FVP Interim Report

January – March 2020

FVP Parent Representatives

Introduction:

The final quarter of the 2019/2020 year has been one wrought with fast paced changes, resulting in a total lockdown for all individuals residing in England due to the Covid-19 global pandemic. The quarter started strongly, with continued increased engagement of parent carers, including those from seldom heard communities – with numerous events and activities planned in during March to engage said parents in participation work. Unfortunately all March events have been postponed, impacting on the year's final engagement and data, FVP have also closed the Goldhay Community Centre, as well as the two caravans used to provide short breaks for families with a disabled child.

In order to adapt to the stay at home order, FVP have moved to remote working – setting up a daily hotline for parents to dial in to if they are struggling, or in need of advice and signposting. FVP have also worked to gather parent carer views and information on their needs via two online surveys, and Facebook engagement in order to feed this into Peterborough City Councils response strategy.

Population

From January 1st – March 31st we have engaged with a total of 83 new named parent carers, with 127 occasions of individuals participating across all workstreams. We also engage with parent carers informally in situations which will be discussed below, and while we do use their experiences to shape our work we do not record specific data on their demographics. The overall demographics of our named parent carers are displayed below:

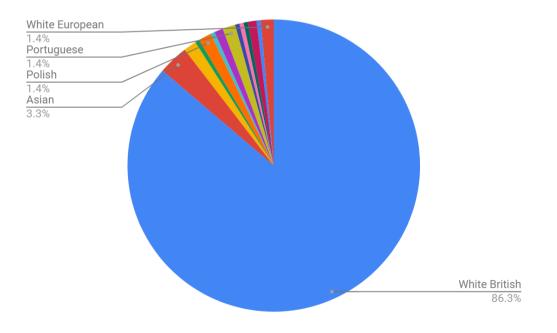


Fig. 1 Ethnicity of Participating Parent Carers

As per our previous interim reports, the majority of individuals who have engaged with the forum have been White British females. During this period 2 additional males have engaged strategically. The engagement of male parents has proven to be difficult and requires additional thought and planning. In order to combat this FVP are looking to organise father specific events and activities moving forwards. In addition to this FVP had arranged for a parent engagement session to be held at Phoenix School during March, which would have been held at 6pm to enable working parents to attend and engage. This session has had to be postponed due to the stay at home order, however a strong turnout of fathers is expected when this event does take place, and FVP will look to arrange additional events at this time to improve engagement.

FVP have maintained a close working relationship with the Aiming High Group – a community of Asian mothers who all have children with a Special Educational Need or Disability (SEND). In addition to this, FVP's outreach worker has engaged with a number of specific BAME groups within the city, including forging links with a Lithuanian community which has led to representatives attending Saturday school gatherings. Contacts have also been made with leaders within the East Timor, Latvian, Nigerian, Syrian, Ghanian and Portuguese communities. Work is underway to build upon these contacts to forge a trusting relationship whereby we are able to access parent carers within these communities to offer advice and signposting, as well as feeding their views into our strategic work. During this period FVP have held one Activity World Event, specifically for the families of members of the Aiming High Group, and other ethnic minority groups. During this event parents were enabled to share their views via FVPs end of year survey, a total of 115 individuals attended.

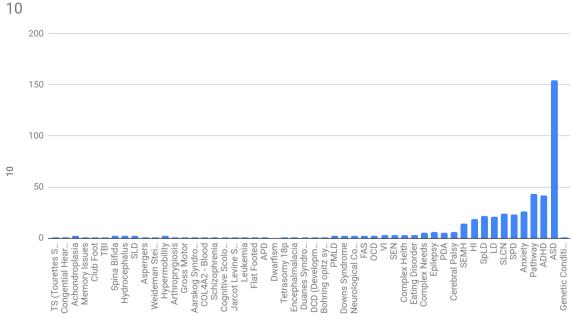


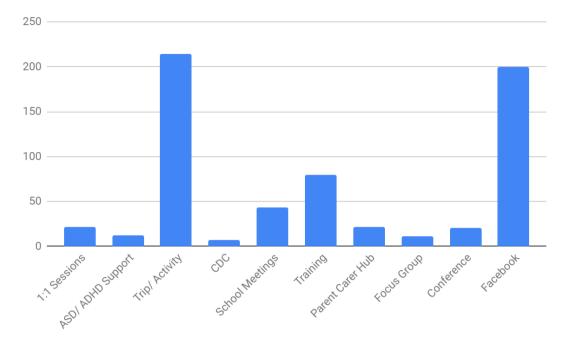
Fig. 2 Child/Young Person SEND as reported by parent carers

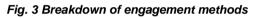
Autism Spectrum Disorder (ASD) remains the predominant area of need declared by parent carers, regardless of this the proportion of other areas of need is increasing. Through the work done within the Child Development Centre and specific outreach work with Phoenix School and Cherry Lodge we have increased the number of parent carers who have a child with physical or sensory needs who are engaging with the forum. FVP also maintain our close working links with Peterborough and Area Downs Syndrome Group, and Peterborough and District Deaf Children's Society (PDDCS) – raising awareness of the forum within specific disability communities. During March, FVP had scheduled a coach trip to Drayton Manor in partnership with PDDCS, whereby two coach loads of families would enjoy a safe day out at a vastly reduced cost – during this time parent carers would have been able to talk to members of the FVP team and share their views on our end of year survey during the journey – again this has been postponed due to the Covid-19 pandemic.

We are able to engage a large number of parent carers who are currently going through the Early Help Pathway – this is largely due to a partnership that we have developed with Barnardo's and the Early Help team who deliver the city wide Webster-Stratton as part of the Social, Emotional and Behaviour Pathway. We find that the pre-diagnosis stage is often a crisis point for parent carers, who do not yet have the full picture of their child's needs, and are unable to access disability specific support. Parent carers whose child or young person is on the Neurodevelopmental Pathway are often attendees of our two free training workshops, whereby they are enabled to meet others in a similar situation, and share their thoughts and views on the process whilst learning to manage behaviours that challenge, and how to navigate the health system.

There remain a large proportion of Social Emotional and Mental Health (SEMH) needs being disclosed as an area of need within children and young people. This is often disclosed as a co-morbid need associated with neurodevelopmental conditions, but we are seeing a rise in the number of parent carer's whose young people are struggling with standalone anxiety. Mental Health services widely viewed as being inadequate within Peterborough, with CAMHs appearing inaccessible to all but the few most severe cases, and CHUMS currently reporting a 10-12 month waiting time to access support. It is interesting to note that considering the long waiting times, CHUMS Peterborough weekly drop in sessions are currently recording a low uptake from parent carers and young people – this would indicate that more thought needs to go into the way this service is advertised. It has been positive to see that in response to the current lock down CHUMS are now offering telephone drop in consultations, and this service is currently being promoted by FVP via all social media channels, .www.familyvoice.org and the monthly e-news.

Parent Carers are enabled to engage with FVP using a range of different formats. Some are more comfortable with online engagement especially where childcare or work commitments are an issue, whilst others are regular attendees at our trips, events and activities. For all participation specific events, FVP cover the costs of travel and childcare for those parent carers who need it. Below is a breakdown of some of the different forms of engagement used during the reporting period.





Events and Activities

Event Name	Date	Number of Attendees
Community Meet and Eat	30/01/2020	13
Peterborough Kids Festival	09/02/2020	11 Parent Carers
Activity World Session	19/02/2020	118
Activity World Session for Seldom Heard Communities	20/02/2020	115
Totals		257

Fig.4 Breakdown of Attendees at our Events during the reporting period

A total of 257 individuals have attended an event or activity hosted by FVP during this recording period. This figure is a mixture of parent carers, children, young people and other family members. We use these events as an opportunity to reduce isolation within the parent carer community, and to assist individuals in building a supportive network of peer relationships. We also ensure that attending parent carers have an opportunity to share their

views and opinions on specific workstreams whilst attending events. At the end of every event or activity feedback forms are circulated for completion by attendees, the forms include general event feedback as well as space to give general feedback on SEND. As mentioned above, three family based trips and activities have been postponed that were due to be held during this period. Had they gone ahead around 180 additional individuals would have been able to attend.

Parent Carer Hubs.

These sessions are run in conjunction with Peterborough City Council, enabling parent carers to attend one-to-one meetings with professionals from varying services. A maximum of 6 individuals are able to attend each session. Following a high demand for meetings with professionals from the Parent Partnership Service (PPS) at their initial Hub we have arranged for the PPS to attend every hub session alongside interchangeable professionals from across the SEN and Inclusion Services. Attendee numbers are displayed below, an additional session with the Educational Psychology Service along with the Parent Partnership Service was booked in for March however this has been postponed again due to the Covid-19 pandemic.

Hub Date	Services	Attendees
27/01/2020	Parent Partnership Service Statutory Assessment and Monitoring Service	4
24/02/2020	Autism and ADHD Specialist Teaching Service Parent Partnership	3
Totals		7

Fig. 5 Attendees at Parent Carer Hubs

Parent Carers are asked to complete a feedback form post attending a Hub session. The responses to these are consistently overwhelmingly positive, and indicate how valuable a service this is. The two sessions held within this reporting period captured the following feedback:

Area to score	Average rating given across both sessions
Overall usefulness of session	9.71/10
Information provided	9.71/10
Overall content	9.57/10
Overall structure	9.71/10

Fig. 6 Parental Scoring of Parent Carer Hubs

Attendees are also asked to detail which parts of the session they found the most useful, and to share any other comments they felt were relevant. Responses included:

"Ease of contact, actual help"

"Speaking with Jackie from SEND Partnership was very useful and provided lots of useful information"

"Thanks for making this happen, we couldn't do without it"

"Great for parents looking for additional support and information"

Focus Groups

During this reporting period, FVP have held three topic specific focus groups, one of which was a family event and the others specifically for parent carers.

Focus Group Topic	Date	Attendees
Preparing For Adulthood, Independent Living	20/01/2020	7
General SEND Services Feedback	08/02/2020	16
Peterborough's Autism Strategy	11/03/2020	6
Totals		29

Fig. 7 Attendees at Focus Groups Hosted by FVP

<u>Workshops</u>

Workshop Topic	Date	Parent Carer Attendees
Guide to Mental Health Services	30/01/2020	7
Disability Living Allowance Application Training	14/03/2020	6
Totals		13

Fig. 8 Attendees at FVP Workshops

Parent Carers are telling FVP that they are struggling to access mental health services, not only for their children and young people, but also for themselves. In response to this FVP

have hosted an additional Guide to Mental Health Services Workshop, following on from the first earlier in the year. These are held in conjunction with mental health practitioners. Parent Carers are also telling FVP that they are struggling to access support for form filling, most specifically the forms required to apply and reapply for Disability Living Allowance and Personal Independence Payments. FVP have devised their own training programme for this, and the first session held was met with really positive feedback, and an overall course rating of 4.8/5

<u>Training</u>

Family Voice conduct two training courses; The Expert Parent Programme and the Challenging Behaviour Workshop, which are free of charge to all Peterborough parent carers. These courses are joint funded between Family Voice Peterborough and Cambridge and Peterborough Foundation Trust (CPFT) and are held six times per year - one per each academic half term. Two sessions have been held at FVP during this reporting period, with the attendees detailed below:

Session Name	Date Held	Number of Parent Carers Booked to Attend	Number of Parent Carers in Attendance
Expert Parent Programme	07/02/2020	13	5
Managing Behaviours That Challenge	14/02/2020	25	8
Totals		38	13

Fig. 9 booking figures for training Jan – Mar 2020

As seen with previous sessions held, booking numbers are much higher than the number of parent carers who do attend.

Upon completion of the courses, parents are asked to complete feedback forms. The feedback remains overwhelmingly positive. Parents report they feel empowered to manage their child/young person's challenging behaviour and have an increase in knowledge of SEND systems and how to achieve the best possible outcomes. One of the most common issues raised comes in regard to the Challenging Behaviour Workshop, which is currently run over 3 hours. Parents are telling us that they want this to be at least a full day so that there is more time available to discuss individual issues and receive advice, taking this on board FVP are currently working on the development of an extended course. Examples of feedback received are detailed below:

Very good, well facilitated, good encouragement of parent participation.

Great speaker full of helpful info. Well presented.

Fig. 10 Comments gathered following training courses

Schools Sessions

Family Voice are currently running a "Schools Offer" Pilot, working with a small number of named educational settings to provide training, coffee mornings and SEN Information Report support. Full details on the pilot can be found in our April – July Interim Report and a full report will be compiled upon the pilot's completion. Sessions which have occurred within the current reporting period are as follows:

Setting Name	Session Type	Date	Number of Parents Engaged
Hampton Gardens	SEN Information Report Co- Production	27/02/2020	9
Arthur Mellows Village College	Coffee/Information Session	31/01/2020	6
Arthur Mellows Village College	Coffee/Information Session	03/03/2020	3
Arthur Mellows Village College	Managing Behaviours that Challenge Workshop	13/03/2020	12
Totals			30

Fig. 11 Parental Engagement at Schools Sessions

Facebook Participation

FVP manage two main Facebook platforms: a Page entitled "Family Voice Peterborough" and a Group named "Family Voice Peterborough SEND Participation." The group is made up purely of Peterborough parent carers, whereas the page is a mixture of interested individuals, and is also used as a platform for our community work. The use of Facebook Polls enables FVP to gather feedback on a large scale whilst eliminating barriers relating to childcare, transportation and time. Polls are used to gather basic initial data which is then explored in more detail.

In addition to the traditional Poll format of gathering information, FVP have also made a concerted effort to engage parent carers via written posts during March, in order to ascertain how they are coping with lockdown.

Poll Name	Number of Responses – "Have a Professional Call you"	Number of Responses "Dial in virtually, ie: via Skype"
How would you prefer to talk to professionals during the Covid-19 Lockdown?	8	1

Fig. 12 Breakdown of Responses for Facebook Polls

<u>Surveys</u>

When more in depth responses are required from parents, FVP create surveys using the online platform Survey Monkey. Surveys are taken anonymously, and as such demographics of parent carers are not collected, however, parents are required to affirm that they have a child or young person with SEND and provide their postcode to ensure Peterborough residency. Most recently, FVP have utilised Google Forms to enable parent carers to share their current situation, and map how this has changed as the lockdown progresses.

Survey Title	Number of Respondents
Community Equipment Provision Service	11
Preparing for Adulthood – Independent Living	7
Annual Survey	52
Covid-19 #1	94
Totals	164

Fig. 13 Responses per Online Survey

Strategic Work

Family Voice engage in a number of strategic workstreams, working in co-production with professionals across health, education and social care. Parent Representatives attend a wide variety of strategic boards, working groups and the SEND panel; a new system of specific monitoring has been put in place this year in order to accurately demonstrate the amount of time spent with these. These sessions are the platform which FVP mainly use to feedback information from parents into the system.

FVP have a total of 8 fully trained parent carers who are able to represent the views of others strategically. The parent representatives (reps) come from a wide range of backgrounds, with a mix of ethnicities and a range of additional needs between their children and young people. As such the reps are a wealth of knowledge on Peterborough's SEND systems and are able to offer signposting, advice and collective support to parent carers

whilst gathering their views. During this reporting period FVP have recruited and trained an additional representative, who will be joining the organisation on an ad hoc basis.

Number of	Hours Spent at	Administration	Travel Time	Total Hours
Sessions	Meetings	Time (Hours)	(Hours)	
46	84	63	55	202

Fig. 14 Sessions Attended by Parent Representatives

During this reporting period, Representatives of Family Voice have attended a total of 46 sessions with professionals across SEND Services. This has amounted to a total of **202** hours of time spent.

Short Breaks Provision

Family Voice own and manage two caravans in order to provide affordable short breaks to families who have a child/young person with an additional need or disability.

Butlins Skegness

At Butlins is a 2017 Rio Willerby Premier Wheelchair Accessible caravan, which has two bedrooms and sleeps 6.

Haven Caister:

At Haven Caister is a 38 foot long 2014 Swift Serenity which sleeps 8 individuals but is not fully disabled accessible. The caravan at Haven has proved to be less popular than that at Butlins, and as such in order to avoid running at a loss financially FVP have reached an agreement with Haven whereby they will sublet the dates that we do not fill with local families, boosting the income so that the short breaks offer remains sustainable.

The caravan sites operate between March and October each year. From August to October 2019 a total of 170 individuals have accessed this service and had a short break at one of our caravans. Unfortunately the Caravans and sites are currently closed as per government guidance. These will be reopened as soon as it is safe and practical to do so.