

1<sup>st</sup> April 2016 to 31<sup>st</sup>  
March 2017

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



fvp

Family Voice Peterborough

11/1/2016

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## Executive Summary

### **Purpose**

Participation occurs at an individual and strategic level where services are designed and delivered based on this participation. The Special Educational Needs and Disability (SEND) reforms have shaped how parent participation is occurring locally, and the work on the services such as the Early Help Pathway and support offered demonstrates this. The right to have a voice and participate have been further embedded through the Section 19 Principles of the Children and Families Act 2014. This report is intended to provide a snapshot of what is happening for parent carers in terms of support and participation opportunities.

Why Family Voice Peterborough, why parent carers? To answer these questions the report contextualizes parent participation and parent carer forums and goes on to demonstrate the work of the Family Voice Peterborough (FVP) primarily, with some detail on work also involving Pinpoint through partnership working.

Unlike the previous iteration of this report covering the academic year 2015 to 2016 which focused solely on participation this report will also look at FVP as a charity and how the charitable purposes as defined in FVP's objects are met by the Board of Trustees. There is some repetition between the last report and this one especially in the context section as this information has not changed.

This report also provides evidence to support grant funded work and demonstrates how outcomes have been achieved or in some areas exceeded. The different chapters can be used as stand-alone reports for monitoring purposes relating to specific income streams.

### **Section One: CAMHs Transformation and Early Help Pathways**

The development of the Early Help Pathway, which is part of the Child and Adolescent Mental Health service (CAMHs) Transformation programme, has impacted on parent carers. Due to the constantly changing systems, parent carers have reported confusion and experience of negative journeys through the pathway(s). FVP and Pinpoint Cambridgeshire have been involved in enabling parent participation in developing this pathway, from pathway development to delivery of some services available via the pathway.

#### **Key themes;**

1. There is misunderstanding of the pathway with an associated lack of knowledge of what support is available, which means better marketing is required.
2. Work has been slow with less numbers attending the Behaviours that Challenge Workshops, The Expert Parent Programme (EPP) and Autistic Spectrum Disorder (ASD)/ Attention Deficit Hyperactivity Disorder (ADHD) Support Groups. There has also been less work occurring across Cambridgeshire compared to Peterborough for Behaviours that Challenge Workshops and The EPP with the reverse being true for the ASD/ ADHD Support Groups. There has also been some change to how data is presented for the ASD/ ADHD Support Groups.
3. Those who take part in the pathway support programme provide positive feedback.
4. The data gathered in terms of costs/ attendance/ outcomes is used to further inform commissioning relating to Emotional Mental Health and Wellbeing.

## **Section Two: SEND Reforms**

The SEND reforms have changed how parent carers engage with, and become involved in, SEND services their children/ young people access. SEND covers various areas including the Local Offer, Education Health and Care plans (EHCP's) and processes, Personal Budgets and Independent Support all of which are explored in relation to understanding and experience.

Key themes;

1. FVP survey data has shown there is still mixed understanding and experience of the SEND Reforms.
2. The Local Offer (LO) is under used and viewed negatively.
3. Independent Support is viewed very positively when used but uptake is very low compared to the numbers of new EHCP's and transfers from statements to EHC plans.
4. Experience of transfers from Statements to EHCP's is mixed with parent carers reporting positively and negatively.

## **Section Three: Participation**

Parent Participation in Peterborough is based on the ladder approach, but with the understanding parent carers can participate in any way they choose. Participation data, methodologies and evidence are explored in section three of this report.

Key themes;

1. Participation is varied and parent carers are representative of a diverse populace with reported children/ young people needs varying from ASD through to Complex Health.
2. Parent carers participate through FVP or directly through the LO.
3. Parent carers engage with many local groups/ organisations/ charities for the purposes of support, advocacy and short breaks/ activities.
4. Online methods of participation are preferred with the use of a Facebook chat room leading to an increase in numbers taking part in polls and topic specific discussions.
5. Understanding of participation is still varied amongst parent carers and professionals.

## **Section Four: Seldom Heard**

Participation from parent carers who are considered as seldom heard is often low, and more focused on information or engagement at best. The work in this area has been undertaken by the FVP's Participation Co-ordinator who is herself considered a "seldom heard parent carer". Time has been spent gaining trust, signposting and finding alternative ways to enable participation.

Key themes;

1. Parent carers from the Black Asian and Minority Ethnic (BAME) community have taken up training opportunities with two now acting as parent representatives.
2. There is increasing engagement from a more diverse range of parent carers and some work has started based on responding to needs they have identified. This includes the introduction of SEN surgeries run in conjunction with the Statutory Assessment and Monitoring (SAM) service from Peterborough City Council (PCC).
3. More parents are attending working breakfast sessions and focus groups to participate in work relating to areas such as short breaks.
4. A key outcome is that Parent carers have co-produced a guide to the Child Development Centre (CDC) to help other families access the local service.

**Section Five: Meeting the Charity's Purpose**

The charity has been through much change in the past year including a move to new premises and recruiting of a new trustee. There has been a growth in the number of parent carers signing up to the forum membership to over 650 households which is approximately an 18% increase on the previous financial year. Work has been taking place to find ways to meet the charity's purpose as defined in its objects.

**Key Themes;**

1. FVP have secured funding to upgrade the caravan at Butlins Skegness to a fully accessible caravan.
2. FVP now have four members of staff, a new trustee and support over 650 households where there is at least one child/ young person with SEND
3. FVP have been working closely with Peterborough and District Deaf Children's Society (PDDCS) and Families First to assist the them in supporting a growing number of families with varying needs.

**Acknowledgements**

Participation, and ultimately co-production, occurs when systems are changed and when people see the value of working together to change those systems for a common goal, which in this case are children and young people with SEND. This report reflects changes occurring due to an increasing level of participation and in some areas co-production.

None of this would be possible without the hard work and dedication of parent carers in Peterborough who act as parent representatives (past and present) and the value placed on parent carers participating by Local Authority and Clinical Commission Group commissioning officers.

Also a thank-you should go to all the parents who have taken part at some level as they take time away from their busy lives providing care to their children/ young people with SEND to do so

## **Introduction**

This report details the work of FVP in the main but will also contain reporting from Pinpoint in relation to a joint programme, funded through the CAMHs Transformation work of Cambridgeshire and Peterborough Clinical Commissioning Group (CCG), as detailed in section one. The report will be ordered into five sections; CAMHs Transformation, SEND in Peterborough, Parent Participation, Seldom Heard and Health Participation and FVP as a charity. All sections are structured around the financial year April 2016 to March 2017.

Qualitative and Quantitative methodologies have been employed to gather the evidence presented in this report and to demonstrate what outcomes may be occurring in relation to work programmes. However this is not intended to be a research paper, rather it is a report in to parent participation and how this relates to service development and delivery of services relating to SEND. Conclusions will not be drawn in to any data presented but a brief analysis will be provided in some sections.

There is repetition amongst some of the sections and cross over in the work mentioned and evidence of participation presented. The sections are intended to either be read as part of this report or taken as individual reports for monitoring purposes. The last section is taken from full FVP Trustees Annual Report.

## Participation/ Engagement/ Involvement April 2016 to March 2017

### Headlines

- 206 parents in total have been involved at some level via face to face meetings/ events/ trips/ Facebook Polls and Discussions.
- >105 professionals have been involved at some level via face to face meetings/ events/ attending training or co-delivering training.
- 128 parents have taken part in via eight surveys.
- 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)
  - Inspire Peterborough
  - Carers Trust Peterborough
- Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
  - ASD, ADHD,
  - Global Developmental Delay (GDD),
  - Speech, Language and Communication Needs (SLCN),
  - Complex Health, Obsessive Compulsive Disorder (OCD),
  - Cerebral Palsy (CP),
  - Tourettes,
  - Leukaemia,
  - Learning Disability and Difficulty (LDD),
  - Hearing Impairment (HI), Depression, Behavioural Needs,
  - Achondroplasia,
  - Goldenhar Syndrome,
  - Duchene Muscular Dystrophy,
  - Downs Syndrome,
  - Hypochondroplasia,
  - Physical Disabilities
  - Anxiety Disorder
- Approx. 15 fathers have been involved which is an increase on the previous year and 1 father has had regular involvement in person and another via social media
- Parent carers reported the ages of their children/ young people as between 2 to 34.
- 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.
- Evidence is both qualitative and quantitative in nature.
- Ethnicity has been self-reported as; British, Pakistani, Afghanistan, White Mixed Caribbean, Albanian, Belgian, Hungarian, Dutch, American, Portuguese, Chinese, Brazilian, Gambian, Kenyan, Polish, Czech, Ukrainian, Slovakian, Irish Traveller, Romany.
- Data has been evidenced through completed feedback forms, attendance registers, social media groups posts, completed online surveys and written case studies.

## **Context**

FVP are 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). There are currently over 150 parent carer forums (PCF) for England with each one representing a local authority area. Representation on the NNPCF is based on regions of which there are 9. FVP is a member of the Eastern Region Parent Carer Forum (ERPCF) of which there are 11.

**Table 1 – ERPCF Details (2016 to 2017)**

Area	Forum Name	Forum Membership	Funding
Bedford Borough	Bedford Borough Parent Carer Forum	251	£15 DfE £15K LA (Participation) £15K LA (SEND)
Cambridgeshire	Pinpoint	>1000	£15K DfE £70k LA £18k Health
Central Bedfordshire	Special Needs Action Panel Central Bedfordshire Parent Carer Forum	116	£15k DfE £37kLA
Essex (2015 to 2016)	FACE (Families Acting for Change Essex)	1500	£15K DfE £30K LA
Hertfordshire	Herts Parent Carer Involvement	570	£15k DfE; £10K LA (Education); £7.5K LA (SEND Training) £20K LA (Social Care - SEND)
Luton	Luton Parent Carer Forum	234	£15K DfE £15K LA
Norfolk	Family Voice Norfolk	624	£15K DfE and approx £40K LA
Peterborough, City of	Family Voice Peterborough	>650	£15K DfE £25K Health £45K LA SEND £8K LA Early Intervention
Southend on Sea	Family Voice Southend-on-Sea	250	£15k DfE
Suffolk	Suffolk Parent Carer Network		
Thurrock	Thurrock Parent Participation Group	193	£15K DfE and some carry over from £17K LA start up grant



Each forum has one or two representatives on the ERPCF, and the ERPCF is represented on the NNPCF steering group by an elected member from the EPRCF. The NNPCF effectively represents over 80,000 parent carers across England.

The choice of operating model of the individual forums rests with the parent carers who are involved in running them, but certain parameters exist in relation to being recognised as the DfE funded forum and member of the NNPCF. The forums that form part of The ERPCF have different operating models, from registered charities through to Independent Steering Groups and Community Interest Companies (C.I.C). Some of the forums, such as Family Voice Southend-on-Sea, are small and rely solely on the DfE grant, whilst others are much larger, such as Family Voice Norfolk who receives LA funding of approximately £45K per annum on top of the DfE grant.

To receive the DfE grant for parents forums certain parameters are put in place whereby the forum must be;

1. pan-disability,
2. not involved in one service only,
3. represent parent carers not children and young people,
4. be an avenue for participation not support,
5. not support one family only to access support and/ or services

*“There is only one grant for each local authority area. The grant will be awarded to the parent carer forum or organisation who can demonstrate that they will use the grant to develop credible and inclusive parent led participation and co-production within their area, and who has the support of the local authority. The purpose of the grant is to:*

- *strengthen and sustain parent carer participation*
- *maintain, enhance or increase effective parent carer participation”*(Contact a Family, 2016)

Organisations other than independent parent carer led groups can hold the DfE grant, but as specified above by Contact a Family (CaF) the funding should be used to develop parent led participation. Some forums have their grant held and managed on their behalf. This context will be explained further in the next section (Background to FVP and Pinpoint).

CaF are the current parent participation support partner for the NNPCF, and the organisation who have been chosen by the Government to administer and monitor the DfE grant for forums. Put simply NNPCF are the “voice” of parent carers and CaF are the grant programme administrators.

There is now a statutory requirement to include children and young people with SEND and their parent carers in decision making and parent carer forums are a route by which this can be facilitated.

**Section 19 of the Children and Families Act 2014**

Local authority functions: supporting and involving children and young people

In exercising a function under this Part in the case of a child or young person, a local authority in England must have regard to the following matters in particular—

- a) the views, wishes and feelings of the child and his or her parent, or the young person;
- b) the importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned;
- c) the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions;
- d) the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.

**SEND Code of Practice January 2015**

Parent Carer Forums

1.13 Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families. Parent Carer Forums have been established in most local areas and local authorities are actively encouraged to work with them. More information about Parent Carer Forums is available from the websites of Contact a Family and the National Network of Parent Carer Forums.

Parent Carer Forums are also referred to in sections 2.6, 2.8, 3.18, 3.29, 3.35, 3.44, 4.9, 4.10, and 4.23 in relation to Impartial Information Advice and Support, Working together across education, health and care for joint outcomes and the Local Offer

## **Background – Family Voice Peterborough**

The Aiming High for Disabled Children programme was launched in May 2007. Its stated aim was “*to improve service provision across the board for disabled children and their families, enhancing equality and opportunity for them*” (DfE formally DCFS, 2007, archived webpage). The Parent Participation work stream of Aiming High was “*designed to develop the active involvement of parents in service planning and decision making processes at a local level to ensure that parents are active agents in shaping services*” (DfE formally DCFS, 2007, archived webpage). Some of FVP’s grant monies were provided through aiming high for disabled children and administered by Together for Disabled Children (TDC). There was a five million pound grant programme to be delivered to groups setting up as forums and administered in three phases over three years between 2008 and 2011. The Aiming High Programme and TDC ended in March 2011.

The previous government (2011 to 2015) committed to continue with the parent participation programme until 2013, and then the current government (2015 to 2020) also committed to continue it further until 2018 due in part to the SEND reforms.

FVP was formed in May 2009 under the umbrella of the Voluntary Sector Forum, who received the initial £3000 aiming high for disabled children (AHDC) grant in January 2009. The initial £3000 was to establish a parent led voice for participation in disabled children’s services. The main person supporting FVP initially was Bev Walsh. The funding was used to hold two key events in March to raise awareness of Aiming High for Disabled Children and to ask parents to sign up or express an interest in setting up a forum. The Voluntary Sector Forum applied for Phase 2 of the Parent Participation Grant Programme from Together for Disabled Children. The application for Phase 2 was £10,000 submitted to TDC and was successfully awarded to in May 2009. The funding was used to set up a steering group and organise the new Parents Forum Family Voice Peterborough. When the Voluntary Sector Forum closed due to loss of funding in October 2009, the parents involved formed an independent voluntary steering group called Family Voice Peterborough. The steering group was led by co-chairs Michelle King and Louise Ravenscroft. The steering group went on to secure the phase 3 grant of £10,000 in 2010. In 2010 the steering group also went through some changes due to growth, the need to secure extra resources and the changing needs of those involved in running the forum. Michelle King stepped down and became involved in setting up Little Miracles with Tessa Capon. FVP helped in this process and held the initial £5000 LA grant used to set Little Miracles. At the same time, with support of CaF, Louise Ravenscroft went on to chair FVP and was supported to move the steering group towards taking on charitable status as of 23<sup>rd</sup> March 2011. During this period PCVS also provided some vital support in the form of office space and administration resources.

## **FVP as a Charity**

FVP currently operates as an unincorporated charity; registration number: 1141009. 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 has also expanded during this period from having a mailing list of just over 50 families and running entirely voluntarily to over 700 to having paid employees and running a community premises.

Table 2 – FVP Principles

PRINCIPLES FOR FAMILY VOICE PETERBOROUGH					
Parent Carer Focus	Engagement/ Participation	Training	Development	Information and Communication	Funding
We will ensure the voices of parent carers are heard throughout the health, education and social care system and their views drive planning and delivery in collaboration with LA and Health Professionals	We will enable parent carers to participate in ways they are comfortable with and to ensure as many parent carers are included as possible. We aim for FVP to be fully inclusive	We will invest in parent carers by way of enabling them to gain accredited qualifications in training and facilitate their involvement in developing and delivering training.	We will encompass the voices of parent carers in growing numbers to support the on-going development of the organisation and include their views in any future planning.	We will share information and intelligence between professionals and parent carers to allow the best possible services for children with additional needs and disabilities.	We will seek to ensure further sustainability in financial terms.
INDICATORS/EVIDENCE THAT WOULD REFLECT MEASURABILITY/ ACHIEVEMENT OF THE PRINCIPLE					
<ul style="list-style-type: none"> <li>Numbers of meetings/ focus groups and feedback.</li> <li>Annual conference which has themes decided by parents</li> <li>Network dinner attendance</li> </ul>	<ul style="list-style-type: none"> <li>Reports produced will demonstrate mixed use of methods</li> <li>Numbers of parent carers participating</li> <li>Attendance at HTRG meetings, feedback and increase range of parent carers participating</li> </ul>	<ul style="list-style-type: none"> <li>PTLLS trained parent carer team</li> <li>Team of parent carers listed on CDC website as approved EPP trainers</li> <li>Suite of in house training programmes developed</li> </ul>	<ul style="list-style-type: none"> <li>The use of away days for the growing team of volunteers, reps and staff</li> <li>A clearly devised business plan</li> <li>Feedback form parent carers via surveys and feedback forms</li> </ul>	<ul style="list-style-type: none"> <li>A quarterly newsletter will be shared amongst parents and professionals.</li> <li>Regularly updated website</li> <li>Updated Facebook page</li> <li>Increased numbers on mailing list</li> </ul>	<ul style="list-style-type: none"> <li>We will have held at least 3 fundraising activities over the year.</li> <li>We would see to develop a clear fundraising strategy and action plan</li> <li>A completed funder finder and at least 3 grants applied for</li> </ul>

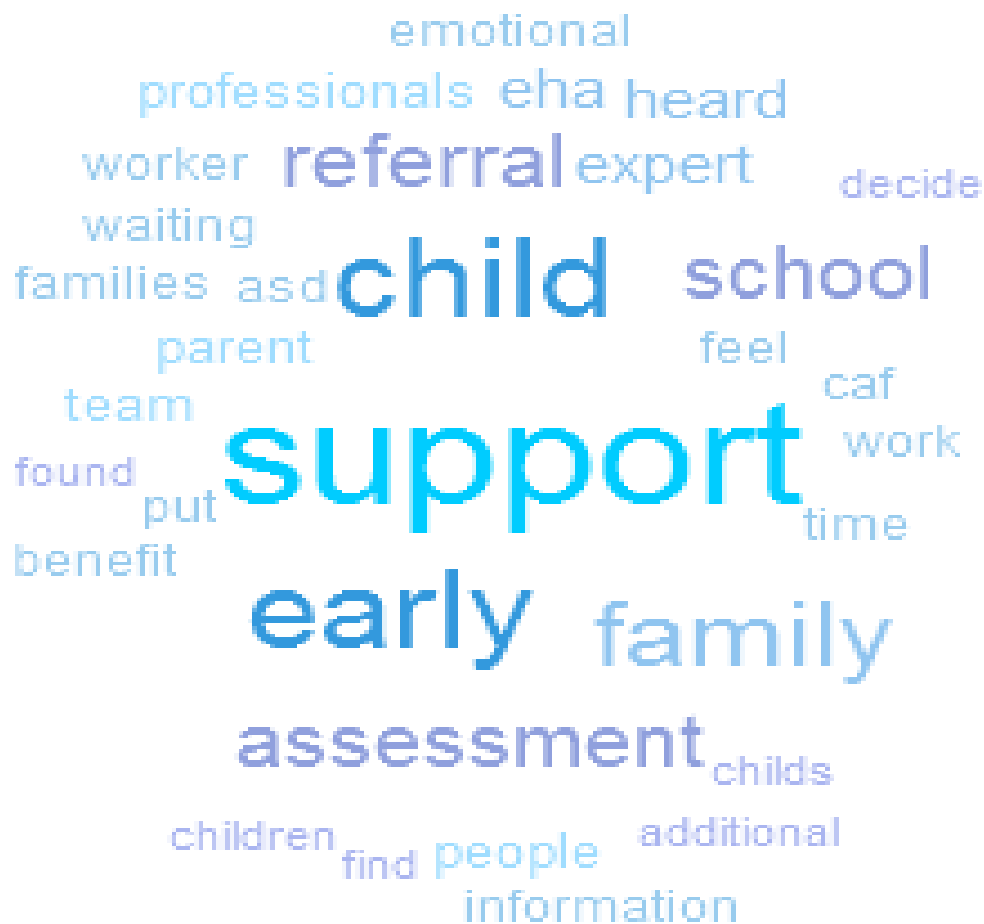
## **Background – Pinpoint**

Pinpoint Cambridgeshire was founded in October 2008 as a community organisation and parent carer forum with the aim to bring parents' views to the local Aiming High for Disabled Children agenda. Pinpoint became a Charitable Incorporated Organisation (CIO) June 2014 and now runs as an independent charity with a Board of Trustees. Pinpoint has 6 part-time staff, 4 are parent carers. We have over 50 volunteers registered with us and over 850 parents on our mailing list. We continue to receive funding from Cambridgeshire County Council for parent participation and from the Department of Education as Cambridgeshire's parent carer forum. We also receive grants from other sources to run support groups and training.

We run termly parent participation events across Cambridgeshire's five districts to gather parents' views around agreed 'hot topics' such as SEND reforms and mental health. We also run regular information and support groups on preparing for adulthood, self-harm and autism / ADHD. We attend strategic board meetings as parent representatives and send parent representatives to workshops, meetings and events. We signpost and support parents who contact us via telephone, email and Facebook. And we raise concerns regarding services to senior management and local councillors as needed. If needed, we run Action Groups or bespoke workshops with parents, commissioners and providers with an aim to improve services e.g. wheelchairs, continence and dyslexia. We've recently introduced an 'Are you listening to parents?' form to ensure we get feedback on how parents' concerns are being addressed. Finally, we chair the Partners in Commissioning Group which is a collection of parent representatives, commissioners and senior managers from health and the local authority to address and action issues raised by parents through our work.

Written By Lenja Bell (Pinpoint CEO)

## **SECTION ONE (CAMHS TRANSFORMATION)**



Word Cloud (Formed from parent carer feedback comments)

## **Introduction**

FVP and Pinpoint have been working in partnership since September 2015 in a joint funded project delivering support, training and participation opportunities to parent carers across Cambridgeshire and Peterborough. The partnership work is a joint funded project through the CAMHs Transformation programme. Between September 2015 and March 2016 a pilot was conducted that offered parent carers, who had children, and young people with behaviours that challenge associated with possible ASD/ ADHD and LD, training and support opportunities. The pilot was conducted after some joint participation work by both FVP and Pinpoint demonstrated concerns with ASD/ ADHD referrals, pathways and support.

(*CAMHs Focus Group*, [www.familyvoice.org/participation](http://www.familyvoice.org/participation) and *CAMHs Report*, [www.familyvoice.org/participation](http://www.familyvoice.org/participation))

This work has continued in the financial year 2016 to 2017 and will be funded from 2017 to 2018; the data gathered so far will be referred to in this report. FVP data will be for May 1<sup>st</sup> 2016 to March 31<sup>st</sup> 2017 and Pinpoints data will be for June 1<sup>st</sup> 2016 to March 31<sup>st</sup> 2017. Following this will be a synopsis of what has occurred so far for FVP and Pinpoint.

## **Family Voice Peterborough**

FVP have continued to deliver the EPP, Behaviours that Challenge Workshops and work around what is being termed a “parent carer hub” in place of the originally planned Care and Treatment Review (CTR) work. The reporting period is May 2016 to March 2017, with the start date being May due to when funding was received and also capacity issues of the organisation.

During this reporting period there was also a hiatus during the Summer Holiday as the work is being delivered mainly by parent carers and FVP took time to look at how work was progressing, complete some interim monitoring and spend time planning work for the next school term.

Each workshop and training session has an associated report detailing attendance, feedback, trainer perspective and a general synopsis of the session. All individual data is then collated to help present an overall picture.

**Table 3 - Outcomes Matrix – FVP responsibilities**

Part of the outcomes matrix has been included to demonstrate what has been achieved so far by inclusion of examples of outputs and measures.

No	Outcome	Output/activity	How Measured	Whose Responsible
4	Increased resilience and confidence in navigating health pathways and services and increased partnership working with health professionals (collective individual participation)	<ul style="list-style-type: none"> <li>• Delivery of Expert Parent Programme by CDC approved trainers who are themselves parent carers</li> <li>• Access by early help pathway and self-referral if space is available.</li> <li>• Appropriately advertised using variety of methods</li> </ul>	Quarterly reporting detailing - <ul style="list-style-type: none"> <li>• Number of session provided - target of 10 in Peterborough and 10 in Cambridgeshire</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> </ul>	FVP
	What has happened so far	<ul style="list-style-type: none"> <li>• EPP advertised using various methods</li> <li>• Sessions run across Cambs/ Pboro</li> <li>• Referrals via MASG/ Early Help Team (Low)</li> <li>• More referrals through schools, CPFT and self-referral</li> </ul>	<ul style="list-style-type: none"> <li>• 8 Sessions in Peterborough</li> <li>• 1 session in Wisbech</li> <li>• 38 attended and 22 no show (two of these have gone on to complete the EPP)</li> </ul>	
5	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>• 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</li> </ul>	Quarterly reporting detailing - <ul style="list-style-type: none"> <li>• Parents and carers self-report positive change in their communications with the health providers and their partners</li> </ul> Case studies provided (1 per quarter)	FVP
	What has happened so far	<ul style="list-style-type: none"> <li>• All workshops have been either delivered by parent carers</li> <li>• Feedback from workshops, training is used to inform commissioning cycle with respect to how parents are navigating the health system (Early Help for example)</li> </ul>	<ul style="list-style-type: none"> <li>• First quarterly report was produced and presented for monitoring purposes</li> <li>• Data in report details views on the work and access to range of support, training</li> </ul>	



6	Increased confidence from parent carers in managing behaviours that challenge that are associated with possible ASD/ ADHD/ LD	<ul style="list-style-type: none"> <li>Parent carers gaining new skills through sharing of hints/ tips from professional and signposting from parent reps</li> <li>Access to the workshops is via self-referral with bookings taken by Pinpoint and Family Voice</li> </ul>	Quarterly reporting detailing - <ul style="list-style-type: none"> <li>Parent carers self-reporting that they are able to manage children's behaviour better</li> <li>Parent carers self-rating their confidence at the start and end of the workshops for comparison purposes</li> <li>Access measured via social media requests, email and phone logs and completed attendance register</li> </ul>	FVP
	What has happened so far	<ul style="list-style-type: none"> <li>3 workshops have been co-delivered</li> <li>Feedback from workshops, training is used to inform commissioning cycle with respect to how parents are navigating the health system (Early Help for example)</li> </ul>	<ul style="list-style-type: none"> <li>Completed feedback forms detailing confidence and understanding</li> </ul>	
7	Training and Development so Parent carers have increased skills, knowledge to facilitate self-help	<ul style="list-style-type: none"> <li>Undertake the co-planning of workshops 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/FVP</li> <li>Parent carers gaining new skills through sharing of hints/ tips from professional and signposting from parent reps</li> </ul>	Quarterly reporting detailing - <ul style="list-style-type: none"> <li>Number of workshops provided - target of 6</li> <li>Details of workshop content</li> <li>Number of parent carers attending– target of 20 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>	FVP
		<ul style="list-style-type: none"> <li>As Above</li> </ul>	Final report details that 3 workshops have taken place with 34 parents in total taking part in a workshop. Of these 18 were unique attenders	

### **Predicted targets/ measurers**

The following were predefined as measures of the outcomes relating in particular to the workshops and EPP.

#### Workshops

- Number of workshops provided - target of 6.
- Details of workshop content.
- Number of parent carers attending– target of 20 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 eight EPP sessions to be run – 4 in Peterborough and 4 in Cambridgeshire for target total of 10 parents per session.
- Parent Carer Feedback.
- Parents carers self-report positive change in their communications with the health providers and their partners.

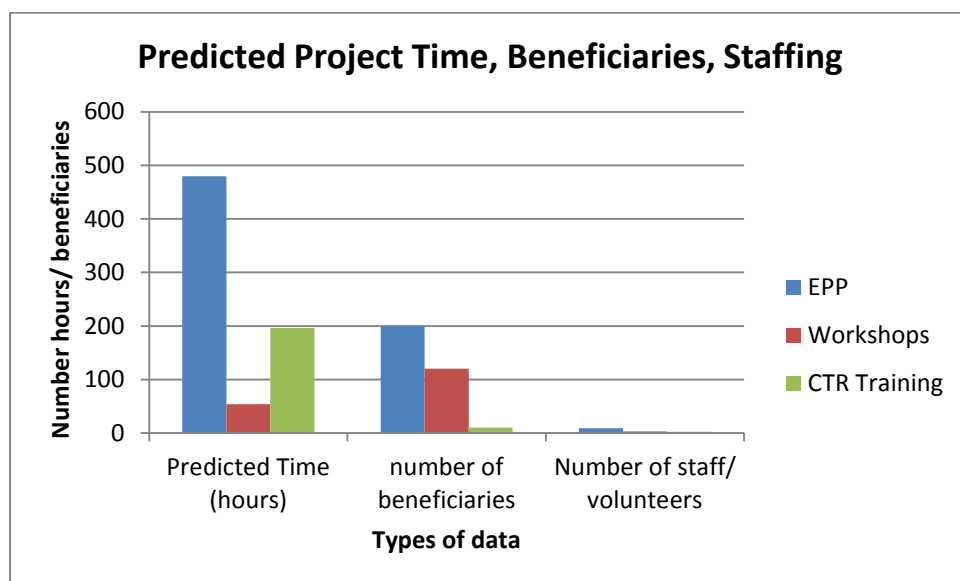
From these targets the following number of parent carers should have been involved/ supported in total

- 120 parent carers across six workshops
- 80 parent carers across two EPP courses
- 10 staff/ volunteers/ parent reps (all themselves parent carers)

#### CTR

This area of work is slightly different as no set numbers have been applied ahead of time and the measures are softer.

- Feedback from parent carers who have attended training EPP/ Parent rep course.
- Details of parent carers wishing to form team of EbE.
- Details of processes, requirements and support associated with CTR work.

Chart 1Predicted costs

Project predicted cost = £25,000

Predicted Project costs where calculation of total cost is divided by either hours or beneficiaries.

	Predicted Time (hours)	number of beneficiaries (including staff/ volunteers as also parent carers)
Hours and beneficiaries	730	330
Cost per unit	£34.25	£75.75

The cost per person to the project budget would equate to £75.75 per person.

Where total cost/ beneficiaries = cost per person.

Cost per time invested to the project would equate to £34.25 per hour.

Where total cost/ time invested = cost per hour.

Project costs:

1. Sundries (Includes any fees)
2. Childcare
3. Travel
4. Refreshments
5. Print

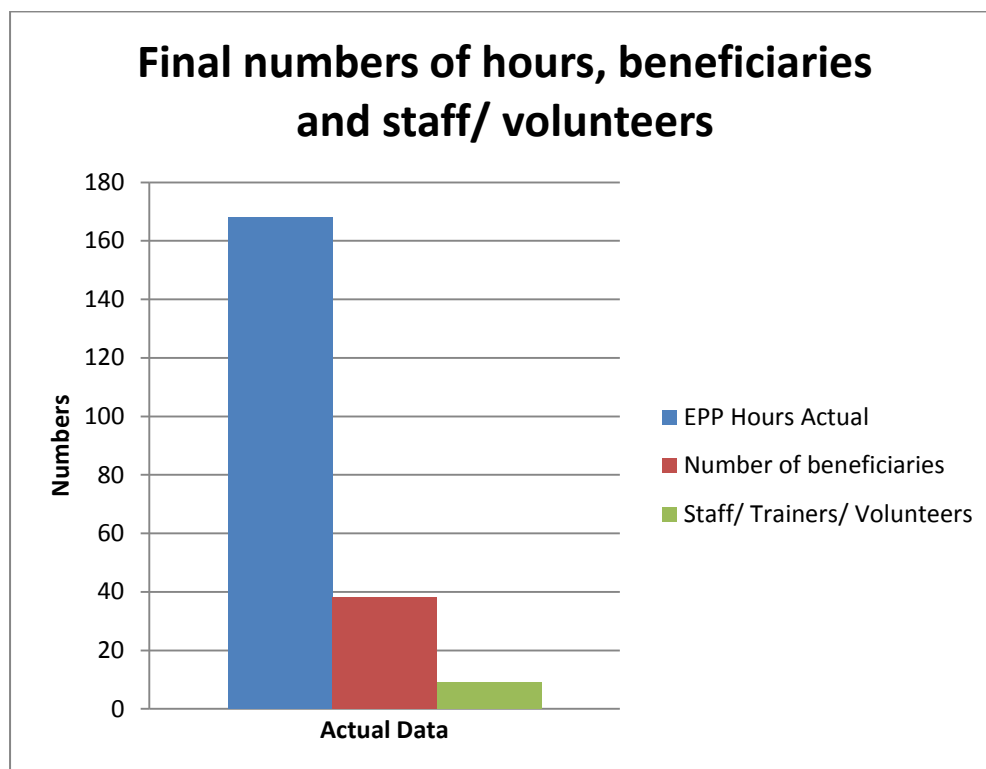
6. Post
7. Stationary
8. Equipment
9. Staff Wages
10. Venue Costs/ Rent
11. core costs (Utilities, Insurance, Bin Collection, Repairs, Rates etc)

A note of caution should be considered with the figures above as time and number of beneficiaries in relation to the CTR element has not been included in full (the only element included relates to the training in parent representation) so the predicted costs per beneficiary should be actually lower and the number of beneficiaries should be higher.

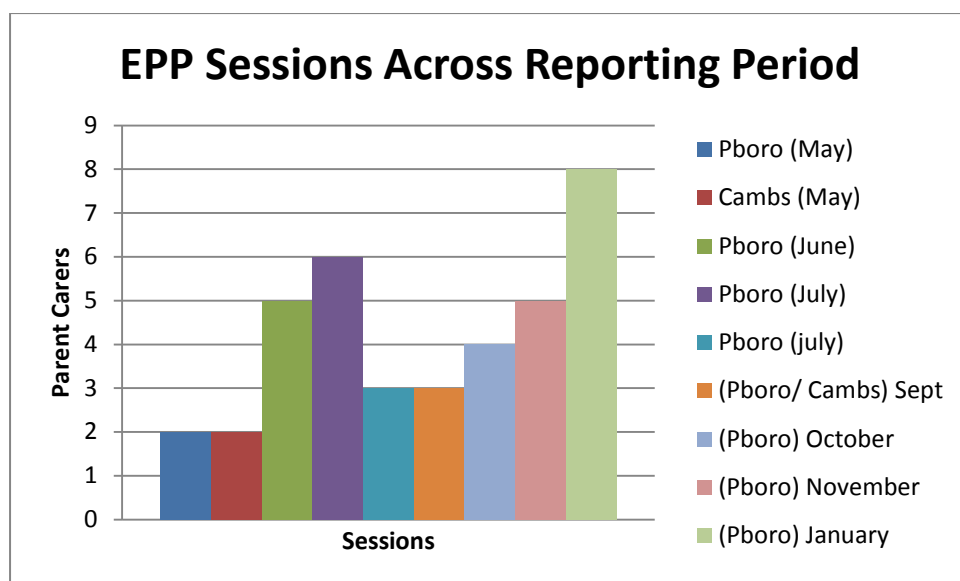
### **Actual Data**

#### **Expert Parent Programme**

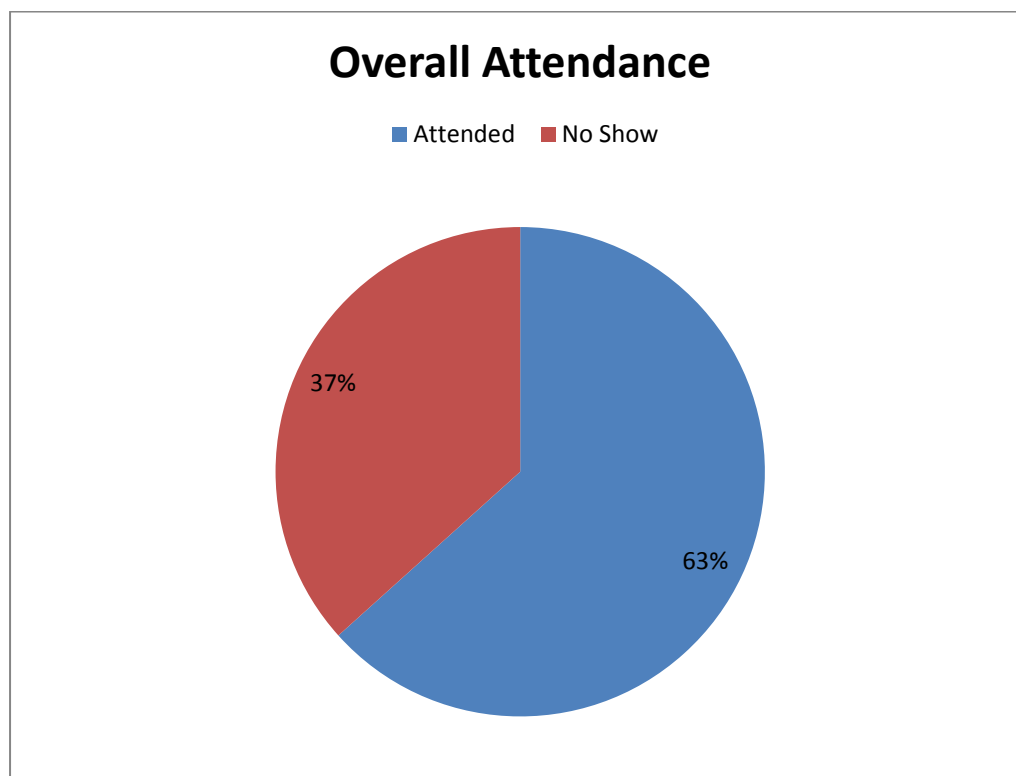
Chart 2



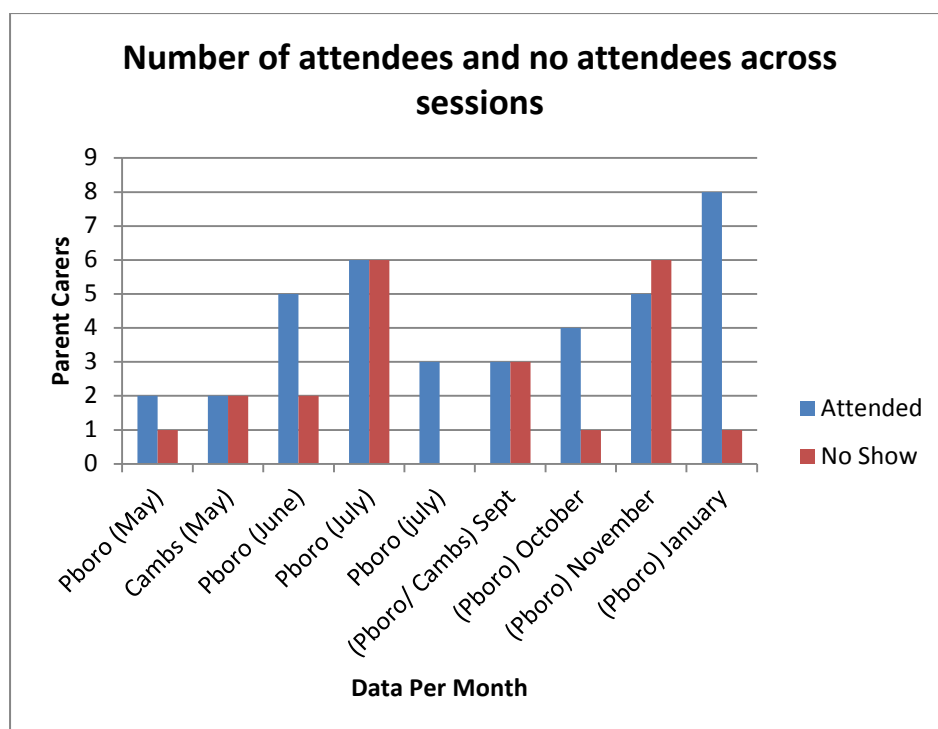
The final figures are far lower than predicted due to issues over lack of referrals from Early Help and confusion over dates whereby the parenting courses organised by PCC were set at the same time as the EPP so parent carers had to prioritise the parenting courses.

Chart 3

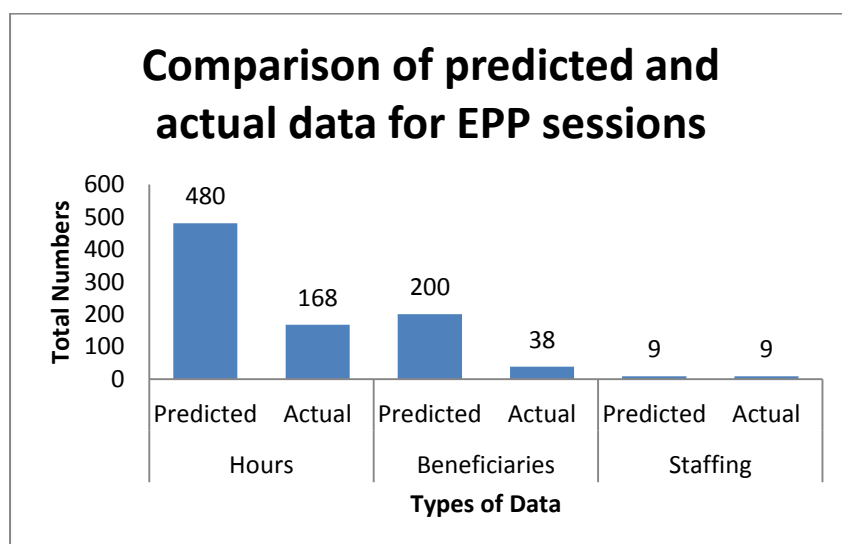
Based on final data it can be seen that no sessions have taken place in Cambridgeshire which has resulted in a difference between the predicted and actual data. The session delivered in September was attended by parent carers all from the Fenland/ Wisbech area. The highest attendance at a single session was in January.

Chart 4

There was 37% non-attendance rate across the sessions over all with reasons only provided on some occasions which were usually relating to having children off school ill.

Chart 5

There was only one month where all who booked on actually attended. Also of the non-attenders two parent carers repeatedly did not show up however one of these did complete the session in October. The session with largest difference between attendance and non-attendance was January.

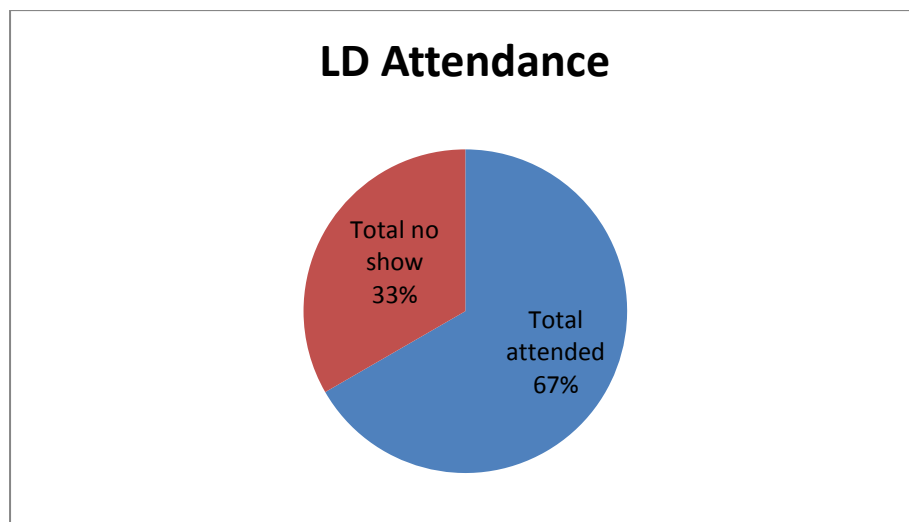
Chart 6

## Workshops

One full set of workshops has taken place and only in Peterborough so data is minimal. The sessions have covered Learning Difficulties, Social Communication Difficulties and Attentional Difficulties.

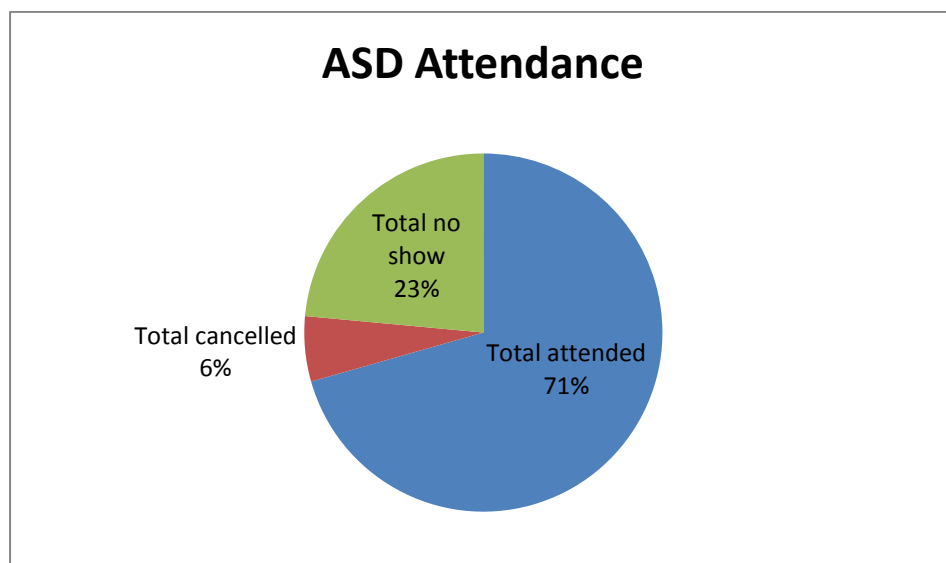
The first workshop focused on behaviours that challenge associated with Learning Difficulties with the following information being gathered.

Chart 7

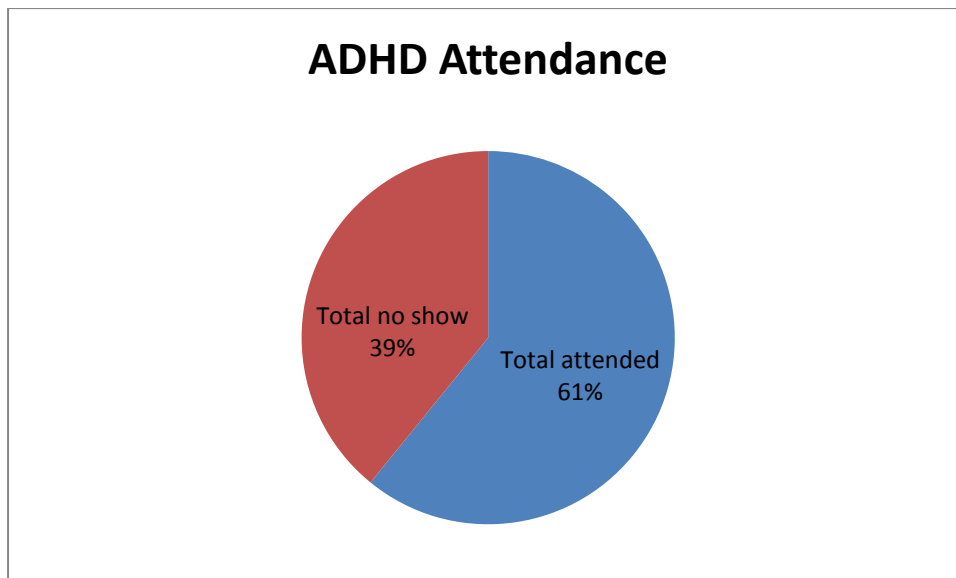


Approximately one third of the potential attendees didn't show up for the session. None of the non-attendees cancelled they simply did not attend.

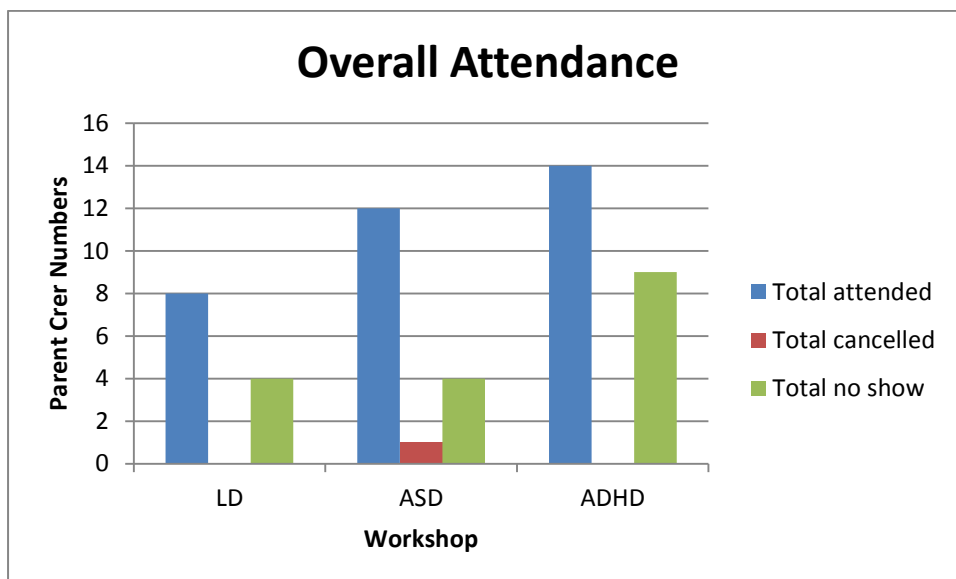
Chart 8



For November there was an attendance level of approx. 70% and of those who did not attend 6% cancelled stating attendance at other parent workshops, child ill and off school or other reason.

Chart 9

As with previous sessions a number did not attend and gave no reason for non-attendance they did just not show up on the day.

Chart 10



## CTR

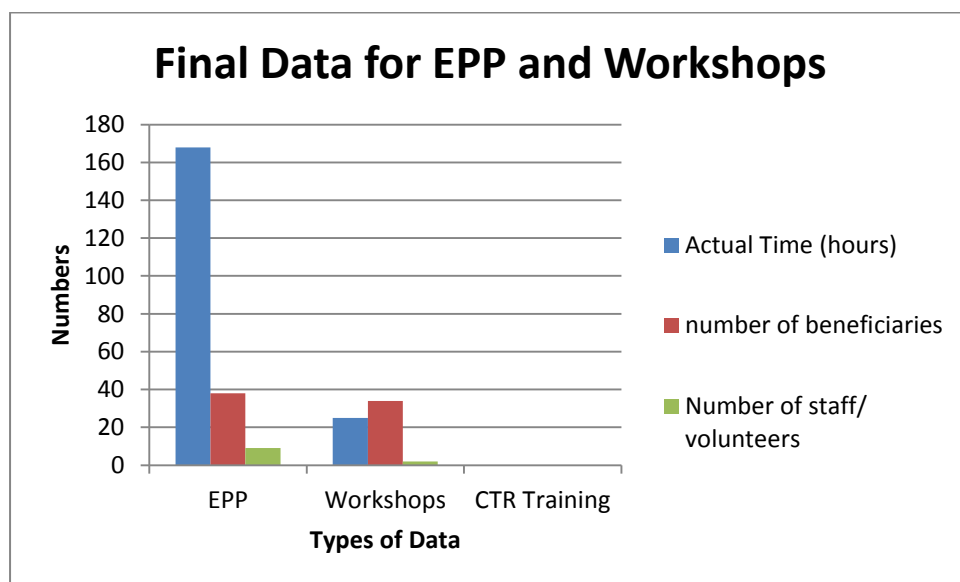
The Care and Treatment Review work has not commenced, and has been put on hold until meetings can take place with commissioning. All that has occurred so far is the development of an adapted job description and person specification to take account of CAMHs understanding and experience.

### Current Time invested

The number of hours invested per beneficiary is as follows:

Hours/ Beneficiaries = 3.3 of work invested in each beneficiary which is the very similar to quarterly reporting figures.

Chart 11



### Current Costs

Project spend so far (FVP only) = £24,234.20 as at March 24<sup>th</sup> 2017

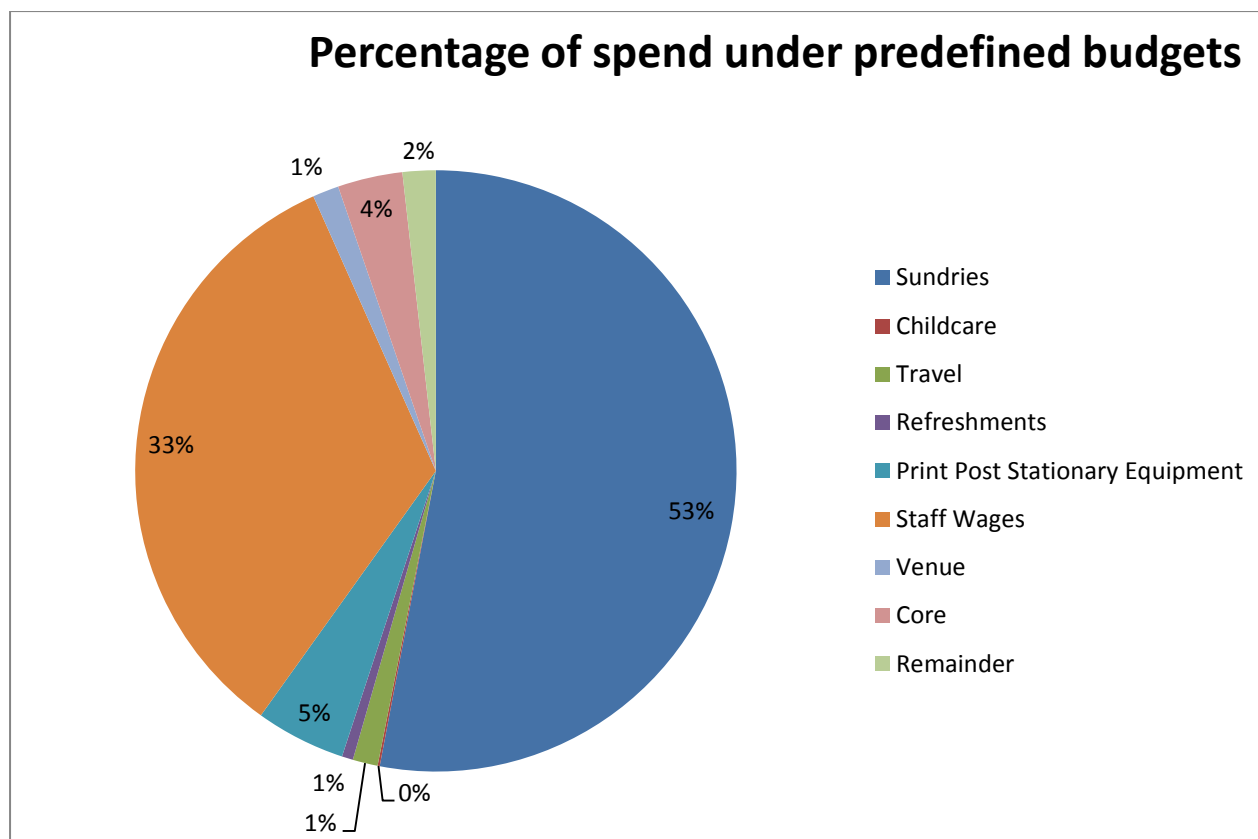
Actual costs against actual beneficiaries/ workload

	Total time invested	number of beneficiaries
Hours and beneficiaries	Time/ cost	beneficiaries/ cost
	193	67 (includes volunteers/staff)
Cost per unit	£125.57	£361.70

The final costs are higher than predicted in terms of cost per hour and cost per beneficiary due to a lower number of overall attendees. There has also been a high number of non-attenders who book on and then do not actually attend which also skews the spend/ investment in the programme. The staff/ volunteers have been classed as beneficiaries for the final data as they are all parent carers who have benefitted at some level.

The biggest spend for FVP comes under sundries which includes the payment of £18,000 to Pinpoint and then after this the breakdown in sundries is trainer fees for delivery of the EPP and workshops where parent carers have been remunerated for delivery and reporting of the sessions.

Chart 12



### **Understanding and Experience of EPP and Workshops and Early Help**

The following section of the report remains the same as the version presented in the academic reporting period September 2015 to October 2016 which was detailed in the first iteration of this report.

During this phase of the programme especially when raising awareness of the EPP/ Workshops and Support Groups and also when addressing parent carer concerns about what is being offered a particular theme emerged relating to viewing the pathway as a barrier to support in particular the parenting course element. The pathway/ support/ assessment have been understood by some parent carers and some front line staff across sectors in particular Education as a gateway. It was decided to gather some data around this theme which has been based on anecdotes up to now. To balance this it needs noting some do report positive feedback and a clear understanding of the pathway and support available and one parent has expressed the view that the new pathway is beneficial.

Three participatory methods have been used to gather data; case study evidence, a small scale survey and a Facebook discussion. (Details on such methods will be expanded on later on in the report).

## **Case Study:**

### Initial Contact

A Parent carer contacted FVP via a Facebook group asking for information *“Hi, was wondering if someone at family voice can help me at all. Had a CAMHS appointment yesterday and they suggested I contacted you about helping me understand where I stand with my daughters secondary school in terms of their failure to support her correctly?”* After this initial contact a meeting was arranged to listen to the parent and establish what signposting may help.

The parent carer (Mum A) gave written permission for her “story” to be used for participatory purposes in highlighting parental issues relating to both the EHA and pathway and Education Health and Care (EHC) requests for Personal Budgets (PB)

### Family Details

Mum A is separated from children’s father and is the primary carer for three children/ young people:

- Child 1 is female, aged 15 has Mental Health needs has been receiving support via core CAMHS and possible previously unrecognised neurodevelopmental needs and has been referred to the Neurodevelopment service (NDS)
- Child 2 is male, aged 11 and has a diagnosis of ASD since age 3 and an EHCp and attends special school
- Child 3 is female, aged 4 and has a diagnosis of ASD since age 3 and an EHCp and attends special school

### EHA Issues

Mum has support for child 2 and child 3 via special school and EHCp’s and has been seeking help for child 1 and is now in the process of pursuing a complaint against an educational setting about child 1. Child 1s anxiety and mental health needs triggered when she was off school for 3 months with glandular fever and parent A couldn't get the setting to call her back or communicate about how to help. It resulted in a complete breakdown by child 1 who by now was unable to leave the house due to anxiety. CAMHS were involved at this point and advised. Parent A organised a phased return to school for child 1 with no support from the school

During the process of organising work experience for child 1 her mental health changed and anxiety levels increased to the point it was agreed further support would be required to help her remain in educational setting. Some assessment was conducted at setting and issues were found regarding discrepancy between where child 1 was in setting in terms of year group and actual academic level child 1 was working at.

The situation resulted in the decision to complete an EHA and mum has provided the following notes:

- Mum attended EHA 2 weeks ago – no health representative in attendance, but had said they wanted to be involved. CAMHS practitioner had date and time in the diary but school cancelled the appointment but meeting went ahead
- Mum, Dad, all educational settings in attendance. No-one led the meeting, the staff struggled to carry out EHA and were confused over who instigated the EHA and how to complete it. Struggled through the meeting to gather the information, what it needed to include was incomplete due to lack of knowledge from professionals in the meeting. Mum asked for help with respite.
- No further contact has been made since the EHA meeting

Mum has been left confused with whole process and still in need of help.

### PB

Mum during the EHC process for Child 2 requested a personal budget and has had no information since, mum has exchanged emails with SAM (previously SEN) service. Mum is unsure of what to do next. A request was made for a PB to be taken as a direct payment to provide alternative care for child 2 and child 3 so some focus and attention could be given to child 1

### Concerns

Mum finds herself in a situation where due to having more than one CYP with SEND the system intended to provide support and access to services creates barriers.

*“I was even at the CDC for an appointment and saw ..... Who asked why I was there and when I said I was there for child 2/ 3 they (the professional) said they hadn't realised I had other children with SEND”*

*“I just felt that the system has let us down regarding me asking for respite and being told we won't qualify. I feel I'm at breaking point with everything and can't understand why there is no help available. I'm not entirely sure as to what exactly this early help assessment has achieved for us. I've not heard anything yet but I don't even see that anything was requested anyway. So what exactly happens next? What I need above anything right now is support and I've seen little of any of that by the council.”*

### **Early Help and EPP Knowledge Facebook Discussion**

#### Questions asked:

- What do you know about the Early Help Pathway and what it is meant to achieve?
- What do you think the Expert Parent Programme is?

#### Answers received:

*“The EHP has replaced the CAF and should be used to identify any additional support x”*

*“Early Help ....., it's an early intervention to help families with children/young people to help tackle emerging problems.”*

*“Early help pathway is when you need support with making sure the child gets what they need but doesn't meet the requirements to get a social worker.”*

*“ The expert programme is about teaching parents more so they can be confident when dealing with professionals :) x”*

*“Never heard of expert parent programme. And only heard of early help very recently. It is very difficult to find out information about a child's rights... i have had a child with sen for a long time and have only recently found out about the sen code of practice... a fantastic read to know ur child's rights... would recommend to any parent with a child school age”*

*“Never heard of either - the early help pathway may have been called or was something different in the past? We've been in the "system" since birth, so may have forgotten the terminology.. Not heard of the expert parent programme”*

*“There seems to be a lot of confusion about the Early Help Assessment and I feel quite passionately that parents need better information on it. The Early Help Assessment has replaced the old CAF (Common Assessment Framework) and is now being used as the route to referral for ASD/ADHD assessment. If you feel your child has additional needs and is in need of further support your school Senco/family support worker can initiate an EHA, this is something you should work on together and should contain all the various aspect of your child's life and their various struggles. You will then need to sign a consent form for it to go to panel. The Early Help team will assess it and decide whether a referral will be sent straight away or more likely it will be sent to the Multi Agency Support Group (MASG). MASG is a team of professionals that will read the EHA and decide what level of support the family will need I.e would they benefit from a Family Support Worker, referral to Sleep Solutions or if the child is presenting behavioural challenges they may be a referral put in for Webster-Stratton or Triple P. After these support systems are put in place a family may feel they no longer need a paediatric referral or on the other hand these interventions may have not had a significant enough impact, at this point the family would go back to the school and resubmit the EHA and the Early Help team would then see that all these interventions have been tried and then put the referral into the Neurodevelopment team. It is a lengthy process and I know how difficult it is, my own son is going through the pathway but I do think it is a lot better than the old system where families sit on a waiting list potentially for years with no support at least this way support is given prior to a diagnosis. P.s I think the Expert Parenting Programme is awesome and all parent Carer's would benefit from it but I am bias! ☺”*

## **Early Help Survey**

### Method

A small survey consisting of 8 questions was used to see who knew of Early Help, who had experience of the early help Assessment, who had accessed any support on the pathway and why the EHA may have been accessed in relation to seeking a diagnosis.

The survey was shared in a closed Facebook chat room where parent carers are provided with participation opportunities.

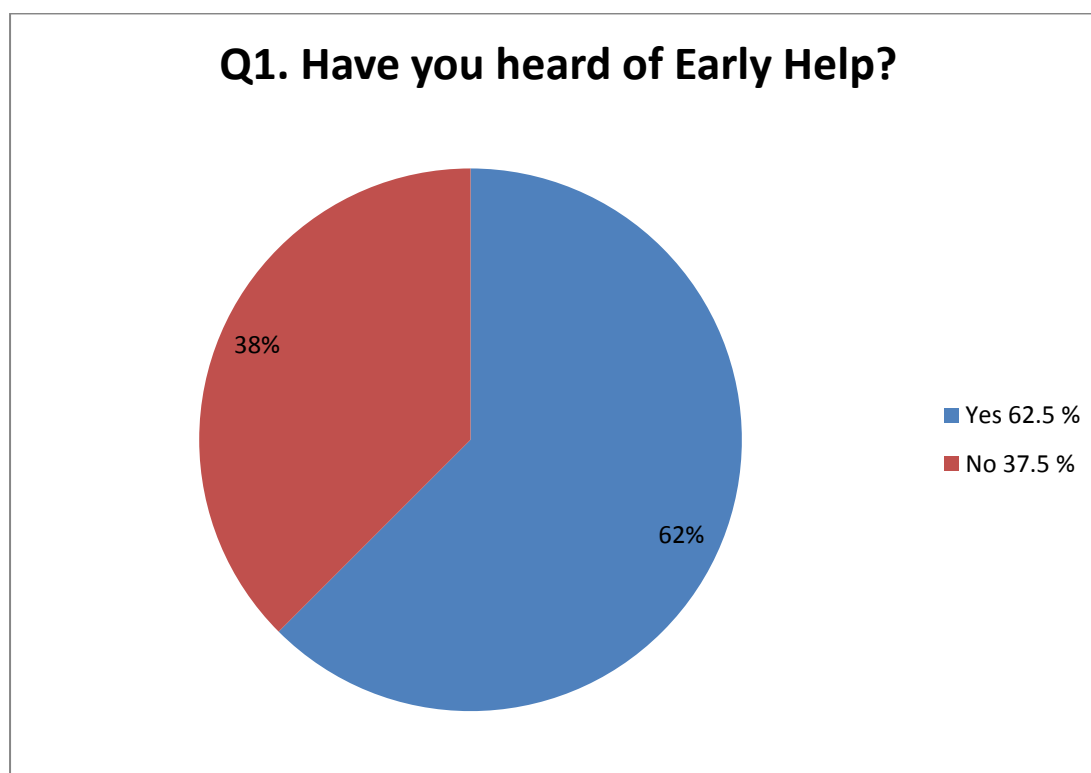
### Respondents (parent carers)

There were 8 responses to the survey; all responses were parent carers in the Peterborough area. There are no details about the parent carers as all surveys were completed anonymously.

### Results

The results cannot be used to draw conclusions they simply demonstrate views from a small group of respondents. There have to date been 8 responses to the survey. The following section will look at the responses given and who many people provided responses to each question. There was a mix of closed and open questions for parent carers to respond to.

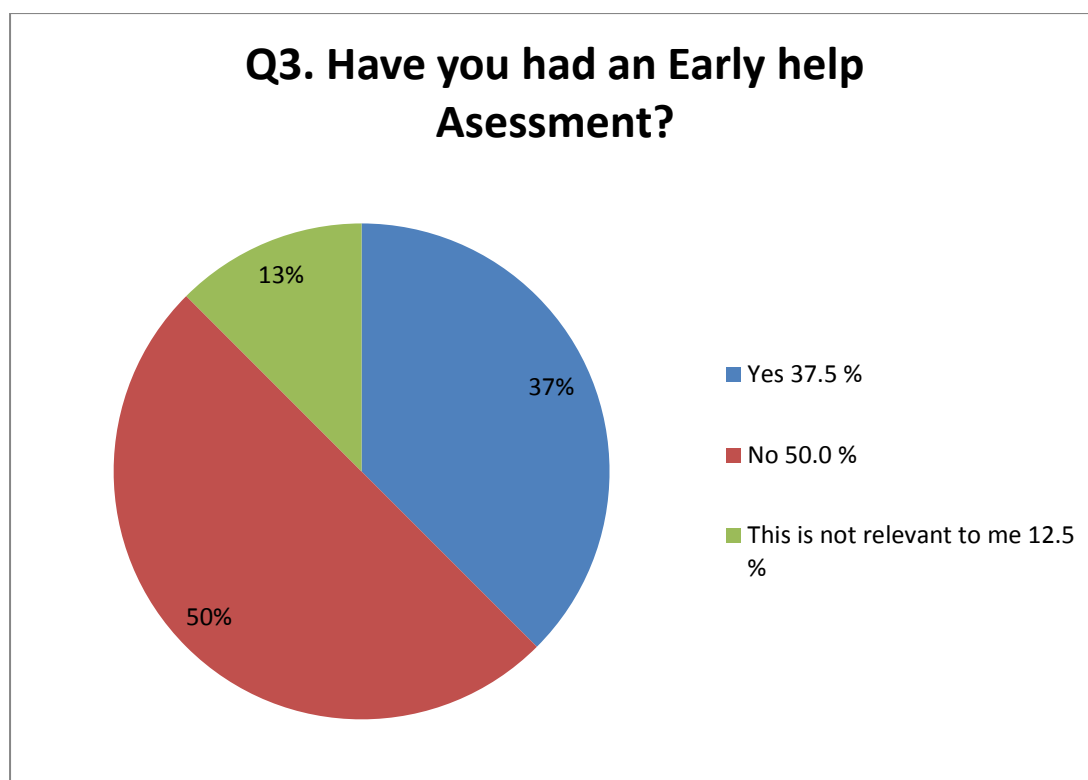
### Chart 13



All respondents answered the first question; 5 said they had heard of Early Help.

Question 2 asked respondents to explain what they thought Early Help is. There was only one response to this question which is as follows:

*An Early Help Assessment use to be called a CAF and it is a form that should cover various aspects of your child's strengths and difficulties. EHA is mostly used for behavioural support, where a family is struggling with child problem behaviour, sleep difficulties or where a child is suspected to need an ASD/ADHD assessment. The EHA goes to MASG and from there various support agencies are able to offer support to the family. Once this support is accessed and given a period of time to embed if the issues still persist then a child will be referred to the community paediatrician.*

Chart 14

In response to question 3 asking if parent carers had, had an EHA all 8 respondents answered the question with 3 stating they had and 4 stating they had not had an EHA.

The following two questions were designed to either be answered if someone had answered yes to question 3 or no. So when asked:

Q4. How was the EHA and were you offered any support (asked if people selected yes to previous question)

The following answers were provided

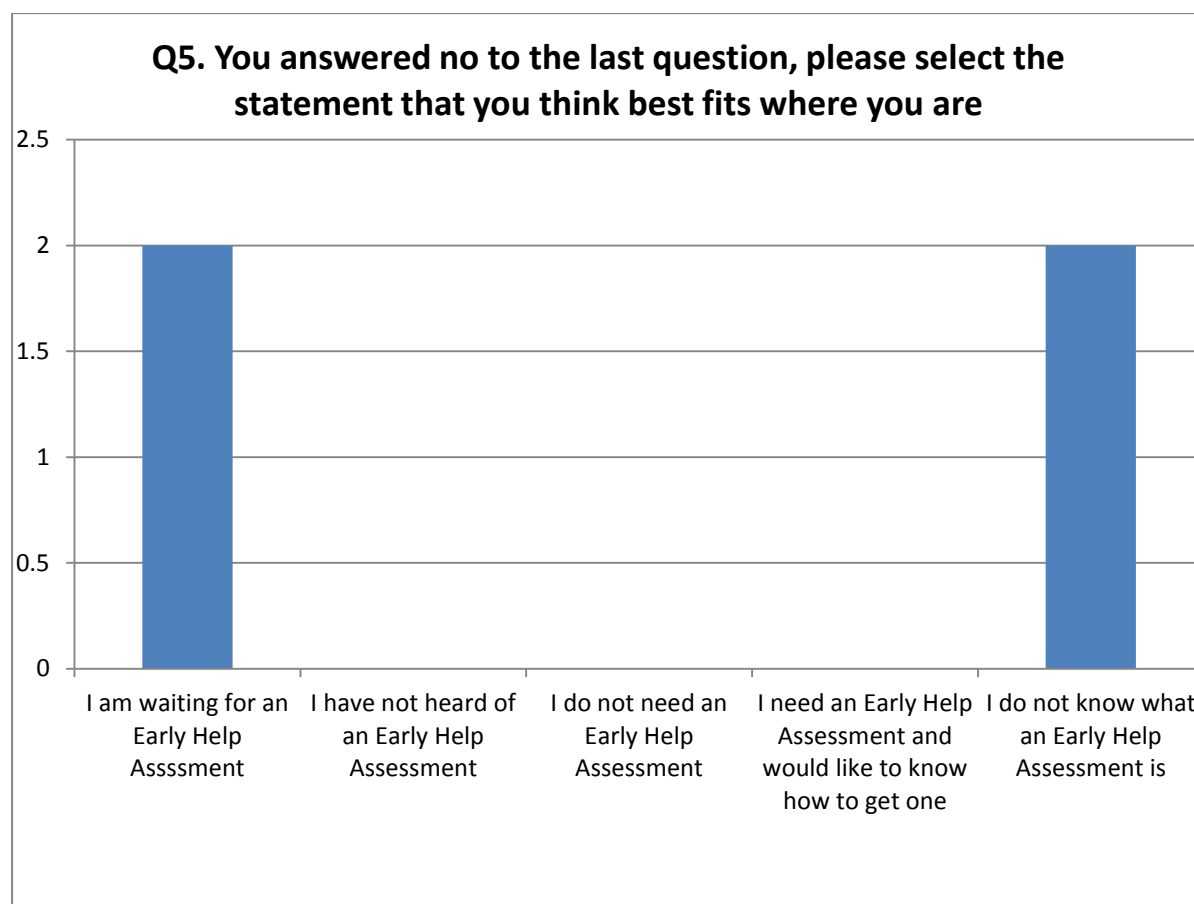
*“Not very informative.”*

*“I find it quite an emotional experience. I work within family support and therefore have worked with families that have CAF's and knew there would be a possibility of my work colleagues becoming privy to my personal family life. I am private person and struggle with people having so much personal information about my child and our family. Apart from the emotional aspects I found it ok, my son's school were good and it was first time that all the professionals were in agreement that my child would benefit from an ASD assessment. When I was given a copy of the EHA I did become emotional on the things the school had added about him at school, as this was the first time I was hearing about these things. Our EHA resulted in my son going straight on the waiting list for an ASD assessment, we were referred to sleep solutions but 10 months later and still have heard nothing. We are currently waiting to hear feedback on my son's MD assessments. We have had no support other than what I have sought out for myself.”*

When the respondents selected no as an answer to question 3 they were presented with the following statement:

Q. 5 You answered no the last question please select the statement that you think best fits where you are?

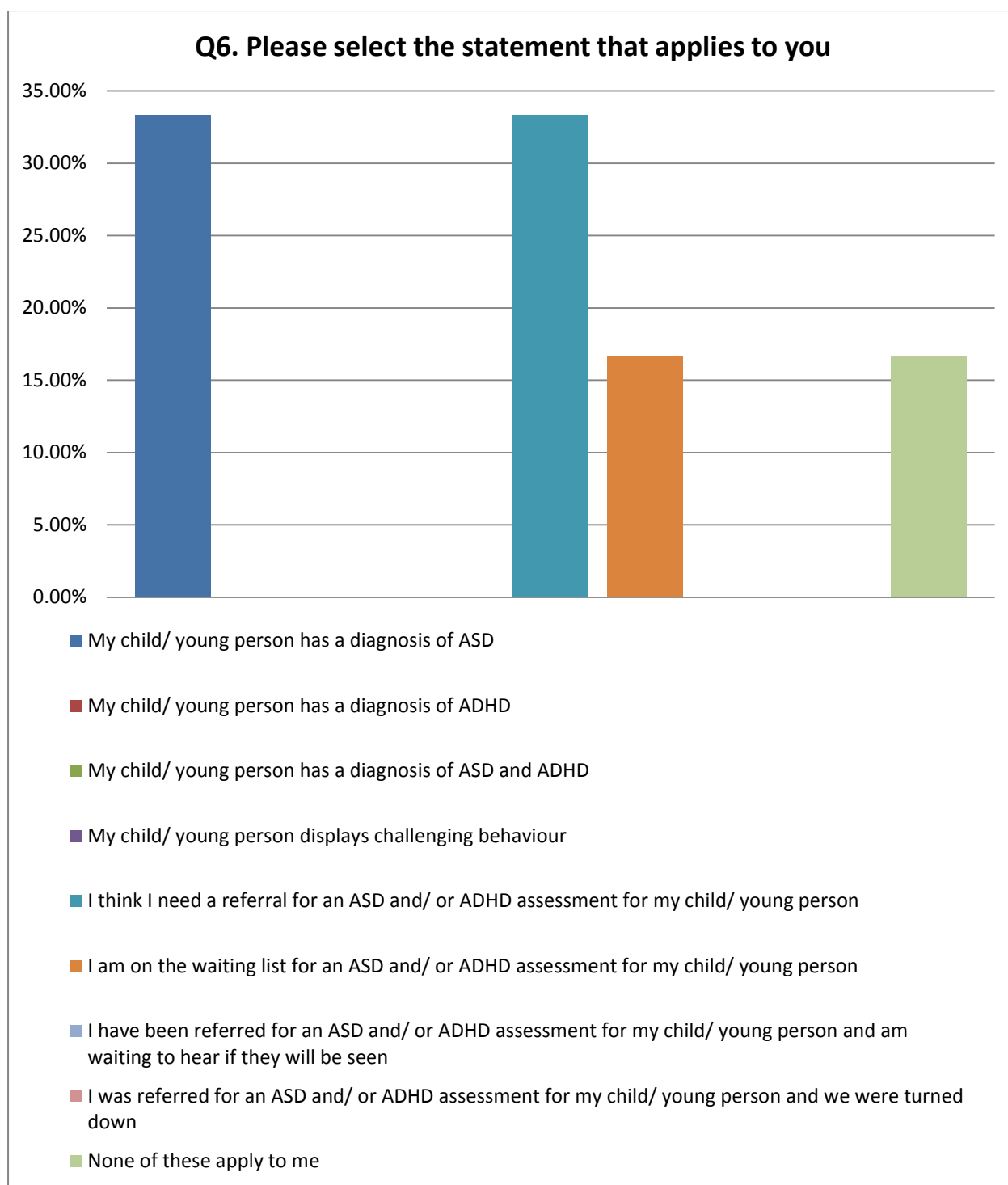
Chart 15



Two chose the statement 'I am waiting for an EHA' and two chose 'I do not know what an EHA is'

The next question was used to see where parent carers may be in relation to the Early Help Pathway if anywhere.

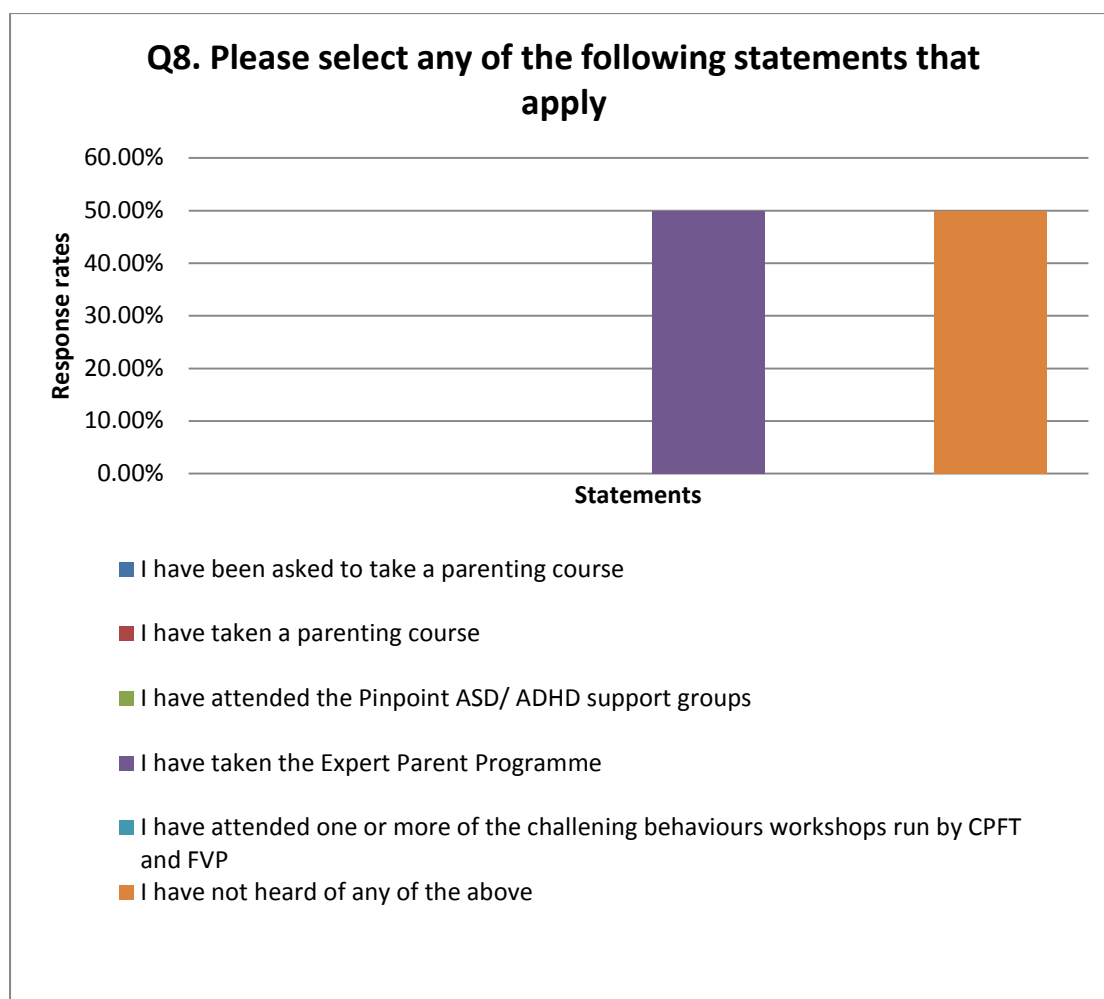


Chart 16

There were six responses with four of the eight statements being selected. The two most popular statements were ‘my child/ young person has a diagnosis of ASD’ and ‘I think I need a referral for an ASD/ ADHD assessment.’

Question 8 was used to see if anyone taking the survey had been on any of the workshop/ training/ support groups that form part of the Early Help Offer.

Chart 17



Four people responded to the question with two choosing the EPP option and two stating that they had not heard of any of the options.

One parent carer who answered most questions in the survey and said they had had an EHA was one to select the 'I have not heard of any of the above' in question 8.

### Experience of EPP and Workshops

Further work has taken place to gather views of parent carers who have taken the EPP and/ or challenging behaviours workshop. This is gathered via a combination of feedback forms, a small follow up survey and a question/ answer discussion via Facebook. The feedback gathered is positive for both.

### Small EPP/ Workshop Survey

The survey is designed as a follow up to the actual feedback gathered on the day people attend either the EPP or workshop. Parent carers were contacted via phone/ email and asked to complete the survey. Two people have completed it already and others will be contacted in due course.

The survey asked parent carers to provide contact details and basic information regards their child(ren) followed by identifying which EPP or Workshop they attended. The survey then asked the parent carers to rate the EPP or workshop they attended for helpfulness and there was the opportunity to provide some extra information about any aspects that were found useful and whether any tools shared have been put in to practice.

Some of the data from the survey is as follows:

#### EPP Questions Asked

Have you put any of the things you learnt during the Expert Parent Programme in to practice?

From what you remember of the Expert Parent Programme what part did you find most useful and why?

#### EPP Answers Given

Yes, put a lot into place regarding his health and care at school

Finding out about the rights of ur disabled child.

#### LD Workshop Questions Asked

Have you put any of the things you learnt during the workshop in to practice? (If you have please tell us a little more about this)

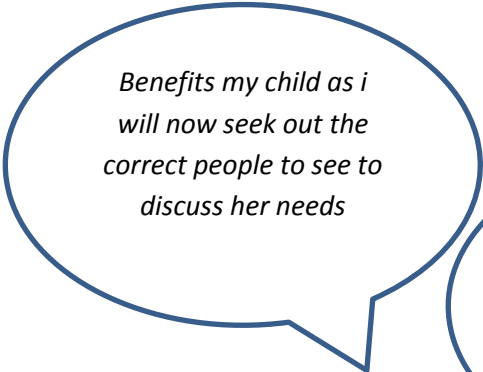
#### LD Workshop Answer Given

speaking to them in simple language and one instruction at a time also letting them know of future plans ahead so letting them know our daily routines if anything is bound to change or

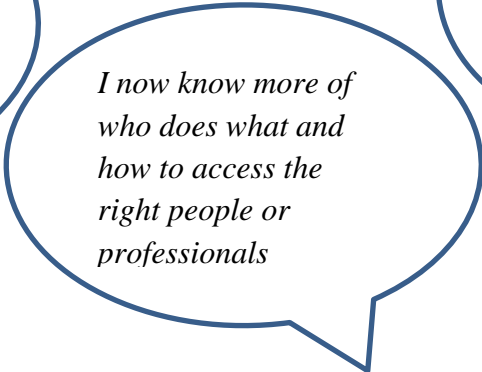
Both parent carers rated the EPP/ workshop they had attended highly.

### **Overall Programme Feedback on the day**


Following are some quotes from parent carers who have attended the EPP:



*Benefits my child as i  
will now seek out the  
correct people to see to  
discuss her needs*

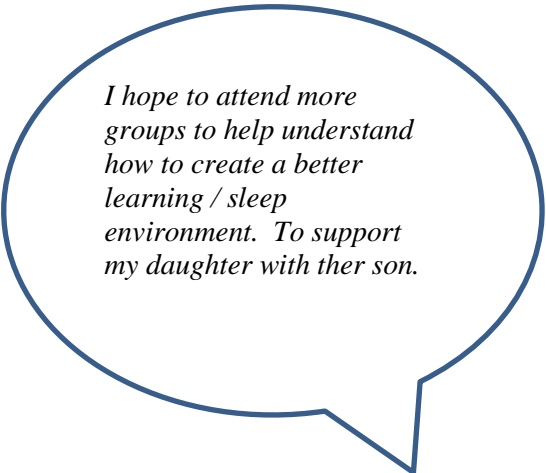


*I now know more of  
who does what and  
how to access the  
right people or  
professionals*

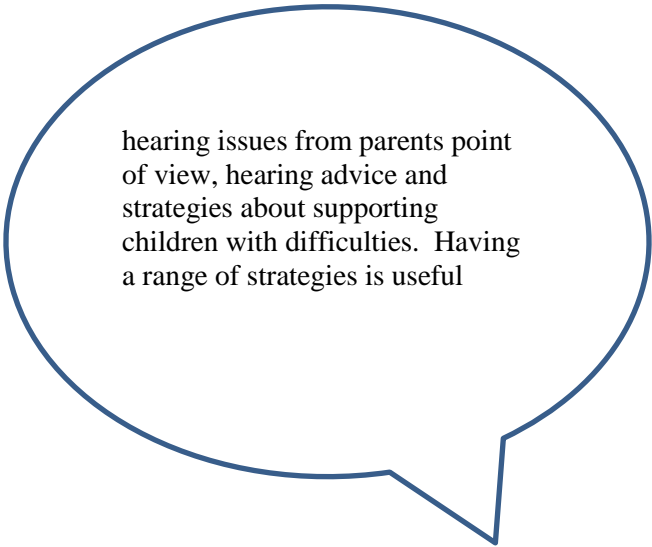


*Reminded that I am  
an expert of my  
children's conditions  
and my opinion of  
them is important*

Quotes from the Workshop (LD, ASD, ADHD) attendees



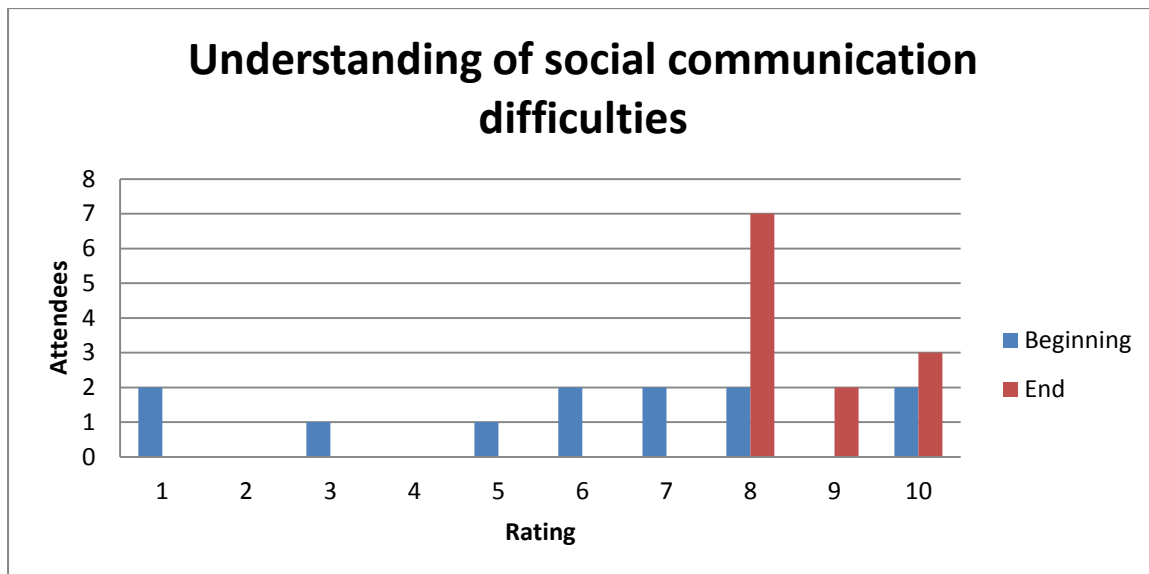
*I hope to attend more  
groups to help understand  
how to create a better  
learning / sleep  
environment. To support  
my daughter with ther son.*



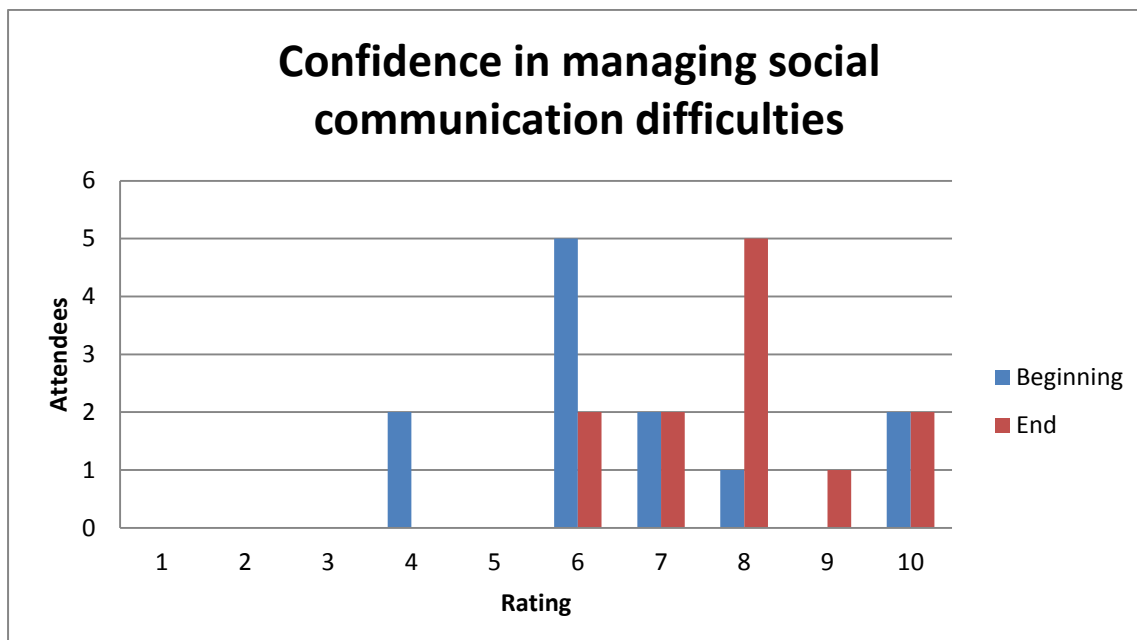
hearing issues from parents point  
of view, hearing advice and  
strategies about supporting  
children with difficulties. Having  
a range of strategies is useful

Chart 18

The following chart demonstrates a general self-rated increase in understanding what may be factors in social communication difficulties.

Chart 19

The following chart shows an overall increase in self-rated confidence in managing behaviours associated with social communication difficulties.



## **Changes**

After some discussion with PCC commissioning a few amendments have been made to the work delivered. The amendments are based on responding to the changing requirements of parent carers and ensuring that value for money can still be delivered via the grant. The amendments include the introduction of a parent carer hub and inclusion surgery.

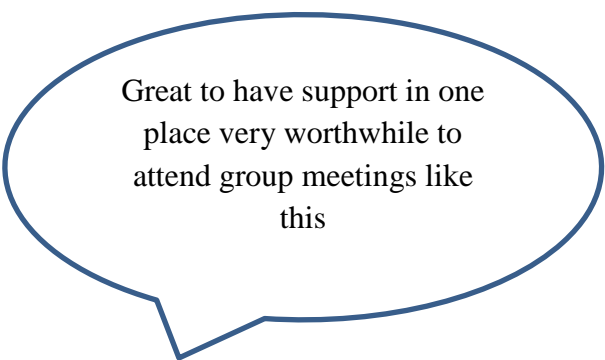
### **Parent Carer Hub**

Since the start of the financial year FVP have been trialling monthly parent carer drop in sessions run in conjunction with Carers Trust. These sessions have been attended by 15 individual parent carers who have all benefitted from direct support from Carers Trust in areas such; as accessing the workshops/ EPP and support groups delivered by FVP and Pinpoint, having an EHA conducted, having support to access benefits, carers assessments and advocacy. Generally the parent carers in this group have at least one child/ young person who has challenging behaviour or mental health needs.

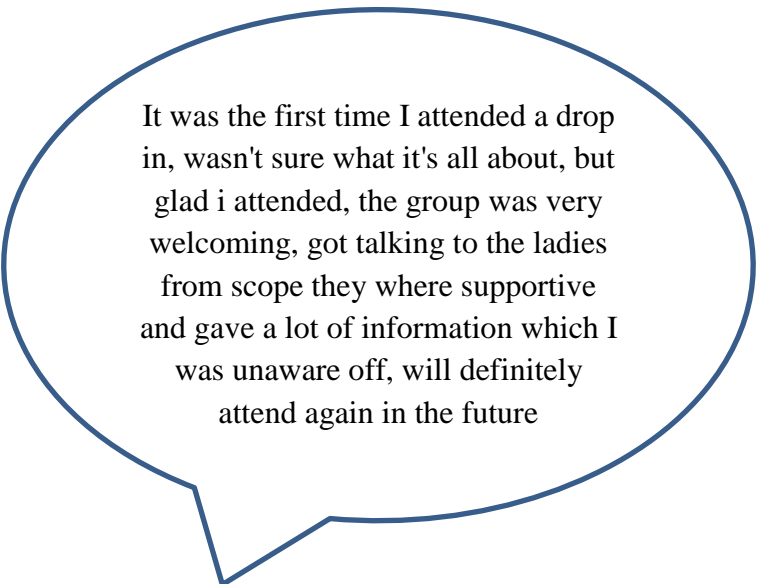
Up until recently FVP has funded these sessions entirely from a variety of fundraising efforts. Going forwards the parent carer drop in sessions will be expanded upon and added to the outcomes matrix defined above. This will equate to a change to some of the work delivered described in this section of the report. To encourage parent carers to attend where required expenses will be covered for travel/ childcare/ refreshments. If required external partners will have support to attend the sessions also by way of travel expenses. Most of the partners FVP works with at these sessions are themselves charity/ 3<sup>rd</sup> sector organisations and working together in this way ensures more parent carers will benefit.

At the parent carer drop in sessions parent carers received some form of 1:1 support from IS, Family Action and Carers Trust. Some of this work is about building trust and improving relationships between parent carers and other organisations. This is especially important due to some parent carers feeling unsupported through all the changes as detailed above.

### **Feedback on the drop-in's**

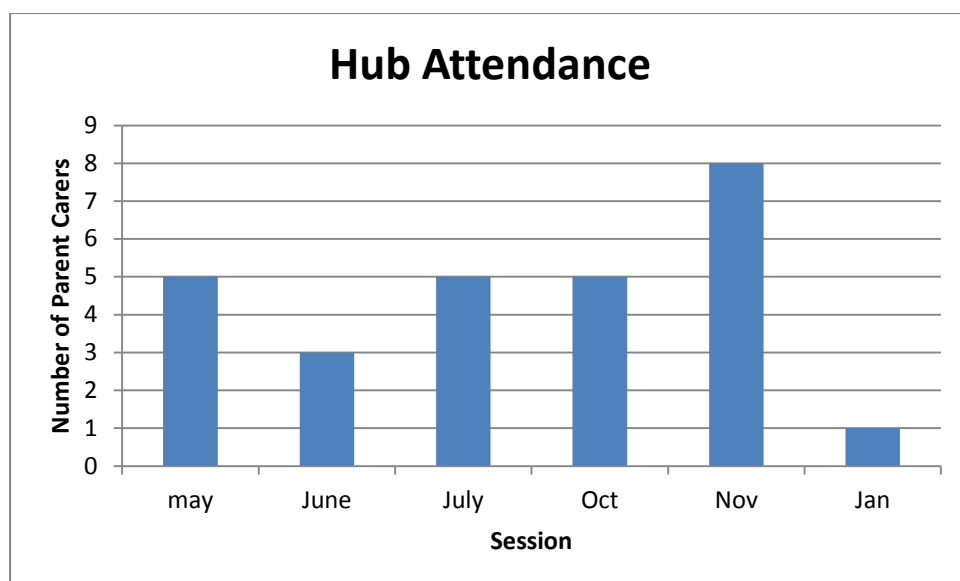


Great to have support in one place very worthwhile to attend group meetings like this



It was the first time I attended a drop in, wasn't sure what it's all about, but glad i attended, the group was very welcoming, got talking to the ladies from scope they where supportive and gave a lot of information which I was unaware off, will definitely attend again in the future

Chart 20



To date 27 individual parent carers have benefitted from attendance at the drop-in session.

### Evidence (Carers Survey)

FVP conducted a survey into parent carers needs/ support after the parent representative to the carers partnership board raised concerns over the lack of understanding of parent carers and sharing anecdotal information from parent carers feeling unsupported. The survey was designed by the parent representative and then shared with parent carers from across Peterborough. (*Parent Carers Survey 2016*, [www.familyvoice.org/participation](http://www.familyvoice.org/participation) )



The main themes that emerged were:

1. Lack of recognition
2. Lack of support
3. The need for respite
4. Coping is difficult in school holidays

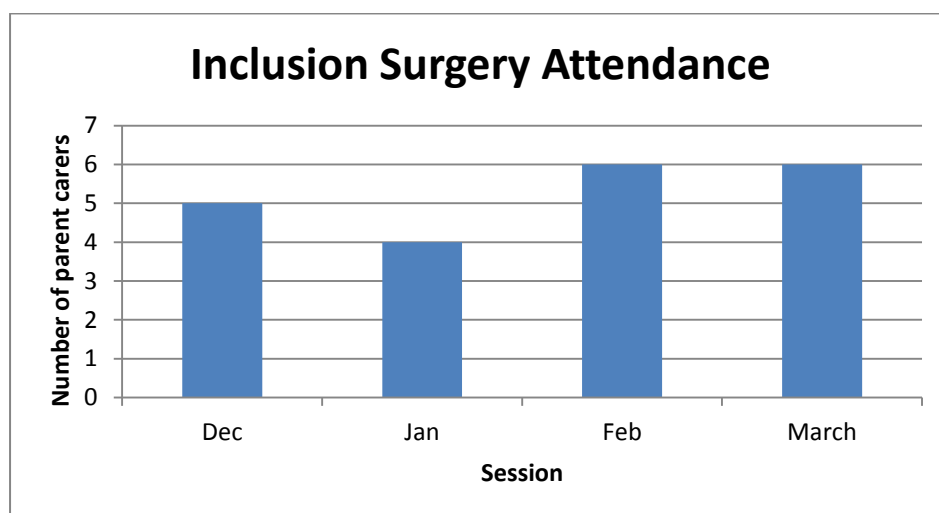
Thirty parent carers completed the survey and to date none have reported positive views of the current system for supporting and recognising parent carers in particular in terms of the Local Authority. The report highlighted a need for parent carers to be listened to and supported and the parent carers hub is being used to address this need.

### Inclusion Surgery

Another addition to the work will be to link a new initiative termed “Inclusion Surgeries” to the work relating to emotional health and wellbeing. Over the past few months FVP have had families who have CYP with a diagnosis of ASD (particularly families in early years and where English is an additional language) request support and/ or ask for advice in relation to accessing educational support. These requests were fed back to the LA Statutory Assessment and Monitoring service (SAMs) and SEND Partnership. After discussion with senior management it was decided to pilot a few sessions at the FVP premises. The first session three parent carers attended and all reported positive feedback about the whole experience.

To date there have been 4 sessions with data available on 3 at the time of writing this report.

Chart 21



15 parent carers have attended the inclusion surgeries.

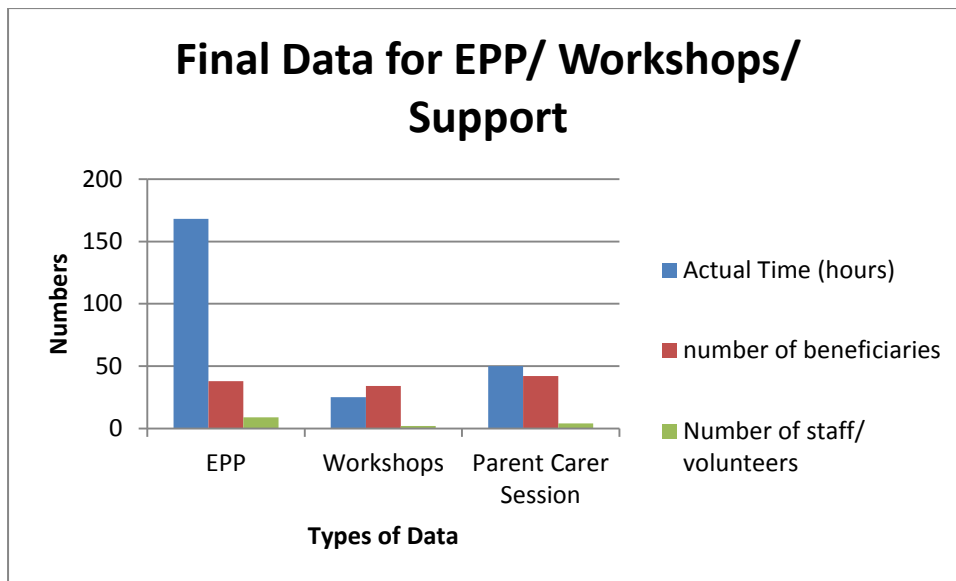
With the inclusion of the hubs and inclusion surgeries in place of the CTR work and to supplement the lower numbers attending the workshops the data mentioned in costs above is as follows:

Project spend so far (FVP only) = £24,234.20 as at March 24<sup>th</sup> 2017

Actual costs against actual beneficiaries/ workload

	Total time invested	number of beneficiaries
	Time/ cost	beneficiaries/ cost
Hours and beneficiaries	243	135 (includes volunteers/staff)
Cost per unit	£99.73	£179.51



Chart 22

## **Pinpoint**

The information provided here has been supplied by Pinpoint. The data is different from that presented in the section relating to FVP above. The data does not show of the numbers who have attended the support groups how many are single or multiple attendances or how many no-shows occurred. From November Pinpoint did start capturing data on new attendees at meetings; going forwards the data will show unique attendance.

### **Review of the ADHD / ASD Support Groups June 2016 – March 2017**

#### **Background**

Pinpoint Cambridgeshire has continued to run the ADHD / ASD support groups following a successful pilot from December 2015 – May 2016. This report cover the groups from June 2016 through March 2017. No groups were run during schools holidays in August.

#### **Delivery of Support Groups**

We expanded the number of groups from three to four to cover more geographic areas and we've responded to parents' requests to run some evening sessions. Each group runs for two hours, usually with a speaker and plenty of time for parents to chat and share ideas. Refreshments are provided, and childcare and travel expenses reimbursed by request. A parent volunteer helps run most sessions.

The groups are open to any parent who had a child with suspected ADHD / ASD, were waiting for assessment or diagnosis, or had a diagnosis.

The objective for having a speaker is that parents have the chance to hear from an expert about ASD / ADHD, learn how to manage aspects of the condition, hear about local services, etc. Speakers are usually free but occasionally we pay speaker costs and / or their travel expenses.

The following tables show each group by area, the speaker / topic and number of parents that attended. From November 2016 we tracked whether the parents were new attendees to the group. 295 parents attended across the four groups over nine sessions. Of the 153 parents that attended between November 2016 and March 2016, 67 were unique attenders (44%). Just under 70% of the parents said their child(ren) with special needs are boys and 48% are between 5-10 years old and 47% between 11-15 years old.

**Table 4**

<b>Histon</b>			
<b>Date</b>	<b>Speaker</b>	<b>Parents</b>	<b>1st Visit</b>
June	Contact-a-family	6	
July	SENDIASS	16	
Sept	Communication Cambridge	18	
Oct	Dr Anna Conway-Morris, CPFT	12	
Nov	Think Autism	17	6
Dec	ADHD Parenting Information, CAMHS	6	2
Jan	SENDIASS	14	6
Feb	Children's OT, CCS	10	4
Mar	Independent Supporters, Core Assets	9	2
Total		108	20

Table 5

<b>Ely</b>			
<b>Date</b>	<b>Speaker</b>	<b>Parents</b>	<b>1st Visit</b>
June	SENDIASS/Core Assets	5	
July	CPFT	12	
Sept	Communication Cambridge	8	
Oct	Core Assets (last minute cancellation)	5	
Nov	Think Autism	8	6
Dec	ASD Parenting Information, CAMHS	4	0
Jan	Independent Supporters, Core Assets	8	4
Feb	Contact-a-Family	3	2
Mar	Contact-a-Family	6	2
Total		59	14

Table 6

<b>Huntingdon</b>			
<b>Date</b>	<b>Speaker</b>	<b>Parents</b>	<b>1st Visit</b>
June	Think Autism	15	
July	Contact-a-Family	5	
Sept	Communication Cambridge	14	
Oct	Researcher, Department of Psychiatry, University of Cam	7	
Nov	Children's OT, CCS	15	3
Dec	Think Autism	4	2
Jan	Contact-a-Family	3	1
Feb	Sensory Workshop, Little Miracles	6	3
Mar	SENDIASS	5	1
Total		74	10

Table 7

<b>Peterborough</b>			
<b>Date</b>	<b>Speaker</b>	<b>Parents</b>	<b>1st Visit</b>
June	SENDIASS Peterborough	7	
July	Scope	4	
Sept	Communication Cambridge	6	
Oct	Think Autism	2	
Nov	Independent Supporters, PCVS	8	5
Dec	Parent Volunteer Speaker - Linda Roberts	6	6
Jan	Sensory Strategies, CPFT	15	7
Feb	S&LT, CPFT	2	2
Mar	Contact-a-Family	4	3
Total		54	23

## Outcomes & Feedback

The success of the groups are measured against the outcome objectives in Appendix 1. Appendices 2 and 3 illustrate the evaluation forms used.

### Parent Feedback:

Overall parents were very positive about these groups. Some feedback that parents gave is listed below:

What ideas do you think you have gained from the session?

- More understanding of condition, ways of dealing and supporting son.
- Slow things down. Work through issues. Contacts of people to help.
- Using different methods to meet my children's needs.
- This is the most help we have received in 7 years!!!
- How to be more proactive in help from school and other support groups

How do you feel after attending today?

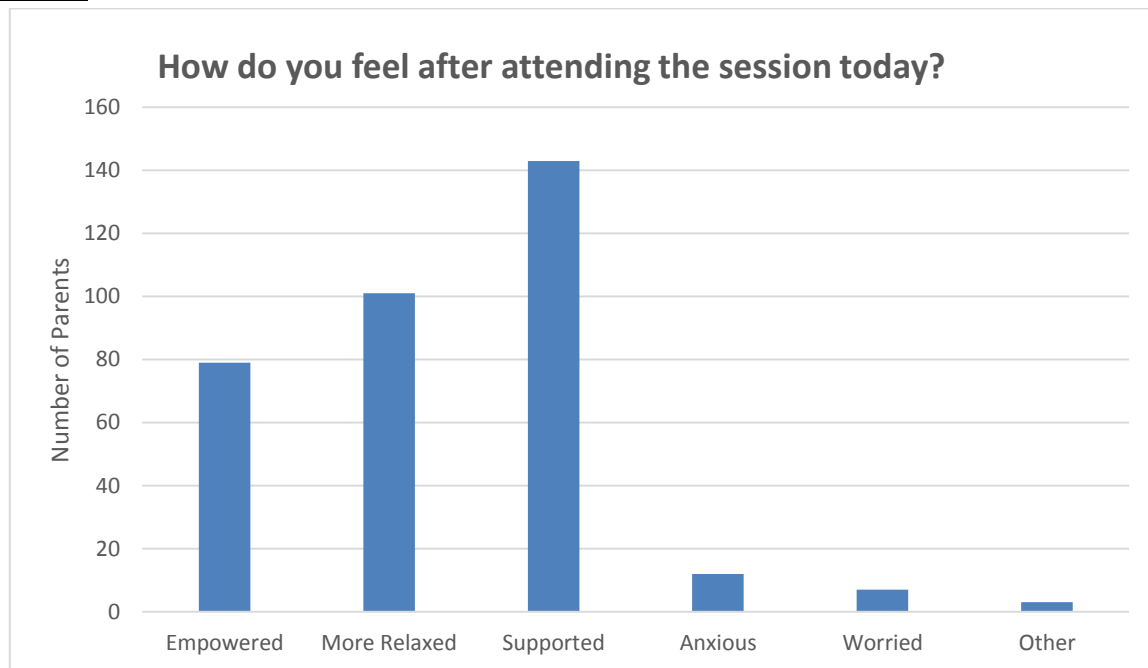
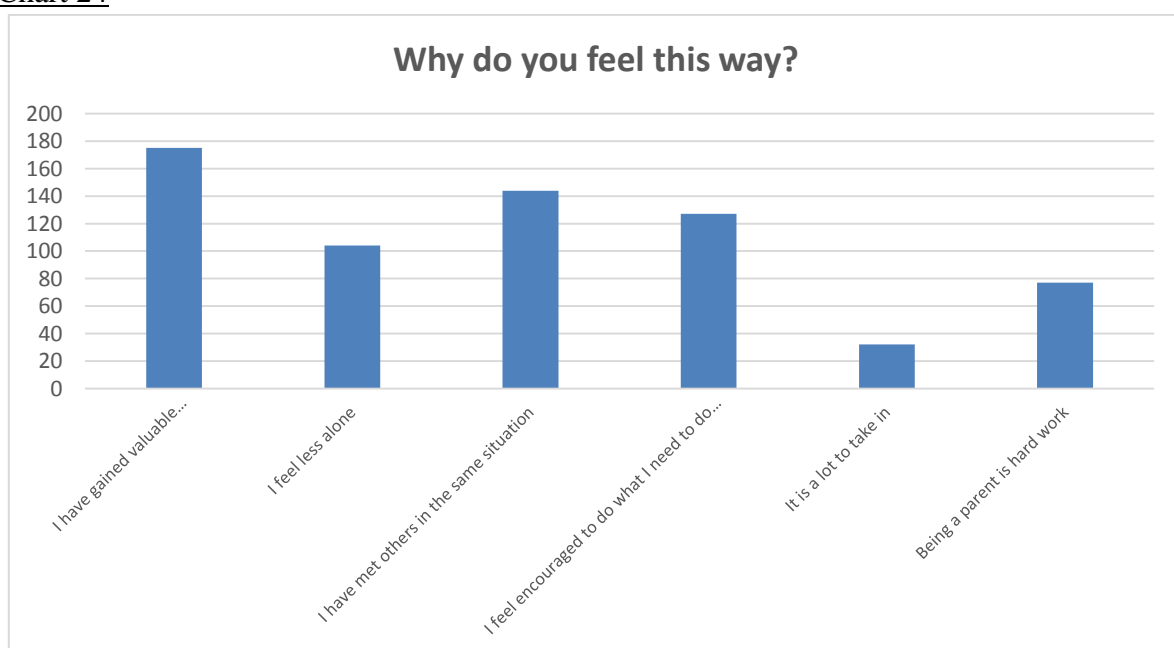
- Supported, looking forward to using strategies from session.
- Supported and more confident
- Empowered
- Relaxed
- With hope
- Informed

Any other comments?

- Thank you to the lovely staff for kindness, listening ears and useful advice.
- Explained a lot of sensory issues.
- Thank you! These meetings really mean a lot!
- Obtained a number of services of information to follow up
- I have a better understanding of sensory issues and how to help my son
- A huge thank you to all at Pinpoint for the support, encouragement and strength
- I just wanted to thank you for all the support Pinpoint gave me a few months ago when I attended the Histon support group.
- Pleased to be able to help parents with younger children.
- I've been given great ideas of how to help my child and really workable suggestions to give his school.
- Thank you, after years of struggling it is great to have some information and support
- Please consider running life skills courses - to help us counter educational ??? I feel that due to the interruptions the session could have benefitted from being longer. Also wondering if separating sessions for ADHD and ASD would help with the issue.
- Made me think about the future
- My mum and I attended the group at HRC a couple of months ago and we both found it extremely helpful and informative. It is great to have parents I can talk to that are going through the same things as we are.
- I thought we would learn more about strategy and coping mechanisms and it did not do that e.g. how to handle a child with ASD. (SENDIASS speaker)
- Group not what I expected at all. (SENDIASS speaker)

In terms of meeting their expectations, 53% said 'more than', 45% said 'yes' and only 3 parents said 'no'. **In summary, 98% of parents felt that the groups met or exceeded their expectations.**

From July, we started to collect further feedback in a quantitative format. The following feedback is from July 2016 through March 2017 only.

Chart23Chart 24**Professional Feedback:**

Professionals who attended the sessions as speakers were asked to rate and comment on the sessions. Comments include:

- It was a really good session. Good discussion amongst parents-helping each other. Eve - fantastic as always. (SENDIASS / Core Assets, Ely)
- Siblings session and in depth EHCP sessions would be good to put on for parents (Contact-a-Family, Histon)
- Information about post 16 EHC plans and provision would benefit future groups (Scope, Peterborough)

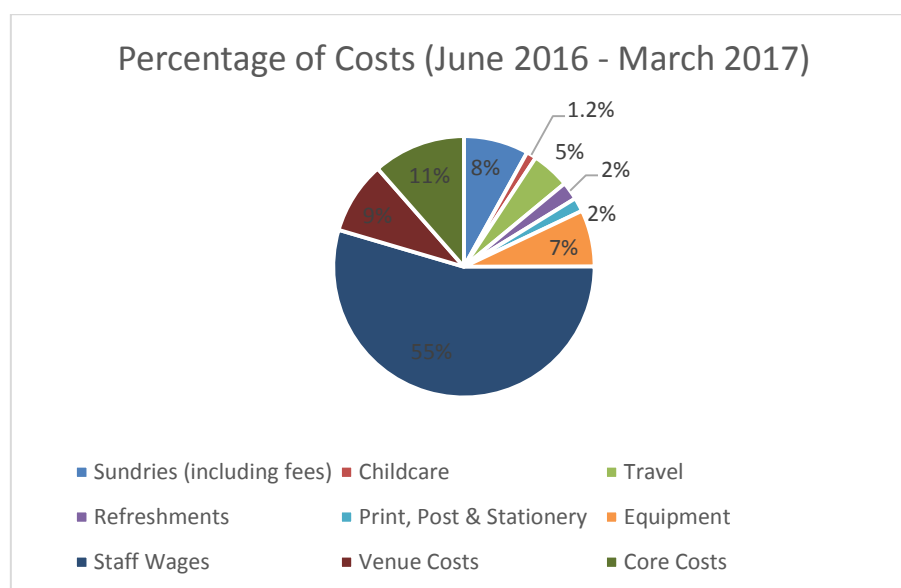
- It felt a very positive experience. The group of parents were very attentive and asked key questions and several followed up with a more individual discussion during the break which, I hope was helpful to them. (SENDIASS, Histon)
- Really difficult to gauge. Good responses and feedback. Great session. Parents interested and engaged. More longer courses for parents on strategies and behaviour and social communication would be great!! Thank you. (Histon, Communication Cambridge)
- I think a lot of parents resonated and had 'a-ha'!! moments. (Think Autism, Histon)
- Parents seemed to benefit from opportunities to connect with one another and share personal stories about their experiences. (CAMHS, Histon)
- I thought the session was really positive. It was a very interactive session and parents obviously benefit from this group. It is a good venue. I was pleased so many parents attended and I was able to provide the information parents needed. I was introduced by Eve and supported by directing discussions and keeping everyone (including me) on track. Thanks Eve. (Core Assets, Ely)

They also rated how beneficial they thought each session was for parents. The average rating was 4.7 on a scale of 0 to 5 with 5 being very beneficial.

### Financial Summary

The pie chart below gives a breakdown of expenditures for the 4 groups from June 2016 – March 2017.

Chart 26



Most expenditure is on staff costs which includes organising, promoting, facilitating and following up the groups.

A cost benefit analysis shows:

- Cost per unique attender (parent attending for the first time) £86
- Cost per all parents attending £38
- Cost per employee hour £32

## **Conclusions**

The sessions are continuously attended by new parents and we are getting more referrals from schools, family workers and CAMHS. The numbers vary widely per session and location with no pattern or consistency. The average number of parents attending is around 8 per session. The feedback shows that parents are gaining knowledge and confidence by attending, and they are grateful for the support and information from Pinpoint, the speakers and each other. We are working well with both statutory and voluntary sector partners to arrange speakers. We look forward to continuing this work in 17/18.

## **ANALYSIS**

The work in this section is based on parent carer views gathered via a variety of sources; Facebook Discussions, Surveys and Feedback Forms. The data is qualitative and quantitative. The data gathered can be used to demonstrate the following findings:

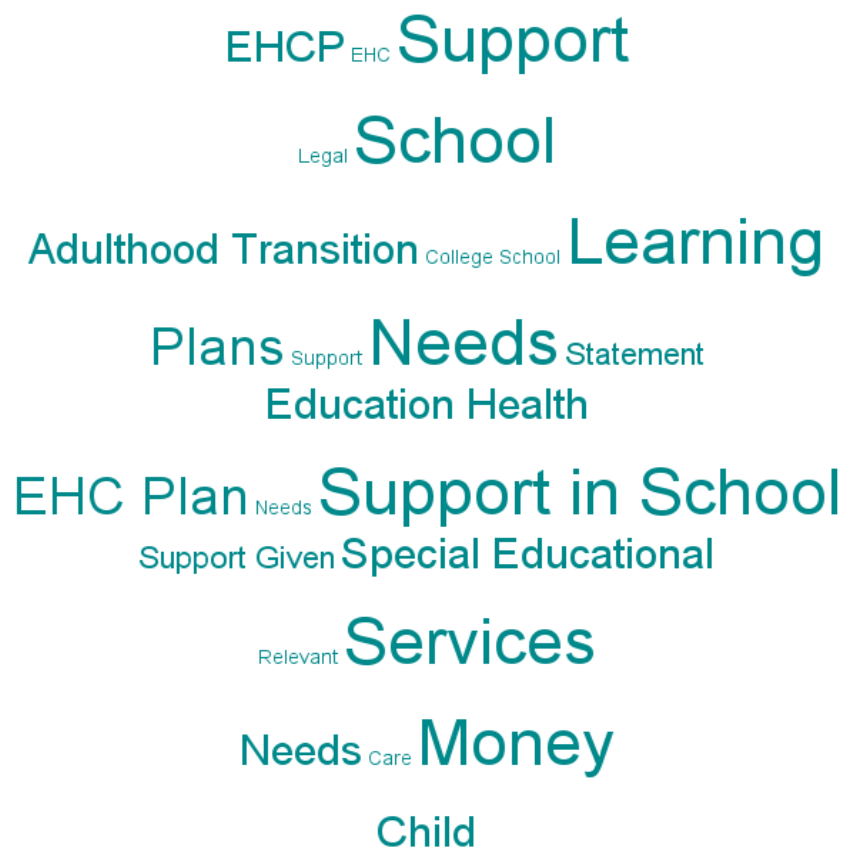
1. There is misunderstanding of the pathway and also a lack of knowledge of what support is available.
2. Work has been slow with less numbers attending the Behaviours that Challenge Workshops, The Expert Parent Programme and ASD/ ADHD Support Groups. There has also been less work occurring across Cambridgeshire compared to Peterborough for Behaviours that Challenge Workshops and The Expert Parent Programme with the reverse being true for the ASD/ ADHD Support Groups.
3. Those who take part in the pathway support programme provide positive feedback.
4. The data gathered in terms of costs/ attendance/ outcomes is used to further inform commissioning relating to Emotional Mental Health and Wellbeing.
5. The introduction of the Hub and Inclusion Surgeries has increased confidence in participating, led to an increase in feeling supported which impacts on parental mental health and wellbeing and also increased trust in professional relationships.

The work will continue in 2017/ 2018 with some amendment to include the Hub and Inclusion Surgery combined. It may be that the drop in attendance between the full year of the project and the previous pilot could be down to a lack of understanding, knowledge and low numbers of referrals.

Once parent carers have accessed what is on offer via the pathway they report positively on this. The negative reporting is associated with trying to access support and receiving mixed messages about the new pathway.

For any further work there is also a need to look at streamlining how monitoring occurs in terms of measuring outcomes and providing evidence of a quantitative nature especially for the Pinpoint part of the work.

**SECTION TWO (SEND Peterborough September 2015 to September 2016)**



Word Cloud (Formed from parent carer feedback comments)



## **Introduction**

A previous report looked at SEND between September 2014 and September 2015 (*FVP, October 2015, [www.familyvoice.org/participation](http://www.familyvoice.org/participation)*) and focused on parent carer understanding and experience of the SEND reforms as well as data on EHCp's and the use of Independent Support (IS). The following section in this report will focus on the same areas of SEND in Peterborough between September 2015 and September 2016. As in the previous section there will be a link between the information discussed and parent participation. The information in this section regarding parent carer understanding and experience has been gathered via online surveys, feedback form data captured during trips and activities, focus groups and Facebook discussions. The information has been fed back to Peterborough City Council Commissioning, SAM service and the Local Offer team. There have also been two online surveys conducted looking at the Local Offer and Personal Budgets. A Schools SEN Information Report examination has been conducted by a parent representative as well.

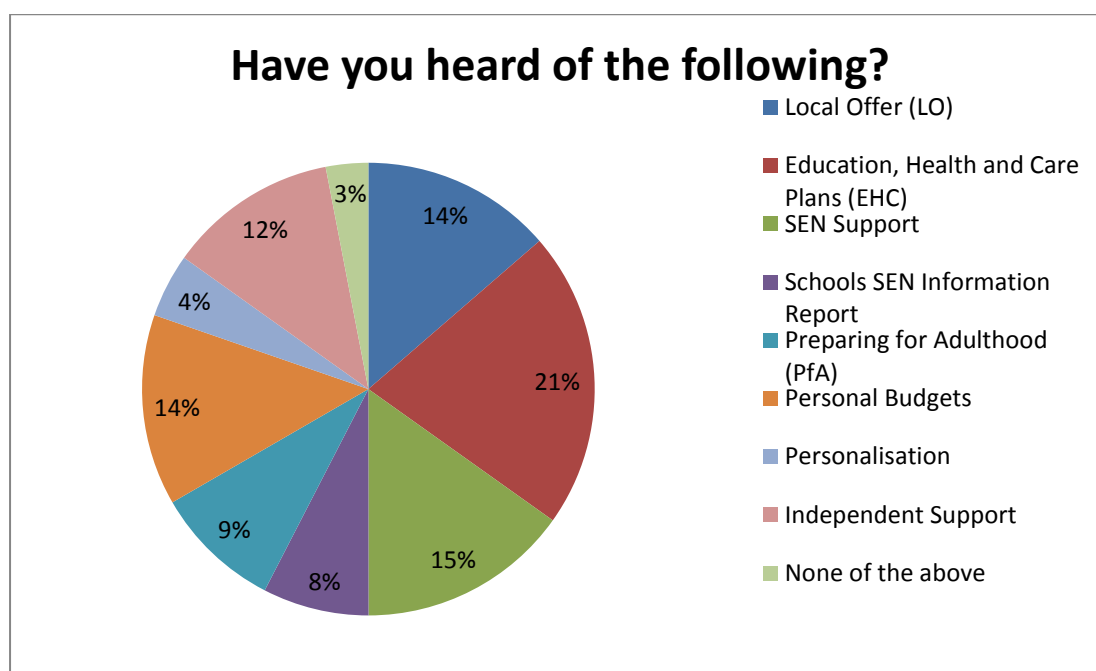
### **SEND 2015 to 2016 Survey**

The SEND survey has been re-visited and this year there have been 20 responses, with 16 being completed. The survey is an online survey designed and delivered via "survey monkey". The survey is designed to be completed anonymously if people wish and uses a combination of open and closed questions. The survey has 15 questions which are designed to gauge SEND awareness across themes such as the Local Offer and EHC's as well as experience of the system.

## **Results**

Question 2 asked the respondents to select from a pre-set list what aspects of SEND they had heard of. 16 respondents answered the question. The top three choices were EHCp's, SEN Support and the Local Offer

**Chart 1**



Question 3 asked respondents to say what they thought the different aspects of SEND were and as with the previous question 16 respondents answered the question. Some of the answers are as follows:

#### *Local Offer*

- *Information which local authority have to provide online about services they provide with in the local area.*
- *a place on the PCC website where all information, services, education and activities a child between the ages of 0-25 may access*
- *is public document that support parents and young people from 0-25 by making relevant information public and keeping it up to date*

8 stated don't know

#### *Education Health and Care Plans*

- *Helps child with extra support at school*
- *a replacement of statement, to assist the child with reaching outcomes with the assistance of education health and social care*
- *accumulation of information for a specific child for their health education provision*
- *personalised support for a child that has educational needs or medical needs that impact on education.*

2 stated don't know

#### *SEN Support*

- *support in school for those not with an EHC plan or statement as they do not reach the criteria, but they need more intervention and support within the school setting than other children*
- *support given to parents going through and after a EHC plan is in place or are going through a process of getting one.*
- *support for children with additional needs*

7 stated don't know

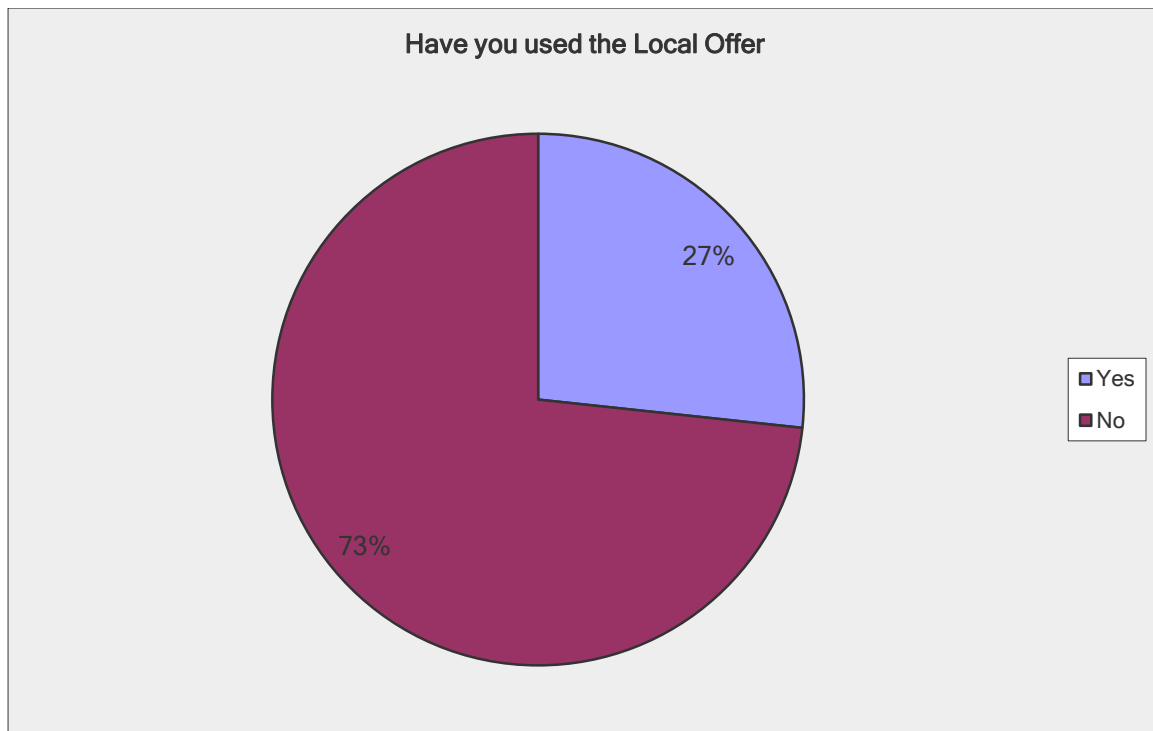
#### *Independent Support*

- *Scope advocacy family support groups carers trust pinpoint*
- *is offered as impartial service that is there to inform and support parents and young adults to ensure that law*

8 stated don't know.

Question 4 asked respondents if they had ever used the Local Offer

Chart 2

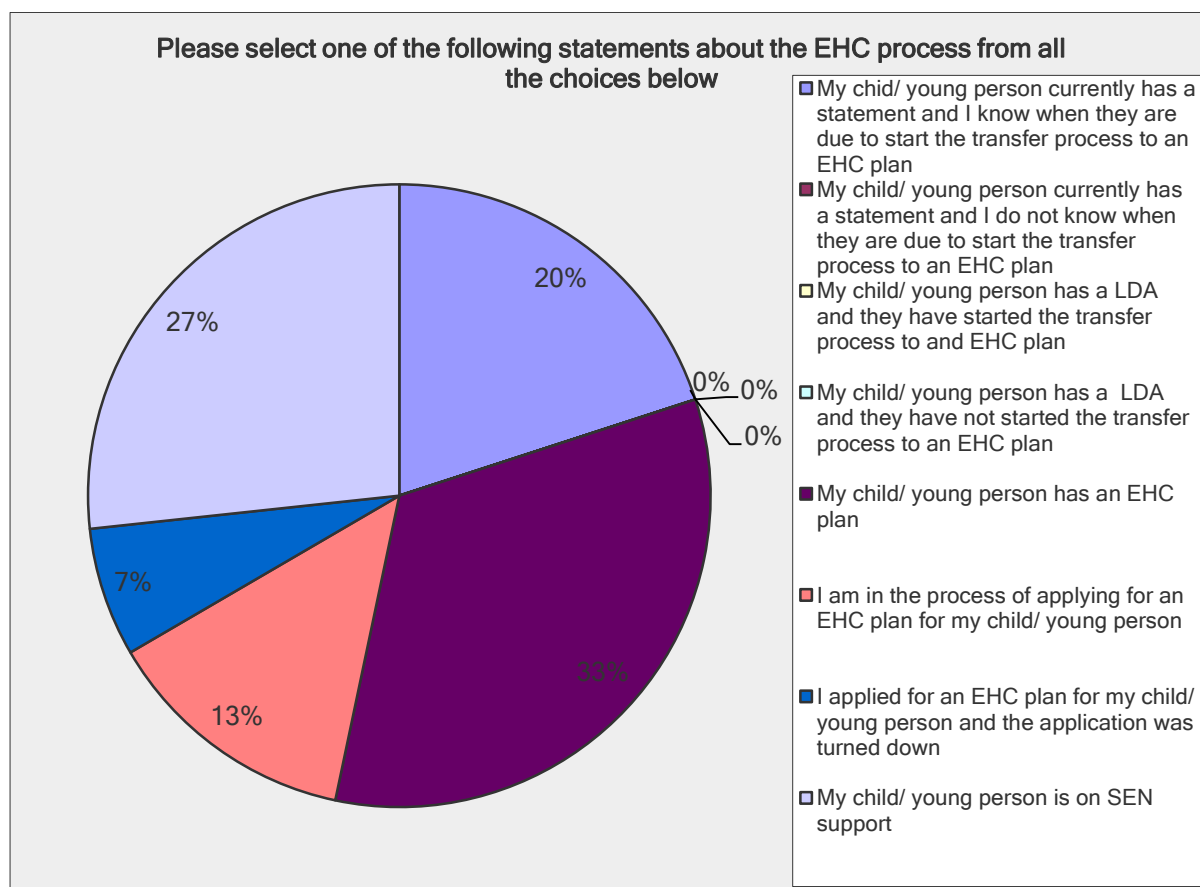


Usage is very low and views are not positive evidenced by responses to Question 5 where respondents were invited to explain how they found the Local Offer or why they did not use it.

- *wanting to compare to another you have to open another window as you cannot just go back a page*
- *I found the local offer confusing on the peterborough website. It was definately not user friendly*
- *Didn't know about it*
- *It is ok, I managed to find the information I was looking for.*

Question 6 asked respondents to say where they were in the system in relation to statements, EHCp's and SEN support

Chart 3



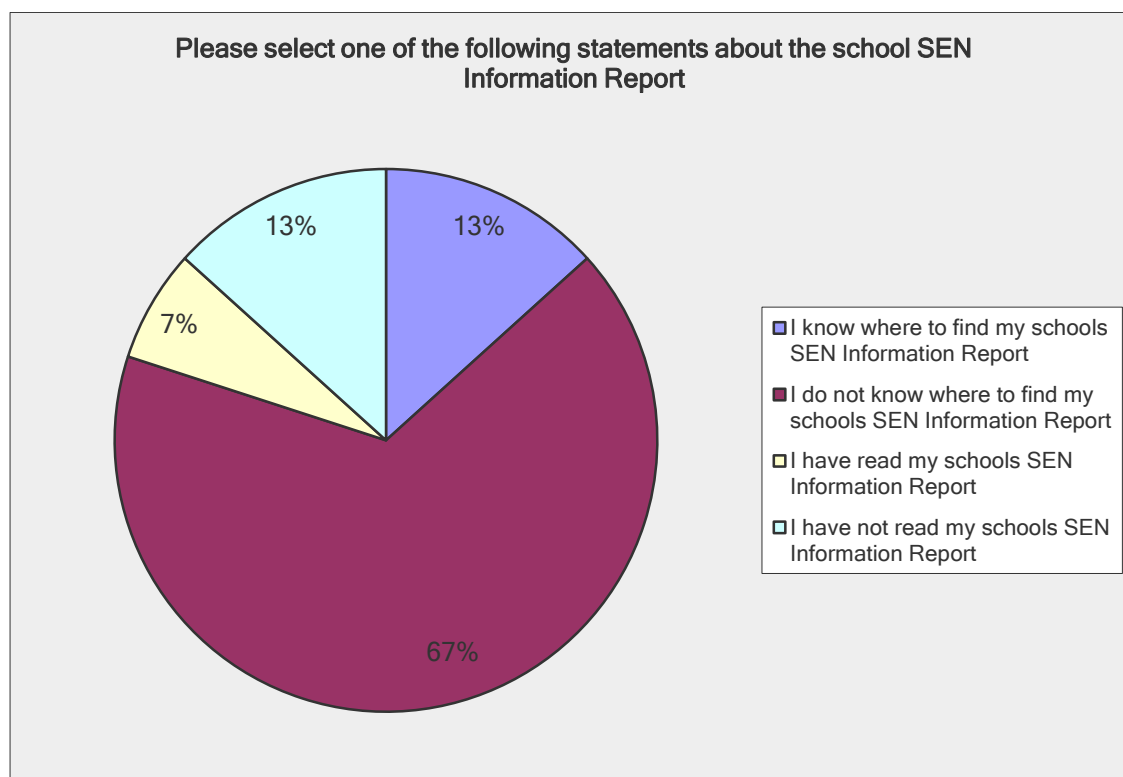
15 parent carers responded to the question and the statement selected most was “my child/ young person has an EHC plan

Question 7 asked respondents to provide further information after selecting the statement that suited them best in question 6

- *we have been through the transfer process of statement to EHC plan. found it very good and useful. more information*
- *I think my son would benefit for an EHCP as he is not attaining or engaging academically at school. The school have*
- *The ehcp transfer process was started in november/december time. At post 16 cut off for it to be finalised i believe was*
- *My child has Sen support of 15 hours. He isn't making a year progress in last two years and is currently running two years behind. We applied for a ehc assessment but was turned down at panel*

Question 8 asked respondents to select a statement about school SEN information reports. This was designed to gauge knowledge.

Chart 4



15 responses were given to the question. The highest responses was for the statement 'I do not know where to find my schools SEN information report.'

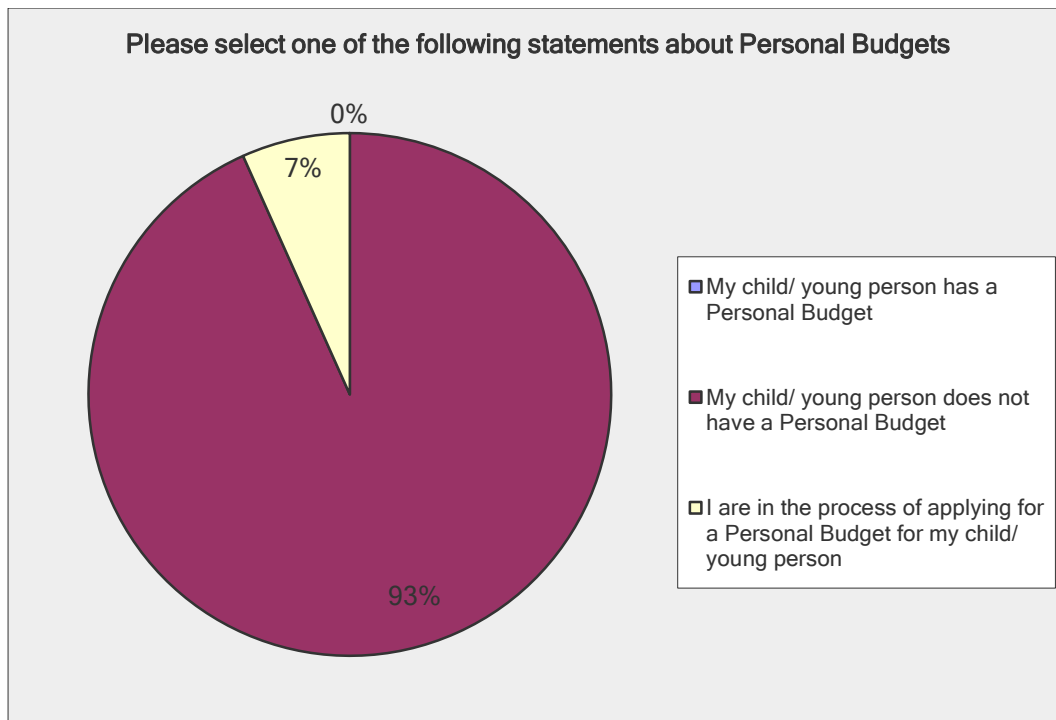
Question 9 asked respondents to expand on their answers

- *I like to know what the school does and can my child and other children*
- *I know where to find it and if in need know how to use the information.*
- *I have no idea what this is, I heard of it recently through Family Voice but don't know what it is. I will ask my son's*

This section was difficult to follow up as even though there was an opportunity to provide contact details none were.

Question 10 focused on Personal Budgets

Chart 5



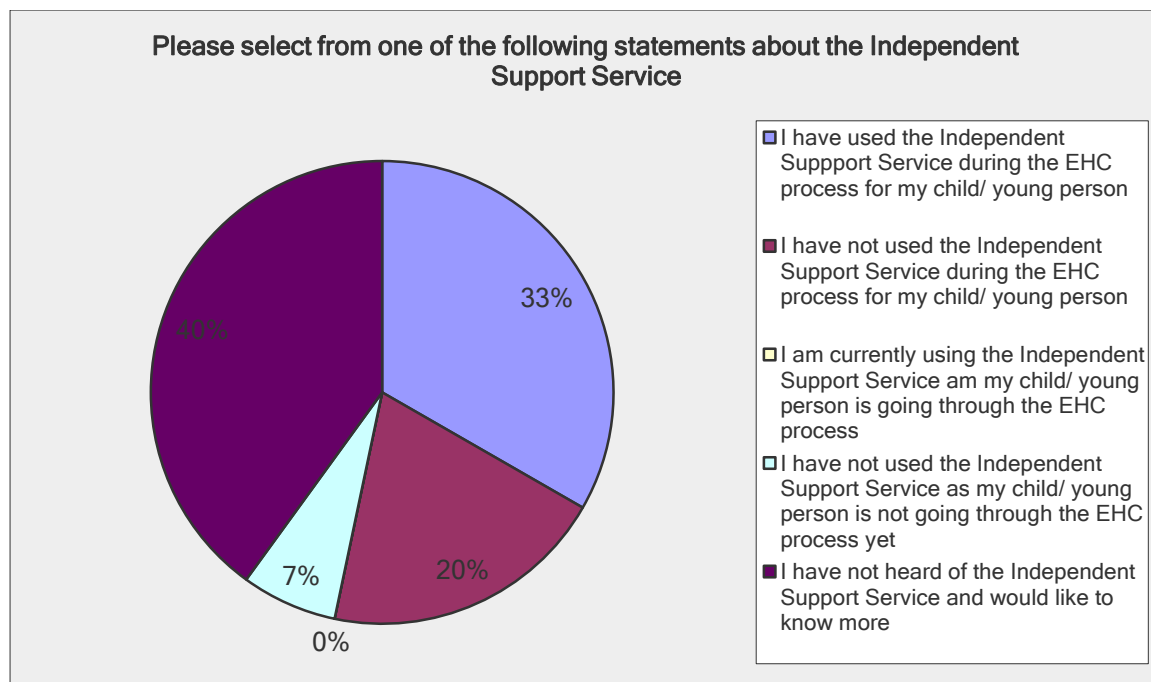
Only 1 person selected an option for going through the process of applying for a personal budget.

Question 11 followed on from this and asked respondents to expand on their answers.

- *we did not request a PB due to knowing there wasn't anything that would be agreed to*
- *it was not awarded.*
- *In progress of EHC personal budget not been offered yet*
- *My child does not have an EHCP*

Question 13 asked respondents to select a statement about Independent Support awareness

Chart 6



The most popular response was 'I have not heard of the Independent Support Service and would like to know more'.

As with previous questions Question 14 was used to elicit further responses based on the options selected in Question 13.

- *Amazing support, would not have managed without them...5 star*
- *I have used independent support for the EHC process support was excellent fully recommended service*
- *I have spoken to Maxine McCulloch from Scope she was amazing and filled me with the confidence to pursue an EHCP for my son. I will be enlisting her help once I start the process, my son is being assessed soon so it will be in the next couple of months.*

All feedback relating to IS was positive which matched feedback provided direct to the IS providers.

The survey ended at question 15 with respondents having the opportunity to give their views of current SEND services and their experiences.

- *Very good, SEN officer who did our EHC planning meeting was very thorough and patient with my son. I would recommend that in letters that go out to parents to advise the approximate time it would take to have a planning meeting as well as the EP meeting which was another 2 hours*
- *Lack of information being passed on feels like a fish out of water and in a minefield of information that we don't know*
- *I find the SEND services in general to be woefully inadequate. Parents are left fumbling in the dark and are not given consistent and accurate information. It is independent charities like Family Voice, Carer's Trust and Scope that are helping parents and subsequently their children to ensure their rights are upheld. We are talking about vulnerable children and young people here, whose parents are desperate to help them and they face barrier after barrier with very little help and support. This is a truly shameful situation, they say a society is judged on how they treat their children, if this is true then the judgement in regards to SEND would be very harsh. We need to put our children's welfare and wellbeing above the bottom line, there lives are worth more than the savings of a few pounds.*

### SEND Experience Facebook Discussion

Questions asked:

- Do you have a statement/ EHCp for your child/ young person?
- If you have an EHCp for your child/ young person is this a new plan or a transfer from a statement?
- What do you think to the new EHCp's?
- Do you prefer the old system or the new system?

Answers received:

*"We have just received our final EHCP - process etc was fine, problems arose but were dealt with. I didn't find it any worse than the old system. Actually it was less painful than anticipated. The only real problem was hand delivered documents got lost - which has happened previously..... Our was a more bespoke arrangement than a PB as the LA/head teacher agreed Flexi-school with some funds from the school funds. I have to say despite their initial concerns they have bent over backwards to make this happen for us - we were also within the 20 week timescale, a really positive experience."*

*"Ours is happening this year... Fingers crossed"*



*“We received my son's EHCP a few months back. I prefer it as it seems to go more into the child's needs than the statement, which is good. It was one of the first the school had done but we got through it! Off to college in September so will see how things go there!”*

*“We are still stuck in the system. Have received my sons draft ehcp, which is really helpful. Much more needs centred. The draft has helped enormously. My boy is now away in east Sussex doing an apprenticeship in blacksmithing!! Having the ehcp for the placement to check before he started was so beneficial for him. Much easier to understand what it requires and what his needs are. A bit long winded getting it, ours was over 10 months, but I know they are so short staffed. Good results in trying circumstance's.”*

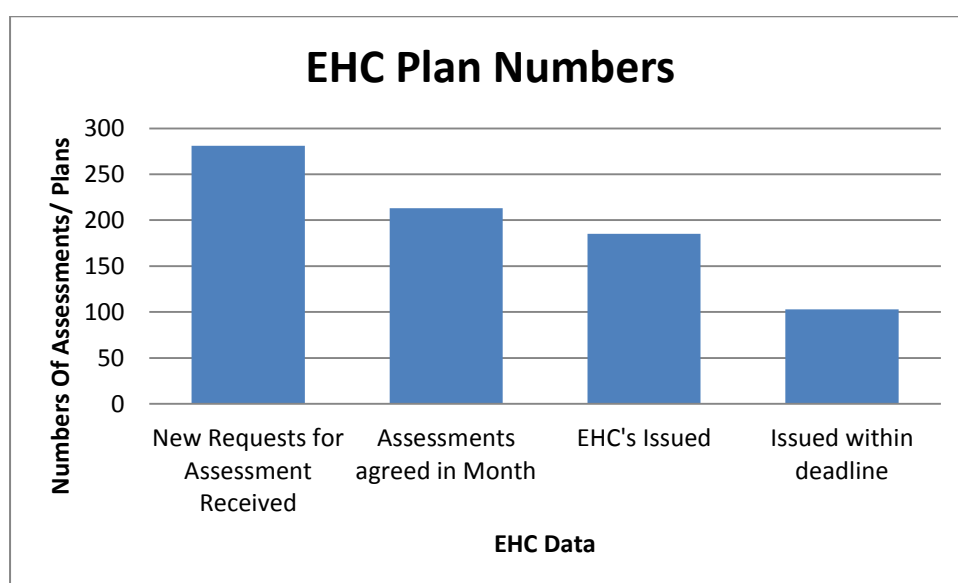
*“I feel the whole system is a sham and wastes so much time that the support the children need by the time the ehcp meeting takes place to the time they write up (some months down the line) have often changed... 9 months into the ehcp process and we have no placement arranged for september, highly stressed 16 yr old who should have been a priority and one very stressed out mum... for the second summer in a row! Grr”*

*“My daughters EHC process has been fantastic and everything she needs has been put in place. My son's however a. Completely different story completely ignored in two separate settings as he is post 16”*

### SEND Data

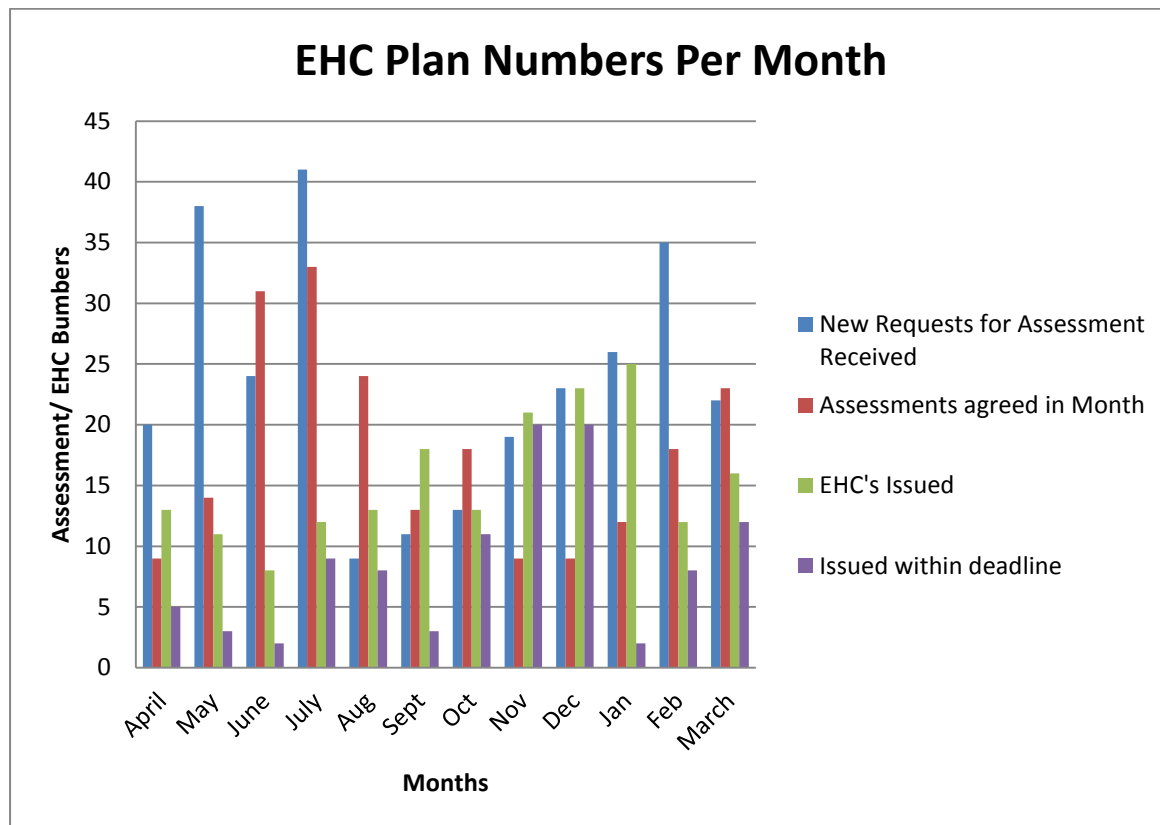
The following information has been provided by Peterborough City Council SAM service and relates to new EHCp's issued and conversations to EHCp's. The numbers sharing their experiences are small in comparison to the numbers that follow and any data cannot be used to draw any conclusions simply demonstrate people's experiences who are willing to share their views.

### Chart 7



The data is from across 2016/ 2017, however it must be noted that the number of new assessments and plans issued does not mean that the difference between the two figures relates to plans not issued as a number of assessments are ongoing.

Chart 8



The above chart shows the data on a month by month basis as opposed to a whole year.

Chart 9

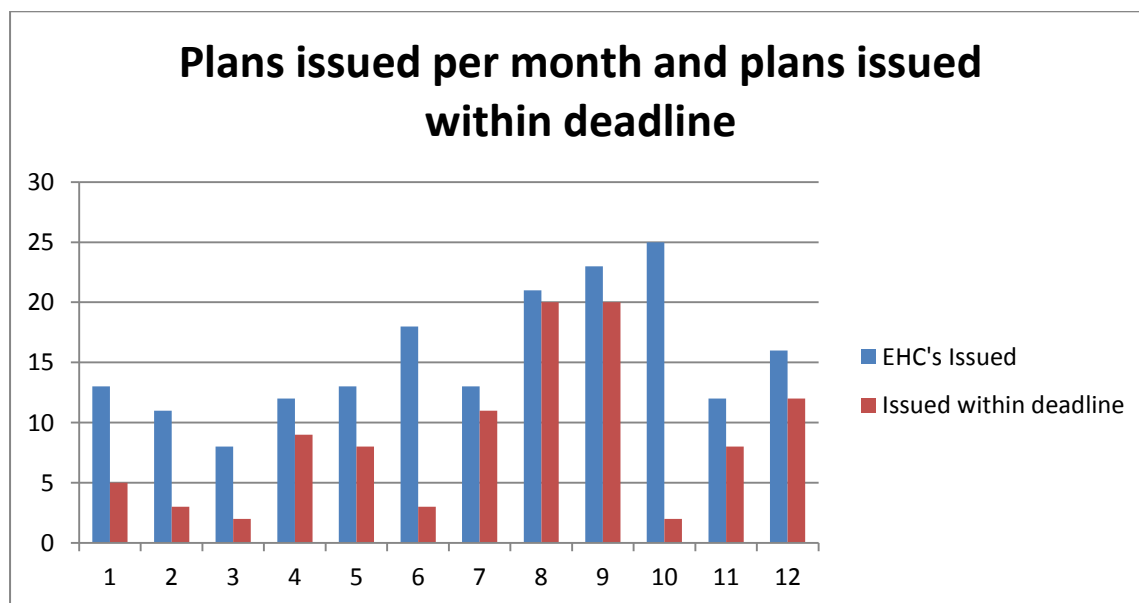


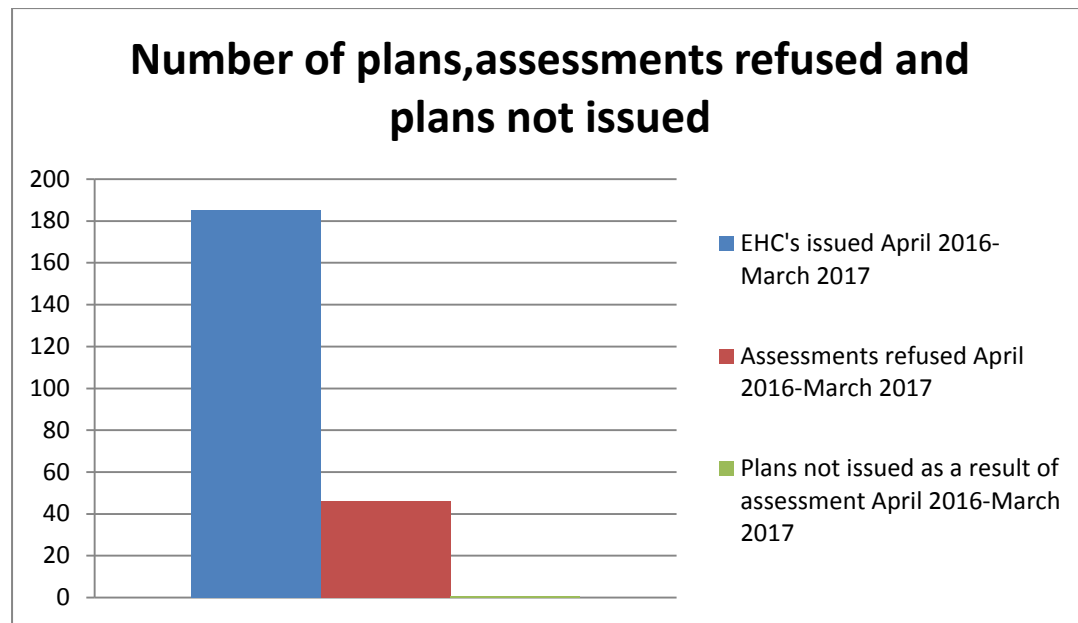
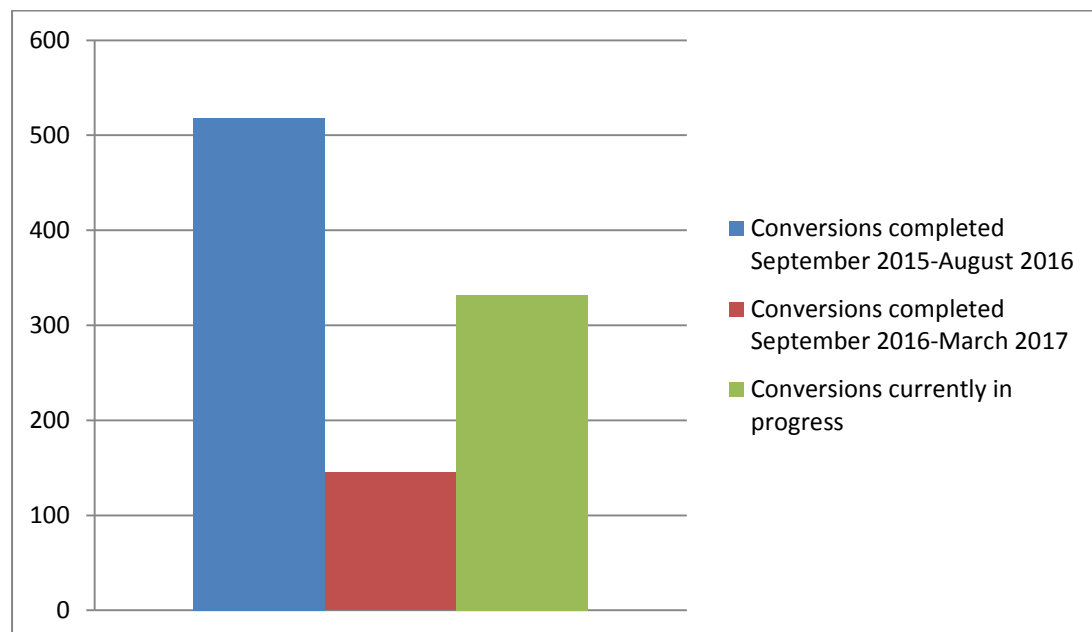
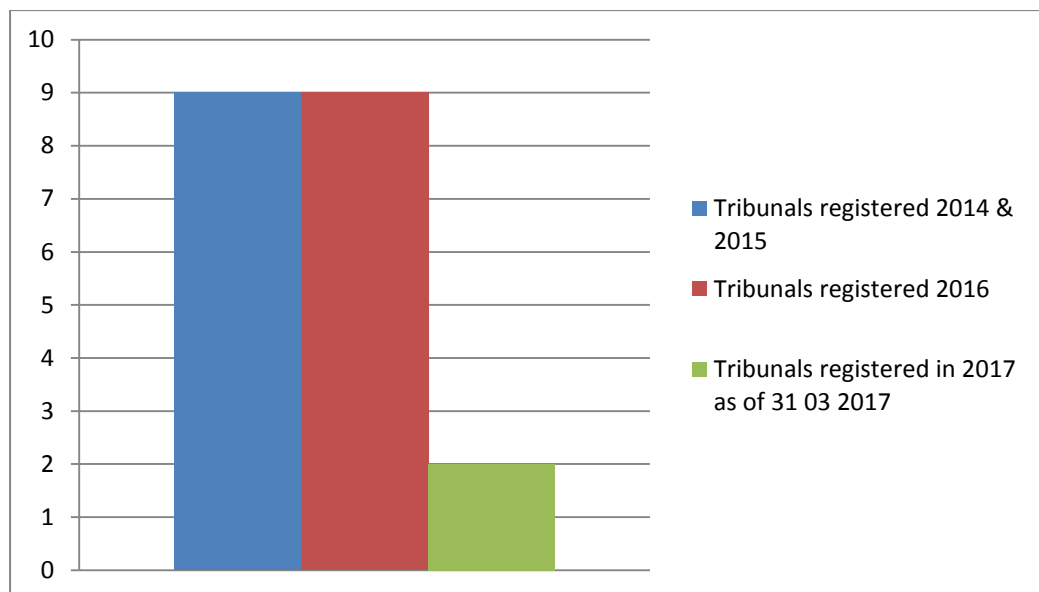
Chart 10Chart 11

Chart 12

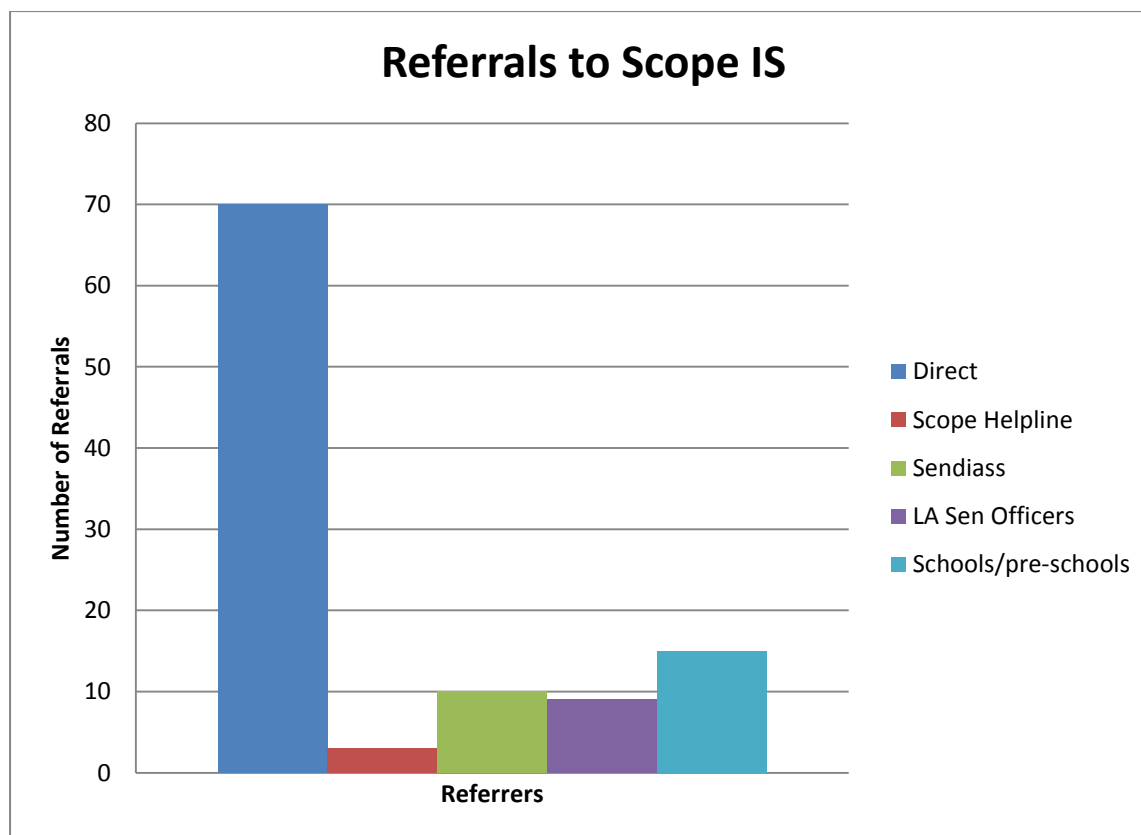
Tribunals registered 2016 = 9 (1 ongoing, 5 withdrawn, 3 upheld)

### Independent Support Data

Independent Support is provided via Scope, PCVS and SEND partnership.

### **Scope IS**

Chart 13



The following information was provided by Scope IS about the service they provide and its use:

All of the feedback we have received has been very positive, saying they found the service very responsive and supportive. We have a good working relationship with Sendiass.

School Senco's don't engage with our service as much as we would like, this is a shame as we would be taking some of the workload from them.

In some counties all parents are contacted by the IS services so that they can have the process explained to them and be offered support. At this point they can choose to opt out rather than having to contact us themselves to opt in.

We have had no negative feedback at all. Here are a couple of examples:

- *I used this amazing service and cannot recommend them enough.*
- *Scope were amazingly helpful and knowledgeable! A great support at a difficult time. Thanks so much*

## **SEND Partnership Service**

- There have been 12 cases via this service.
- Data on age groups has not been provided.
- Referrals have been mainly through direct phone calls from parent/yp, SAMS, schools, previous involvement at SEN Support
- concerns - numbers are low compared with amount of EHC requests/transfer of SSEN to EHCP
- working well - good working relationship and partnership working with both PCVS and SCOPE

## **Local Offer and Personal Budgets Surveys**

Two surveys have been conducted in relation to SEND, one focused on the Local Offer and the other focused on Personal Budgets. There have been 17 responses between the two surveys.

### **Local Offer**

The survey is still live so a sample of the answers and questions will be provided in this report to give an idea of some current views.

### **Question**

Are there any areas of information about services and support for children with special educational needs/disabilities and their families that you have found particularly difficult to locate?

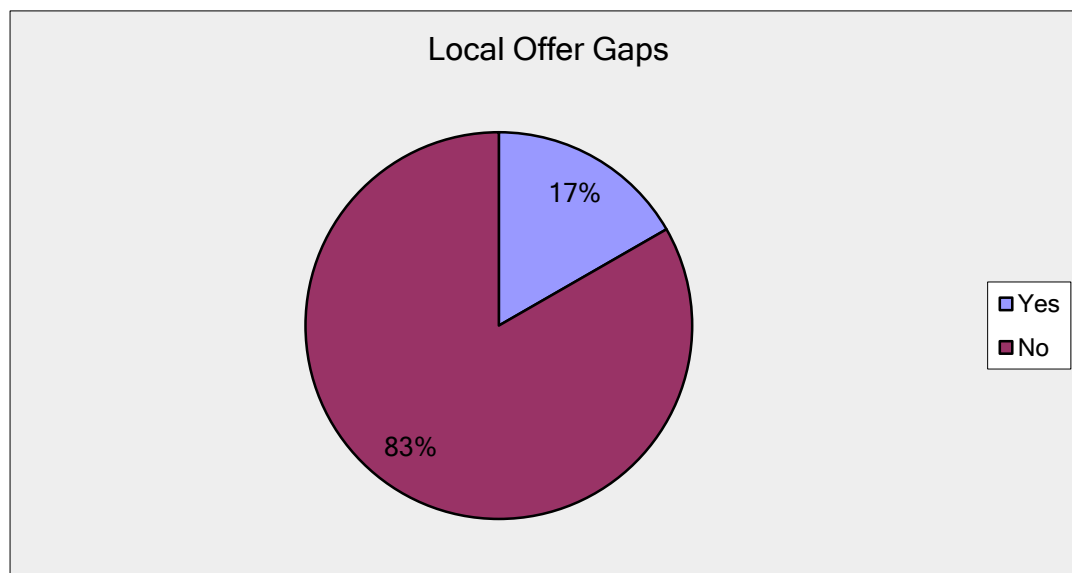
### **Responses**

- *We can't get any support from any service*
- *Some of the Preparing for Adult section is a bit wordy*
- *Transition to adulthood*
- *Respite care*
- *Lucky to have received great support. However when I have accessed some services in Peterborough found them very clique and did not return. Face to face group was fantastic*

### Question

We want to know if there are any gaps in Peterborough's Local Offer. Are you aware of services children and young people with special educational needs and/or disabilities required but which are not currently available?

Chart 14

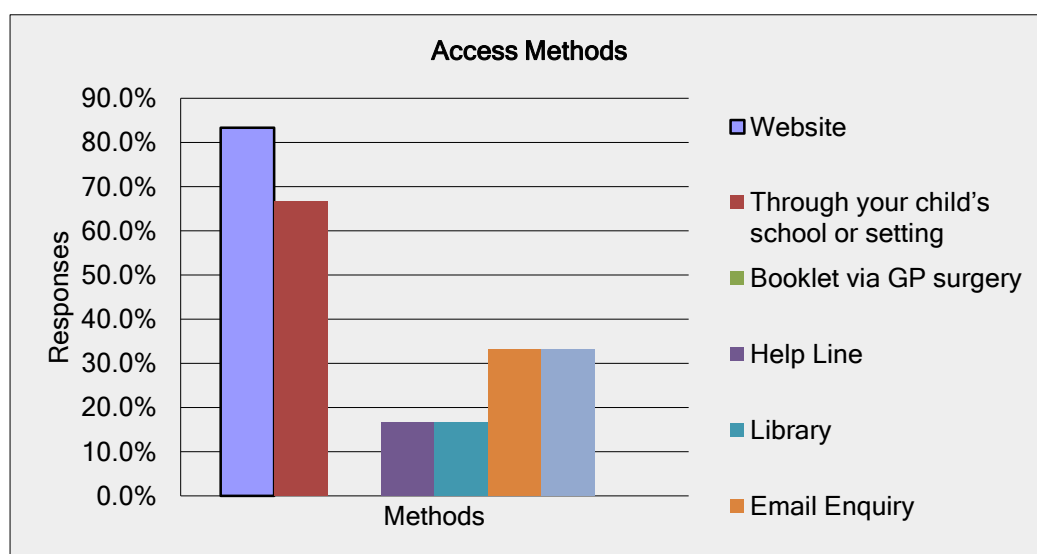


An extra comment was provided; *“Support when children are in mainstream school and support for siblings”*.

The majority did not know of any services that may be available to go on the Local Offer.

Another question asked respondents how they would like to access the Local Offer.

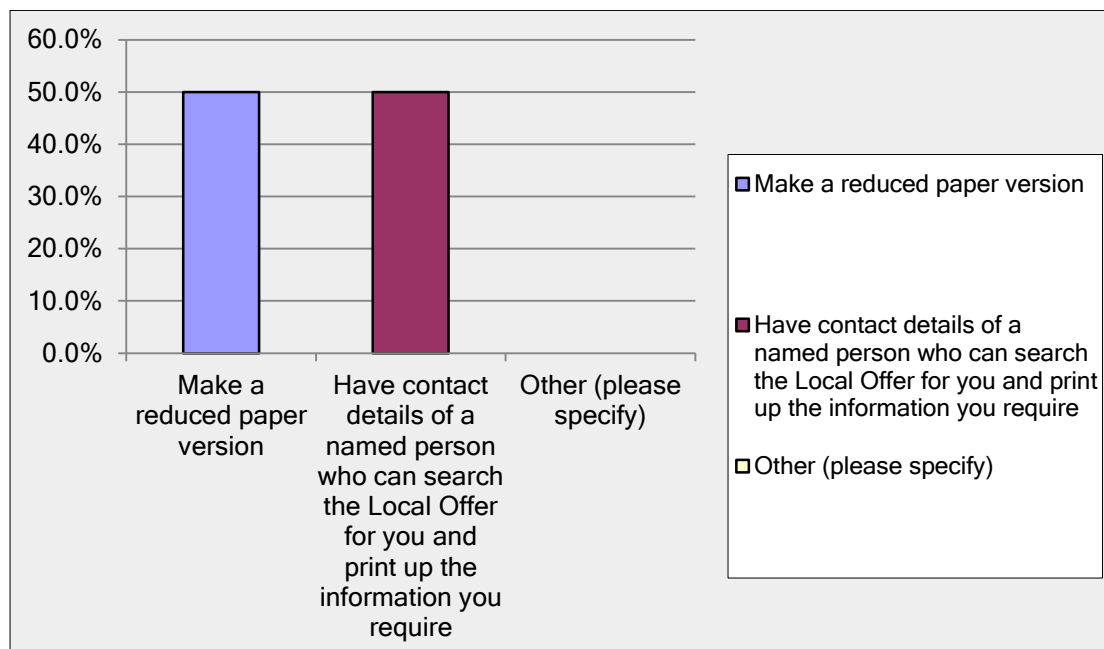
Chart 15



The most popular method for accessing the Local Offer was via a website and the least popular was at the Library.

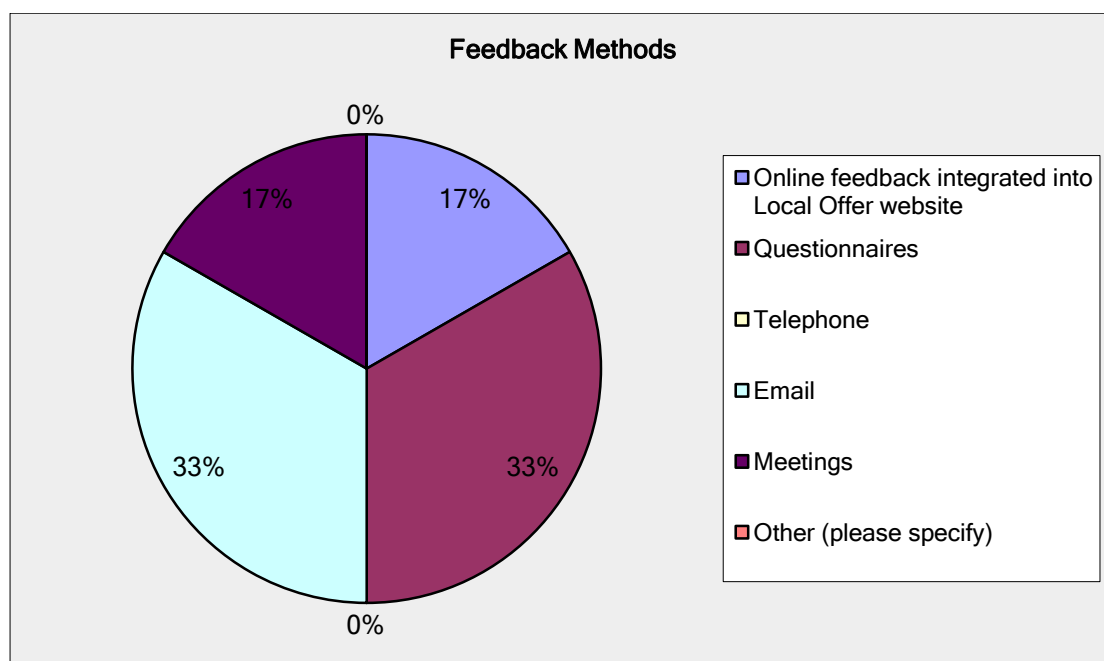
The next question asked what methods should be available other than online.

Chart 16



Another question related to what preferred methods for feedback on the Local Offer would be.

Chart 17



The most popular method was via either email or questionnaires.



## Personal Budgets

This survey was used to gather information on Personal Budget awareness and also the types of questions parent carers would like to see as FAQ's on the Local Offer.

Some of the suggested FAQ's were:

- Can you spend your personal budget on out of school learning?
- What is a personal budget and how and where do I get?
- Can I add to my daughters budget?
- what services or support can you "buy" with a personal budget?
- I applied for one in draft stage of ehc, how long before I hear, it's been 2 months
- What can and can't they be used for?

The information from the survey has been fed back to commissioning and incorporated in a leaflet informing people about the Local Offer.

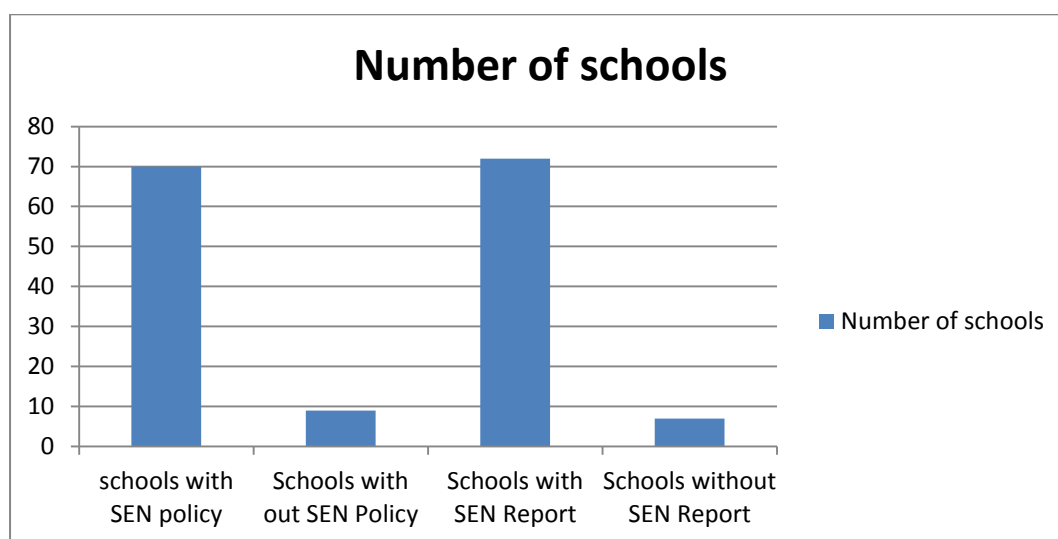
## Schools SEN Information Report Examination

A parent representative on FVP conducted an analysis of local schools SEN Information reports as a follow up to work conducted in 2014-2016. The idea was for a parent to provide their perspective on how easy it was to find the reports, to gauge how informative they were and whether they matched up with what was required as specified in the SEN Code of Practice 2015.

The full report "*Schools SEN Information Report 2016 SR*" can be downloaded from [www.familyvoice.org/participation](http://www.familyvoice.org/participation)

One of the first areas investigated by the parent representative focused on whether schools had a SEN report or not. The results of which are in the chart below.

Chart 18



## **ANALYSIS**

Understanding and experience of the new SEND system is still mixed which is evidenced by completion of surveys and Facebook discussions. Some of the data provided above has been gathered via a survey that was administered in 2014, 2015 and again in 2016. The response rate was lower this year but there are still enough responses to provide evidence of parent carers views. Some of the key findings are as follows:

1. Survey data has shown there is still mixed understanding and experience of the SEND Reforms.
2. The Local Offer is under used, and viewed negatively.
3. Independent Support is viewed very positively when used but uptake is very low compared to the numbers of new EHC plans and transfers from statements to EHC plans.
4. Experience of transfers from Statements to EHC plans is mixed with parents reporting positively and negatively.

EHC experience is mixed and views seem to relate to how the process has occurred at an individual level. There are more positive than negative views being expressed. Very positive views also seem to be expressed in relation to IS in particular but knowledge of IS and use of IS is low. The use is very low compared the number of new plans and transfers that have occurred.

The data on the number of new plans and conversions has been supplied by PCC SAMs and is much higher than the number of parent carers providing feedback which means any negative or positive feedback can only show how parent carers feel not whether the process is working or not. There is a perception amongst some people that the new system is not working and there is a high level of dissatisfaction but the data presented cannot back this perception. It is not possible to say whether the system is working or not. A total of 20 tribunals have been conducted since 2014 with data available showing that 3 have been upheld.

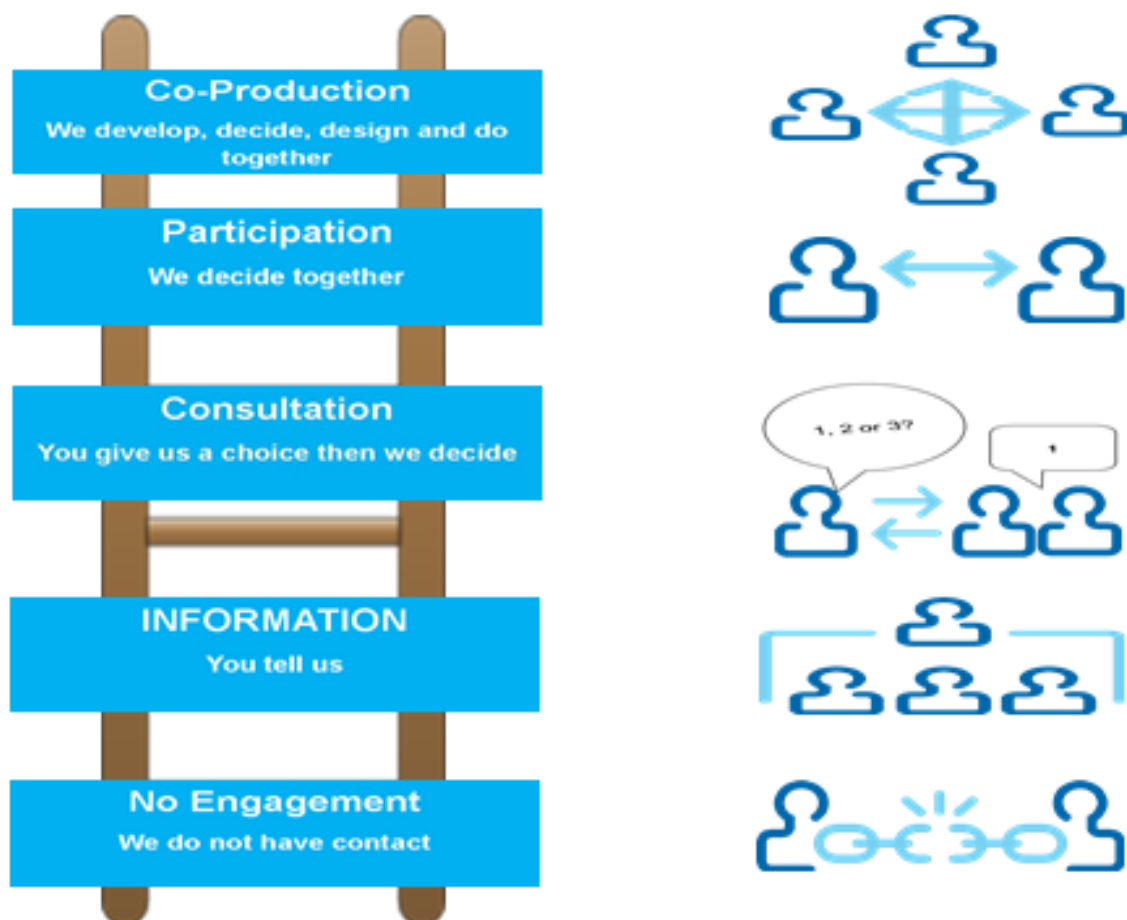
There is consistent negative feedback on the Local Offer and use of the Local Offer is also very low. There has been feedback provided by a diverse range of parent carers however participation in this area is consistently low.

**SECTION THREE (Participation April 2016 March 2017)**



## **METHODS**

A combination of methods are used to enable parent carers to participate which take account of parent carer preference, service/ commissioning requirements and forum capacity especially in terms of finances and actual time. Over time a specific approach has taken place in Peterborough which is based on the ladder of parent participation:



(Info graphic Developed by L Ravenscroft for the FVP parent participation and representation course, September 2014)

An adaption of this representation was used recently by Contact a Family in their Health Toolkit For Parent Carer Forums p. 10

Co-Production	Parents and professionals work jointly on the development of decisions that are made in an equal and reciprocal relationship .
Participation	Parents and professionals work together in strategic groups and decision making groups to decide what should happen and shape services.
Consultation	Parents/ carers are asked what they think about particular developments or issues
Information	Parents/ carers are provided with information from the department/ provider about what is happening
No Engagement	Parents/ carers do not know who to contact and have no working relationship with department/ provider

The ladder approach does not imply there is a point to be reached rather that parent carers can participate at any level that suits them. Parent representatives will participate at the top of the ladder via the forum and other parent carers will be enabled to share their voice or simply receive information via the methods described in this section of the report.

Table 1 - Parent Representation

Board	Organisation	Designated Parent Representative
Cambridgeshire and Peterborough Mental Health and Emotional Wellbeing Board	PCC, CCC, CCG	J Ravenscroft
Peterborough Children and Families Joint Commissioning Board	PCC	J Ravenscroft
PSHFT Maternity, Children and Young People Programme Board	PSHFT	J Woodhams
SEND and 0-25 Transformation Strategic Board	PCC	L Ravenscroft
SEND Project	PCC	V Perry
Carers Partnership Board	PCC	S King
Learning Disability Partnership Board	PCC	C Dias
Eastern Region Parent Carer Forum	ERPCF	J Woodhams
Healthy Child Board	PCC	R Ndow , S Nawazi, C Dias, R Jan and N Jan
Early Support Stakeholders	PCC	V Perry
Diversity and Cohesion	PCC	J Woodhams
Multi Agency Forum	PCC	J Merrill
Autism Board	PCC/ CCG/ CPFT/ 3 <sup>rd</sup> Sector	C Dias
Preparing for Adulthood (PfA)	PCC	J Merrill
Local Offer	PCC	C Dias

This information can change from time to time and the parent representatives may also attend boards other than the ones where their name is listed. All those acting as parent representatives have had training to enable them to carry out this specific role.

Parent Representatives are Parent Carers first and foremost and are acting in a role that calls for their unique knowledge and experience of raising a child/ young person with Disabilities and Additional Needs. They are representative of parent carers they are not in their role to represent individual parent carers as they are not advocates.

Parent Representatives attend meetings at a strategic level and help inform the process in the development and delivery of services for SEND. They have to write brief reports to feedback to the forum of the meetings they have attended. At the meetings they will share views of parent carers relevant to the topic being discussed and they will also gather information to evidence these views.

### **Focus Groups**

There have been 9 Focus groups covering the Local Offer, EHC plans and processes, CAMHs, SEND information and OFSTED and CQC inspections. The focus groups have taken place between April 2016 and March 2017. Attendance is generally below 10 parent carers per session. This is due to interest in the topic, notice of when the focus groups will take place and parent carer commitments. The most well attended focus group was a joint themed one covering the Local Offer and CQC/ OFSTED inspections readiness.

All focus groups have reports produced detailing attendance data, feedback, discussion points and any outcomes including where possible “you said – we did”. The reports are all placed on the FVP website for people to download and view [www.familyvoice.org](http://www.familyvoice.org). The Local Offer focus group reports are also available via the Peterborough City Council Local Offer as part of an evidence base of parent participation.

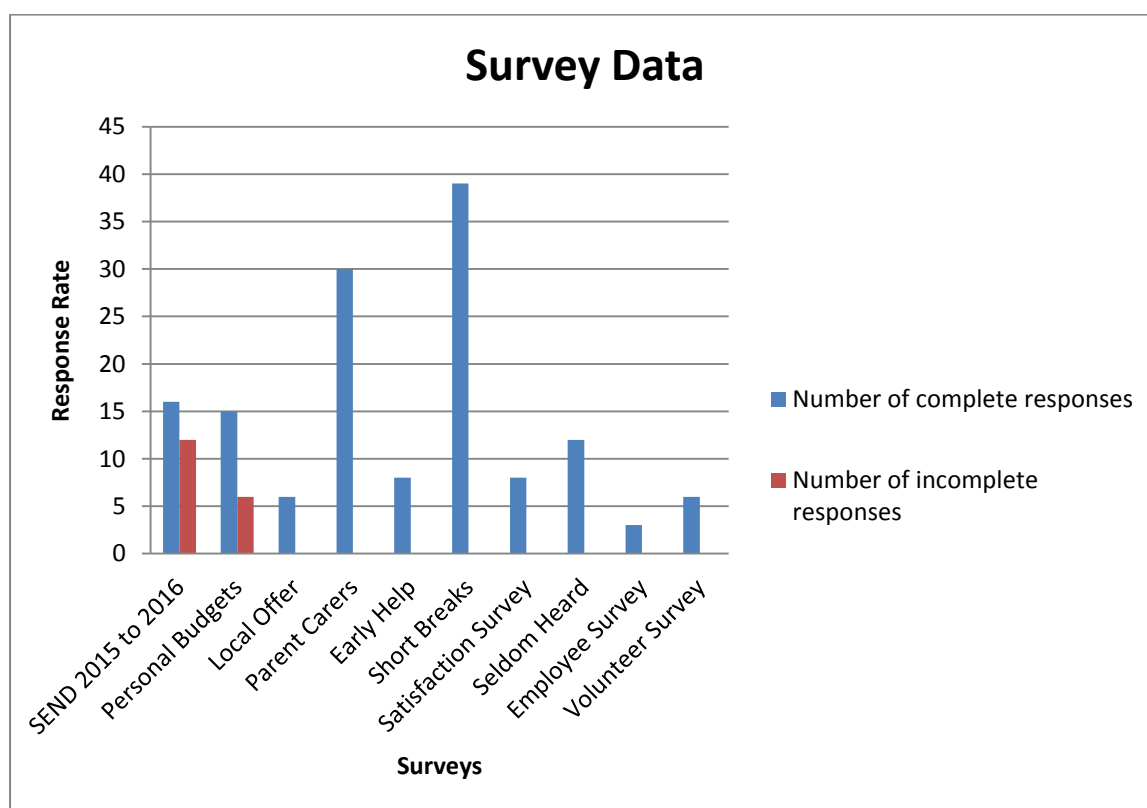
### **On-line Surveys**

10 surveys about Parent Carer Support, Personal Budgets, SEND Knowledge, The Local Offer, Early Help and Charity/ Forum satisfaction have been produced and reported on. The surveys are designed by Parent Representatives and any data from them forms an evidence base when the representatives attend strategic meetings.

There were a total of 143 responses across the surveys; it is not possible to determine the number of unique responders as many complete the surveys anonymously.

Table 2

Survey Title	Number of complete responses
SEND 2015 to 2016	16
Personal Budgets	15
Local Offer	6
Parent Carers	30
Early Help	8
Short Breaks	39
Satisfaction Survey	8
Seldom Heard	12
Employee Survey	3
Volunteer Survey	6

Chart 1

The highest response rate occurred on the survey looking at short breaks and the lowest response rate was for the survey on the employee satisfaction.

The online surveys are general completed anonymously and provide a mix of qualitative and quantitative data by using both open and closed questions.

### **Annual Conference**

1 annual conference which is open to parent carers and professionals to attend jointly and have the opportunity to inform SEND services together has taken place. This could be seen as a form of co-production especially the work shop section. Discussion and information in the workshops directly informs and shapes SEND services/ information. An example of this is the ongoing development of PB leaflets. As with the focus groups reporting on the conference is made available via the FVP website.

Evidence is taken from attendance registers, feedback forms, discussion notes and minutes.

### **1:1 Meetings**

10 meetings with parent carers from seldom heard groups to facilitate engagement and build trust have occurred. The parent carers have needed extra time to talk and explain their issues/ needs in a way that builds confidence in participating and seeking support in the form of signposting.

### **Aiming High Group (AHG) and Seldom Heard Group Meetings**

2 AHG meetings have taken place which are used for gathering views on documents and planning joint activities and fundraising events. One such area of work included the planning

and development of a joint “Asian Cuisine” day which was also a fundraiser to help facilitate a coach trip for the parent carers and their families from both the AHG and also Seldom Heard groups. The other meeting provided parent carers the opportunity to complete the short breaks review survey.

2 AHG/ Seldom Heard specific sessions at Activity World were utilised to increase membership, raise awareness of being a parent carer and inform the Early Help work and short breaks review.

3 Seldom Heard meetings have taken place where the parent carers come together and work on a particular topic using post-it notes, question and answer sheets and feedback forms. Topics have included planning the joint fundraiser mentioned above and views on what information would help make a visit to the Child Development Centre (CDC) easier. The final booklet can be downloaded from the FVP website

### **Working Breakfast Sessions**

4 Working Breakfast sessions have taken place at which surveys are completed and discussions held where minutes are taken. Themes have included CAMHs and EHC documentation.

### **Facebook Polls**

1. Areas of CYP Need
2. Preferred ways of participating
3. What is NDS and CAMHs
4. Who is interested in SEN surgeries
5. Private Therapy Use
6. Information for Parents
7. Autism Strategy
8. Groups Accessed
9. Do you know what the SEN information report is
10. Have you seen and read your schools SEN information report
11. Have you input into your schools SEN information report
12. SEN School Transport

The Facebook Polls enable users to add choices and to answer more than one choice. They enable quick responses which can be viewed by anyone in the chat room. It is also easy for responses to take place across multiple platforms from phones to computers. Some Polls are also followed by comments where parent carers have expanded on their choices.

The Polls can also be created by anyone in the chat room and two have been created by parent carers who want to get involved but not as parent representatives. The most popular Poll has been the one looking at groups accessed. The Autism Strategy also had a good response rate as well as eliciting the most discussion.

### **Facebook Discussions**

1. Early Help and EPP experience
2. EHC's

These discussions have been mentioned in highlight reports made available to commissioning.



## **Feedback Forms from Trips and Activities**

12 Trips/ Activities to places such as Activity World or Twin lakes with have occurred where feedback forms have been used which have including sections on topics such as, short breaks, CAMHs and EHC plans.

## **EVIDENCE**

A range of evidence is used to demonstrate numbers and types of involvement. The evidence includes all forms listed below.

1. Survey results
2. Case Studies
3. Photographs
4. Photo permission forms
5. Attendance sheets (registers)
6. Completed feedback forms
7. Facebook Poll results
8. Facebook discussion comments and quotes

This evidence is qualitative and quantitative with numbers completing polls through to direct quotes from parent carers being used.

## **Reports (Click on the Links)**

[CAMHs Report](#)

[LO Focus Group 3](#)

[EPP Report 1](#)

[Annual Conference 2016](#)

[Local Offer Focus Group June 2016](#)

[Parent Carers Survey 2016](#)

[SEN Information Report](#)

[SEND 2015 to 2016](#)

[Transport Report](#)

[Wheelchair Services Report](#)

[School Engagement Report](#)

[Autism Strategy Report](#)

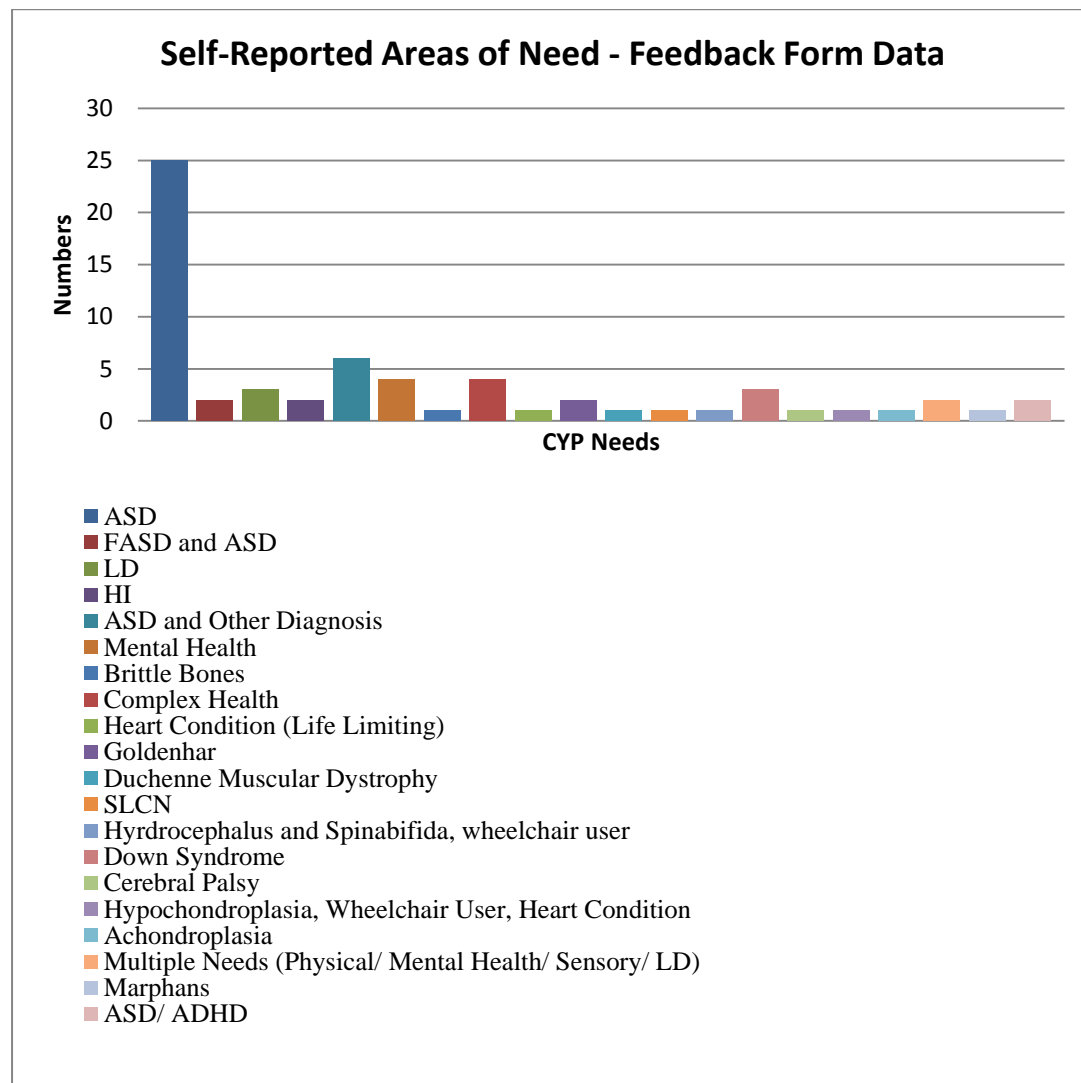
Other reports are available detailing specific projects and work programmes.

## **PARTICIPANTS (Parent carers)**

### **Demographics**

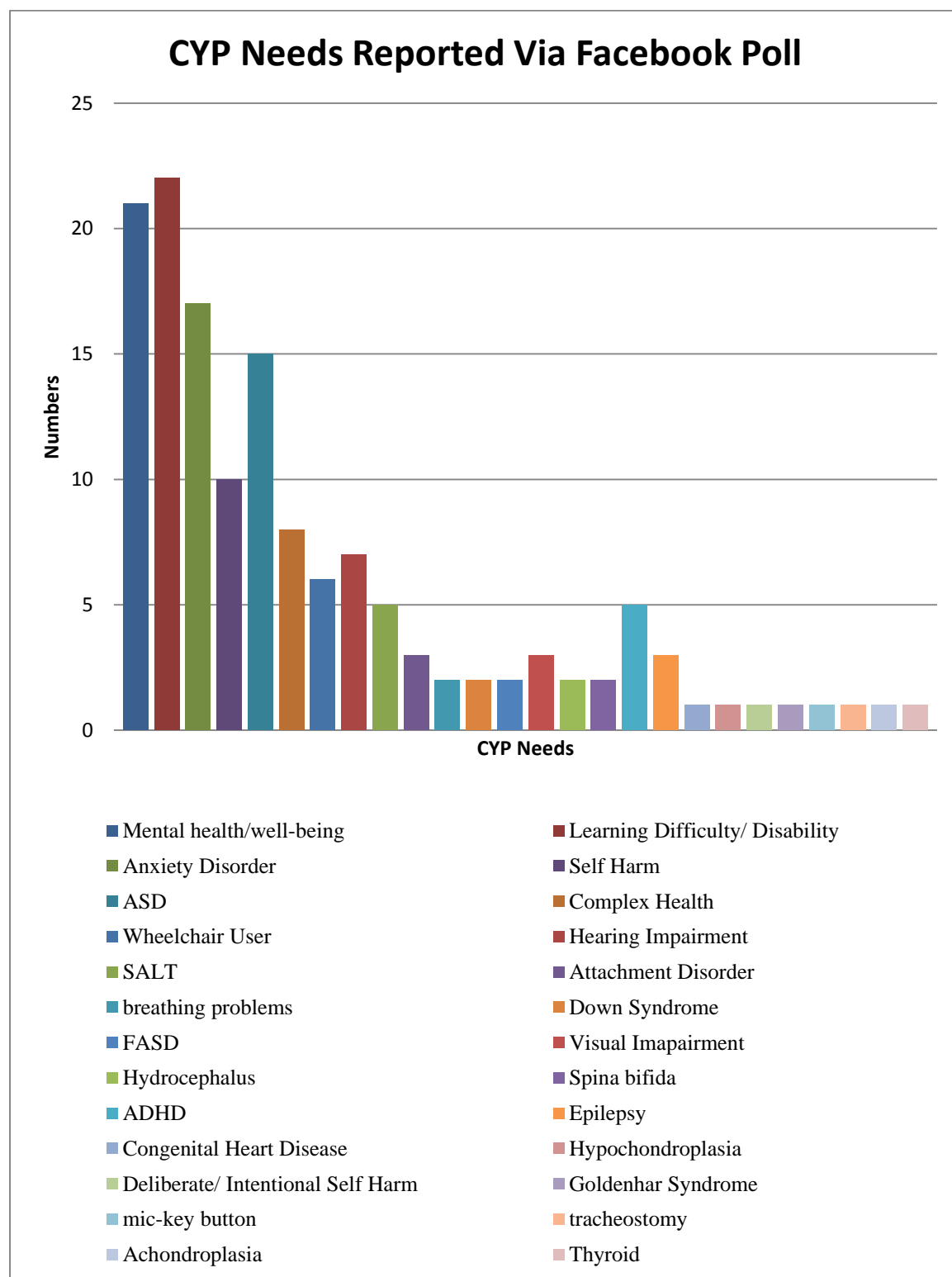
206 parent carers constituting 191 mothers and 15 fathers have participated at some level between March 2016 and April 2017. Parent carers have provided data on CYP needs and Age, family ethnicity and groups accessed. A note should be made here that data is based on self-reporting by parent carers. Four methods are used to gather details on CYP needs; feedback forms, database forms, survey questions and a Facebook Poll. Two charts follow which demonstrate some of the areas of need represented. Another chart demonstrates self-reported family ethnicity.

- Chart 28 details CYP needs captured on feedback forms and the numbers are indicative of areas of need. Feedback forms are completed as an option after trips, activities, events, workshops and focus groups. The results give an idea of needs not an accurate number.
- Chart 29 shows the results of a Facebook Poll and again whether to take the Poll or not is optional meaning data is only indicative.
- Chart 30 details parent carer self-reported ethnicity and as with other charts and data in this section of the report it is indicative.

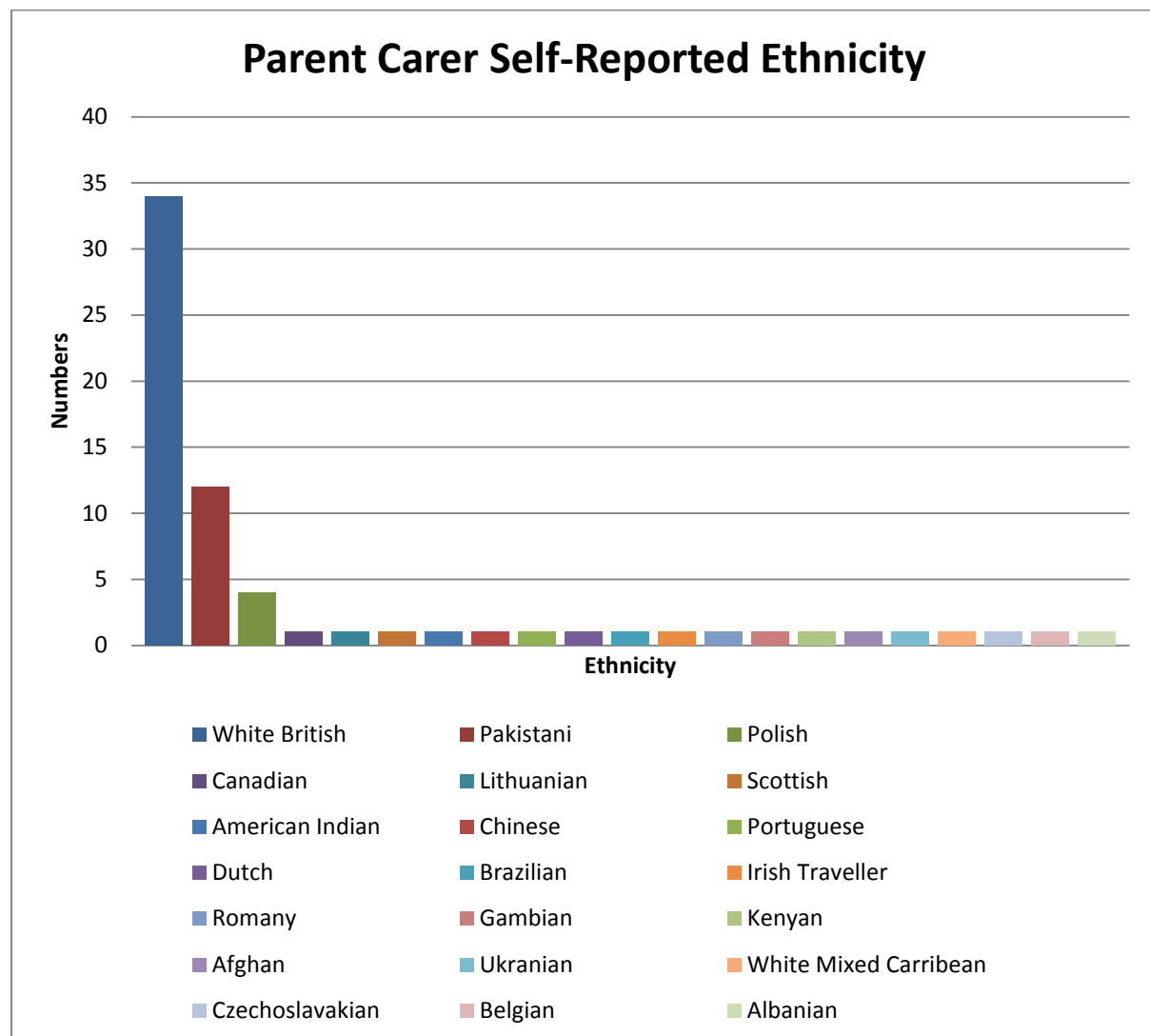
Chart 2

The highest area of need reported is ASD and the least reported are rare genetic disorders such as Marfans.

Chart 3



The responses defined in this chart where the data has been taken from a Facebook Poll shows the highest area of CYP as LDD and the least reported as rare genetic and health conditions. Parent carers could also choose more than one area of Need and there were 38 parent carers who took the Poll.

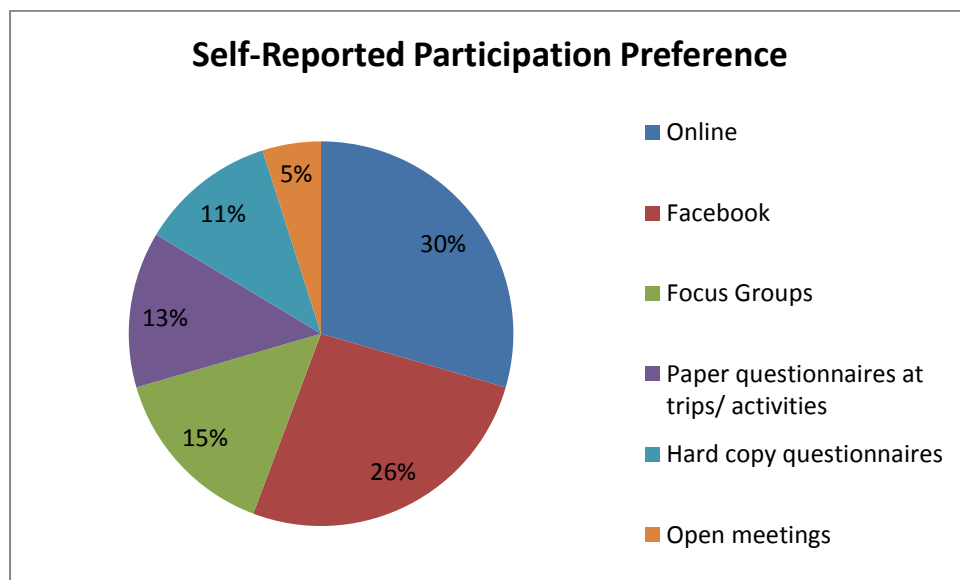
Chart 4

The most frequent self-reported ethnicity is White British followed by Pakistani British. There is engagement from parent carers from other backgrounds but it tends to be individual parent carers.

## **PARTICIPATION PREFERENCE**

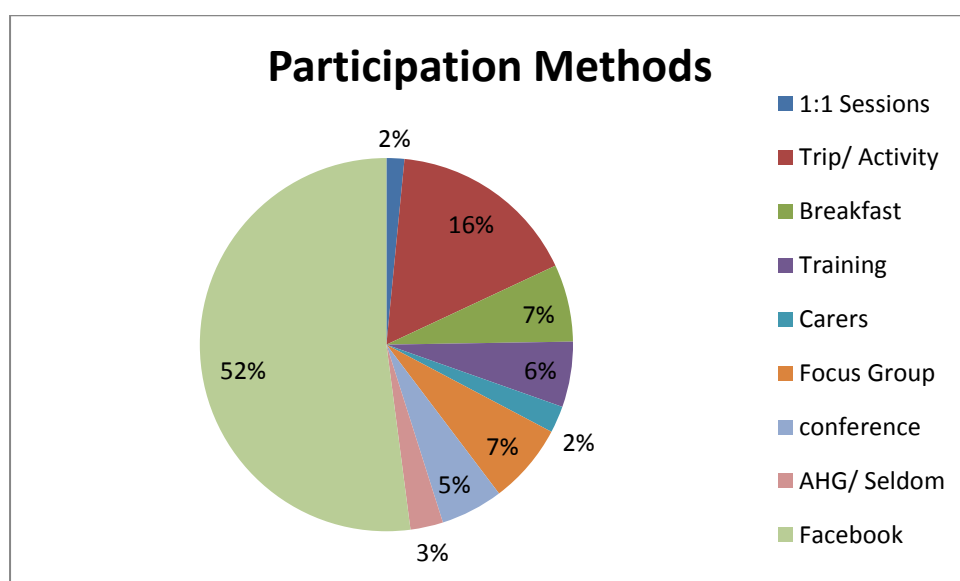
To determine what methods parent carers prefer for participating a Facebook Poll was added to the FVP chatroom and several options included, the results of which are in shown in Chart 31

Chart 4



Parent carers expressed a preference for on-line and Facebook. This is also demonstrated by looking at what methods are used the most taking data from attendance registers, Facebook Polls, feedback forms and completed surveys. 31 people took the Poll out of a total of 87 who saw the Poll meaning it had a response rate of 36%.

Chart 5



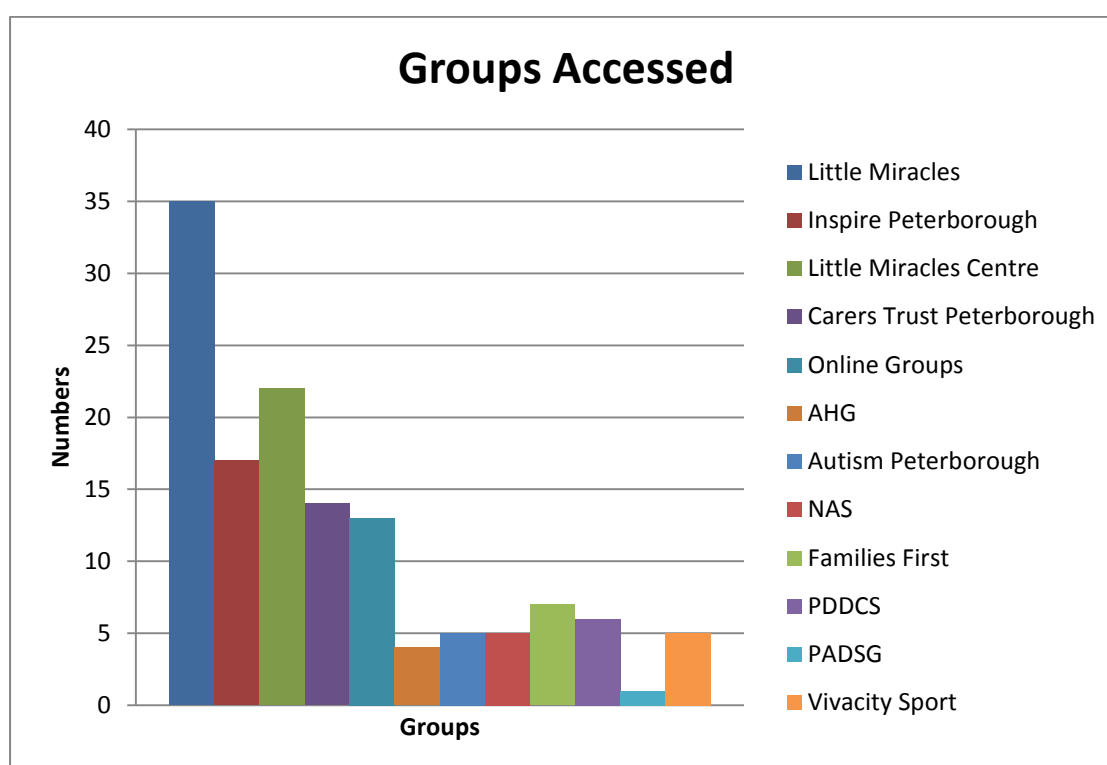
The most popular method was Facebook.

## Other Groups

A question usually asked on feedback forms after events/ activities/ workshops and other face to face sessions relates to what other groups are accessed. This is to demonstrate that those participating via FVP also take part in other groups around Peterborough for access to direct support, activities, information and advocacy.

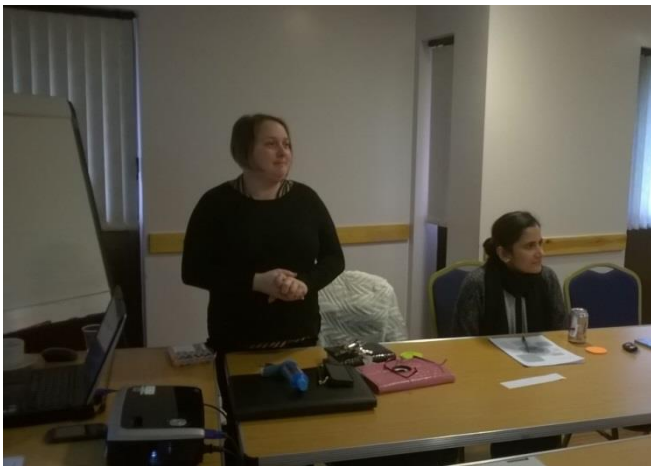
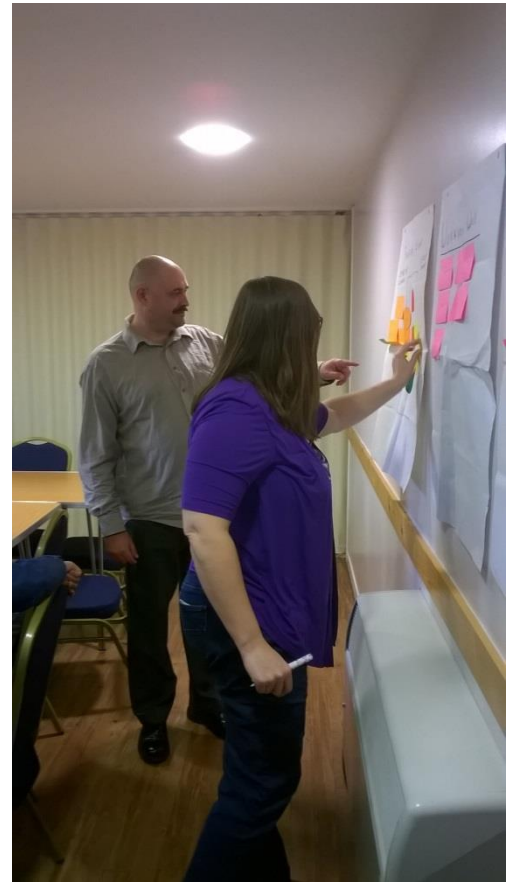
Chart 33 is based on data captured on a Facebook Poll completed by 47 individual parent carers. It should be also noted that parent carers added in the “Little Miracles Centre” choice themselves as a differentiation between the centre and online chatroom.

Chart 6



47 people took the Poll out of 134 who saw it meaning it had a response rate of 32%. The three most popular groups to access were Little Miracles (online) followed by Little Miracles Centre and then Inspire Peterborough. The least accessed was PADSG but this is a disability specific group with a particular remit.

## **PHOTOGRAPHIC EVIDENCE**





## **SOME OUTCOMES**

### **Co-produced work**

- EHC Needs assessment guidance
- Being educated out of year group guidance
- Personal Budgets leaflet
- Easy Read Local Offer guide
- Guidance for Hearing Impairment Services

### **You Said – We Did**

You (parent Carers) said you wanted a resource page on the Local Offer – We (Peterborough City Council) have added this page to the Local Offer

You said (Parent Carers) you felt unrecognised and unsupported – We (Peterborough City Council) have listened and are exploring ways to help you have your needs recognised and looking at how a parent carer hub can be set up supported by Carer Trust.

You said (parent Carers) you felt the Autism Strategy did not go far enough and it should cover children adults/ - We (Peterborough City Council) have listened and drafted a new strategy that covers children and adults with Autism.

### **Common Themes/ Concerns**

- Behaviours that challenge and lack of support
- Part time timetabling
- Academies and SEN
- Early help pathway confusion
- Accessing CAMHs

## **ANALYSIS**

Participation has occurred across all aspects of the work of FVP and in many ways. Even when carrying out the work described in Section One there has been a participatory aspect where information gathered has informed commissioning, the way the work is actually delivered and what form this work takes. Participation has seen an increase with the re-introduction of the FVP SEND chat room which matches parent carer self-reported preference for online participation methods.

Through gathering data on parent participation for this section the following findings have been identified:

1. Participation is varied and parent carers are representative of a diverse populace with child/ young person needs varying from ASD through to Complex Health.
2. Parent carers participate through Family Voice and also engage with many local groups/ organisations/ charities for the purposes of support, advocacy and short breaks/ activities.

3. Online methods of participation are preferred with the use of a Facebook chat room leading to an increase in numbers taking part in Polls and discussion
4. There is an increasing number of parent carers who are considered seldom heard who are becoming informed/ getting involved.

The findings demonstrate an increase in participation from a diverse group of parent carers who have very different views on areas they have participated in. There has been an increase in documents being co-produced which are used to inform service delivery at Peterborough City Council particularly in relation to Education.

Despite the increase in diversity in relation to parent carers participating there is still a majority who self-describe as White British with CYP with ASD. There is also an increasing level of participation from parent carers who self-describe as Pakistani British with CYP with other needs such as Complex Health and LDD.

Parent Representation remains an area that only a small number of parent carers are interested in as it requires more time, training and personal investment. Parent representatives take part in areas they are interested in and also act on a voluntary basis when they are available.

## **SECTION FOUR (SELDOM HEARD)**



## **INTRODUCTION**

The work relating to seldom heard groups is in its second year and is still ongoing. There has been a lack of engagement with and involvement from parent Carers from Seldom Heard Groups:

1. BAME or EAL (Including new arrival families)
2. Working Parents
3. Parent Carers with Disabilities
4. LGBT
5. Parent Carers of CYP with Mental Health Needs
6. Fathers
7. Parent Carers on low income/ benefits
8. Rural families
9. Traveller Communities

There are a variety of reasons these groups of parent carers in particular are seldom heard and they range from economic to cultural. For some of the groups there is a stigma associated with having a CYP with a disability or additional needs and for others the type of disability or additional need has its own stigma, particularly in the case of mental illness.

The aim of this work stream is to facilitate engagement and involvement from parent carers within these groups; to build their trust and confidence in participating and to enable them to become active in co-producing services for those with SEND. Over the two years a small but increasing number of parent carers from diverse backgrounds have started to engage with FVP and become involved in more active participation. The next section to this report will provide some detail on whom FVP is engaging with, how this engagement is occurring and where engagement has led to participation.

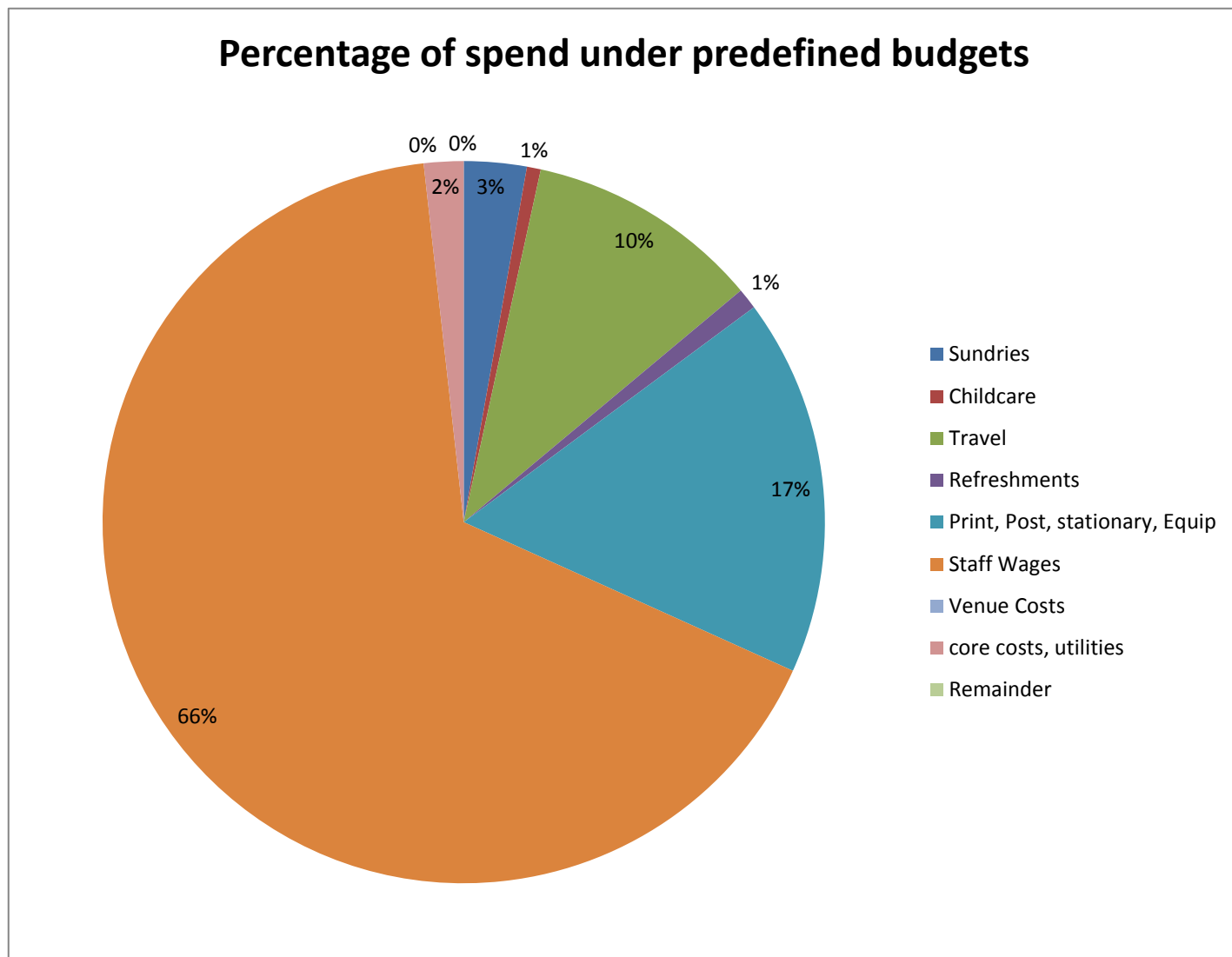
Work from the FVP Participation Officer, FVP Office Administrator and Lead Parent Representative on ASD Services and the Learning Disability Partnership Board (LDPB) will also be included to demonstrate the work of parent carers from Seldom Heard Groups who

The rest of this section of the report has been written by Jo Woodhams (Parent Participation Co-ordinator Seldom Heard) with some minor editing.

## **GRANT FUNDING**

The main focus of this work is early intervention and prevention in line with where the funding sits but utilising participation. By increasing participation and improving trust in relationships between parent carers from a range of backgrounds and the health sector isolation decreases and parent carers are more inclined to access services as active participants.

Chart 1



Childcare and Refreshment costs were low at 1% each of the overall spend whereas travel was more at 10% of the overall spend. This is in part due to the changing needs of those who are accessing work funded by the grant. Those actively involved have school aged children or older. Also although offers of childcare expenses are offered they have not been taken up. Staffing costs for this grant were high but overall charity staffing costs were lower. Staffing is split across grants including the DfE Parent Participation grant.

## **Introduction**

Family Voice Peterborough (FVP) is a registered charity who is actively seeking to improve services in all areas for the lives of families with children and young people who have disabilities or additional needs. FVP works with parents and carers to enable them to be included in service development, design and delivery through a variety of participation methods for example; attending focus groups, filling in surveys or attending meetings. These are just some of the methods we use which allows for families to have a positive influence in shaping services right through design to delivery.

When looking at any service development with in Health or SEND we have included a wide variety of parents including parents from Hard to Reach Groups (HTRG) now called Seldom Heard and the Aiming High Group (AHG). Parents from these particular groups often find it hard to engage with services and very rarely have the opportunity to have their voice heard. This can be for a variety of reasons for example English as a second language, socially not acceptable within their own communities, stigma, they may have a learning difficulties themselves, lack of knowledge and so on.

## **Health engagement**

This year health engagement has increased positively. At FVP we have are taken part in the development of a social story for 0-5, 5+, which has been co-produced with our service users, and the Child Development Center (CDC) to help parents and children and young people (CYP) see their journey through the CDC. This gives them pictures of where they are going and what they are likely to see as well as an explanation for the parents of what to expect, the facilities available and so on.

FVP has work closely with the CDC on other opportunities for example the ASD / ADHD workshops that have been provided to give parents the opportunity to understand and improve their knowledge so that they can better support their CYP waiting to be seen.

Other areas of health engagement that FVP have had the opportunity to be involved have been have around raising our profile so others are aware FVP the work we do and how we can support families through participation as well as the strategic work we take part in. This year FVP have given a talk to professionals at the local hospital about parent careers, the knowledge they have, their value, as well as explaining who we are and what FVP do. FVP have also attended two careers events all at the hospital.

## **HIGHLIGHTS**

- Greater parent involvement
- Community integration - twin lakes / activity world
- Asian cuisine day
- Greater partnership working
- Development of the social story
- ASD/ ADHD workshops

- Participation breakfasts for the seldom heard and HTRG
- Aiming high meetings
- Eid in the park
- portage presentation
- Feedback from parents

**Table 1 - Outcomes Matrix – Seldom Heard****Outcomes and activities for Seldom Heard Participation 2016 to 2017 – Family Voice Peterborough**

**I have demonstrated these outcomes by or using colored writing in a traffic light system show green as were we are doing grate and amber for where improvements could be made**

No	Outcome	Output/activity	How Measured
1	Parents and Carers are empowered to participate in engagement activities with the Local Authority and their partners through representation activity	<ul style="list-style-type: none"> <li>• Parent representatives are trained through the Family Voice parent participation training course</li> <li>• Reasonable expenses are met to facilitate parents and carers to attend meetings – childcare travel, etc</li> <li>• Appropriate supervision and support given to participation reps who attend groups/meetings</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</li> </ul>	<ul style="list-style-type: none"> <li>• Appropriate details of the parent reps given to facilitate planning and Local Authority organisation – scheduling meetings, etc, with acknowledgement of their training, skills, etc</li> <li>• Monthly highlight reports for each work stream, contributed to by the reps attending meetings</li> <li>• On-line parent rep feedback form system created and used by parent reps after meetings</li> <li>• Annual report</li> </ul>
		<ul style="list-style-type: none"> <li>• Currently FVP has 8 active parent representatives who are from the seldom heard categories aiming high group and hard to reach, two of which are new to the position.</li> <li>• FVP facilitate all out of pocket expenses.</li> <li>• FVP seeks to ensure that all representatives are given a paper work ahead of schedule and have the opportunity to ask questions when needed in order to support their roll</li> <li>• Within our seldom heard categories, aiming high group, FVP often looks at identifying barriers for participation and Co-production for example for some parent carers is impossible to get out for long so at FVP we you will still look to seek their opinions</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="https://www.familyvoice.org/Participation">https://www.familyvoice.org/Participation</a></li> <li>• Reports of work are uploaded to the FVP website</li> <li>• Parent reps complete their feedback via an online form</li> </ul>



		<p>whether it be a through a participation breakfast, focus group, for 1:1 meetings, Facebook polls, On-line surveys and so on. FVP also looks at other barriers such as the timings of meetings, cultural timings for example the aiming high ladies were we work around Ramadan etc</p>	
2	Improved trust in relationships between parent carers from a range of backgrounds and the health sector	<ul style="list-style-type: none"> <li>• Change in self-rating of relationships/ involvement with health sector</li> <li>• Involvement in health sector work streams (development of a “social story journey through Child Development Centre)</li> <li>• Access to training (Expert parent Programme)</li> </ul>	<ul style="list-style-type: none"> <li>• On-line questionnaire reports</li> <li>• Case study (at least one)</li> <li>• Co-produced “social story – journey through the CDC”</li> <li>• At least 10 parent carers from diverse backgrounds have completed the EPP and report positive change</li> </ul>
		<ul style="list-style-type: none"> <li>• Involvement with in the health sector has been positive and is increasing as we are developing relationships and aim to a work throughout the health sector.</li> <li>• We have had a huge increase in the work streams with the health sector a for example the completion of the social story, the development for wheelchair services, being asked to speak in staff training on issues, challenges that parent / carers and CYP face. as well as looking at preventative and early intervention measures</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• <a href="https://www.familyvoice.org/Participation">https://www.familyvoice.org/Participation</a></li> <li>• There are a series of booklets in draft relating to visiting the CDC</li> <li>• Over 10 of the parents who have completed the EPP are from diverse backgrounds and reports created show positive feedback</li> <li>• FVP gives all its members the opportunity to participate in training for example approximately 12 parent / carers from seldom heard categories attend the expert parent programme, with a combined total of 33 parent carers are across these courses. And the ASD / ADHD workshops approximately 11 parent/ carers attend from seldom heard category and combined total of 32</li> </ul>
3	Operational representation across SEND work streams; LO, PB, EHC Processes, PfA leading to co-production across SEND services	<ul style="list-style-type: none"> <li>• Attendance and representation at work stream and task and finish groups</li> <li>• Parent representations 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 SEND services</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> </ul>

		<ul style="list-style-type: none"> <li>FVP has an excellent and wide variety of representation and diversity across seldom heard network for example were FVP identified an area of need then FVP seeks to meet the provision of need i.e. if it's a physical need then ensuring the appropriate access, timing of the meetings and presenting information ahead of schedule are done. Or if there is a learning need a then looking at the appropriate the level of support needed and then facilitating this</li> </ul>	<ul style="list-style-type: none"> <li><a href="https://www.familyvoice.org/Participation">https://www.familyvoice.org/Participation</a></li> <li>FVP encourages an empower all parent/ carer representatives to take an active, crucial role in all areas of work are including co-production and facilitation a for example we have a parent representative who is a wheelchair user a who lead on are PFA work, are wheelchair services contracts, and regularly attends other meetings such as cohesion and diversity, there are other representatives where for example English is their second language and they regularly represent FVP on boards such the healthy child program, learning difficulties board. FVP has regular contact with its representatives and offers training in areas where more support might be needed for example expert parent programme for health work, cultural safeguarding awareness and so on.</li> </ul>
4	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>
		<ul style="list-style-type: none"> <li>Currently FVP has 8 parent represents from a diverse mix of backgrounds this includes 4 where English is a second language, 1 wheelchair user, 2 that have dyslexia, 1 that with ASD, are all representatives are encourage two reach their full potential and access as many training opportunities as possible.</li> <li>Although FVP champions each and every individual through participation FVP will be looking at a the facilitation of this development</li> </ul>	<ul style="list-style-type: none"> <li><a href="https://www.familyvoice.org/Participation">https://www.familyvoice.org/Participation</a></li> <li>At FVP we are supporting individual parent / carer represents two try out and widen are they a scope into other areas of work where possible are this is allows them the opportunity to see what they think of a particular work stream we often facilitate this by or having a more experience representative go with them to the first meeting and answer any questions they may have regarding the work streams, and ask them to feedback on how they feel and their prospective of the meetings, work streams, and look at where further support maybe provided.</li> </ul>
5	Parents and Carers are empowered engage with the Local Authority and their partners	<ul style="list-style-type: none"> <li>Partnership approach through the steps described above, and the provision of themed focus groups – this may include task and finish groups, surveys and involvement</li> </ul>	<ul style="list-style-type: none"> <li>Parents and carers report positive change in their communications with the Local Authority and their partners</li> <li>Case study provided</li> </ul>

		through social media <ul style="list-style-type: none"> <li>• Be part of the feedback process for families, to facilitate the understanding of the effectiveness of participation</li> </ul>	
		<ul style="list-style-type: none"> <li>• Throughout this year we have used a variety of methods to engage parent / carers to actively participate or in ways that feel comfortable for them and give them the opportunity to have their voice heard. FVP use survey monkey, face book polls, feedback, focus groups,</li> <li>• With using all of the above methods. The feedbacks prompt's and direct the way forward as FVP find using you said so we did.</li> </ul>	<ul style="list-style-type: none"> <li>• See case study</li> <li>• See parent / carers views on page</li> <li>• Survey monkey</li> <li>• Face book</li> <li>• What's APP</li> </ul>

The matrix has been included to demonstrate what has been achieved so far by inclusion of examples of outputs and measures.

## **Forward Plan**

- continue building relationships with both health and seldom heard communities
- Set and prioritise realistic goals
- strengthen and focus on areas that have not been met
- evaluate what the families are saying
- building up participation and empowerment

## **Evidence**

### **Case study A**

#### **Back ground**

Parent A has been with FVP for approximately 3 year and has 2 children with-additional needs

One is 16 years old who is in specialist education provision diagnosed with ASD and the other is

6 year old and again in specialist educational provision diagnosed with ADS but at a different end of the spectrum. Parent A is part of the seldom heard group as English is her second language, her native language is Portuguese. Parent A is currently studying psychology at university level. Over the last 3 years she has a participated in various forms of participation. From parent meeting to focus groups.

#### **The journey**

When Parent A first started with FVP, although highly educated had little knowledge of participation and what it involved and was misunderstood due to language barriers. This took time to develop and it was not a smooth transition as there was new world to learn about and issue that arose where around professional boundaries, confidentiality, structure and hierarchy. However despite issues in the beginning FVP were able to overcome all issues by support, guidance and training.

Parent A is a successful parent's representative and has completed courses for example The Expert Parent Program and Parent Rep courses, as well as completing PTLLS in her own right which has now led to her been able to be a trainer within FVP.

#### **The future**

Parent A is successfully involved in many work streams including acting as lead parent rep on the Learning Disability Partnership Board and ASD Board. She also works on the local offer delivery board including associated sub groups. She regularly works on specific pieces of work such as the social story. Parent A plans on continuing in these areas.

## **Report for the Co-production of the social story**

### **The scope**

When FVP looked at the gaps in services for health they asked parent /careers were they felt these gaps are and what they would like FVP to help with.

- So FVP first worked on the completion of service directories. And then FVP then facilitated creating a social story for patient's journey through the child development center. The first steps in doing this were for FVP to have a meeting with the lead head of therapy's at child development center.
- Secondly we then looked at what parent /careers would like to see in this and then finally FVP put together a draft 0-5 and a 5+ social story which will be completed by the end of the financial year 16/17

The purpose of the health related work is to give parent /careers the opportunity to have their voice heard and break down barriers between parents / careers, professionals to navigate their way through a complex Health System, and involve families in co-producing for the guidance to support then and be involve the production.

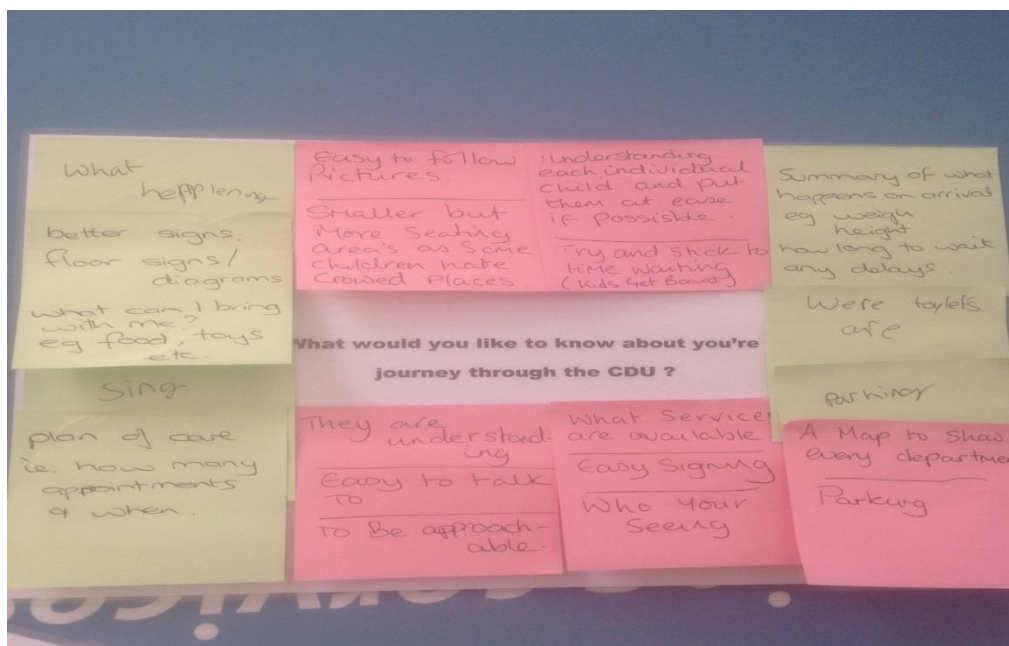
### **How we collated the information**

We facilitated the collation of information by hosting a participation breakfast were FVP asked parent/ careers to look at a series of photos. This would help then to think about what they would like to see included and why this would be useful for then. FVP also posed some sample questions you are in order to facilitate this. The questions were:

Q1 what would you like to know about you're journey through the CDC?

Q2 what would your CYP like to see?

Q3 would this have a benefited you?



**What parent / carer said?****Q1**

- Plan of care i.e. how many appointments am I looking at.
- What will happen
- Summary of what will happen on arrival e.g. height, weight, how long am I likely to be there, could they be any delays.
- Sign what to look for.
- What can I bring with me e.g. toys food
- Who you will see
- Map
- A map of where the toilets are

**Q2**

- Have a clear map of where they are going
- written in understandable language
- Quiet waiting area
- What's there?

**Q3**

- Needing to know a more facilities are available once their i.e. toilet facilities
- Parking I.e. if the blue badge spaces are full or and you have a wheelchair and then where can I a safe park and a have the room to get the equipment and passenger out.
- Easy to follow signs of where I am going i.e. Arrow's, foot prints, picture signs.

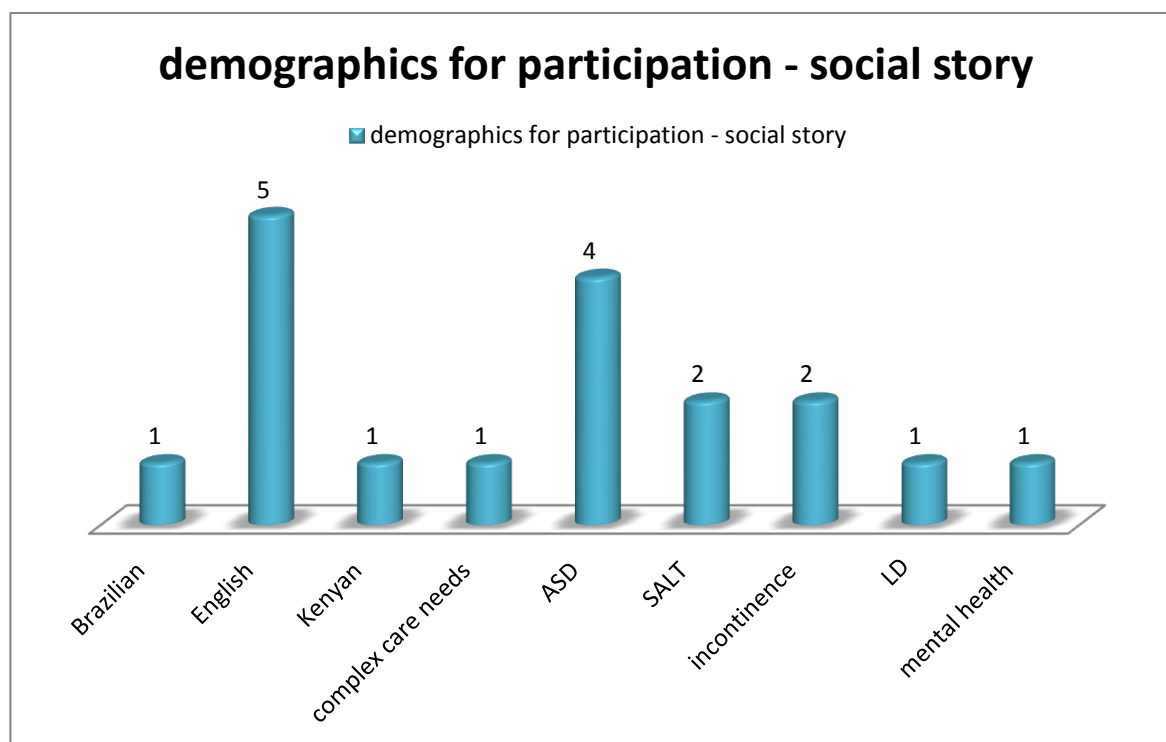
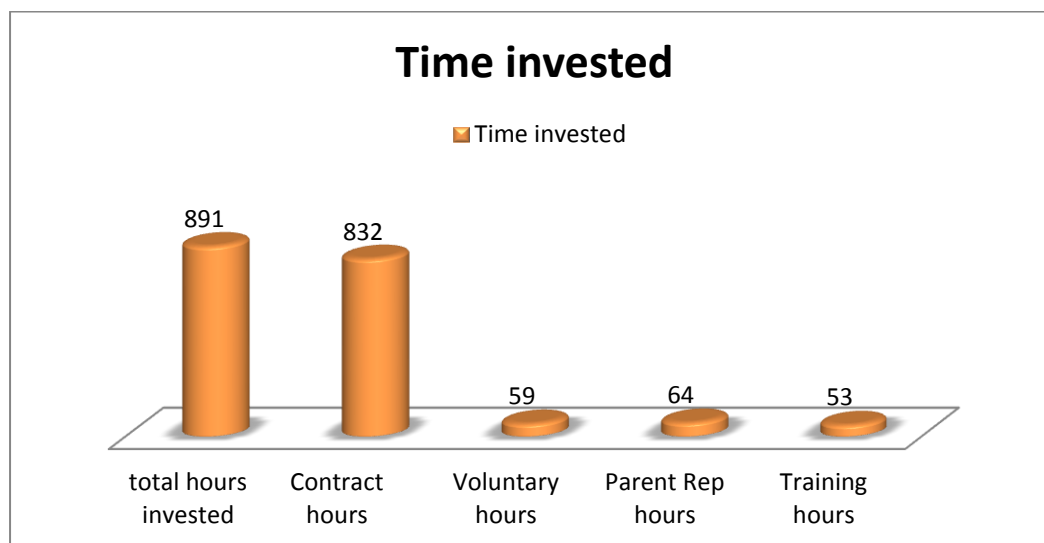
**Chart 2**

Chart 3

### **Output from the HTRG/ seldom heard/ aiming high**

The following is a list of all activities, training courses that enabled us to engage with service users:

- 1 parent rep for the MAF meeting
- 3 parent reps for healthy child program
- 1 parent reps doing preparing for adulthood
- 2 careers events at hospital
- 1 talk at the hospital about parent careers from seldom heard backgrounds
- 2 talks on hate crime
- 2 focus groups
- 7 participation breakfast club
- 9 parent / careers inputting and working on the social story
- 1 parent reps is on the ADS broad,
- 1 parent rep is on the LD, broad
- 1 parent rep is on local offer working group
- 13 parent /careers complete the expert parent program
- 11 parent /careers complete the ASD/ADHD workshops

### **Courses**

1. EPP
2. Health Workshops ASD/ ADHD
3. Parent / professional Participation
4. IS / legal section 19 principles training
5. Microsoft

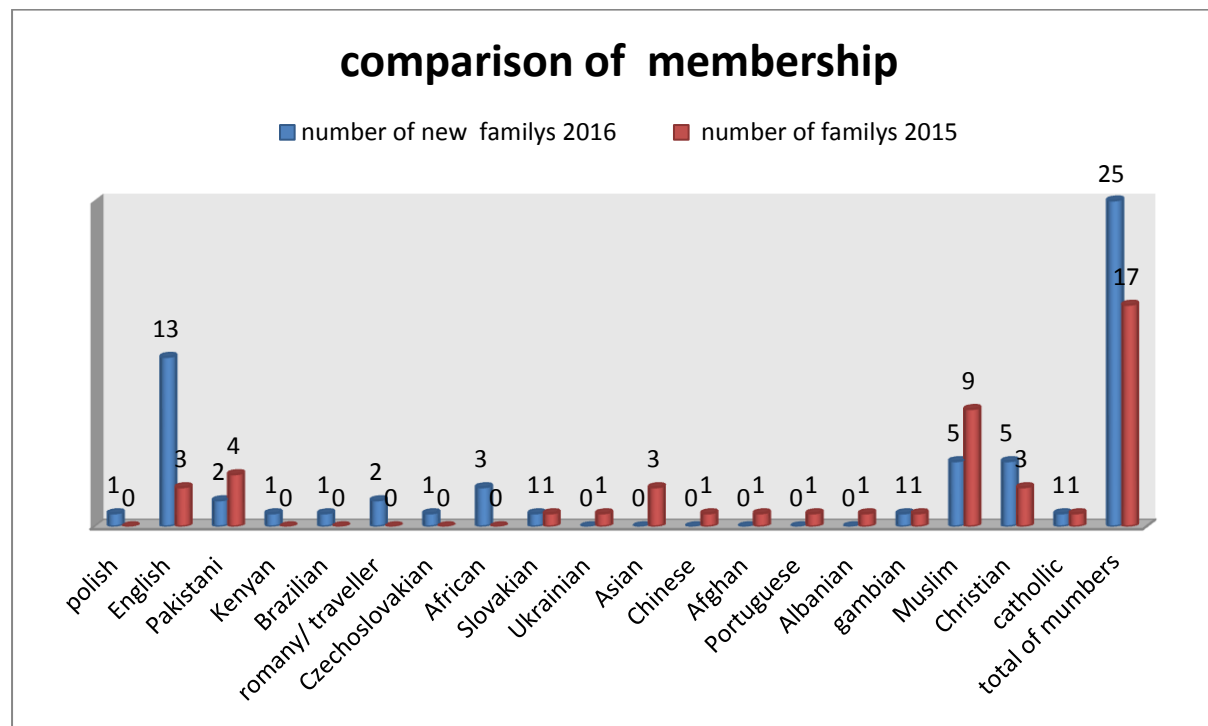
## Meetings/ Events

1. Breakfast meetings
2. Multi Agency Forum
3. Healthy Child Program
4. HTRG meeting
5. CYP hospital board meeting
6. Aiming high
7. cohesion and diversity
8. Strategic migration partnership

## **Beneficiaries & Demographics**

This shows the increase in the numbers of new members within the HTRG, seldom heard, a aiming high categories

Chart 4





This demonstrates the number and variety of individuals the imported during the breakfast meeting

Chart 5

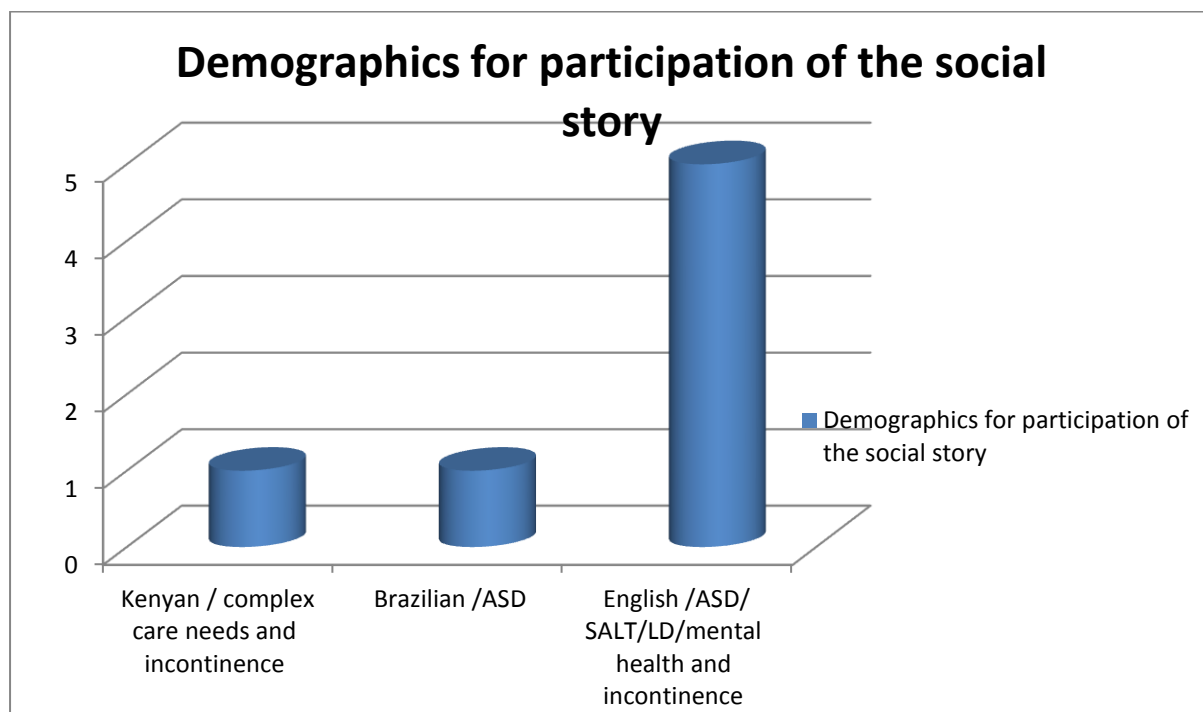


Chart 6

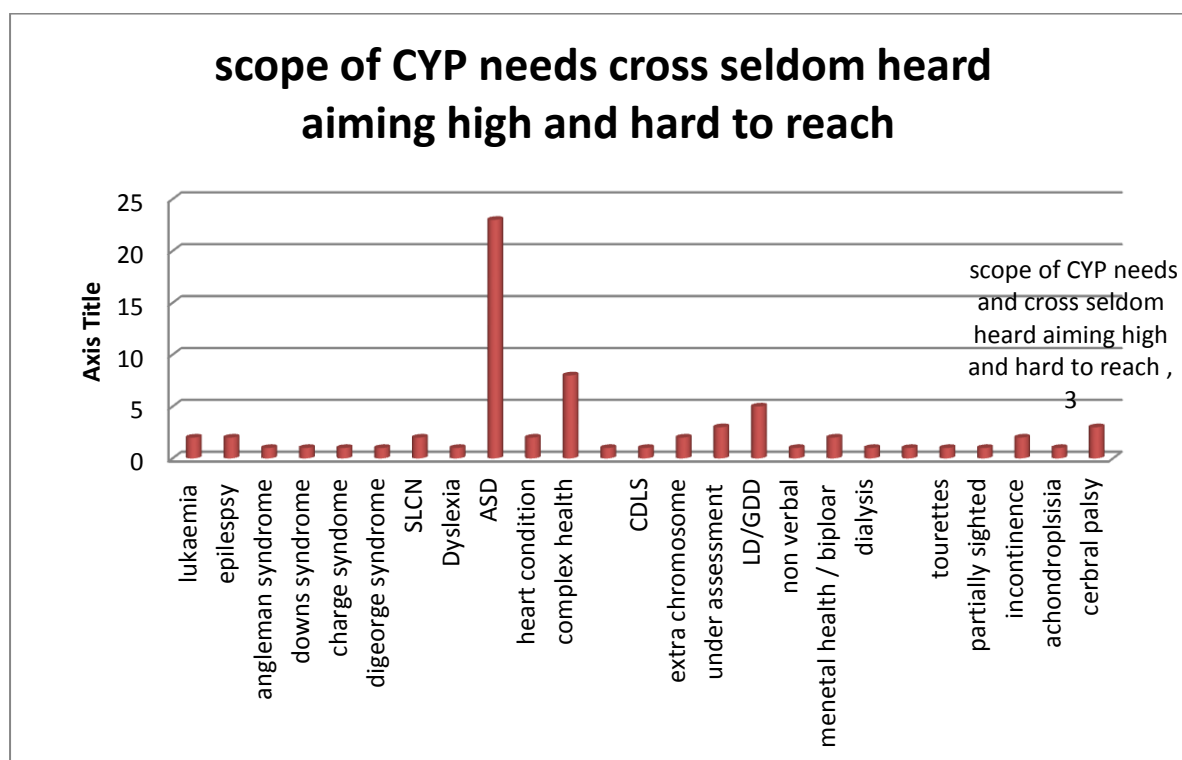
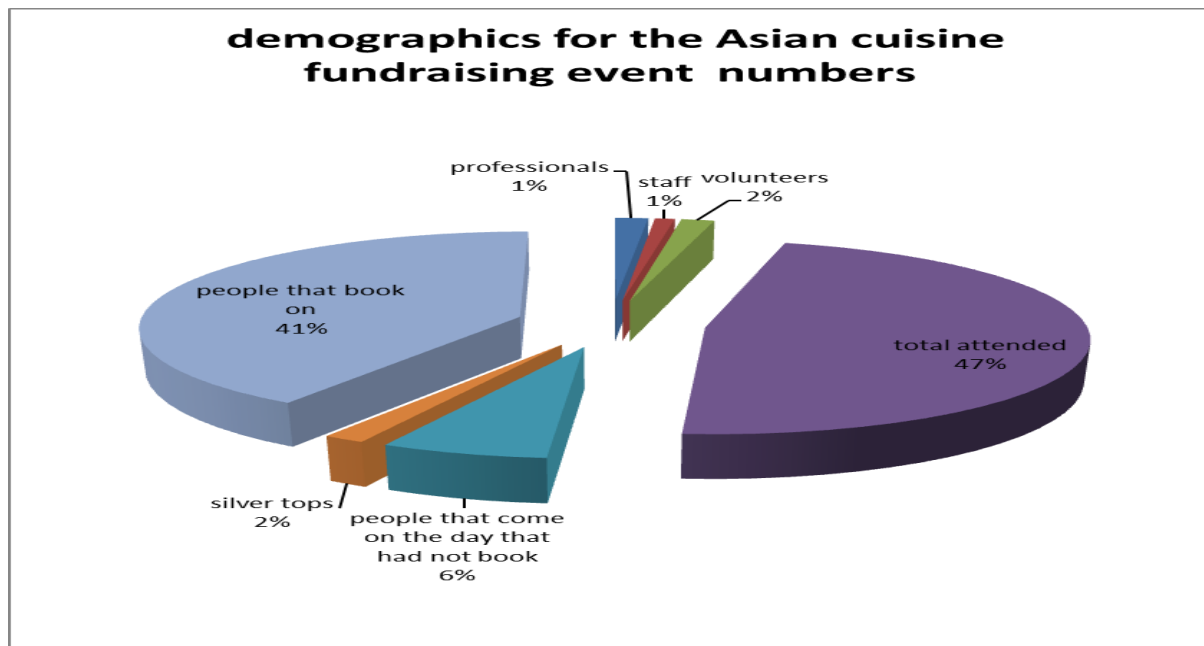


Chart 7Comments from parents:

"It has been lovely to be working with FVP again this year. They are always there when we need them"

It's been a fabulous experience working with Jo and FVP. I have learnt a lot in bettering my skills as a special needs parent.

I have really enjoyed being part of the seldom heard participation breakfast as it's been a great relaxed way you to meet others and understand and services better

I have found the Involvement from FVP helpful as they always go above

## **You side we did**

Earlier on during the financial year FVP did a piece of work around asking parents / carers if they had the opportunity to ask a question of a professional such as a paediatrician or Inclusion officer what would be useful for them to have known and how this could help?

The questions were in four categories:

- 1 general to all professionals,
- 2 education
- 3 paediatrician (health)
- 4 Salt (health)

We made a list of questions to ask health and education professionals and then feedback to the parent / carers what the health and education professionals had said. This then helped both professionals and parent / carers to see the gaps in communication and see the type of FAQ's that interested both parties, this then helped both services and service users to communicate better and appreciate one another's opinion. For example here are some of the questions and answers that we received:

Q1) to all professionals how can we find out what services are available for my child /family?  
A1) directed to the local offer and shown what to look for.

Q2) my child has a physical disability she is going from Pre School to mainstream school this year so who can help with this and make sure she gets the help she we need?  
A2) early dialogue with the school and preschool to see what reasonable adjustments can be made.

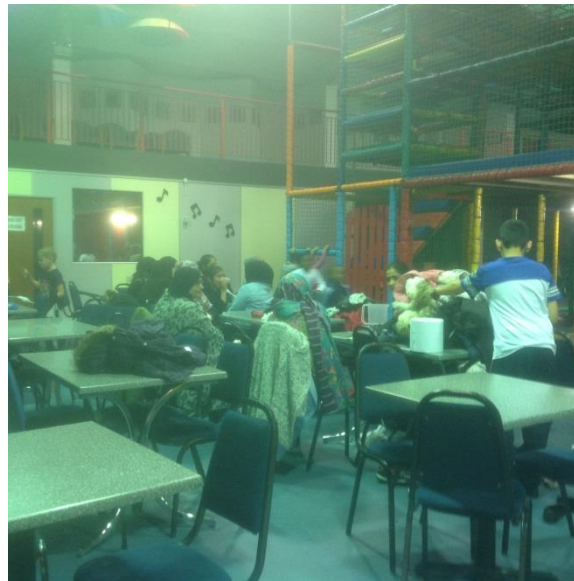
Q3) with English not being my first language's there any way I could get a copy of the questions that I'm likely to be asked so I can prepare myself?  
A3) YES

Q4) my child does not fit the criteria for an EHC. But has significant difficulties and is not receiving the support that they require within the school so what can I do?  
A4) dialogue at the school and checking and looking at if the school are following their own policies and procedures. These are just some of questions that came up frequently.

**Pictures tell a fuller story**







## Conclusion

This has gone extremely successfully and all the participants have really enjoyed their involvement in process and feel that this will benefit a wide range of individuals using these services.

The purpose is to include and encourage participation for parents /careers that are considered to be part of those groups. Parents from these particular groups often find it hard to engage with services and very rarely have the opportunity to have their voice heard. This can be for a variety of reasons for example social barriers, culture, learning difficulties,

We have nine categories in which they can come in to which are

- 1 Parents who work
- 2 BME OR EASL
- 3 LGBT
- 4 Parents and disabilities /LD
- 5 families where a CYP has mental health
- 6 father's
- 7 parents on low incomes /benefits
- 8 geographically isolated
- 9 traveler community

Although everyone has a primary category most families fall into more than one category through various circumstances.

In order for FVP to build relationships and breakdown barriers, FVP facilitates these groups in a number of ways for example working participation breakfast meetings, focus groups, fundraising events, activities and using an approach called you said we did which is helped FVP with monitoring. These are often facilitated by going out to the individual communities and building good working relationships are laying solid foundations. Over the last financial year we have achieved a big increase in membership across all communities by 25 new members, whereas last year there was only 17 new members, FVP successfully fund raised with aiming high group on the Asian cuisine day were FVP hosted over 150 individuals in this one event, successfully brought together all community through activity's i.e. twin lakes, twice to activity world. Other ways in which FVP has enabled others to come together and seek services improvement by having are several participation breakfast events where we have seen the development of the social story with groups of up to nine service users having input, taking part in short breaks surveys, looking at documents and feeding back on how improvements could be made and their particular thoughts.

FVP have also raised their profile by raising awareness of who we are and what we do, this has been achieved in numerous ways, for example the Peterborough Multi-Agency forum (MAF) that FVP has a good working relationship with which has led to opportunities such as a special parliamentary visit, being asked to a speaker about who we are and what we do with the Syrian refugees and Being invited on the confusion and diversity form, if strategic migration Partnership This is just a snapshot of what FVP has achieved and how we have managed it.

I have thoroughly enjoyed stepping up to this challenge after being thrown in at the deep end. This year has not only gone fast it has enabled me to learn and grow both professionally and personally. I feel like we're going in the right direction and I look forward to strengthening the existing foundations and reaching out to more families and being able to support service change through this work and personal development.

Over this next month I will continue to plan, prepare and set future goals so we can continue to develop and grow. For example I will facilitate this by doing: setting dates and outcomes such as aiming high, seldom heard, hard to reach groups. FVP have hand some new opportunities in regards to involvement with health as this is an area that we are looking to strengthen and build foundations within.

## **ANALYSIS**

Much time is spent building relationships with parent carers from seldom heard groups and gaining their trust. Parent carers themselves report not wanting to talk openly about having a child/ young person with needs for reasons related culture, religion and stigma. During the past financial year some of the funding for this work has been utilised to employ a parent carer who herself could be considered seldom heard to act as Participation Officer. Part of her role is to facilitate participation from parent carers in this group. This has meant changes to the way participation is achieved; the use of 1:1 meetings to gain trust, working breakfast meetings with the use of different tools for gaining input into discussions and assisting with setting up and running joint family based activities to name a few.

There has been an increase in engagement and three parent carers from the AHG have acted as parent representatives on the Healthy Child Programme Board. Work has been undertaken to raise awareness amongst the parent carers that there are support services available to help them and new ways of working have been introduced such as the SEN Surgeries. Some key findings are as follows:

1. Parent carers from the BAME community have taken up training opportunities are now acting as parent representatives.
2. There is increasing engagement from a more diverse range of parent carers and some work has started based on responding to needs they have identified. This includes the introduction of SEN surgeries run in conjunction with the SAM service from Peterborough City Council.
3. More parents are attending working breakfast sessions and focus groups to participate in work including the development of a book for families accessing the Child Development Centre.

## **SECTION 5 – 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 in such ways as the Trustees shall think fit, in particular by the provision of advice, information, support and advocacy*



## **Trustees**

John Ravenscroft

Sara Rourke

Amanda Rennie (April 2016 to October 2016)

Ian Frederick Ralph Middlebrook

## **Declarations of Interest**

- An employee of FVP is married to John Ravenscroft.
- Sara Rourke is a trustee on 3<sup>rd</sup> Nene Scouts and member of staff for Families First
- Ian Frederick Ralph Middlebrook is a trustee on Goldhay Arts

## **Governance and Structure**

Table 1

Operating Model:	Constitution
Legal Structure:	Unincorporated Charity
Trusteeship:	<p>Appointment by Board of Trustees and/ or election by members</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>

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 Carers Trust Peterborough, PCVS, PDDCS, Pinpoint, Families First and Family Action 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.

The Board of Trustees has been made up of a majority of parent carers which could be perceived as being a risk and 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. This does

pose some risk which is managed by appropriate risk management and all associated procedures are detailed in the risk management policy.

### Holding/ Custodian Trustees

To facilitate proper governance of the assets of the charity; the premises and caravans holding trustees are named on any leases/ contracts.

*“Sometimes a charity also has custodian or holding trustees, whose function is solely to hold its property. Custodian or holding trustees usually have no power to make management decisions and must act on the lawful instruction of the managing trustees”*

The Holding Trustees are

### **Premises**

- Ralph Middlebrook
- Amanda Rennie
- John Ravenscroft
- Sara Rourke

### **Caravans**

- Sara Rourke
- John Ravenscroft

Decisions relating to all assets are taken at full trustee board meetings and the holding trustees make no decisions in their own right.

### **Staff 2016 to 2017**

Louise Ravenscroft (Participation Lead)  
Jo Woodhams (Participation Co-ordinator)  
Ramou Ndow (Admin office/ finance)  
Vanessa Perry (Participation Co-ordinator)

Through grant funding there has been an increase in the number of staff employed by the charity. The staffing of the charity is in relation to participation and the administration.

Taking on staff as well as facilitating the increasing work of the charity/ forum does lead to potential risks associated with becoming employers which the trustees will continue to mitigate through suitable financial planning, employee support and trustee board development and all work will be underpinned by the risk management policy.

### **Volunteers/ Reps 2016 to 2017**

Vanessa Perry (Now listed as an employee)  
Jo Woodhams (Also listed as an employee)  
Jason Merrill  
Sarah King

Nabela Jan  
Claudia Dias

The parent representation work continues to grow and has this year seen parent reps facilitating focus groups as well as attending strategic meetings and task and finish groups relating to the Special Educational Needs and Disability (SEND) Reforms.

The number of active volunteers with FVP has decreased this past financial year due to changes in personal circumstances of those volunteering. Volunteering continues to be a transient area of work within FVP and time will need to be invested in recruiting and supporting volunteers. The area of work FVP is involved in is not one that attracts volunteers readily so some work on advertising and raising awareness will be required going forwards.

## **Objectives and Activities**

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**

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 defined by some of our donors/ funders:**

- Increased levels of employment or volunteering
- Reduced isolation or social inclusion
- Improved community cohesion and interactions
- Parents and Carers are empowered to participate in engagement activities with the Local Authority and their partners through representation activity
- Parents and Carers are empowered to engage with the Local Authority and their partners
- Training and Development so Parent carers have increased skills, knowledge to facilitate self-help
- Increased confidence from parent carers in managing behaviours that challenge associated with possible ASD/ ADHD (More specific impact)

- Parents and Carers are empowered engage with Local health providers and confident in understanding how to get the best from health services

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

- Improved services for children/ young people with disabilities and additional needs,
- Increased parent participation which can include involvement, engagement, information sharing,
- Increased empowerment of parent carers leading to more involvement in the services accessed by their children and increased confidence.
- Increased employment including volunteering,

### Measuring Social Impact

FVP utilise a variety of qualitative and quantitative data to measure the outcomes and impact of the work of the charity; examples of the measurement methods include case studies, activity/ event feedback, survey results, quotes, numbers in attendance, demographic information, changes to services for children/ young people with disabilities through a “you said – we did” approach from the Local Authority.

1. FVP have seen three parent carers who spent time taking training courses and volunteering with the charity move towards employment with FVP. The parents fed back that through their time with FVP they gained confidence and felt more empowered and ready to move towards new ventures.
2. Services accessed by children and young people with special educational needs and disabilities have been co-produced by parent carers from parent representation and participation through to consultation. EHC processes and documentation, The Local Offer and CAMHs are areas that have had parent carer input. In the past year 209 parents in total have been involved at some level via face to face meetings/ events/ activities (unique attendance).
3. Through training and workshops 72 parent carers have been supported to gain understanding of specific conditions; gained confidence in managing their children’s needs and reported increased positive relationships with the health sector.
4. The trips, activities and parent carer sessions lead to self-reporting of increased well-being, new friendships being formed, and the opportunity to spend time with other people leading to less isolation for at least 50 families.
5. 8 out of 11 parent carers who completed a survey reported that they felt their involvement had had some or more impact on services.
6. 9 out of 11 parent cares who completed a survey reported feeling either less isolated or no longer isolated as a result of the work of FVP.

The activities conducted that demonstrate how FVP meets its purposes fall into the following categories:

#### Information

1. Training sessions in understanding specific areas of need (ASD, LD, ADHD) to provide parent carers/ family members with basic skills to self-manage behaviours associated with the disabilities.
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.
3. Production and provision of promotional literature such as 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.

#### Advocacy (Collective)

1. Focus groups, an annual conference and running 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).
2. Parent representation enabling parent carers to share concerns and views about disability services with education and social care commissioners.

#### Support

1. Coach trips to places chosen by families who have children with disabilities and complex needs. The coaches hired for the coach trips are accessible to enable families with children who have mobility needs to take part. Support is offered to take part in the trips by provision of meeting accessibility needs and providing coach trip hosts on the day of the trips.
2. Access to family based activities where parent carers can let their children play while they talk to other families who understand their needs.
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 .

#### Advice

1. Provision of parent carer support sessions covering SEN services, benefits support, emotional support and access to specialist advice. The sessions are provided by FVP at the community premises managed by the charity in partnership with third sector partners and Local Authority Officers.

## **Achievements and Performance**

### **Trips, Family Activity Days & Parent Carer Sessions**

#### **Coach Trips**

- FVP ran three coach trip in the financial year 2016/ 17 which was funded through monies raised for parent carer and family based activities.
  - The coach trips were to Robin Hood Festival, Twinlakes and Hunstanton both of which took account of accessibility needs by way of hiring of wheelchair accessible coaches.
  - 30 families benefitted from the coach trips and the needs of the children ranged Complex Health needs and Duchenne Muscular Dystrophy through to Autistic Spectrum Disorders and Hearing Impairment.
  - The ethnicity of the families ranged from White British to Chinese.

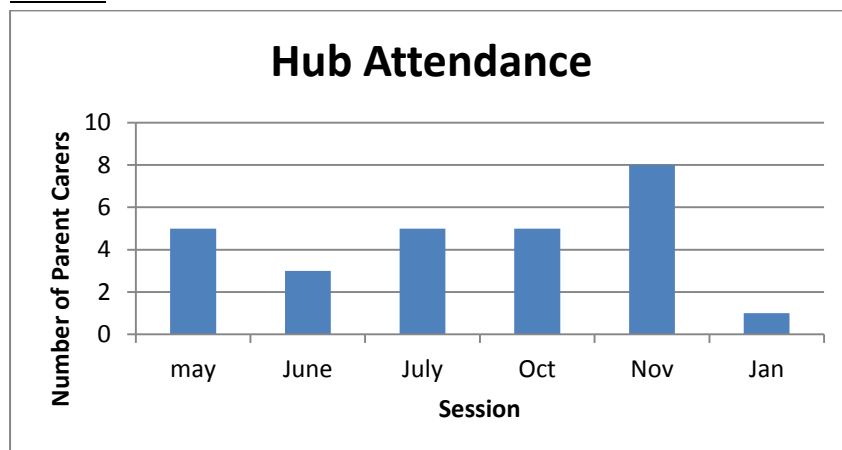
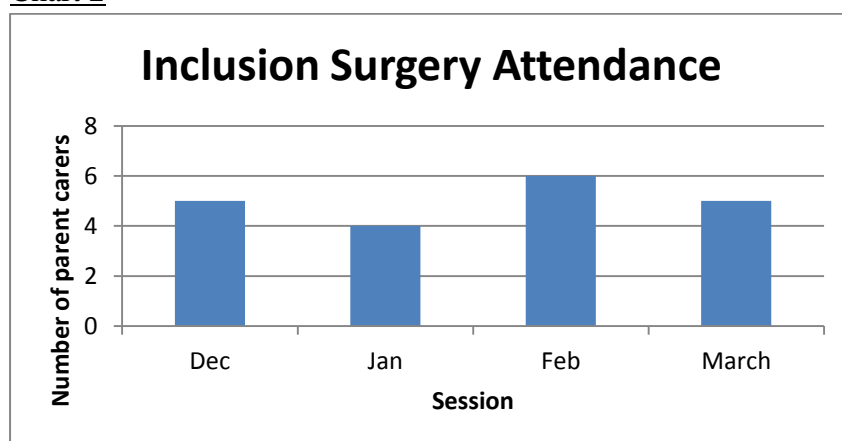
#### **Local Family Based Activities**

- FVP facilitated access to local family based amenities through a mixture of grant funding and donations.
  - Halloween Party attended by 21 families (30 adults and 63 children) The children's needs ranged from Genetic Conditions to ASD and they were aged between 4 and 16
  - Christmas Party attended by 10 families. The children's needs ranged from GDD to Golden Harr Syndrome and the family ethnicity ranged from White British to Polish
  - 2 Activity World Private Hire Sessions
  - A joint organised family based cultural awareness day (Asian Cuisine Day)

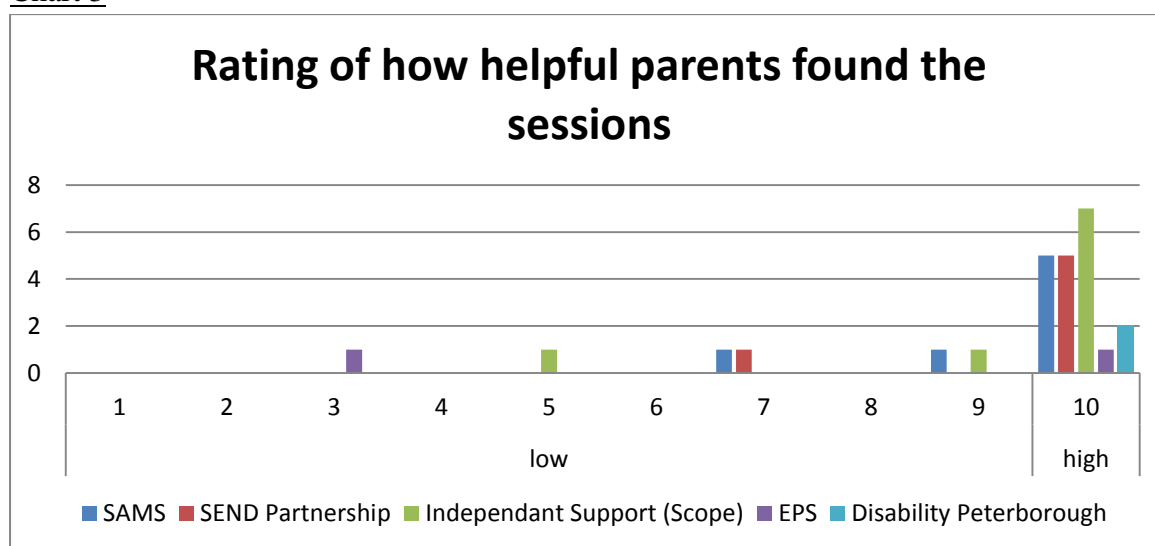
#### **Sessions for Parent Carers**

The attendance at the following has varied according to the topics and need; numbers have been anywhere from 4 to 20

- 3 Breakfast Club Sessions
- Carers Rights Day Get Together and Lunch
- Festive carers get together
- 7 general and 2 themed parent carer hub sessions in partnership with Carers Trust
- 4 Inclusion surgery sessions in partnership with SEND Partnership, Peterborough City Council and Scope Independent Supporters

Chart 1Chart 2

Across the Parent Carers Hub and Inclusion Surgery sessions 35 individual parent carers have been supported,

Chart 3

Overall parent carers rated the helpfulness of the sessions as high.

## **Training**

FVP have worked on various training projects this financial year including:

- 1 Parent Participation and Representation Course (HTRG)
- 1 Microsoft Basics Work Shop(HTRG)
- 9 Expert Parent Programme (EPP) – CAMHs Transformation Funded
- 3 Understanding Behaviours that Challenge
- 1 Health Participation Sessions delivered by CaF Trainer
- 1 EHC Bespoke Independent Support Session delivered by CDC Trainer

The above training courses/ workshops have resulted in:

- Four parents have gained Microsoft basics skills which have helped in their understanding of the work their children are doing in school
- 38 Parent carers from completing the EPP
- Joint working with Pinpoint (Charity/ Parents Forum) for Cambridgeshire
- 34 parent carers attending and reporting positive outcomes from the understanding conditions workshops
- 10 Parent representatives, volunteers and FVP trainers (who are parent carers) gaining new knowledge and understanding to help them in the work

## **Participation**

The financial reporting period this report relates to of 2016 to 2017 has seen for FVP an increase of 57% in participation compared to 2015 to 2016. This is in part related to an increased awareness of participation amongst parent carers and professionals, an increasing number of requests for parent involvement from service commissioners and personal interest from parent carers in the areas of work where participation is being requested.

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. 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. As you said – we did method has been adopted to help demonstrate where parent carers have been heard and what changes have been made.

### **Parent Participation Data**

- 206 parents in total have been involved at some level via face to face meetings/ events/ trips/ Facebook Polls and Discussions
- >105 professionals have been involved at some level via face to face meetings/ events/ attending training or co-delivering training



- 128 parents via eight surveys
- 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) and Inspire Peterborough and Carers Trust Peterborough
- Children's/ Young people with disabilities have been reported by parents as including Autistic Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Global Developmental Delay (GDD), Speech, Language and Communication Needs (SLCN), Complex Health, Obsessive Compulsive Disorder (OCD), Cerebral Palsy (CP), Tourettes, Leukaemia, Learning Disability and Difficulty (LDD), Hearing Impairment (HI), Depression, Behavioural Needs, Achondroplasia, Goldenhar Syndrome, Duchene Muscular Dystrophy, Downs Syndrome, Hypochondroplasia, Physical Disabilities and Anxiety Disorder (This list is not exhaustive)
- Approx. 15 fathers have been involved which is an increase on the previous year and 1 father has had regular involvement in person and another via social media
- Reported age of children ranges from 2 to 34
- Methods used include; 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
- Evidence is both qualitative and quantitative
- Ethnicity has been self-reported as; British, Pakistani, Afghanistan, White Mixed Caribbean, Albanian, Belgian, Hungarian, Dutch, American, Portuguese, Chinese, Brazilian, Gambian, Kenyan, Polish, Czech, Ukrainian, Slovakian, Irish Traveller, Romany
- Data evidenced by feedback forms, attendance registers, social media groups posts, completed online surveys and written case studies

## **Participation and Engagement Work**

Table 2 - Boards attended

Board	Organisation	Designated Parent Representative
Cambridgeshire and Peterborough Mental Health and Emotional Wellbeing Board	PCC, CCC, CCG	J Ravenscroft
Peterborough Children and Families Joint Commissioning Board	PCC	J Ravenscroft
PSHFT Maternity, Children and Young People Programme Board	PSHFT	J Woodhams
0-25 and SEND Transformation Board	PCC	L Ravenscroft
SEND Project	PCC	V Perry
Carers Partnership Board	PCC	S King
Learning Disability Partnership Board	PCC	C Dias

Autism Board	PCC	C Dias
Eastern Region Parent Carer Forum	ERPCF	J Woodhams
Healthy Child Board	PCC	Varies
Diversity and Cohesion	PCC	J Woodhams
Multi Agency Forum	PCC	J Woodhams
PfA Sub-Group	PCC	J Merrill

### **Conferences/ Work Shops/ Focus Groups**

- Annual Conference
- Focus Groups
  - Local Offer
  - Wheelchairs
  - CAMHs
  - Short Breaks
  - Transport
  - OFSTED
  - EHC processes
- Understanding Challenging Behaviours
- Parent Participation for Professionals
- Parent Participation for Parents

### **Surveys**

- SEND 2015 to 2016
- Personal Budgets
- Local Offer
- Parent Carers
- Early Help
- Short Breaks
- Satisfaction Survey
- Seldom Heard
- Employee Survey
- Volunteer Survey

### **Co-production**

- CDC Guides
- Autism Strategy

### **Facebook Polls**

- What is your preferred method of participating?
- Self-Described Areas of CYP Needs
- Who is interested in SEN surgeries
- Do you know the difference between CAMHs and NDS
- Private Therapy Use
- Information for Parents

- Autism Strategy
- Do you know what a SEN Information report is?
- Have you seen and read your schools SEN report?
- Have input into your schools SEN report?
- Groups Accessed

## **CHARITY DEVELOPMENT (Premises)**

### **Premises Details**

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

- Section 1 is a community premises comprising, Kitchen, Hall, Accessible WC and WC and outside play space
- Section 2 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.

FVP are pleased to have been awarded a 5 star rating for food hygiene on completion of the first inspection of the premises.

### **Premises Costs**

FVP now lease the Goldhay Centre on a peppercorn lease from Peterborough City Council with a view for going for asset transfer in the next two years. The decision whether to move towards asset transfer is based in part on whether FVP can make the premises running costs self-sustaining rather than relying on grants and/ or public donations.

By analysing the financial summary data presented in Appendix 1 it is clear that the running costs of the premises can be secured by hiring out the community hall and kitchen. Since June FVP have taken £7,249.73 in fees. The utilities, insurance and building costs for the Premises have been £9,309.00 so there needs to be some work to secure more income via fees to ensure the premises becomes self-sustaining. This year most of the utilities have been paid via core costs in grants so funds can be built up to ensure premises running costs long term can be covered.

Although the hall hire fees are unrestricted as income the FVP trustees have allocated them as designated funds to cover the premises running costs.

### **Premises Use**

#### **Parent Forum Opportunities**

1. The move to the new premises has helped to make the forum more accessible to parent carers and provides FVP with more in-house participation and training opportunities. Previously much time and cost was expended on hiring other venues for such purposes.

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, sign-posting and face to face contact more easily.

### **Community Opportunities**

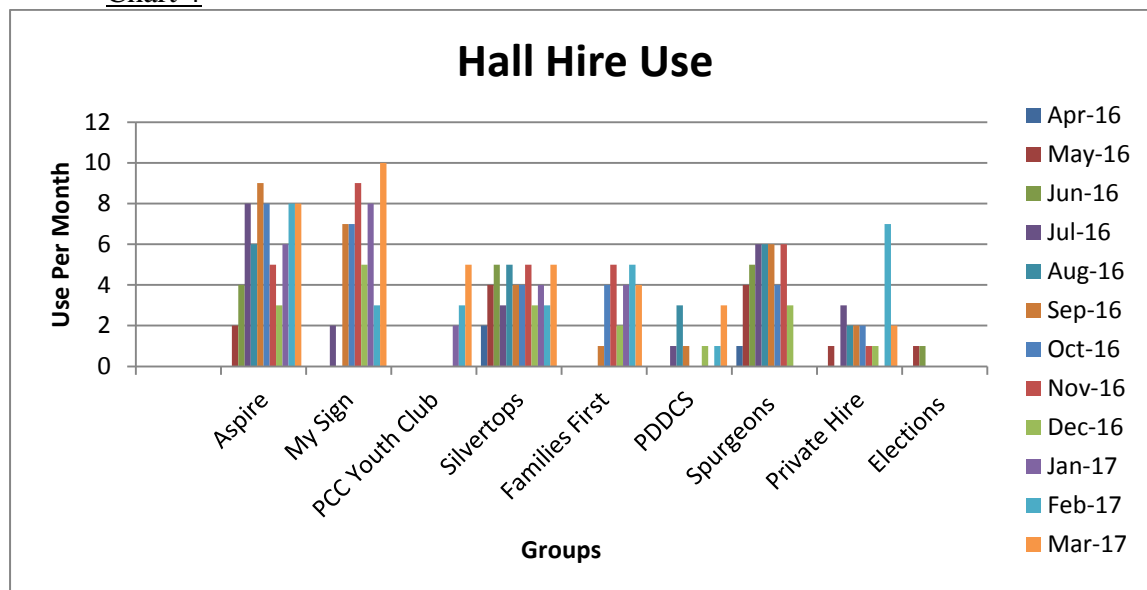
1. The premises has been provided to the following groups/ organisations for a small fee during 2016 to 2017
  - a. The Silvertops
  - b. Spurgeons (Parents and Tots and Saturdays Sessions)
  - c. Aspire
  - d. MySign Tuition
2. There have been bookings for private events and parties from people within the local community
3. PDDCS provided their summer play scheme at the premises
4. FVP have been able to provide parties and other family based activities for parent carers and their children/ young people

### **Working With Families First**

1. The FVP premises are provided for free to Families First on Tuesdays in Term Time, and on some days in School Holiday Periods.
2. Families First provide open access play to the local community for 5 to 13 year olds for free during these times.
3. Families First provides open access play around Peterborough and also provide support for children and young people as part of their early intervention and prevention work for Peterborough City Council. By providing free access to the premises to Families First, FVP are enabling them to keep their costs down.

### **Working with PDDCS and MySign**

1. FVP have been working closely with PDDCS and MySign Tuition to enable access to support tailored specifically to members of the Deaf Community.
2. The premises has been used to facilitate a Deaf Toddlers Group
3. There has also been a special Inclusion Surgery run for the benefit of families who have children who have hearing impairments.
4. Work has also begun to make the premises more accessible for members of the Deaf Community.

Chart 4

## Caravan

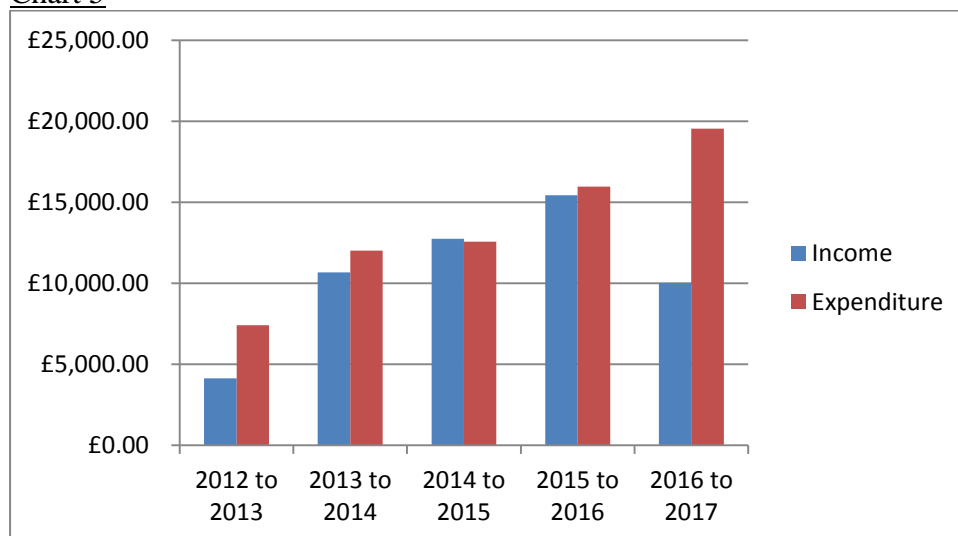
### Management and Structure

FVP trustees own and manage the caravans on behalf of the charity with the current chairperson and secretary being named as owners (holding trustees) on contracts with Butlins and Haven due to the charity itself being unable to own/ lease property or sign contracts. The choice of trustees was in part based on prior caravan ownership experience and time and capacity to be able to attend the caravans to carry out required works.

### Finances and Sustainability

#### Income and Expenditure from 2012 to 2017

The chart gives an indication of yearly income and expenditure relating to the caravan. The figures do not include and yearly carry forward

Chart 5

Generally expenditure has been slightly higher than income apart from the period 2015 to 2016. There was a large difference between income and expenditure in 2016 to 2017 in part due to costs relating to upgrading the caravan at Butlin's. There was also a need to replace all bedding for the Haven caravan which specialist bedding.

### General Operating Costs

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

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

### Bookings

Season runs from March to October at both sites but much of March and September are given over to adult only weekends at Butlins.

Table 3

	2012 to 2013	2013 to 2014	2014 to 2015	2015 to 2016	2016 to 2017
Number of Bookings	4	28	48	45	42

There has been decrease in bookings between 2015 to 2016 and 2016 to 2017 which in part relates to how people are booking breaks at Haven. There is a preference for 7 night breaks were as at Butlin's there is a preference for 3 and 4 night breaks. Such a difference may be due to the travel time required to reach the Haven caravan.

Chart 6

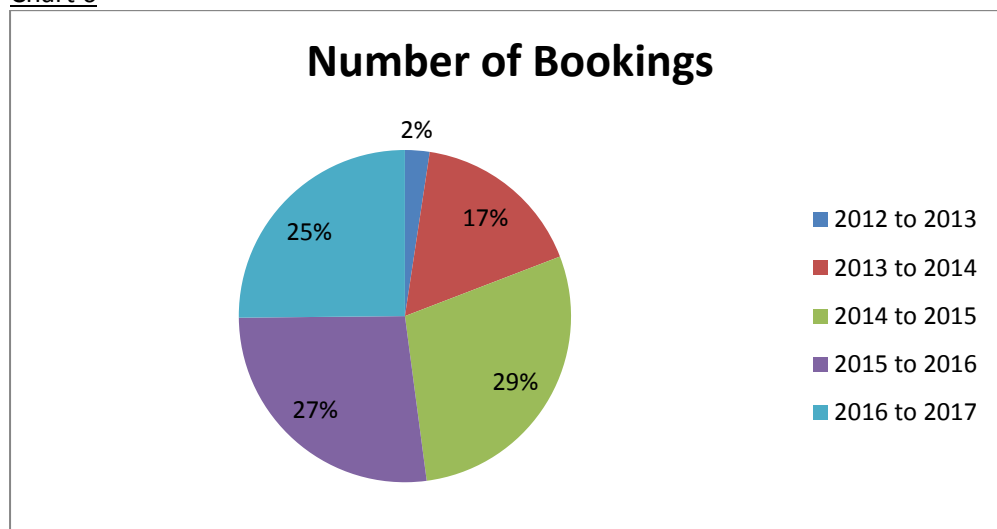
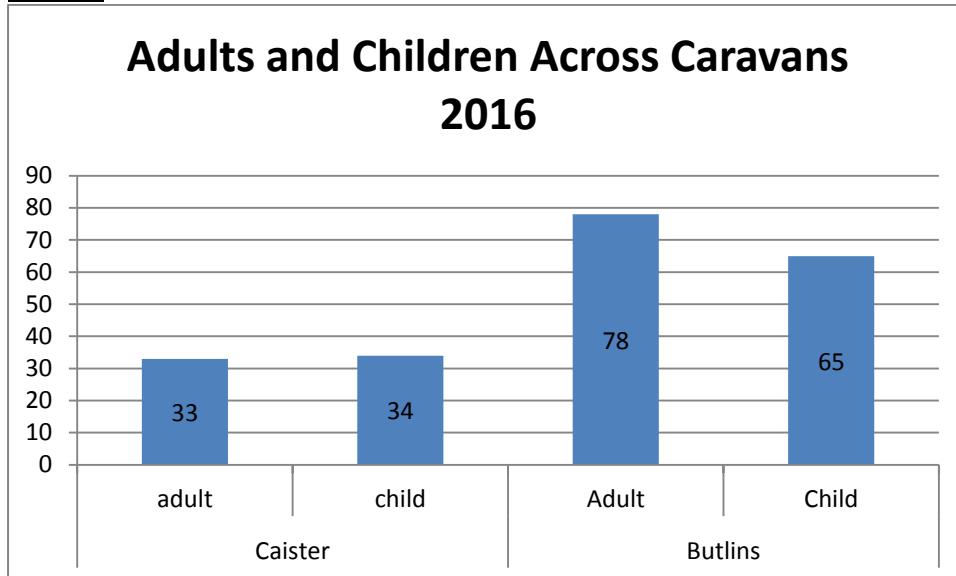
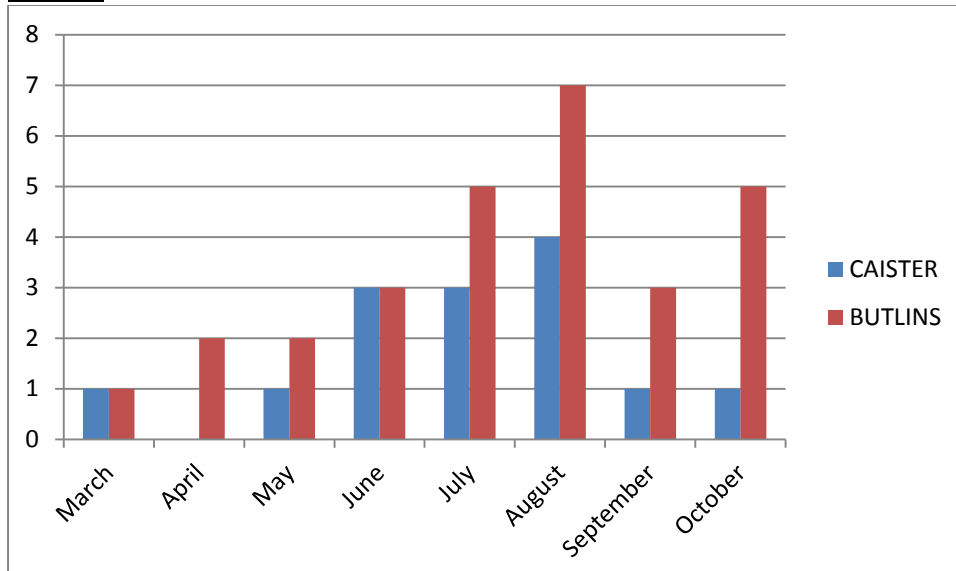


Chart 7Chart 8

## **Financial Review**

### **Reserves Statement**

The trustees worked to establish sustainability and good governance for the charity and have developed various policies and procedures and one such policy under development is a reserves policy. The policy will establish 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 going forward. This has not been achieved yet and has risks around holding low reserves have been acknowledged. The charity currently has an equivalent of two months free reserves and work is taking place to increase the level of free reserves. This will need balancing against the high level of grant income and expenditure which is restricted.

### **Principle Source of Income**

As with previous years the principle source of income for FVP remains grant funding which is linked to predefined outcomes. Grants have been allocated by Contact a Family on behalf of The DfE, The Local Authority on behalf of the CCG and The Local Authority. The total grant income equates to 71% of the charities total income and is restricted.

FVP have secured a similar level of income in grants for 2017 to 2018 however long term sustainability will need to be explored by The Board of Trustees. This income unlike previous years will be paid in the relevant financial year.

### **Fundraising**

Through fundraising and donations FVP has generated approximately £15,000 over the course of the financial year; some of this was designated for example where it was through joint events and intended for other organisations or where stipulations of use had been added such as to provide trips.

Expenditure on fundraising related to provision of items such as refreshments, entertainment and venue costs at fundraising events. The payments to other charities of jointly raised funds were also allocated under fundraising expenditure.

### **Donations**

The larger donations to FVP have been specifically for the FVP caravans.



## Network Event and Participation Awards 9<sup>th</sup> December 2017

FVP hosted the fifth Network Event and Participation Awards and the event exceeded previous years for attendance and funds raised. There were over 200 people in attendance from parent carers and third sector partners through to Local Authority and Health Partners. The charity partners for the event were PDDCS and Inspire Peterborough.

Work seeking support and items donated for the purposes of fundraising on the night was shared jointly by both partner charities. The efforts of led to total of over £4500 being raised.

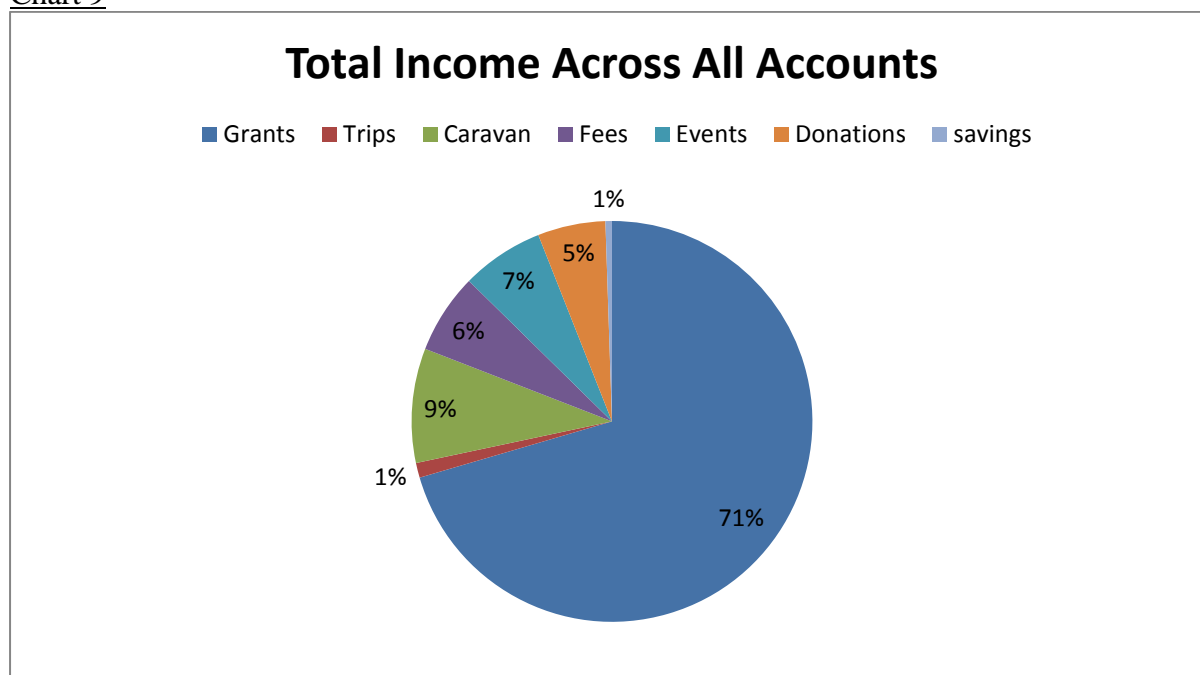
## Joint Fundraising

As with previous years FVP has endeavoured to work closely with partner charities which leads to a maximising of funds being raised to support a larger number of beneficiaries. The chosen charities for joint fundraising in 2016 – 2017 were PDDCS, Inspire Peterborough and the Aiming High Group.

## Fundraising Methods

- Tombola at Bretton Festival
- Raffle/ Auction at Network Dinner
- Fees and Raffle At Asian Cuisine Day

Chart 9



## Expenditure

The majority of the charity expenditure is from restricted funds carried forward and paid in the financial year this report relates to. Overall 74.89 % of expenditure was restricted. The grant expenditure is set against pre-defined outcomes with specific outputs. The outcomes match the objects of the charity. Expenditure has been on providing families with access to information, advocacy, support and advice. All staffing is funded via grants, as are the majority of core costs of the charity.

The expansion in staffing levels has enabled an increase in demand for work relating to the provision of information and advocacy in particular. Parent carers who would otherwise be unable to access certain activities have also been supported by way of access to expenses for travel and childcare.

## **Further Details**

1. All employees within FVP are currently parent carers who volunteer extra time to the charity over their contracted hours of employment. All costs relating to employment are linked to grants.
2. The Expenses budget for the charity may appear high but this is to enable parent carer participation via transport and childcare costs reimbursement. The expenses spend also includes refreshments at event/ meetings and training attended by parent carers.
3. Fees include:
  - a) remuneration to parent carers for delivering training,
  - b) speakers fees from the FVP annual conference,
  - c) fees for external specialists to provide support on a range of areas to the Board of Trustees
  - d) Entrance/ ticket costs to conferences attended by parent representatives
  - e) The grant portion held by FVP for Pinpoint
4. The caravan expenditure is covered by income generated through caravan sub-let fees. The expenditure is on site fees, utilities, repairs, ground rates, insurance and cleaning.

Chart 10

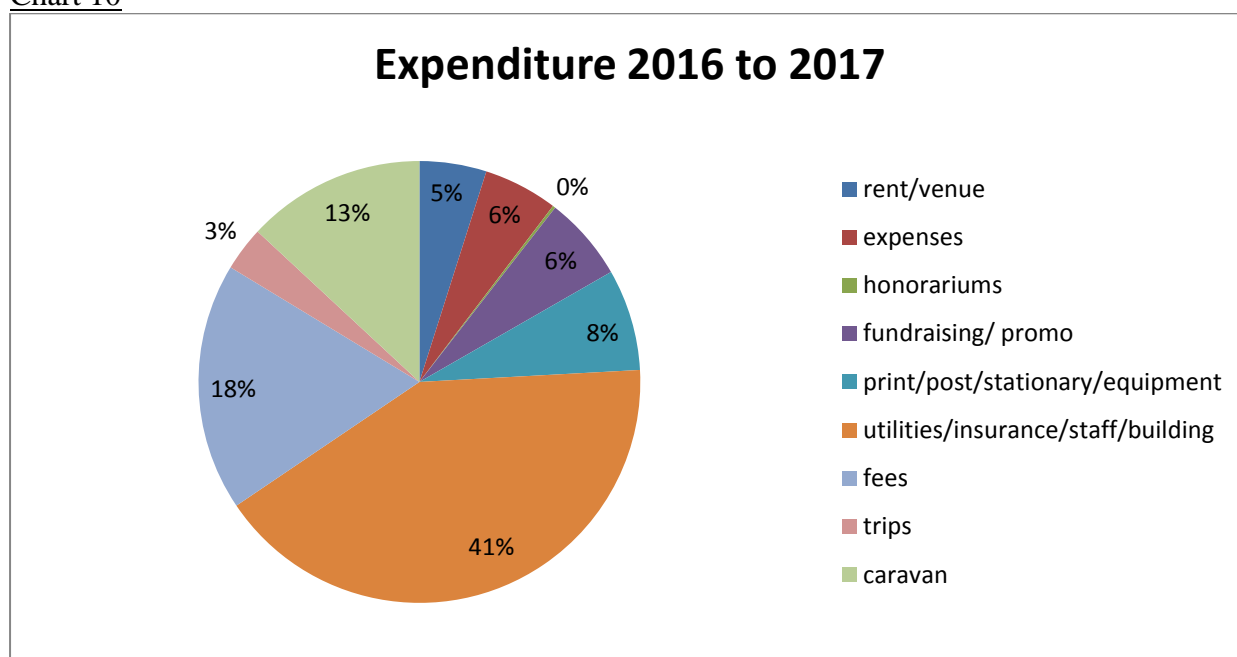
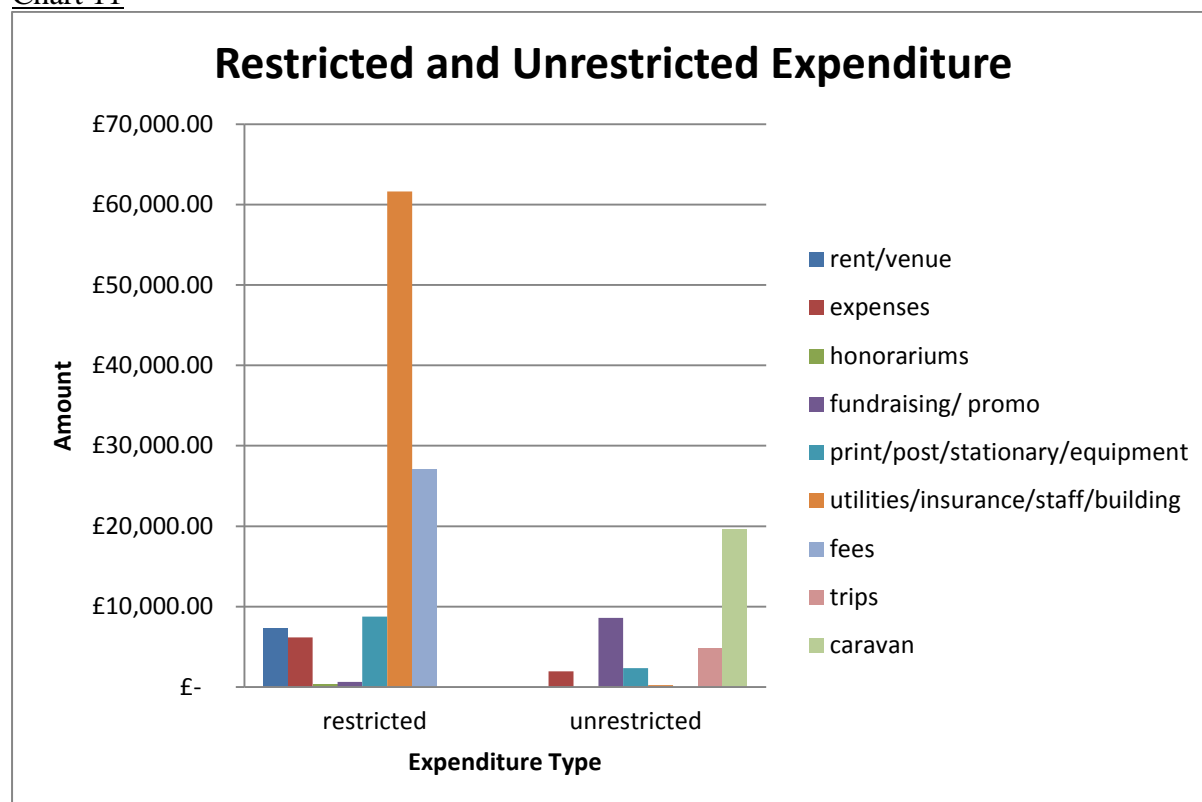


Chart 11



The above charts show that all core costs are funded via grants (restricted) sources of income. The grants can be used to cover core costs.

#### Trustee Remuneration and Expenses

During the financial period 2016 to 2017 two trustees received remuneration for training and IT services which was paid from grant income. The remuneration took place in line with FVP's constitution and grant outcomes.

Trustees received reimbursement for reasonable travel and sustenance claims.

## **Statement of Accounts 2015/ 2016 and 2016/ 2017**

	<b>Unrestricted funds</b> to the nearest £	<b>Restricted funds</b> to the nearest £	<b>Total funds</b> to the nearest £	<b>Last year</b> to the nearest £
<b>A1 Receipts</b>				
Grants		79,075	79,075	176,655
Trips	1,341		1,341	804
Caravan	10,356		10,356	19,993
Fees	7,250		7,250	1,750
Events	7,467		7,467	2,124
Donations	5,779		5,779	10,386
Savings Accounts	587		587	7,580
<b>Total receipts</b>	<b>32,780</b>	<b>79,075</b>	<b>111,855</b>	<b>219,292</b>
<b>A3 Payments</b>				
Rent/ Venue		£7,321.12	7,321	7,828
Expenses	£1,951.23	£6,165.95	8,117	9,437
Trips	£4,837.31		4,837	3,356
Honorariums		£300.00	300	400
Fundraising/ Promo	£8,587.65	£632.32	9,220	2,381
Print, Post, Stationary, Equip	£ 2,334.44	£8,761.75	11,096	5,211
Caravan	£14,544.44		14,544	16,138
Utilities, Insurance, Staffing, Building	£223.86	£61,626.17	61,850	42,595
Fees		£27,096.41	27,096	21,841
<b>Sub total</b>	<b>32,479</b>	<b>111,904</b>	<b>144,383</b>	<b>109,187</b>
<b>A4 Asset and investment purchases, (see table)</b>				
caravan (contribution)	5,000	-	5,000	-
office equipment	-	-	-	5,315
<b>Sub total</b>	<b>5,000</b>	<b>-</b>	<b>5,000.00</b>	<b>5,315</b>
<b>Total payments</b>	<b>37,479</b>	<b>111,904</b>	<b>149,383</b>	<b>114,502</b>
<b>Net of receipts/(payments)</b>	<b>- 4,699</b>	<b>- 32,829</b>	<b>- 37,527</b>	<b>104,790</b>
<b>A6 Cash funds last year end</b>	<b>11,275</b>	<b>93,515</b>	<b>104,790</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>6,576</b>	<b>60,686</b>	<b>67,263</b>	<b>104,790</b>

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