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# FVP Interim Report

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April – July 2019

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FVP Parent Representatives

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## Introduction:

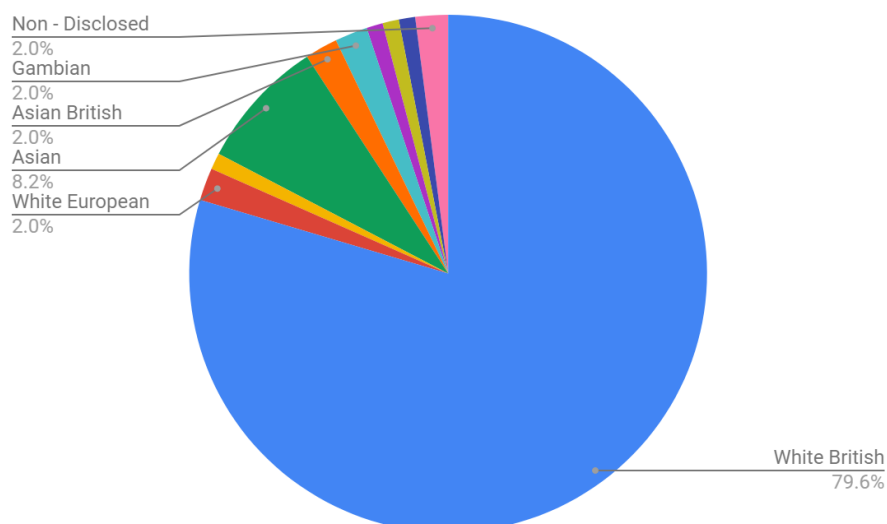
This period has been one of self reflection and development for Family Voice Peterborough. It was brought to our attention during the recent Peterborough Local Area Ofsted/CQC SEND inspection that we are viewed as being too focussed upon Autism Spectrum Disorder as a predominant need, and that regardless of our best efforts to date, we still needed to do more to engage with a wider variety of Peterborough parent carers. This feedback has been taken on board and number of steps have been taken as a result, including:

- A partnership with Peterborough Child Development Centre whereby our Parent Representatives attend different clinics on a monthly basis to gather feedback from new parents, and offer signposting to other services as required.
- A partnership with BGL via their Corporate and Social Responsibility department whereby we have benefitted from the expertise of their marketing department in order to ensure we are reaching as many individuals as possible with the advertising of the forum and our services.
- The creation of an online membership form enabling parents to join the forum directly via social media or the website.
- An increase in awareness and information stands at various locations across the city.
- A renewed focus on schools engagement, and the development and implementation of our “Schools Offer”.

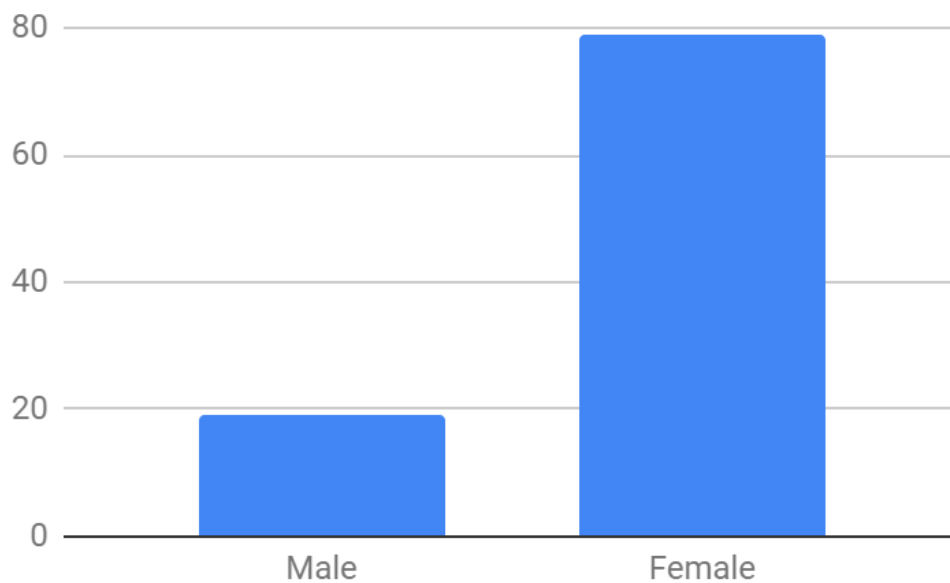
These steps are proving effective thus far. We have had increased levels of participation with seldom heard groups, specifically those of minority ethnic origin and fathers, and we are on course to increase our like for like participation figures for the year.

## Population

From April 1st - July 31st we have engaged with a total of 105 named parent carers on 125 occasions. 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 demographics of our named parent carers are displayed below:



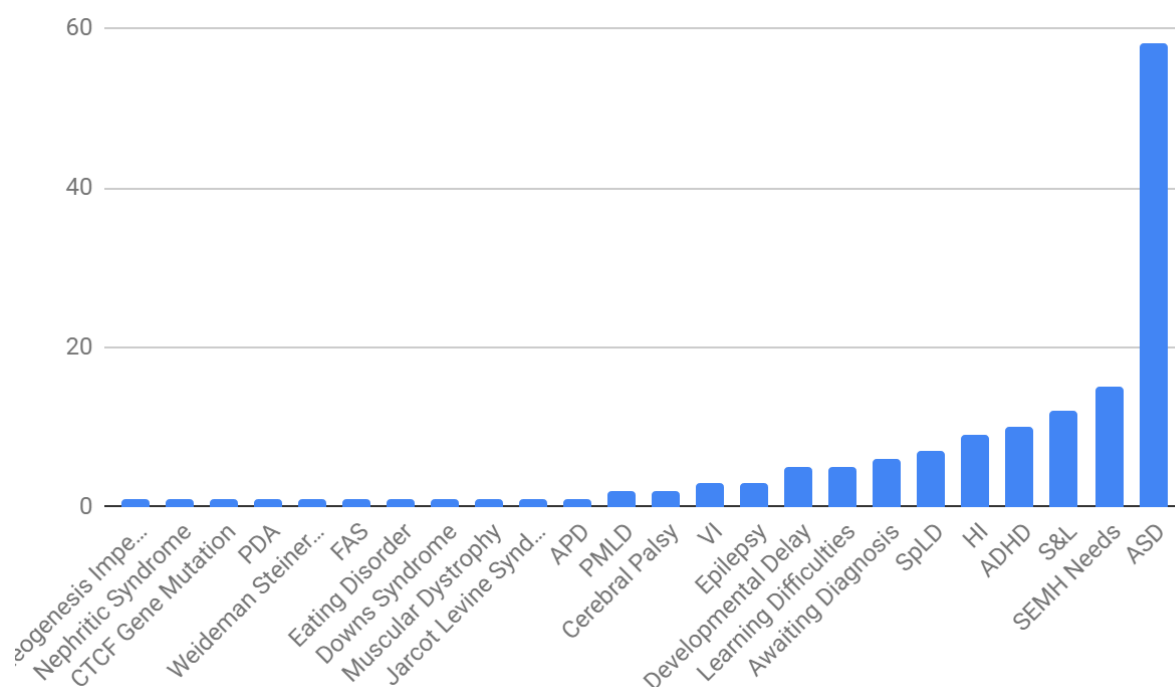
**Fig. 1 Ethnicity of Participating Parent Carers April - July 2019**



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**fig. 2 Gender of Participating Parent Carers April - July 2019**

As expected, the majority of parent carers who have engaged are White British females which is consistent with national trends. We actively seek to engage with seldom heard groups, and use a number of different methods to facilitate their participation. We maintain close links with the Aiming High Group - a community of Asian mothers who all have children with a Special Educational Need or Disability (SEND). As a part of our commitment to ensure they are able to engage we have two targeted events for the group so far this year: a workshop on carers rights and a family session at a local soft play centre. To date 19 male parent carers have engaged. A total of 41 Male parent carers engaged during the period of 2018/2019 and as such we are well on track to exceed that figure by the end of 2019/20/



**Fig. 3 Child/Young Person SEND as reported by parent carers**

Autism Spectrum Disorder (ASD) remains the predominant need declared regarding the children/young people of engaging parent carers, although it is important to note that we have engaged with numerous individuals whose details have not been collected - many of whom have children and young people with alternate diagnosis. Of the 60 individual declarations of ASD, 27 of those were stand alone, with the remaining 33 having a comorbid diagnosis. There are a large number of SEMH needs being disclosed, mainly manifesting as anxiety. Mental health services are a contentious talking point within Peterborough, with parents reporting that there is a lack of provision for young people with less severe needs. There is a wide variation of other declared needs, including Cerebral Palsy, Downs Syndrome, Visual and Hearing Impairments and Genetic conditions.

We have used a number of different methods to gather feedback from parent carers, with the most popular being Facebook interactions and Trips/Activities.

Each method will be discussed in detail below:

## Preferred Participation Methods

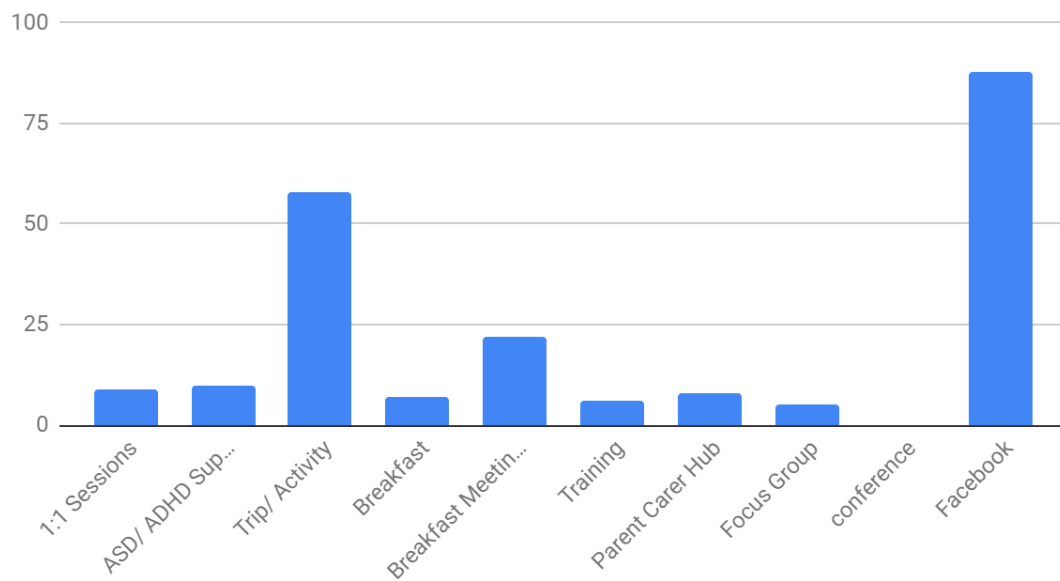


Fig.

**4 Breakdown of methods used to engage with parents**

## Events and Activities

Event Name	Date	Adult Attendees	Child/Young Person Attendees	Professional Attendees
Activity World Session	10/04/2019	34	79	0
Easter Egg Hunt	20/04/2019	7	19	0
Seldom Heard Activity World Session	09/06/2019	29	67	0
10 Year Anniversary Party	15/06/2019	41	61	21

**Fig.5 Breakdown of Attendees at our Events**

A total of 358 individuals have attended an event or activity so far this year. This figure is a mixture of parent carers, family members and professionals. We use these opportunities to meet new parent carers in an informal situation and gather their feedback anecdotally on SEND services. We also target specific work streams to individual events, for example, at our Seldom Heard Activity World session, parent carers were asked to complete our “your say” form to share their experiences so they could be anonymously shared with the Local Authority and the Ofsted/CQC Inspectors.

Parent Carer Hub, Focus Groups, Workshops.

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. There have been two run so far this year, with professionals from the Specialist Teaching Service, SEND Partnership and the Educational Psychology Team. The initial session had two parent carers booked on, with one no show. The second session was particularly popular, and became fully booked soon after initial advertising, both available services are viewed as prestigious and useful but hard to reach. All attending parent carers had sessions with both sets of professionals.

Hub Date	Services	Attendees
13/05/2019	Specialist Teaching Service: HI/VI and Physical Disability	1
03/06/2019	Educational Psychologists SEND Partnership	5

**Fig. 6 Attendees at Parent Carer Hubs**

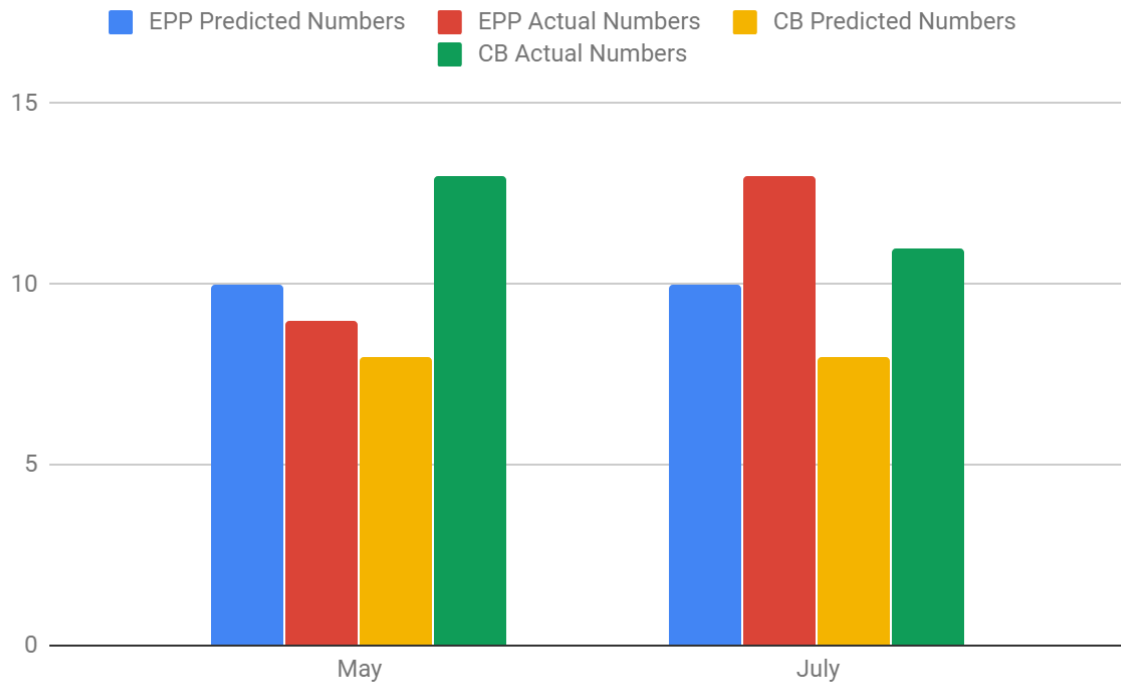
We have six focus groups planned in over the course of 2019/2020. The first of these was held in July and was attended by 6 Peterborough parent carers. The focus group was managed by professionals from Peterborough City Council in addition to representatives from Family Voice on the topic of Autism, and feeding back into the development of an all age strategy.

Within the time frame FVP have held one workshop targeted at women of the Aiming High group. The topic was Carers Rights and completing assessment forms, the workshop was attended by three female parent carers all of Asian descent.

Training

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. There has been a notable increase in uptake of these courses so far this year; this is inline with a push on face-to-face advertising as well as 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 and recommendations made to new contacts made at information stands.



**Fig. 6 Predicted vs Actual Attendees at training courses**

Upon completion of the courses, parents are asked to complete feedback forms. The feedback has been overwhelmingly positive, with examples of comments detailed below:

This course has been a great tool to aid me to achieve my desired outcomes for my children - thank you!

Brilliant course, full of lots of info

**Fig. 7 Comments gathered following training courses**

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. To date FVP have posted three polls to gather opinions and feedback and direct our workstreams:

Poll Name	Total Number of Responses
Approval of Schools Directory Format	44
Possible Workshops Topics	18
Type of Educational Setting Attended by Child/Young Person	26

**Fig. 8 Breakdown of Respondents per Facebook Poll**

Facebook polls are a quick and efficient way to gather feedback on a large scale. Parents are able to engage from the comfort of their own homes, which eliminates barriers relating to childcare, transportation and time.

Surveys



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 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. Information has been gathered to inform the Ofsted/CQC SEND Inspection, to provide an insight into parental experiences of communication and information sharing, and to gather feedback on parental input into educational settings SEN Information reports. Upon the closure of all surveys a full report is completed detailing the data collected, and is placed on our website at [www.familyvoice.org/participation](http://www.familyvoice.org/participation)

<b>TOI - Information Sharing and Communication</b> Created 04/11/2019	06/24/2019	10
<b>Peterborough's OFSTED/ CQC SEND Inspection</b> Created 06/03/2019	06/09/2019	18
<b>SEN Information Report</b> Created 05/27/2019	06/07/2019	11

**Fig. 9 Responses per Online Survey**

Child Development Centre and City Hospital Sessions

This period has seen the development of a new partnership with Peterborough Child Development Centre (CDC). On a monthly basis Parent Representatives attend the CDC on behalf of FVP, on a variety of differing clinic days, in order to raise awareness of the organisation with previously unaware parent carers. While onsite the reps gather service feedback, offer signposting and support and enable parents to sign up to our database and attend the training courses and events. These sessions are invaluable due to the nature of the location: almost all attending adults are parent carers.

There is not, as yet, a suitable feedback method being used to gather data from attending parents due to the informality of the discussions and pressures being faced to attend their appointments whilst with their children. Data on themes raised, numbers engaged and general demographics are captured by the Parent Representatives and fed back into an ongoing forum development document.

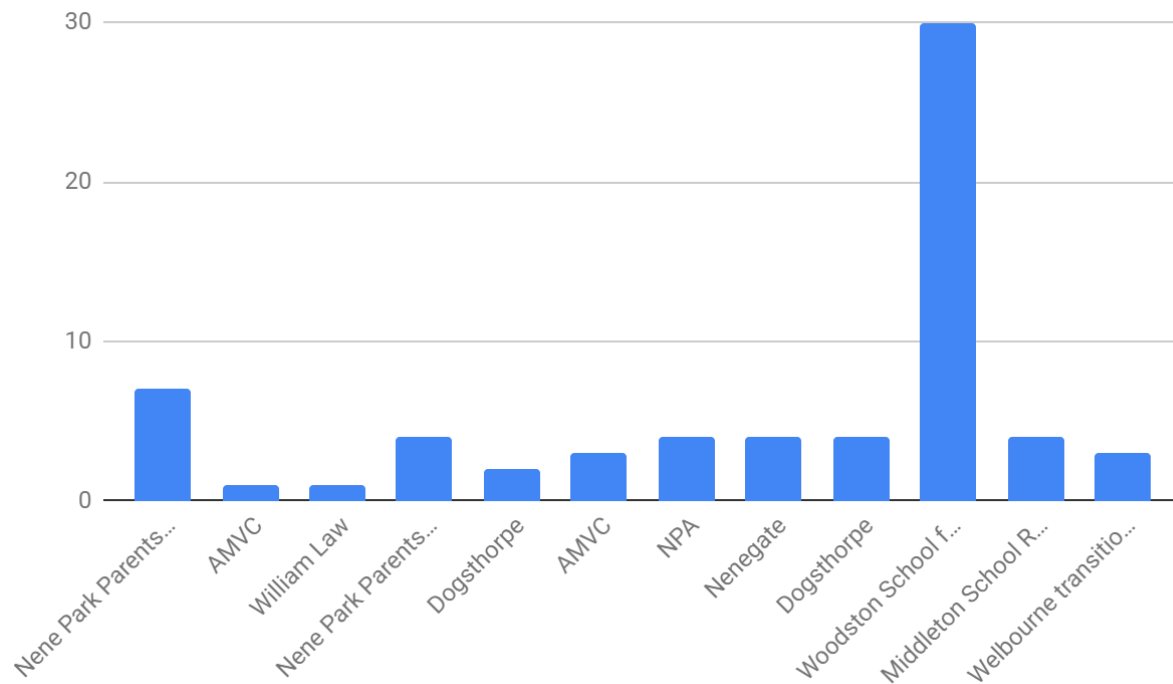
Date and Clinic Details	Number of Parents Engaged	Membership Packs Handed Out	New Members Signed up on the Day
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May - Downs Syndrome Clinic	10	5	1
May - Hearing Impairment Clinic	12	10	
June - ADHD Feedback Session and Cygnet Course	7	6	2

**Fig. 10 Details of Child Development Sessions**

Schools Work

During this period FVP has worked to solidify links with local schools, and continue holding parent sessions in individual settings. This has been in addition to the piloting of our “Schools Offer” work which is discussed in the next section. The meetings are designed to provide a location that parents are comfortable within, to enable them to come along and find out more about FVP and the services that we offer, whilst enabling the development of a peer support network and micro forums. Within the period we have held sessions at 8 different settings within Peterborough, with varying levels of attendance.



**Fig. 11 Breakdown of attendance at schools sessions**

The sessions with the highest attendance are those which have a dual purpose, ie: stands at parents evening or summer fetes. With those taken out of the equation the mean attendance

figure is 2.2 parent carers per session. Smaller sessions allow more time for Parent Representatives to hear individual stories and relay signposting advice; moving forward we are aiming for 6-8 parent carers per session, so that it becomes clearer to attendees that they are not alone in their predicament and there are other parents within the same setting with similar issues and concerns. There will be a review of the way the sessions are marketed to parents over the summer, with an increased push on attendance to start in the autumn term.

### Schools Offer

Family Voice Peterborough are currently in the process of launching a pilot programme for our School Offer. The School Offer came into being through the themes that kept on re-occurring through our work with parent-carers. There is a growing number of parent-carers who are dissatisfied with their relationships with the school their child or young person is attending. Schools in Peterborough are experiencing considerable financial difficulties in being able to meet their statutory duty to children with SEND due to a decrease in revenue support from central government. The impact of this is that trust and relationships are breaking down between parent-carers and educational settings to the point that the systems are being viewed as more adversarial and parents are increasingly feeling the need to fight to gain resources for their children from an ever shrinking pot. In our position as the parent-carer forum for Peterborough we are gravely concerned about the breakdown of these relationships and have developed our School Offer as a way to help repair and rebuild the trust and reconciliation in the relationships between schools and home.

With our School Offer pilot we are proposing to spend one academic year with the five selected educational establishments and provide information based coffee mornings, parent-carer training and consultation with SEN information reports and policies. The offer we are presenting will be of no-cost to the educational settings during the course of this year and in return we are asking for feedback from them throughout the process in order that we can further develop our School Offer. This pilot has the full backing of the Local Authority who are providing the funding to cover the costs for the year so we are able to offer it to our five selected educational settings for free. The offer we are developing would ordinarily cost in the region of £1950 per year.

The School Offer will comprise of the following three elements:

### Coffee Mornings/Afternoons & Micro Forums

The School Offer will initially begin with FVP coming into the educational setting for information based coffee morning/afternoon sessions at one per half term. We will work with the schools to set up, assist in advertising and provide support at the coffee mornings/afternoons. These coffee mornings/afternoons will be themed according to the particular needs of the demographic population of the educational setting. We aim to use these sessions to provide a supportive environment for parent carers to decrease feelings of isolation whilst simultaneously providing accurate information that leads to greater

empowerment, self efficacy and resilience.

These coffee mornings will be the springboard from which we will aim to educate parents on the principles of participation and co-production and these will form the basis of the micro-forums. The overall aim of this project is for the parents to assume responsibility for the coffee mornings and micro-forums and for these to be self-sustaining. The aspiration for the micro-forums is for them to be the vehicle from which SEND information reports and other SEND related policies and procedures can be utilised by the educational settings. Our vision is that by parent-carers and educational professionals working together this will open up and strengthen the lines of communication and thus lead to more positive and productive relationships.

### Parent-Carer Training:

Family Voice Peterborough has a highly trained team of professional trainers who have a great understanding of the local demographics of the population in Peterborough and the particular needs of parents with children with special educational needs and/or disabilities. We can provide a full or bespoke package for individual settings that will be based on the particular needs of their population. Our training includes:

**Parent Participation Workshop** - This is a one-day workshop designed to give parent carers an overview of the principles behind parent participation and how to work collaboratively with partners (professionals within the educational settings) to ensure their voice is heard. We understand that by gaining parent participation outcomes for children are improved.

**The Expert Parent Programme** - The EPP is a DoH funded programme in conjunction with the Council for Disabled Children. It is a parent carer empowerment programme that is designed to help families understand how to navigate the NHS system and to get the best out of their time with professionals to gain the best outcomes for their children.

**Behaviours that Challenge Workshop**- This CPFT course is aimed at parents who have children that may be exhibiting challenging behaviour due to difficulties with attention and/or social communication. These workshops give parents an insight into the difficulties that are faced by children with attention and/or social communication difficulties and strategies on how to manage their challenging behaviour.

### SEND Information Reports Service:

Family Voice Peterborough as part of their ongoing work annually audits schools SEN Policies and SEN Information reports over this time we have witnessed an improvement in the way that schools seek to support children with SEND. However, parents are frequently reporting that they feel unsupported, with this in mind how can schools redress this? One way is through how schools communicate their support on their websites, such as through the SEN Information Reports and SEN policies.

We have found that this is an area where some schools seem to be struggling and could

benefit from some guidance. At FVP we understand the pressures that schools are under to deliver services in an increasingly difficult economic environment. As an organisation part of our ethos is to seek to help empower professionals to continue to do the good work they are doing and being able to deliver best practice to our children with SEND.

FVP, as part of our School Offer we will meet with educational settings SENCo and review their current SEND Policies and/or SEND Information report and advised on areas that could benefit from improvement. We can help advise on content to ensure that educational settings are compliant with the SEN Code of Practice and the Children's and Families Act 2014 and help schools to showcase the dedication, enthusiasm and innovation that is taking place in their settings for children with SEND. When this service is used in conjunction with our coffee mornings/afternoons and training packages we will work together to promote co-production between parent carers and the school to endeavour that going forward this is a sustainable model.

### Work to Date:

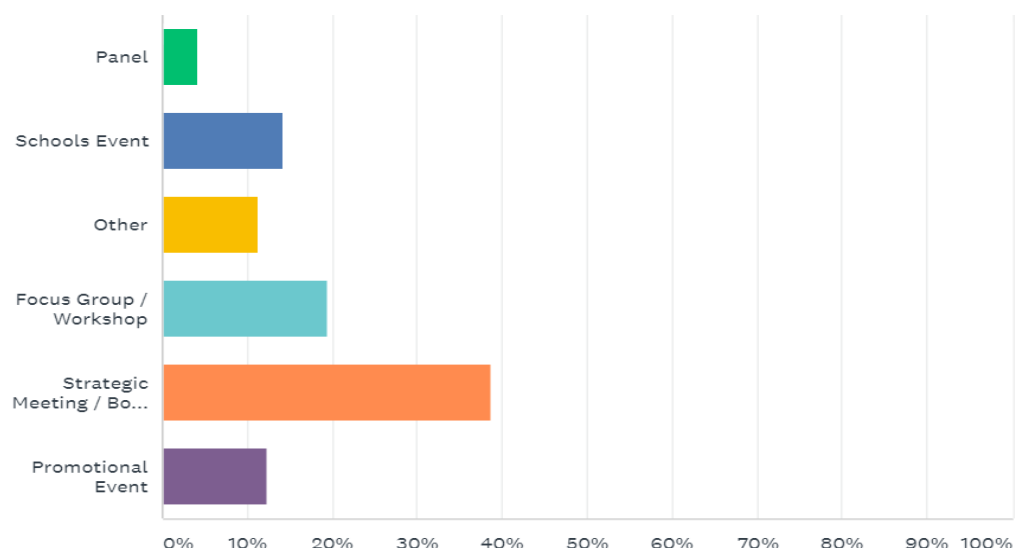
Contact has been made with five educational settings to date and they have all agreed to take part in the pilot programme for the School's Offer. Within the cohort we have three specialist schools and two mainstream secondary schools. These schools have been selected due to either previous good relationships or as an opportunity to increase our participation with parent-carers who may not currently engage with our services. The response to the Schools Offer by the educational establishments that we have entered has been overwhelmingly positive and displays a real desire by schools to increase engagement with parents and improve outcomes for children with SEND.

### 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 we mainly use to feedback from parents into the system.

## Meeting Attended

Answered: 98 Skipped: 0



**Fig. 12 Sessions Attended by Parent Representatives**

The majority of sessions attended have been in the form of strategic boards and meetings. FVP sit on a number of different boards, including the Learning Disability Partnership Board, Physical Disability Partnership Board, Child and Young Person Mental Health and Wellbeing Board and play an active role in SEND Partnership work.

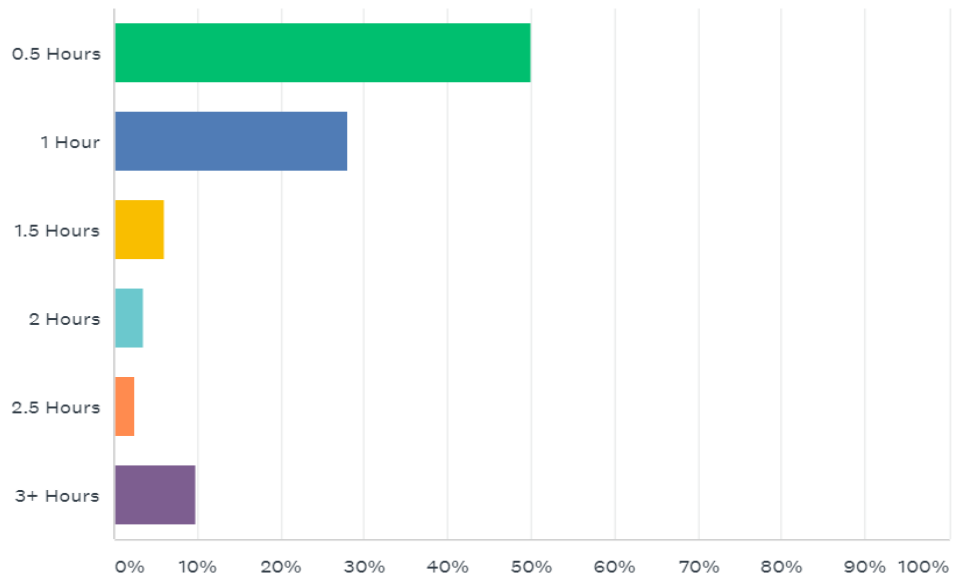
ANSWER CHOICES	RESPONSES	
▼ 1 Hour	27.84%	27
▼ 1.5 Hours	20.62%	20
▼ 2 Hours	22.68%	22
▼ 2.5 Hours	8.25%	8
▼ 3 Hours	2.06%	2
▼ 3.5 Hours	1.03%	1
▼ 4 Hours	3.09%	3
▼ 4.5 Hours	2.06%	2
▼ 5 Hours	4.12%	4
▼ 5.5 Hours	2.06%	2
▼ 6 Hours	4.12%	4
▼ 6.5 Hours	0.00%	0
▼ 7 + Hours	2.06%	2
<b>TOTAL</b>		<b>97</b>

**Fig. 13 Breakdown of time spent at events/meetings**

Since April 1st Parent Representatives have spent in excess of 211 hours at the events as broken down in figure 12, time spent travelling and completing related administration is displayed below:

### Administration/ Preparation Time

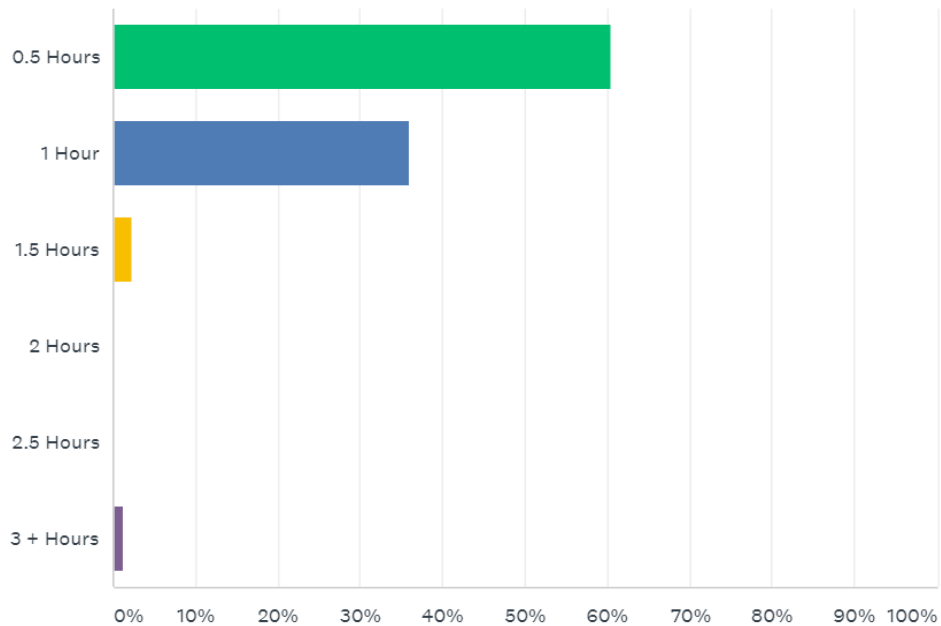
Answered: 82 Skipped: 16



**Fig. 14 Breakdown of Administration and Preparation Time for Events and Meetings**

# Travel Time

Answered: 86 Skipped: 12



**Fig. 15 Breaktime of time spent travelling to events and meetings**

In addition to feeding back to strategic boards, Family Voice have commenced using the National Network of Parent Carer Forums preferred information sharing tool; Topics of Importance (TOI). These documents are an in depth investigation into the most pressing issues reported by parent carers, and an amalgamation of feedback from service users.

There are five TOI's planned for submission through 2019/2020 - the first being Parents on Panel, submitted in April to Peterborough City Council and Responded to shortly thereafter. The TOI and it's response can be viewed on our Website at [www.familyvoice.org/participation](http://www.familyvoice.org/participation). The second planned TOI is Information Sharing and Communication and is due for submission imminently.

In order to feedback effectively to board meetings, a document is produced and updated frequently compiling an overview of forum progress to date, and a section detailing parent carer feedback, concerns and common themes that are being reported. This method enables our representatives to effectively depict a view of gaps in service provision, what is working well and what needs improving as well as how positively service users view the SEND systems.

## Enabling Wider Engagement



During this period we were made aware of a small minority of parent carers who did not want to engage via the forum, yet still wanted their voices to be heard. Our overarching goal as a forum is, and always has been, to break down barriers and enable full parent carer participation. In order to enable these parents to participate, FVP published a public statement offering any individuals the opportunity to set up a meeting with directors at Peterborough City Council at a location funded by the forum. This offer was taken up, and a meeting was arranged and paid for at The Fleet. In order to ensure attending parent carers were fully comfortable there was no involvement or attendance by any of the FVP team.

### 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:



**Fig. 16 FVP Caravan at Butlins Skegness**

At Butlins is a 2017 Rio Willerby Premier Wheelchair Accessible caravan, which has two bedrooms and sleeps 6. Since the season opening in March, 23 families have made use of this caravan, a total of 109 individual adults and children.

Haven Caister:



**Fig. 17 FVP Caravan at Haven Caister**

At Haven Caister is a 38 foot long 2014 Swift Serenity which sleeps 8 individuals but is not fully disabled accessible. Since the season opening in March, 11 families have made use of this caravan, a total of 70 individual adults and children. 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.

### Parent Carer Experiences

Areas where parent carers say they are unhappy:

1. ASD support in mainstream settings
  - a. Part time timetabling is reported
  - b. Parent carers feel not listened too and isolated
  - c. Feel settings do not understand needs - CYP often reported as good in settings and behaviour escalates when collected at the end of the school day
  - d. Feel they have no option but to homeschool - forced on them, not a choice
  - e. Lack of support for "school refusers"
2. ASD Support in General
  - a. Not enough for young people 19 to 25

- b. College choices are not viable choices - geared more to those with LD or no needs
  - c. Having to make use of major pushchairs/ nappies that are purchased on the open market - lack of access to physio/ OT/ Continence
3. Complex Needs and Physical Disabilities Service and Support
- a. Provision does not meet the needs of CYP and is not understanding of physical barriers
  - b. Continence service not good - rationed pads and quality of pads an issue
  - c. No PfA options from parent carer perspective