
FVP Interim Report

July - September
2020

FVP Parent Representatives

Introduction

The following quarterly report will be as closely aligned as possible to a format utilised in Family Voice Peterborough's (FVP) annual reports; laid out in such a way as to demonstrate work against income streams. Work where possible will fall under the headings of:

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

There can be much cross over in the above mentioned areas, especially more recently due to the Coronavirus Pandemic COVID-19 mentioned from here on as COVID-19 only.

The period from July 1st to September 30th has again seen quite a change in delivery and themes arising mostly due to COVID-19 as in the last quarterly report. There is a continued move away from face to face work to online, virtual and phone contact only with parent carers. From data collated the main method of participation has been via Facebook with 11 Polls, 1 surveys (shared on Facebook via google forms) and a number of discussions in FVP's chatroom.

It has also been decided this quarter to trial a new way of working and find a way to continue the trips and activities approach that used to enable wider participation. In return for vouchers to family based activity places parent carers complete a specially developed feedback form that captures views for feeding into services with senior health and LA managers. 9 parents have completed the "your say" form to provide general service feedback so far.

A renewed effort has been undertaken to attempt to enable parent carer participation via virtual sessions; a hub is planned to take place towards the end of September with 3 new parents wanting direct support relating to transition to secondary settings during COVID-19 and a seldom heard engagement session is planned with community leaders to say what help FVP can provide to parent carers.

Participation/Engagement/Involvement July to September 2020

Headlines

- 1) **110** up from 74 named parents in total have been involved at some level, with a total of **134** up from 85 children and young people with SEND within the households, and **57** up from 41 siblings.
- 2) **665** up from 320 parent carers have participated across 33 up from 20 online surveys or Facebook polls.
- 3) Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
 - a) Autism Spectrum Disorder
 - b) Attention Deficit and Hyperactivity Disorder
 - c) On the Neurodevelopmental Diagnostic Pathway
 - d) Varying degrees of Learning Disabilities and Difficulties
 - e) Global Developmental Delay
 - f) Genetic Disorders
 - g) Downs Syndrome
 - h) Cerebral Palsy
 - i) Spina Bifida
 - j) Achondroplasia
 - k) Social, Emotional and Mental Health Needs, including Eating Disorders and Anxiety Disorders.
- 4) **6** 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, Asian, Gambian, Lithuanian, Polish, African, Portuguese and White European.

CAMHs and General Support

Food Support

Support to enable a small number of families to eat has continued during the summer period for new families with very specific needs relating to CYP with more complex health needs. Three families in particular have had more or less weekly food deliveries during the summer break. One parent had the following to say about the impact food support had on her

“I was trying to cope during COVID to go shopping but due to my disability this was really difficult and Family Voice stepped in and were like a ray of sunshine. I got regular food parcel deliveries complete with treats and luxuries which was a massive weight off my mind. In fact the first food parcel I had had fresh bread and vegetables which I hadn't eaten in over six weeks. To say it made me cry with happiness is an understatement”

The food support has an impact on emotional wellbeing for the whole family.

CETR's

During COVID-19 the Experts by Experience (EbE's) have reported there has been an impact on the delivery of support for families who fall under transforming care that they come into contact through their involvement in care Education and Treatment Reviews (CETR's). There is less support available in the community through reduction of services due to many changes as a result of the lock down that occurred. It has been reported thought that in some ways virtual CETR's have been better in terms of ability for the EbE's to attend and participate. So far 15 CETR's have occurred and one was cancelled on the day

Transport Anxiety

Returning to school has led to an increase in parental anxiety and reported difficulty in CYP behaviour which may be related to parental anxiety. Much of the anxiety has been linked to home to school transport, but not specifically COVID-19 concerns rather the annual concerns relating to timings of home to school transport pick up and collection times and who will be providing any transport. A Topic of Importance (ToI) linked to this is now in draft and with the LA waiting for response and will be published shortly. The ToI is based on feedback from 9 parent carers taking part in discussions on Facebook and 17 parent carers completing a survey. The survey results are as follows:

In the survey questions were asked to establish as much as possible that there were a good range of views being incorporated into the data being presented in the ToI and as is demonstrated below this is clear:

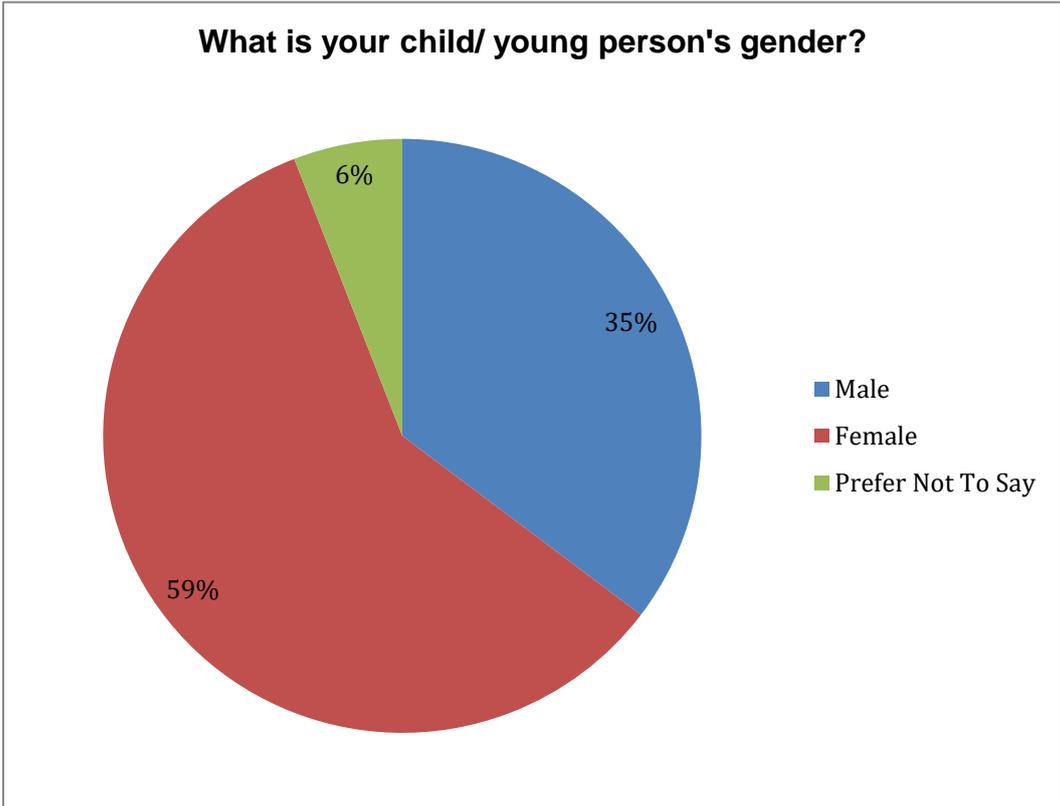


Fig.1 Gender of CYP

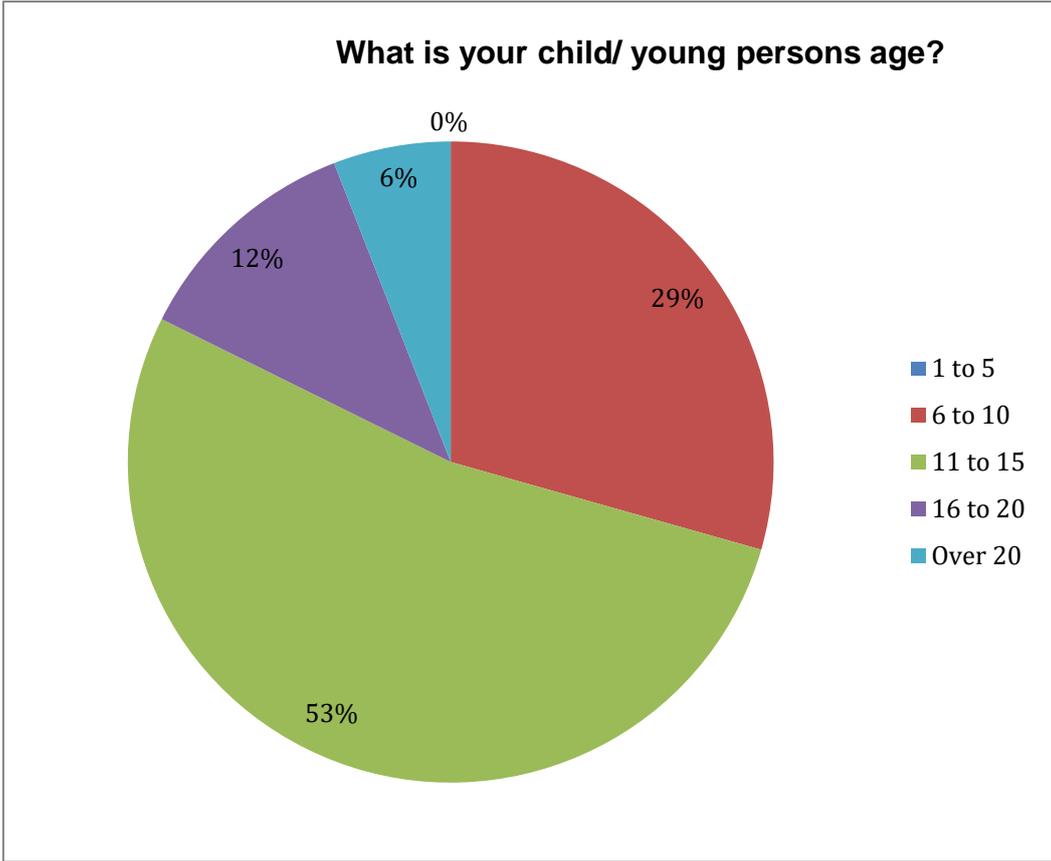


Fig.2 Age Range of CYP

**What type of educational setting does your child/
young person attend?**

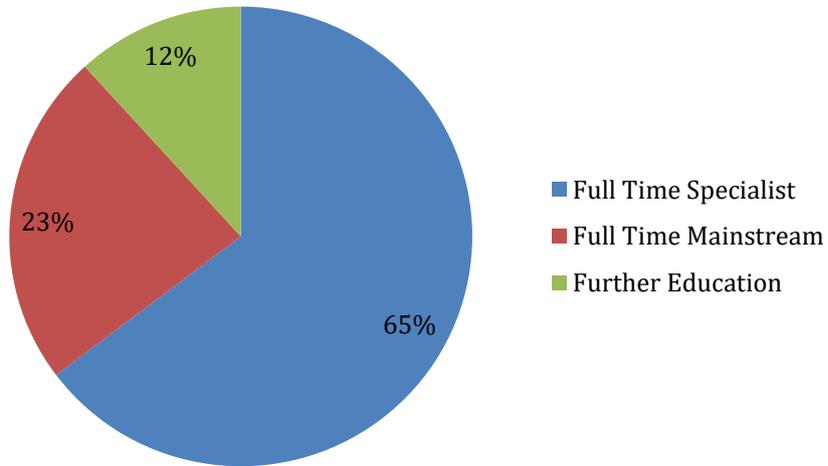


Fig.3 Educational Setting

**Does your child/ young person have any of the
following?**

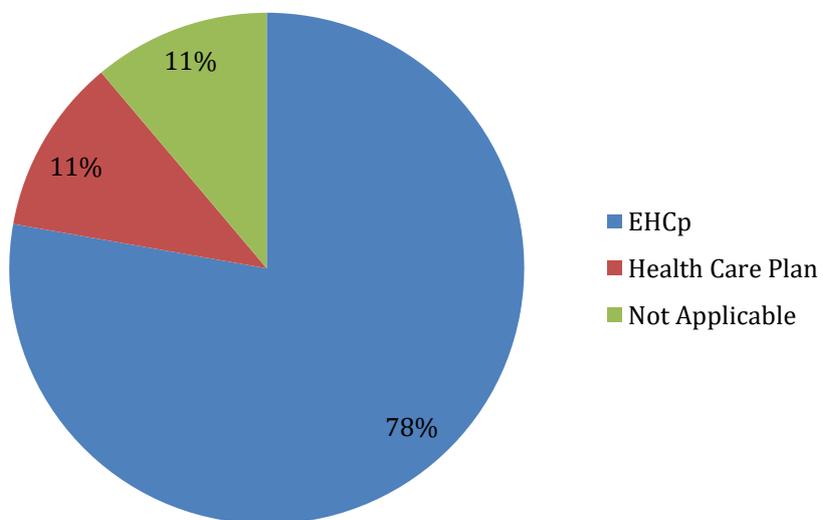


Fig. 4 Educational Support

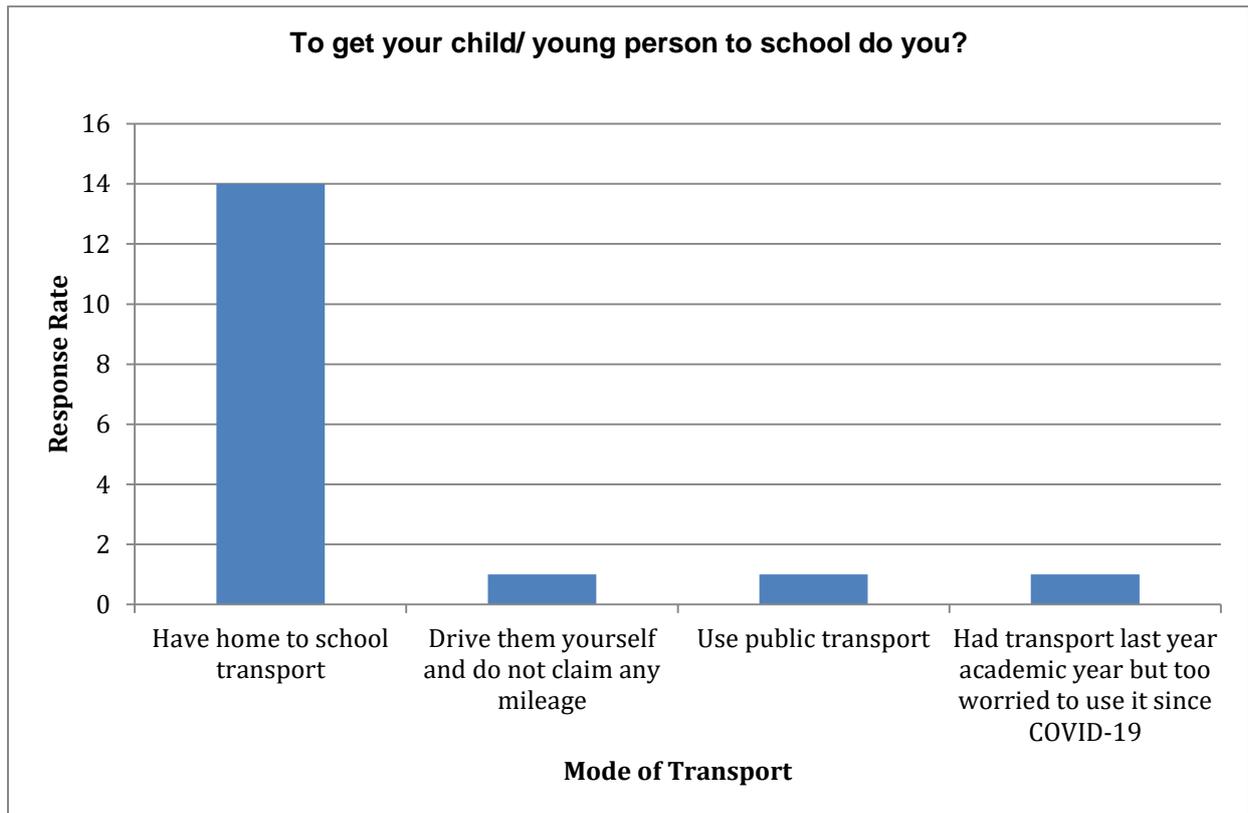


Fig.5 How Parents Get CYP To School

In the survey parents were presented with a range of options of how they got their children/ young people (CYP) to school with home to school transport being one option as shown in figure 5 and this was the most frequently chosen option.

To further establish some of the themes occurring in the face book discussions further questions on the survey were:

- When first applying for home to school transport did you know what to do?
- If you child/ young person uses home to school transport is this the first year they have done so?
- If your child/ young person has used home to school transport before please tell us for how long

The responses to which are in figures 7, 8 and 9, and from which figure 8 shows that for over 65% home school transport has been used in previous years.

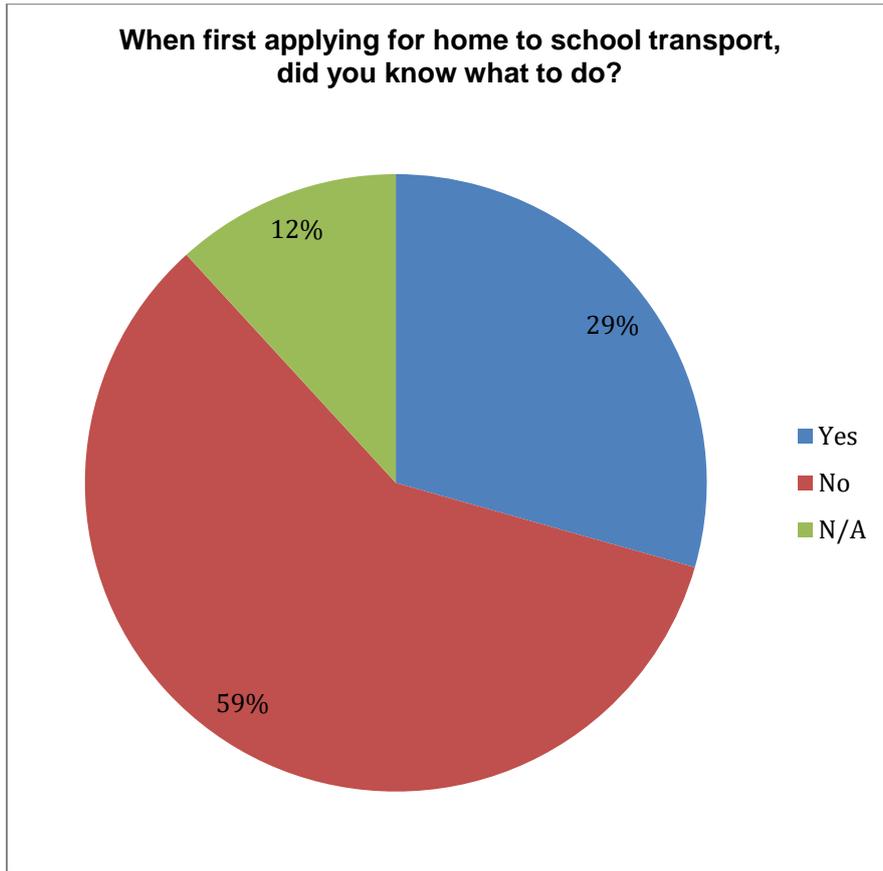


Fig.7 Applying for transport

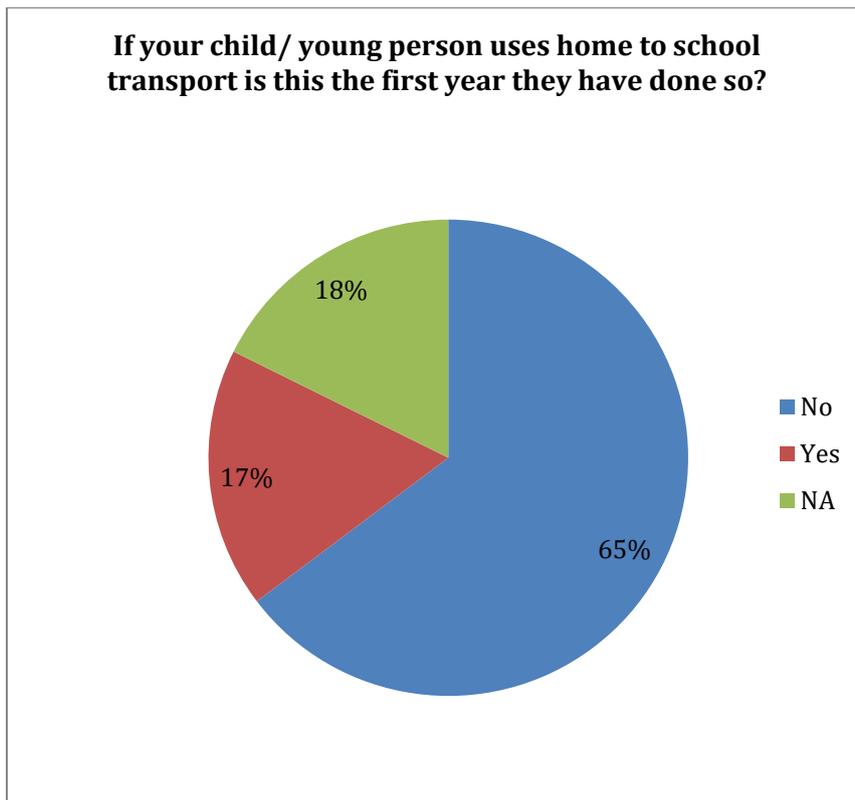


Fig.8 Years using transport

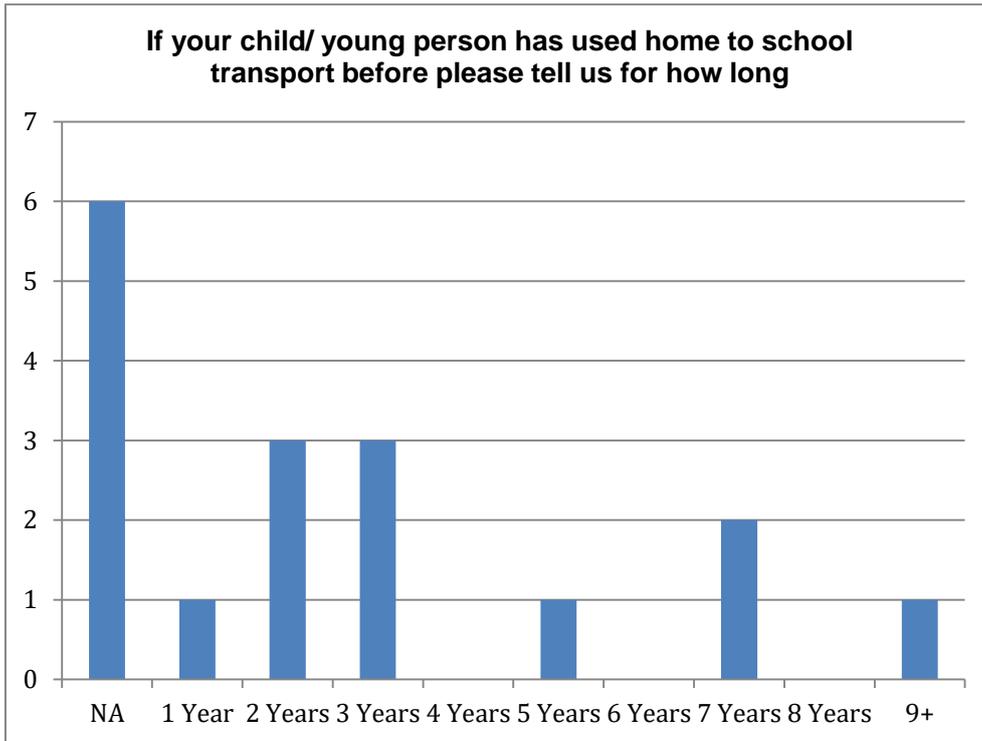


Fig. 9 Length of Time Using Transport

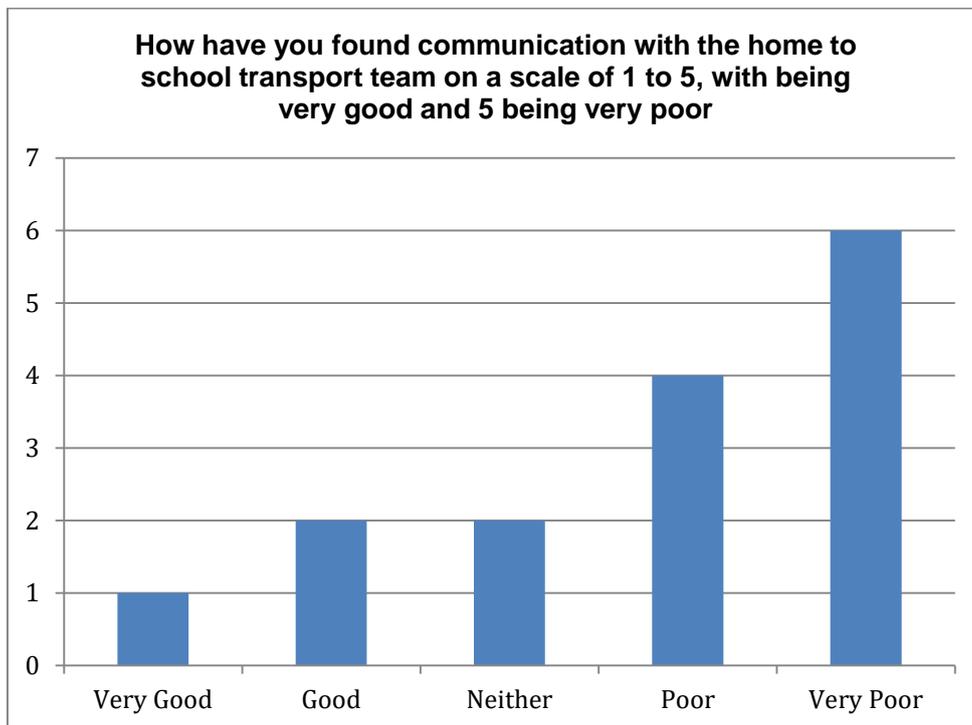


Fig. 10 Satisfaction with communication

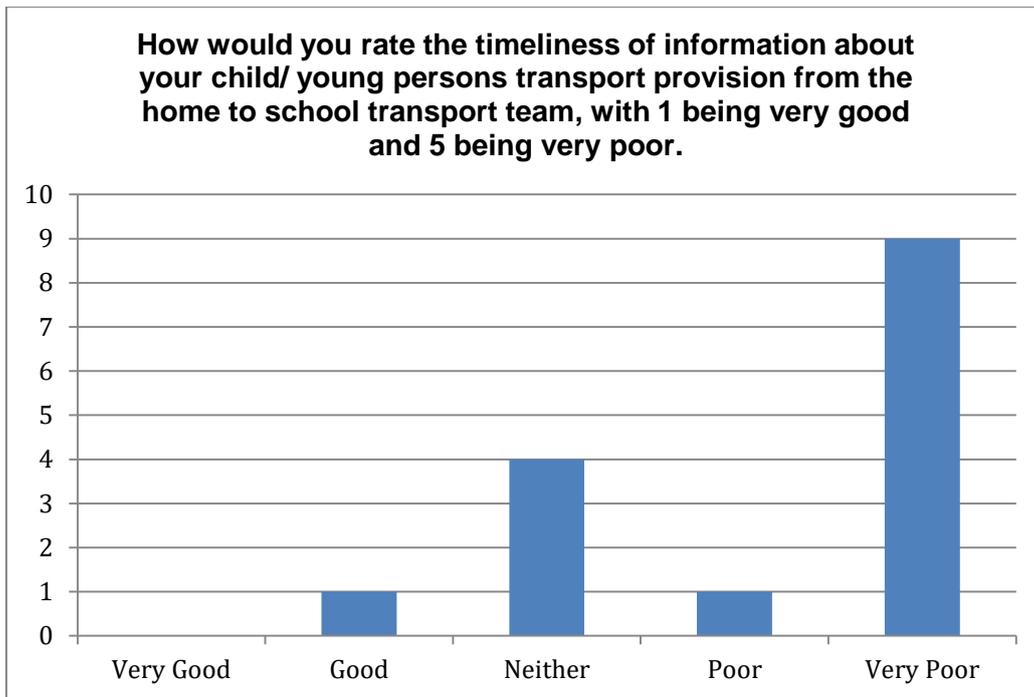


Fig. 11 Timeliness of communication

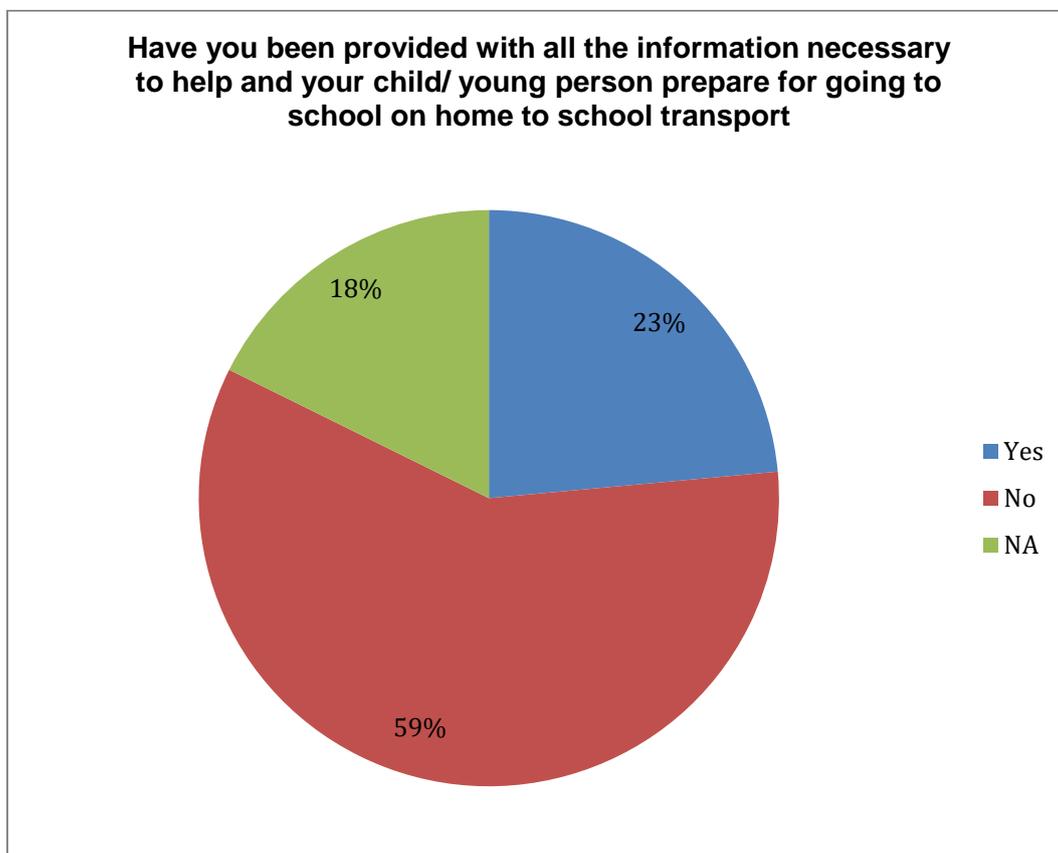


Fig.12 Information Provision

Figures 10 to 12 and the evidence from the discussions and open questions show a level of dissatisfaction with transport provision in terms communication about whether a CYP will receive transport, when they will be collected and by whom.

Parental Comments

1. Sometimes a little frustrating with timing but on the whole it is a complete life saver for us and we are really grateful for it.
2. We were initially denied transport as they said we lived too close to the school. This was despite several neighbour's children attending the same school & accessing transport. Our school eventually sorted this for us. The bus is never on time & has been cancelled several times with the call advising of cancellation coming after the bus should have picked my child up. Alternative transport has been provided but this has left my child waiting at the bus stop for long periods. Receiving transport updates are always short notice.
3. We have lovely supervisors and drivers on our bus
4. Process was very easy but lack of communication as to who would be taking them was non-existent. On his first day on transport. They didn't have adequate seating. Only a 5 point booster seat which is too small. So had to have seatbelt. Which is not adequate to keep him seated?
5. It caused me and my disabled child so much stress!!! We found out about the transport a night before which is simply not good enough. I have applied well in advance and even though I have had a phone call to say they are sorting it nothing was actually getting done. Made a numerous phone calls, sent them emails with no response. Very frustrating. My child was asking questions that I was unable to answer which led to sleepless nights and behavioural difficulties.
6. It was good when used last year
7. Changing drivers chaperones without telling having random people come to collect my child (i don't send her in on transport then), Very impatient school end, Late pick up, Not interested in risks and needs of child, Drives fast
8. did not receive covid survey only got details for transport 2 days after it restarted
9. Why do they always send the information so late? I mean a couple of days before school opens isn't good enough. Every year it's the same issues.
10. Emails unanswered. When I got through to speak to someone they brushed off my request for my son to have a photo of or meet the escort/driver of the transport. As this is my sons first time on school transport.
11. We had no information no letter no phone call no email
12. So far this year I have had no formal confirmation that transport was being provided. It is and taxi turned up although on the wrong day during her first week. I did manage to get an answer by phoning about 10 days prior to start of term and was told a letter would follow. Particularly tricky this year as she is now in supported accommodation.
13. When my daughter moved from school to College last year I didn't know that she needed to reapply from scratch. She had had transport throughout secondary education and I was prompted to reapply each year, but those prompts stopped when she left school and there was a flurry of activity at the start of term and a week at least of no transport.
14. The service is generally good once you get it but the communication is chaotic
15. I had to chase up 2 days prior to him returning to school as we had heard nothing regarding who was picking him up, what time etc
16. Terrible so far.
17. First day didnt turn up, phoned to find out why and was told he had been picked up!!. He was standing next to me while I was making call.

As a way to further facilitate improvement in communication and service experience the final question asked for “***What improvements do you feel could be made to make things easier when using home to school transport?***” and the following are a selection of the answers that were provided:

1. Better organisation & pre-planning. Earlier communication.
2. Photos/picture of staff on transport would have been useful. Having correct method of securing my child in his seat.
3. Timelines and communication is a key! And this can be easily improved.
4. Proper introduction of driver and chaperone before collecting child.
5. Chaperones that understand risk and what to look out for.
6. more communication more people manning the phone lines
7. Get the info out early enough.
8. Drivers and escorts should be sensitised on the types of passengers they are carrying and how to deal with them as none of them have a clue whatsoever.
9. Communication with parents
10. Earlier communication with parents

Virtual Workshops

FVP Parent Carer Hub 24th September 2020

Background

This is the first FVP Parent Hub hosted under the new way of working during C19. We need to develop a way of continuing with the Forum which one of the key platforms FVP uses to engage with Parent Carers.

Population

- Hub was poorly attended by only one parent despite repeated advertising on FVP social media. Three parents had booked on, one dropped and there was one no-show. The parent attending was a regular contact with FVP so already had a good understanding of our aims and also was familiar with our guest speakers.
- Guest Speakers from PCC attended – Jess Conway (Area SENCO) & Marion Deeley (SEND Partnership Manager). Inclusion Manager was unable to attend.

Discussion/Feedback

- Parent concerned about transition to secondary school for son who has additional needs but no EHCP. Due to go up to secondary Sept 2021 but would like assurance/advice around additional transition support should C19 measure still be in place. Also raised concerns re 2 older children attending same secondary provision, both who have diagnosis. Parent feels school have constantly failed to provide her children with the additional support they need and does not want the experience repeated.
- JC – gave appropriate advice and offered to contact secondary school on parent's behalf to discuss existing issues. These will be communicated to parent via FVP.
- MD – Appropriate guidance and processes will be in place should C19 measures continue next year.
- Parent was asked if she was happy with responses and she said she was

Recommendations

- Due to the confidential and sensitive nature of the issues being discussed, future Forums hosted via ZOOM will not be open forums. Forums spaces must be booked in advance using the link provided on the pre event flyers and each parent will be allocated an individual time slot of at least 15 mins.
- Better use of our existing contacts (eg schools) and social media to ensure the invite to Hub reaches all Parent Carers in our demographic.
- Ensure Hub invite is communicated to Seldom Heard Communities via established contacts.

Report by: Jan Mead, Forum Coordinator 24/09/2020

SEND Data and Schools Work

Surveys

During this quarter FVP have conducted 2 surveys gathering views from Peterborough parent carers, with a total of 18 responses.

Survey Title	Number of Respondents
Wheelchairs	1
Transport	17
	18

Fig. 13 Survey Data

The data results of the transport survey are shown in the section above. Survey topics are currently being planned based on WSoA themes and parental feedback, which will run between now and the end of the financial year. The annual survey will take place between January and March 2021.

Engagement on Social Media

Face to face engagement is still on hold, despite some restrictions being lifted towards the end of August beginning of September under changing government guidelines. Plans were developed to host small scale gatherings but these were not successful as further changes were introduced due to an increase again in COVID-19 cases and the risk deemed too high for staff and parent carers.

Poll Question	Response Options	Number of Responses
We use Parent Representatives to attend strategic meetings and feed back the views of Peterborough parent carers - if we offered remuneration at £10ph for this role, would you be interested?	Yes	7
	I Would Do This Voluntarily	4
	No	0
This is the first of a series of polls about returning to school in September.Poll 1: Do you want your child/	Yes	14

young person to go back to school in September? (FVP SEND group)		
	Yes, Part Time	2
	Undecided	2
	No	0
POLL 1: For Parent Carers in Peterborough - Do you want your child/ young person with SEND to return to school in September? (FVP main page)	Yes	4
	No	2
Poll created for FVP in PwA Group If you have a child /young person with special needs or a disability do you want them to return to school in September	Yes	29
	No	6
POLL 1: For Parent Carers in Peterborough - Do you want your child/ young person with SEND to return to school in September? (Posted on the PDDCS)	No	1
	Undecided	1
	Yes	24
Following on from our most recent poll; here is our next element . If you are ready to send your child/young person back to school in September,would you prefer the option of choosing whether this was full or part time?(Posted on FVP SEND page)	Full Time	8
	Part Time	3
If you are ready for your child/young person to go back to school in September would you like to have a choise of Full time or Part time ?(posted on PDDCS page)	Full Time	14
	Part Time	2
Next education based Poll. As part of the Written Statement of Action work Peterborough need to look at satisfaction with the EHCp process as part of quality assurance work.One of the areas that has been looked at by reps involved relates to feedback gathered as part of the EHCp process.If your child/ young person has an EHCp you would have been invited to give feedback. Did you complete the form requesting feedback. If you select no, can you provide a reason in the comments box.	Yes	4
	Did Not Receive Feedback Form	3
	No	2
We are looking at running another challenging behaviour workshop in mid-october. Would you prefer virtual or in person with social distancing measures	Virtual	5
	In Person	3
Transport: We have seen a number of posts in here and	Yes	6

had communication about transport via other channels too. The main concerns appear to relate to communication and timeliness would you agree?		
	No	
We are looking at working with Safari Adventure Play and Party Venue Peterborough to enable families to have access to an activity. We are going to be sorting vouchers for individual parent carers to access for free via FVP in return for taking part in virtual sessions/ online surveys etc. Is this something you would be interested in?	Yes	19
	No	
TOTAL		165

Fig. 14 Poll Responses July-Sept

To work on ways of identifying areas of improvement/ change/ good practice driven by parent carers FVP have used the Facebook chatroom to ask the questions what would make a difference to you and your child, in relation to their SEND? What support would you like? What can the school, local authority, health service do differently? What suggestions do have of practical things would make a difference/ help?

The following conversations ensued:

P1	Listen to parents and take their concerns seriously
FVP	thanks for your response. Could you go into more detail on how services could make parents feel they are being listened too and being taken seriously?"
P1	take notes so it's on child's record. Give parent written information about services. Ask relevant questions about child. Respond to phone calls, emails, letters. Arrange meeting to discuss how child is doing."
FVP	Thank you. These are really helpful suggestions and something we will be able share. Going from what you have said, do you feel there is a bias where parents are not thought to have clear view of their child's difficulties

Fig. 15 FVP conversation with P1

From this the suggestions that can be ascertained are:

1. Takes notes and places on child's records
2. Provide parents written information about services
3. Ask relevant questions about the child
4. Respond to communications
5. Arrange progress meetings

P2	Where to start with this one! Being listened to, with girls you have years of battling every professional and play a long waiting game till they happen to present in setting and those families go years with no advice or support. It's like being left in a blackhole in terms of services. Once your finally listened to (3ish years later for us) the system is so overwhelmed in takes a couple of years to get through the pathway with an absence of support till you get a magic diagnosis. By that point your family is completely broken, your child has lose all hope of early intervention, is so far behind at school and your playing major catch up which all could have been avoided if parents were taken seriously from the get go.
P2	I think the eha services which are only designed for short term input should allow for longer periods of support. Receiving 8 weeks from a family support worker is great but on a 4 year journey so far doesn't really provide any meanful input. And once you've used your 'allowance' it's hard to receive again. Maybe do a parenting course for those on the pathway, cos your can't access the apex or cygnat courses until you have a diagnosis, but those skills would be helpful to manage challenging behaviour whilst in the long waiting game to get an assessment, and being sent on the standard parenting courses repeatly is unhelpful and quite patronising
FVP	Thanks for your input and sharing your experience. Could you give me some practical ways in which services could be changed to make this process better for parents and their children?"
P2	Make schools ring-fence send funding, so the money allocated to your child has to be spend as such, and make it so the schools have to evidence this spending to help support parents applying for ECHP's, currently it's hard to get the school to support due to 'funding' and due to the reduced support from school the ECHP people say needs can be met from the school without additional support, huge catch 22."
P2	I have put several comments i here with suggestions, re. Longer lengths of ongoing support whilst on the pathway, access to more tailored parenting courses prior to the apex and cygnat courses post diagnosis, ring fence sen funding in schools and open information sharing about how this is spend. have an appeals process to use when peds reject eha referrals printed information regarding the pathway and processes that are followed to set correct expectations for parents in terms of time scales so we can prepare ourselves accordingly. Lobby the MP who is meant to have an interest in SEND/Autism, and apparently is on several government groups regarding this topic area. To get more funding for the city's system to reduce/clear the backlog of referrals and waiting lists, also to increase the support that can be offered families.

Fig. 16 FVP conversation with P2

From this the suggestions that can be ascertained are:

1. Longer lengths of ongoing support whilst on the pathway
2. Access to more tailored parenting courses prior to the apex and cygnet courses post diagnosis (Reason for current parent programmes explained to parent in response to this suggestion)
3. Ring fence SEND funding in schools and open information sharing about how this is spent (Explained to parent this is national not local issue)
4. Have an appeals process to use when Health reject EHA referrals

5. Set correct expectations for parents in terms of time scales so we can prepare ourselves accordingly
6. Lobby the MP who is meant to have an interest in SEND/Autism, and apparently is on several government groups regarding this topic area. To get more funding for the city's system to reduce/clear the backlog of referrals and waiting lists. (Explained forums do not lobby – FVP did with PCC to central government)

P3	<p>It seems that that a lot of support pulls out of your child's life when hitting school age in reception. You then left alone with no advice by professionals and you then have to re refer and go through the pathway again. A lot of schools aren't knowledgeable about what's ther to offer you support unless your child is in a special school which needs a echp. Although lockdown lv had no support from speech and language although my child is non verbal and autistic. Iv found out they pulled out at Easter as ther was no contact. Obviously we were in lockdown then so that does not even make sense. I think I could go on forever</p> <p>So the point to my comment is I suggest that support shouldn't be pulled by services your child has been involved in from early years until the end of ks1</p>
FVP	<p>Thanks for your input. Again, this is a common issue that arises. Could I just confirm that you are suggesting for better support/information transitioning from Early Years to school? And, that you feel that schools lack understanding and training in issues of SEND and the services that are available? You have mentioned about services ending. It sounds like this was an abrupt ending and not managed very well. What could be done by professionals when ending services that could make this an easier transition?</p>
P3	<p>No I feel that it's a lack of support after the children are in reception. All services like children psychologist pull out. My child has autism with no other physical medical needs. Non verbal. And from the moment he attended reception we had no support from anyone medical. We had speech and language for around 4 months. Coming out twice while he was at school. As a parent we fight for everything our children needs but we get tired to ring and chase. It shouldn't be that hard for a professional to keep that child up to date with new ideas and tasks to bring on that child. As the kids are still very small I don't think the end of services should end until the end of ks1</p>
P4	<p>A lot of support is given in early years but nothing after reception/ks1, unless there are specific medical issues. Then you're passed to the school nursing service who have next to no idea and want to refer to social services who then say your kids are fine in school so they see no reason for involvement.</p> <p>If you have more than one child with issues. Well you've already dealt with this you should know!</p>

Fig. 17 FVP conversation with P3&4

From this the suggestions that can be ascertained are:

1. Support shouldn't be pulled by services your child has been involved in from early years until the end of ks1

P5	<p>Erm stick to their deadlines stop saying their short staffed then all going on annual leave at same time!!! currently in week 26 of Ehcp process with no final plan or secondary school place !!!</p> <p>More training for all teachers so they can recognise SEN earlier. Teachers to be more aware of APDR cycles as this often gets given to the senco and the teachers are clueless to targets being set.</p> <p>I requested an up to date Ed psych assessment and couldn't get one as the school hadn't subscribed to the service.</p> <p>Listen to parents. My son needed his Ehcp 3+ years ago. Couldn't even get him assessed for one, as school wouldn't support me. Said he was fine. (So Couldn't get an up to date Ed psych report in year 4) He's now finally got his Ehcp at end of year 6 (after having a year out of school with mental health issues) but it's too late as he's so far behind (4 years) he now can't go to a mainstream secondary school! Why can't we get access to Ed psych when we need it?!</p> <p>The only pathway in to services is if school makes the referral - that relies on the school being good enough to recognise a child's needs!!! Schools are failing our kids and the parents!</p> <p>Stop blocking access to services and refusing to make referrals I had to go to my GP to bypass the school who wouldn't get my son a camhs referral as my son "didn't have any emotional and mental health needs". At that point he had already tried to get ran over and tried to hang himself in wardrobe.</p> <p>Mental health services for kids with SEN - not just fobbing them off saying their anxiety is just their adhd or autism. And it taking suicide attempts to get seen by camhs.</p> <p>There is a massive gap between CHUMS mental health (very basic anxiety level) and being able to get intervention with camhs for depression and anxiety. Our kids literally need to be trying to kill themselves and self harming to get help. Where is the middle ground?</p> <p>Parents need the help way before any referrals are made. That all then gets delayed by the parenting courses. My ASD son for example needed an adhd assessment - in order for him to get assessed for adhd they wanted to send me on an Autism course (son has been diagnosed for 8 years now so we done all ASD courses back then) but had no spaces on the course for 6 months . . . surely you'd do an adhd course for an adhd assessment</p> <p>Schools to work with parents - not against them. God the list goes on!</p> <p>Schools need someone clued up on Ehcp's when parents apply and how best to support them. I fought against the school, not one single piece of evidence was from school for my sons Ehcp as they weren't giving him any provision as said he didn't need it it was the Ehcp assessment process that found all the issues and support actually needed - which is shocking.</p>
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Fig. 18 FVP conversation with P5

From this the suggestions that can be ascertained are:

1. Stick to deadlines
2. More training for teachers to recognise SEN earlier
3. Listen to parents
4. Don't always link anxiety to ASD/ ADHD – Mental Health needs to be seen separately

All contact from parent carers whether on Facebook or via phone is documented and themes are captured to inform the more strategic work of the forum from highlight reports though to topics of importance (ToI)

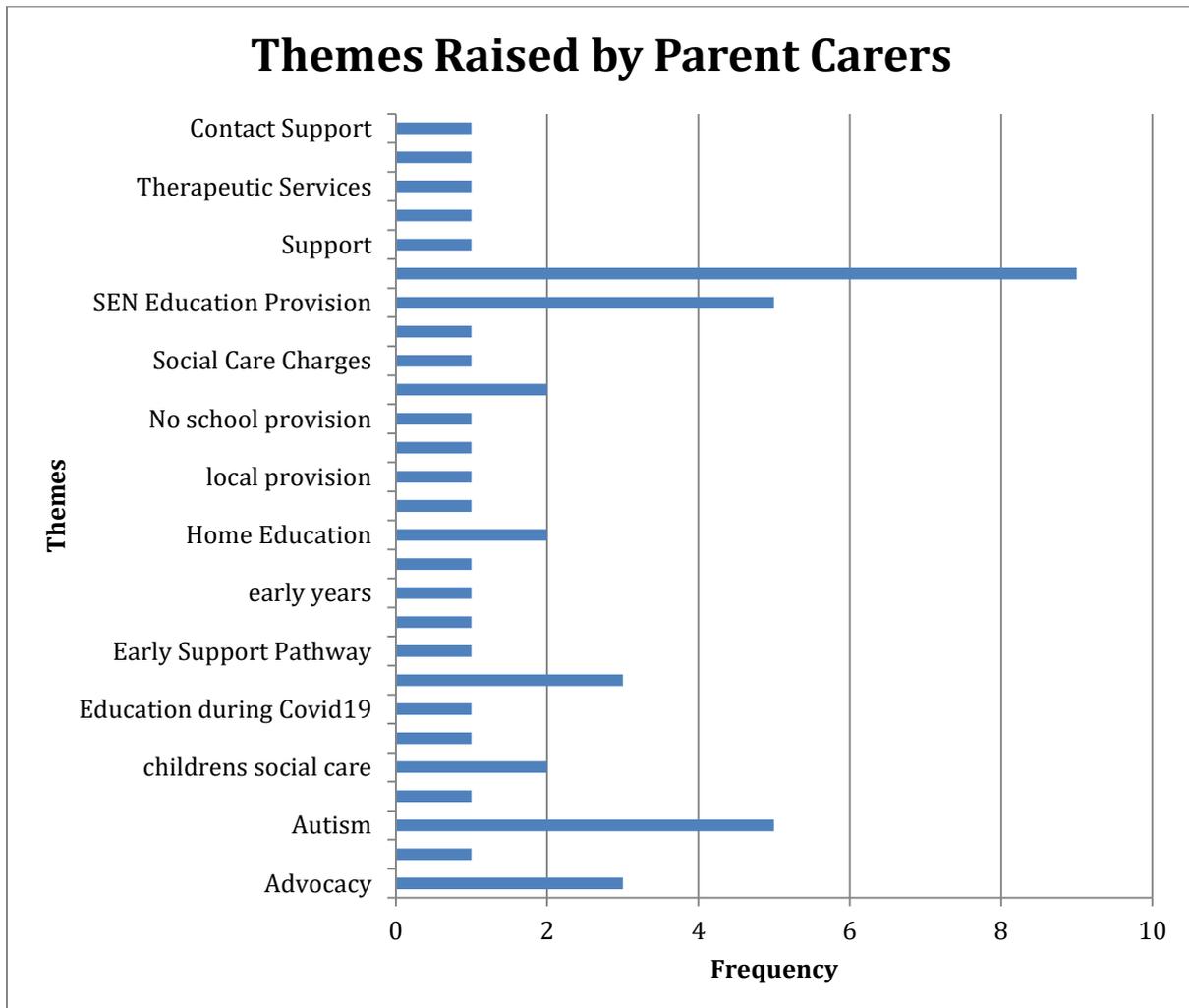


Fig. 19 Frequency of themes raised by parent carers

Some parent carers raise more than one theme when they get in contact and some themes are inter linked. During the August/ September the most frequent theme was Transport and as lock down eased and the government prepared to re-open schools there was a rise in educational based themes.

Parent Representation and Strategic Work

The number of meetings this quarter remains high as using virtual methods to run meetings makes attendance easier and it is possible to fit in more meetings. Travel time is extremely low and in most cases zero (the time below really relates to where reps wished to use FVP office resources)

Number of Sessions	Hours Spent at Meetings	Administration Time (Hours)	Travel Time (Hours)	Total Hours
46	66.5	33.5	4	104

Fig. 20 Breakdown of Time spent at Strategic Meetings July-Sept

Much of the meeting focus during July/ August was still COVID-19 related with August/ September moving towards returning school/ the new normal and more recently a second wave and impact on families from FVP's perspective.

Every meeting attended results in a rep report being completed and FVP are now also using highlight reports for reps to take to meetings as required to detail what parents are saying about specific issues and/ or services. This system creates a much better way of demonstrating a two way flow of communication between strategic boards and the forum via parent representatives. This system is being developed and all the team will be trained in its use.

Seldom Heard Communities

“What Can Family Voice Do for You” 21st September 2020 11:00 am Via ZOOM

Background

During C19 it has been increasingly difficult to progress with engagement with our Seldom Heard Communities within Peterborough. As an organisation FVP needs to ensure that during C19 we continue to offer advice and guidance to our demographic. FVPs engagement with seldom heard communities is a priority as we are aware that there are families with SEND children who are becoming increasingly isolated but need ongoing support. As a way of reaching out the families out Community Development Officer made contact with Community Leaders and invited them to participate in a virtual forum which would introduce FVP. The aim of the forum was to discover further parent carers and find a way of engaging them with our work.

Population

The meeting was attended by representatives from the following communities:

1. Lithuanian (2 inc FVP Family Voice Rep)
2. Hindu
3. Nigerian
4. A representative from Health watch also attended.

Discussion

1. Some confusion over what FVP does and the demographic that it offers guidance to.
2. Hindi community has a lot of home carers (both for adults and children) and there was a concern that these people were not aware of support that they may be able to access.
3. Explanation about the function of Caring Together and their offers in relation to Adult and Young Carers.
4. Nigerian Community can be very wary of support being offered – this is mainly due to the families not wishing their personal issues being “made public”.
5. Lithuanian Community rep stated that they have worked with FVP for many years and would continue to promote to Parent Carers within their community
6. Feedback forms will be circulated via email to all participants after meeting – participants will receive a family voucher for Safari Play upon receipt of the feedback.
7. Forum Coordinator explained that the voucher was to thank individuals for participation but also to ensure that events usually hosted by FVP for families were continuing.

Feedback

4 feedback forms have so far been received – all scoring the Zoom event as 9 or 10.

Feedback from participants:

“ It was informative meeting”

“Thank you, very useful”

“The meeting was excellent and I am sure it will bring all the communities close to each other. I am glad I am part of the group”.

Recommendations

- It was felt that the Forum would benefit from more representation from other communities
- Health watch would like to work with FVP to ensure that appropriate guidance and messages are getting across to all health groups. FVP are invited to attend the Health watch monthly Forum.
- All agreed that the forum had been useful and would like the event to continue on a regular basis – FVP Development Worker will organise this. Meetings will all initially be via ZOOM.

Report by: Jan Mead, Forum Coordinator 24/09/2020

Working with The Aiming High Group

Planned engagement with parent carers from the Aiming High Group had been focussed on family based trips and activities at which participation activities occurred. The participation was varied from gathering case studies (on video) through to completing surveys/ feedback forms. These have been methods that have proved popular and at the request of the parent carers themselves.

Due to COVID-19 all the planned work stalled, which caused some disappointment to the families involved. A discussion occurred with the Aiming High Group and it was suggested that they would happily complete online surveys etc and in return FVP would enable

individual family attendance at bowling sessions. The parents completed a form FVP have developed called "your say" which enables general feedback across health, education and social care. Of the 10 parent carers who completed the form the CYP details are:

- 7 were male and 3 were female
- The average age for the boys was 11.5 and the girls 7
- The areas of need listed were GDD, SLD, HI, Complex Needs, ADHD, Cancer and Cerebral Palsy

Do you have any positive feedback to share about Education?

1. She has settled really well in school and likes it there
2. yes , online services are helpful
3. My daughter's care and education were well managed in primary school and she was able to progress at her own pace.
4. Excellent communication with school SENCO & Sensory support services

Do you have any neutral or negative feedback to share about Education?

1. Only school transport could do with improving by making drivers and escorts more aware of the needs of the children they are transporting
2. Updates on EHC Plan are very slow
3. Nothing in place for my child to return to school completely been left and forgotten
4. School is taking advantage of my non verbal child. And push him to special school and not taking him to full time. And excluded him from school because he bit school Assistant. He can communicate through writing and he told us that she said to my boy that how stupid you are and thing trigger his bad behaviour. He is Autistic and in year 2. He is going to school for 1 hour only he has EHCP with full day supporting teacher.

Do you have any positive feedback to share about Health Care?

1. I am happy with the service
2. "she has been well so no problem"
3. Good experiences
4. They have tried but still very poor

Do you have any neutral or negative feedback to share about Health Care?

1. The dental service for children with special needs could be improved further
2. Takes so long to get back genetic blood tests results

Do you have any positive feedback to share about Social Care?

1. Not at present but i suppose it's benefits a lot of people
2. Just recently got a social worker abit late

Do you have any neutral or negative feedback to share about Social Care?

1. Carers at home could have more help and support before crashing out themselves as some carers get so exhausted but have nowhere to turn to. Also more funding could be put into support parents and carers
2. Service is absolutely diabolical. Never know who the social worker is, they change constantly and no one tells me about it! You just don't know where to turn! New social worker knocked on my door during Covid pandemic and without showing her ID or anything started asking my 14 y/o child questions about her disabled sibling! No adequate communication at all.

Co-production and Change

Topics of Importance

One topic of importance have been compiled and is due to be this published:

1. Transport and Communication

Progress since April/ June Recommendations/ Forward Plans

1. Consideration be given to the recommendations in the live ToI (Education and Communication) – **Response Given and Published and Section M in use as discussed in Co-production and change section**
2. FVP to look further at Seldom Heard engagement and what is and is not working – explore new ways of increasing engagement – **new sessions being trialled using ZOOM and a rep in role specific to engaging with seldom heard parent carers**
3. Further google forms to be created that match issues being raised by parents, themes within Peterborough City Councils (PCC) Written Statement of Action (WSoA) – **Still in progress, with FVP action plan under review**
4. Continue recruitment of parent representatives – **3 new parent reps recruited to the team and further ongoing recruitment under way.**

Recommendations/ Forward Plans

Parent Suggestions to PCC/ Health

1. Takes notes and places on child's records
2. Provide parents written information about services
3. Ask relevant questions about the child
4. Respond to communications
5. Arrange progress meetings
6. Longer lengths of ongoing support whilst on the pathway
7. Access to more tailored parenting courses prior to the apex and cygnet courses post diagnosis (Reason for current parent programmes explained to parent in response to this suggestion)

8. Ring fence SEND funding in schools and open information sharing about how this is spent (Explained to parent this is national not local issue)
9. Have an appeals process to use when Health reject EHA referrals
10. Set correct expectations for parents in terms of time scales so we can prepare ourselves accordingly
11. Lobby the MP who is meant to have an interest in SEND/Autism, and apparently is on several government groups regarding this topic area. To get more funding for the city's system to reduce/clear the backlog of referrals and waiting lists. (Explained forums do not lobby – FVP did with PCC to central government)
12. Support shouldn't be pulled by services your child has been involved in from early years until the end of ks1
13. Stick to deadlines
14. More training for teachers to recognise SEN earlier
15. Listen to parents
16. Don't always link anxiety to ASD/ ADHD – Mental Health needs to be seen separately

Recommendations

1. Due to the confidential and sensitive nature of the issues being discussed, future Forums hosted via ZOOM will not be open forums. Forums spaces must be booked in advance using the link provided on the pre event flyers and each parent will be allocated an individual time slot of at least 15 mins.
2. Better use of our existing contacts (eg schools) and social media to ensure the invite to Hub reaches all Parent Carers in our demographic.
3. Ensure Hub invite is communicated to Seldom Heard Communities via established contacts.
4. It was felt that the Seldom Heard Forum would benefit from more representation from other communities
5. Health watch would like to work with FVP to ensure that appropriate guidance and messages are getting across to all health groups. FVP are invited to attend the Health watch monthly Seldom Heard Forum.
6. All agreed that the Seldom Heard Forum had been useful and would like the event to continue on a regular basis – FVP Development Worker will organise this. Meetings will all initially be via ZOOM.
7. Start rolling out further to whole FVP team who attend strategic meetings highlight report system
8. Work with LA and ensure timely response to Transport and communication Tol