
FVP Interim Report

January to March
2021

FVP Parent Representatives

Introduction

This quarterly report is set out in the sections as listed:

- 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 January to 31st March again has proved challenging especially as it has coincided with a third lock down due to COVID-19 (C-19). The impact of the pandemic remains challenging across a range of areas for families and evidence is showing increased levels of anxiety and decreased resilience amongst parent carers and their families. There has been a change in the way participation occurs and data is collected. Facebook is slightly less popular and surveys have proved more popular. From data collated the main method of participation has been via Facebook again with 129 parent carers taking part in 7 surveys.

Uptake on virtual sessions has increased with 9 sessions including 117 participants. Most sessions are also now being made available online via YouTube

https://www.youtube.com/channel/UCN-Zqf_9Sbz0a_kTQ1SsY2w

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. In response to either survey completion or general open applications 757 (parents and children) have taken part in 5 forms of activity; activities equate to access to tickets/ passes/ vouchers/ wellbeing and family activity packs.

All of the work so far has led to the identification of the following themes which are unchanged from the last quarter; Decreased familial resilience, increased levels of frustration with changes to educational access and increased requests for general information across a range of topics. This has been pulled together across a range of Topics of Importance and general reporting.

Participation/Engagement/Involvement January to march 2021

Headlines

- 1) **310** up from 305 named parents in total have been involved at some level, with a total of **395** up from 370 children and young people with SEND within the households, and **181** up from 106 siblings.
- 2) **871** up from 716 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) 19 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 13 households 80 individuals have received food support on more than one occasion during this period.

Number of adults	Number Children without SEND	Number SEND 0-25
18	43	19

Table. 1

This quarter has coincided with a period of lock down, February half term and the start of the Easter break. Families have reported finding this stressful and continued to experience financial hardship impacting on their ability to feed their families and keeping their children occupied and calm.

Again instead of delivery of face to face school holiday activities or other face to face family bases sessions work has taken place to achieve the same outcomes working differently. The use of vouchers/ tickets for local use and well-being and activity packs continues to work better. This way of working affords a wider reach for less money.

Family Based Event/Activity	Number of Adults	Number of Children
Distribution of Tickets/ Passes for annual survey	47	70
Activities Pack	194	240
PFA- Independent living	9	13
Your Say - Lime Orton Academy (Phoenix School)	35	19
Well being and activity packs for Easter break	60	70

Table. 2

All of the above activities have an impact on the emotional wellbeing and mental health of those who have benefitted from their delivery. A short survey has also been drafted and completed by 10 parent carers/ local families who have benefitted from food support during C-19.

Food Support Survey

Parent carers

10 parent carers took the survey with 9 parent carers being female and 1 being male. The needs of the CYP were self-reported as ASD, SpLD, HI and ADHD, Arthrogrypsis. Parent carers also reported themselves as having the following needs; Diabetes, ASD, Fibromyalgia, Asthma, High Blood Pressure and Anxiety.

The household break down in terms of adults and children can be seen in fig. 1 where there were 20 adults and 34 children.

Adults and Children in the household

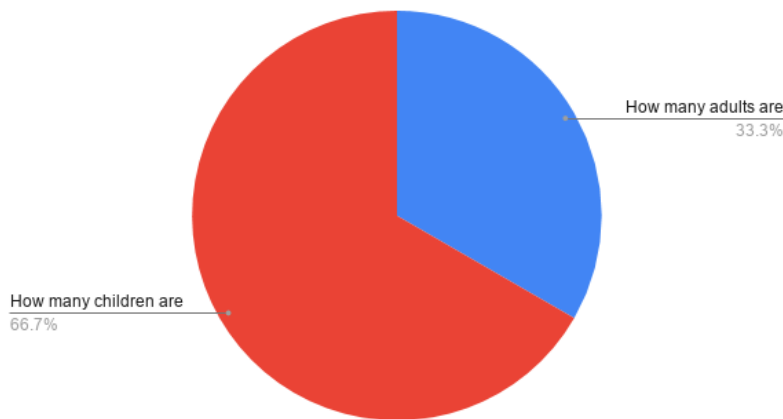


Fig. 1

Questions

The following questions were asked in the survey:

1. What circumstances caused you to need additional food support from FVP?
2. Has your reason for continuing to require support changed over time?
3. One of the reasons provided in previous survey responses for requiring support related to the financial impact of COVID-19 through factors such as an increase in the cost of shopping/ being placed on furlough. Has this?
4. Another reason for requiring support related to being unable to access shopping at a supermarket. Are you now able to start accessing shopping via your local super market?
5. We have also heard from families that many other areas of household finances are affected and the cost of living has increased. Have you experienced an increase in costs associated with any of the following?
6. Please describe how Covid-19 has impacted your household. For example: have you seen a reduction in your household income, have you struggled with having your children at home during lockdown, has your family benefited from having this time together, are you struggling to pay increased bills such as gas, electricity.
7. Please describe what further support you would like to help you during this difficult time, for example: activity packs for your children, befriending service to talk through any problems, access to accredited counselling service for children, young people and adults, support with day to day domestic tasks such as cleaning, dog walker, gardening.
8. On a scale of 1 to 5 with 1 being Not Useful and 5 being Very Useful how have you found the support offered by FVP?
9. What impact has the support you have received had upon your family?
10. Do you need us to continue making food deliveries to yourselves? If yes, then wh
11. Do you need a food bank voucher?
12. Do you have any signposting/training needs relating to SEND Services in general
13. We have also had families requesting other essential household items.
14. Please select any from the list below that you may have also required.

15. Work Status of Adults in Your Household (Choose any that apply)
16. What if any benefits do you receive for any members of your household?
17. Any additional comments

The questions could largely be placed in to support, COVID impact, finances as overall categories.

Support

The reasons listed for leading to the need for support in the first place were:

1. Loss of wages due to covid
2. Isolating, homelessness
3. Struggling to get out and lack of funds due to paying for Leo's funeral
4. Cost of living expenses
5. Change of circumstances
6. Lockdown & bereavement
7. Corona virus and big family
8. Not continuous work because of Corona virus

List 1 – reasons for support

Why support is still required:

1. Because my daughter still on ferlow an council have messed up an now telling me I owe them lots more money
2. Family Situation
3. Because I simply cannot afford fresh fruit or veg
4. At the moment we still haven't been out and we r in isolation and struggling
5. Having the children home
6. Can't get to shops because of the travel costs and have just had a baby
7. still struggling

List 2 – why support still required

Extra support required

8. If I can get help to move to smaller home I'd be financially better of an my health would get better then I wouldn't need to ask for help an feel worthless
9. People just to understand the abuse you get when you have to take children anywhere in a pandemic as no childcare
10. I got some vouchers that were so helpful, things for the kids to do would be so nice like little movie packs containing popcorn and some sweets so we can sit and watch a film with snacks. The fresh fruit and veg was really helpful as well and I would love to continue receiving help with that
11. I'd love to be able to help the boys find safe, appropriate housing. I'd also like an OT assessment to be sure I've got all aids I need.
12. Activity packs or something. To keep Ruby busy
13. Activity packs would be great
14. Would be grateful for any help with activity packs for children
15. Activity pack for kids
16. Activity packs for children, food, pet food, personal hygiene products, sanitary products.

List 3 - Extra support required

From the responses to questions relating to why support was first required and what types are still required in list 1 to 3 some themes are common; change in household finances, impact of lock down and having children out of school.

Has your reason for continuing to require support changed over time?

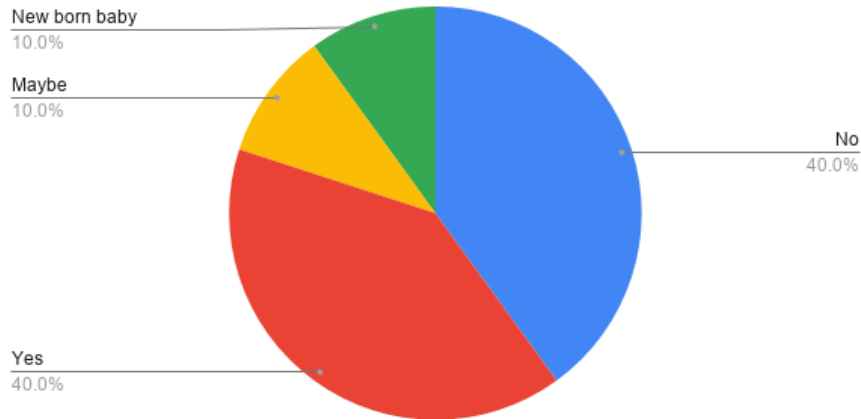


Fig. 2

One of the reasons provided in previous survey responses for requiring support related to the financial impact of COVID-19 through factors such as an increase in the cost of shopping/ being placed on furlough. Has this?

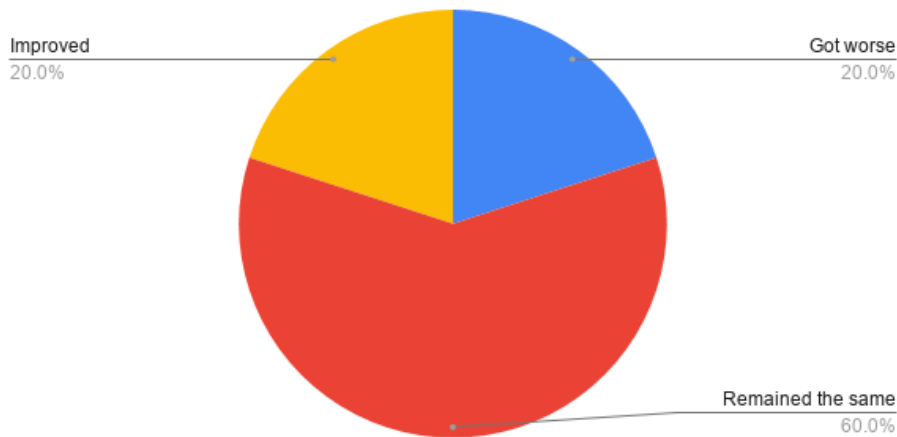


Fig. 3

Fig. 2 and 3 also show that parent carers still feel the impact of COVID and generally the financial situation has not changed. It is interesting to note from fig.2 that equal numbers of parent carers felt that either the reasons for still requiring support had changed or not changed.

Do you need us to continue making food deliveries to yourselves?

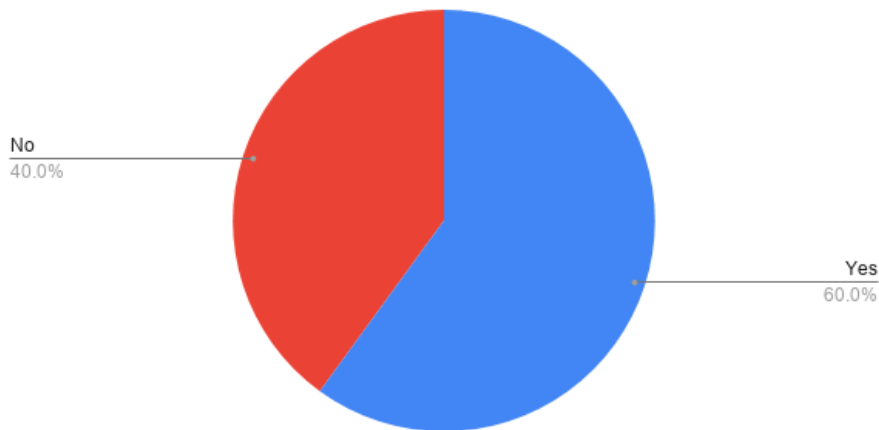


Fig. 4

100% of those who took the survey stated they had found the support offered by FVP very useful out of scale ranging from 1 to 5 with 5 being very useful.

Impact of support

1. It has meant we can all eat
2. Felt dearly cared for and supported stopping me suffering too much with my mental health and not getting to crisis point
3. We have been able to eat fresh food
4. We only had fresh veg when FVP delivered us a food parcel. It was amazing!! Also, their Xmas parcel had some amazing recipes to help stretch out what we had and still eat well.
5. Been amazing we would be lost without you
6. Very good made such a difference
7. Has reduced stress and worry
8. Feed family
9. reduced struggling with food

List 4 – Impact of support

From list 4 it appears that parent carers felt that the support offered meant they could afford to feed their families and their mental health was improved.

COVID-19 Impact on households

1. Struggled with household bills going up food price increases my depression got worse my older daughter assaulted me because all stressed being locked up together now paying room tax. my other daughter on furlough and getting depressed and I having to help her with her bills leaving us no money and my autistic son having more meltdowns as he doesn't understand it
2. Struggling
3. Increased gas and electric bills. Reduction in household income

4. My son's are homeless so I feed them, I do their laundry and I help whenever possible. They also help me as my previous carer no longer comes due to Covid
5. Payment on outgoings have increased but we have lived spending time together to. Make memories
6. Yes cost is so much more having them all home
7. Have struggled with having the children at home and the added cost of the constant snacks and drinks they require during the day
8. Struggled with entertainment for the kids
9. Reduction in household income, struggling with having children at home during lockdown, struggling to pay increased bills: gas electricity, council tax.

List 5 – COVID-19 Impact

The overall impact of COVID-19 on households as reported by parent carers, demonstrated by comments provided in list 5 again fall into particular themes; change in household finances, impact of lock down and having children out of school.

Finances

From the survey it has also become clear support required goes beyond food and includes things such as toiletries through to baby formula. This can be seen in fig. 5

Other forms of essential household items required.

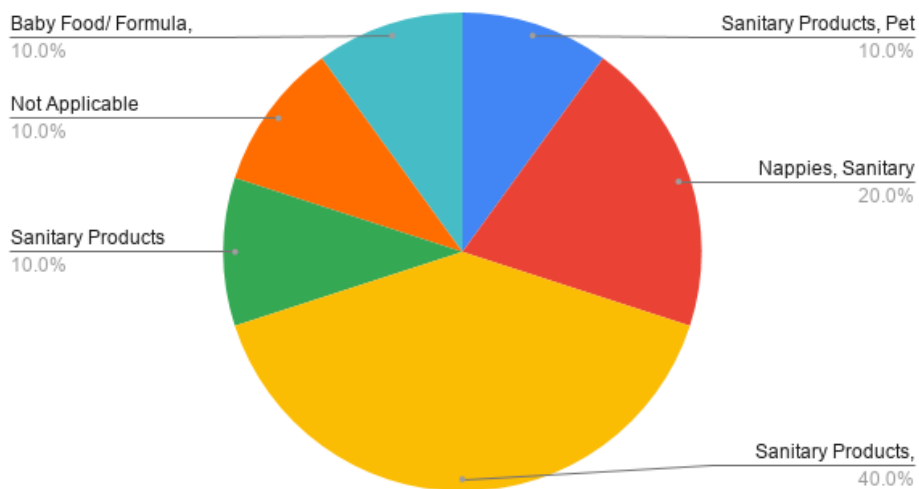


Fig. 5

Fig 6 and 7 looked at what household finances were like for families and whether families were working or reliant on benefits. From fig. 6 it is clear that some parent carers are in work, but also in receipt of universal credit.

Work Status of Adults in Your Household (Choose any that apply)

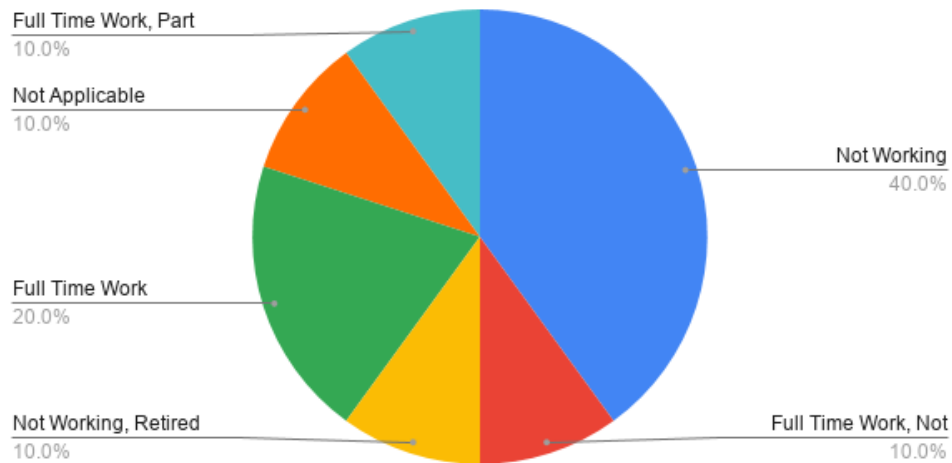
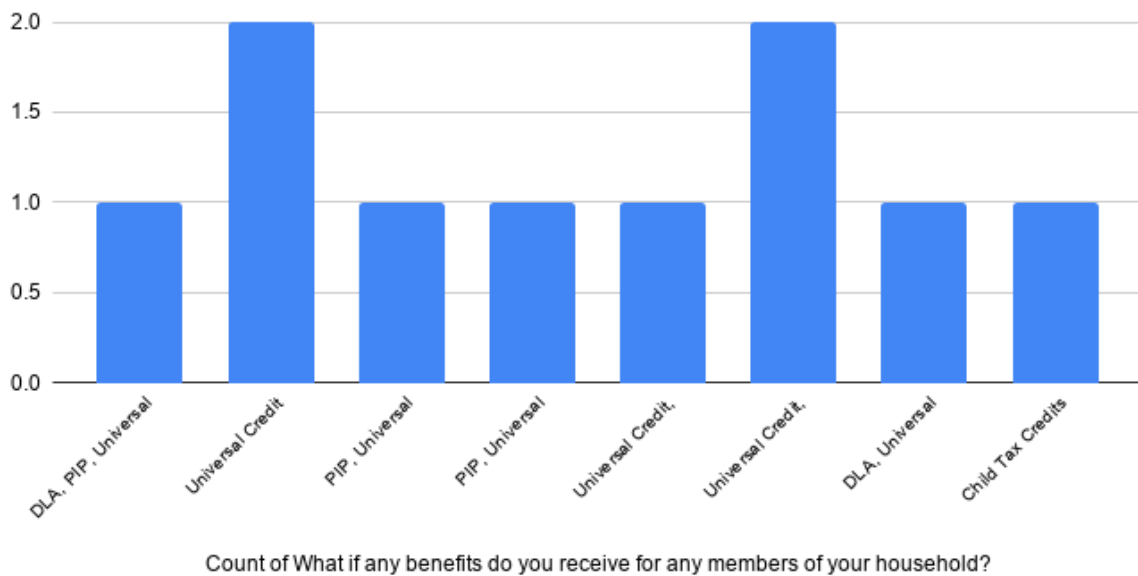


Fig. 6

What if any benefits do you receive for any members of your household?



Count of What if any benefits do you receive for any members of your household?

Fig. 7

Benefits chosen:

- DLA
- PIP
- Universal Credit

- Carers Allowance
- Child Tax Credits
- Working Tax Credits
- Pension
- Child Benefit

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.

C-19 Impact and Emotional Well-being

One survey looked in particular at the types of support and help parent carers feel they need and when asked what impact caring for a SEND child has they provided the following responses:

1. *It is a daily struggle. It's harder to do the easier day to day things when you have a child with SEND. It impacts the whole family and affects everyone's mental health.*
2. *Occupies all free time for family.*
3. *Not wanting to go out because off loud noises*
4. *It makes life a bit more difficult, each day brings its own challenges and a lot more time is needed on my daughter to support her with basis daily tasks. It's not always clear who you can get support from and how.*
5. *We feel totally isolated at times and alone with it all as their behaviours are not accepted by many in society and we feel safer to just keep ourselves to ourselves so we don't get hurt or let down like we have in the past by so called family or friends*
6. *You often feel isolated and alone affecting our own mental health but when we realize we have others around us who are in the same situation we try and support one another acting like family to each other*
7. *Feel isolated,alone and sometimes very anxious*
8. *it means we have to research everywhere we go beforehand to check we can change my son and wheelchair friendly.Rarely get time with my husband away from children as no one else can look after our son at present. disturbed sleep, lots of forms and appointments. difficult emotionally.*
9. *Emotionally you feel like you need a break especially when you have a few children with additional needs.It's also hard physically you feel exhausted & mentally drained & you feel like you can't connect with the 'perfect neurotypical' child.Just pure exhaustion*
10. *Leaves you lonely, always feeling like you have to fight to defend their needs. A most of all an emotional mess.*

11. *I have spent the last 16 years of my life not working so I can be a stay at home parent and carer and to be available at all times for my son and his school needs and other needs over the years ie. Occupational therapy.*
12. *I have 11 year old who is very lively happy little boy who has gobel development delay and hearing imperment*
13. *Being so busy and not having enough hrs.also getting right support and help for your child*
14. *Find it very isolating and can't always plan to do anything with friends due to tommy having lots of hospital appointments x*

Parent carers reported feeling isolated, anxious, tired and physically exhausting all of which point towards an impact on emotional well-being and general resilience.

Virtual Workshops/ Hub

There have been no virtual workshops relating to behaviours that challenge or the expert parent programme in this quarter. This is despite having over 10 parent carers requesting 1:1 sessions. There have been a high number of no shows on the day. Some parent carers have reported that they forgot they had a session or were too busy to attend due to ill health and/ or general stresses associated with caring.

SEND Data and Schools Work

Surveys

During this quarter FVP have conducted 7 surveys gathering views from Peterborough parent carers, with a total of 129 responses.

Survey Title	Number of Respondents
Accessing Education	14
Annual Survey	61
PfA	7
Lime Academy Your Say	17
Annual Health Checks	3
Early Support	17
Food Support	10

Table 3

These surveys have been reported on in other reports/ topics of importance or in the case of food support in this report. All surveys seem to elicit similar themes; impact of COVID 19 on emotional health and finances, a decrease in resilience amongst parent carers, views on how accessible services are, the impact of good and poor communication and information and the need for a wider range of practical types of support such as advice and advocacy services.

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	2	48
Facebook Discussions (parent led)	4	17
Facebook Discussions (FVP led)	3	27

Table 4

Parent carers are still engaging via social media especially the chatroom and there they are initiating conversations more.

Poll Question	Response Options	Number of Responses
If your child/ young person has an EHCp and as such falls under the vulnerable category as defined by central government, do you still want them to go school?	Yes	14
	No	4
	Undecided	3
If you are entitled to Free School Meals for your child/children are you receiving	£15 Supermarket Voucher	21
	Food Parcel from school	4
	£15 voucher	1
	£12 Morrison's voucher	1
TOTAL		48

Table 5

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)

7 parent carers have also been in touch with FVP for a more detailed signposting discussion with one of the parent rep team,

Frequency vs Theme

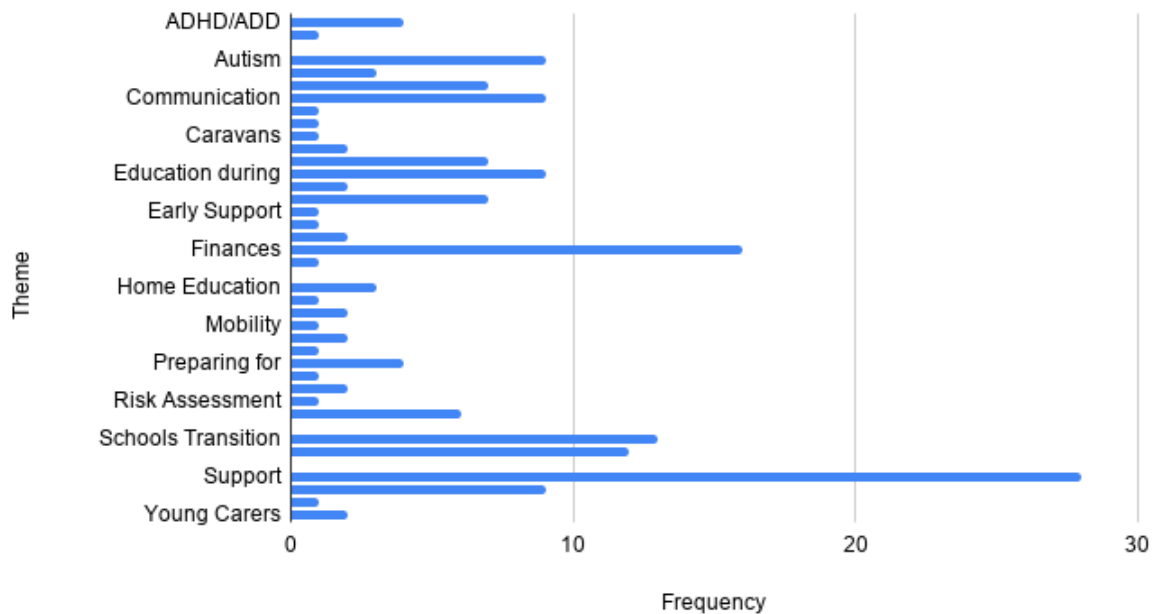


Fig 8

Some parent carers raise more than one theme when they get in contact and some themes are inter linked. After the topic of transport was removed from the data to better establish overall themes support and finances appeared most frequently.

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
57	89.5	38	6	133.5

Table 6

Most meetings have focussed on C-19 and ongoing work relating to the Written Statement of Action (WSOA) with more involvement in meetings relating to mental health as well.

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.

Virtual Sessions

A new way of working was also trialled to facilitate general participation Zoom. The sessions were recorded and sign-supported. Once finished the sessions were edited and made available via YouTube. Attendance at the sessions has been good and well received. Some parents have reported attendance at such sessions is easier as they fit better with the demands of also being a parent carer. You can dial in fairly easily and are not bound by being in a particular place at a set time. Fig. 7 shows the range of parent carers who have participated in this new way of working.

Information and Awareness	Number of Adults	Number of Children	Gender	Ethnicity
Open Forum Meeting (Health) 11/02/2021	9		1 Man, 8 Women	Indian, Polish, Lithuanian, White British
Open Forum Meeting (EHCp's) 22/02/2021	17		All Female	Lithuanian, Polish, Pakistani, White British
Open Forum Meeting (WSoA) 11/03/2021	14		2 Men, 12 Women	Pakistani, Irish, White British, Polish, Lithuanian

Table 7

Schools Sessions

As demonstrated in Table 8 below it can be seen that parent carers who have CYP with more complex needs are also starting to engage and as a result of the two sessions being well received more have been planned.

Topic	Number of Adults	Ethnicity	CYP Needs
Lime Academy Orton(formely Phoenix school) PFA Zoom Session	5	Polish, Pakistani, White British, Lithuanian	Rare Genetic Conditions, ASD/ LD, HI, Complex Physical Needs
Lime Academy Orton(formely Phoenix school) Signposting and Support session	6	Polish, Pakistani, White British, Lithuanian	Rare Genetic Conditions, ASD/ LD, HI, Complex Physical Needs

Table 8

Seldom Heard Communities

Information and Awareness	Number of Adults	Gender	Ethnicities
Seldom Heard Zoom Session 27/01/2021	12	4 Men, 8 Women	Gambian, Indian, Lithuanian, Kurdish, Traveller, White British, Nigerian, Polish, Pakistani
Seldom Heard Zoom Session 18/02/2021	24	18 Women, 6 Men	Gambian, Indian, Lithuanian, Kurdish, Traveller, White British, Nigerian, Polish, Ghanian, American Indian, Pakistani
Seldom Heard (CENSUS) 15/03/2021	9	7 Women, 3 Men	Lithuanian, Gambian, Indian, Pakistani
Seldom Heard (Support) 23/03/2021	21	18 Women, 3 Men	Chinese, Gambian, Lithuanian, Indian, White British, American Indian, Kurdish, Polish

Feedback for these sessions has been generally positive and the chat was recorded on one session with the following being stated:

- Excellent information thank you
- Thanks Healthwatch for sharing your information
- Thank you all Family Voice
- Just given you a follow PADSG, thank you
- Hello! I am due to speak about our Young Carers service at Centre 33 next month in this meeting. As there are lots of people here today who are carers, I wanted to share that we run a service for young people (up to 19) who help to care for someone. We offer confidential support and a range of free workshops, trips and activities. I am currently trying to build links with seldom heard groups and may be in touch with some of you to ask about how we can reach all young people in need of our support. You can find more information on our website: <https://centre33.org.uk/help/caring/> or you are welcome to contact me directly: francest@centre33.org.uk
- we do cover the peterborough postcode area and often the wider area - happy to help all areas
- This is an excellent platform to bring focus on family needs and recognise great work done by our families in the city. Thank you Family Voice.
- - message us on our peterborough area downs syndrome group page - we have lots of siblings who are supporting each other.
- <https://www.cambridgeshireandpeterboroughccg.nhs.uk/news-and-events/latest-news/covid-19-national-vaccination-programme/>
For local health information please visit the CCG website
- Thank-you to everyone today. It is sessions like these that can help us break down barriers, make connections and support one another
- PDDCS can you contact our page peterborough area downs syndrome group - i think our families would benefit from getting to know you all. Thank you

- Thank you so much for a really valuable meeting. Please do keep me on the invite list as it is so important to work together for our families. Linda from Pinpoint :)
- Apologies all I need to leave, this has been a really valuable meeting and good to hear about all the amazing work groups are doing, thank you for sharing with me.
- Thank you for informative session. Unfortunately I really need to go now.
- This was amazing to meet everyone and hear about all the fantastic work in Peterborough. I'm excited for our organisation to be part of this community and i look forward to speaking to you more next time. Thank you!
- Thank you everyone. An excellent meeting and I am pleased to be invited. I am happy to support and help to provide NHS information so please get in touch.
- Understanding family needs and share our experience is what I think tops my list for this platform.
- I had no idea that there was a down syndrome group in peterborough had this meeting not happened. Thank you so much for bringing so many organisations together and the fact that YOU ALL MATTER ! X
- great platform - such a lot of valuable information - well worth attending - Thank you for your time
- Making connections to other professionals and community leaders, understanding the challenges and strengths of different communities in Peterborough. Spreading the word about our work with young people! Centre 33 - <https://centre33.org.uk/>
- So important to connect with any family that does not have the support they need for their SEND child. To be able to hear from and speak to other cultures is vital to make sure we do this! Thank you for your openness and willingness to share. Linda from Pinpoint
- Hearing everyone's views and concerns - sharing and giving information. Learning new things and connecting with new people in our community
- great plateform to share information and connect with community leaders and organisations

The sessions have created new connections, bought parent carers, community leaders and LA/ CCG professionals together and broken down barriers to participation.

Co-production and Change

Topics of Importance (ToI)

Two ToI have been developed and finalised with a full response to one and a response in drat to the other. The ToI were Transport and Preparing for Adulthood (PfA). All are viewable via the participation page of FVP's website.

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. Virtual sessions are being planned on an ongoing basis and more surveys are under development.

Progress since October/ December Recommendations/ Forward Plans

Recommendations/ Forward Plans

1. A formal response be provided to the Transport Tol. – **Complete and on website**
 2. Schools/ Settings be encouraged to communicate better with parent carers (issue identified in various reports). – **Two sessions have taken place and more are planned to include Lime Orton Academy and Beeches Primary**
 3. Clear communication from the LA to parent carers on the impact of their participation. – **Ongoing with development of the Local Offer underway and a new communications group run by the LA attended by parent reps**
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1. New surveys are being planned as well as virtual sessions from April to July,
 2. Ongoing work is taking place to develop the next Tol which is most likely to focus on support and services – this is an area parent carers would like to see more of.
 3. It would be good to see a focus on parent carer resilience in any planning relating to SEND services