
FVP Interim Report

April – June 2021

FVP Parent Representatives

Introduction

The following report will be structured to match annual reporting, which is designed to demonstrate work conducted against different funding streams. The report will have four main sections:

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

As with the reports throughout the past year, much of the work can cross over into different sections. COVID still continues to impact Family Voice Peterborough (FVP) and the work of the parents forum. The reporting period has been relatively quiet until June with respect of general parent participation.

Use of virtual working has continued throughout the past three months with monthly sessions relating to Seldom Heard Communities and Mental Health combined taking place and the use of wellbeing packs and tickets/ passes for family outings continuing. From data collated the main method of participation has been via Facebook with 38 Polls, 1 survey (shared on Facebook via google forms) and a number of discussions in FVP's chatroom.

There have been 14 online sessions covering Seldom Heard Communities, Open Forum Discussions and more Signposting and Support with a total of 109 attendees. Most of the sessions have also been made available via YouTube¹. Work has also continued to ensure where possible that the sessions are sign supported with BSL interpretation. As well as the online sessions there have also been 107 adults and 116 children supported by way of wellbeing packs and/ or activity passes.

¹ https://www.youtube.com/channel/UCN-Zqf_9Sbz0a_kTQ1SsY2w

Participation/Engagement/Involvement April – June 2021

Headlines

- 1) 127 named parents in total have been involved at some level, with a total of 169 children and young people with SEND within the households, and 57 siblings.
- 2) 193 parent carers have participated across 39 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, Latvia, Indian, Pakistani and White European.

CAMHS Transformation/ Parent Carer Mental Wellbeing/ Online Support

Introduction

After some discussion with funders for this area of work it was agreed that there could be a temporary move away from the delivery of workshops relating to Challenging Behaviour and The Expert Parent Programme as there was a need amongst parent carers to provide other support with mental health and resilience support. The plan is to deliver these workshops later in the year. Other areas of work have been incorporated here too, as such areas have an impact on the parent carer and the wider family, these include; Food Support, Wellbeing Packs and Activity Voucher use.

Some of this work is funded via more than one source especially where the grants have similar outcomes. The funding split can include one grant covering the cost of items for example and another grant covering the cost of staffing and volunteers to administer the work.

Food Support

One of the key themes arising from the work started during lock down as a result of Covid-19 which continues to be impacting families is that parent carers are still finding it incredibly difficult to feed their families well. This is for a number of different reasons including:

- 1) Long waits for Universal Credit
- 2) Still being on furlough,
- 3) Increased food costs.

Support has been provided to 14 households:

| Adults | Children (Total) | Children with SEND |
|--------|------------------|--------------------|
| 22 | 38 | 19 |

Fig.1 Numbers of adults and children receiving food

Of these households over 78.57% report having an adult with a disability the majority of which relate to mental health needs.

Reasons supplied for continued support are being unable to find work, having been self-employed previously and didn't qualify for furlough, the impact of COVID, having a larger family, benefit changes, increased cost of utilities and changes in family set up.

Virtual Workshops

Virtual workshops have taken place in relation to the CAMHS funded Parent Carer Hubs, DfE funded coffee mornings and two sessions relating to ASD and Challenging Behaviour that were funded across a couple of grants.

From Fig. 2 it can be seen that it was still possible to deliver 3 parent carer hubs with of those in attendance 5 were parent carers and 4 were professionals providing direct signposting and advice. Over time issues relating to delivering the hubs have been worked

on so for the last session there was maximum attendance from parents. The timings allow for three 45 minute long 1:1 sessions.

| CCG/ Training | Date | Number of Adults |
|--|---------|------------------|
| PC Consultation Session - Early Years | 26/4/21 | 2 |
| PC Consultation Session - Sensory Impairment | 24/5/21 | 3 |
| PC Consultation - EPS/ SEND Partnership | 21/6/21 | 4 |

Fig. 2 Attendance Information

| Support and Signposting | Date | Number of Adults |
|---|---------|------------------|
| Coffee Morning - Appointeeship/ Power of Attorney | 29/4/21 | 8 |
| Coffee Morning - Support | 24/6/21 | 2 |

Fig. 3 Attendance Information for Coffee Meetings

| Workshops | Date | Number of adults |
|---------------------------|---------|------------------|
| ASD Strategy | 29/4/21 | 8 |
| Behaviours That Challenge | 10/5/21 | 9 |

Fig. 4 Attendance information for workshops

Signposting/ Support Requests

There have been 10 contacts recorded where parent carers new to FVP have requested signposting. The requests have covered topics from how to request and EHCp or diagnosis through to challenging school decisions (appeals/ mediation/ complaints)

Wellbeing and Activities

| Family Based Event/Activity/ Wellbeing | Date | Number of Adults | Number of Children |
|--|---------|------------------|--------------------|
| May Half Term Vouchers | 31/5/21 | 75 | 116 |
| Carers Week Packs | 13/6/21 | 32 | |

Fig. 5 Voucher and Wellbeing Pack Information

The use of hand delivered wellbeing packs and vouchers for local activities sent out in time for school break periods has proved popular again. It is also a more cost effective way to enable access to short breaks for families and some time for parents carers to support their own emotional health.

"Thank you so much. What a lovely thing, it is really appreciated, especially the day before surgery with my 7 year old."

"It was great and definitely brightened up my day."

Schools Data/ SEND

Surveys

During the first quarter only one survey has been conducted covering parent carer support

| Survey Title | Responses |
|----------------|-----------|
| Carers Support | 48 |

Fig. 6 Survey Response Numbers

A brief analysis of this survey can be found in the most recent Topic of Importance (ToI) detailed further down in this report.

Engagement on Social Media

As all face to face engagement has been put on hold this quarter due to Covid, FVP have focussed upon enabling participation via other methods. One of the most popular ways parent carers engage is via our social media platforms. FVP manage a page, followed by 1885 interested parties, and a closed group with 408 members – exclusively for Peterborough parent carers.

Within the Facebook group, FVP often share polls to enable parent carers to quickly provide instant views and feedback on specific topics, which can then be explored further via other methods. During this period there have been 14 polls, the details of which, along with the responses, can be found below:

| Poll Question | Response Options | Number of Responses |
|---|----------------------------------|---------------------|
| We have a Facebook page and group for our caravans, have you liked them yet? Get liking to see what we have available for some low cost staycations | Yes | 5 |
| | No | 3 |
| | Didn't know you had any caravans | 3 |
| Have you heard of the Local Offer - | Yes | 8 |
| | No | |
| Do you have a child or young person who uses wheelchair services? | No | 6 |
| | Yes | 2 |
| If you do have a child who uses wheelchair services, do you recall having a good or bad experience? | Good experience | 2 |
| | Bad experience | |
| | | |
| Do you know what PfA means? | No | 4 |
| | Yes | 2 |
| Do you as a parent carer feel like you've been given | No | 6 |

| | | |
|---|--|----|
| the support you require? | | |
| | I am unaware of what support is available | 5 |
| | Yes | |
| | | |
| Does your child have a EHCP? | Yes | 16 |
| | No | 5 |
| Does your child have a EHCP? | Yes | 19 |
| | No | 4 |
| Do you have a family member who uses a wheelchair? | No | 10 |
| | Yes | 9 |
| Do you know what Early Help is and do you know what Early Support is | I know what Early Support is | 5 |
| | I know what Early Help is | 3 |
| | I do not know what Early Support is | 1 |
| | I do not know what Early Help is | 1 |
| How has parent carer responsibility impacted your mental health? | It has affected my personal relationships | 13 |
| | Most Days I feel stressed | 12 |
| | I dont eat well | 11 |
| | I dont sleep well | 11 |
| | I am anxious | 9 |
| | I am sleep deprived | 9 |
| | Most days I feel low in mood | 9 |
| | It has affected my financial situation | 7 |
| | I feel socially isolated | 7 |
| Parent carer mental health is widely misunderstood concept. As parent carers our roles are far removed from normal parenting day to day activities. As a parent I: | I make sure my child has clean clothes | 17 |
| | I take my child to the GP when they are unwell | 16 |
| | I make sure my child attends school | 15 |
| | I drive my child to activities like football | 8 |
| Parent carer mental health is widely misunderstood concept. As parent carers our roles are far removed from normal parenting day to day activities. Please add your own, As a carer I: | I have developed an understanding of behaviour(Challenging and otherwise) | 10 |
| | I monitor my child's diet | 9 |
| | I organise my day around my child's | 9 |

| | | |
|---|---|----|
| | day/needs | |
| | I take attend my child's hospital appointments | 8 |
| | I have been assisting , supervising my child at all times | 7 |
| | Manage family finances | 7 |
| | I attend EHC/ CIN meetings | 6 |
| | I spend my time supporting my YP to PFA | 5 |
| | I spend my time appealing decisions | 4 |
| | Organizing hospital appointments/ time management | 3 |
| | I provide personal care for my adult child | 2 |
| | Understanding benefits | 1 |
| | I have to find staff for my child | 1 |
| It looks as though we are aware of how our parent carer role is different to normal or typical parenting. How old was your child when you first realised that what you were doing was different from normal parenting? | 2-4 | 16 |
| | 6-8 | 6 |
| | 8-10 | 1 |
| | 10-12 | 1 |
| | 14-16 | 1 |
| | Perinatal | 1 |
| | 4-6 | |
| | 12-14 | |
| | 16-18 | |
| at what point did you realise your role was different? | Before Diagnosis | 14 |
| | After diagnosis | 2 |
| | When diagnosed | 2 |
| | My child has no diagnosis | |
| what strategies do you think helped the most with maintaining a healthy (whatever that is) mental state? | Counselling | 11 |
| | sharing experience with other parent carers | 10 |
| | Respite/ time away from caring responsibilities | 8 |
| | Going out for meal with a friend | 7 |
| | Spending time with family/ partner | 7 |
| | Having bubble bath or long shower | 5 |

| | | |
|---|---|----|
| | Arts and crafts | 4 |
| | Medication/ anti depressants/ sleeping meds | 4 |
| | Getting you hair done | 3 |
| | Listening to music | 3 |
| | Gardening | 3 |
| | Specialist mental health input | 1 |
| | Getting nails done | |
| | Watching favourite movie | |
| | Laying in bed for 10 mins doing nothing | |
| | Social care input | |
| | Going to GP | |
| Upcoming online workshops will include Understanding Challenging Behaviour Parental mental well-being What is it that you find the most useful? Please add your own in the poll. | Finding new ideas and strategies | 15 |
| | The opportunity to meet other people experiencing similar things | 14 |
| | Developing and understanding of key concerns, and finding out what can be done to address these | 10 |
| | Sharing ideas and experiences | 8 |
| | Learning new things | 7 |
| | Meeting new people | 7 |
| | Information | 5 |
| | Group homework | 3 |
| regarding accessing a wheelchair we want to understand some of the reasons why children need a larger buggy or wheelchair? | Because they are physically disabled and unable to walk | 4 |
| | Because they find walking painful or difficult | 4 |
| | Because they refuse | |
| How many parents on here are employed? | Employed | 27 |
| | Stay at home (choice) | 13 |
| | Self employed | 6 |
| | Disabled | 5 |
| | Cant find work to fit caring responsibilities | 3 |
| | Volunteer | 1 |

Fig. 7 Poll Responses Apr-Jun

Following on from the Polls 15 parent carers have taken part in 7 conversations, demonstrating how parent carers are feeling currently. Themes for the discussions have included EHCp views, what makes a parent carer and the impact of caring on working and family life and mental health. Previously parent carers reported that sharing views and being able to ask questions in the closed Facebook group has decreased isolation and improved access to information. The ongoing use of the group demonstrates this, as do the views parents are willing to express. The most powerful messaging that can be ascertained relates to the impact on mental health, wellbeing and resilience by virtue of being a carer too as well as parenting a child with SEND.

I felt so lost and still do. Because of the role I had in previous employment I was not made to feel welcome at the place that other professionals touted as the place to go for support so I had to find my own coping strategies. I sought help from my GP and was on antidepressants for a while.

Just that amount of care needed wasn't changing the way you'd expect, for example instead of a walking toddler I had one who was unable to weight bear etc. With the eldest one was much more difficult. It sort of hit me how difficult things are and how much care I need to provide. Although they both have very

With typical/normal parenting often we read magazines, have a good idea of what it entails although nobody can be truly prepared but there is limited guidance/information on what the parent carer role entails and how it impacts our mental state and consequently our ability to respond to our child's behaviours/needs. Often professionals see this as failure on the parents part, I would argue that the professional approach needs to change

Strategic attendance

Through the ongoing use of the online forum used for parent representatives to report on strategic meetings attended, it has been easier to demonstrate time invested and work/actions as a result of the meetings attended

FVP have a total of 7 parent carers have been attending meetings either through volunteering their time or as casual workers. Fig. 8 shows the number of meetings attended where reports have been completed; the number is actually higher as a further 21 reports are still to be completed at the time of producing this quarterly report.

| Number of Sessions | Hours Spent at Meetings | Administration Time (Hours) | Travel Time (Hours) | Total Hours |
|--------------------|-------------------------|-----------------------------|---------------------|-------------|
| 69 | 91 | 38 | 0.5 | 129.5 |

Fig. 9 Breakdown of Time spent at Strategic Meetings Apr-Jun

Seldom Heard Communities

Seldom heard community engagement has continued primarily online with the opportunity for one face to face event held outside where community leaders came together with local ward councillors to celebrate joint working. In a move towards letting the communities take the lead more, the community development worker now chairs the online session and the seldom heard parent rep works to ensure topics under discussion are based on the requests of those attending the sessions. Feedback from the sessions is generally for more time/ longer sessions.

| Information and Awareness | Date | Number of Adults | Number of Children |
|---|---------|------------------|--------------------|
| Seldom Heard Community Forum - Finances | 30/4/21 | 10 | 0 |
| Seldom Heard BBQ | 26/5/21 | 22 | 1 |
| Seldom Heard Community Forum - Carers | 27/5/21 | 17 | |
| Seldom Heard Community Forum - Pandemic | 28/6/21 | 26 | |

Fig. 10 Seldom Heard Engagement



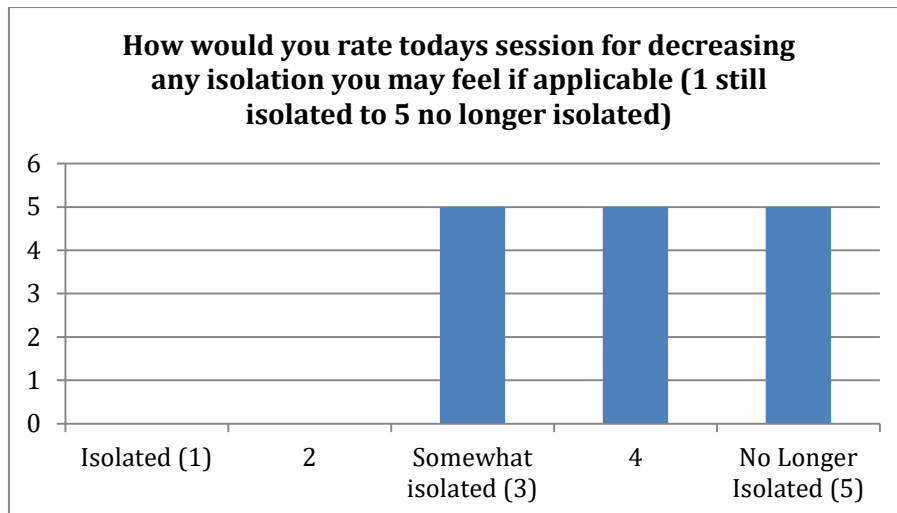


Fig.11 Reported Impact on Feelings of Isolation

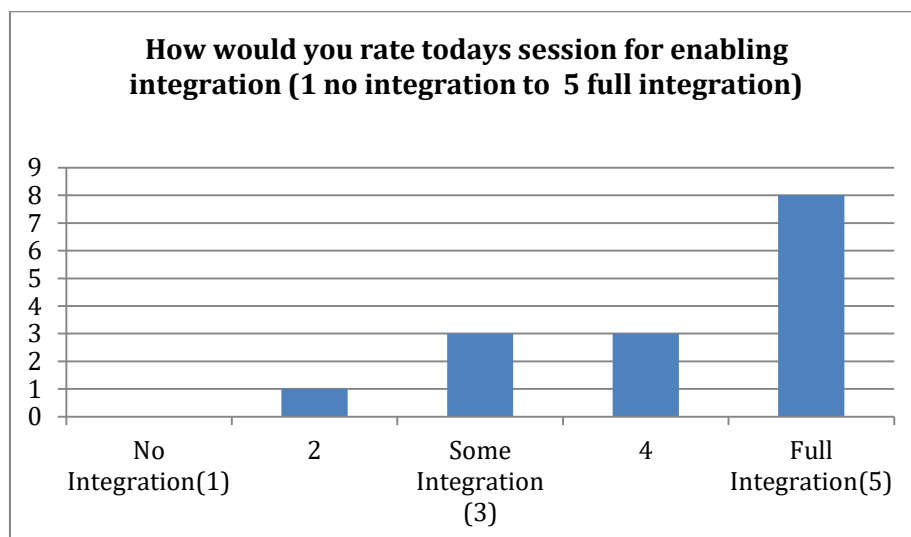


Fig. 12 Reported Impact on Integration

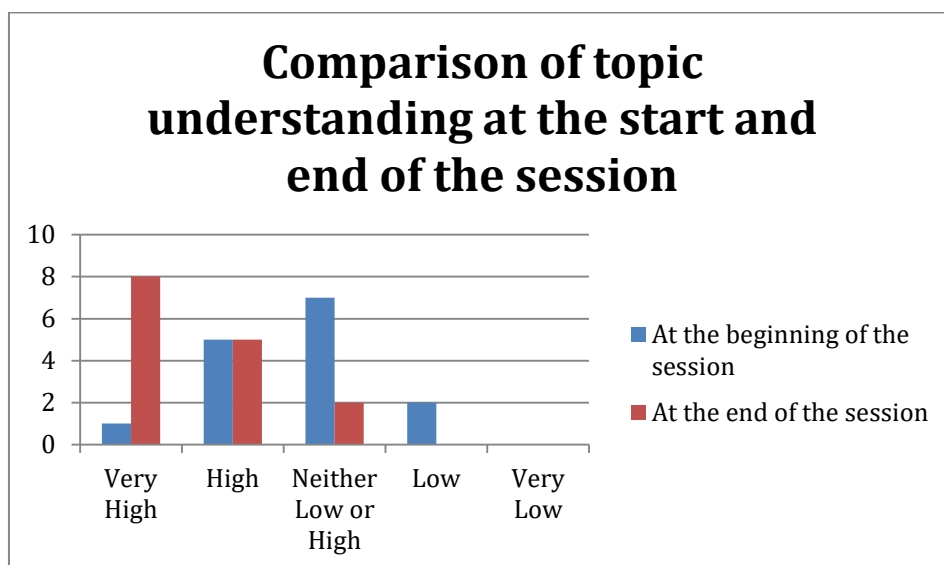


Fig. 13 Topic Understanding

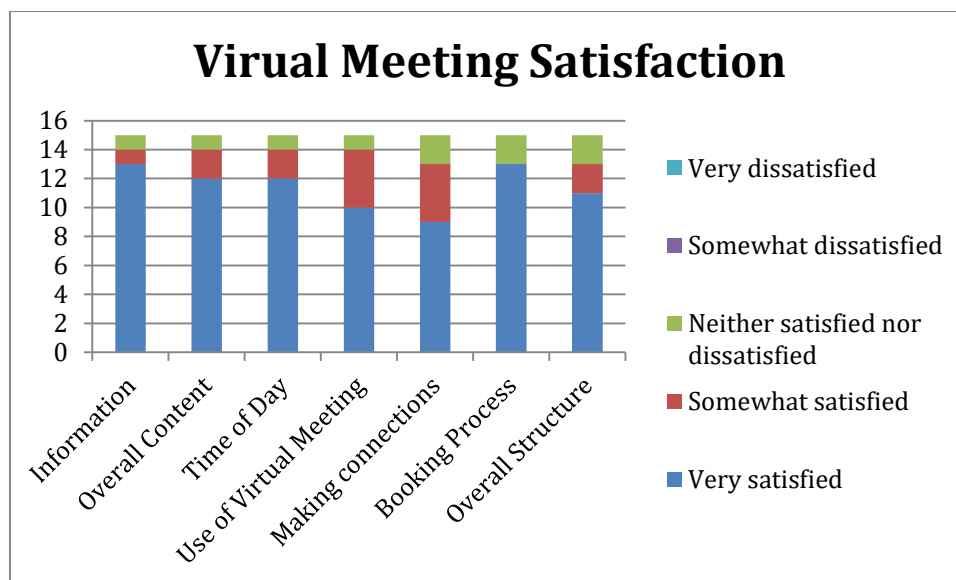


Fig.14 Overall Event Satisfaction

Overall looking at Fig.11 to 14 it would seem that satisfaction in the sessions is high and they have an impact of feelings of isolation and integration in a positive way. Session attendance has been relatively high, with parent carers, community leaders and various professionals coming together to discuss the topics that are relevant to the parent carers.

Co-production and Change

Topics of Importance

One Topic of Importance (Tol) has been compiled and published this quarter:

1. Early Help, Early Support and Parent Carer Wellbeing²

This Tol draws on two surveys conducted in March 2021 and a survey just completed in June 2021. The results of the three surveys and a number of Facebook Polls/ Discussions all point towards the following concerns/ views from parent carers:

1. Where support is received it makes a difference to how the parent carers cope with caring.
2. Support is good in early years but doesn't translate to other areas past early years.
3. Not enough information about where to go for help/ lack of knowledge of the Local Offer.
4. Feelings of isolation, exhaustion and in some cases sleep deprivation.
5. Seeking information to navigate the SEND system, especially in relation to EHC needs assessment applications.

² <https://www.familyvoice.org/sites/default/files/Topic%20of%20Importance%20-%20Early%20Help%2C%20Support%20and%20Carers%20Wellbeing.pdf#overlay-context=Participation>

6. Needing support with finances, managing CYP behaviour, accessing family based activities, emotional wellbeing,
7. Loss of community, family and friendship networks

Recommendations/ Forward Plans

1. Consideration to be given to the recommendations in the live ToI (Early Help, Early Support and Parent Carer Wellbeing).
2. FVP to look further at seldom heard engagement and explore ways to increase contact with seldom heard parent carers.
3. Work continues to engage with a wider more diverse section of the parent carer community locally.