can be helped in that aspect	
I tried hard to get EHCP but it is got rejected.	
More cheap activities for kids to do	

Yes yours I have used your services for years I don't know what I would do without you	
Carers days are fab, run by family voice	

Fig. 11 General Feedback and Other Services

Fig. 7 to 11 shows a very mixed picture for local families in relation to how they experience SEND services. The numbers responding to experiences of Social Care are lowest and also generally more negative. Fig.10 where Parent Carers were asked what support they felt they required show that hands on support and short breaks are two areas of need clearly not being addressed for local SEND families. This matches with Parent Carers lacking resilience as reported in previous reports for 23/24 including FVP's annual report.

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 7 parent carers have been attending meetings either through volunteering their time or as employees. Fig.12 shows the number of meetings attended where reports have been completed.

Number of	Hours Spent at	Administration	Travel Time	Total Hours
Sessions	Meetings	Time (Hours)	(Hours)	
53	101.5	8.5	36.5	146.5

Fig.12 Breakdown of Time spent at Strategic Meetings Apr-Jun

Meetings attended included:

Family hubs Joint Partnership board meetingAlliance: Children, Young People & Families GroupPINS Early Adopters Support ForumAlliance: Children, Young People and Families GroupPfA strategy meetingChildren & Young Peoples Mental Health and Well-being BoardAll Age Autism StrategyCHB Crime & Cohesion Working GroupStrategic Transformation Partnership All Age LD and Autism Pathways Autism StrategyParent Carer Listening Event Attendees: Roger Valentine James Bird Jane Mee Janaki Kc (Parent)Francesca Elliot(Parent) Siobhan Weaver Nicole Hill Patronesia LeaporaPFA Independent Living Working GroupPins project meetingChildren, young People and families co production	
PINS Early Adopters Support Forum Alliance: Children, Young People and Families Group PfA strategy meeting Children & Young Peoples Mental Health and Well-being Board All Age Autism Strategy CHB Crime & Cohesion Working Group Strategic Transformation Partnership All Age LD and Autism Pathways Autism Strategy Implementation Workshop Parent Carer Listening Event Attendees: Roger Valentine James Bird Jane Mee Janaki Kc (Parent) Francesca Elliot(Parent) Siobhan Weaver Nicole Hill Patronesia Leapora PFA Independent Living Working Group Pins project meeting	Family hubs Joint Partnership board meeting
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All Age Autism Strategy CHB Crime & Cohesion Working Group Strategic Transformation Partnership All Age LD and Autism Pathways Autism Strategy Implementation Workshop Parent Carer Listening Event Attendees: Roger Valentine James Bird Jane Mee Janaki Kc (Parent) Francesca Elliot(Parent) Siobhan Weaver Nicole Hill Patronesia Leapora PFA Independent Living Working Group Pins project meeting	PfA strategy meeting
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	PFA Independent Living Working Group
Children, young People and families co production	Pins project meeting
	Children, young People and families co production

EHCP Improvement Meeting East of England Learning Disabilities and Autism share and learn Peterborough SEND Operations 17 in meeting James Bird the lead. MDT EHCP QA - Early years PCC SEND FORUM 45 people in meeting Claire Nunn was the lead. Early help Julaybib Project coffee morning Caring for Complexity Event 7 profesionals and 5 parent/carers **H&CS PDPS Moderation** Adult Co-production Collaborative - Mental Health, Learning Disabilities and Autism ERPCF PFA Independent Living Working Group Meeting Peterborough SEND ops group Alliance Crime & Cohesion Working Group Sendiass Steering Group Next steps workshop Path Event Carers Strategic Oversight Group Meeting MDT EHCP QA - Complex health needs 6 in meeting joint lead Karen Charles - Hollis and Alison Tolson Situational Mutism Working Party Meeting **PFA Health Group** Peterborough Independent Advisory group All Age Autism Strategy Improvement Programme PFA Health Group Action Set 3 SALT Pathway **APP** Meeting Autism Strategy implementation - communications delivery group PfA Strategy meeting Next steps workshop **EHCP** Improvement Meeting Children and Young peoples mental health and well-being board PCC SEND FORUM PINS COMMUNITY OF PRACTICE MEETING PCC Listening event East of England Preparing for Adulthood regional network

Singapore Visit at CDC

Carers Strategic Oversight Group

Strategic Transformationpartnership all age learning Disabilities and Autism Pathways

Inclusion Health Workshop-Vulnerable, homelessness and Access to Health

Fig.13 Range of meetings attended

Schools Work

Since the 1st April and the full commencement of the schools meetings that FVP are conducting as part of the PINS Project (Partnership for Inclusion of Neurodiversity of Schools) 18 settings have been engaged with. The project calls for an initial survey to be administered at the start and end, along with three coffee sessions per setting. The PINS project is funded by the ICS but calls for joing LA and PCF working; as such it is being reported on here:

Setting	Survey	Parents at Coffee		
(Numbered)	Responses	Session		
1	13%	5		
2	8%	3		
3	4%	1		
4	20%	0		
5	12%	9		
6	8%	0		
7	3%	3		
8	13%	2		
9	11%	0		
10	5%	3		
11	8%	8		
12	7%	0		
13	4%	10		
14	8%	7		
Fig.14 Pins Data				

Responses from the survey were mixed with 55% reporting negatively about their

experiences.

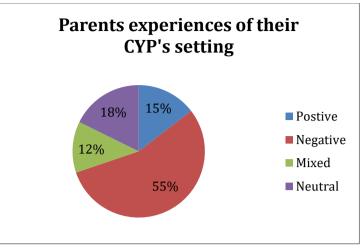


Fig.15 Parental Experiences with local settings

Other School Sessions

Date	Number of adults	Number of Children
5/6/24	7	
10/6/24	10	
20/6/24	3	
	5/6/24 10/6/24	Date adults 5/6/24 7 10/6/24 10

Fig. 16 General School Sessions

Parent Carer Coffee and Listening Sessions

Workshops, Focus Groups, Coffee and School Sessions	Date	Number of adults	Number of Children
Parent Carer Listening Event 25/4/24		2	
Sanctuary Coffee session	7/6/24	9	
Parent Carer Listening Event	20/6/24	1	

Fig. 17 Coffee Sessions

Information and Awareness	Date	Number of Adults	Number of Children
CDC Stand 24/4/24	25/4/24	12	
Caring for Complexity	20/5/24	5	
CDC Stand	26/6/24	19	

Fig. 18 Information and Awareness Sessions

Seldom Heard Communities

Household Ethnicity				
	April	May	June	
White British	0	13	18	
Gypsy or Irish Traveller	0	1	0	
Roma	0	0	0	
Any Other White background	0	1	3	
White and Black Caribbean	0	0	0	
White and Black African	0	1	0	
White and Asian	0	0	0	
Any Other Mixed or Multiple Ethnic Background	0	0	0	
Indian	0	2	1	
Pakistani	4	3	12	
Bangladeshi	0	0	0	
Chinese	0	0	0	
Any other Asian Background	0	2	4	
African	0	4	1	
Caribbean	0	0	0	
Black British	0	1	0	
Any Other Black or Caribbean Background	0	0	0	
Arab	0	0	0	
Any Other Ethnicities	0	0	0	
Rather Not say	0	0	0	
Unknown	0	4	6	

Fig. 19 Household Ethnicity

Seldom heard engagement with parent carers has continued this year utilising face to face meetings and activities as detailed below in fig.20

Information and Awareness	Date	Number of Adults	Number of Children
Julaybib (17/4/24)		6	
Julaybib	15/5/24	6	
Julaybib	19/6/24	8	
AHG Meal	13/6/24	10	16

Fig. 20 Seldom Heard Engagement

Many of the queries coming though from parent carers requesting signposting are from parent carers from local seldom heard communities and the majority of those engaging through settings are also considered seldom heard.

Co-production and Change

Topics of Importance

There have not been any Topics of Importance (ToI) yet. Two are awaiting responses from the last end of the 23/24 financial year. The themes are Education and Inclusion and Health Inequalities.

Co-production has been ongoing across a range of areas including:

- Accelerated Progress Plan
- Autism Pathways
- Preparing for Adulthood
- Home Support

Recommendations/ Forward Plans

- 1. Based on data gathered and requests from strategic leaders gathers views on the what it means to be a Parent Carer locally and the impact this role has on the individual.
- 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