

1<sup>st</sup> April 2020 to 31<sup>st</sup>  
March 2021

# Participation, Engagement and Involvement – Charity and Forum Annual Report



fvp

Family Voice Peterborough

4/16/2021

## Executive Summary

### Purpose

This report has been written as we as a nation come to the end of our first year in a new way of living and working often called the new normal brought about as a result of the global pandemic related to the virus COVID-19 (C-19). The past year has seen much change in the way we deliver a large proportion of our work especially in relation to delivery of support and participation. This different way of working has also resulted in an increase in coproduction and responding to parental need.

A factor not foreseen from the new way of working not only for Family Voice Peterborough (FVP) but also Peterborough City Council (PCC) and Cambridgeshire and Peterborough CCG and other partner organisations in respect of SEND has been the marked increase in participation and also a move towards co-production at various levels. Virtual working has meant a reduction in some participation barriers. There has been less silo working, more joint decision making and much clearer communication. More work has taken place in virtual meetings rather where professionals and parent representatives have been able to look at issues and formulate plans together. This change is in part as a result of the need to provide support to SEND families resulting from the impact that C-19. It is no longer just the area wide CQC/ OFSTED SEND (Special Educational Needs and Disability) Inspection which resulted in the requirement of PCC to produce a Written Statement of Action (WSOA) that is driving this shift in working more collaboratively. Participation is becoming more embedded in PCC but there is still work to embed it more in the CCG and other health partners. It is still important to note that external political, economic and environmental factors are still impacting on how SEND services are delivered and experienced.

This report will also show the significant impact that C-19 has had in particular on SEND families and seldom heard communities. The report will also be set into two sections; the first will focus on the specialist work of the forum which is a function of FVP as a charity and the second section will form the Trustees Annual Report. The report will present qualitative and quantitative data to demonstrate the experiential impact of the changes that have occurred especially in the past financial year. For a full picture over time of the impact of the reforms previous reports are available to review and can be found on our website [www.familyvoice.org](http://www.familyvoice.org).

### SECTION ONE

As in 2019 to 2020 FVP were funded by PCC/ CCG to deliver work around CAMHs Transformation, Special Educational Needs and Disability (SEND) and Seldom Heard in one amalgamated funding stream.

The funded work has built on work already established and the following themes have been identified:

1. There has been an upward trend of how well parents' views of have been taken into account at assessment and how well services are identifying needs. Health services are doing particularly well with this. Professionals and parents understanding their child

needs is improving, all of which may reflect the needs of different cohort participating in the work of the forum.

2. Information sharing and communication have been a core focus of much work, with a range of communications being co-produced to share key messages with parent carers.
3. Planned work in terms of training around the Expert Parent Programme and Behaviours that Challenge has been greatly impacted with a large drop in delivery.
4. Issues relating to C-19 are paramount in people's minds and proving to be a main area of focus and have led to an increase in online participation.
5. C-19 on appears to have impacted families with SEND children in a number of different ways:
  - a. Families have experienced a decrease in finances and difficulty in being able to feed their children.
  - b. Closure of schools due to the three lock down periods has affected behaviour of the children/ young people and led to increases in anxiety amongst different members of the same families.
  - c. Parent carer resilience over the course of the past year has gradually decreased to the point now where they are struggling to cope and seeking more practical support.
6. There has been an increase in seldom heard communities engaging in the work of the forum and a broader more diverse range of parent carers and community leaders have been attending online topic specific sessions.
7. There has been an increase in demand of topics relating to mental health and family support.
8. Preparing for Adult (PfA) remains a concern especially in relation to finances, what the future holds and what services are available for young people approaching adulthood.

## SECTION TWO

The wider work of the charity detailed in section two makes reference to the assets retained for charity use namely the community centre and caravans and explores further the real impact of C-19.

Key Themes:

1. Closure of Centre and Caravans
2. Impact of COVID-19

## Acknowledgements

We would like to thank all those who have contributed to this report and the work that has gone in to it.

This report would not be possible without; the level of co-production the forum has achieved between the Local Authority, Clinical Commissioning Group, Local Health Trusts and Educational Settings and the number of parent cares willing to participate with the forum and afore mentioned partners.

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## **Report Introduction**

As the reports produced yearly have been used to inform each other and some data gathered to inform the reports is similar, it has been possible for this report to also introduce some comparative data. The work detailed will primarily focus on the reporting period 1<sup>st</sup> April 2020 to 31<sup>st</sup> March 2021 but draws on previous data sets.

The evidence presented in the report has been gathered utilising qualitative and quantitative methodologies but the report is not intended as a research paper. Rather the use of evidence is to demonstrate what outcomes have occurred or may be occurring in relation to work programmes. This report will also contain some viewpoints/ concerns of the forum regards to how experiences of parent carers are being impeded by C-19 whereby access to services/ support appears to be more difficult.

A brief overview of Family Voice Peterborough (FVP) will be given in this introduction as a means to putting in to context the different functions of FVP as a Charity including the changes as a result of C-19.

## **Forum Context**

FVP have been recognised and funded as the Department for Education (DfE) designated parent carer forum for the City of Peterborough and a member forum of the National Network of Parent Carer Forums (NNPCF) since 2009.

The main aim of the forum element of FVP is facilitating parent participation and ultimately co-production of services relating to children and young people with SEND. The work of the forum takes place from commissioning through to provision. In the past year with some slight changes parent carer views have been gathered via; social media using discussions in a chatroom and online Polls, online surveys, chat messages via zoom/ teams events, recording of parent carer contact via email and/ or phone, recordings of parent carers in zoom sessions and case studies for publication in the local press. All the information gathered is collated in to reports and fed back to key partners by parent representatives in various meetings.

FVP use a variety of different methods to gather parent/carers views on how they are and have experienced services to support their children's need and their own needs. FVP share views of parent/carers with the local authority and clinical commissioning group to enable these organisations to consider parent/carers views in their commissioning and delivery decisions. FVP also promote co -production - so involving parent/carers in the design and delivery of services. FVP work the Local Authority and Health to find solutions to concerns raised by parent/carers. This way of working does not deliver instant results and changes that take place may not be easily recognised by individuals.

## **Charity Context**

FVP currently operates as a Charitable Incorporated Charity (CIO); registration number: 1171389. FVP's charitable purpose is defined in the following objects '*to relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough in such ways as the trustees shall think fit, in particular by the provision of advice, information, support and advocacy*'. FVP operates under a foundation model where the trustees are the members of the charity and the CIO holds the assets of the charity. The charitable assets are a community centre and two caravans. FVP also hold the details of approximately 900 households and regularly send an e-news to over 500 people

who are primarily parent carers and in 2020 – 2021 engaged with 310 parent carers on an individual level. FVP are supported by board of trustees who provide strategic direction and oversight and a small team of employees supported by regular and ad hoc volunteers to conduct the operational work of the charity.

### **Community Provision**

FVP as of February 2020 completed asset transfer of the Goldhay Community Centre from PCC. This should have been cause to celebrate but as a result of C-19 the centre had to close to the public. The centre is used as the head office of the charity and would ordinarily be a hub for the community where local residents and the wider community can access a variety of services delivered by many different groups and organisations. The community provision enables support, information and advice to be provided by different groups and organisations based on need and requests from those who use the centre.

### **Short Breaks Provision**

FVP own two caravans which are used to supplement the short breaks offer to families with SEND children and young people in Peterborough who receive priority in terms of booking especially in peak periods. The caravans are assets of the charity and the full responsibility of FVP in terms of management, sustainability, upkeep and use.

The caravans have seen extensive growth in relation to usage since 2012 when there were only 4 bookings. The past year alone has seen 92 short breaks being accessed with a total of 349 people benefitting. Year on year there has also been a change in booking preference to 3 and 4 nights now being the preferred option. 2020 to 2021 saw a large decrease in bookings as the caravans were closed for most of the season due to the national lock down periods and new C-19 site restrictions.

## Participation/ Engagement/ Involvement April 2020 to March 2021

### Headlines

1. 310 known parents in total have been involved at some level via virtual meetings/ events/ online activities/ Facebook Polls and Discussions.
2. >100 professionals have been involved at some level via virtual meetings.
3. 871 parent carers have taken part 54 online surveys or face book polls.
4. Parents have self-reported being members/ attendees at; Peterborough District Deaf Children Society (PDDCS), Peterborough Area Down Syndrome Group (PADSG), Little Miracles (LM), National Autistic Society (NAS), Autism Peterborough, , Aiming High Group (AHG)
5. Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
  - a. ASD, ADHD,
  - b. Global Developmental Delay (GDD),
  - c. Speech, Language and Communication Needs (SLCN),
  - d. Complex Health, Obsessive Compulsive Disorder (OCD),
  - e. Cerebral Palsy (CP),
  - f. Tourette's,
  - g. Learning Disability and Difficulty (LDD),
  - h. Hearing Impairment (HI), Depression, Behavioural Needs,
  - i. Achondroplasia,
  - j. Goldenhar Syndrome,
  - k. Downs Syndrome,
  - l. Hypochondroplasia,
  - m. Physical Disabilities
  - n. Anxiety Disorder
6. 19 fathers have been involved which is a decrease on the previous year and 1 father has had regular involvement in person and another via social media
7. Parent carers reported the ages of their children/ young people as between 2 to 34.
8. Participation methods used included; one conference, focus groups, online surveys, paper surveys/ feedback forms at trips and activities, training – workshops, Facebook discussions and polls, working breakfast meetings, case studies, seldom heard group sessions and parent representation.
9. Evidence is both qualitative and quantitative in nature.
10. Ethnicity has been self-reported as; White British, Asian, Gambian, Lithuanian, Polish, Albanian, African, Portuguese, Scottish, Canadian, Bangladeshi, South African, Latvian, White European and American.

## **CAMHs Transformation, SEND and Participation including Seldom Heard**





## **Introduction**

FVP have conducted work across a variety of areas as the forum for the Peterborough City Council (PCC) and Cambridgeshire and Peterborough Clinical Commissioning Group (CCG). All funded forum work conducted regardless of whether for PCC or the CCG has a participatory focus with the aspiration of working towards achieving co-production.

## **CAMHS Transformation (s256 work)**

### **FVP**

FVP were commissioned to continue with the delivery of the Expert Parent Programme (EPP), Behaviours that Challenge (CB) Workshops and Parent Carer Hub. These have been difficult to deliver due to C-19 and other work has been conducted instead designed to achieve similar outcomes. The ongoing provision of Experts by Experience (EbE) for CETR's has been delivered. Some of the work relating to this area has been reported on in quarterly monitoring reports. As well as this parent representatives have been included in various health based strategic meetings including the Mental Health and Emotional Wellbeing Board.

## **SEND and Schools Engagement**

This area of work has seen engagement and participation across a number of areas from 310 individual parent carers. The participation has taken place through a variety of methods including; online polls and discussion via social media channels, online surveys and via virtual meetings. Due to C-19 no face to face methods have been used for direct participation work.

### **Data Gathering**

Data to ascertain parent carer views and experiences has been through a series of Facebook Discussions and Polls; via online surveys, case study work and discussions with parent via email or phone. More video evidence exists of the participation work of the forum as well through the use of Zoom recordings which have been shared via YouTube [https://www.youtube.com/channel/UCN-Zqf\\_9Sbz0a\\_kTQ1SsY2w](https://www.youtube.com/channel/UCN-Zqf_9Sbz0a_kTQ1SsY2w).

### **Schools Engagement**

The work around schools engagement has taken a slightly different approach and focused more on engagement with the SENCo Network; contact with settings regards their SEN Information reports and some meetings and targeted surveys with a local special school.

## **Seldom Heard Engagement**

Work has continued in this area in relation to general engagement and facilitating participation through virtual means. A community development worker (CDW) has also invested time in outreach work to identify new contacts and groups; the CDW has also been supported by a Parent Representative who may be considered as Seldom Heard. Between the two team members a new virtual forum has been started bringing together community leaders, professionals and parent carers to focus on a range of topics chosen by those who attend the sessions.

## **Coproduction and Change**

In the last annual reporting period the concept of Topics of Importance was introduced as a means to demonstrate more clearly what views and concerns were being reported by the forum to PCC and the CCG and what was being done as a result. This way of working has been actively adopted and in part resulted in a new participation page on the Local Offer. There has been a higher level of coproduction and change in the past year which this report refers to. From temporary solutions to C-19 issues through to a general better approach to communication with parent carers.

**Table One** – partial matrix to demonstrate what has been achieved so far by inclusion of examples of outputs and measures.

No	Outcome	Output/activity	How Measured
1	<p>Parents and Carers are empowered to give each other information and support through peer to peer support with professionals input.</p> <p>Parent carers have the opportunity to share experiences leading to increasing sense of confidence and shared experience to embed co-production</p>	<ul style="list-style-type: none"> <li>• Parent representatives are trained through the Family Voice parent participation training course across all work streams</li> <li>• Reasonable expenses are met to facilitate parents and carers to attend meetings – childcare travel, etc. all work streams</li> <li>• Appropriate supervision and support given to participation reps who attend groups/meetings all work streams</li> <li>• Activities related to identifying blocks and barriers to parent carer participation, and co-producing the city's response in terms of addressing the issues and development all work streams</li> </ul>	<ul style="list-style-type: none"> <li>• Quarterly reporting detailing - <ul style="list-style-type: none"> <li>A. Numbers of unique/ repeat/ new parent carers attending sessions</li> <li>B. Overall attendance numbers</li> <li>C. Evaluation of sessions</li> <li>D. Satisfaction rating</li> <li>E. Sessions run across planned areas to be inclusive of seldom heard groups/ rural areas.</li> </ul> </li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• FVP held a six week training course for current and potential parent reps which was attended by four parent carers. One is now on the list of parent reps</li> <li>• Parent reps are attending meetings and taking part in discussions relating to service development and delivery which can impact on co-production</li> </ul>	<ul style="list-style-type: none"> <li>• A recruitment campaign has resulted in there being a team of seven parent reps from a diverse range of backgrounds.</li> </ul>

No	Outcome	Output/activity	How Measured
2	Improved trust in relationships between parent carers from a range of backgrounds and health , education and social care sectors	<ul style="list-style-type: none"> <li>• Parent representatives are trained through the Family Voice parent participation training course across all work streams</li> <li>• Reasonable expenses are met to facilitate parents and carers to attend meetings – childcare travel, etc. all work streams</li> <li>• Appropriate supervision and support given to participation reps who attend groups/meetings all work streams</li> <li>• Activities related to identifying blocks and barriers to parent carer participation, and co-producing the city's response in terms of addressing the issues and development all work streams</li> <li>• Involvement in health, education and social care sector work streams (development of early years guides, a schools directory)</li> </ul>	<ul style="list-style-type: none"> <li>• Change in self-rating of relationships/ involvement with health sector</li> <li>• Increased attendance at newly formed Seldom Heard Communities Forums</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• A series of virtual sessions for community leaders, professionals and parent carers</li> <li>• Sessions attended by a diverse range of parent carers, given the opportunity to make new connections across ethnicity, culture and social economic areas.</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Recordings of online meetings</li> <li>• Attendance records</li> <li>• Interest from parents from seldom heard groups in rep work, attendance at sessions where parent carer feedback is sought. Increase in diversity, as evidenced by names gathered and recorded on participation spreadsheet</li> </ul>

No	Outcome	Output/activity	How Measured
3	Increased resilience and confidence in navigating health pathways and services and increased partnership working with health professionals (collective and individual participation) Parents and Carers are empowered engage with Local health providers and confident in understanding how to get the best from health services	<ul style="list-style-type: none"> <li>• Access by early help pathway and self-referral if space is available/ schools requesting sessions.</li> <li>• Appropriately advertised using variety of methods</li> <li>• Individual trainers taking lead in Partnership approach through the steps described above, and the provision of co-delivered workshops</li> <li>• Be part of the feedback process for families, to facilitate the understanding of the effectiveness of participation facilitating their own sessions.</li> </ul>	<ul style="list-style-type: none"> <li>• Number of session provided - target or one per half term across Peterborough and Cambridgeshire</li> <li>• Use of external providers to host sessions (schools/ early years providers/ children's centre etc.)</li> <li>• Details of EPP content and delivery</li> <li>• Number of parent carers attending—target of 10 per session</li> <li>• Parent carer feedback</li> <li>•</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• Most of this work relating to training has not occurred as the sessions are not designed for f2f delivery.</li> <li>• Virtual workshops, especially related to health and C-19</li> <li>• Involvement in CPFT mental health boards</li> </ul>	<ul style="list-style-type: none"> <li>• 1 EPP</li> <li>• Total attendees have been 6</li> <li>• See FVP YouTube channel for health discussions</li> <li>• Rep reports produced from meeting attendance</li> </ul>

No	Outcome	Output/activity	How Measured
4	<p>Training and Development so Parent carers have increased skills, knowledge to facilitate self-help</p> <p>Increased confidence from parent carers in managing behaviours that challenge that are associated with possible ASD/ ADHD/ LD</p>	<ul style="list-style-type: none"> <li>• Undertake the co-planning of workshops developed jointly by FVP and CPFT in understanding behaviours around hyperactivity, social interaction and learning difficulties</li> <li>• Co-delivery of workshops with FVP/ parent reps, to increase parent carer understanding of behaviours linked to hyperactivity, social interaction and learning difficulties with professional input and Challenging Behaviour</li> <li>• Access to the workshops groups is via self-referral with bookings taken by Pinpoint and Family Voice</li> <li>• Parent carers gaining new skills through sharing of hints/ tips from professional and signposting from parent reps</li> <li>• Access to training (Expert parent Programme, Microsoft Basics, Parent Participation)</li> </ul>	<p>Quarterly reporting detailing -</p> <ul style="list-style-type: none"> <li>• Parent carers self-reporting that they are able to manage children's behaviour better</li> <li>• Number of workshops provided - target of one session per half-term</li> <li>• Use of external providers to host sessions</li> <li>• Details of workshop content</li> <li>• Number of parent carers attending—target of 10 per workshop</li> <li>• Parent carer feedback</li> <li>• Feedback, evaluation from professionals co-delivering workshops</li> <li>• Access measured via social media requests, email and phone logs and completed attendance register</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• An attempt was made to deliver the sessions virtually</li> <li>• Parent reps have been involved in the work relating to the ASD strategy</li> </ul>	<ul style="list-style-type: none"> <li>• 3 sessions have taken place with 15 attendees</li> <li>• 2 reps from diverse backgrounds have attended ASD meetings.</li> </ul>

No	Outcome	Output/activity	How Measured
5	Parent Carer Hub (inclusion surgery), development and access to facilitate parent carer support and wider participation.	<ul style="list-style-type: none"> <li>• Undertake the development of a parent carer hub working in partnership with 3<sup>rd</sup> sector and Local Authority Professionals</li> <li>• Plan and deliver inclusion surgery as part of parent carer hub supported by parent representative</li> <li>• Provide feedback on support offered through parent carer hub</li> <li>• Parent carers accessing hub gain support to navigate early help pathway and increased understanding of EHC pathway and processes</li> <li>• Ongoing development of Hub via joint work with PCC (SENI Services)</li> </ul>	<p>Quarterly reporting detailing –</p> <ul style="list-style-type: none"> <li>• Monthly Parent Carer Hub – target 11 (excludes summer break)</li> <li>• Details of numbers of parent carers attending hubs</li> <li>• Parent carer feedback</li> <li>• Feedback and evaluation from professionals co-delivering hubs</li> <li>• Access measured by booking forms and attendance records</li> <li>• Targeting educational settings to increase their involvement.</li> <li>• Numbers of new parents attending sessions</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• The move towards virtual working has proved a learning curve. The sessions have been moved to teams.</li> <li>• One themed open forum session relating to EHCp's was held</li> </ul>	<ul style="list-style-type: none"> <li>• 3 sessions were planned but only 4 people had sessions, with a high no-show rate.</li> <li>• The open forum session had over 20 attendees and was made available on YouTube</li> </ul>

No	Outcome	Output/activity	How Measured
6	<p>Training and support leading to development of team of "Experts by Experience" (EbE) for involvement in Care and Treatment Reviews (CTR) and Care, Education and Treatment reviews (CETR) for children and young people.</p> <p>Provision of a team of EbE</p>	<ul style="list-style-type: none"> <li>• Development of governance for EbE work</li> <li>• Working co-operatively with PCC &amp; CCG to establish team of EbE and in conjunction with JCU (SEND Sub-Group) Guidance</li> <li>• Process detailing requests for CTR/ CETR support with clear record keeping</li> <li>• Measures of how parent carers feel during work as EbE</li> <li>• Offer to partner's details boundaries and protection for parent carers with no personal contact details being passed on and clarity over what is and is not in scope of service.</li> <li>• Peer to peer support sessions to pull out overarching themes</li> <li>• Establish a mechanism for professional support for EbE if required.</li> </ul>	<p>Quarterly reporting detailing -</p> <ul style="list-style-type: none"> <li>• Governance documentation for EbE role and work</li> <li>• Details of parent carers wishing to form team of EbE</li> <li>• Family Voice and Pinpoint targeted parent carers who are either staff/ volunteers/ parent reps</li> <li>• Parent carers to take EPP course in Peterborough and Cambridgeshire</li> <li>• Parents to take part in or have already taken part in FVP parent participation and representation course</li> <li>• Details of processes, requirements and support associated with CTR/ CETR work</li> <li>• Facilitate EbE attendance at average of 3 -4 CTR/ CETR per month</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• supervision for EbE is via CCG</li> <li>• Regular communication between EbE and involvement in feedback to CCG over process.</li> <li>• Involvement in key worker discussions.</li> <li>• Wellbeing has been supported for parent carers via hand packed gift packs</li> </ul>	<ul style="list-style-type: none"> <li>• 2 EbE have attended between them over 55 CETR's</li> <li>• Forum attendance at planning meetings and input into key worker bid</li> <li>• Over 100 parent carers have received packs.</li> </ul>



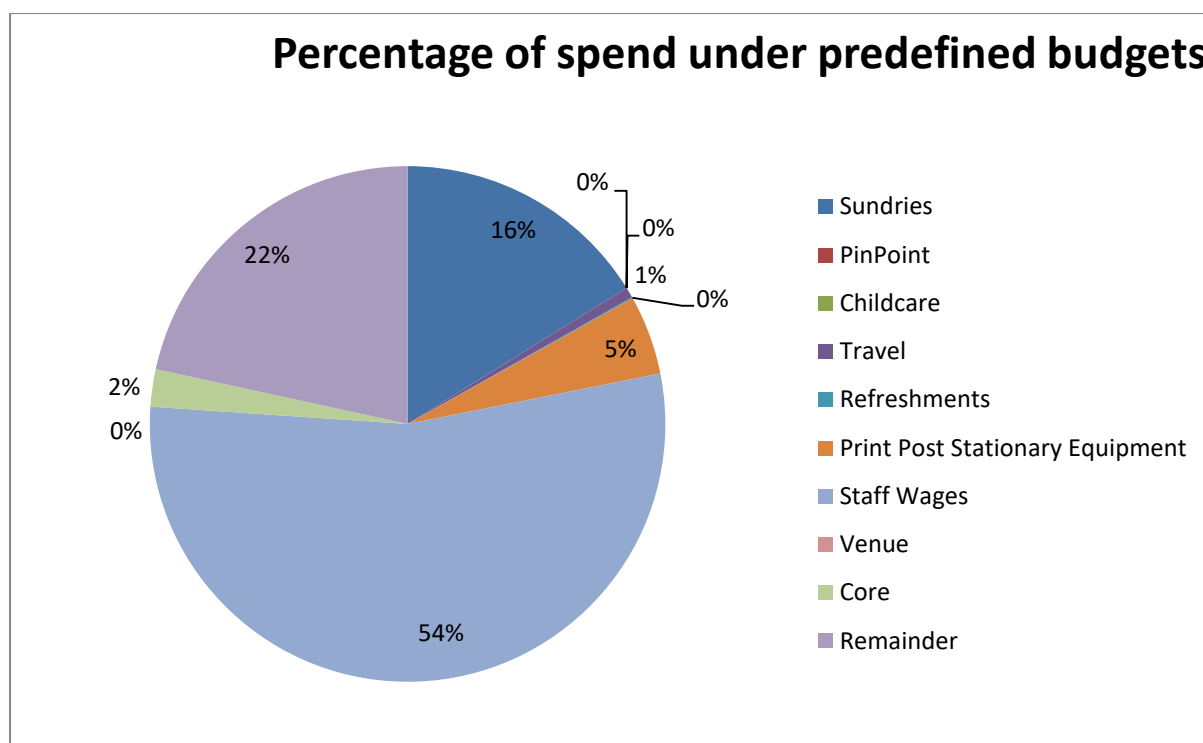
No	Outcome	Output/activity	How Measured
7	Strategic representation on various boards including; Operational representation across SEND work streams	<ul style="list-style-type: none"> <li>• Undertake the planning of workshops with parents, carers and professionals to increase awareness of the current position and next steps</li> <li>• Work alongside partners, including those in the voluntary sector to share information and good practice</li> <li>• Attendance and representation at work stream and task and finish groups</li> <li>• Parent representatives undertake the planning and delivery of workshops, task and finish groups and focus groups with parents, carers and professionals to facilitate co-production and wider parent carer participation in services for CYP</li> <li>• Attendance on LDPB, Carers, PDPB, Autism Partnership Board, SEND Transformation Board, leads to embedding of participation to promote inclusion across services relevant to children and young people with SEND</li> </ul>	<ul style="list-style-type: none"> <li>• Named, trained, Family Voice trustees who may be attending meetings</li> <li>• Monthly highlight reports for each work stream, contributed to by the reps attending meetings</li> <li>• Annual report</li> <li>• Attendance/representation at strategic meetings</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• Attendance takes place across a number of boards and groups and a number of focus groups have taken place with reporting informing strategic planning.</li> <li>• Involvement in WSoA, SEND Action Plan, ASD Strategy</li> </ul>	<ul style="list-style-type: none"> <li>• 5 focus groups with 35 attendees</li> <li>• 7 parent carers acting as reps at 216 strategic meetings. Reps are Lithuanian, Pakistani, White British, and Scottish and have CYP with needs from HI and ASD through to Down Syndrome.</li> <li>• Action plan developed including growing list of strategic meeting involvement.</li> </ul>

No	Outcome	Output/activity	How Measured
8	Improved participation as a volunteer or parent representative	<ul style="list-style-type: none"> <li>• A more diverse range of parent carers acting as parent reps on operational boards</li> <li>• Development of champions of participation amongst diverse groups of parent carers</li> <li>• FVP support in form of buddying, pre-post meetings, admin support</li> </ul>	<ul style="list-style-type: none"> <li>• Registers and feedback forms from a range of opportunities for parent carers to come together, share experience and meet other parent reps</li> <li>• Parent reps acting as buddies to parents who want to attend meetings/ focus groups then completing joint reports</li> <li>• One parent rep course for parent carers to attend and learn more</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• Regular virtual team meetings.</li> <li>• A shared rep report system is being used, as is a shared diary.</li> </ul>	<ul style="list-style-type: none"> <li>• 2 new parent rep representative; one from Lithuanian Community and One from Asian Community.</li> <li>• 1 new parent carer acting as volunteer on admin work and data monitoring</li> </ul>

No	Outcome	Output/activity	How Measured
	Improved trust in relations between settings and parent carers  Increased schools engagement	<ul style="list-style-type: none"> <li>• Undertake planning of work to increase number of settings offering attendance at coffee mornings/ parents evenings</li> <li>• Develop offer for schools and develop marketing tools detailing offer.</li> <li>• Dedicated staff/ parent rep time for developing relationship with settings, SENCo Network</li> </ul>	<ul style="list-style-type: none"> <li>• Number of settings FVP has contact with.</li> <li>• Numbers of sessions attended in settings.</li> <li>• Number of training sessions settings arrange on behalf of FVP.</li> <li>• Numbers of new parent carers engaging</li> <li>• feedback from parent carers/ settings</li> </ul>
	Example of how this has been met	<ul style="list-style-type: none"> <li>• Virtual coffee mornings held at Lime Orton Academy for a range of parent carers to talk with SEN team and one another</li> <li>• SEN Information report review</li> <li>• Attendance at SENCo Forum</li> <li>• Co-production of education CYP with SEND in lock down</li> </ul>	<ul style="list-style-type: none"> <li>• 5 new parents engaged/ informed at Lime Orton Academy</li> <li>• Completed Your Say Form</li> <li>• Rep reports</li> </ul>

## **OVERALL PROJECT WORK COSTS AND DATA**

### **Overall Costs**



**Fig.2 Overall LA/ CCG grant spend**

There was a slight change in funding for 2020 to 2021 with a decrease in the core grant and additional top up to cover only Expert by Experience (EbE) fees from the CCG.

Staffing equates to salary costs, HMRC costs and pension costs. The budget for sundries covers training costs, licencing and EbE remuneration. Unlike previous years FVP were only awarded funds to cover work delivered by FVP. Pinpoint received their CCG funds directly this year.

The following information is based on data where recorded, which is refined year on year and covers all expenditure.

CCG/ PCC Grant Spend - £67,220

DfE Grant - £18,200

Pears Grant £3,700

Lottery Grant - £50,220

Other Funds - £49699

Total Hours (project) – 1094

Number of Beneficiaries - 2342

Unique Parents/ Families (SEND) – 310

Funding/Hours – £17.24

Funding/number of beneficiaries – £8.05

Funding/ unique parents - £60.84

Number of Hours\*Cost of Beneficiaries – £2,562,148 .00

## Overall Data

Type of Session	Sessions	Activity Hours	Time	Travel Time	Total Hours	Beneficiaries
EPP	1	5	2	0	7	6
CB	3	10	3	0	13	15
Parent Carer Hub	3	4	2	0	6	4
Themed Workshops	1	2	0	0	2	6
CETR	59	354	0	0	354	59
Sessions	9	12	54	0	66	121
CDC Sessions	0	0	0	0	0	0
Focus Groups	2	2	0	0	2	5
Schools Offer	0	0	0	0	0	0
Lunch) Meeting	3	6	0	0	6	15
Conference	0	0	0	0	0	0
Facebook Polls	38	0	0	0	0	550
Surveys	16	0	0	0	0	363
Activities	22	7.5	0	0	7.5	1070
Strategic Meetings	216	333.5	147	19	499.5	7
Volunteer Support	12	131	0	0	131	32
Hall Hire						
Caravan Hire	40					89
<b>TOTALS</b>	<b>425</b>	<b>867</b>	<b>208</b>	<b>19</b>	<b>1094</b>	<b>2342</b>

**Fig.3 Grant funded work for 2020 - 2021**

The level of staffing, and volunteer/ rep time to deliver the work detailed above is as follows:

Staff Hours – 6945

Core Volunteer Hours - 780

Volunteer Support – 131

Total Hours = 7700 (the staffing hours does not account for any extra hours put in over and above contracted time)

If funds were used to cover all hours worked then everyone will have been remunerated at £2.40 p/h

## **CAMHs WORK**

### **Predicted CAMHs Work Data (No Change from 2019 to 2020)**

The following were predefined as measures of the outcomes relating in particular to the Challenging Behaviour (CB) workshops, Expert Parent Programme (EPP), Hubs and CETR's. Other elements of the work did not have predefined targets detailed as numbers but rather as set work.

	Predicted Sessions	Predicted Hours	Predicted Parents
EPP	6	60	60
CB	6	42	60
Hub	11	77	55
CETR	36	216	36
Totals	59	395	211

**Fig.5 Predicted data for CAMHs funded work**

### CB Workshops

- Number of workshops provided - target of 6.
- Details of workshop content.
- Number of parent carer's attending– target of 10 per workshop.
- Parent carer feedback.
- Feedback, evaluation from professionals co-delivering workshops.
- Access measured via social media requests, email and phone logs and completed attendance register.

### EPP

- Parent carer details from 6 EPP sessions to be run across Cambridgeshire or Peterborough with 10 per session.
- Parent Carer Feedback.
- Parent carers self-report positive change in their communications with the health providers and their partners.

### HUB

This area of work has been added after a successful pilot.

- Feedback from parent carers who have attended one of 11 hub sessions.
- 5 parent carers per session
- Details of any recurring issues/ themes

### CETR Work

- Development of a core team of EbE – Target 3
- Attendance at 3 CETR per month

### Total Numbers

- 60 parent carers across six workshops
- 60 parent carers across six EPP courses
- 55 parent carers across 12 Hubs
- 36 CETR sessions attended

### Predicted CAMHs Work Costs

Based on the predicted data if a cost analysis is conducted for the CAMHs element of the work the following can be ascertained:

Grant Funding - £32,725

Total hours - 368

Number of Parents -81

Funding/ Hours - £88.93

Funding/ Parents - £404.01

£25,000 from CAMHs Transformation and £7725 CETR top-up equates to the £32,725 detailed above.

## Actual CAMHs Work Data 2018/19 to 2020/21

	Actual Sessions			Actual Hours			Actual Parents		
	18/19	19/20	20/21	18/19	19/20	20/21	18/19	19/20	20/21
EPP	4	5	1	40	45	7	30	41	6
CB	4	5	3	25	30	1	21	41	15
HUB	6	6	3	29	20	6	8	20	4
CETR	38	39	59	311	279.5	354	28	39	56
Total	52	55	66	405	374.5	368	87	141	81

Fig.6 Actual data for CAMHs funded work

## Variance

Fig.6 Actual data for CAMHs funded work

	Yearly Data			Variance	
	18/19	19/20	20/21	18/19 to 20/21	19/20 to 20/21
Grant Total	£30,850.00	£30,775.00	£32,725.00	£1,875.00	£1,950.00
Total Hours	405	374.5	368	-37	-6.5
Parents	87	141	81	-6	-60
Funding/Hours	£76.17	£82.18	£88.93	£12.76	6.75
Funding/ Parents	£354.60	£218.26	£404.01	£49.41	185.75

Fig.7 Variance Data 2018 to 2021

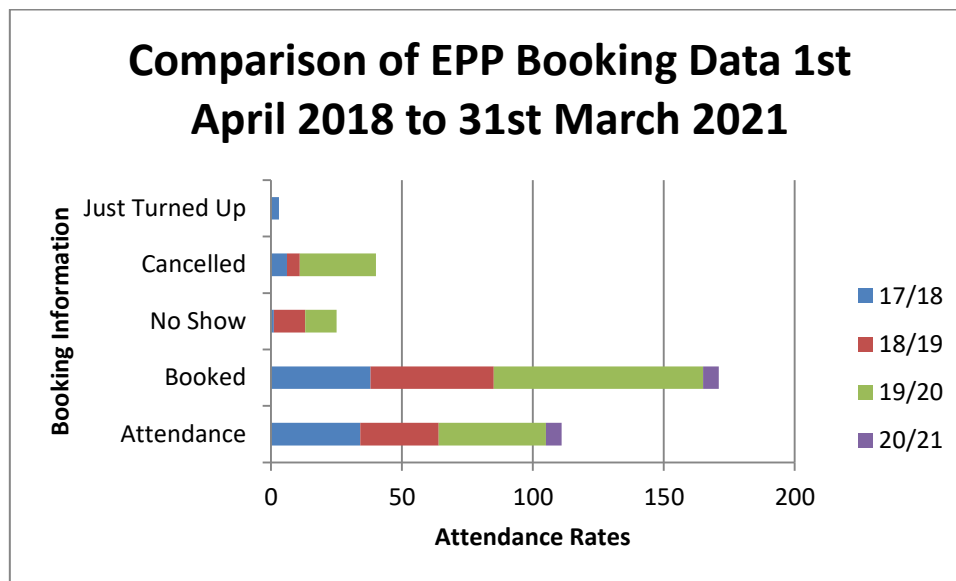
There was a large decrease in delivery of training relating to the EPP and CB sessions due to C-19 and being unable to work face to face.

## Training

The training delivered to parent carers as part of the CAMHs funded work remains a vital service, but this past year has been greatly impacted by C-19 to the point that delivery has virtually stalled and other types of work have been delivered instead. The main change has been a move towards support with practical help especially in relation to food support and sign-posting. This will be detailed in a later part of the report. For now where it is possible a cursory examination of what delivery has occurred will be conducted alongside a comparison with previous year's data.

## Expert Parent Programme

The expert parent programme was designed as a six hour face to face workshop with many hands on practical activities. Work occurred in the form of a pilot to deliver this virtually via Zoom using the new team of reps as participants. Their feedback will be discussed in this section of the report. Due to the nature of the workshop parent carers being focussed primarily on C-19 and the changing government guidance resulting in three periods of lock down it was not possible to run a session after the pilot to ascertain viability as a virtual workshop.



**Fig 8: EPP Participation Comparison from 2017 to 2021**

What can be seen from Fig.8 is that there was a year on year increase in attendance on the EPP workshop and in previous reports this was identified through links made with Barnardo's who were leading on the Early Help pathway parenting workshops which were used as a feeder into this programme.

### Parental Feedback

At the end of each course parental feedback is sought, as a way of being able to gauge the efficacy of the course and to be able to engage in some self-reflection about what is working and what is not working. This is measured against the following statements with which respondents have to strongly agree, agree, neither agree or disagree, disagree or strongly disagree:

- Have an Increased understanding of how the health system operates in relation to services for my child.
- Have gained some ideas and strategies to help me navigate and get a better deal out health services for my child
- Have gained some ideas and strategies to help me secure health services for my child
- Have a better understanding of where I can find information relating to my child's health
- Have increased knowledge of the roles of health professionals who may be involved with my child and increased confidence to work in partnership with them
- I recognise the importance and benefits of sharing my unique knowledge and expertise with everyone involved in my child's care
- I have gained some tools and ideas to be more confident when discussing my child's needs
- I would recommend this workshop to other parents

On the feedback for the session all participants either strongly agreed or agreed with each statement.

Further information is sought in terms of broader more quantitative data whereby the participants can expand on how they found the training against the following headings:

Something you've learnt today:

- *That there is a website to download the disabled child's legal handbook, at the Council for Disabled Children*
- *I've learned today a lot of new things and points of view Beringo Parent Carer.*
- *The benefit of a diagnosis is that the child/adult will have more protection under the equality act 2010*
- *General refresher*

What worked well for you today:

- *Breakout rooms!!*
- *Discussions and workshops in small groups.*
- *Sharing experiences and finding new ways to work in partnership with professionals*
- *Working remotely*

What didn't work well for you today:

- *Rejoining the main group after the breakout room!!*
- *I couldn't name any gap.*
- *Just IT issues*
- *Nothing*

Something that I will do as a result of today's session:

- *Download the legal handbook, and read the equalities act*
- *Better understanding of how health system works.*
- *That I'm not alone and there are many parents with similar experiences*
- *Ask for help when I need it*



## Challenging Behaviour Workshop:

The Challenging Behaviour (CB) Workshop is designed to be a three hour workshop delivered by parent carers trained as part of a pilot train the trainer in 2017. The workshop was delivered primarily by a parent carer who was also a trainer parenting and family support worker between the pilot and November 2020. The course was overtime adapted by the trainer based on their personal work experience. There were only three sessions delivered in 2020 which ended up becoming more support as opposed to training sessions. Ultimately only 15 parent carers benefited and there was a high no show and cancellation rate.

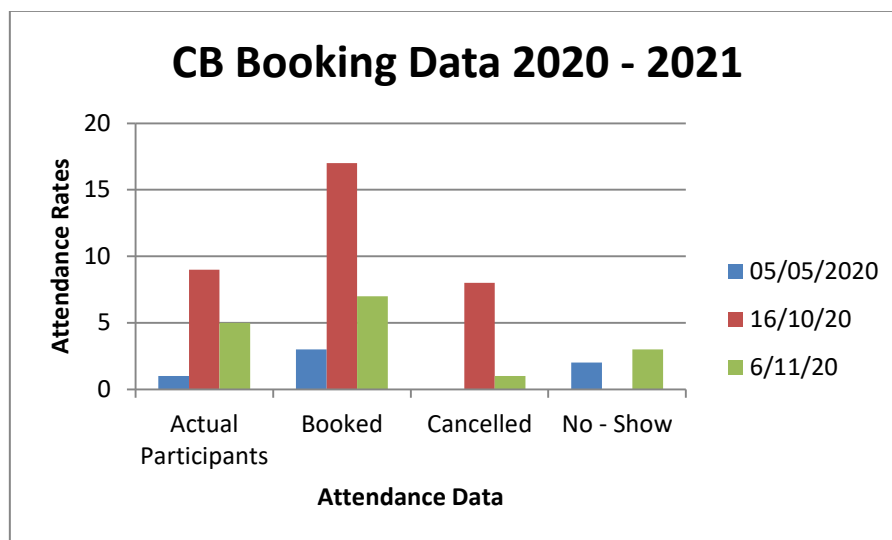


Figure 9: CB Participation Rates 2020 - 2021

The past year has shown how the course does not lend itself easily to virtual working and also FVP have seen that over reliance on one person for training delivery is high risk. The trainer is no longer in the position of being able to deliver the training for FVP which has resulted in a service gap. The mix of C-19 and over reliance on one person has meant that delivery and attendance have stalled.

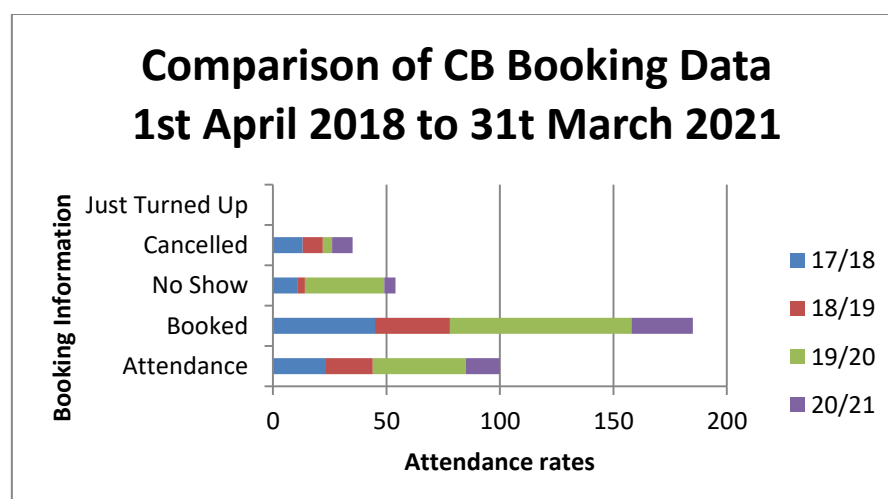
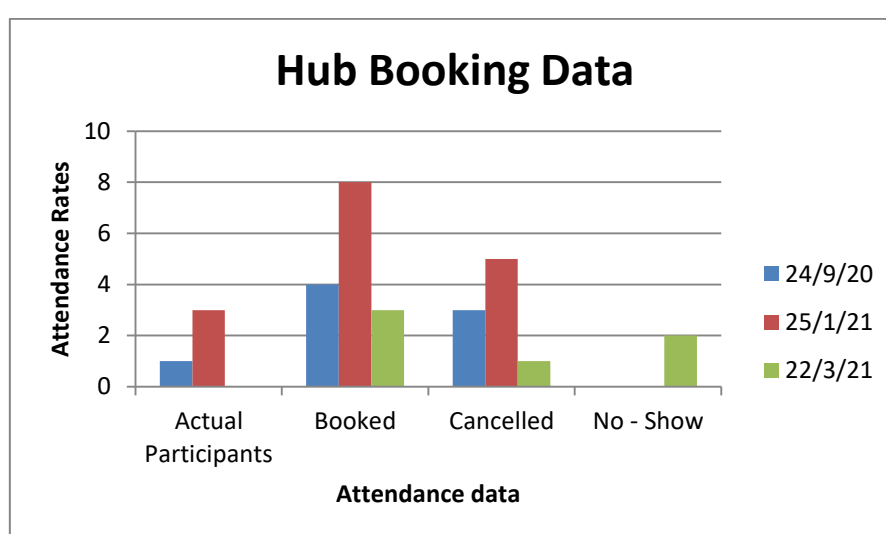


Fig 10: CB Participation Comparison Rates from 2017-2021

Work needs to take place to find other ways to deliver on this element of the training offered by FVP; to include exploration of different workshops, more train the trainer work and sourcing of other trainers. Also unfortunately due to the way the sessions were delivered and time constraints, feedback was not sought from those who attended the sessions. Going forwards this is being managed by sending out feedback forms with booking details and encouraging the use of messaging in the chat function of Zoom primarily.

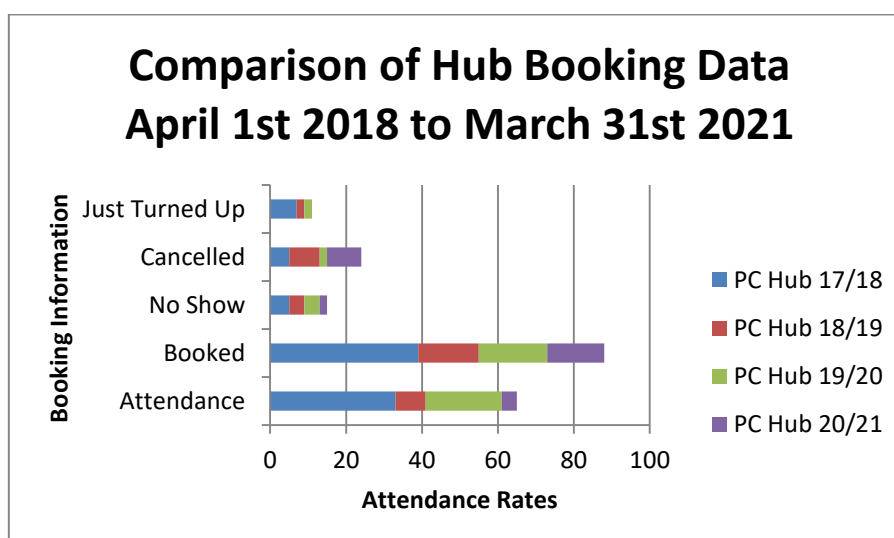
### Parent Carer Hubs

The Parent carer hubs have proved extremely challenging to manage virtually from booking through to administration. The concept is still wanted, but delivery needs much work. There have been issues relating to the use of Zoom versus Teams; training of new temporary team members to oversee the sessions; high non-attendance rates mainly due to C-19 and general administration of the sessions.



**Fig 11: Hub Participation Rates 2020 – 2021**

Fig. 11 shows that there were a high number of cancellations in January and no-shows in March which coincided with periods of lock down. The March period also saw FVP have more staff on home working which may have impacted on the administration.



**Fig. 12: Hub Participation Comparison Rates from 2017-2021**

## Food Support/ Signposting

An area FVP focussed on in 2020 to 2021 was the provision of food and phone/ email support. Although not strictly linked to the planned work relating to this part of the funded work it was felt to still be needed.

Total Households	Number of adults	Number Children without SEND	Number SEND 0-25
27	39	66	32

Fig. 13 Food Support During C-19

Overall	Xmas Box Beneficiaries	
	Parents	Children
233	93	140

Fig. 14 Food Support – Xmas Campaign

Total Contact	Follow up required	
	Yes	No
38	26	12

Fig. 15 Signposting Direct Contact

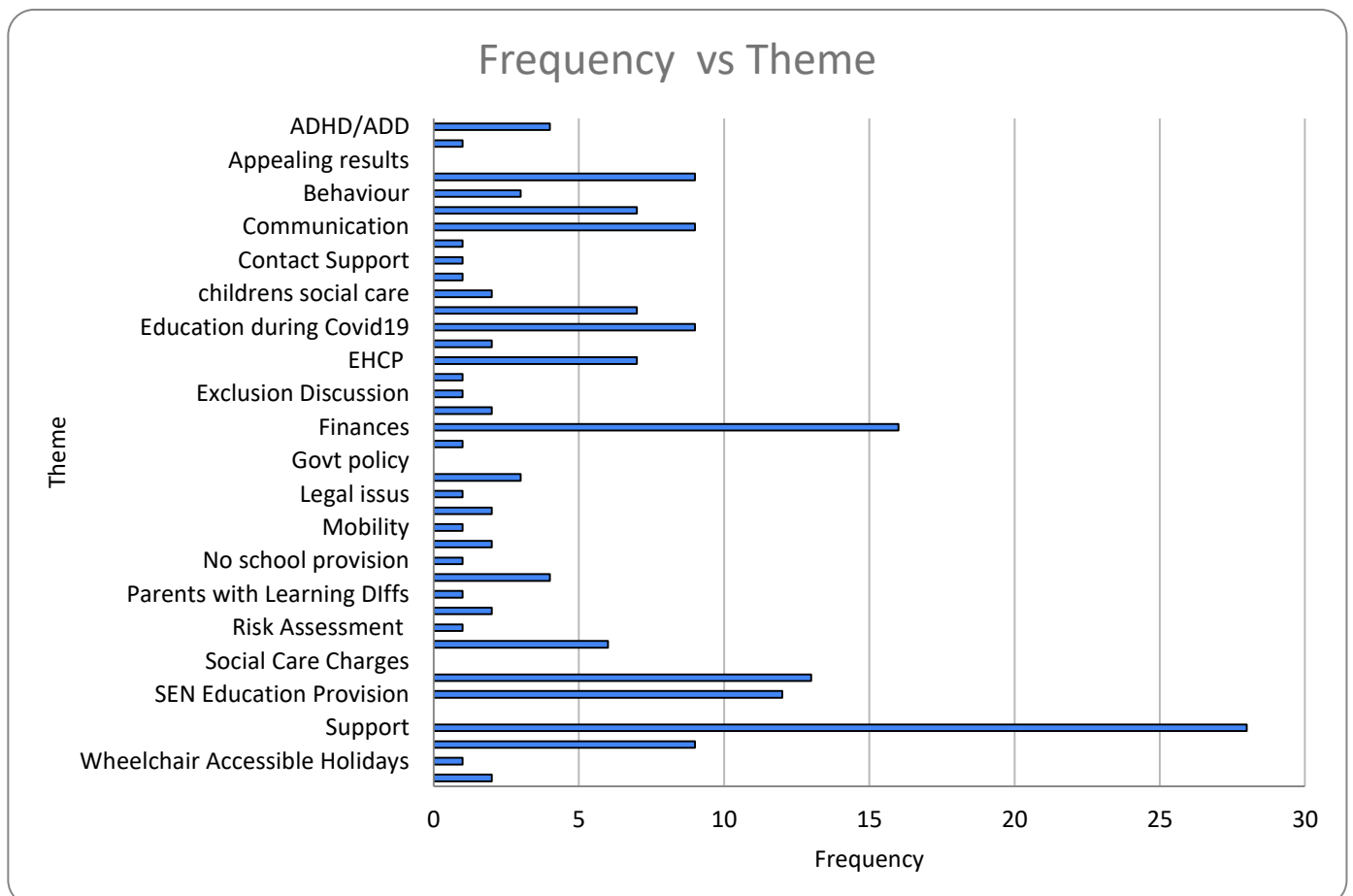


Fig. 17 Signposting Themes (direct contact and via FB discussions)

## **Impact of C-19 on Mental Wellbeing**

FVP also explored throughout the year the impact of C-19 on familial and parent carer mental wellbeing. This was through a number of surveys and analysis of the themes being raised by parent carers when seeking support. This has been reported on previously in a report looking specifically at the impact of C-19

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

Some of the key findings were:

- There was a negative impact on emotional health and wellbeing
- Household finances were detrimentally affected
- Access to support and services was negatively impacted
- Where education was maintained experiences were slightly improved.

Two parent's responses to the impact of C-19 were tracked across surveys and the following case studies demonstrate how one area is working well invariable other areas work better and emotional wellbeing increases.

Parent 1:

Child male, 8 years old with ASD, Moderate Learning Disability, Hearing Impairment and challenging behaviour who attends a full time mainstream setting

### **Emotional Wellbeing**

*"At home, his anxiety and stress have caused him to be volatile and have violent outbursts. His behaviour was very challenging just before and when he first returned to school"*

### **Education**

Did not attend school in lock down, however returned full time in September *"He initially returned for one hour a day and gradually built up to full time, he was able to be back in full time much quicker than expected because the school put such fantastic provisions in place for him."*

Transition plan was implemented to support return to school.

*The school have been fantastic and provided a lot of support for us, they arranged a telephone consultation with an autism specialist and she was very helpful and kept in touch with us. This sort of service was very helpful for me.*

### **Support and Services**

Support was available through health *"As the parent carer I had phone and/ or video calls with health services"*

### **Finances**

Not applicable was selected in relation to financial impact questions

Parent 2:

Child Male aged 9 years old with Moderate Learning Disability who attends a Full Time Specialist setting

### **Emotional wellbeing**

*“I'm worried as if I'm not working I can't pay rent, bills and just provide all the things my child may need. It's a very worrying, stressful time.”*

*“My son is a lot happier and alert he actually enjoys going to school and his behaviour all round has been much better.”*

### **Education**

During the initial lock down a risk assessment was conducted and school was attended for a short time *“Only went school back to school mid June, for about 5weeks”*

Was involved in section M discussions and rated the involvement, provision and usefulness as good.

Son returned to school full time in September with no transition plan/ risk assessment.

### **Support and Services**

Not applicable was selected In relation to questions pertaining to support and services.

### **Finances**

When asked questions relating to finances

*“ Its impacted my work life as my son's school is finishing at 2pm instead of 3pm I work until 3pm so am currently on a temp contract which will end after the half term in October. I am at risk of losing my job if the school do not go back to finishing at 3pm. This is a major worry for me as I am a single parent and have no other income.”*

Some questions in the surveys enabled parent carers to provide more in-depth details as to how C-19 had affected them; as demonstrated by the replies below, it has had a negative effect on their wellbeing:

- I am a single parent and work full time, I rely on family for childcare but my parents are in the high risk category for Covid-19 so myself and my adult daughter are having to try and arrange opposite shift patterns when we can, she mainly had to work midweek so I will be working mostly nights and weekends. I am therefore not at home a lot of the time my son has free time so cannot provide the level of emotional support he needs from me at the moment or generally spend time with him. Everyone in the household is currently struggling with mental health issues and this time of year is always a struggle but will be even more so this year. I take medication has been getting increasingly difficult to obtain as supplies are low and without it there is a high chance I will end up needing to have time off work and to be treated as an inpatient whilst I trial replacement medication, this would have a massive impact on my*

*children and if lockdown restrictions are put back in place they will be isolated and without support.*

- I have anxiety and this has definitely made it worse as things I worry about come true I can't keep them safe in our bubble he has to go to school the government say children are not really affected but that doesn't help my anxiety*
- It's stressful every day sending my two girls to school, are at different schools so this increases the chance of the virus getting in. My husband is vulnerable and I'm the main carer for him and my son. I am worried about keeping them safe from the virus. Just have to be very careful.*
- A lot of scared. Fears. I was 24 h with child. I have no time for myself. The needed visit in hospital was stressful. I haven't care. I'm scared used bus or taxi.*
- During the lockdown, life has totally changed not only for us for everyone. Keep thinking about the virus and terrifying. Just think we don't catch a virus on any cost. We didn't go anywhere in lockdown just went to a walk in the park. My husband just goes to work now and during the lockdown. Even we are not having any takeaway food yet. We clean every stuff when we bought something even Grocery either. So it's so many things we are going through during this terrible time.*
- Lock down had been very difficult being so isolated and dependent on others for essentials. Anxiety and fear has been very high as that was all that was being shown on TV or talked about. Not having my normal network of support and help has been very hard*

A sense of isolation and the loss of support networks have all led to a decrease in resilience amongst parent carers, which can further be demonstrated by some responses to FVP's Annual SEND survey; particularly when considering the following comment *"I had reached the end of my capacity to care by the time she moved. the pressure felt enormous made worse by Covid."* and *"Children and families are missed out in the care needs and support we need we are left to it"*

From surveys completed, it is also clear parent carers have already been feeling isolated and unsupported for some time. One survey asked the question 'Parent carers often tell us that caring for a child/ young person with SEND impacts many aspects of their life and seeking support is vital to being able to manage their caring role. Please use this space to tell us a bit about how caring for a child/ young person with SEND affects you' which elicited the following responses:

*Not wanting to go out because off loud noises*

*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.*

*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*

*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*

*Feel isolated, alone and sometimes very anxious*

*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.*

*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*

*Leaves you lonely, always feeling like you have to fight to defend their needs. A most of all an emotional mess.*

*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.*

*I have 11 year old who is very lively happy little boy who has global development delay and hearing impairment*

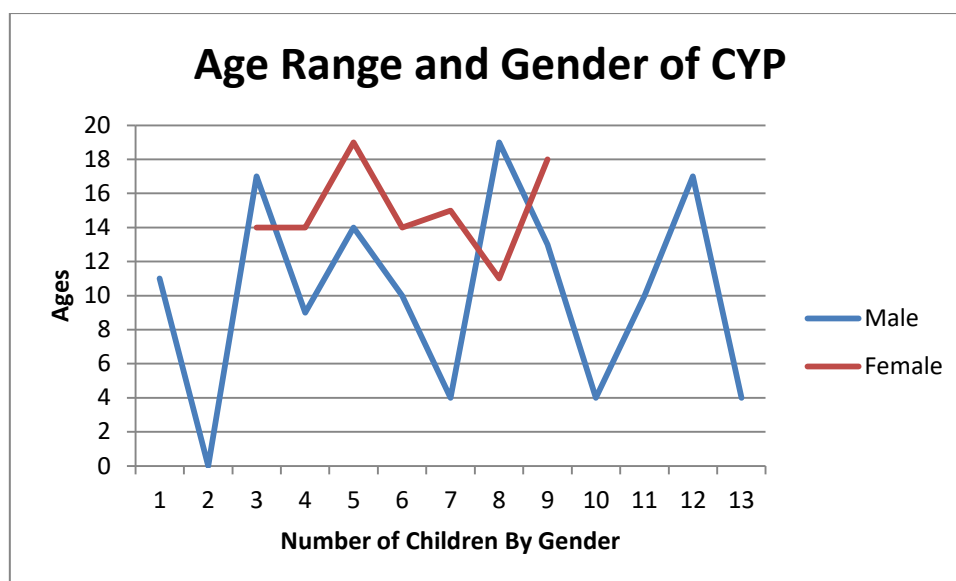
*Being so busy and not having enough hrs. Also getting right support and help for your child*

*Find it very isolating and can't always plan to do anything with friends due to tommy having lots of hospital appointments x*

*Raising my daughter, has at times left me feeling guilty for my other children as well as isolated from other families. I have avoided going on days out due to worrying about the struggles it may bring for me and my daughter.*

Something that has come up unlike in previous years has been parent carers providing more examples of the sort of support they would like to see and a common theme was emotional support often mentioned as 'someone to talk to'. Other more practical areas of support from form filling and advice relating to education for SEND children through to help with EHCp needs assessment applications are also mentioned.

It is worth noting here, that not all experiences are negative, especially where parent carers have their children in supporting educational environments. We asked a group of parents from Lime Orton Academy and also three families with children with health needs/ physical disabilities in mainstream settings for their general views on education, health and social care. In the main experiences have been positive and there is evidence of services working well together. Unlike data gathered in previous work across the past couple of years, responses were more positive than negative and the main area of need was not ASD.



**Fig. 18 CYP Needs of parent carers completing your say form**

Needs	
Male	Female
<ul style="list-style-type: none"> <li>• Cerebral palsy,</li> <li>• ASD</li> <li>• Social Interaction Difficulties,</li> <li>• Arthrogryposis,</li> <li>• learning disabilities 3 years below his age sensory issues,</li> <li>• requires 24 hour full assistance with every aspect of living</li> </ul>	<ul style="list-style-type: none"> <li>• global development delay and complex health needs,</li> <li>• complex health needs,</li> <li>• Respite -Learning difficulty,</li> <li>• global development delay</li> <li>• adhd and autism,</li> <li>• adhd &amp; lung condition</li> </ul>

**Fig. 19 Table of CYP needs by gender**

Education (negative/ positive/ neutral		
Negative (4)	Positive (12)	Neutral (4)
<ul style="list-style-type: none"> <li>• No not about the education my son receives</li> <li>• Poor communication remains a problem. I didn't think much to the home schooling and was useless for my deaf blind son. I don't get on with senior management at school.</li> <li>• Where is the update on their progress always or lack of it if they are on Sen support why is there nobody governing the schools and academies monitoring them on</li> </ul>	<ul style="list-style-type: none"> <li>• My son loves it at school and enjoys his lessons.</li> <li>• Yes the lime academy has been fantastic</li> <li>• Enjoy all the activities, interaction and stimulations, we are very pleased with all the professional effort to give ..... a little bit of what he has lost.</li> <li>• Yes I think the school have done amazing doing online classes for him to take part in. Seeing his teachers and friends on screen really pleases him.</li> <li>• In reception the teachers have been great with supporting his needs and communication between</li> </ul>	<ul style="list-style-type: none"> <li>• Full time</li> <li>• Peterborough with their lack of support is it because the funding is not ring fenced unfortunately for primary and secondary mainstream schools hence why parents feel the need to apply for ehcps so their children are supported properly as they should be to be the best they can be</li> <li>• Schools should offer tailor made</li> </ul>



<p>this no ieps nothing what is going on in</p> <ul style="list-style-type: none"> <li>Schools cant met all needs that a child needs relating to the ehcp</li> </ul>	<p>home and school has supported sustain his learnings.</p> <ul style="list-style-type: none"> <li>Yes, choosing a school was easy and I had plenty of support</li> <li>He gets a lot of support from primary school he is at</li> <li>He get on at great college</li> <li>Great education when she had a stricter teacher that could control the class &amp; an experienced senco</li> <li>I am very grateful for the school provision provided during lockdown</li> <li>My son loves school and the teachers and ta's are lovely</li> <li>My children went to kings and have had amazing educations</li> </ul>	<p>activities for send children. My son would benefit from swimming activities as he loves water and the lockdown made it difficult for him to develop this skill</p> <ul style="list-style-type: none"> <li>Moved class 3 times due to teacher not able to cope with behaviour</li> </ul>
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**Fig. 20 Table of views on Education**

Health (negative/ positive/ neutral		
Negative (2)	Positive (10)	Neutral (1)
<ul style="list-style-type: none"> <li>Some health care are quick to judge the parents</li> <li>Not all teachers are made aware of her health needs or medication so her care plan isn't always followed</li> </ul>	<ul style="list-style-type: none"> <li>I think overall they are great</li> <li>We are very happy with all the support, guidance and treatment ..... Received, the health care team are very good and professional, thank you very much.</li> <li>I receive a phone call every week and am asked how he is doing and if I need any help</li> <li>Great always keep us up to date with check-ups meds reviews and any advice going forward to future</li> <li>NHS are doing their best under the circumstances</li> <li>The school has supported to sustain my son's toilet training by developing a schedule for toilet times. This supported with the number of accidents he had whilst in school building his confidence and self-awareness.</li> <li>We have always found healthcare excellent in Peterborough</li> </ul>	<ul style="list-style-type: none"> <li>None just waiting times due to coved but that can't be helped</li> <li></li> </ul>

	<ul style="list-style-type: none"> <li>• They assessed him and explained well</li> <li>• She has been a regular attender of hospital appointments in school health care &amp; outside such has been great</li> <li>• My sons ccn, ..... Is amazing. Nothing is ever too much trouble. His physio,.... And ot, .... Are also brilliant and have been getting stuff done for us over lockdown. Think the children's ward is very good and communication between depts. is very good. E.g. between hospital, gap and nurses.</li> </ul>	
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**Fig. 21 Table of views on Health**

Social care (negative/ positive/ neutral		
Negative (5)	Positive (4)	Neutral (3)
<ul style="list-style-type: none"> <li>• It's always been about funding and not what the child actually needs</li> <li>• Yes constant change of social worker and having to go through all of the process in explaining the issues and problems we are having and as soon as the social worker starts to understand they are changed again. The whole process then starts again. The service we have had has been bad to worse. We never have anything explained to us and every time we ask for any help it's turned down. We are constantly told that we can't have respite and the we are already receiving a lot of help.</li> <li>• It's always been about funding and not what the child actually needs</li> <li>• Was refused help despite being ill myself an struggling with my child</li> <li>• I have been fighting to get support from social</li> </ul>	<ul style="list-style-type: none"> <li>• I think I'm one of the lucky ones who now finally have the right support for her daughter social worker has been brilliant</li> <li>• We have been very well supported from all the social care team; I just have to say very thanks for your help, really appreciated.</li> <li>• Yes I receive weekly phone calls</li> <li>• When we needed support we were able to receive it</li> </ul>	<ul style="list-style-type: none"> <li>• We don't have a social worker</li> <li>• No involvement</li> <li>• No social worker</li> </ul>

services. I appealed 4 times and also put in a complaint, but the case was closed and my daughter receives absolutely no support from social services, so as a family we just have to struggle to cope as best we can. I am incredibly disappointed with the contact and lack of support I have had from children's ss disabled team.		
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**Fig. 22 Table of views on Social Care**

<b>Any other services you wish to mention?</b>	<b>Any other feedback</b>
Charities little miracles and parent carer forum family voice thank goodness for them also caring together are great in helping apply for grants to home educate children with being able to get computer for home	I think that the school is doing amazing, sending certificates home for his online sessions when he does well.
Family voice an little miracles	The 2 above charity's have been our life savers
Think charities such as Sense and Amber trust need more signposting as have been brilliant for us over lockdown	Thanks to all staff that have continued working over the last year.

**Fig. 23 Table of views on other services**

Where it was possible to identify ethnicity of the families was also more mixed and those who declared having CYP with complex physical needs were less likely to declare themselves as White British. From fig.8 and 19 above it is can be seen that the age range of male CYP was broader and female CYP were more likely to be aged in their mid-teens.

Fig. 20 and 21 show a more positive than negative experience of education and health whereas fig.22 shows experiences of social care were more negative. It is worth noting here though that parent carers were more likely to state they had no experience of social care.

There appears to be something from this data that shows good support leads to positive reporting and parent carers being more able to cope with better resilience as a result. It may also be worth exploring whether this is also related to the types of needs the CYP are reported as having and the settings attended.

A case study that further demonstrates how working together, supporting the family based on the views and wishes of the family and working in a more person centred way has a positive impact on Mental Health and Emotional Wellbeing can be seen here:

## IMPACT OF COVID/LOCKDOWN ON SEND FAMILY - ANONYMOUS CASE STUDY

### **Family Details**

Young person aged 13 – complex health needs: GDA, scoliosis, they are peg fed, have self-injurious behaviour – but has no specific diagnosis. Mum has had serious heart problem and a major operation 6 years ago which still impacts and they is often poorly herself.

### **Pre-COVID**

Prior to COVID – family received direct payments for young person and was supported in residential/ respite setting 1-2 nights per week. Originally, Young person's respite was only 1 night in 14. Once this increased to at 1 night per week the direct payments were cut.

February 2020 – young person was seriously self-harming and had to be admitted to hospital. Positive experience during their protracted stay in hospital – they had appropriate level of support and therapeutic input and there was a reduction in young person self-harming behaviour and emotional wellbeing improved. In hospital they had 2 carers.

Needs became more complex and challenging and this warranted 1:1 care. Local Authority suggested to the family that the young person could spend more time at the residential/ respite setting in a shared care arrangement. LA awarded funding for 1:1 care whilst the young person was at the setting – but parents did not want the young person to be away from home for such long periods of the week. Why could the 1:1 care not be funded and replicated within the family home?

### **During COVID**

In March 2020 mum became ill and could no longer cope with young person behaviour – a call was made to Children's Services Emergency Duty Team – 2 carers were allocated almost immediately –mum says they received an excellent service .

As a result of lock down the young person was unable to attend setting, so LA transferred care package to their own home – 2 carers as per hospital. This additional support has had a positive impact on their emotional and physical health – ongoing reduction in incidents of self-harming and the young person has also had a reduction in their prescribed medication – this is an extremely positive move forward.

Young person is far happier with the current care package – CAMHS Consultant at Child Development Unit recommended that Young person needs 2 people at all times and that medication was not the answer.

Young person has had lots of positive interactions and experiences with their new carers and has seen an ongoing improvement in health and wellbeing.

Young person returned to setting in September 2020 after first lockdown ended – mum has said family has been concerned as the LA suggested again that the full care package within the setting as the social worker feels that family still need respite, but mum wants Young

person to be at home as much as possible. Discussions have been ongoing and currently young person has support in school and via care in the community which is working well, with family very happy with the arrangement.

## **SEND DATA AND SCHOOLS ENGAGEMENT**

The SEND Data is broken down into themed workshops, focus groups, schools meetings, schools offer and online participation methods (Surveys/ Facebook Polls). All sessions have relied on virtual methods via Zoom or Teams with some being sign supported by BSL interpreters and made available online.

### **Virtual Sessions**

There have been a total of 6 participation sessions through virtual methods with a total of 26 overall attendees. The Schools based sessions had the highest level of engagement.

<b>ACTIVITY DESCRIPTION</b>	<b>SESSIONS</b>		<b>ATTENDEES</b>		<b>VARIANCE</b>	
	(19/20)	(20/21)	(19/20)	(20/21)	Sessions	Attendees
<b>Focus Groups</b>	5	2	35	5	-3	-30
<b>Workshops</b>	4	1	21	6	-3	-15
<b>Schools Meetings</b>	9	3	47	15	-6	-32
<b>Open Forum Sessions</b>		3		40		
<b>Totals</b>	<b>18</b>	<b>9</b>	<b>103</b>	<b>66</b>	<b>-9</b>	<b>-37</b>

**Fig. 24 Total number of sessions and attendees across types of work**

The low numbers compared to 2019-2020 relate in part due to C-19 and for some months being unable to conduct much work, followed by having to learn and then set up a new model of delivery.

### **Schools Engagement**

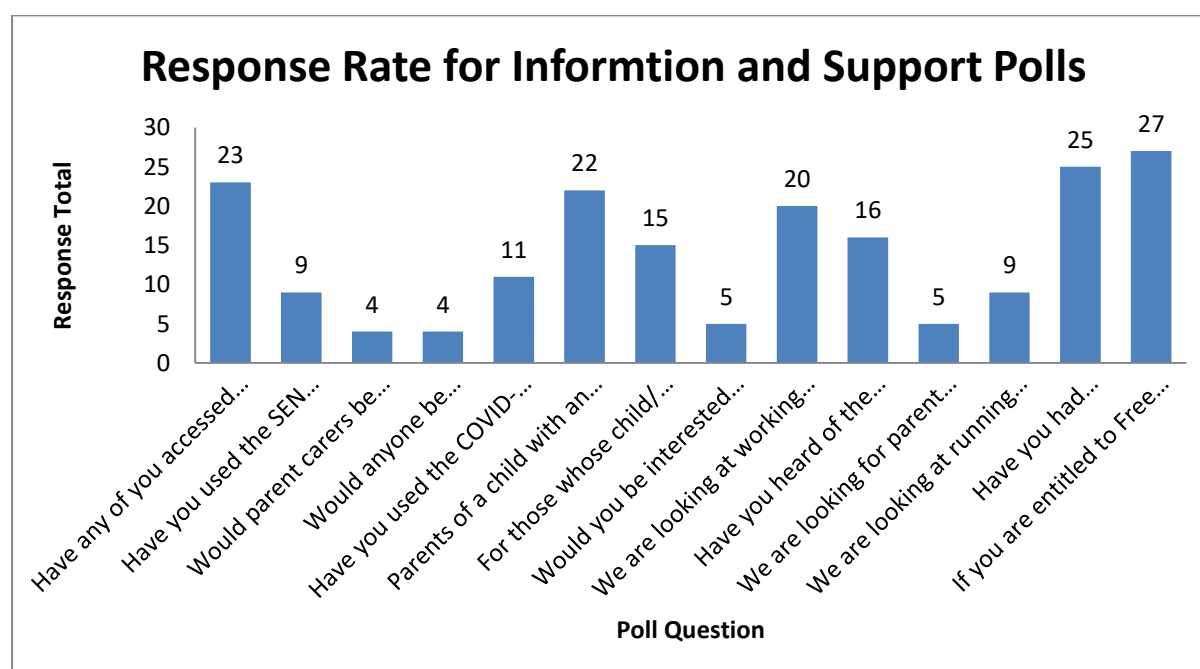
Schools engagement has been conducted mainly with Lime Orton Academy through three online sessions and then also via parent rep attendance at the SENCo Forum. 6 schools have also asked for email feedback on their SEN information reports.

### **Online Participation Methods**

#### **Facebook Polls**

As reported in previous annual reports Facebook Polls have been conducted for two purposes to ascertain what type of support/ information parent require and to gather data on specific topics for participation purposes.

Fig. 25 below shows the most popular polls relating to information and support were about access to direct support and communication.

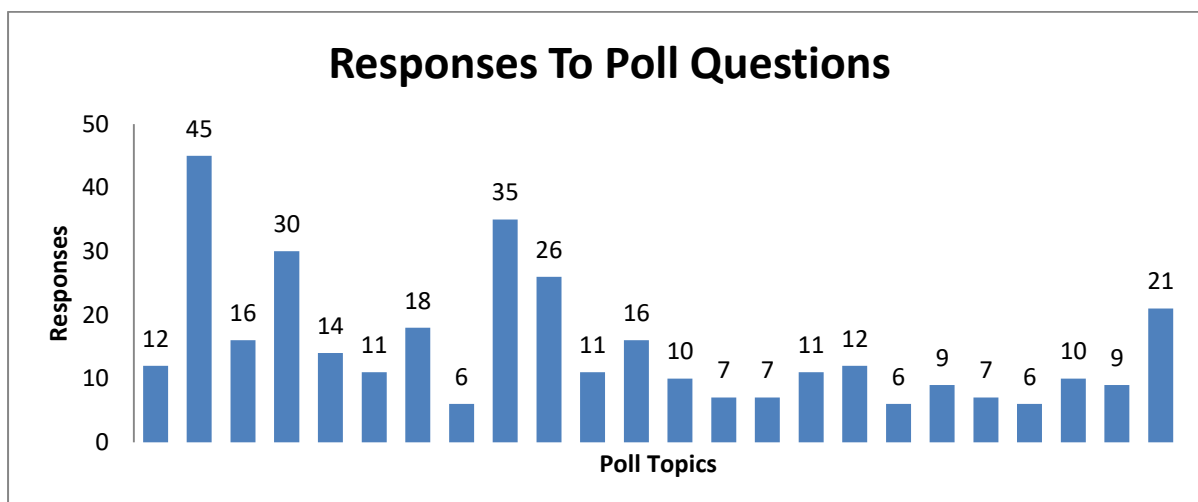


**Fig.25 Facebook Poll Response Data (Information and Support)**

#### Poll Topics:

- Have any of you accessed the Peterborough Local Offer Covid 19 Page?
- Have you used the SEN and Inclusion Services Helplines to speak to a member of the team? (Specialist teachers, educational psychologists etc.)
- Would parent carers be interested in a virtual focus group where we can discuss what support will be needed to transition back to a normal way of life post lock down?
- Would anyone be interested in a live virtual challenging behaviour workshop?
- Have you used the COVID-19 LO Page
- Parents of a child with an EHCP - have you had any communications from the Local Authority during lockdown? Please comment with what if any you have had.
- For those whose child/ young person has an EHCP. Have you received a letter about EHCP support and request to complete a survey from Peterborough City Council
- Would you be interested in a virtual session with Marion Deeley?
- 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?
- Have you heard of the SEND Strategy, coproduced by Peterborough City Council, Cambridgeshire County Council and both Parent Carer Forums
- We are looking for parent carers to share their stories with us to raise awareness of parent carers more generally. Your story will be added to our e-news and shared with local press outlets. Our latest one has raised awareness of Rhetts Syndrome. Would you be interested?
- We are looking at running another challenging behaviour workshop in mid-October. Would you prefer virtual or in person with social distancing measures
- Have you had contact/support from your child's school during lockdown?

- If you are entitled to Free School Meals for your child/children are you receiving



**Fig.26 Facebook Polls (Participation Questions)**

Are you aware of what options are available for special schools within Peterborough and what their individual requirements are?	12
Will you be sending your child back to school when it re-opens in June	45
Has your child's school been providing you work during lock down	16
Has your child been risk assessed to determine whether they are safer at home or at school?	30
Parents of children and young adults with an EHCP - Has your child now got a completed Section M in addendum to their Plan that you were consulted on?	14
We use Parent Representatives to attend strategic meetings and feedback the views of Peterborough parent carers - if we offered remuneration at £10ph for this role, would you be interested?	11
Do you want your child/ young person to go back to school in September? (FVP SEND group)	18
Do you want your child/ young person with SEND to return to school in September? ( FVP main page)	6
Poll created by in PwA If you have a child /young person with special needs or a disability do you want them to return to school in September	35
Do you want your child/ young person with SEND to return to school in September? (Posted on the PDDCS)	26
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)	11
If you are ready for your child/young person to go back to school in September would you like to have a choice of Full time or Part time ?( posted on PDDCS page)	16

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 have been looked at by reps involved relates to feedback gathered as part of the EHCp process. If your child/ young person have 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.	10
Transport: We have seen a number of posts in here and had communication about transport via other channels too. The main concerns appear to relate to communication and timeliness would you agree?	7
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:	7
Would you like virtual meetings for the ANNUAL REVIEW process to be offered after Covid?	11
Have you been invited to a meeting relating to your child / yp's EHCP?	12
Have you attended a virtual NEW ASSESSMENT meeting relating to your child / yp's EHCP?	6
Have you attended a virtual ANNUAL REVIEW meeting relating to your child / yp's EHCP?	9
Would you like virtual meetings for the NEW ASSESSMENT process to be offered after Covid?"	7
(New Ways of Working) Are you happy with the current process of documents being sent electronically during Covid?	6
(News ways of working) Would you like documents to be sent electronically or via post after Covid?"	10
If you have to take part in virtual sessions/ meetings would you prefer to join using?	9
If your child/ young person have an EHCp and as such falls under the vulnerable category as defined by central government, do you still want them to go school?	21

**Fig. 27 Table of Poll Questions**

From the Polls in fig.26 and 27 it can be seen the most popular related to education and lock down.

### Online Surveys

Survey Title	Survey Response Rate
Covid 19 #2	52
Communication and Support	12
Food support (1)	15
Food support (2)	11
Seldom heard community support	6
Covid 19 and Education	26
Wheelchairs	2
Transport	17
COVID-Return To School	103



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

**Fig. 22 Total number of responses per survey conducted**

A number of surveys have been completed and are designed to be anonymous. The surveys do have filter questions so they are completed by parent carers in Peterborough only. It is important for the surveys to be completed by this specific group as the results are intended to inform commissioning in Peterborough relating to SEND services.

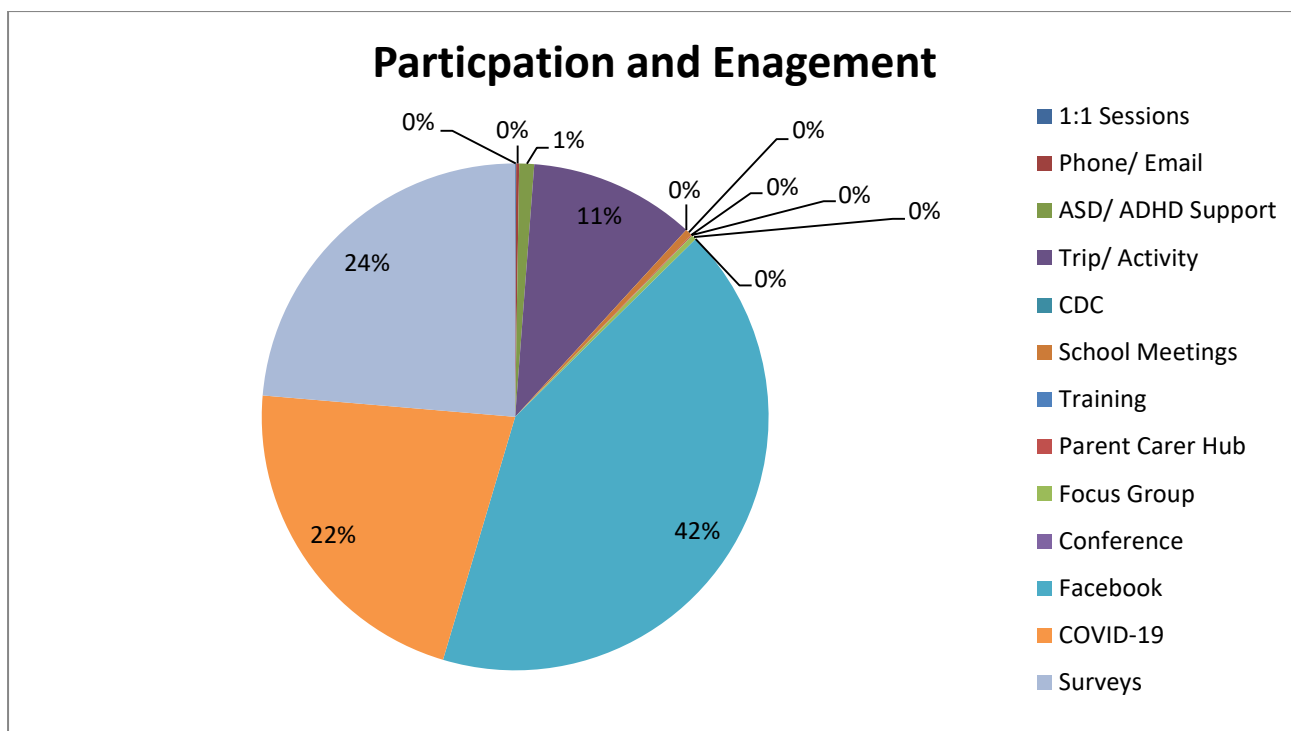
There have been 16 surveys completed in 2020 to 2021 with one directly informing the offer of support to families. There have been a total of 373 responses. The main end of year survey has been reported on in a separate report where the results have been compared to data gathered since 2018. The full comparative report is available via this link <https://www.familyvoice.org/Participation>

### Overall Survey Analysis

Although the surveys cover a range of topics some key themes occur across all of them; Information and communication, support, emotional wellbeing and C-19 impact (financial, access to support, school closures, resilience decrease). It can also be seen from the numbers responding to surveys and the actual responses that participation in such methods has increased and those participating although experiencing difficult situations are at times more positive in their responses.

### Engagement and Participation Methods

Where we are able to identify the participation and engagement methods for individual it can be shown that some methods are more popular than others.



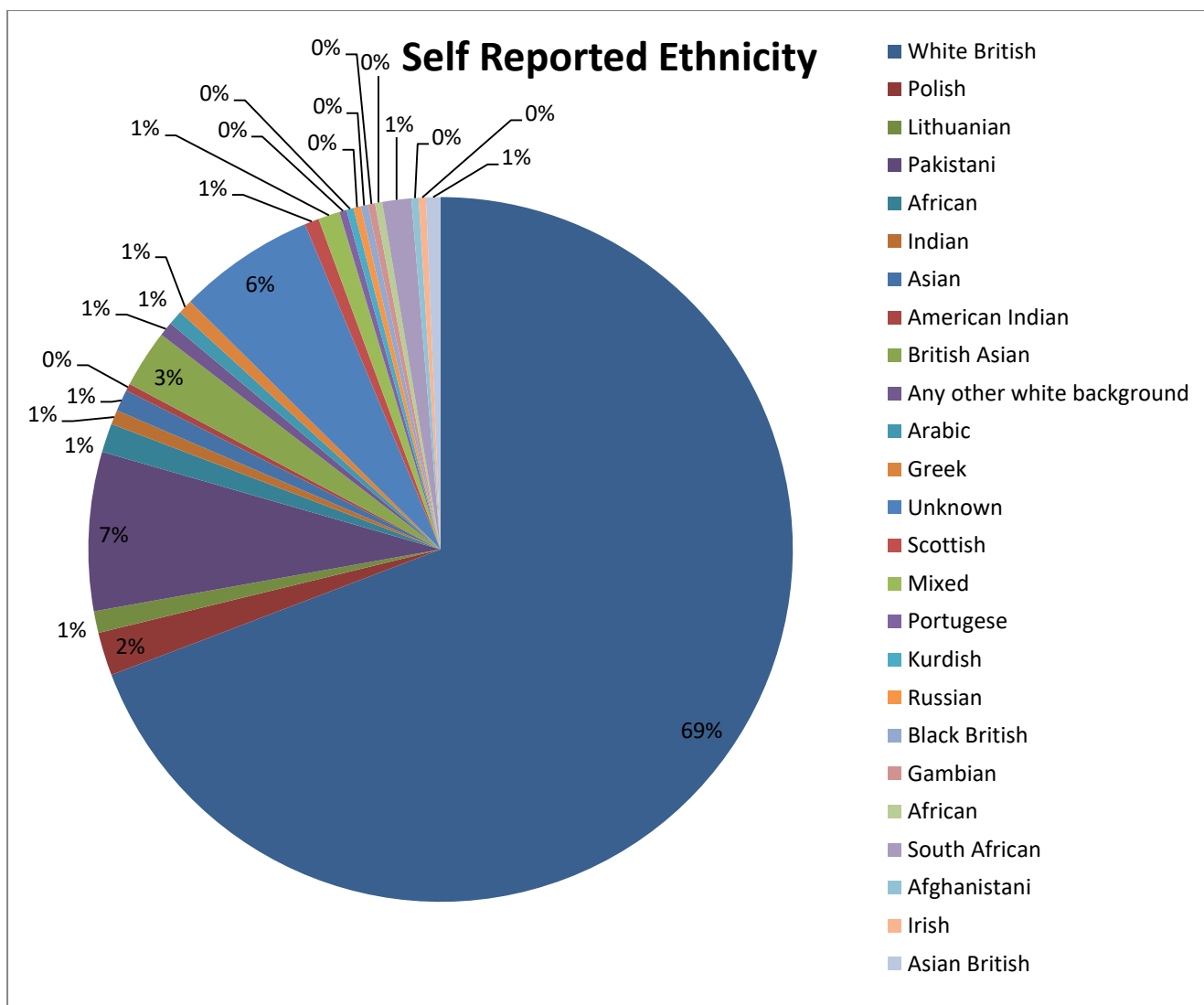
**Fig. 23 Preferred methods of participation as percentages**

The preference this year for online methods has been led not just by choice but also circumstance. With three periods of lock down, virtual and online engagement had to take place for the work to continue.

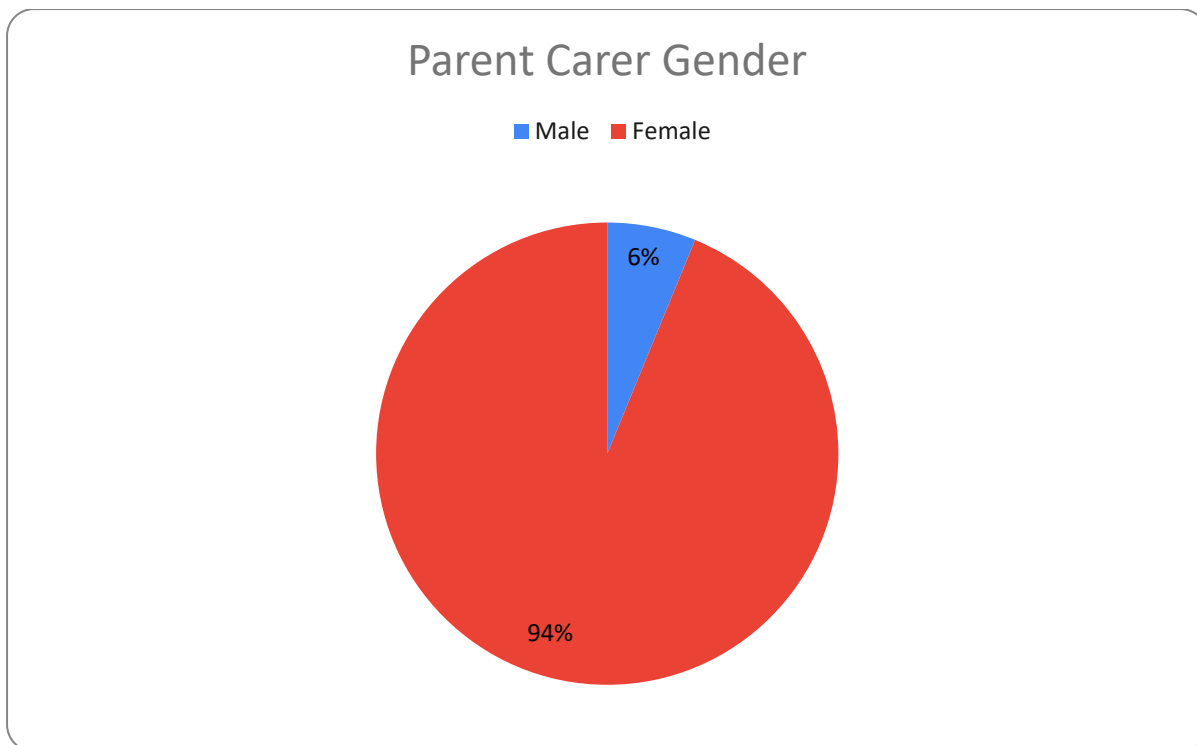
### **Demography of those engaging**

FVP also gather data on the ethnicity and gender of the parent carers who participate and the needs of their child (ren). The findings where know are as follows:

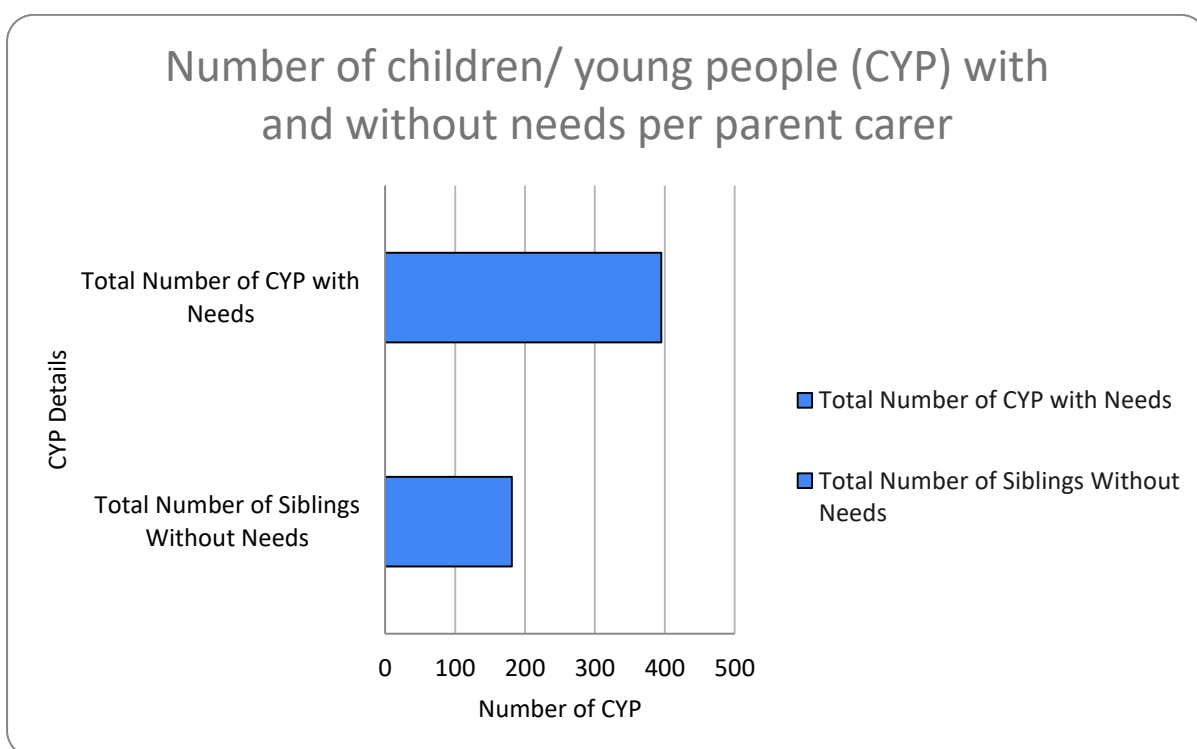
Fig.24 and 25 reflect self-reported ethnicity of the family and parent carer gender. The predominant ethnicity was White British and the predominant gender was Female.



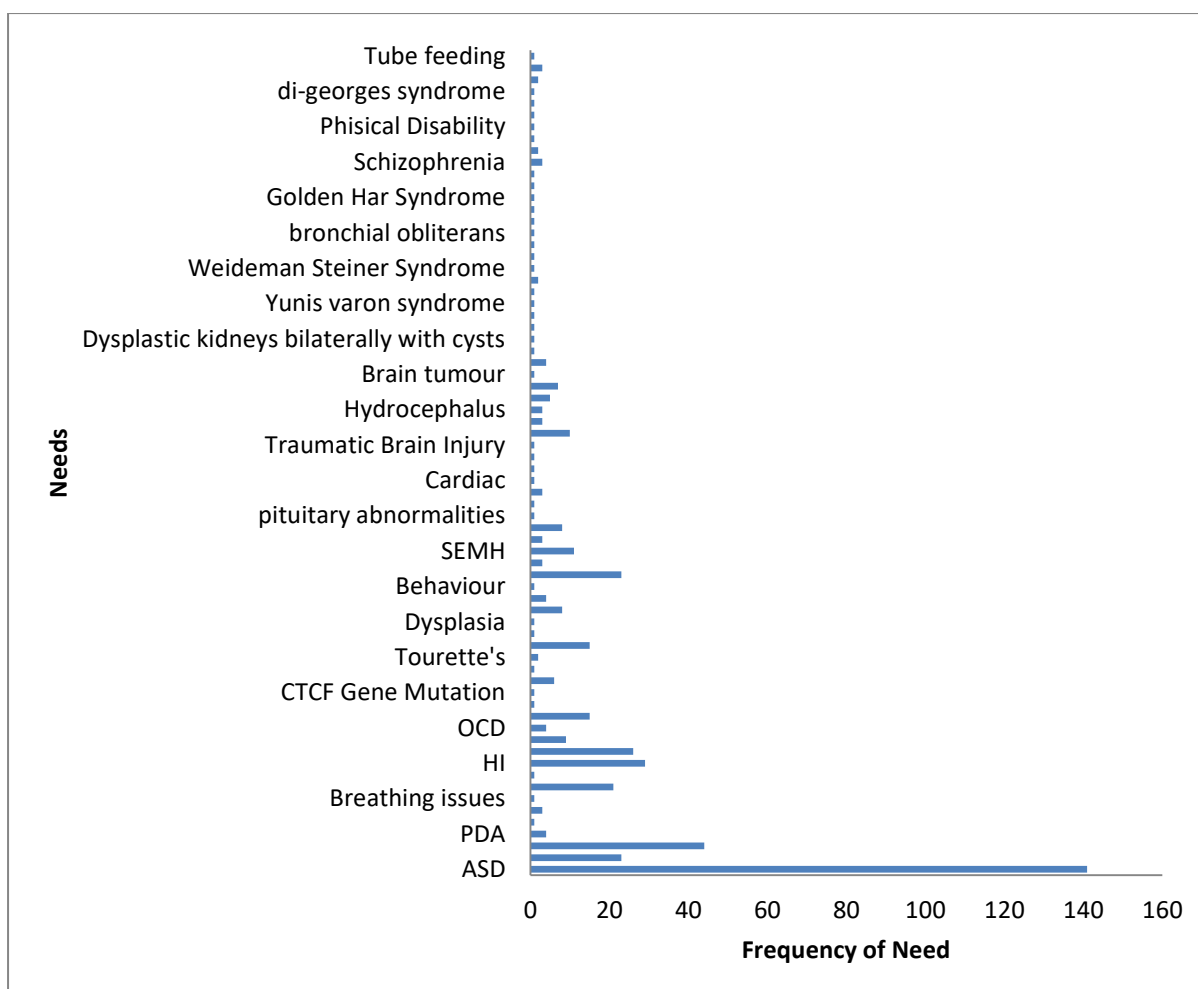
**Fig. 24 Self-reported familial ethnicity**



**Fig. 25 Self-reported parent carer gender**



**Fig. 26 Number of CYP with and without needs per parent carers**



**Fig. 27 Needs of children/ young people as reported by parent carers**

The predominant area of needs reported was ASD and a growing number of parents report their CYP as having more than one area of need. Compared to previous years more parents of CYP with complex health, physical disabilities and other needs are also engaging.

### **SELDOM HEARD ENGAGEMENT**

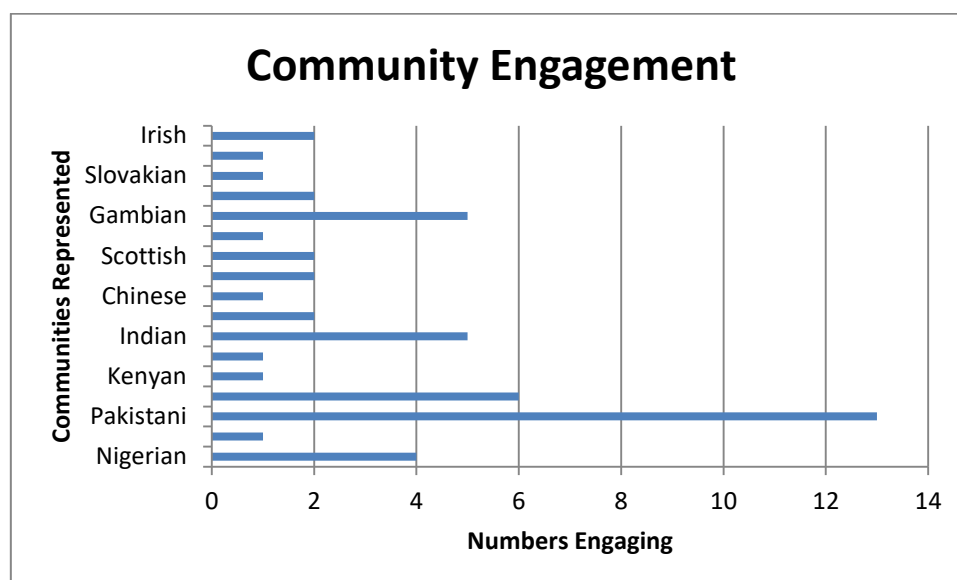
The work relating to seldom heard communities has a further reach than just parent participation. The work aims to identify, reach and engage with seldom heard parent carers and their wider community networks. The way the work is delivered has a few drivers from; requests for activity themed work by seldom heard parent carers through to a need to work virtual due to C-19.

Topic	Attendees
Community Leaders	5
Community Leaders	10
Brexit	12
C-19	24
C-19 Vaccinations/ Disability Groups	9
Mental Health	21

**Fig. 28 Seldom Heard Session Attendance**

Over time the sessions have become more popular and seen engagement from a growing number of communities. The past few sessions have also seen parent carers and community leaders attending the session together.

Where data is captured FVP have seen engagement from the following communities:



**Fig. 29 Community member engagement**

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](mailto: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 platform to share information and connect with community leaders and organisations

Much of the work relating to Seldom Heard Community engagement and participation is being led by two members of the communities themselves; FVP's Community Development Worker is also Chair of The Gambian Community of Peterborough and the Seldom Heard Parent Representative is also Chair of the Lithuanian Community Group. The following has been written by the Seldom Heard Parent Representative for inclusion in this report:

## FVP for Seldom Heard Communities

1. I am Judita Grubliene, Parent Carer Representative, FVP. I'm also a chair of Peterborough Lithuanian Community „Lighthouse” and a member of Peterborough Communities Group Forum, PCGF. I came to FVP first of all as a Parent Carer, asking for the help to my family – I was supported by FVP with a right signposting, useful advices and great care, help with food delivery during the first lockdown, when my family needed it. Then I started to work for FVP as a Parent Carer Representative from September last year.
2. I'm bridging different communities, making connections with communities leaders and key members of the communities. I am the connecting link between the communities and FVP, representing FVP to different communities and engaging communities with FVP.
3. One of my aims is to find out Parent Carers within the community's, and especially within the Seldom Heard community's. Using the various methods to share key messages on getting involved we share the information using social media sharing the stories of Parent Carers for press releases on Peterborough Matters, Peterborough Telegraph, BBC Cambs. We also using other media possibilities to share information about FVP to different communities.
4. One of the aims also is to translate information of FVP to all main languages of communities – partners. I've already done the translation into Lithuanian language. FVP also have another translation in to Arabic language which was made by my colleague, Community Development worker Ousman Gaye.
5. Me and Ousman, we are also involved into organizing very successful and fast growing with participants monthly Seldom Heard Community's Leaders Zoom sessions, inviting professionals speakers to cover the topics of the sessions.
6. We had Dr Grace Spencer from Anglia Ruskin University on one of our sessions and she presented her project for different background communities. We've got Cllr, Dr Shabina Quyyum, Asian background, as a speaker for our last Zoom session with a topic of Vaccination.
7. The topic of our last Zoom session on 23rd of March was Mental Wellbeing for Parent Carers during Lockdown. We had representatives from different services for Mental Wellbeing. The main speaker Kathryn Goose from CCG represented a new document – New Partnership for Delivering Children and Young People's Mental Health Services. We also had representors from such of organisations like Healthy You, Young Carers, Centre 33, Healthwatch, Pinpoint, PCVS, Macmillan, Little Miracle.
8. And also we had an extra session on 15th of March regarding the Census to help the people to know about it and learn how to use the new system. The speaker of that zoom session was Nicola Warnock, Census Engagement Manager Peterborough.
9. All our SHCF zoom sessions are recorded and available at FVP YouTube channel.
10. Understanding importance of working together, especially at this time of pandemic, we cooperating with various organizations and institutions, local authority, community's as well as with individuals – leaders, parent carers, professionals. FVP joined a partnership with Healthwatch Cambridgeshire and Peterborough, with Peterborough City Council Community Cohesion Team, with PARCA, with Near –



Neighbours, With Anglia Ruskin University, Healthy You, Young Carers, Centre 33, PCVS, Pinpoint, Little Miracle and others, also with different communities and other organizations – Peterborough Lithuanian Community ,Lighthouse‘, Lithuanian Supplementary School, Peterborough Chinese Community, Peterborough Asians Communities, Peterborough Polish Community, Peterborough Africans Communities and others. They also takes part in our Zoom sessions and they supporting us with professionals and professional advices, represents their new projects, makes updates about the services they‘re providing.

11. FVP organizing discussions on the most important topics for Parent Carers.
12. Our Zoom sessions are the great platform for communication, sharing information, making contacts, raising and discussing the issues, making useful links for the cooperation. Also that’s the platform to encourage Parent Carers and Seldom Heard groups to have a say in local consultations.
13. The best feedback to us is when after the meeting session’s people contacting FVP, asking for a help, for an advices, or for cooperation. And also when they introducing other people from different organizations and communities to FVP as a reliable and valuable partner. FVP has significantly raised and expanded its network during the year.
14. FVP is here for the families and Parent Carers to support them.  
So one of our aims also is to encourage families, Parent Carers to ask for the help, if and when they need it, to contact the FVP and to cooperate with the FVP.  
So that would be the main aspects of my work at FVP as a Parent Carer Representative.

Judita also very kindly had her story shared in Peterborough Today as part of a campaign to raise awareness of SEND during C-19 which shows the importance of feeling supported and working together:

### **You‘re not alone, you‘re not left, you‘re not forgotten**

At the same time as a lock down started, one of my family members got serious health issues and he was getting worse and worse each day. One week after the disease started he could no longer walk and couldn‘t do anything by himself. It was very clear that he can‘t continue his work anymore. Me also because I had to take permanent care of him. I was afraid and confused of what will happen to us now because our life’s changed totally.

Where and how to get help, what to do, how to live? – It was the only one thought in my mind at that time. And I remembered that I have a contact of member of FVP, Ousman Gaye, Community Development Worker at FVP, whom I was cooperating in some projects before. I emailed to him asking if he could help me in my current situation or maybe he knows who could do any help to us.

I was so grateful and happy when received useful information from FVP regarding my situation. They did right signposting to us, helping sort out with documents and all other stuff needed. They also did food supply and delivery during lockdown to us and some other

families in need, recommended by me. FVP staff were keeping contacting me and asking if we need something else they could do for us.

I am so grateful to FVP for their help and support, for everything they've did for my family. And especially I am grateful to them for that exceptional feeling that you are not alone, not left, not forgotten with what you're have to go through. It is feeling of Real Family. And I am very proud now to be part of FVP and make help to other families.

Sharing my personal story I'd like to encourage people to ask help when you really need it - FVP is here to help you.

Judita Grubliene

Parent Representative at FVP

A few activities have also been conducted with parent carers from the Aiming High Group which in part have facilitated participation and supported their wellbeing. One activity saw some of the parents complete a "Your Say" form and as a thank-you were provided with tickets to take themselves and their children bowling on their own. Usually a group trip would have been organised but C-19 prohibited this.

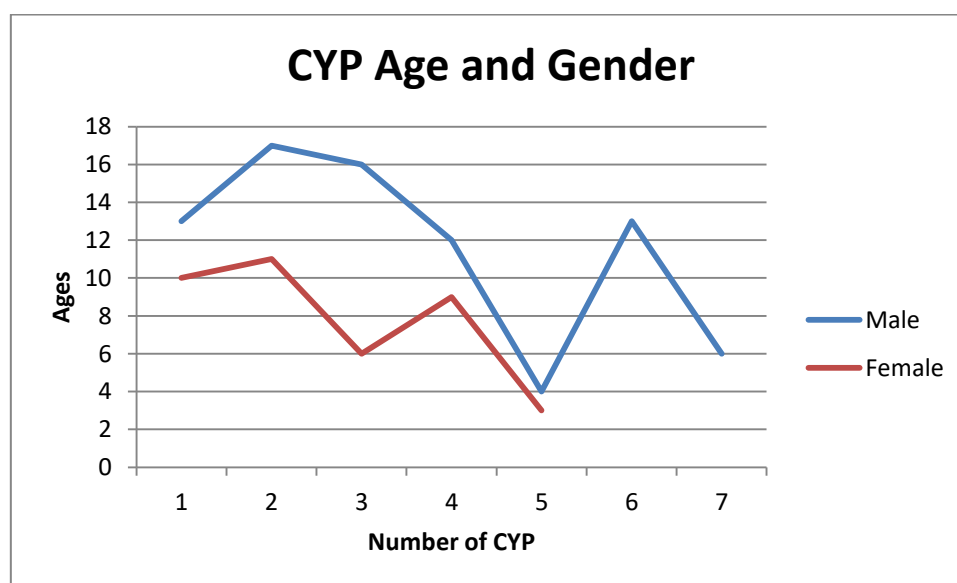


Fig.30 Ages and Gender of CYP

Areas of need were listed by the parent carers as: GDD, SLD/ ASD, GDD/ Hearing Loss, ADHD, in remission, Complex needs, ASD, ASD/ADHD/ Sensory Loss, Cerebral Palsy and Communication Needs.

Education (negative/ positive/ neutral)		
Negative (3)	Positive (5)	Neutral (1)
<ul style="list-style-type: none"> <li>Only school transport could do with improving by making drivers and escorts more aware of the</li> </ul>	<ul style="list-style-type: none"> <li>She has settled really well in school and likes it there.</li> <li>yes , online services are helpful</li> <li>My daughter's care and</li> </ul>	<ul style="list-style-type: none"> <li>Updates on EHC Plan are very slow</li> </ul>

<p>needs of the children they are transporting</p> <ul style="list-style-type: none"> <li>• Nothing in place for my child to return to school completely been left and forgotten</li> <li>• 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.</li> </ul>	<p>education were well managed in primary school and she was able to progress at her own pace.</p> <ul style="list-style-type: none"> <li>• Good</li> <li>• Excellent communication with school SENCO &amp; Sensory support services</li> </ul>	
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**Fig. 31 Education Feedback from AHG**

Health(negative/ positive/ neutral)		
Negative (0)	Positive (3)	Neutral (2)
	<ul style="list-style-type: none"> <li>• I am happy with the service</li> <li>• she has been well so no problem</li> <li>• Good experiences</li> </ul>	<ul style="list-style-type: none"> <li>• The dental service for children with special needs could be improved further</li> <li>• Takes so long to get back genetic blood tests results</li> </ul>

**Fig. 32 Health Feedback from AHG**

Health(negative/ positive/ neutral)		
Negative (2)	Positive (0)	Neutral (2)
<ul style="list-style-type: none"> <li>• 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</li> <li>• Service is absolutely</li> </ul>		<ul style="list-style-type: none"> <li>• Not at present but I suppose it's benefits a lot of people</li> <li>• Just recently got a social worker abit late</li> </ul>

<p>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.</p>		
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**Fig. 33 Social Care Feedback from AHG**

<b>Any other services you wish to mention?</b>	<b>Any other feedback</b>
<ul style="list-style-type: none"> <li>• Autism outreach and speech and language were absolutely amazing with my daughter and her school and helped her enormously! Cannot thank the ladies enough!</li> <li>• Deaf CAMHS have been excellent</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• A lot of people need help with people to support them but there isn't much support services available</li> <li>• No respite or anything in place for help. It's disgusting and been a total fail</li> <li>• Every child has right to study at mainstream but this is the second school who want to kick out my child from mainstream. They should remember that he is not a regular child. It's discrimination!!!</li> <li>• There is help available for signposting but it's the support part which is lacking.</li> </ul>

**Fig. 34 General Feedback AHG**

## **COPRODUCTION AND CHANGE**

The concept of Topics of Importance (ToI) was introduced in the last reporting period, in part as a means to demonstrate more clearly the participatory cycle of work between FVP representing what the parents are saying and the LA responding with any changes they have implemented as a result. This facilitates a better approach to the idea of 'You Said, We Did'.

### **Change and Co-production**

As a result of raising concerns there is:

1. A new approach to ensuring the outcomes of EHCp's are delivered during C-19, especially during lock down.
2. Regular joint communications to parent carers regards education and other matters during C-19.
3. A new Transport FAQ available on the LO

4. Information is added to the Local Offer with regard to appointeeship specifically.

#### Ongoing Involvement

1. SEND Strategy for Cambridgeshire and Peterborough (Including Action Plan)
2. Continuous Local Offer development
3. SEND WSoA
4. COVID-19 Response
5. SEND Communication

#### Topics of Importance

1. Transport
2. PfA
3. Lockdown and Access to Education
4. Communication and Education
5. COVID-19

### **ANALYSIS**

**From an analysis of the work completed throughout 2020 to 2021 a number of themes have become apparent:**

1. C-19 has had a major impact on all aspects of the lives of SEND families and been particularly difficult for families of CYP:
  - a. Those who have CYP with complex needs have seen some services in particular but not exclusively respite being put on hold and/ or stopped especially during the three periods of lock down.
  - b. School closure led to extreme anxiety amongst parents who have CYP with ASD, as this led to increases in behaviours that challenge.
  - c. Families have become increasingly reliant on food support with some experience shame over needing such support.
  - d. A large number of parents reporting increased anxiety, increased feelings of isolation and difficulty in coping with caring for their CYP. This all points towards decreased resilience.
2. There do seem to be more positive views on education and health in particular especially in relation to assessment and identification of needs. This may be linked to a different cohort of parent carers engaging who are younger and newer to the SEND system.
3. Where support is person centred and tailored to the needs of the family then mental health and emotional wellbeing is improved.
4. Virtual working has had a positive impact on the seldom heard work with:
  - a. Increased and more diverse engagement.
  - b. Improved accessibility.
  - c. New parent carers engaging and taking part in discussions with community leaders.
  - d. New connections between organisations, increasing the breadth of support available to parent carers.
5. There has been a clear improvement in the level of coproduction and participation operationally and strategically in relation to SEND services.

## **SECTION 2 – FAMILY VOICE PETERBOROUGH AS A CHARITY**

*To relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough is such ways as the Trustees shall think fit, in particular by the provision of advice, information, support and advocacy*

## **Chairs Forward**

We are now in our fourth year as a CIO and we have continued to work during the Covid-19 pandemic, although this has been quite different in relation to pre Covid-19 years. FVP have continued to work as a forum, although this has almost all been online. We have been engaging with parent carers using zoom, some of our sessions were public and have been made available on our YouTube channel. As part of this work we have started engaging with more parents from seldom heard communities and have had themed sessions. We continued with the food support where the Goldhay centre was used as a Hub. We received support from Peterborough City Council (PCC), Fareshare donations and Foodbank. We also received support from the “British Red Cross” from their temporary Alconbury base during the initial Covid-19 lockdown. We really appreciated the support in helping us support some of our beneficiaries. I am glad that in times of real need we all worked together and as a charity we were able to productive.

Due to the restrictions we were closed as a community centre and our caravans remained closed, this was a financially challenging time although with the help of some Covid-19 related grants we have been able to protect the caravans and community hall, both of which are important community assets. We continue to operate in relation to guidelines and the caravans are now open and PCC have been using the community hall. Many of the groups that previously used the hall are still unable to do so due to the restrictions. We currently have twelve employees, this is a mixture of full time, part time and casual. In addition to this we currently have three regular volunteers and receive support from the Rotary Club of Peterborough Orton’s who have helped with the community centre and garden.

## **Trustees**

John Ravenscroft (Chair Person)

Samantha Ronnay (Interim Treasurer – Joined September 2020)

Amanda Rennie (Secretary – Joined February 2021)

Graham Casey

Natasha Leahy (Resigned January 2021)

## **Declarations of Interest**

- An employee of FVP is married to John Ravenscroft.
- Graham Casey is a local ward councillor where the charity premises is based
- Samantha Ronnay works for the BGL group who have supported FVP through their CSR program

## **Governance and Structure**

Operating Model:	Constitution
Legal Structure:	Charitable Incorporated Organisation
Trusteeship:	<p>(1) Apart from the first charity trustees, every trustee must be appointed [for a term of [three] years] by a resolution passed at a properly convened meeting of the charity trustees.</p> <p>(2) In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.</p> <p>FVP has adopted a safer recruitment policy with associated procedures for the purposes of ensuring any appointed trustees:</p> <ul style="list-style-type: none"><li>• Understand their role within FVP</li><li>• Understand what FVP's purpose is, who its beneficiaries are where it operates.</li><li>• Are eligible to act as a trustee and meet charity commission requirements and safeguarding requirements in relation to children and vulnerable adults</li><li>• Bring skills and experience to the charity that mean it will continue meeting its purpose</li></ul>

**Fig. 1 Governance and Structure for FVP**

The following statement still applies: FVP is run operationally by a small team of paid employees, supported by volunteers. Due to the size of the charity the trustees still have some operational duties which are being gradually devolved to the staff team via delegation which takes account of governance guidance principle 1.5.

FVP works with a number of other third sector organisations including Peterborough and District Deaf Children's Society (PDDCS), Pinpoint and The Aiming High Group as well as acting as a strategic partner of Peterborough City Council in relation to offering collective information, advocacy, support and advice to parent carers which is in line with the purpose



of the charity as defined in its objects. FVP has also started working with a wider partnership of organisations both statutory and third sector as part of the expanding seldom heard communities work.

Potential risk within the charity relates to the majority of the Board of Trustees being made a majority of parent carers and of a small number. Also one staff member is a connected person to a trustee. The constitution allows for beneficiaries and connected persons to be trustees and employees which, is handled via the declarations of interest/ loyalty policy and procedures. Regular risk assessment is conducted to ensure all matters are recognised and managed; furthermore recent work has taken place around a functions analysis to help inform the strategic plans of the charity whilst being mindful of all potential risks. Any risks are detailed appropriately on a risk log and at all times the risk policy is followed.

### Assets and Ownership

All assets are under the ownership of the CIO with two trustees signing leases/ contracts as required as per the constitution. The assets of the charity are the Goldhay Community Centre and two caravans which are sited at Haven Caister and Butlin's Skegness respectively. The community centre was transferred to the CIO in February 2020.

### Staff 2020 to 2021

A Chief Operating Officer has been employed to oversee all operational elements of the charity, supported by a team of Parent Representatives, a Senior Administrator, Office Assistant and Charity Development Worker, Cleaner. No staff member is remunerated over £40,000 and the staff costs are covered through specific grant funding and income generated from the hire of the premises. The staffing for the charity covers the forum functions of FVP, all administration and management of the assets. There are currently 11 staff members employed by FVP.

The trustees are aware of risks associated with being employers, especially as the charity is a relatively small organisation. The trustees will continue to mitigate risk through suitable financial planning, employee support and trustee board development. All work will continue to be underpinned by the risk management policy which is reviewed annually. The board continue to seek with respect to employment where required.

FVP have also had to rely on temporary staff members due to ongoing funding constraints in the past year and have introduced the use after careful consideration of zero hour contracts. More detail of the financial constraints is discussed in the financial reporting section.

### Volunteers/ 2020 to 2021

FVP have secured the support of 3 regular volunteers, and a bank of over 30 ad hoc volunteers courtesy of The BGL group have continued to support with skills based volunteering and the Rotary club who have supported with the upkeep of the premises where C-19 restrictions have allowed.

Although FVP still have two key parent representatives who volunteer their time, the majority have moved towards employment with FVP as zero hour workers in line with the longer term plans of the charity.

The total number of volunteer hours across the charity equates to over **131**.

## **Objectives and Activities**

The objects of the CIO are to relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough in such ways as the Trustees shall think fit, in particular by the provision of advice, information, support and advocacy

The Board of Trustees have paid due regard to statutory guidance PB1, PB2 and PB3 issued by The Charity Commission when planning and undertaking activities in relation to the objects that define the purpose of the charity.

The trustees also look to consider social impact when undertaking work as means to demonstrate value for money and positive benefit to individuals and their families.

## **Social Impact – Regular Reviewed and Identified in Strategic Plans**

Definition: The effect of an activity on the social fabric of the community and well-being of the individuals and families (<http://www.businessdictionary.com/definition/social-impact.html>)

Social impact is also about changes which improve people's lives and have positive consequences for the wider community.

### **Ongoing outcomes/ impact:**

Outcome	Indicator	Activity
<b>Supporting parents/carers:</b> Increased Parent Representation and participation within our target group  Increased confidence in ability to return to work after long periods as a carer	Number of parent carers engaging in training programmes Higher number of parent carers working  Number of parent carers either working with us as volunteers, or looking for volunteering opportunities  Increased number of parent carers taking up paid roles as parent representatives.	<b>Training:</b>  Expert Parenting Programme – facilitates an understanding how to navigated the NHS System (empowering parents to engage)  Participation Programme (supports parents/carers to develop skills to engage with professionals strategically)  Challenging behaviour workshop <b>Volunteering:</b>

		<p>Parent carers acting as parent representatives</p> <p>Parent carers conducting volunteer duties.</p> <p><b>Paid Employment:</b></p> <p>Use of casual worker (employment contracts) for parent rep role</p>
<p><b>Improved health and wellbeing:</b></p> <p>Carers and families demonstrate increased personal and interpersonal resilience</p> <p>Improved social capital and interaction</p>	<p>Carers accessing activities remotely and in time face to face</p> <p>Carers utilising those activities in a progressive way. e.g. moving from training to employment or supporting peers</p> <p>Families more able to manage crises, or plan to avoid crises</p> <p>Carers report less social isolation</p> <p>Carers offering to support peers</p> <p>Carers report decreased levels of anxiety relating to financial hardship</p>	<p>Virtual open forum sessions on a range of topics driven by feedback from carers</p> <p>Virtual Parent carer hub (monthly drop in session)</p> <p>Caravan breaks (families accessing holidays together) under new Covid-19 ways of working</p> <p>Use of tickets/ passes/ vouchers to a range of local places for families to attend safely under Covid-19 restrictions</p> <p>Food delivery and support programme through fare share/ corporate partnership</p> <p>Use of wellbeing/activity packs</p>
<p><b>Targeted Community Engagement and Empowerment:</b></p> <p>Contributes to improved emotional health and wellbeing outcomes.</p> <p>Parents/carers are confident to manage meetings and challenges related to services that their child or charge require</p>	<p>Parent/carers accessing less advocacy services</p> <p>Parents/carers offering experiences and solutions to peers</p> <p>Parents/ carer accessing advocacy training</p>	<p>Virtual and sign-supported Community sessions (awareness of diversity and needs, improving the local environment etc.)</p> <p>Themed virtual training and workshop sessions</p>

<p>Parents and carers feel able to contribute to the development of community activities and peer support</p> <p>Local Residents and Community Groups are supported to build more cohesive communities and become less isolated</p> <p>Volunteering Opportunities are afforded to the community</p>	<p>Increased engagement from more diverse user group</p> <p>New volunteering opportunities leading to increased numbers volunteering and gaining new skills</p>	<p>Volunteering opportunities across FVP, which enable building of work based skills</p> <p>Videos of sessions uploaded to YouTube with sub-titles and signed support available to the wider community</p>
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**Fig.2 Outcomes Grid**

For FVP the social impact of the charity relates to activities that result in:

- Improved access to services for children/ young people with disabilities and additional needs.
- Increased parent participation which can include involvement, engagement, information sharing.
- Increased participation from a more diverse group of parent carers.
- Increased empowerment of parent carers leading to more involvement in the services accessed by their children and increased confidence.
- Increase community cohesion and working together
- Improved relationships between parents and settings

#### Measuring Social Impact – 2020 to 2021

To demonstrate social impact of the charity a range of qualitative and quantitative data is gathered. This is used to measure the outcomes and impact of the work of the charity; Some of the methods include activity/ event feedback, survey results, quotes, numbers in attendance, demographic information, changes to services for children/ young people with disabilities as shown in responses to the Topics of Importance introduced in 2019. There has also been a change to the delivery model used this financial year as a result of C-19.

1. FVP has seen four new parent carers join the team as a trained parent reps taking on strategic meeting and general forum administration duties.
2. Improved communication and information from between the LA and parent carers has occurred as a result of the introduction of the Topics of Importance; this is demonstrated by the regular coproduced letters sent to SEND families, the introduction of an addendum to EHCP's called section M used during periods of lock down, clearer and better involvement in risk assessments related to school attendance, the addition of a Transport FAQ to the Local Offer as examples.
3. Through a range of virtual workshops, online sessions, the parent carer hub and engagement with schools covering 19 sessions 172 people were afforded the

opportunity to participate. These provided sign-posting, support, the opportunity build new relationships and connections and increase social inclusion.

4. Parent carers fed back that the deliveries of wellbeing and activity packs were a welcome treat especially during the lock down period. These worked well as an alternative to face to face activities. Through the activities 1070 parents carers and their children and young people benefitted in some way.
5. Only 40 caravan bookings were possible in the past year with the parks remaining shut most of the time due to the three lock down periods.
6. The community centre remained closed to the public throughout the whole year.
7. Practical support was afforded to families through the use of food deliveries which resulted in 27 households with a total of 39 adults 66 CYP without SEND and 32 CYP with SEND benefiting.

Due to C-19 there was an overall decrease in the number and types of sessions delivered and the total number of beneficiaries:

Type of Session	2019 to 2020		2020 to 2021		Variance
	Sessions	Beneficiaries	Sessions	Beneficiaries	Beneficiaries
EPP	5	41	1	6	-35
CB	5	41	3	15	-26
Parent Carer Hub	6	20	3	4	-16
CETR Work	39	39	56	56	17
Themed Workshops	4	21	1	6	-15
Focus Groups	5	35	3	5	-30
Breakfast/ Lunch Meetings (School)	1		2	15	15
Conference/ Online Sessions	1	93	9	121	28
Coffee Mornings	18	47	0	0	-47
Facebook Polls	16	195	38	550	355
Surveys	9	253	14	373	120
Family Based Trips/ Activities	18	1018	19	1070	52
Strategic Meetings	117	5	216	7	2
Hall Hire	416.5	1189	0	0	-1189
Caravan Hire	92	349	40	89	-260

**Fig. 3 Session and Beneficiary Comparison 2019 to 2021**

Despite a marked change in delivery style and the closure of the centre and partial closure of the caravans work was still conducted that demonstrates that FVP met its purposes as a charity.

#### Information

1. Training sessions in understanding behaviours that challenge related to social communication needs, attentional difficulties and learning difficulties providing parent carers/ family members with basic skills to self-manage and gain resilience has continued but scaled back.

2. Training in the health system (EPP), parent participation and Children and Families Act 2014 (Section 19 Principles) to enable parent carers to navigate the new system and help professionals understand what support their children require. This work has been placed on hold and different sessions have been delivered instead.
3. Online sessions based on specific SEND topics have been delivered, supported by BSL interpreters and made available on line to increase their reach. The use of interpreters increased accessibility. The topics provided information and support in navigating the SEND system.
4. Production and provision of promotional literature such as hard copy and e-copy newsletters and leaflets detailing information relating to children with disabilities and complex needs and services they may access. The newsletters also provide information on changes to services and opportunities to get involved.
5. The development of information packs to be made available to settings when C-19 restrictions allow enabling settings to sign-post to FVP and help increase awareness amongst parent carers of the support available. Some literature has also been produced in Arabic and Lithuanian as the start of a piece of work designed to enable participation amongst seldom heard parent carers.
6. Use of social media to enable a wider and more diverse group of beneficiaries to receive information and participate in service change.
7. The use of YouTube to increase the reach of information being provided.

#### Advocacy (Collective)

1. Online participation sessions, Facebook discussions and Polls and the running of on-line surveys to facilitate parent carers raising concerns/ issues and sharing views with relevant organisations such as Local Authority Commissioning (Social Care and Education) via Topics of Importance.
2. Parent representation enabling parent carers to share concerns and views about disability services with education and social care commissioners.

#### Support

1. In place of face to face coach trips and activities FVP have provided tickets/ passes and vouchers to local places of interest and family fun from bowling to safari soft play. FVP have also introduced the use of home delivered family activity craft packs to promote family participation, learning and fun during lock down.
2. Delivery of wellbeing/ pamper packs for parent carers containing items to promote relaxation and mental wellbeing.
3. Provision of two caravans for families who have children with disabilities and complex needs to use for a small fee. The caravans enable families to have holidays at seaside locations at an affordable price. The holidays help families to have the same opportunities afforded to families who are not impacted by disability. The costs of holidays can be prohibitive and having the opportunity to access caravans with some adaption and ramped access provides families with opportunities not normally open to them.
4. Food support was introduced in April to May 2020 during the first period of lock down to alleviate the financial stresses and anxiety of parent carers. Families reported having to choose between feeding their children or cover the increased costs of household budgets through factors such as utilities. Some families also struggled

greatly to source the food types their children would eat especially those who have children with ASD.

#### Advice

1. Parent Carer Hub providing direct access to professionals from Education, Carers Support and SEND Partnership.

#### Community Premises

1. The community centre has remained shut to the public in line with government guidelines. This has meant all groups who would have access to the centre have had to be placed on hold.
2. Community engagement has taken place using virtual meetings based on topics such as mental health, C-19 and disability. These have proved successful and have brought diverse communities together in a C-19 safe way.

### **Achievements and Performance**

#### Family Activities & Parent Carer/ Community Support

##### **Family Activity Opportunities**

- Use of Vouchers/ Tickets/ Passes
  - Instead of face to face activities with participation opportunities, parent carers were provided the opportunity participate and then apply for vouchers/ tickets/ passes for accessing things such as Bowling/ Sacrewell Farm Shopping Trips.
  - Some of these were also accessed by parent carers from the Aiming High Group and Lime Orton Academy which led to an increase in diversity and engagement from more families with CYP with very complex health needs.
  - 228 people (parent carers and their family members) benefitted from
- Activity Packs sourced from Mucky Pups
  - These packs were given to over 240 children for Feb Half Term and 70 children for Easter.
- Themed Treats
  - This year FVP focussed on Halloween and Christmas with two themed delivery activities. The work to put everything together and then deliver the items was conducted on a voluntary basis.
  - 70 children with arrange of needs and from very diverse backgrounds received loot bags.
  - 93 adults and 140 children from households experiencing a range of issues from financial difficulty through to stress related to caring for SEND children and or adults with disabilities received a hand delivered hamper. This was part of the Christmas in Box campaign designed to ensure 50 local families would have a good Christmas with enough food to support their families over the holiday period.
- Parent Carer/ Community Support
  - Wellbeing and Pamper packs were hand packed and hand delivered to parent carers for Carers Rights Day and Easter. 139 parent carers from across

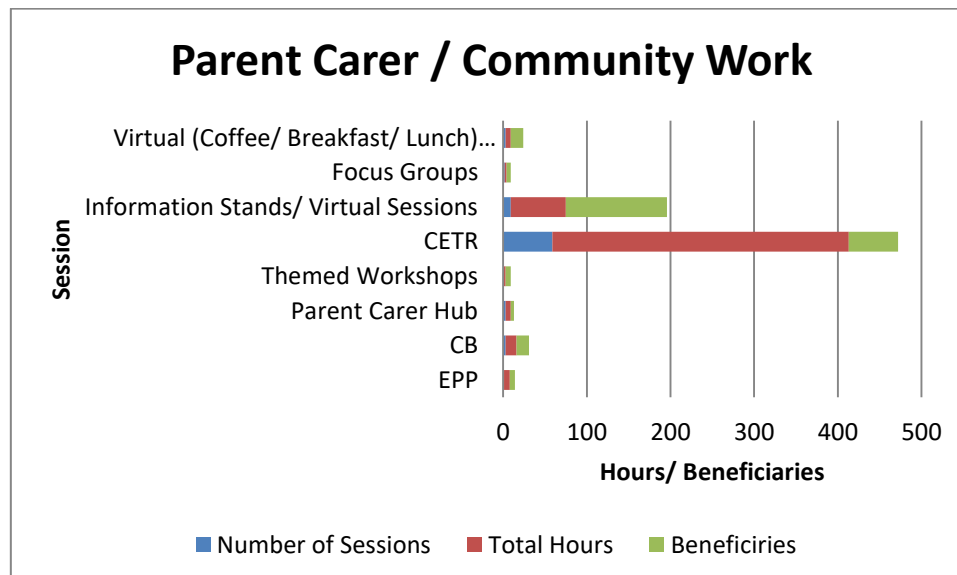
Peterborough benefitted. One parent said the delivery “made their day, as no-one ever thought about the parents”

- Food Support was afforded to 27 households with a total of 39 adults 66 CYP without SEND and 32 CYP with SEND.
- FVP have also been providing phone line/ email signposting support for a range of subjects including; how the move from DLA to PIP works through to how to make a complaint about SEND provision or what would be the best primary school to apply to. FVP sign-posted 38 parent carers with growing number who were new to the SEND system

### Participation and Engagement

The attendance at the following has varied according to the topics and need; numbers have been anywhere from 2 and 30

1. 1 Expert Parent Programme
2. 3 Challenging Behaviour Sessions
3. 3 Parent Carer Hub
4. 1 Themed Workshops
5. 9 Virtual Topics Based Sessions
6. 2 Focus Groups
7. 3 School Based Meetings
8. 59 CETR Sessions



**Fig. 4 Overall Hours, Sessions and Beneficiaries across Forum work of FVP**

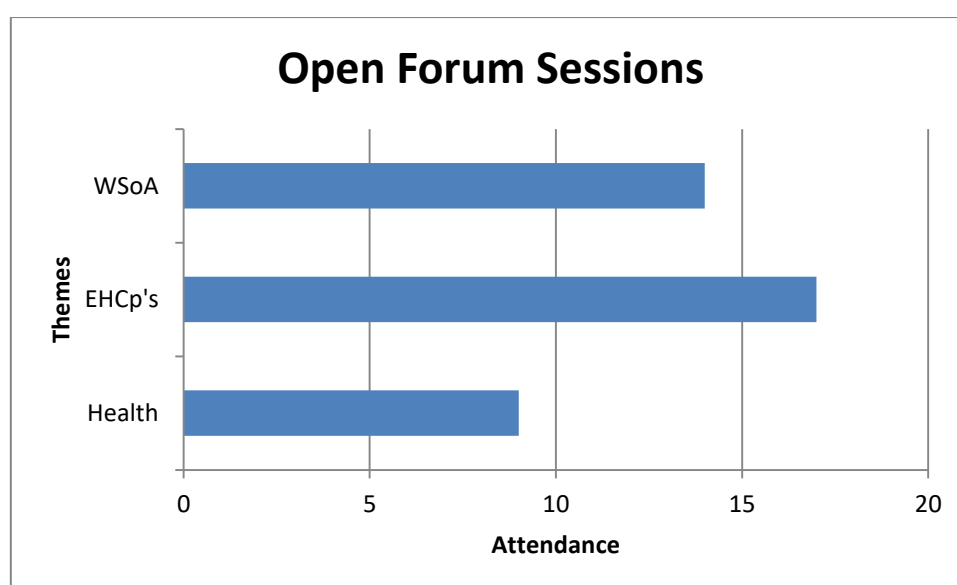
### Parent Participation

The financial reporting period this relates to, 2020 to 2021, has seen for FVP the level of recorded individual participation dip again from 369 (18/19) and 338 (19/20) to 310 (20/21). The numbers of parent carers taking part in online surveys or Facebook polls has also



fluctuate and increased again from 684 (18/19) and 453(19/20) to 923 (20/21). The changes have a number of factors including but not exclusively; C-19 Impact and the need to work virtually, the increased popularity of engaging online and a newer group of parents engaging. FVP has also seen an increase in requests for parent participation from services across sectors operational and strategically.

There has been some investment by FVP in helping parent carers understand their “right” to be heard on a personal and collective level in the services accessed by their children and young people especially at face to face sessions in educational settings. Underpinning the Children and Families Act 2014 are the Section 19 Principles whereby Local Authorities have a duty to pay due regard to the views, wishes and feelings of children and young people with SEND and those of their parents and carers and support them to participate fully. The work conducted by FVP has been shared with the Local Authority to help them understand what the views and feelings of parent carers are. This was partly achieved through the use of virtual themed sessions



**Fig.5 Attendance at Virtual Sessions**

## **Parent Participation/ Engagement/ Involvement April 2020 to March 2021**

### **Headlines**

1. 310 known parents in total have been involved at some level via virtual meetings/ events/ online activities/ Facebook Polls and Discussions.
2. >100 professionals have been involved at some level via virtual meetings.
3. 871 parent carers have taken part 54 online surveys or face book polls.
4. Parents have self-reported being members/ attendees at; Peterborough District Deaf Children Society (PDDCS), Peterborough Area Down Syndrome Group (PADSG), Little Miracles (LM), National Autistic Society (NAS), Autism Peterborough, , Aiming High Group (AHG)

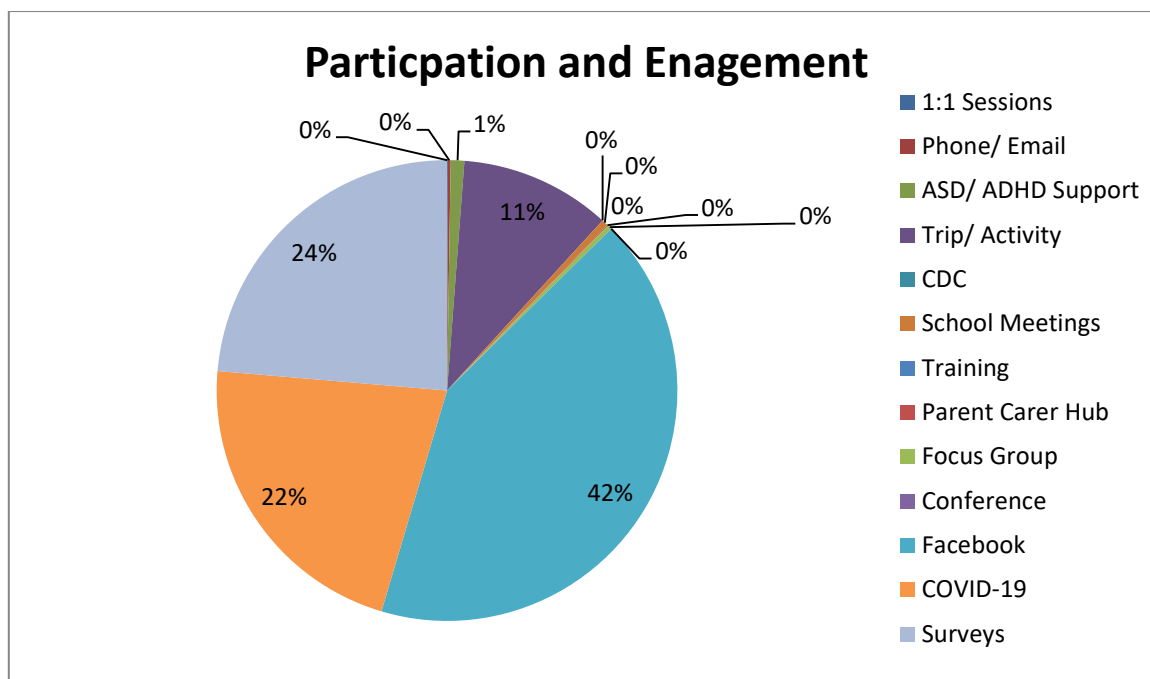
5. Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
  - a. ASD, ADHD,
  - b. Global Developmental Delay (GDD),
  - c. Speech, Language and Communication Needs (SLCN),
  - d. Complex Health, Obsessive Compulsive Disorder (OCD),
  - e. Cerebral Palsy (CP),
  - f. Tourette's,
  - g. Learning Disability and Difficulty (LDD),
  - h. Hearing Impairment (HI), Depression, Behavioural Needs,
  - i. Achondroplasia,
  - j. Goldenhar Syndrome,
  - k. Downs Syndrome,
  - l. Hypochondroplasia,
  - m. Physical Disabilities
  - n. Anxiety Disorder
6. 19 fathers have been involved which is a decrease on the previous year and 1 father has had regular involvement in person and another via social media
7. Parent carers reported the ages of their children/ young people as between 2 to 34.
8. Participation methods used included; one conference, focus groups, online surveys, paper surveys/ feedback forms at trips and activities, training – workshops, Facebook discussions and polls, working breakfast meetings, case studies, seldom heard group sessions and parent representation.
9. Evidence is both qualitative and quantitative in nature.
10. Ethnicity has been self-reported as; White British, Asian, Gambian, Lithuanian, Polish, Albanian, African, Portuguese, Scottish, Canadian, Bangladeshi, South African, Latvian, White European and American.

## **Parent Representation**

7 parent carers acting as representatives have attended 216 strategic meetings investing 499.5 (under estimate) of hours in terms of administration, travel time and actual meeting attendance.

## **Preferred Parent Participations Method**

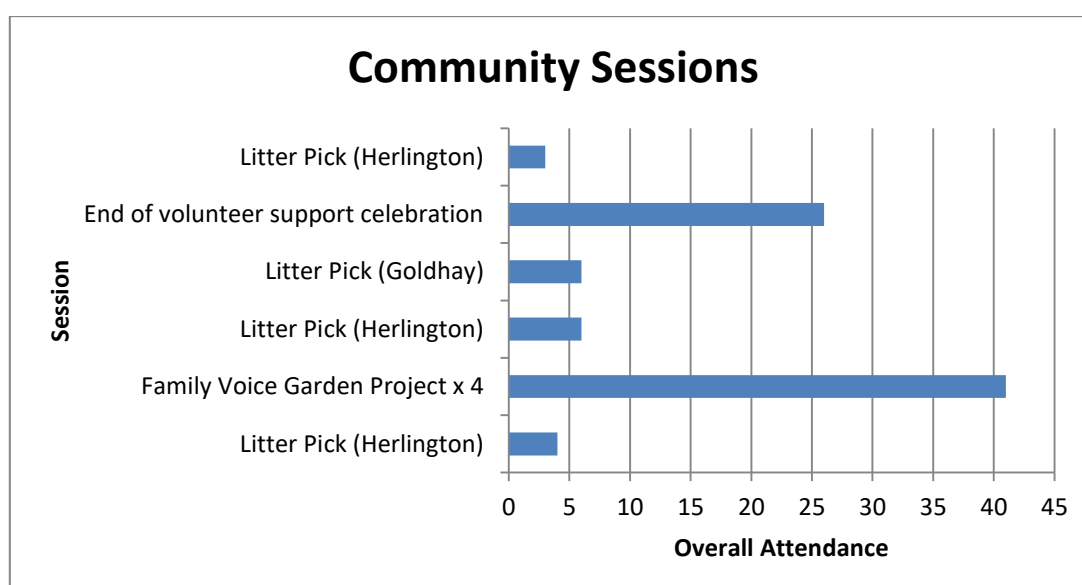
FVP have seen 301 parent carers, some of whom have participated more than once, participate 1577 times.



**Fig.6 Preferred Participation Method**

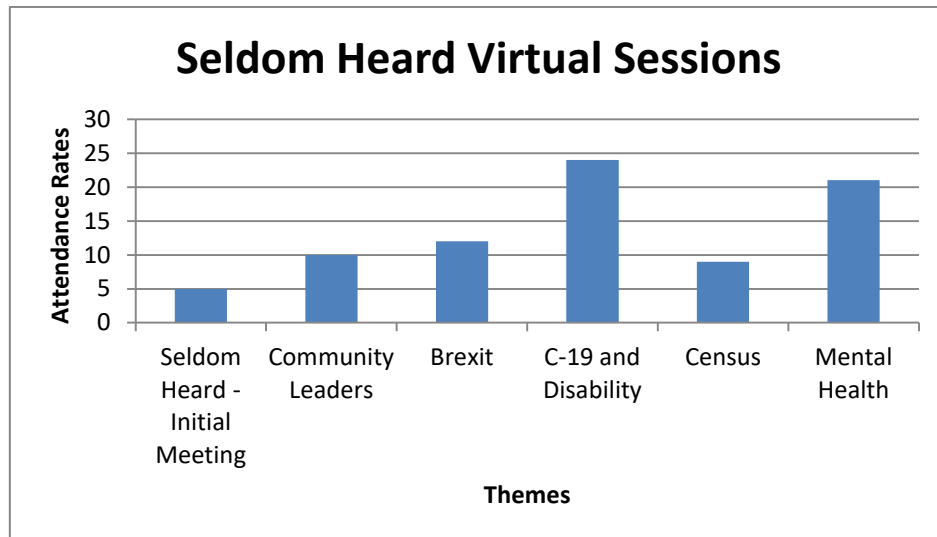
## **Community Participation and Engagement**

Despite the community centre being to the public work still had to take place to maintain its upkeep and provide community support especially to seldom heard communities which is part of FVP's wider charity aims. Work took place through a number of community centre close events when government guidelines allowed and virtual sessions during lock down to facilitate engagement and participation. Fig. 7 shows that overall the garden project saw the highest level of engagement. Feedback also showed that attendance at this activity helped combat feelings of isolation and improved mental wellbeing.



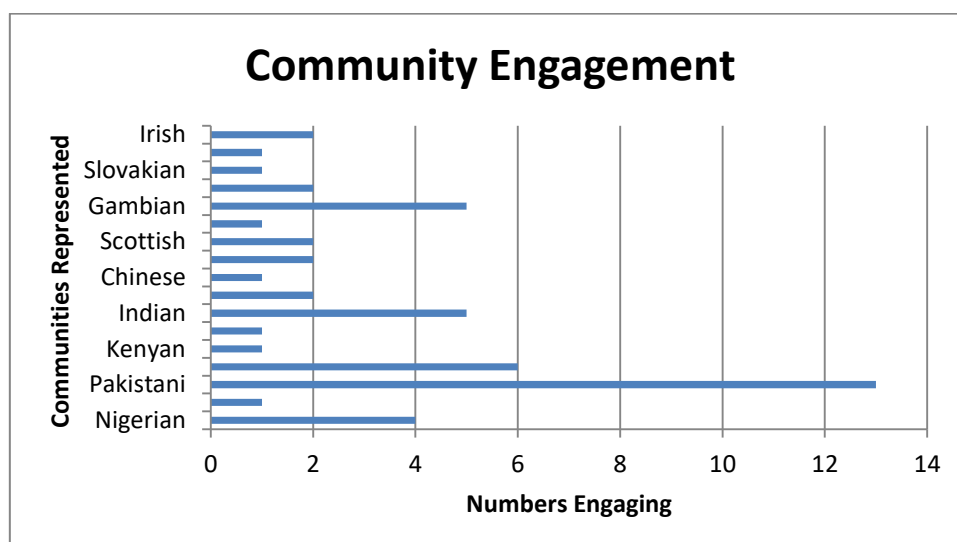
**Fig.7 Community Engagement Sessions**

As well as the activities at the centre work took place during much of the lock down period to still engage with, provide information to and enable participation from the wider community with a focus on seldom heard communities. Work began to run virtual sessions for seldom heard communities via zoom with the sessions being supported by BSL interpreters and made available on YouTube.



**Fig.8 Themed Seldom Heard Sessions**

Fig.8 shows there has been a need for the sessions with the most popular relating to the C-19 vaccination program and then Mental Health. The sessions were attended by parent carers, LA and Health professionals (commissioning and provision) and community leaders. They have created an environment where very diverse communities can come together and talk about a range of topics with SEND and parent carers at the centre of the system. Fig. 9 shows the range of communities represented at the sessions.



**Fig. 9 Communities Attending Sessions**

In total 185 engaged 330 times across the sessions, with the most popular for re-attendance being seldom heard sessions.

## **CHARITY ASSETS (Premises)**

### **Premises Details**

The Goldhay Centre where FVP are based is split into two sections:

- On one side the community premises comprises, Kitchen, Hall, Accessible WC and WC and outside play space
- The other side is a three storey office area with WC and reception/ admin office on the ground floor, small room/ office and training/ staff room on the middle floor and a small office and larger split office on the top floor.
- Funding has been received to further separate the centre and offices, with a new fobbed entry system being installed for the office side. This work has been conducted to ensure the building is as C-19 safe as possible.

FVP are pleased to have been awarded a 5 star rating for food hygiene for a second time.

### **Premises Costs**

FVP have taken on the Goldhay Centre as part of the Local Authorities Asset Transfer programme. The asset was transferred in February 2019 for a period of 40 years.

The past year has proved very difficult for FVP through having to shut the community centre which resulted in a large loss of revenue. Although the centre remained shut to the public running costs were still accrued and had to be covered. In 2019-2020 FVP netted revenue of £10,057 from Hall Hire Fees whereas in 2020 to 2021 FVP only netted £87 from some fees owed before lock down. Fig10 shows the overall running costs associated with the centre which totalled £16,364 which effectively created a deficit of more that -£16,000.

**Fig. 10 Expenditure**

Heat, power, light and water	£1,044.24	£0.00	£0.00	£591.31	£0.00	£0.00	£374.53	£287.27	£309.26	£556.13	£285.01	£407.55	<b>£3,855.30</b>
IT Services	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	<b>£0.00</b>
Hall Repairs and Maintenance	£308.56	£63.60	£91.57	£203.08	£61.00	£78.44	£246.90	£4,658.70	£38.32	£32.91	£0.00	£40.77	<b>£5,823.85</b>
Premises expenses	£222.01	£0.00	£0.00	£0.00	£0.00	£148.49	£542.59	£1,198.08	£0.00	£164.92	£35.47	£0.00	<b>£2,311.56</b>
Telephone	£104.75	£68.74	£148.33	£17.27	£50.00	£67.79	£42.39	£60.00	£60.14	£60.00	£60.00	£62.56	<b>£801.97</b>
Regulatory fees and licences	£71.94	£0.00	£159.00	£0.00	£0.00	£0.00	£288.00	£214.43	£79.00	£0.00	£770.52	£309.99	<b>£1,892.88</b>
Insurance	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£0.00	£1,678.07	<b>£1,678.07</b>
<b>Running Total</b>	<b>£1,751.50</b>	<b>£132.34</b>	<b>£398.90</b>	<b>£811.66</b>	<b>£111.00</b>	<b>£294.72</b>	<b>£1,494.41</b>	<b>£6,418.48</b>	<b>£486.72</b>	<b>£813.96</b>	<b>£1,151.00</b>	<b>£2,498.94</b>	<b>£16,363.63</b>

Although the centre has remained shut, it has still been utilised for C-19 response work, primarily in the form of food support. The centre is also part of the same building as the offices of the charity and so all overheads are connected. FVP secured a small grant from Longueville Parish Council and some top up funding from the Lottery COVID Grant programme that was utilised to carry out remedial capital works to create a separate office entrance. This has ensured the centre is more self-contained and once open again can be used more safely and C-19 secure

### **Premises Use**

#### **Parent Forum Opportunities**

1. Having the premises has continued to make the forum more accessible to parent carers and provides FVP with more in-house participation and training opportunities.

Now it is more established, more effort has gone into the promotion of the activities, training and participation opportunities in the centre leading to an increase in regular engagement with parent/carers at the centre and a decrease in external venue hire costs.

2. FVP staff, parent representatives and parent volunteers are also provided with space and office use to enable them to carry out their duties.
3. Parent carers can attend meetings at the office and seek information, signposting and face to face contact more easily.

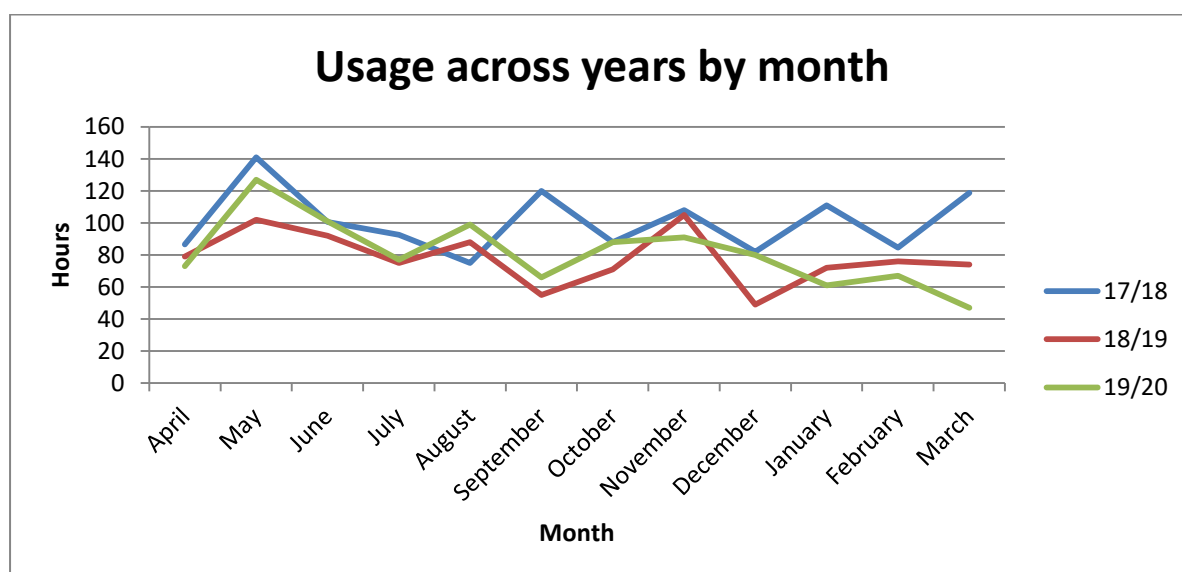
## Community Opportunities

Ordinarily the centre would have been used by a wide range of groups and organisations, however it is still not possible to ascertain when or if they may start up again. Some of the groups would be classified as in the Clinically Extremely Vulnerable group and/ or run in such a way that social distance with or without extra protection such as face masks would not be feasible. Much more in depth risk assessments are required for each individual group to see if the centre use is viable for them.

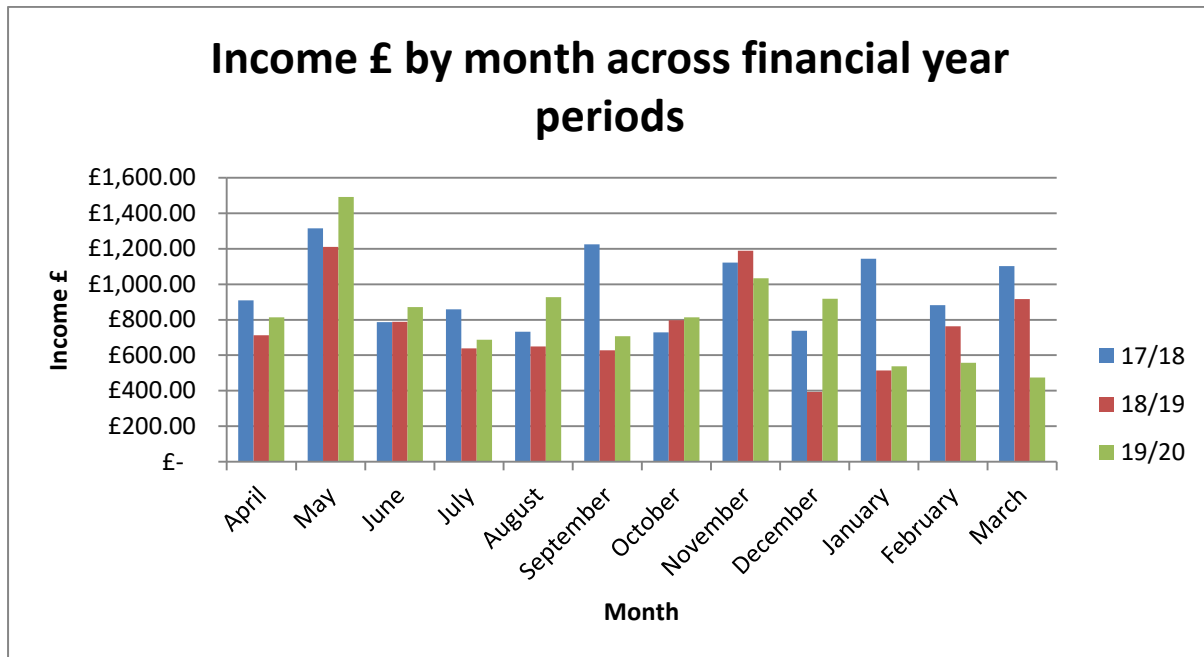
As part of the charity planning the Trustees will be looking at the safe and effective use of the centre alongside income generation possibilities going forwards. There may be more of a focus on outside activities and learning, development and support initiatives inside.

## Overall Usage

An analysis of the hall usage for 17/ 18 to 19/20 in fig. 11 and 12 below demonstrates that over time and with careful planning it may have been feasible for the Trustees to assume with some work that the centre could have moved towards becoming self-sustaining. Plans had already been considered to look at bringing in more regular users, slightly increasing fees and focussing more on community learning and engagement work. This would have more away from relying on private bookings which often resulted in more cleaning and repairs. The centre was being utilised at less than 50% capacity so there was plenty of scope for development.



**Fig. 11 Hall usage across months from 2017 to 2020**



**Fig.12 Hall income across months from 2017 to 2020**

There is no comparison data for 2020 to 2021 due to the closure and cancellation of all sessions. C-19 has really impacted on the charity, its assets and beneficiaries.

## **Caravan**

### **Management and Structure**

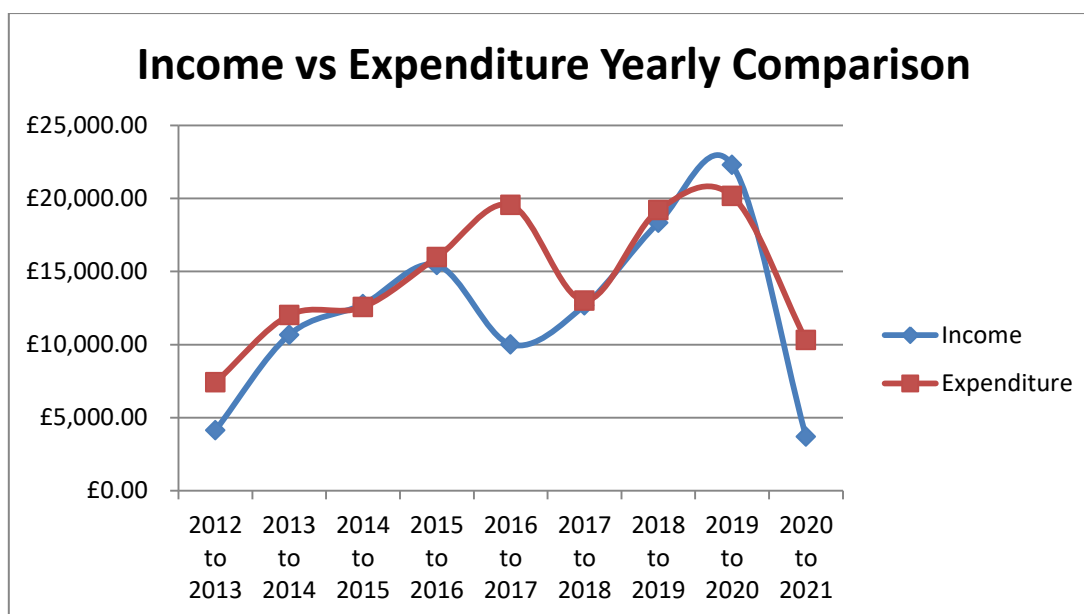
The caravans are owned by the CIO and managed on a daily basis by chief operating officer and admin and the Chair Person is the designated point of contact.

### **Finances and Sustainability**

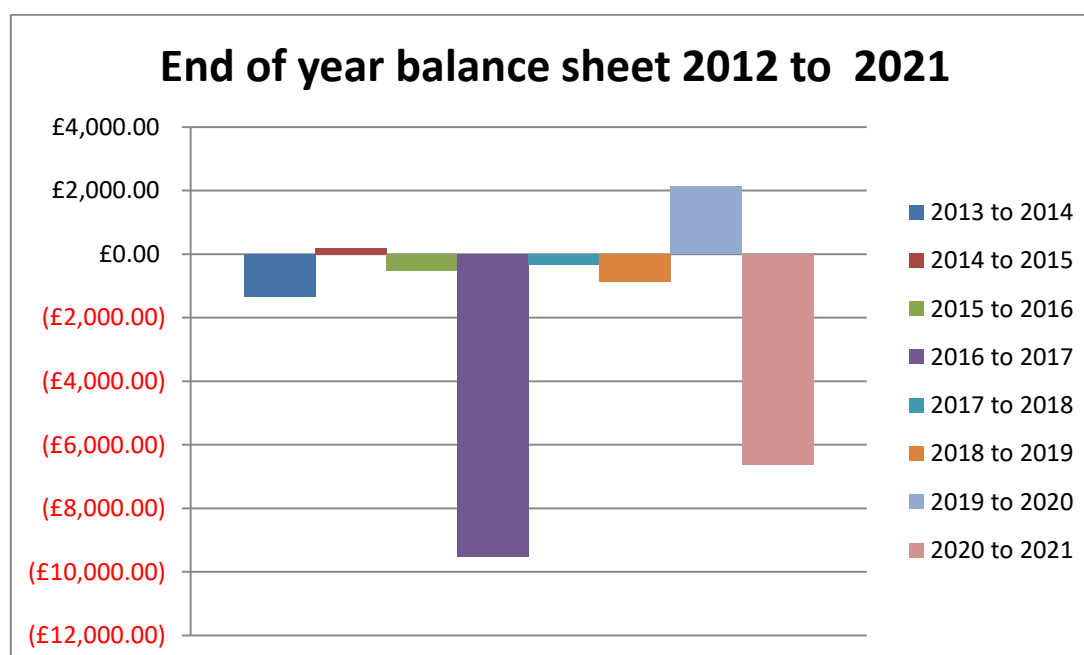
#### **Income and Expenditure from 2012 to 2021**

The chart gives an indication of yearly income and expenditure relating to the caravan. The figures do not include any yearly carry forward. In the 2019 to 2020 season there was a move towards running a slight profit as opposed to loss. This had been partly due to handing some dates to Haven for their sub-let programme which afforded a guaranteed income.

As with the community centre closure the caravans were also impacted by C-19 and the three lock down periods. Fortunately a few breaks were feasible and FVP were given some refunds by the caravan parks which were off-set against site fees which are paid upfront for the season. Despite this off-setting classified as caravan income a large loss still occurred. Despite the closure some costs were still incurred much as with the centre.



**Fig.13 comparison income and expenditure of the caravans since ownership began**



**Fig.14 End of year balance sheet**

#### General Operating Costs 2020 to 2021

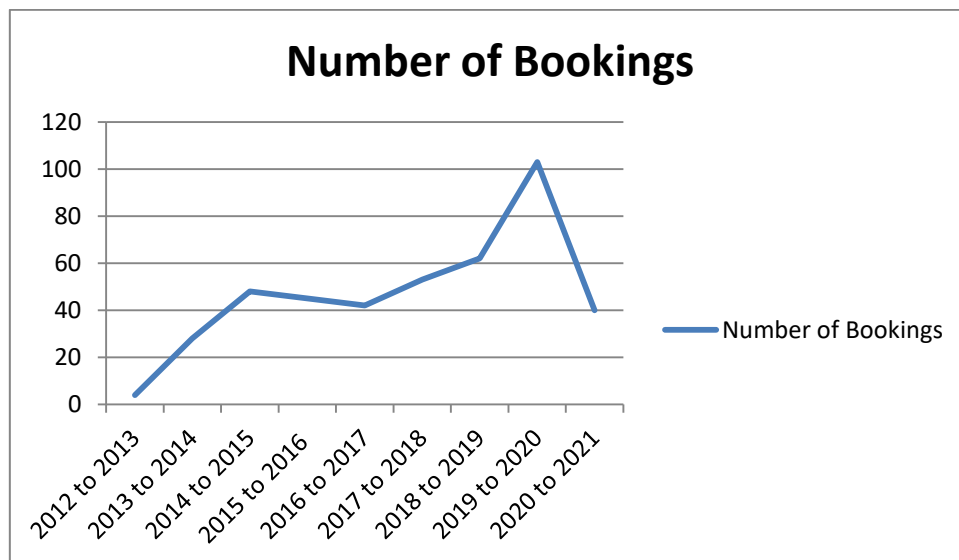
- Utilities
- Cleans
- Site Fees
- Business Rates
- Insurance
- Repairs and Maintenance
- Re-stock (e.g. bedding, crockery)



FVP also stock the Butlin's caravan with a selection of DVD's, games and children activities (colouring books, puzzle books, crayons)

### Bookings

The season runs from March to October at both sites but much of March and September are usually given over to adult only weekends at Butlin's. Year on year there had been an increase in the number of families who have benefitted from use of the caravan until the past season.



**Fig.15 Overall number of bookings per year**

From fig.15 it can be seen that usage dropped the past season to numbers last seen in 2016-2017.

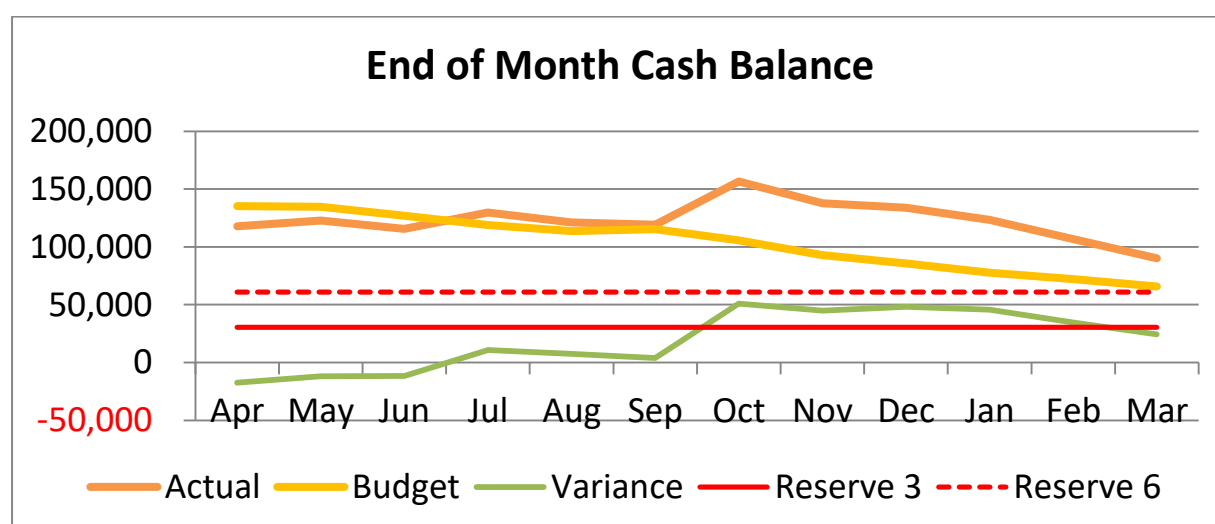
## **Financial Review**

### **Reserves Statement**

The trustees are continuously working to establish sustainability and good governance for the charity and have developed various policies and procedures including a reserves policy to facilitate this. The policy establishes how reserves levels are set and how these relate to unrestricted funds and such levels will be managed.

Although funds for the caravan are unrestricted they have been considered as designated and therefore not to be included in the free reserves of the charity as they are necessary to ensure the continued sustainability of the caravans to ensure ongoing short break provision.

The trustees propose to maintain the charity's free reserves at a level which is at least equivalent to six months operational expenditure and three months as a minimum. The objective had been at the end of the last financial reporting period to increase reserves levels to an acceptable level as they were at an equivalent of only two months. This year the reserves have been increased to just over six months affording some time to re-stabilise the financial position of FVP after being impacted negatively by C-19.



**Fig. 16 Levels of Charity Reserves at March 2021**

### **Principle Source of Income**

The principle source of income for FVP remains grant funding which is linked to predefined outcomes. Grants have been allocated by Contact behalf of The DfE, The Local Authority on behalf of the CCG and The Local Authority. The total grant income equates to 94% of the charity income up from 76%. The difference between the two would normally have been from fundraising and asset revenue. Such an over reliance on grant income is felt to be unsustainable. This is because in general most income from grants is for a maximum of a year only and has to be spent in the year in grant period in which it is received. The drop in income from other sources as demonstrated by the difference between grant income between 19/20 and 20/21 has meant that further risk has been introduced in the charity finances.

Unrestricted income helps to increase reserve levels and enable expansion of the work of the charity.

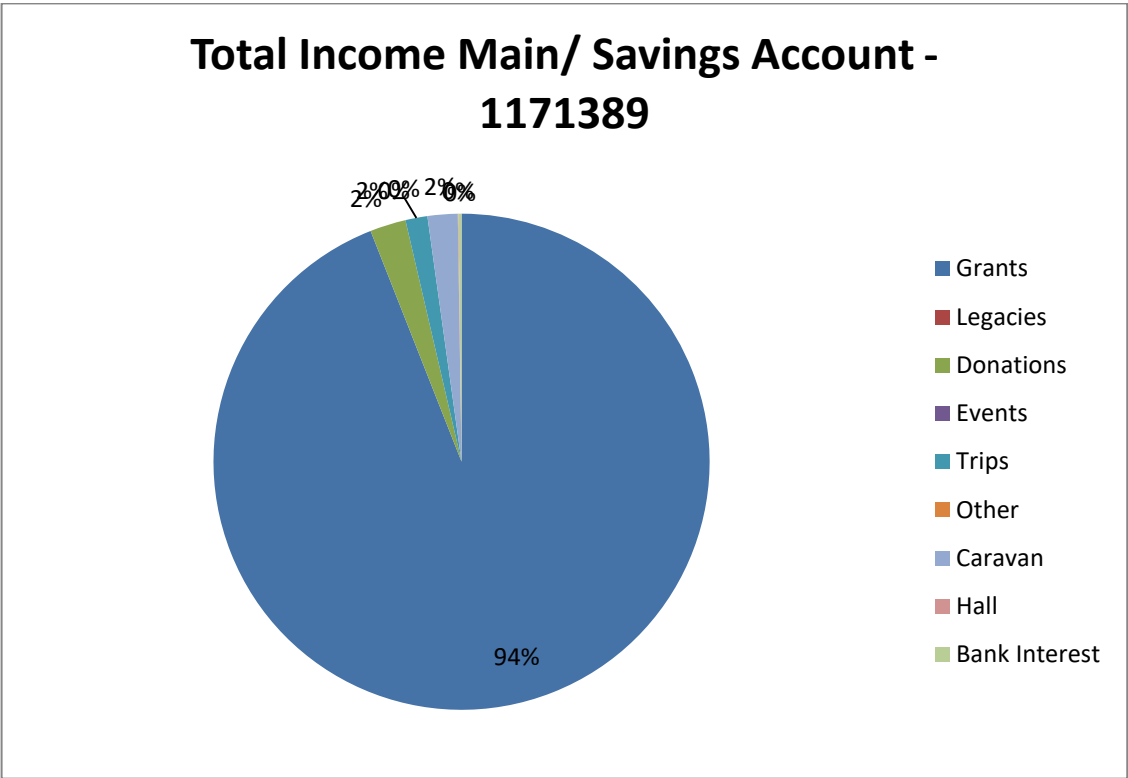


Fig. 17 percentages of different income streams for FVP (1171389)

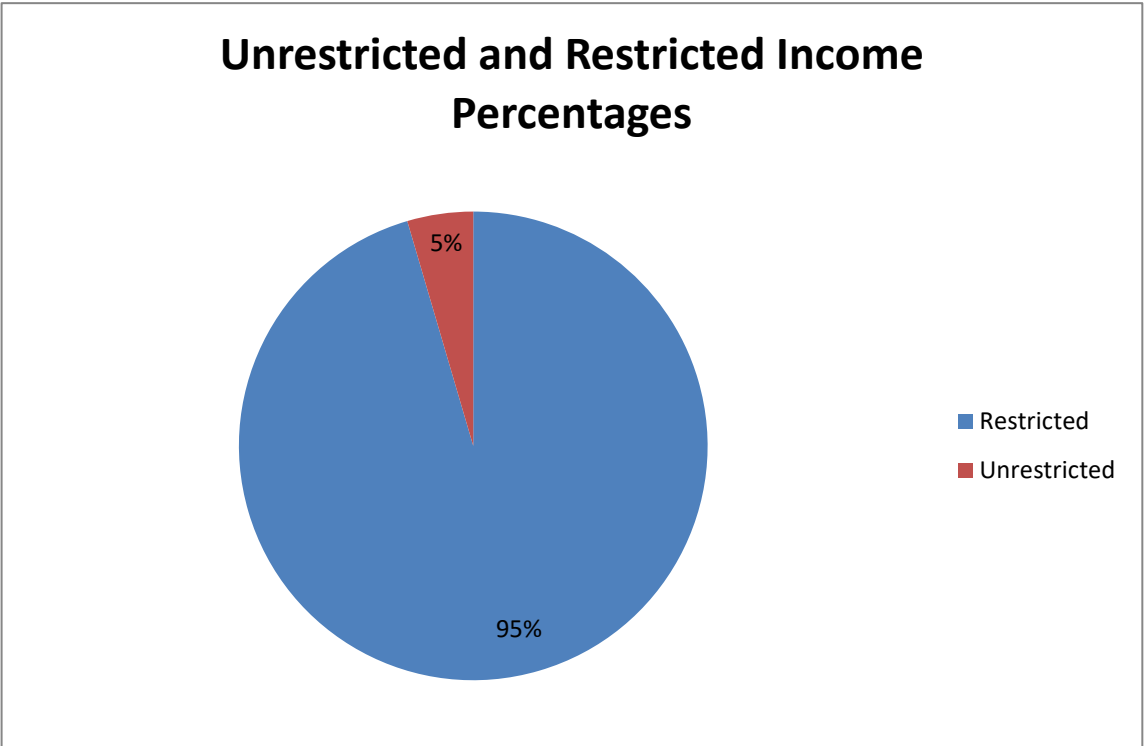


Fig. 18 percentage of income either restricted or unrestricted

Although C-19 has had a negative impact on the income of FVP more grants have been made available to support charities at financial risk. FVP were able to secure a number of these to provide some financial short term stability. The C-19 grants secured have also meant that some of the LA funding could be saved and carried forwards to 2021 to 2022 to cover potential short falls. Funding is required to cover staffing and organisational running costs between grant programmes.

### Fundraising and Donations

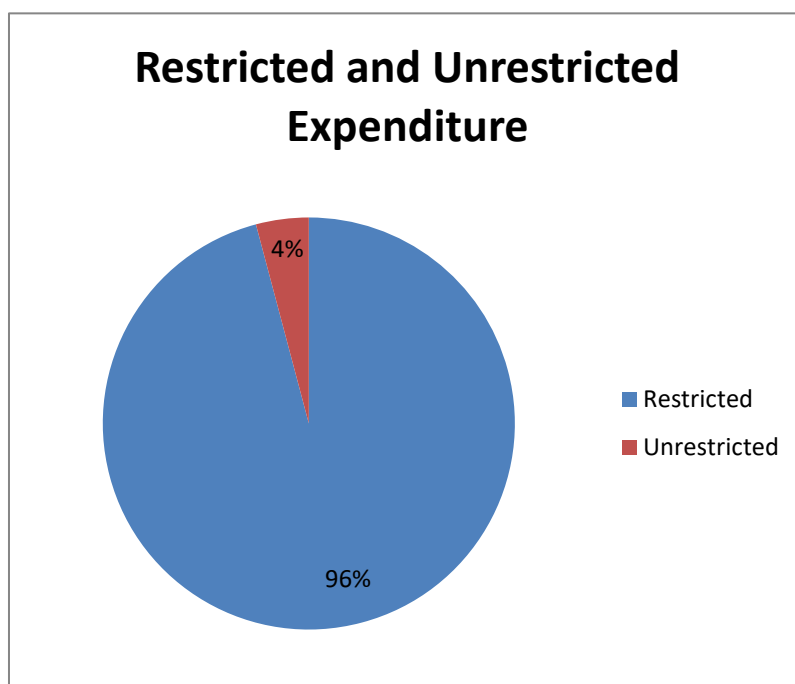
Donations have netted £4426.45 income which is marked decrease from approximate £18,000 raised in 2019/2020. This drop also takes FVP back to the level raised through donations and fundraising in 2018/2019 of approximately £4000.

Any fundraising is managed under an ethical fundraising policy held by the CIO and as such work relating to joint fundraising falls under this. To demonstrate best practice, the CIO is also self-registered with the Fundraising Regulator.

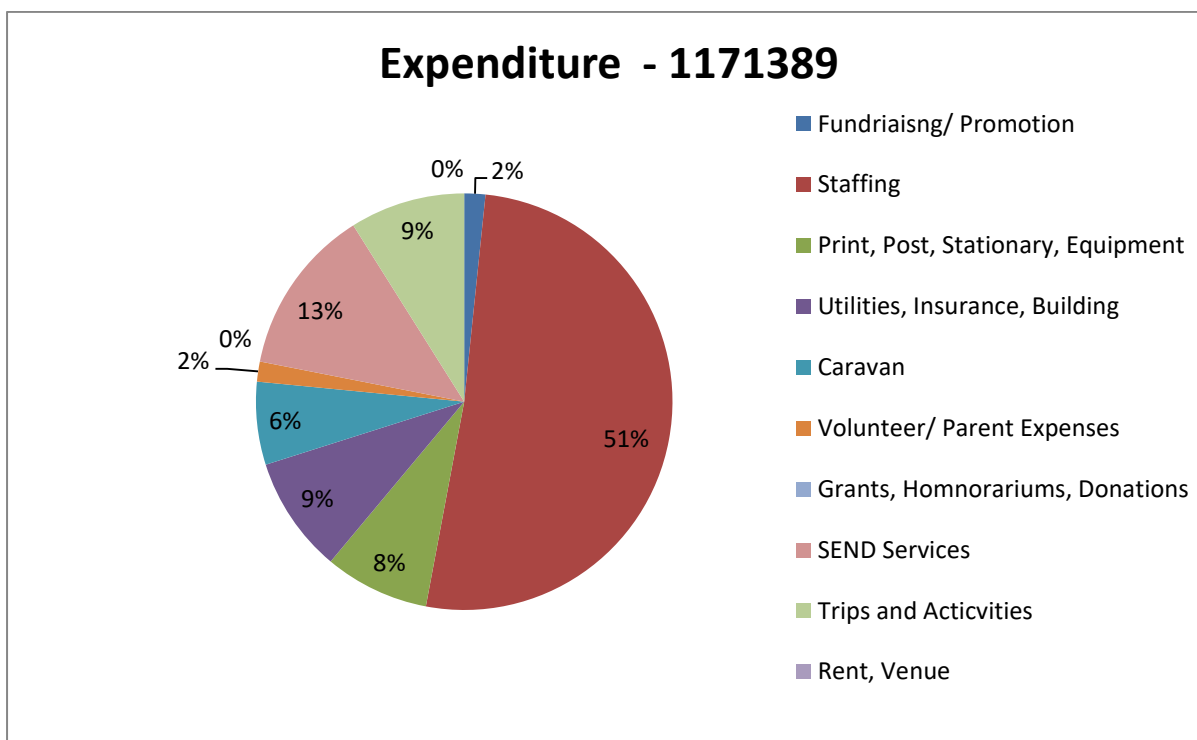
### Expenditure

The majority of the charity expenditure is from restricted funds from grants paid in year. Overall 96 % of expenditure was restricted. The majority of core costs fall into restricted funds expenditure with all staffing covered under restricted funds.

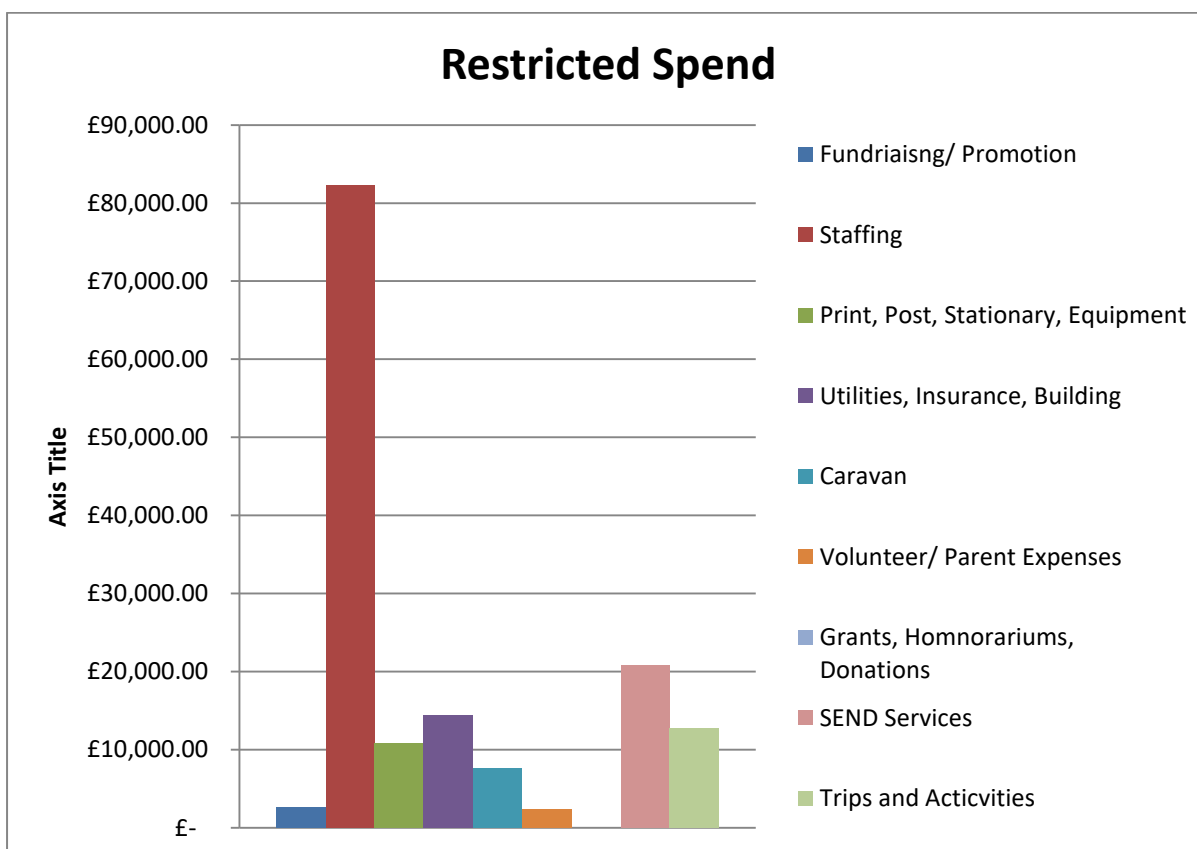
The majority of grant expenditure is set against pre-defined outcomes with specific outputs and measured against an outcomes matrix. The DfE grant although for a small amount is a receipted grant, where every receipt has to be allocated and spending has to be strictly kept within predefined budget. The outcomes match the objects of the charity. Expenditure has been on providing families with access to information, advocacy, support and advice; therefore meeting the objects of the charity.



**Fig. 19 percentage of expenditure under restricted and unrestricted funds**



**Fig. 20 Overall expenditure across natural payment categories**



**Fig. 21 Expenditure across budgets under restricted and unrestricted funds**

## **Further Details**

1. Caravan expenditure is higher than income so a deficit has resulted in caravan finances.
2. Roughly 50% of all expenditure has been on staffing with all staffing time spent on meeting the objects of the charity.
3. Staff turnover has been affected by grant specific work involving temporary contracts. The majority of those employed have been parent carers who volunteer extra time to the charity over their contracted hours of employment. All costs relating to employment are linked to grants.


### Trustee Remuneration and Expenses

During the financial period 2020 to 2021, two trustees received remuneration for specialist work on behalf of the Clinical Commissioning Group (CCG) where the funding allocated was paid on behalf of the CCG.

### Accounts Preparation

In line with the charity's constitution and charity accounting guidelines as defined in CC15d 'charity reporting and accounting: the essentials' a decision has been taken to prepare the accounts using a payments and receipts system (using natural categories)

# Statement of Accounts 2020 to 2021 - 1171389

 CHARITY COMMISSION FOR ENGLAND AND WALES	Family Voice Peterborough		1171389		CC16a
	Receipts and payments accounts				
	For the period from	1st April 2020	To	31st March 2021	
Section A Receipts and payments					
	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations, Legacies and Grants	4,426	177,572	-	181,998	197,196
Fundraising Events			-	-	204
Fees for Charitable Services		2,705	-	2,705	11,661
Hire of Community Premises	87		-	87	11,240
Hire of Caravans	3,697		-	3,697	15,693
			-	-	
Transfer into savings			-	-	
Interest	374		-	374	349
Sub total (Gross income for AR)	8,585	180,277	-	188,861	236,343
A2 Asset and investment sales, (see table).					
	-	-	-	-	
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	8,585	180,277	-	188,861	236,343
A3 Payments					
Cost of Fundraising Events/ Promotion		2,623	-	2,623	2,569
Staffing Costs (wages, pensions, HMRC)		82,249	-	82,249	102,853
Print, Post, Stationary, Equipment	2,186	10,849	-	13,035	12,050
Utilities, Insurance, Building Costs, Repairs	48	14,423	-	14,471	14,192
Caravan Running Costs	2,703	7,606	-	10,309	21,058
Volunteer and Parent Carers Expenses(childcare, travel, refreshments)	104	2,388	-	2,492	8,891
Grants and donations paid			-	-	26,200
Cost of SEND Services (training fees, delivery costs)	5	20,783	-	20,788	10,884
Costs of proving trips/ activities (coach hire, entry fee etc)	1,582	12,745	-	14,328	12,233
Rent/ Hire of rooms			-	-	4,290
Transfer to savings			-	-	
			-	-	
Sub total	6,627	153,668	-	160,295	215,220
A4 Asset and investment purchases, (see table)					
	-	-	-	-	
	-	-	-	-	
Sub total	-	-	-	-	-
Total payments	6,627	153,668	-	160,295	215,220
Net of receipts/(payments)	1,957	26,609	-	28,567	21,123
A5 Transfers between funds			-	-	-
A6 Cash funds last year end	58,461	3,151	-	61,612	35,997
Cash funds this year end	60,418	29,761	-	90,179	57,120

## **COVID-19 Pandemic and Charity Impact**

*At the end of last reporting period FVP stated “During this reporting period the charity has entered in to unprecedented territory in light of the current global COVID-19 Pandemic. This has impacted on delivery of services funded and otherwise, staffing and volunteering, the financial position of the charity and also had a direct impact on the beneficiaries of the charity as a whole.”*

### **Services**

Much work was cancelled between April and July and many fees had to be refunded. After careful risk management and planning there was a move towards virtual working where feasible and a support phone number/ email address were utilised to provide sign-posting, answer queries and provide information to families. FVP also took up food support work and provide a number of families with food parcels and vouchers.

### **Assets**

The community centre was shut effectively immediately which resulted in a direct loss of revenue and closure of services. All sessions providing direct support were cancelled as well. After careful consideration and assessment, it was deemed necessary to conduct remedial works to alter slightly the entry system so when possible the centre could be opened again.

Both caravans were also closed and any fees already secured had to be refunded to guest who had pre-booked breaks. The caravans remained closed for the majority of the season with a greatly decreased number of bookings possible. Fortunately the company who owned both caravan parks introduced a refund system and recompensed owners for loss of the service, which meant site fees that had already been paid, were reimbursed minus some admin fees.

### **Staff and Volunteers**

FVP were unable to furlough any staff due to all roles being funded via public funds and there was a temporary move to full home-work which proved extremely difficult for the team for a number of reasons. It was decided after careful consideration and in line with government guidance to allow a small team to work from the office on a rotational basis. All volunteer initiatives with BGL and the Rotary club were placed on hold as well.

Funds also had to be sourced to furnish those who were home/ remote working with suitable equipment such as laptops and headsets, which placed extra financial burden on the charity. There was also some concern about how people would generally be supervised and supported whilst working remotely and the team did report feeling isolated.

### **Financial Stability**

The pandemic had direct impact on the immediate cash-flow the charity between March and June and then into as far as September. Losses through the caravan and centre closure and cancellation of events created an initial a net loss of approximately £10,000. By September despite securing a handful of C-19 specific grants the forecast was potentially damaging enough as to suggest the closure of FVP completely. Without successfully securing a Lottery C-19 grant totalling £50, 220 with the support of a grant writer FVP would have closed by February 2021. The grant and then a few further C-19 grants and donations provided enough



income to stabilise the accounts and move to actually ending the financial year in a much stronger position.

### Beneficiaries

FVP have continued to gather information from parent carers as to how C-19 and the associated three lock downs has affected them and fed these views to the Local Authority who have continually looked at what measures can be put in place to provide support differently. Key themes identified impacting families are:

1. Increased anxiety.
2. Increased behaviours that challenge.
3. Financial worries.
4. Feelings of isolation.
5. Difficulties in finding enough food or having the opportunity to go and buy food.

## **Forward Plan**

After careful risk assessment and completion of a SWOT analysis areas for development relate to sustainability and capacity. Work has been identified in relation to marketing, fund raising and increase the charity work force. These are subject to change due to the ongoing pandemic.

### **Short Term Goals**

Over the coming year (year 4 of FVP's plan) FVP will:

1. Continue to utilise virtual working, recording of sessions and signing to make them more accessible and take account of social distancing measures Look to recruit more volunteers to increase capacity
2. Respond to emerging need and research concerns/ issues and find solutions to inform participation work
3. Staff review and capacity assessment
4. Continue the development of work identified in the marketing strategy for promoting use of assets
5. Review trustee skills and training, consider widening membership
6. Secure the next stage of lottery funding
7. Look to develop better marketing of the community centre and find ways to attract new regular user groups
8. Look to market the caravans differently and maximise income from a wider range of users.
9. Continue to identify and target potential corporate partners matched to services (events, caravans, centre etc.) based on changed landscape
10. Revisit and review schools engagement work based on new ways of working under C-19
11. Continue and expand on virtual work with seldom heard community leaders, and parent carers.
12. Review and continue to deliver and adapt as required the food support programme to reach a wider number of families

### **Long term goals**

Over years 5 to 7 of FVP's longer term plans:

1. Increase our train the trainer capability
2. Identify opportunities for caravan sponsorship
3. Continue with marketing to increase membership
4. Review and develop next five-year business plan.
5. Explore and implement ways of making our property carbon neutral, and using environmental ways to maximise our efficiency