
FVP Interim Report

October to
December 2020

FVP Parent Representatives

Introduction

As with previous reports and the format adopted for annual reporting this quarterly report is set out into the following sections:

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

As with the last report, the sections are not completely separate as some work crosses over in to other areas of work.

The period from 1st October to 31st December has proved challenging especially as it has coincided with another lock down due to COVID-19 (C-19). The impact of the pandemic is challenging across a range of areas for families and evidence is showing increased levels of anxiety amongst parent carers and their families. From data collated the main method of participation has been via Facebook again with 10 Polls with 80 individual participants and 15 parent carers taking part in a range of discussions. Uptake on virtual sessions has been varied, with the behaviours that challenge and seldom heard communities sessions seeing the most attendance. Generally areas of work that could be termed as supportive have the highest uptake.

During this period some wider charitable work has taken place to address needs identified as a result of C-19; including increased anxiety and decreased financial capability. Wellbeing packs were issued to parent carers and a 'Christmas in Box' campaign was conducted to ensure families could have a Christmas day meal, presents for their children and food for the school holiday period. Overall 312 people benefitted from this support.

All of the work so far has led to the identification of the following themes; Decreased familial resilience, increased levels of frustration with changes to educational access and increased requests for general information across a range of topics.

Participation/Engagement/Involvement October to December 2020

Headlines

- 1) **305** up from 110 named parents in total have been involved at some level, with a total of **370** up from 137 children and young people with SEND within the households, and **106** up from 57 siblings.
- 2) **716** up from 665 parent carers have participated across 46 up from 33 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) 14 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, Latvian and White European.

CAMHs and General Support

Food Support/ Emotional Wellbeing Support

Across 25 households 127 individuals have received food support on more than one occasion during this period.

Number of adults	Number Children without SEND	Number SEND 0-25
36	59	32

During the Christmas period 50 families received what has been termed “Christmas in a Box” which was a meal for Christmas Day, food for the Christmas period and presents for any children in the households.

In lieu of the usual festive parties hosted by FVP that bring families together and afford families opportunities to benefit from a short break from caring and enable contact with likeminded peers, it was decided to enable access to some festive treats instead where 70 children received goody bags which parent carers may not have been able to provide.

Another activity conducted was where parent carers could either be nominated or put themselves forwards to receive a wellbeing/ pamper pack which a number of volunteers hand delivered. These packs contained items including but not exclusively; herbal teas, hot chocolate, bath treats, scented candles and other gifts.

Family Based Event/Activity	Number of Adults	Number of Children	Adult Gender	Family Ethnicity	CYP Needs (Range)
Halloween (Goody bags) (31/10/20)	0	70	Not declared	Polish, White British, Other European,	ASD, ADHD, Complex Needs, HI and VI, Physical Disabilities, Complex Health Need, Rare Genetic Conditions, Down Syndrome
Wellbeing Packs (26/11/20)	79		4 Male, 75 Female	Polish, Lithuanian, Scottish, White British, British Pakistani, Gambian, Asian	
Xmas Boxes	93	140		White British, Asian, African, Polish, Lithuanian	ASD, ADHD, Complex Needs, HI and VI, Physical Disabilities, Complex Health Need, Rare Genetic Conditions, Down Syndrome

All of the above activities have an impact on the emotional wellbeing and mental health of those who have benefitted from their delivery. Work is to be conducted to ask all those who have had food support to complete a short survey looking at the benefits of any support provided.

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

C-19 Impact and Anxiety

A number of surveys have been conducted looking at the impact of C-19 on local families especially in relation to their Emotional Wellbeing and Mental Health. Findings from a survey completed by 103 parent carers identified anxiety relating to catching the virus, finances, lack of wider support including health services and loss of wider support networks. The full COVID report can be found here

<https://www.familyvoice.org/sites/default/files/COVID%2019%20Impact%20on%20Parent%20Carers%20Across%20Peterborough.pdf#overlay-context=Participation>

Emotional Health and Wellbeing				
	Code	Count	Code	Count
	Positive		Negative	
Improved Emotional Health and Wellbeing (return to school)	IEHWB	60		
Increased Challenging Behaviour			ICB	28
Decrease In Emotional Wellbeing			DEW	79
Concern over Restrictions			CR	3
Increased Anxiety			IA	60
Resilience	R	2		
Family Breakdown			FB	6
Concern about C19 Spread			C19	24
Positive Impact on Family Relationships	PIFR	1		
Lack of understanding about C19			LUC19	2
Improved Behaviour	IB	3		

The above table shows that overall experiences are more likely to be negative rather than positive and that anxiety is at worrying levels.

COVID-19 AND THE IMPACT ON PARENT CARERS

EMOTIONAL WELLBEING

65 parent carers are worried about the impact of COVID-19 on their child with SEND

Respite and Short Breaks

- 7** parent carers had breaks cancelled
- 2** parent carers have had them restarted
- 3** parent carers still don't have respite
- 3** parent carers received respite in alternative ways and have found this better

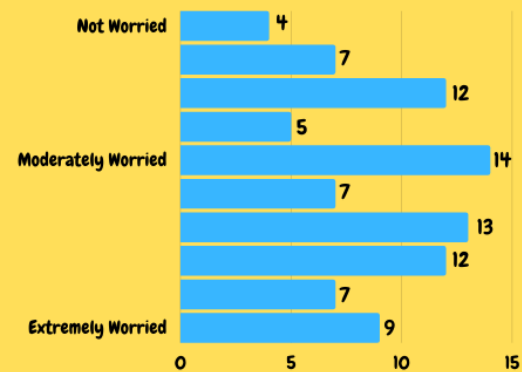
82 would rate their current anxiety in relation to Covid-19 as moderate to severely heightened. Compared to **2** who have no anxiety.



75.3%

of participants told us it was impacting their physical, emotional and mental wellbeing as a parent carer

If your child/ young person has returned to school how worried on a scale of 1-10 are you about the risk of them catching the virus?



Positive Experiences

Our family is pretty well prepared and resilient. If our child's bubble has to isolate for a two week period, it will be tough but manageable, even if this happens a few times. during the course of the year. However if it's longer than two weeks at a time, we will be back to where we were before my child could attend school.

My job is safe, my children are safe in school but their anxieties are heightened and sensory overload frequently happens. It is stressful but not because of Covid-19 - it has always been there.

Our situation is currently excellent. None of us is ill, both children in the family are in school, mother works in a school and father can work from home.

Negative Experiences

Im a single mum.im scared. I have asthma. My child take immunosuppressant drugs. She have got low immune systems. Who will be looking for us if i or my child catch covid 19.
That there will be no light at the end of the tunnel
The unknown, the worry we will go back into covid. The lack of support due to not being able to see friends and family
my husband left in lockdown I have suffered anxiety about going back to work and going outside having new medications to help since lockdown I am worried about getting ill and not being able to look after my son since its now just me
no child care being ill more not going out mixing with people and children not being able to mix with children to learn more things getting anxiety only being with parents
My elder daughter had to shield until August 1st ,she has become even more health anxiety,and as her carer I'm having to go out to sort her needs alot more ,which causes alot of anxiety to her siblings as having to go out at night
I am a single mum. My daughter lived with me until end-June 2020. She continued in College through most of the period March to end-June and respite care continued. She moved into supported living at end-June. That has helped improve our relationship which had deteriorate although not Covid related. The care facility has struggled to find interesting things for my daughter to do because of covid restrictions and she was bored. returning to College has improved this a lot
having to provide extra travel not being able to afford things , affecting my mental health condition. And disability. Schools attitude was not great.
Before COVID we were able to ask friends to babysit for us, to be able to get some respite as a parents. This is currently not possible due to restrictions and behavioural issues having worsened with our child. I am concerned that my husband is planning on working abroad as this is the only work he has been offered since lockdown started; which will mean him being away for a week then quarantining when he returns and the burden of childcare will solely be with me for 3 weeks. This is likely to be a very stressful time, without having access to the usual support network from friends dropping round to help out etc (my child is more violent when dad is away) as well as having to do all the school runs and get to work at the hospital.
Working from home for me is difficult as feel isolated. My son only being in college one day a week, he finds it hard to organise himself when it comes to self supported study.
Managing a household with three young people with SEND, with limited opportunity for breaks from one another has presented challenges and at times been utterly exhausting.
Kids are back to school and to learning which is important, wearing masks everywhere is kinda stressful, Just want to get back to living a normal life. And able to look forward to the future especially for the bigger kids that missed out this Year cause of COVID.
My husband and I have our own training business, we do have a concern that if lockdown was reintroduced then we would be affected financially, and we also have a commitment to our employees. Children being sent home from school to isolate is also a concern as we have 4 children and we would struggle with childcare due to work commitments. The children really missed their friends during lockdown as well as family. Although we tried our best with home schooling, their learning has most definitely been impacted as a result of school closures, especially our daughter either additional needs.
I am a single parent to two children with additional needs. My eldest daughter has severe mental health difficulties. Our household situation has remained the same. My concerns are how schools are handling positive cases and that they might not be being careful enough. We have positive cases now and schools are kept open which worries me more that my children could be exposed. I would rather they learned from home and I worked from home to keep us all safe.

Virtual Workshops

CCG/ Training	Number of Adults
Behaviour Workshop (16/10/20)	9
Behaviour Workshop (06/11/20)	5

Workshops, Focus Groups and School Sessions	Number of Adults
A/S Focus Group (18/11/20)	3
A/S Focus Group (30/11/20)	2

There have been two virtual behaviour workshops and two ASD Strategy Focus Group Sessions. An overall total of 19 parent carers have been involved.

SEND Data and Schools Work

Surveys

During this quarter FVP have conducted 1 survey gathering views from Peterborough parent carers, with a total of 103 responses.

Survey Title	Number of Respondents
COVID – Return to School	103

The survey was used to inform a fuller C-19 report detailed in the previous section. The findings of the report have been used to inform C-19 response planning by the LA

Engagement on Social Media

A longer term move is being made towards virtual engagement as the pandemic is still ongoing and health and safety measures need to be implemented longer term to work towards limiting the potential for transmission.

Face Book Engagement	Number	Total Parents
Facebook Polls	10	80
Facebook Discussions (parent led)	8	15
Facebook Discussions (FVP led)		16

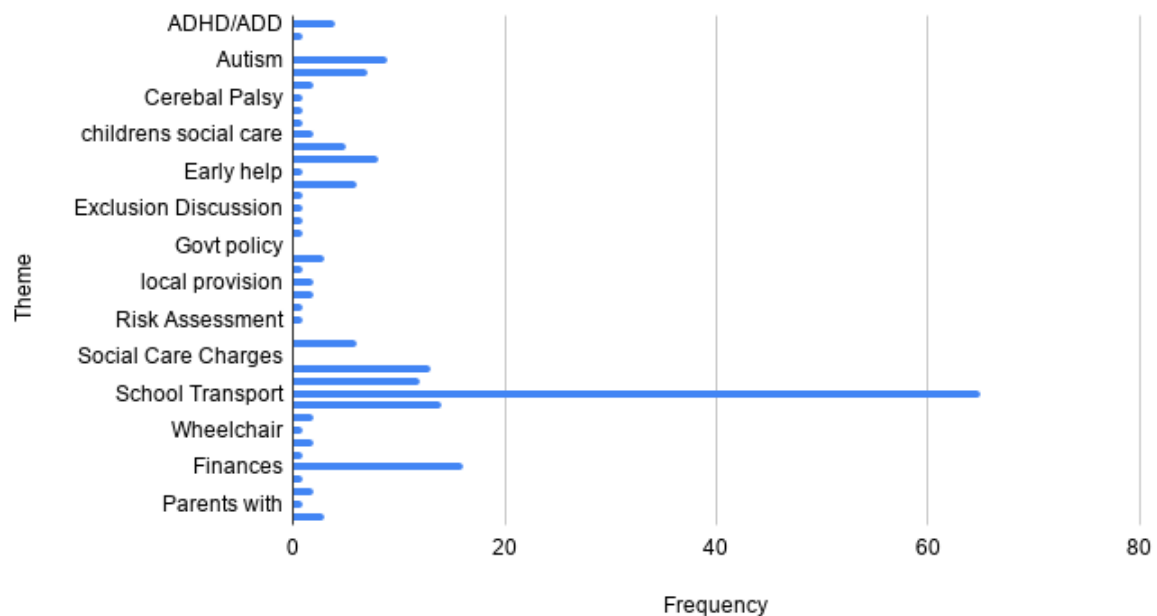
There is a general overall increase in parent carers engaging via Facebook through Polls and discussions.

Poll Question	Response Options	Number of Responses
Poll 1 (New Ways of Working) – During COVID-19 some ways of working have begun to change with a move towards more virtual meetings. We are gathering views on this to help inform ways of working locally. Please select any options that apply: Please select any options that apply:	Would you like virtual meetings for the NEW ASSESSMENT process to be offered after Covid?	3
	Have you attended a virtual NEW ASSESSMENT meeting relating to your child/yp's EHCP	2
	Would you like virtual meetings for the ANNUAL REVIEW process to be offered after Covid?	2
Would you like virtual meetings for the ANNUAL REVIEW process to be offered after Covid?	Yes	7
	No	4
Have you been invited to a meeting relating to your child / yp's EHCP?	Yes	6
	No	6
Have you attended a virtual NEW ASSESSMENT meeting relating to your child / yp's EHCP?	Yes	1
	No	5
Have you attended a virtual ANNUAL REVIEW meeting relating to your child / yp's EHCP?	Yes	4
	No	5
Would you like virtual meetings for the NEW ASSESSMENT process to be offered after Covid?"	Yes	5
	No	2
Poll 2 (New Ways of Working) Are you happy with the current process of documents being sent electronically during Covid?	Yes	2
	No	4
Poll 3 (News ways of working) Would you like documents to be sent electronically or via post after Covid?"	Post	6
	Both	4
	Electronically	
If you have to take part in virtual sessions/ meetings would you prefer to join using?	Zoom	5
	Teams	4
We are looking for parent carers to share their stories with us to raise awareness of parent carers more generally. You story will be added to our e-news and shared with local press outlets. Our latest one has raised awareness of	Maybe	3

Rhetts Syndrome. Would you be interested?		
	No	1
	Yes	1
TOTAL		80

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 through to topics of importance (ToI)

Frequency vs Theme



Some parent carers raise more than one theme when they get in contact and some themes are inter linked. Overall the most frequent theme is transport. Finance is also becoming a recurring theme.

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)

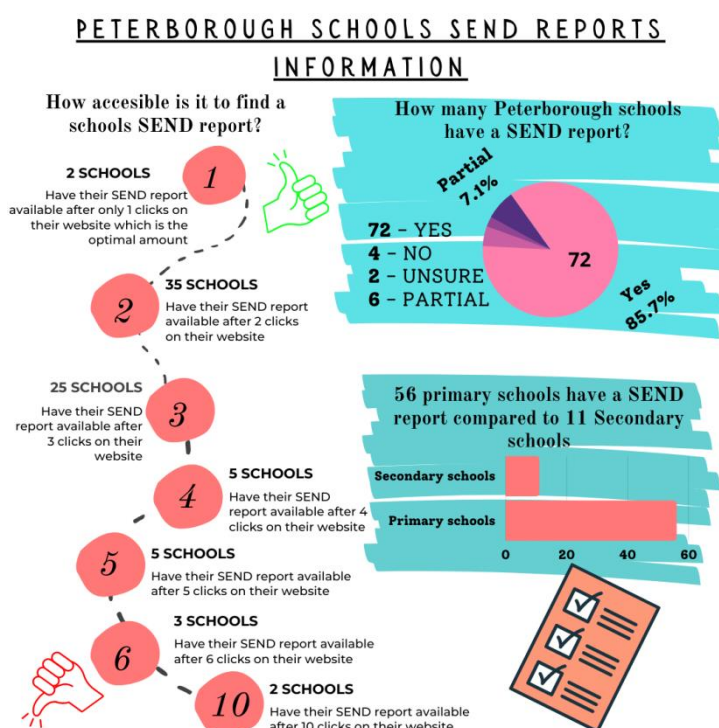
Number of Sessions	Hours Spent at Meetings	Administration Time (Hours)	Travel Time (Hours)	Total Hours
63	97	35	2	132

Most meetings have focussed on C-19 and ongoing work relating to the Written Statement of Action (WSOA)

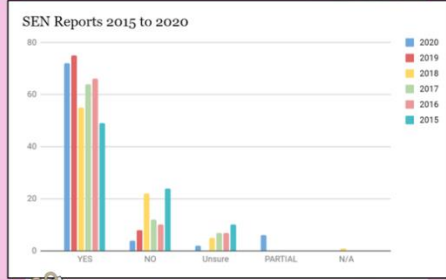
Every meeting attended results in a rep report being completed and FVP are now also using highlight reports for reps to take to meetings as required to detail what parents are saying about specific issues and/ or services. This system creates a much better way of demonstrating a two way flow of communication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

SEN Information Report Review

The annual review conducted by FVP reps of school SEN Information reports took place over the summer months. The final data gathering and analysis occurred during this quarter. Key findings are as follows:



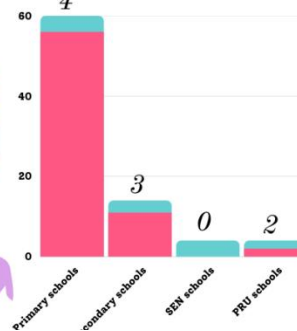
Peterborough schools SEND reports from 2015 to 2020



Seeing a steady
improvement within the past 5 years

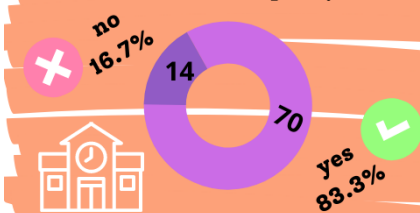
How many Peterborough schools still
don't have a SEND report in 2020

60 primary schools - **56** have
SEND report
14 secondary schools - **11** have
SEND report
4 SEN schools - **all 4** have a
SEND report
4 pru schools - **2** have SEND
report

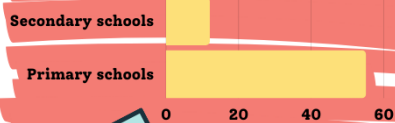


PETERBOROUGH SCHOOLS SEND POLICY INFORMATION

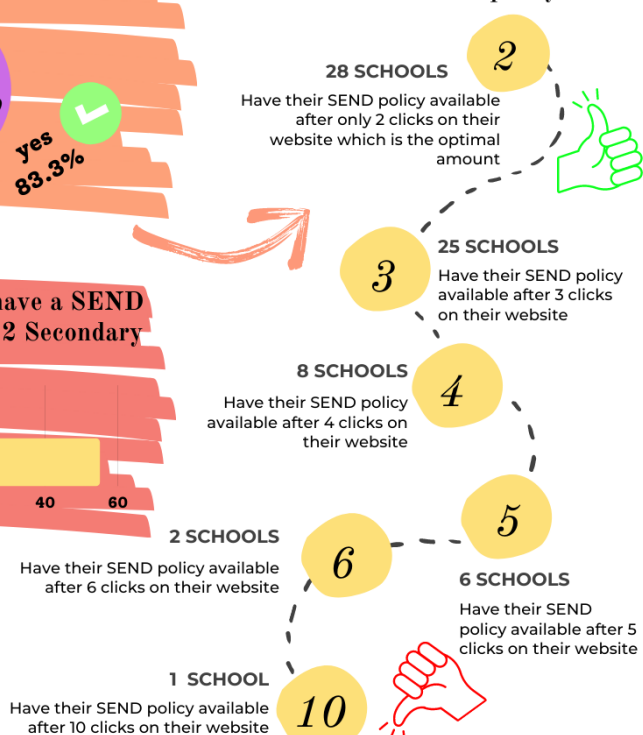
How many Peterborough schools
have a SEND policy?



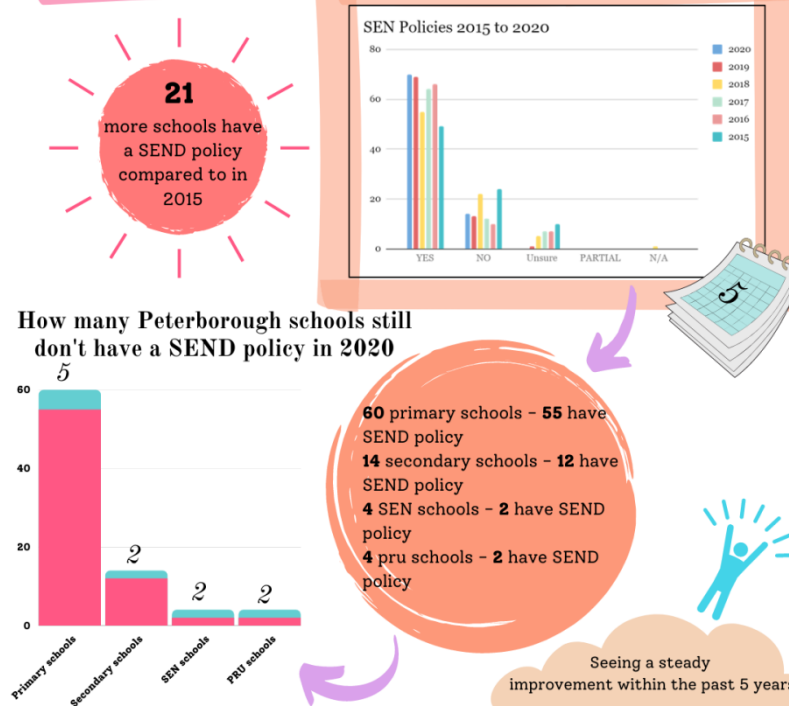
55 primary schools have a SEND
policy compared to **12** Secondary
schools



How accessible is it to find a
schools SEND policy?



Peterborough schools SEND policies from 2015 to 2020



The review takes time, as does analysing the data. What is clear is that despite C-19 the majority of reports have been updated; however parent carer engagement in the process appears to be low.

Seldom Heard Communities

Information and Awareness	Number of Attendees	Gender	Ethnicity
Seldom Heard Zoom Session #1 23/11/2020	7	3 Female, 4 Male,	Chinese, Nigerian, Pakistani British, Indian, Lithuanian

The session focussed on getting to know one another and C-19 concerns; one main theme was picked up as a result which was around racism towards people within the Chinese community relating to C-19 fear and misunderstanding.

Plans have been made for monthly themed sessions with signed support and refreshments on request. General feedback has been positive so far regards the sessions that have occurred including the one from this quarter.

Co-production and Change

Topics of Importance (Tol)

Two Tol have been under development; PfA and Support and Services which are still in the draft stage. The Tol are generally used to demonstrate co-production and changes to SEND locally.

General Work

Work is ongoing with parent representation involved in strategic discussions that inform local planning and service development. Letters and other communications to parent carers continue to be co-produced.

Progress since July/ September Recommendations/ Forward Plans

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. **Teams to be used and 1:1 sessions being offered for 45 minute slots.**
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. **Ongoing and being managed by a marketing assistant**
3. Ensure Hub invite is communicated to Seldom Heard Communities via established contacts. **Not occurred yet**
4. It was felt that the Seldom Heard Forum would benefit from more representation from other communities **Attendance is increasing as is diversity**
5. 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. **Monthly meetings arranged and bookings taking place**
6. Start rolling out further to whole FVP team who attend strategic meetings highlight report system **System under development.**
7. Work with LA and ensure timely response to Transport and communication Tol **Needs to be chased for official response**

Recommendations/ Forward Plans

1. A formal response be provided to the Transport Tol.
2. Schools/ Settings be encouraged to communicate better with parent carers (issue identified in various reports).
3. Clear communication from the LA to parent carers on the impact of their participation.