

1st April 2017 to 31st
March 2018

Participation, Engagement and Involvement – Charity and Forum Annual Report



fvp

Family Voice Peterborough

3/25/2018

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Executive Summary

Purpose

This report is written four years in to the Special Educational Needs and Disability (SEND) Reforms; with much work around parent participation being seen as business as usual. However the report will demonstrate that there is still much to do to completely embed participation and move to a system that truly sees the family as the main focus at an operational level. There has been a move towards ensuring the voice of the parent and young person are heard and the right to be heard is embedded in service design and development. Colleagues across Health, Education and Social care within the Local Authority and Health Authority have worked to take on board the Section 19 Principles of the Children and Families Act 2014. Previously we said that *“Participation occurs at an individual and strategic level where services are designed and delivered based on this participation. The 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.”* This is not the end of the process though.

The implementation phase is over so the real work to help children and young people with SEND achieve the best possible outcomes needs to happen. Family Voice Peterborough has been best placed to help in this process by virtue of being the Department for Education (DfE) designated parent carer forum for Peterborough and by having been involved in the process since the development of the SEND Reforms. In the previous report we asked the following questions *“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)”* This report will hopefully demonstrate the value of working with a parents forum further by presenting the views/ concerns/ experiences of parent carers from the perspective of parent carers. The majority of staff/ volunteers/ trustees from FVP are themselves parent carers who have lived experience of the impact of the reforms in the current economic climate.

As with the report produced for the 2016 to 2017 financial year this report will again 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 and will also provide evidence to support grant funded work and demonstrate 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.

It is also important to understand the context in which this report has been produced in relation to the SEND reforms and current austerity measures facing the Local Authority, Clinical Commissioning Group and Service Providers. The two conflicting factors are impacting detrimentally on parent carers and members of the wider community/ beneficiaries of FVP as a charity. Locally there have not been ‘cuts’ to SEND budgets for example the community short breaks budget has remained the same for the past few years yet there have been reductions through increased demand, higher numbers of child/ young people/ adults with more complex needs and the budget remaining static.

Section One: CAMHs Transformation and Parent Carer Support

The Early Help Pathway has been an area where parent carers have reported issues again. In the last financial year’s work issues related to how the pathway was understood and some work took place to help develop better communication. This time evidence from parent carers has related more specifically to parents being referred to CAMHs when their child/

young person is presenting with different needs and being placed on the Early Help Pathway despite already having a diagnosis of Autistic Spectrum Disorder (ASD)/ Attention Deficit Hyperactivity Disorder (ADHD). The referral for accessing CAMHs is turned down until the Early Help Pathway has been followed.

Key themes;

1. Parent carers feeling frustrated due to being unable to gain support for their child/ young person's mental health needs.
2. Work around the HUB has increased with 33 parent carers being seen during the year and the ASD/ ADHD sessions proving most popular. The Challenging Behaviour (CB) Workshops and Expert Parent Programme (EPP) have worked better where the trainers themselves have overseen the advertising.
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 and Participation

The SEND reforms have changed how parent carers engage with, and become involved in, SEND services their children/ young people access. Services are more open to participation strategically compared to operationally where parent carers report being excluded from decision making. Experiences are mixed with a growing number reporting negatively and struggling to manage. The pressures on parents are two-fold as not only are parents caring they are having to still having to learn a new way of seeking support for their child/ young person from SEND services where funding is decreasing and demand and complexity is increasing.

Key themes;

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.
5. The level of dissatisfaction with services is increasing, particularly in relation to SEN support in educational settings and the Early Help pathway.
6. A larger proportion of parent carers report difficulty getting access to support for their child/ young person especially in relation to mental health support and educational support evidenced through Facebook discussions and surveys.
7. Resilience is low amongst parent carers to manage their lives and care for their children/ young people without support and there is increasing risk of more carers requiring more expensive support services.

Section Three: 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. The way participation and engagement with seldom heard groups is conducted has to be adapted to meet different needs.
2. There has been an increase in the diversity of the parent carers participating.
3. More parents are attending working breakfast sessions and family based activities and participating in work including the development of the early support leaflet and SEND vision.

Section Four: Meeting the Charity’s Purpose

The past year has seen FVP start up as a CIO, continue to see growth in the use of the premises, changes to staff and trustees and growth in the number of parent carers joining the forum to over 750 households which is a 15.3% increase. Further work has been taking place to find ways to meet the charity’s purpose as defined in its objects through business planning, analysis of the work of the charity and trustee time and investment.

Key Themes;

1. The fully accessible caravan at Butlin’s Skegness has seen good use and has enabled families who have children/ young people who are wheelchair bound to also have a short break.
2. FVP now have four members of staff, a new trustee and support over 750 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 them in supporting a growing number of families with varying needs.
4. The use of the premises has enabled over 1600 beneficiaries to access some form of support, advocacy, advice from a variety of service providers, third sector organisations and community based groups.

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 special 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

The following report is a continuation of the SEND and Participation report of FVP from 2016 to 2017 (financial year) therefore it will follow the same structure as the previous report with relevant updates included.

“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 2017 to March 2018.”
(Participation, Engagement and Involvement – Charity and Forum Annual Report, 1st April 2017)

Different 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. This report will also contain some viewpoints/ concerns of the forum regards to how experiences of parent carers are being impeded by the current economic climate whereby access to services/ support appears to be more difficult.

Forum Context

(Taken from Participation, Engagement and Involvement – Charity and Forum Annual Report, 1st April 2017)

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 (EPRCF) of which there are 11.

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	FACE (Families Acting for	1500	£15K DfE

2016)	Change Essex)		£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

Fig.1 Comparison of parent's forums in Eastern Region at 2016 to 2017

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 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.

Fig.2 Section 19 Principles

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

Fig.3 Parent forum references in Code of Practice 2015

Participation/ Engagement/ Involvement April 2017 to March 2018

Headlines

- 368 parents in total have been involved at some level via face to face meetings/ events/ trips/ Facebook Polls and Discussions up from 206 which is a 78.6% increase
- >105 professionals have been involved at some level via face to face meetings/ events/ attending training or co-delivering training.
- 277 parents have taken part in 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. 28 fathers have been involved which is an 133% increase on the previous year where 12 fathers participated.
- 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 and completed online surveys.

FVP as a Charity

FVP currently operates as a Charitable Incorporated Charity (CIO); registration number: 1171389. FVP's charitable purpose is defined in the following objects '*to relieve the charitable needs of disabled children and children with complex needs and their families and carers in Peterborough in such ways as the trustees shall think fit, in particular by the provision of advice, information, support and advocacy*'. FVP has also expanded during this period from having a mailing list of just over 50 families and running entirely voluntarily to approximately 700 and having paid employees and running a community premises. 2017 to 2018 marks the first full year for FVP as a CIO with all assets/ work from the previous charity having been transferred in May 2017.

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 23rd March 2011. During this period PCVS also provided some vital support in the form of office space and administration resources.

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"> Numbers of meetings/ focus groups and feedback. Annual conference which has themes decided by parents Network dinner attendance 	<ul style="list-style-type: none"> Reports produced will demonstrate mixed use of methods Numbers of parent carers participating Attendance at HTRG meetings, feedback and increase range of parent carers participating 	<ul style="list-style-type: none"> PTLLS trained parent carer team Team of parent carers listed on CDC website as approved EPP trainers Suite of in house training programmes developed 	<ul style="list-style-type: none"> The use of away days for the growing team of volunteers, reps and staff A clearly devised business plan Feedback form parent carers via surveys and feedback forms 	<ul style="list-style-type: none"> A quarterly newsletter will be shared amongst parents and professionals. Regularly updated website Updated Facebook page Increased numbers on mailing list 	<ul style="list-style-type: none"> We will have held at least 3 fundraising activities over the year. We would see to develop a clear fundraising strategy and action plan A completed funder finder and at least 3 grants applied for

Fig.4 FVP Principles

SECTION ONE (CAMHS TRANSFORMATION)



Fig.5 Word Cloud from CAMHs work feedback

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.” This work continued between April 1st 2017 and March 31st 2018. The data presented in this section of this report will be from this period. The reporting for FVP will be very similar to that presented in the report produced for 2016 to 2017 and Pinpoints reporting will now also follow a similar format.

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.

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. There was also a change to the planned number of sessions of all elements due to a variety of reasons which will be detailed under each subsection.

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.

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"> • Delivery of Expert Parent Programme by CDC approved trainers who are themselves parent carers • Access by early help pathway and self-referral if space is available. • Appropriately advertised using variety of methods 	Quarterly reporting detailing - <ul style="list-style-type: none"> • Number of session provided - target of 10 for parent carers from Peterborough and Cambridgeshire • Use of external providers to host sessions • Details of EPP content and delivery • Number of parent carers attending– target of 10 per session • Parent carer feedback 	FVP
	What has happened so far	<ul style="list-style-type: none"> • EPP advertised using various methods • Sessions run across Cambs/ Pboro • Most sessions have been after parents have completed a positive parenting course via Barnardos 	<ul style="list-style-type: none"> • 5 Sessions in total • 34 attended 	
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"> • Partnership approach through the steps described above, and the provision of co-delivered workshops • Be part of the feedback process for families, to facilitate the understanding of the effectiveness of participation 	Quarterly reporting detailing - <ul style="list-style-type: none"> • Parents and carers self-report positive change in their communications with the health providers and their partners Case studies provided (1 per quarter)	FVP
	What has happened so far	<ul style="list-style-type: none"> • All workshops have been either delivered by parent carers • Feedback from workshops, training is used to inform commissioning cycle with respect to how parents are navigating the health system (Early Help for example) 	<ul style="list-style-type: none"> • First quarterly report was produced and presented for monitoring purposes • Data in report details views on the work and access to range of support, training 	

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"> • Parent carers gaining new skills through sharing of hints/ tips from professional and signposting from parent reps • Access to the workshops is via self-referral with bookings taken by Pinpoint and Family Voice 	Quarterly reporting detailing - <ul style="list-style-type: none"> • Parent carers self-reporting that they are able to manage children's behaviour better • Parent carers self-rating their confidence at the start and end of the workshops for comparison purposes • Access measured via social media requests, email and phone logs and completed attendance register 	FVP
	What has happened so far	<ul style="list-style-type: none"> • 4 workshops have been co-delivered • Feedback from workshops, training is used to inform commissioning cycle with respect to how parents are navigating the health system (Early Help for example) 	<ul style="list-style-type: none"> • Completed feedback forms detailing confidence and understanding 	
7	Training and Development so Parent carers have increased skills, knowledge to facilitate self-help	<ul style="list-style-type: none"> • Undertake the co-planning of workshops by FVP and CPFT in understanding behaviours around hyperactivity, social interaction and learning difficulties • 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 • Access to the workshops groups is via self-referral with bookings taken by Pinpoint/FVP • Parent carers gaining new skills through sharing of hints/ tips from professional and signposting from parent reps 	Quarterly reporting detailing - <ul style="list-style-type: none"> • Number of workshops provided - target of • Use of external providers to host sessions • Details of workshop content • Number of parent carers attending– target of 10 per workshop • Parent carer feedback • Feedback, evaluation from professionals co-delivering workshops • Access measured via social media requests, email and phone logs and completed attendance register 	FVP
		<ul style="list-style-type: none"> • As Above 	Final report details that 4 workshops have taken place with 23 parents in total taking part in a workshop. All were unique attendees	

8	Parent Carer Hub (inclusion surgery), development and access to facilitate parent carer support and wider participation.	<ul style="list-style-type: none"> Undertake the development of a parent carer hub working in partnership with 3rd sector and Local Authority Professionals Plan and deliver inclusion surgery as part of parent carer hub supported by parent representative Provide feedback on support offered through parent carer hub Parent carers accessing hub gain support to navigate early help pathway and increased understanding of EHC pathway and processes 	<p>Quarterly reporting detailing –</p> <ul style="list-style-type: none"> Monthly Parent Carer Hub – target 12 Details of numbers of parent carers attending hubs Parent carer feedback Feedback and evaluation from professionals co-delivering hubs Access measured by booking forms and attendance records Targeting educational settings to increase their involvement. 	
		<ul style="list-style-type: none"> Hub has been delivered alongside PCC and Carers Trust. 	<ul style="list-style-type: none"> 8 Hub sessions have been delivered supporting 33 individual parent carers 	

Fig.1 CAMHs Transformation Work Outcomes Matrix for FVP

Predicted targets/ measurers

The following were predefined as measures of the outcomes relating in particular to the Challenging Behaviour (CB) workshops, Expert Parent Programme (EPP) and Hubs.

CB Workshops

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

EPP

- Parent carer details from 10 EPP sessions to be run across Cambridgeshire or Peterborough
- Parent Carer Feedback.
- Parent 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

HUB

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

- Feedback from parent carers who have attended one of 12 hub sessions.
- Details of any recurring issues/ themes

Total Numbers

- 60 parent carers across six workshops
- 100 parent carers across ten EPP courses
- 120 parent carers across 12 Hubs

Predicted data

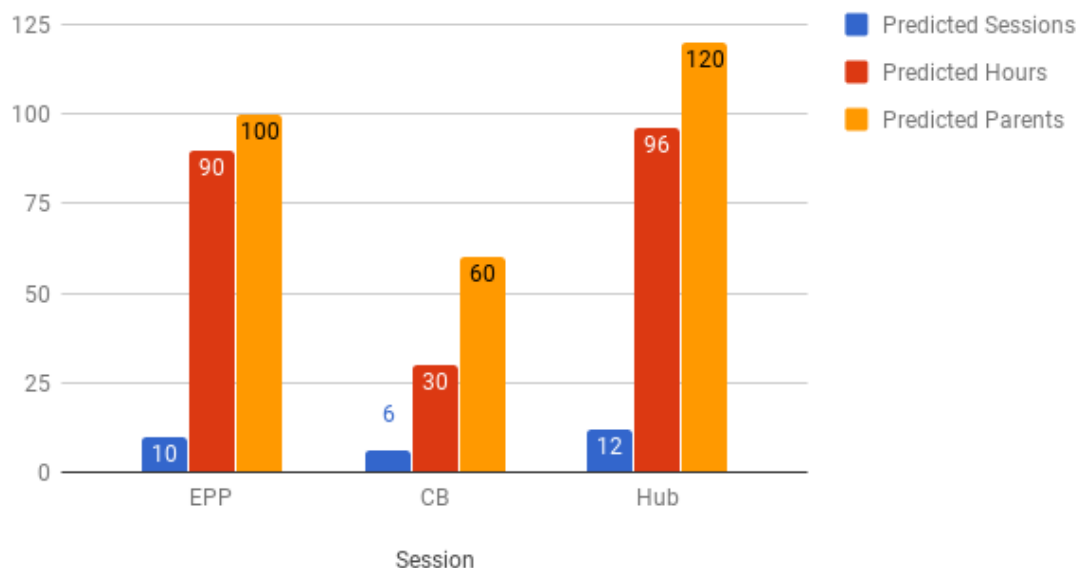


Fig. 2 Predicted sessions, hours and parent carers over the course of the project

The chart shows the predicted costs/ time and number of parents for the CAMHs funded element of the work FVP delivered.

Grant Funding	£25,000.00
Predicted hours (PH)	216
Predicted Parents (PP)	280
Funding/ PH	£115.74
Funding/ Parents	£89.29

Fig. 8 Analysis of predicted hours and number of parents against the total budget

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)

Actual Data

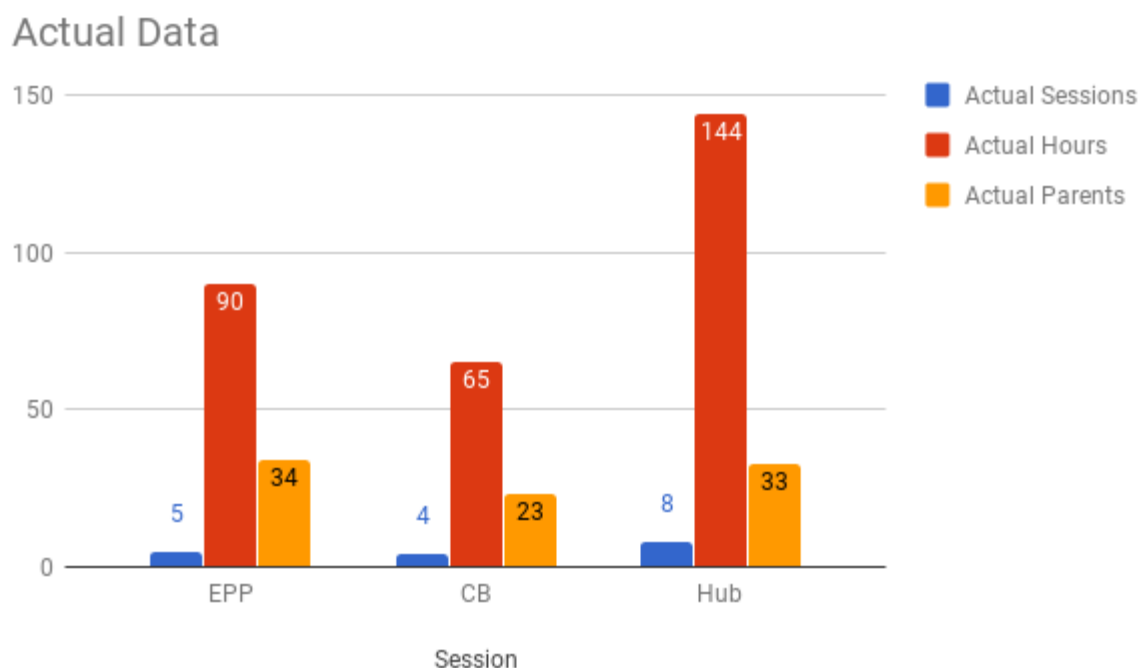


Fig. 3 Actual sessions, hours and parent carers over the course of the project

The chart shows the actual number of sessions/ hours/ parents for the CAMHs funded work.

Grant Funding	£25,000.00
Total hours	299
Number of Parents	90
Funding/ Hours	£83.61
Fundiing/ Parents	£277.78
Hours*parents	£26,910.00

Fig. 4 Analysis of actual hours and number of parents against the total budget

	Actual	Predicted
Grant Funding	£25,000.00	£25,000.00
Total hours	299	216
Number of Parents	90	280
Funding/ Hours	£83.61	£115.74
Fundiing/ Parents	£277.78	£89.29
Hours*parents	£26,910.00	£60,480.00

Fig. 5 Comparison of analysis of budget against the predicted and actual number of hours/ parents

The table shows that overall the more parents the project supports the more costly the project becomes and the more hours invested the less per hour the project costs to deliver.

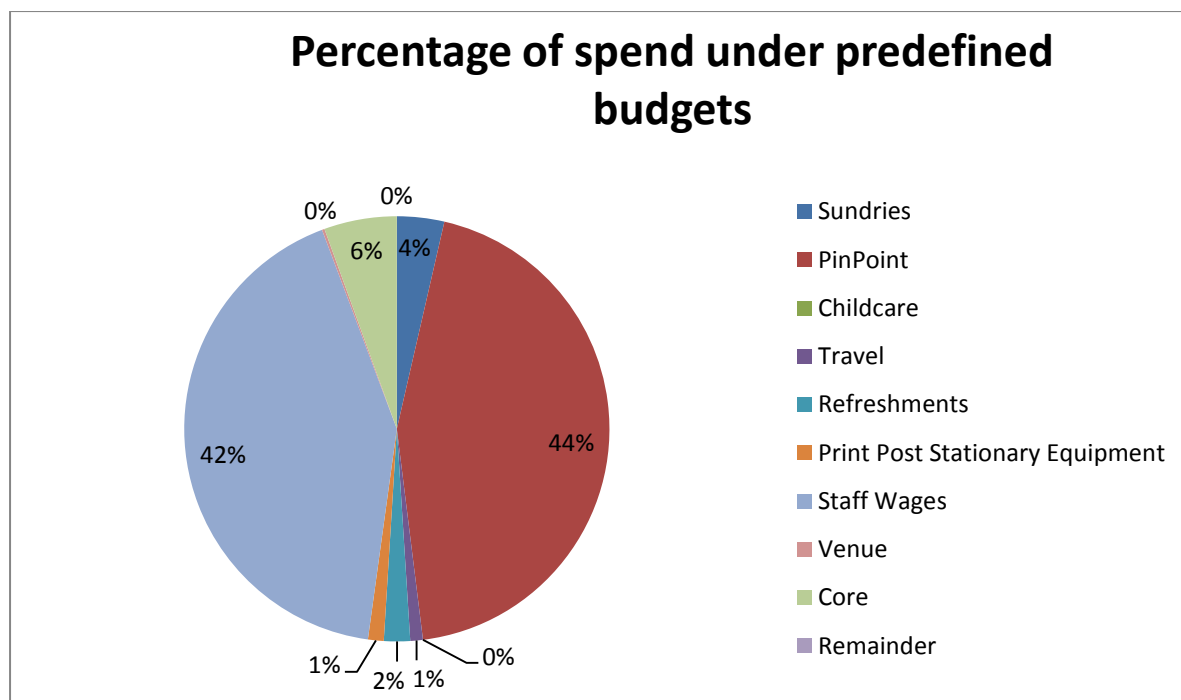


Fig. 6 percentages of spend across different budget headings for the overall grant

The pie-chart above shows what percentage of the grant was spent across items such as staffing and travel.

Comparison of Predicted/ Actual Data Overall

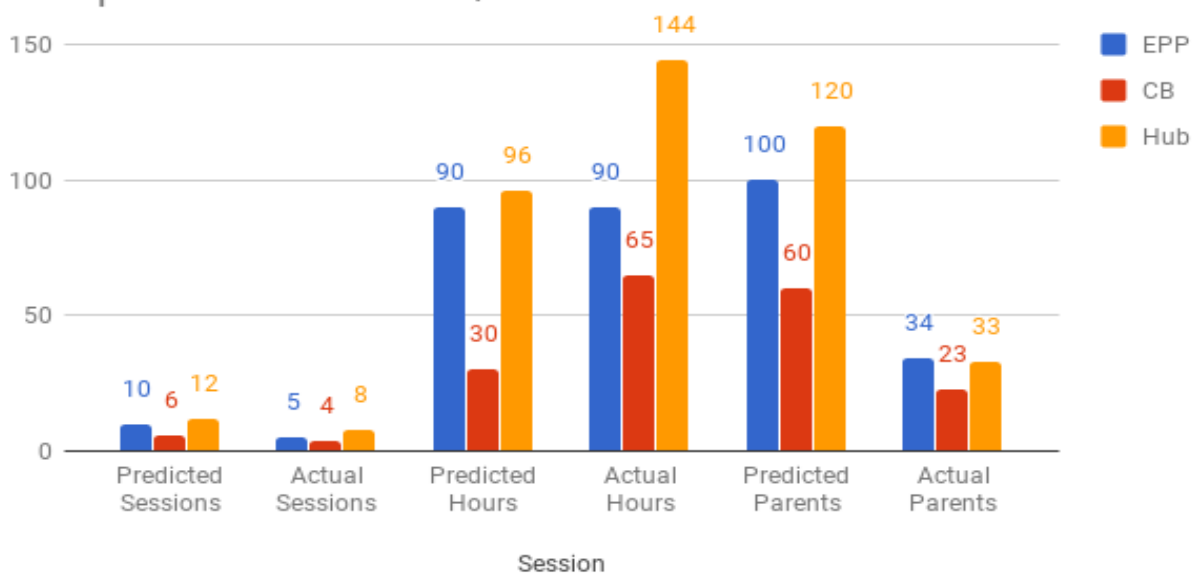


Fig. 7 Comparison of predicted and actual attendance, number of sessions and hours worked

The above chart shows a comparison of the different elements of the work overall. The amount of sessions/ number of parents overall was lower than predicted but the number of hours to deliver the work was higher. Some sessions were not delivered due to timing (coinciding with school holidays) and partner agencies being unavailable. The number of sessions being decreased also meant less parent carers took part. There is also an element of parent carers dropping out after booking on.

Expert Parent Programme

EPP Attendance Data

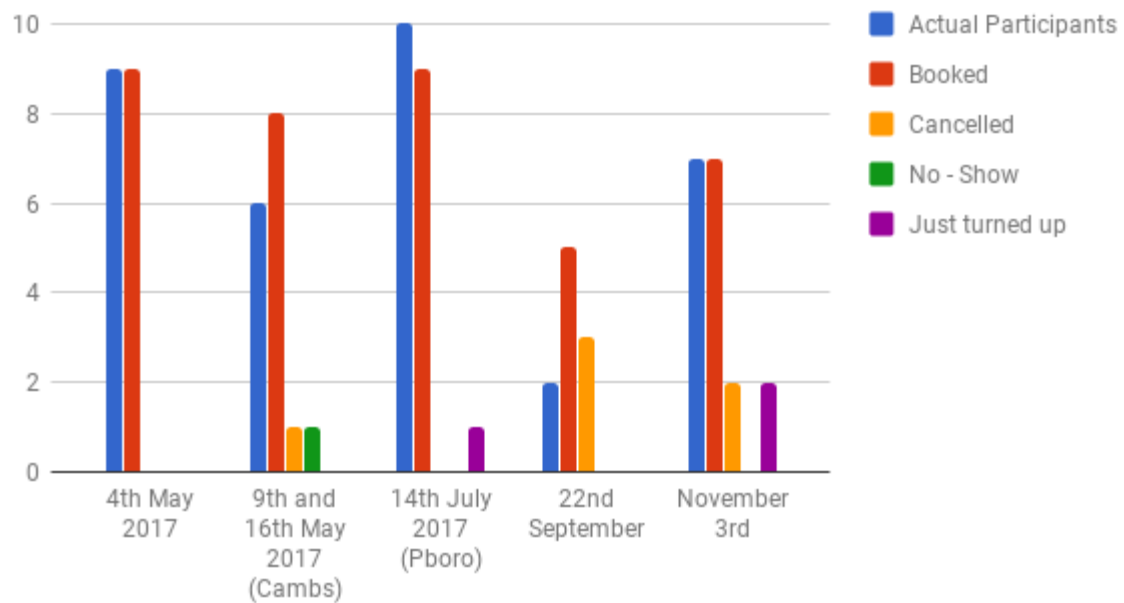


Fig. 8 Booking and attendance data for the Expert Parent Programme

Predicted Participants and Actual Participants

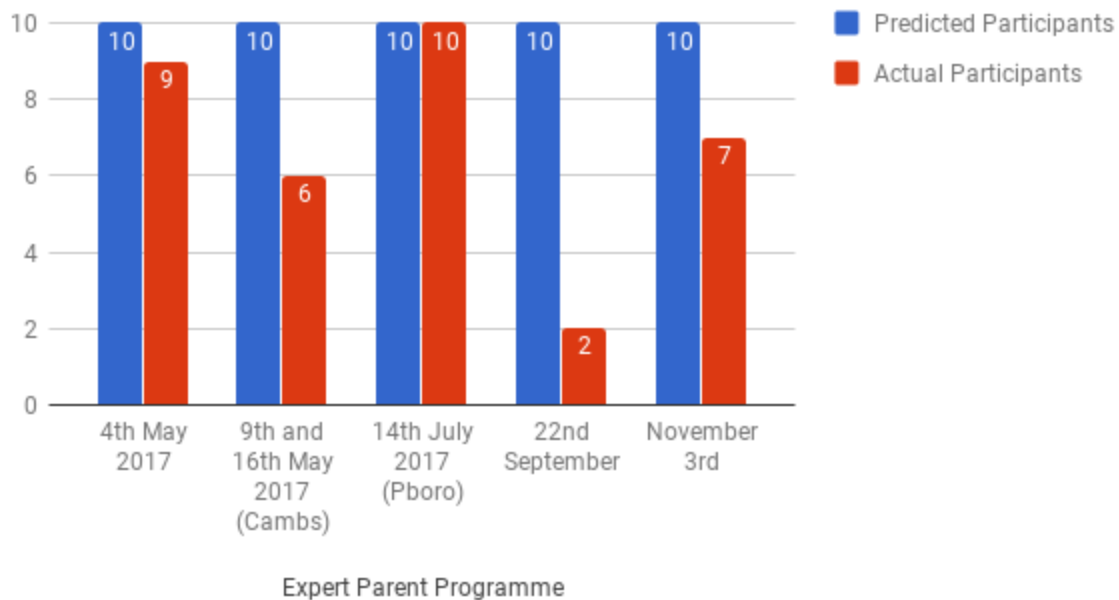


Fig. 9 Number of predicted and actual attendees across each delivered session of the Expert Parent Programme

Overall Expert Parent Programme Attendance Details

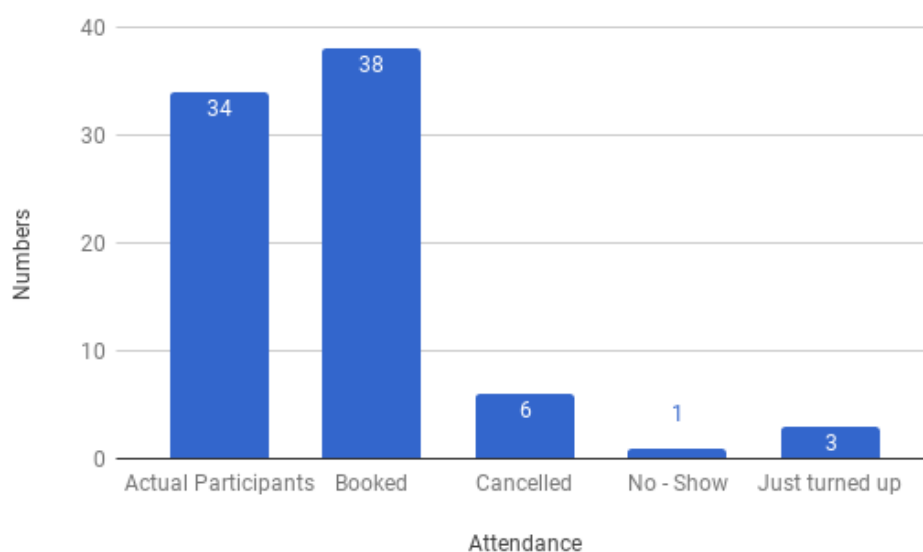


Fig. 10 overall booking and attendance details for the Expert Parent Programme 2017 to 2018

Figures 8, 9 and 10 show the predicted and actual attendance for the EPP sessions that were delivered. The predicted data is for how many parents it was felt would attend each individual session. Overall 68% attendance of the predicted amount occurred. The most well attended EPP was in July and least well attended was in September. Going forwards the timing of sessions will be looked at.

A total of 34 individual parent carers attended the EPP five sessions.

Workshops

Challenging Behaviour Workshop Booking Data

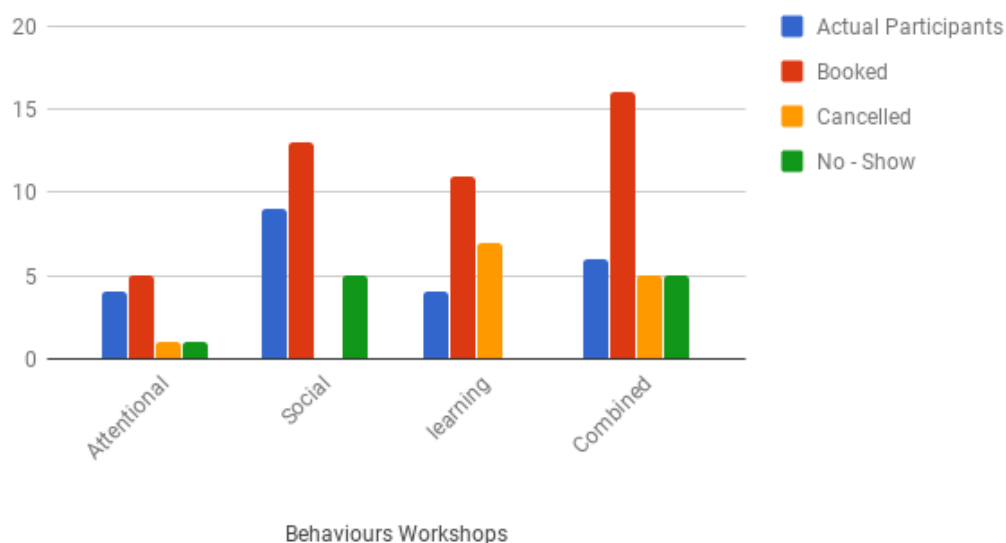


Fig. 11 Booking and attendance data across the individual challenging behaviours workshops

Overall CB Workshop Attendance Details

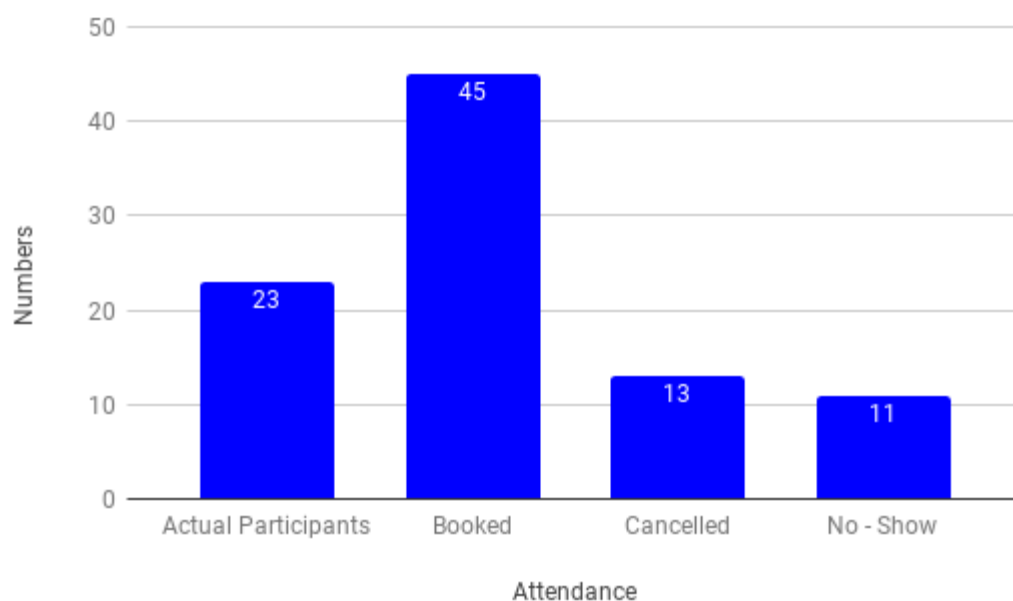


Fig. 12 overall booking and attendance details for challenging behaviours workshops 2017 to 2018

Attendance Across Workshop Topics

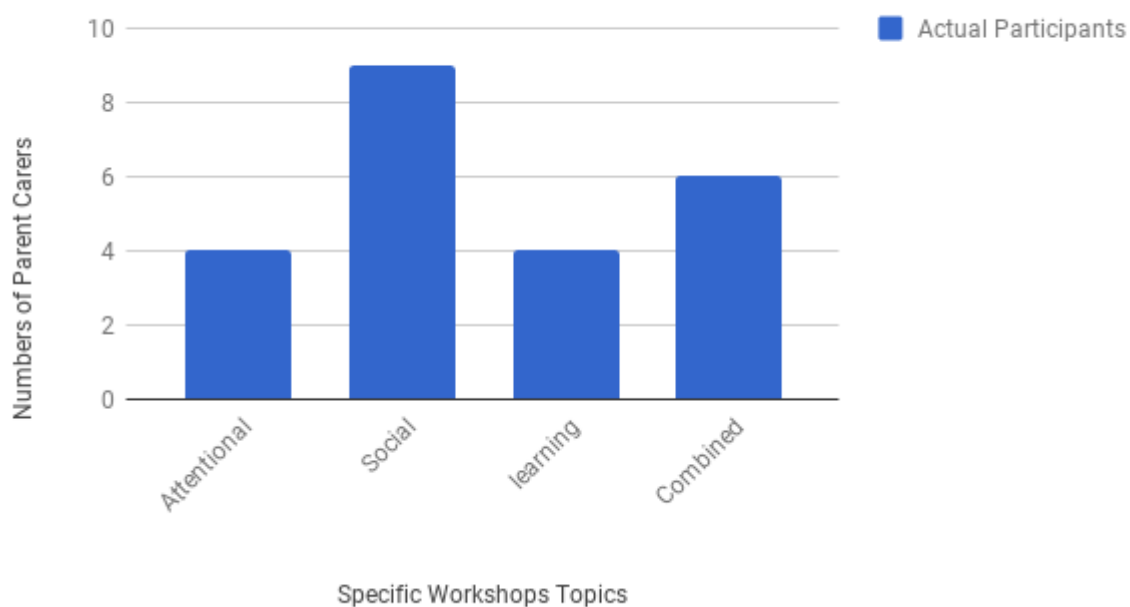


Fig. 13 Number of parent carers across the specific challenging behaviour workshops

CB Workshop Predicted Participants and Actual Participants



Fig. 14 Number of predicted and actual attendees across each challenging behaviour workshop

The charts in figures 11 through to 14 demonstrate the predicted and actual attendance across the CB workshops. 51.15% of the predicted attendees actually attended. The most popular workshop was the social communication one followed by the combined session. There were a higher number of cancellations and no shows for the CB workshops compared to the EPP ones. A total of 23 parent carers attended the four sessions.

Hubs

Hub Booking and Attendance Data

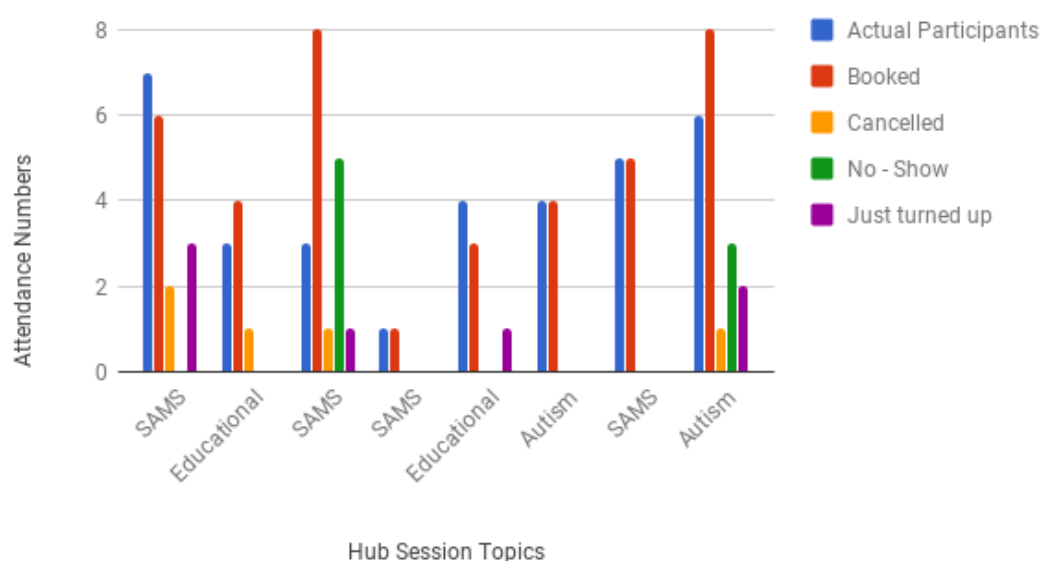


Fig. 15 Booking and attendance data across the individual Hubs

Attendance Across Themed Hub Sessions

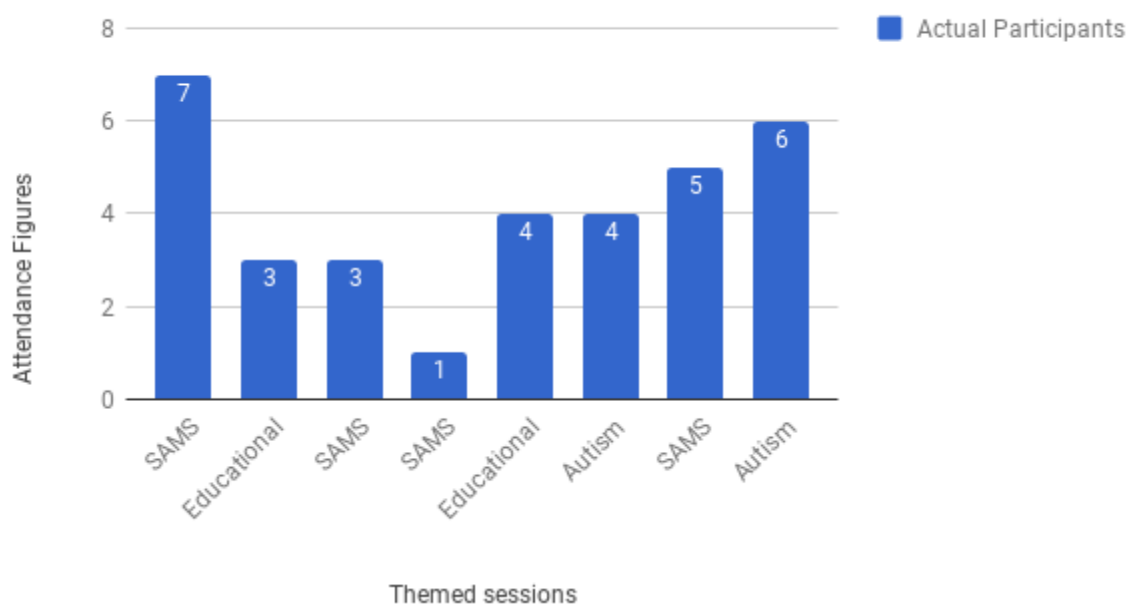


Fig. 16 Number of parent carers across the specific Hubs

Hub Predicted and Actual Attendance

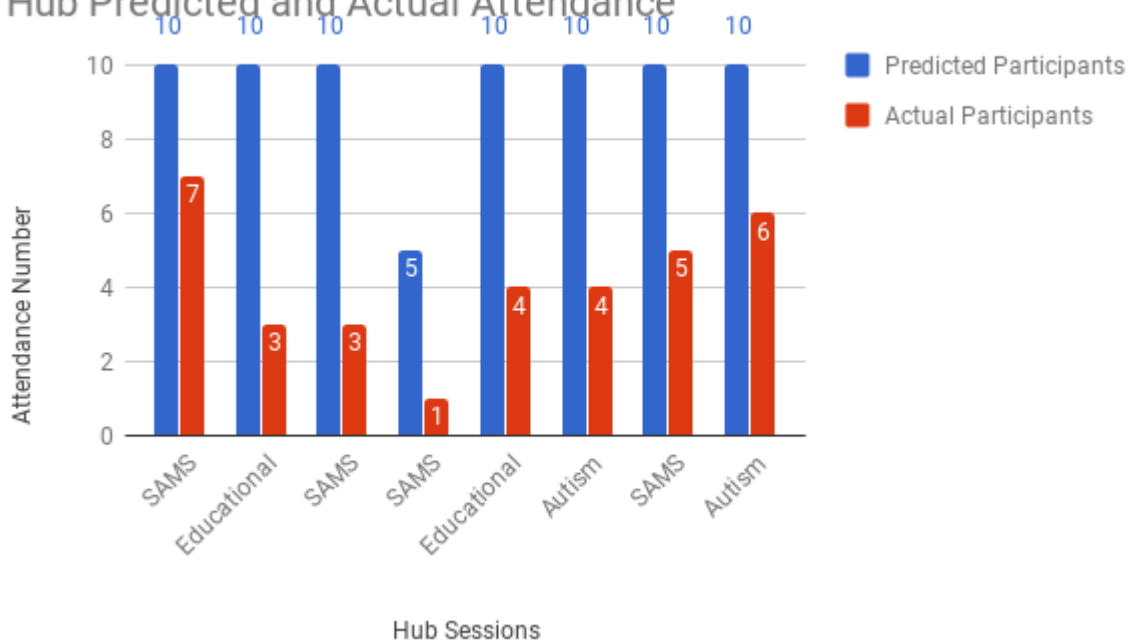


Fig. 17 Number of predicted and actual attendees across each Hub

The charts in figures 15 through 17 show the booking and attendance data for the parent carer Hub between April 2017 and March 2018. The most popular sessions across this period were the SAM's team and ASD/ ADHD sessions.

Overall CAMHs Session

Overall Booking and Attendance Figures for CAMHs Funded Work

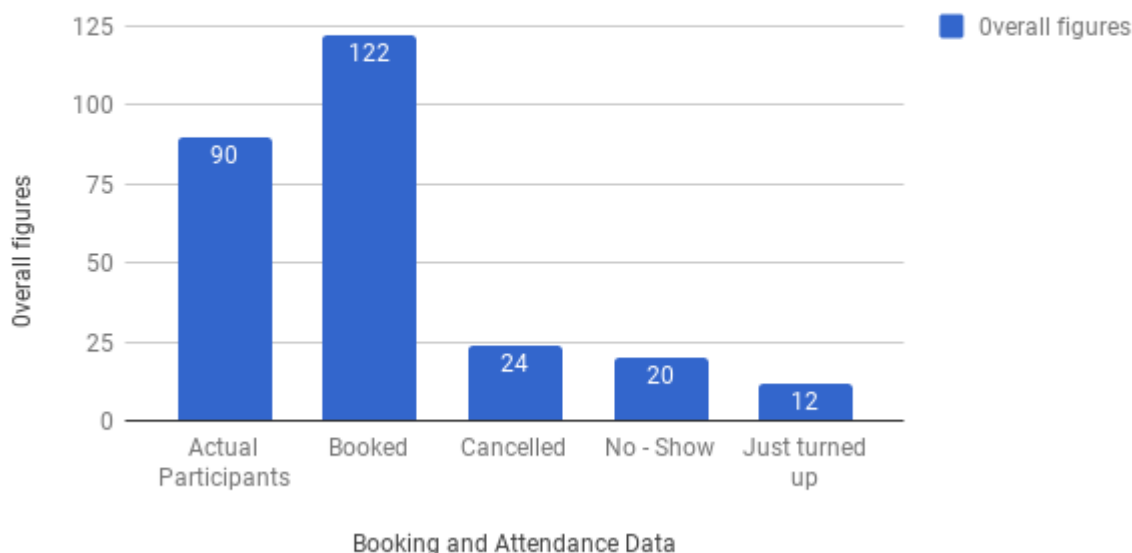


Fig. 18 over all booking and attendance across all of the work relating to CAMHs delivered by FVP

overall percentage of attendance	73.77%
percentage of cancellations	19.67%
percentage of no-shows	16.39%
percentage of cancellations and no-shows combined	36.07%

Fig. 19 percentages overall of attendance against bookings

The chart and table above in figures 18 and 19 showing the overall booking and attendance data from the EPP, CB Workshops and Hub demonstrate an overall non-attendance rate of approx. 36%. The percentage of parents who booked and then just didn't show up was 16.39% which is costly to the project in terms of trainer/ admin time.

Workshop/ EPP/ HUB Feedback

The following data relates to feedback gained from those who attended the various sessions. The numbers do not match precisely the attendance as not all those who attended completed feedback forms. The feedback provided does however present a picture of issues affecting parent carers and the effectiveness of the sessions being provided.

Self Rating Against Set Statements

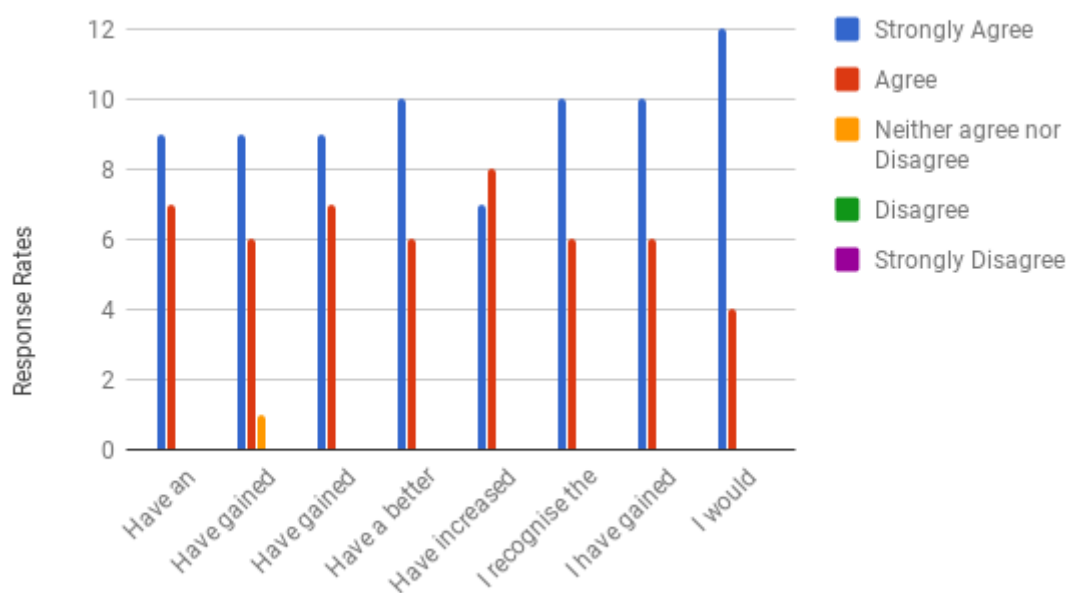


Fig. 20 Collated feedback from the EPP sessions

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

Fig. 21 feedback form statements

For part of the feedback gathered after the EPP attendees are asked to self-rate against a series of statements and expand on their answers as shown in figures 20 and 21. Overall attendees said they agreed/ strongly agreed with the statements and overwhelmingly said they would recommend the training to other parents. Not all attendees completed forms or all sections of the forms.

Part of the feedback also asked attendees to provide comments under set headings. HEAD: Something I've learned today, HEART: What worked well for me today, GAP: What didn't work so well for me, TAKE AWAY: Something I will do as a result of today's session, ADDITIONAL COMMENTS.

HEAD	HEART	GAP	TAKE AWAY
How I can better help my son in the future with his rights and to get the support he needs	Preparing for meetings/Sandwich	Realising how little I have achieved so far!	I will take a completely new approach to future meetings with more knowledge and information

ADDITIONAL COMMENTS
This program should be offered as a matter of course to all parents post-diagnosis I needed this info 6 years ago!

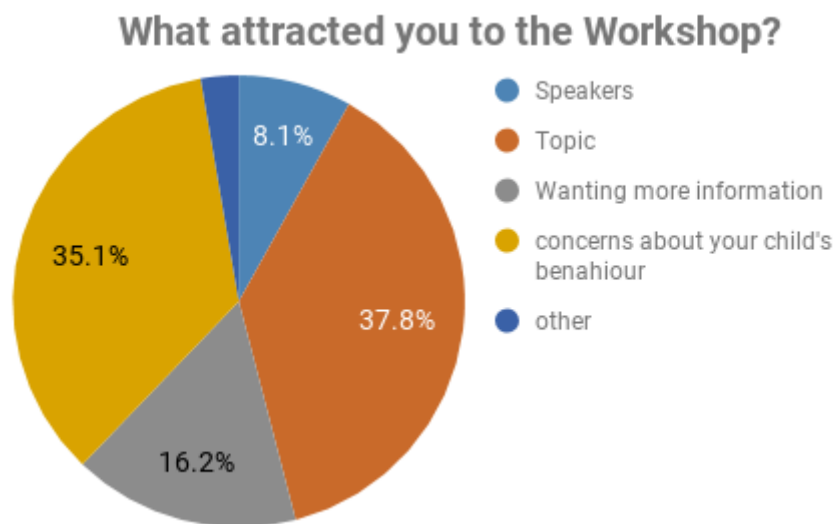


Fig. 22 what attracted parent carers to attend the workshops

When parents who attended the CB sessions were asked why they had attended the top responses were the topic and having concerns about their child's behaviour.

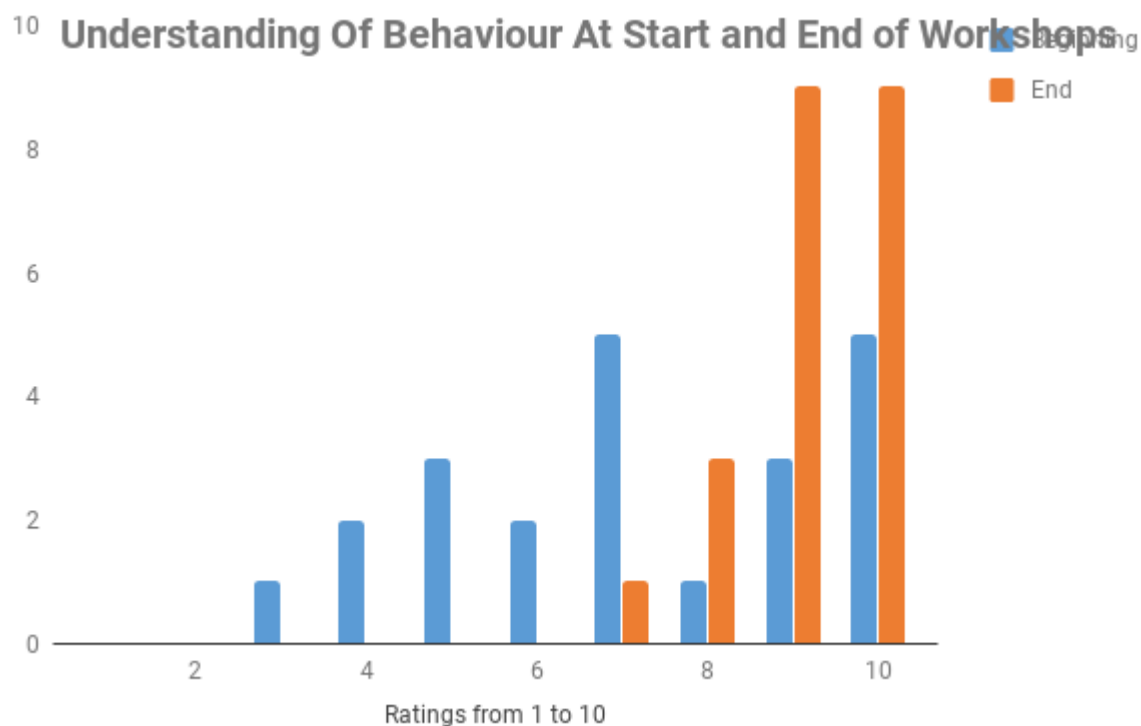


Fig. 23 Parents self-rated their understanding of their child's behaviour before and after the workshop

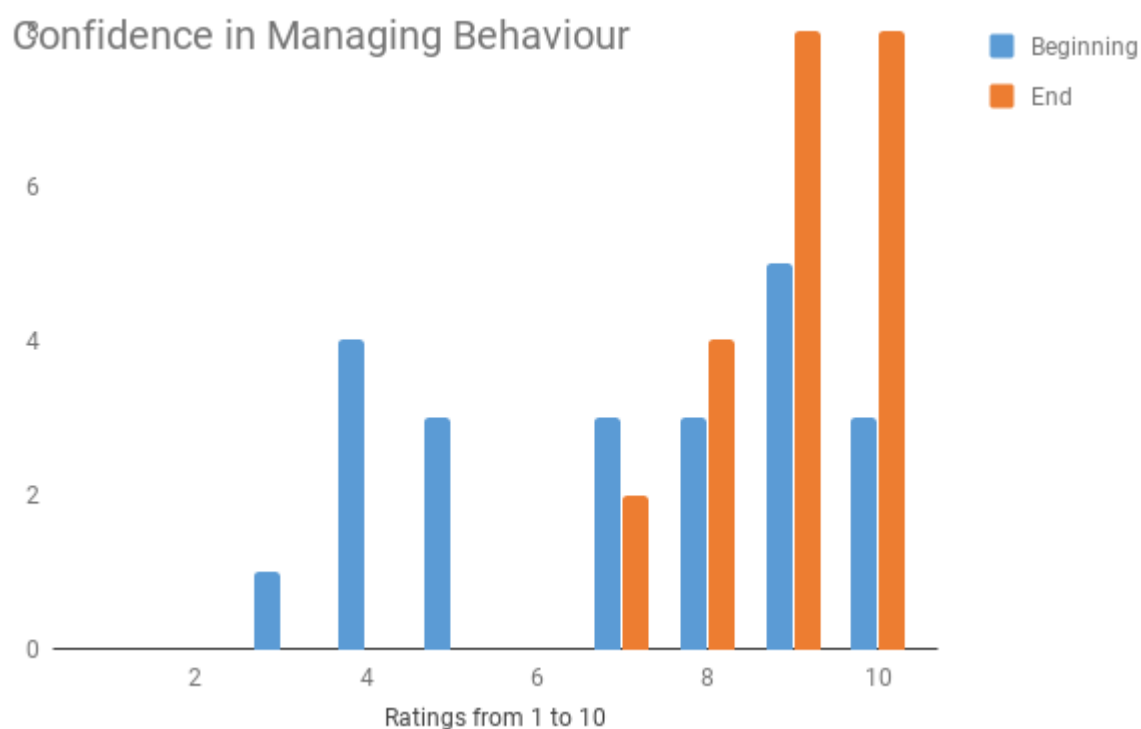


Fig. 24 Parents self-rated their confidence in managing their child's behaviour

The Charts in figures 23 and 24 demonstrate that attendees overall increased their ratings in terms of understanding what may lead to some behaviours and confidence in managing the behaviours.

As with the EPP feedback was taken under a series of headings whereby attendees could provide comments; Which parts of the focus group did you find most useful and why?, Which parts of the focus group did you find least useful and why?, How will this workshop help you as a parent/professional?

Most Useful

All of it strategies very practical and could make all the difference of it strategies very practical and could make all the difference

Least Useful

None all good

How will this help you?

To identify my son's difficulties more easily and provide support

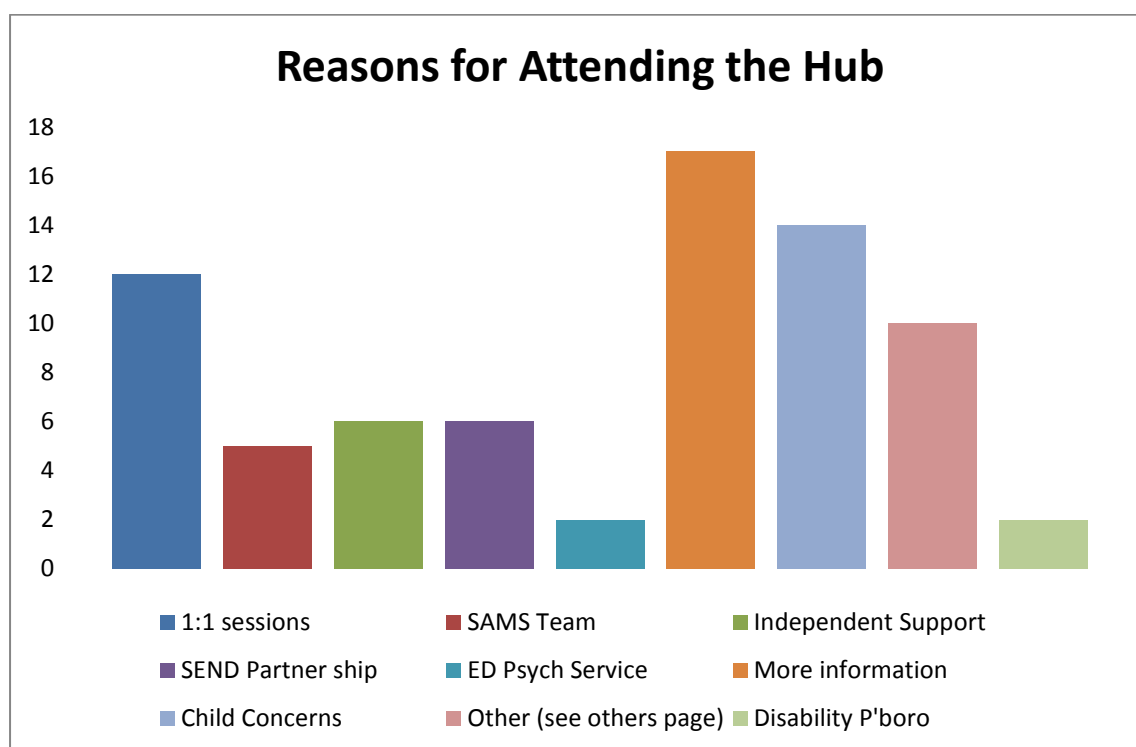


Fig. 25 what attracted parent carers to attend the Hubs

As with feedback from the EPP and CB workshops attendees were asked why they had wanted to attend the HUB and one of the top answers was concerns about their child.

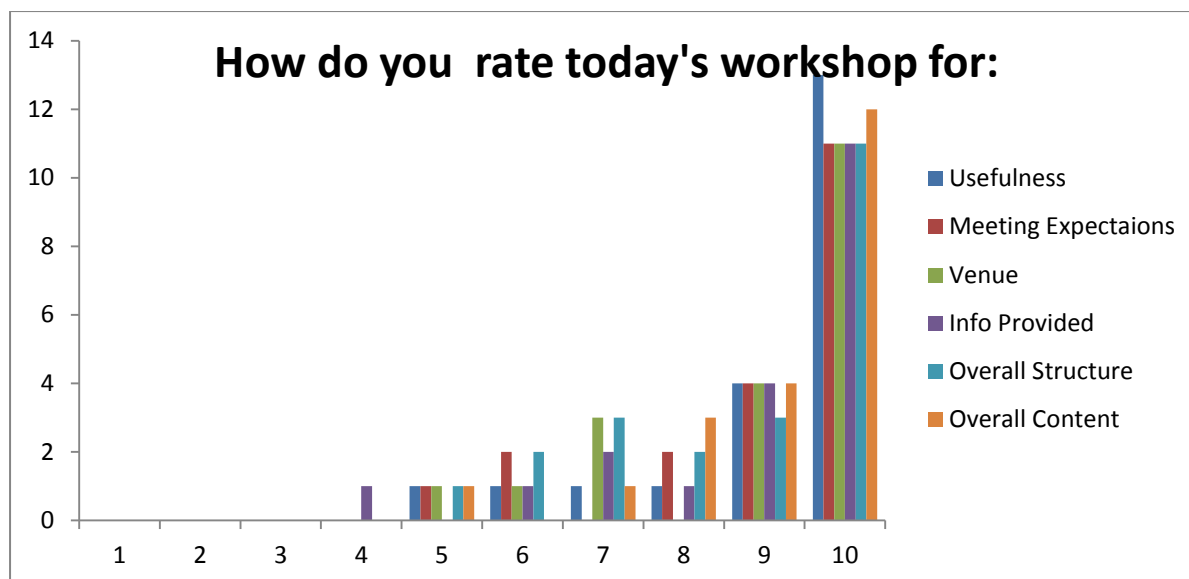


Fig. 26 Overall ratings of the Hubs

Generally from the feedback forms that were completed it would appear looking at the above figure that most of the feedback was positive with high ratings for overall content and overall structure.

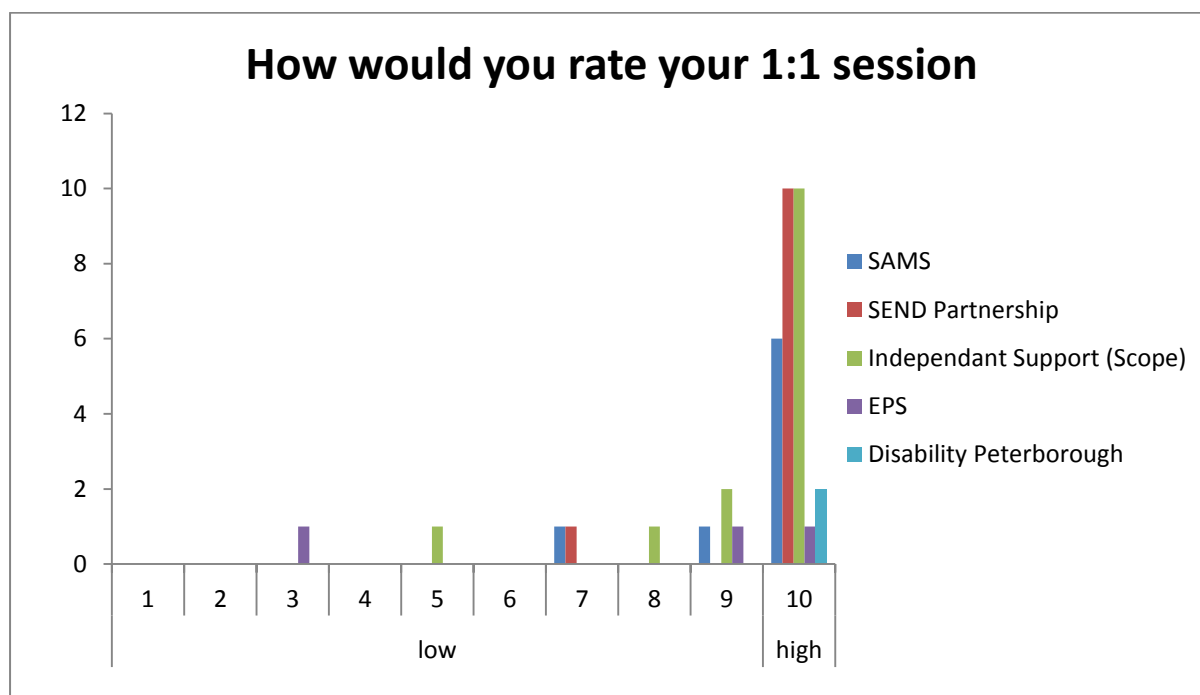


Fig. 27 Overall ratings for the 1:1 sessions

Having time with either IS or SEND Support was rated most highly demonstrating how parent carers value such direct support.

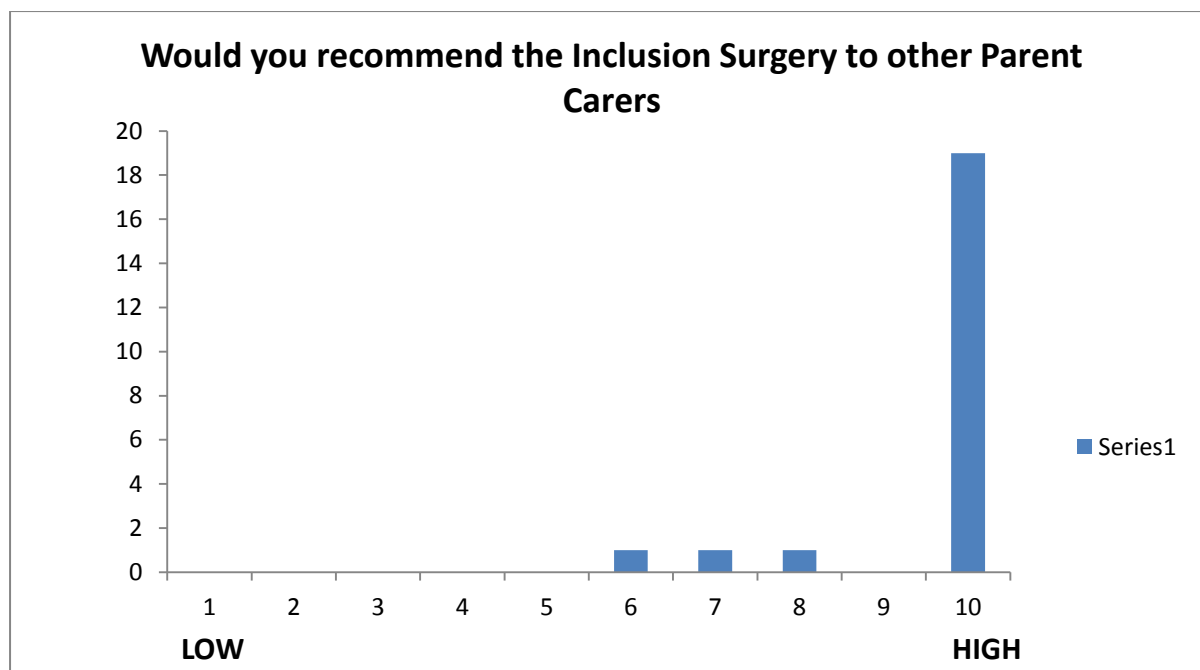


Fig. 28 rating as to whether the Hubs would be recommended

From the above figure it is clear that of those who completed feedback forms the majority rated very highly that they would recommend the Hubs.

As in all other feedback forms some open ended questions were asked; which parts of the Inclusion Surgery did you find most useful, and why? Which parts of the Inclusion Surgery did you find least useful and why? Could we have done better? Other comments, what attracted you to this workshop?

Most useful

Helping to prepare for meeting with Senco- things to ask, preparing for assessment to be sent off and helpful things I hadn't thought of

Least useful

Nothing ! Everything was brilliant

Done better

Longer Time

Comments

We are stuck in the EHC process. Questions between EHC and EHA

General Feedback (Early Help/ CAMHs)

Part of the work of FVP has been to also gather views and experiences of the changing way support relating Emotional Health and Wellbeing is being delivered. This fits with the participatory aims of the forum. Feedback was gathered at coffee sessions – where the theme was carer support and early help/ positive parenting:

Positive	Negative
I think it is a positive step. I am going in one in April after my 13 yo got his diagnosis. My 12yo had an EHA but has been labelled as just anxious by the phaycologist as she was unable to complete the ADOS due to her anxiety. We are not having a positive experience with her referral.	they are not good enough
Found the positive parenting course very helpful.	I didn't find the parenting courses helpful, partly as I knew some of it due to working in the childcare sector, also it did not cover the individual needs of my child.
Helpful in the right situation	still not changed my childs behaviours so still a concern
when our daughter was diagnosed at age 3 and half this was 5 years ago now but we found it helpful	Can be seen or viewed as degrading for parents especially if they have successfully brought up children without needs although since parents just haven't picked up this skills and need help from someone other than family.
Only helpful at ruling out bad behaviour as a cause to what's going on a with a child	It's too long period I started the process nearly 2 years ago and I have only now been given my app to go for feedback from asd assessments
Helps parents understand the system better, how they can get support for their child as early on as possible	I felt very judged when asked to attend the course it was hard as had to change both mine and my partners working hours for the course for 7 weeks and had to find child care for our other child. People were lovely and my child enjoyed it
I endorse it although we never need to do one as this is posterior to both my children diagnosis and assessment of need.	Waiting to hear for more than year do not know what we are waiting for
I think the early help pathway can be useful at times	I have a diagnosis for my younger child and attended Webster Stratton and triple p. Now my older child needs an assessment but even though I have attended the parenting courses I “have” to re do them even though they were recent in order to access help for my older child. This is, I feel not beneficial to me ha
They are brilliant!! Very informative and friendly	I opted to do triple p before EHP was created because I like training. However this way of

	doing things is very difficult for other parents who are carers for those who work. It also makes parents feel like professionals think their child's behaviour is their fault for not being a good enough parent
I think that parents need behaviour support and this is a good way of getting it	It would work for someone who hasn't got already diagnosed adult children.. but makes a mockery of those with children already diagnosed children where it is often runs in families.. just assess the child first and stop wasting valuable time these children don't have
Can be good for some but I have been there done that	Inadequate and not useful
I think it is a good idea but one course does not cover the wide range of different needs that these children have. One size doesn't fit all therefore can leave a large amount of parents no better off than before they started.	I personally don't see why parents who have other children need to do a parenting course it just makes them feel inadequate as a parent I think that's wrong.
I didn't find it specific enough to my son's needs. I think it would help a child without additional needs but for my ASD child it didn't help.	If a child already has a diagnosis or has a clear problem (like being very late talking) the support should be available instead of waiting for months and months to access this support.

Fig. 29 Feedback from coffee mornings

The responses have been split roughly in to “positive” and “negative” and this shows views are fairly evenly split.

Some surveys have also been conducted and of those:

One question asked parent carers what the Early Help Pathway is and the following responses were gathered from 55 parents. The responses can be split into “positive/ some understanding” and “negative/ misunderstanding”.

This was the initial form we filled in at school that started the ball rolling	Too long winded and complex
The beginning /is the way into getting help for children with Needs or Behavioural issues designed to separate out those with a defined SN and simply misbehaving children or parents who struggle to maintain parental authority	Takes too long and if you work full time parent courses are impossible to complete
What was previously the CAF referral - a referral pathway to access health services.	Very long winded service
Replacement of CAF and could be put in place for various reasons in closing social care needs, behavioural, family situations and could be used for first steps for diagnosis etc	For those who need support but don't meet social care threshold
For those undergoing assessments or newly	First step for provision in School

diagnosed	
Nursery helped with the application, it got the ball rolling	
They observe and put on pathway if needed	To refer to other services? Although it didn't work for us, our GP helped us.
the earlier of your child been diagnosed the better	The route which has to be taken in order to get ANY support or assessments for your child in relation to their additional needs which also wastes a lot of time
The beginning of where the assessments begin	A Course on how to support your child when your getting a diagnosis.
Gets you started towards a diagnosis	
Early intervention x 2	
Put support in place early on	
it is the pathway followed by the child to have their needs identified, health, educational or care.	
Helping identify whether your child has additional needs, and help to access the services needed	
5+ referral route for ASD/adhd Assessment team that holistically looks at the needs of a young child	

Fig. 30 Responses to Early Help Pathway question from SEND and Parent Carer Survey

19 parents also responded with “don’t know”. One other question asked parents about their experiences of the pathway.

I do not know what the Early Help Pathway is
I have not heard of the Early Help Pathway
I have had an Early Help Assessment
I am in the process of having an Early Help Assessment
I have been asked to attend a positive parenting course as part of my Early Help Assessment
I attended a positive parenting course as part of my Early Help Assessment
My Child/ young person was referred for an ASD/ ADHD after my Early Help Assessment
I was referred for an Early help Assessment even though my child/ young person already has a diagnosis of ASD/ ADHD
I have been asked to attend a positive parent course even though my child/ young person has a diagnosis of ASD/ ADHD
My Child/ Young Person has been referred to CAMHs and I been asked to take a positive parenting course before they will be seen.
I would like to attend a positive parenting course but do not know what I need to do
I followed the early Help Pathway and my child/ young person now has a diagnosis of ASD/ ADHD
Not Applicable
Other (please specify)

Fig. 31 Response to question asking parent carers to describe their experiences of the pathway

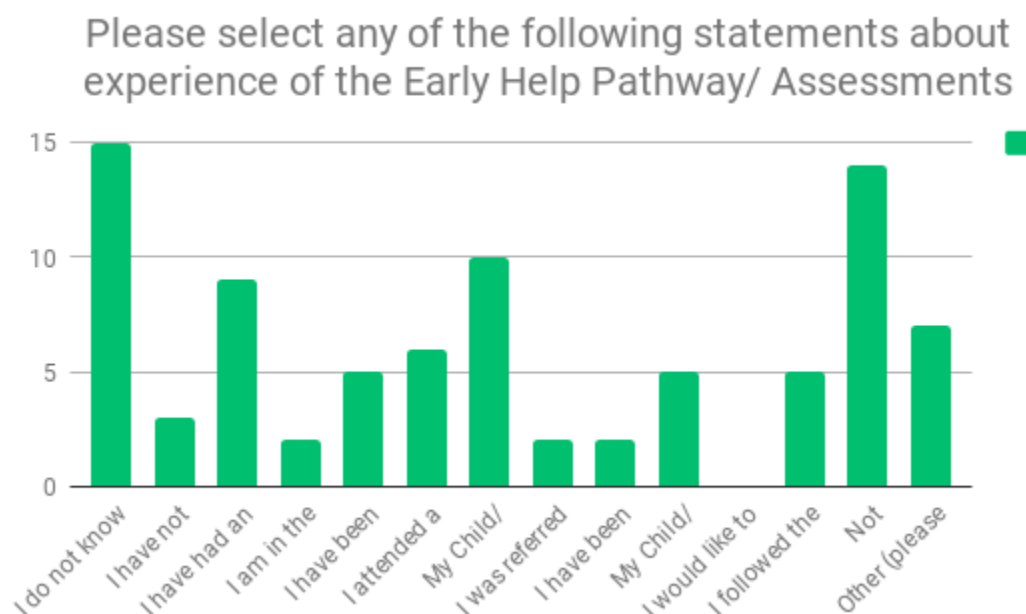


Fig. 32 Response rate of pre-selected statements relating to the Early Help Pathway

A high number of parent carers either selected the “don’t know” or “not applicable” options. Of the 54 who answered the question 15 chose an option relating to their experience. Of the 15 parents 5 selected the option referring to wanting to access CAMHs but being put on the pathway and 2 stated they already had a diagnosis for their child/ young person yet were still placed on the pathway.

A follow up question to this one asked about the positive parenting courses that are part of the pathway:

I have already attended a positive parenting course but I have been asked to attend another one
I have had a referral to CAMHs for my child/ young person turned down even though they have a diagnosis of ASD/ ADHD
My child/ young person already has a diagnosis of ASD/ ADHD yet I have been asked to attend a positive parenting course and I have already attended Cygnets/ APEG
I attended a positive parenting course and found it helpful
I attended a positive parenting course and it has not helped
I have not attended a positive parenting course as this does not apply to me/ my family

Fig. 33 Statements from parent carers relating to the Positive Parenting Courses

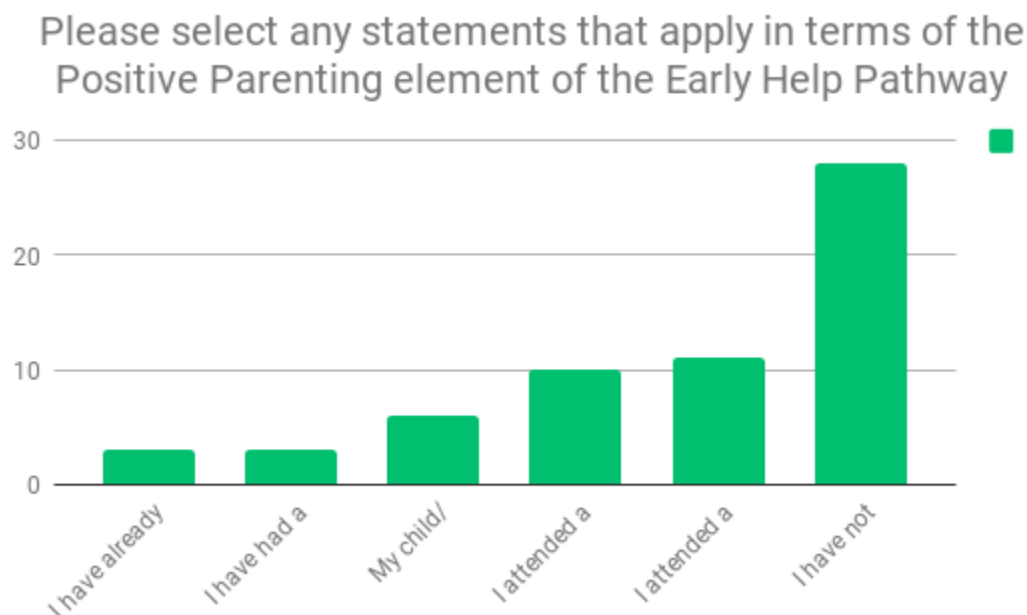


Fig. 34 Response rate of pre-defined statements relating to the Positive Parenting Courses

Again a higher proportion had not heard of the courses and of those who answered the question 26 had some experience. Of the 26 38.46% found the courses helpful and 42.31% did not. Also as with the previous question 6 parents stated their child/ young person already had a diagnosis and they were still asked to attend a course and 3 parent carers who wanted a referral to CAMHs were turned away despite their child/ young person already having a diagnosis.

One final survey question asked parent carers to say what they thought about the Early Help/ Positive Parenting work; 37 parents responded to this question:

"I think it is a positive step. I am going in one in April after my 13 yo got his diagnosis.	They are not good enough
My son is older so this would not help us now. Attended early bird, early bird plus and cygnets when he was younger.	My 12yo had an EHA but has been labelled as just anxious by the phaycologist as she was unable to complete the ADOS due to her anxiety. We are not having a positive experience with her referral."
Found the positive parenting course very helpful.	I didn't find the parenting courses helpful, partly as I knew some of it due to working in the childcare sector, also it did not cover the individual needs of my child.
Can be good for some but I have been there done that	still not changed my childs behaviours so still a concern
	"Can be seen or viewed as degrading for parents especially if they have successfully brought up children without needs. Although since parents just haven't picked up this skills and need help from someone other than family. "

	It's too long period I started the process nearly 2 years ago and I have only now been given my app to go for feedback from asd assessments
I have been on the cygnet course but have no idea what the positive parenting course is	I felt very judged when asked to attend the course it was hard as had to change both mine and my partners working hours for the course for 7 weeks and had to find child care for our other child. People were lovely and my child enjoyed it
Helpful in the right situation	Only helpful at ruling out bad behaviour as a cause to what's going on with a child
Helps parents understand the system better, how they can get support for their child as early on as possible	Waiting to hear for more than year do not know what we are waiting for
I think the early help pathway can be useful at times	I opted to do triple p before EHP was created because I like training. However this way of doing things is very difficult for other parents who are carers for those who work. It also makes parents feel like professionals think their child's behaviour is their fault for not being a good enough parent
They are brilliant!! Very informative and friendly	It would work for someone who hasn't got already diagnosed adult children.. but makes a mockery of those with children already diagnosed children where it often runs in families.. just assess the child first and stop wasting valuable time these children don't have
I endorse it although we never need to do one as this is posterior to both my children diagnosis and assessment of need.	I personally don't see why parents who have other children need to do a parenting course it just makes them feel inadequate as a parent I think that's wrong.
I think that parents need behaviour support and this is a good way of getting it	If a child already has a diagnosis or has a clear problem (like being very late talking) the support should be available instead of waiting for months and months to access this support.
Good	I didn't find it specific enough to my son's needs. I think it would help a child without additional needs but for my ASD child it didn't help.
	I have a diagnosis for my younger child and attended Webster Stratton and triple p. Now my older child needs an assessment but even though I have attended the parenting courses I "have" to re-do them even though they were recent in order to access help for my older child. This is, I feel not beneficial to me having done them and also for the parents who need to access them who don't have the support or benefit of prior experiences

Fig. 35 Parent carer statements (positive and negative) relating to the Early Help Pathway and Parenting Courses

Pinpoint

Background

Pinpoint Cambridgeshire has continued to run the ADHD / ASD parent groups following a successful pilot from December 2015 – May 2016. This report covers the groups from April 2017 to the end of March 2018. No groups were run during school holidays in August. 3 out of 4 groups ran in April and 1 out of 4 ran in December averaging 10 per area per year.

Delivery of Parent Groups

On average four groups have been successfully running per month over this period. Each group runs for two hours, usually with a speaker and plenty of time for parents to talk and share ideas between themselves. 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 at the groups 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 sometimes we pay speaker costs and / or their travel expenses.

Topic and Location

The following tables show each group by area, the speaker / topic, number and type of parents that attended. 366 parents attended across the four groups over the ten sessions. 145 of the 366 were unique attenders (40%). 61% of attendees booked first before attending. There were 39% of parents who booked but then did not attend. 70% of the parents said their child(ren) with special needs are boys with 1 instance of a parent attending with a transgender child. 56% of the children are between 5-10 years old, 36% between 11-15 years old and 8% under 5s.

Peterborough							
Date	Speaker	Total Parents	Unique Attendan ce	More than one attendanc	Booked and attended	No Shows	Drop Ins
April	No Meeting	0	0	0	0	0	0
May	Little Miracles	10	3	7	4	3	6
June	Think Autism	6	0	6	6	2	0
July	EP CCC	3	1	2	3	2	0
Sep	Contact, Parent advisor	4	2	2	3	3	1
Oct	Occupational Therapist	7	4	3	4	0	3
Nov	Communication Cambridge, SALT	4	1	3	1	2	2
Dec	Send partnership officer, PCC	5	5	0	1	11	4
Jan	Scope, independent supporters	6	4	2	2	1	4
Feb	Contact, Parent advisor	0	0	0	0	0	0
Mar	Family worker, ADHD	3	2	1	2	1	1
Total		48	22	26	26	25	21

Fig. 36 overall data relating to attendance at Pinpoint Session in Peterborough

Histon							
Date	Speaker	Total Parents	Unique Attendance	More than one attendance	Booked and attended	No Shows	Drop Ins
April	Medication CPFT	11	0	11	10	1	1
May	NAS/Romsey Mill/Core Assets	9	4	5	5	3	4
June	Think Autism	8	2	6	3	2	5
July	Independent Supporter, Core Assets	8	3	5	4	4	4
Sep	Communication Cambridge, SALT	24	10	14	18	2	6
Oct	Educational Psychologist CCC	17	5	2	10	2	7
Nov	Occupational Therapist	18	6	7	9	0	9
Dec	No meeting	0	0	0	0	0	0
Jan	Independent Supporter, Core Assets	10	3	2	8	2	2
Feb	Contact, Parent advisor	9	5	4	6	2	3
Mar	SENDIASS	12	0	12	8	6	4
Total		126	38	68	81	24	45

Fig. 37 overall data relating to attendance at Pinpoint Session in Histon

Ely							
Date	Speaker	Total Parents	Unique Attendance	More than one attendance	Booked and attended	No Shows	Drop Ins
April	Specialist Family Worker CCC	7	6	1	6	2	1
May	Think Autism	9	2	7	5	0	4
June	The Owl Therapy Centre	10	3	7	6	1	4
July	OT Sensory Workshop	14	7	7	10	2	4
Sep	Educational Psychologist CCC	29	13	16	11	8	18
Oct	Communication Cambridge, SALT	17	5	12	9	5	8
Nov	Occupational Therapist	12	3	9	8	3	4
Dec	No Meeting	0	0	0	0	0	0
Jan	The K9 Project	12	5	7	11	4	1
Feb	SENDIASS	10	2	8	10	1	0
Mar	Contact, Parent advisor	11	6	5	7	1	4
Total		131	52	79	83	27	48

Fig. 38 overall data relating to attendance at Pinpoint Session in Ely

Huntingdon							
Date	Speaker	Total Parents	Unique Attendance	More than one attendance	Booked and attended	No Shows	Drop Ins
April	Independent supporter, Core Assets	5	1	4	2	1	3
May	Think Autism	5	1	4	5	0	0
June	Educational Psychologist CCC	8	0	8	5	0	3
July	Independent Supporter, Core Assets	4	3	1	2	0	2
Sep	Occupational Therapist	13	2	6	8	1	5
Oct	Communication Cambridge, SALT	3	1	2	3	2	0
Nov	Occupational Therapist	12	4	3	10	1	2
Dec	No Meeting	0	0	0	0	0	0
Jan	Independent supporter, Core Assets	1	0	1	0	0	1
Feb	SENDIASS	8	4	4	6	2	1
Mar	Independent Supporter, Core Assets. Original speaker cancelled at short notice.	2	2	0	0	0	0
Total		61	18	33	41	7	17

Fig. 39 overall data relating to attendance at Pinpoint Session in Huntingdon

Outcomes & Feedback

The success of the groups has been measured against the outcome objectives in Appendix 1. Appendix 2 illustrates the evaluation forms used for parents. Appendix 3 shows the evaluation form used for professionals from April to July 2017 and the following survey link has been used for professionals from September 2017

<https://www.surveymonkey.co.uk/r/FFWGPQR> Professionals are not always able to feedback quickly via survey monkey though so we intend to offer more paper based forms at the actual session in the future.

Parent Feedback:

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

Comments

- Very helpful Information and Support given. Thank you.
- Informed. Bit disheartened at times, but also good to hear of services.
- Great session - wish I'd had this years ago! Thankyou
- Fantastic wisdom and information
- Still have some confusion re diagnosis or not and how relevant this may be. Have recognised similarities from others' comments.
- Learnt new ideas/potential strategies/tools.
- So pleased I came, I will practise things I have learned
- (anxious) but still feel more confident in finding support
- Great to share insights and tactics to manage with others.
- light at the end of the tunnel, good practical advice. Helpful to hear from people with older ASD kids.
- Still not sure I can speak out to who I need easily.

The following charts show parents responses to the evaluation survey.

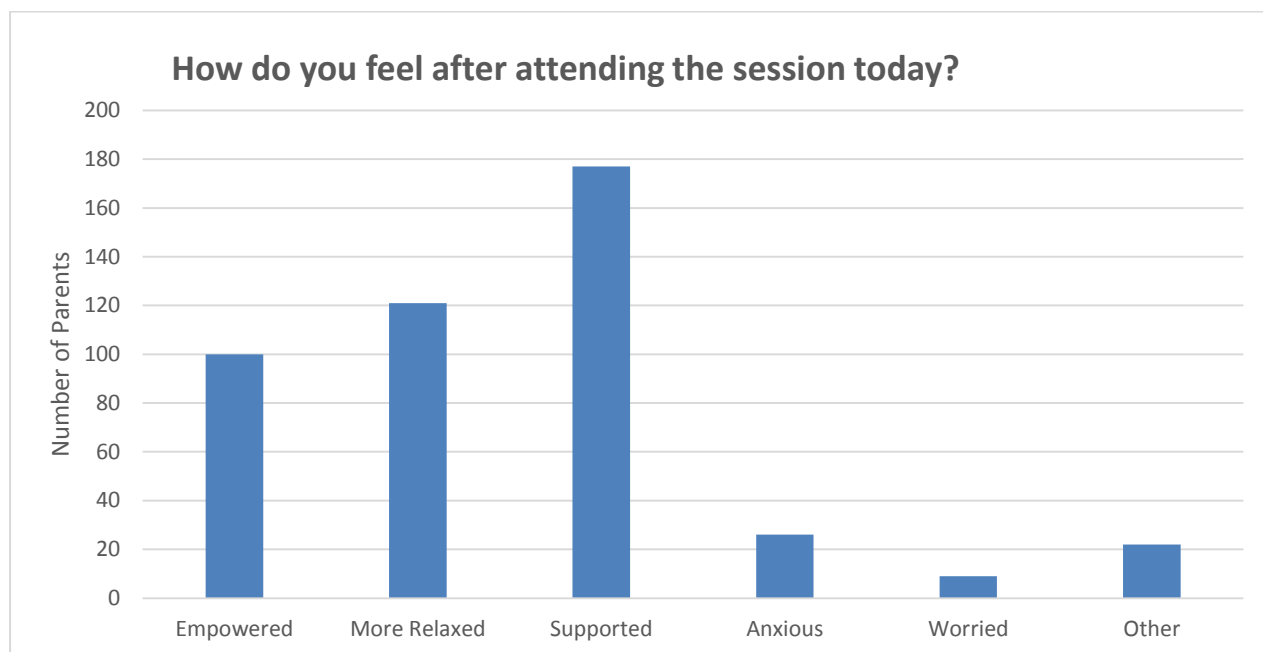


Fig. 40 overall evaluation of feeling as a result of attendance

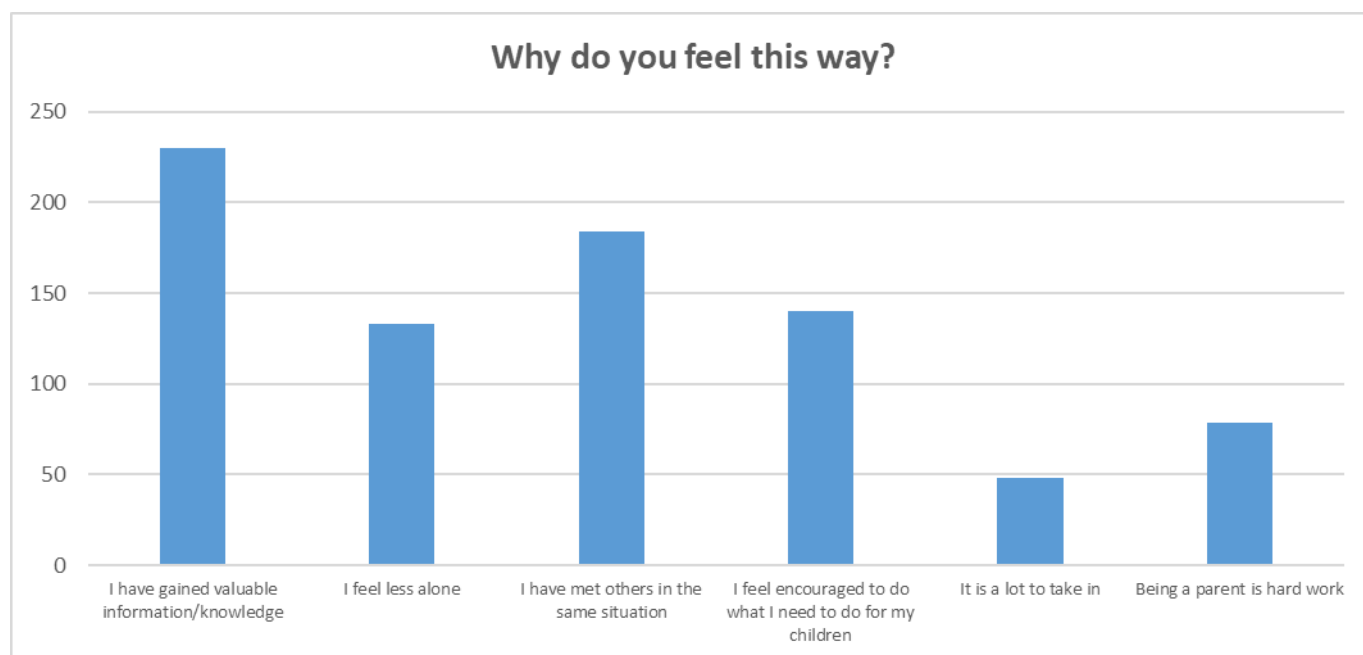


Fig. 41 overall evaluation of reasons for feelings

Both forms of feedback show positive and a small amount of negative outcomes from attending with parents feeling worried and anxious. This can be attributed to parents' realisations of their situation and that in most instances this is a life-long responsibility to care (Above and beyond what is considered 'normal') for their child.

However, 99% of parents felt that the groups met or exceeded their expectations.

Professional Feedback:

Professionals who attended the sessions as speakers were asked to rate the sessions according to the outcomes below (See Appendix 1). Comments include:

- Really great session, I feel it benefits parents as they can talk about their difficulties within a space that they are comfortable.
- I think that parents got a lot of benefit from it, as I could see them working out how to change their communication for their own child.
- Plenty of lightbulb moments and some good information sharing.
- A really interactive session, all parents seemed to gain a lot and I did too.
- I hope it was helpful for Parents. I felt as though the session in Peterborough brought about some very good and helpful questions. I also thought it was helpful to have an EP from both Peterborough and Cambs. I think the fact that the group was small was really helpful because we were able to give pretty much personal advice. The talk wasn't specifically about ADHD/ASD, more about ways of accessing support (either EP, EHCP or other referral routes – e.g. medical).
- It was really useful to meet with Eve and to be able to network and gain further knowledge of the work we could do alongside Pinpoint and hope that there will be opportunities for some joined up working.

They also rated how beneficial they thought each session was for parents, based on the outcomes mentioned previously in Appendix 1. The average rating was 4.5 on a scale of 0 to 5 with 5 being very beneficial to parents, based on the outcomes listed below. Professional speakers felt that the larger groups where there were between 15-20 parents were less beneficial than smaller groups. Some professionals felt it wasn't appropriate to rate the session they spoke at.

Financial Summary:

The pie chart below gives a breakdown of expenditures for the 4 groups from April 2017 – March 2018.

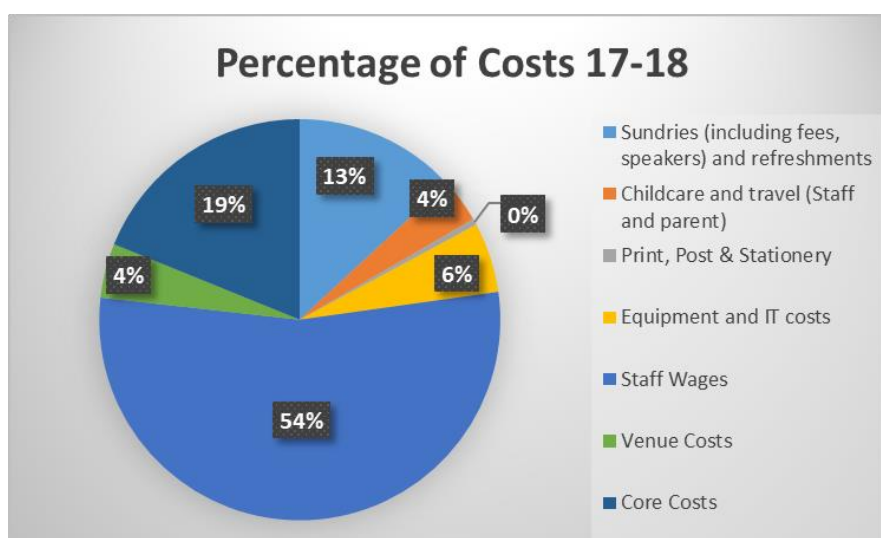


Fig. 42 Overall percentage of spending across predefined budget headings

Most expenditure is on core costs of running the organisation in order to deliver this service. A high proportion is also staffing costs which includes organising, promoting, facilitating and following up the groups.

A cost benefit analysis of the data we have shows:

- Cost per unique attender (parent attending for the first time) £118
- Cost per all parents attending £47
- Cost per employee hour £43

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 little pattern or consistency. The average number of parents attending is around 9 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 the future.

Appendix 1: Outcomes and Activities for Wellbeing Pathway – Pinpoint (in partnership with Family Voice Peterborough, PCC & CCG) – ADHD / ASD Support Groups (April 2017 to Dec 2017)

No	Outcome	Output / Activity	How Measured	Whose Responsible
1	<p>Parents and Carers are empowered to support one another through peer to peer support.</p> <p>Parent carers have a place to share experiences leading to increasing sense of confidence and shared experience</p>	<ul style="list-style-type: none"> Support groups are organised by Pinpoint (parent led) and attended by “professionals” who can provide hints/ tips/ signposting Monthly support groups over a year which have been appropriately advertised Access to the support groups is via self-referral with bookings taken by Pinpoint Appropriate supervision and support given to participation reps who attend groups/meetings Reasonable expenses are met to facilitate parents and carers to attend support – childcare, travel, etc. 	<p>Quarterly reporting detailing -</p> <ul style="list-style-type: none"> Numbers of parent carers attending support groups Evaluation of sessions Satisfaction rating Support groups run 4 x in a month during a 10 month period Feedback, evaluation from attending professionals 	Pinpoint
	<p>Parent quotes:</p> <p><i>‘Helpful to hear from people with older ASD kids’</i></p> <p><i>‘Great to share insights and tactics to manage with others’</i></p> <p>Statistics - of 366 parents that attended and completed</p>	<ul style="list-style-type: none"> Monthly groups organised in four areas with professionals attending each session Groups promoted by Facebook, e-newsletters, emails to service providers, Pinpoint and FVP websites Parent representative / volunteer supported to attend and help with each session Parent and childcare expenses reimbursement advertised and paid upon request 	<ul style="list-style-type: none"> 366 parents attended 4 groups over 10 months (no groups in August and split between April and December) From April 17 – March 18, 40% of parents attended for the first time Parents filled in evaluation forms at the end of each session 99% of parents reported that the groups met or exceeded their expectations Professionals rated the group 4.5 out of 5 on how beneficial they thought the sessions 	Pinpoint

	<p>evaluations, said: They felt supported 70% I feel less alone 53% I have met others in the same situation 73%</p>		were for parents	
2	<p>Parent carers experiencing difficulties gain an increase in understanding in parenting a child/ young person with additional needs</p>	<ul style="list-style-type: none"> Support groups are organised by Pinpoint (parent led) and attended by “professionals” who can provide hints/ tips/ signposting Monthly support groups over a year which have been appropriately advertised Access to the support groups is via self-referral with bookings taken by Pinpoint Appropriate supervision and support given to participation reps who attend groups/meetings Reasonable expenses are met to facilitate parents and carers to attend support – childcare travel, etc. 	<p>Quarterly reporting detailing -</p> <ul style="list-style-type: none"> Numbers of parent carers attending support groups Evaluation of sessions Satisfaction rating Support groups run 4 x in a month during a 10 month period Feedback, evaluation from attending professionals 	Pinpoint
	<p>Parent quotes: <i>‘Fantastic wisdom and information’</i> <i>‘Learnt new ideas/potential strategies/tools’</i> <i>‘So pleased I came, I will practise things I have learned’</i></p> <p>Statistics - of 366 parents that attended and completed evaluations, said:</p>	<ul style="list-style-type: none"> Monthly groups organised in four areas with professionals attending each session Groups promoted by Facebook, e-newsletters, emails to service providers, Pinpoint and FVP websites Parent representative / volunteer supported to attend and help with each session Parent and childcare expenses reimbursement advertised and paid upon request 	<ul style="list-style-type: none"> 366 parents attended 4 groups over 10 months (no groups in August and split between April and December) From April 17 – March 18, 40% of parents attended for the first time Parents filled in evaluation forms at the end of each session 99% of parents reported that the groups met or exceeded their expectation Professionals rated the group 4.5 out of 5 on how beneficial they thought the sessions were for parents 	Pinpoint

	<p>I have gained valuable information / knowledge 91%</p> <p>I feel encouraged to do what I need to do for my children 56%</p>			
3	<p>Parent carers have an increased confidence in supporting their Children, Young People and feel better able to manage family routines</p>	<ul style="list-style-type: none"> Support groups are organised by Pinpoint (parent led) and attended by “professionals” who can provide hints/ tips/ signposting Monthly support groups over a year which have been appropriately advertised Access to the support groups is via self-referral with bookings taken by Pinpoint Appropriate supervision and support given to participation reps who attend groups/meetings Reasonable expenses are met to facilitate parents and carers to attend support – childcare travel, etc. 	<p>Quarterly reporting detailing -</p> <ul style="list-style-type: none"> Numbers of parent carers attending support groups Evaluation of sessions Satisfaction rating Support groups run 4 x in a month during a 10 month period Feedback, evaluation from attending professionals 	Pinpoint
	<p>Parent quotes:</p> <p><i>‘Very helpful Information and Support given. Thank you’</i></p> <p><i>‘Great session - wish I'd had this years ago! Thankyou’</i></p> <p><i>‘Fantastic wisdom and information’</i></p> <p>Statistics - of 366</p>	<ul style="list-style-type: none"> Monthly groups organised in four areas with professionals attending each session Groups promoted by Facebook, e-newsletters, emails to service providers, Pinpoint and FVP websites Parent representative / volunteer supported to attend and help with each session Parent and childcare expenses reimbursement advertised and paid upon request 	<ul style="list-style-type: none"> 366 parents attended 4 groups over 10 months (no groups in August and split between April and December) From April 17 – March 18, 40% of parents attended for the first time Parents filled in evaluation forms at the end of each session 99% of parents reported that the groups met or exceeded their expectation Professionals rated the group 4.5 out of 5 on how beneficial they thought the sessions 	Pinpoint

	parents that attended and completed evaluations, said: Empowered 40% I feel encouraged to do what I need to do for my children 56%		were for parents	
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Fig. 43 Outcomes for Pinpoint element of CAMHs funding

ANALYSIS

As with the previous year's report this section has been based on parent carers experiences of the new and emerging Emotional Health and Wellbeing systems relating to SEND, as evidenced by Feedback from sessions, Surveys, and coffee mornings. The evidence is again both qualitative and quantitative. The evidence appears to demonstrate that:

1. There is misunderstanding of the pathway and also a lack of knowledge of what support is available. Also that the misunderstanding is from both parent carers and operationally within services. As evidenced by the number of parents whose children/ young people are already diagnosed still being placed on the Early Help Pathway. This also supports the view that the pathway is being seen as a barrier to support especially during the current economic climate.
2. There is some positive feedback from those who take part in the pathway support programme provide positive feedback, especially if they have then gone on to receive a diagnosis for their child/ young person.
3. There have been a number of non-attendances at sessions offered under the CAMHs funded work which has impacted on the overall delivery time and cost. This is something that needs some consideration going forwards. Overall though there has been an increase on numbers from the previous year from 67 to 90 parent carers equating to a 25.5% increase
4. The data gathered in terms of costs/ attendance/ outcomes is used to further inform commissioning relating to Emotional Mental Health and Wellbeing. The introduction of the Hubs this year has also facilitated an increase in support being offered to parent carers.

Overall experience is mixed with a growing number of negative 'stories' being discussed. This growth in discontent with the way services are being viewed and the idea that changes are designed to be a barrier to support have the potential to lead to families struggling further not less; the reforms were about making things better and placing the family at the heart of the system however this is not what families are reporting.

The Hub feedback has also shown how working differently with parent carers can provide support in a more economical way and there was a high level of feedback for having access to Independent Support and SEND Partnership.

SECTION TWO (SEND and Participation in Peterborough April 2017 to March 2018)

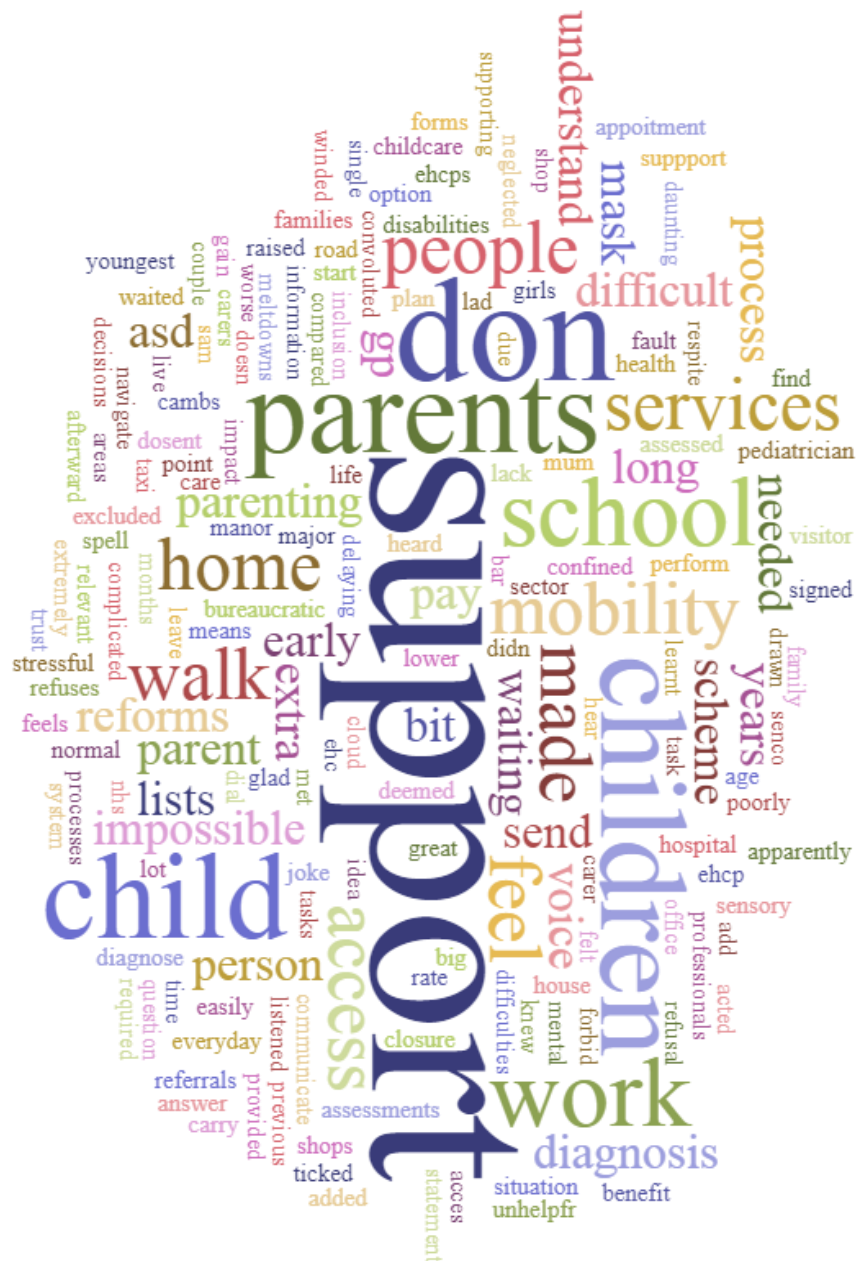


Fig. 1 Word cloud formed from feedback relating to parent carer support

Introduction

Two larger surveys were conducted to help inform this section of the overall report. The main topic in this section is SEND and Parent Participation. There is cross over with other sections with the two surveys that are presented here as they have also been used to inform other elements of the work conducted by FVP. There will also be a brief description of the other participation work of FVP detailing methods used, general attendance/ participation, preferred methods of participation and other relevant factors.

Project Running Costs

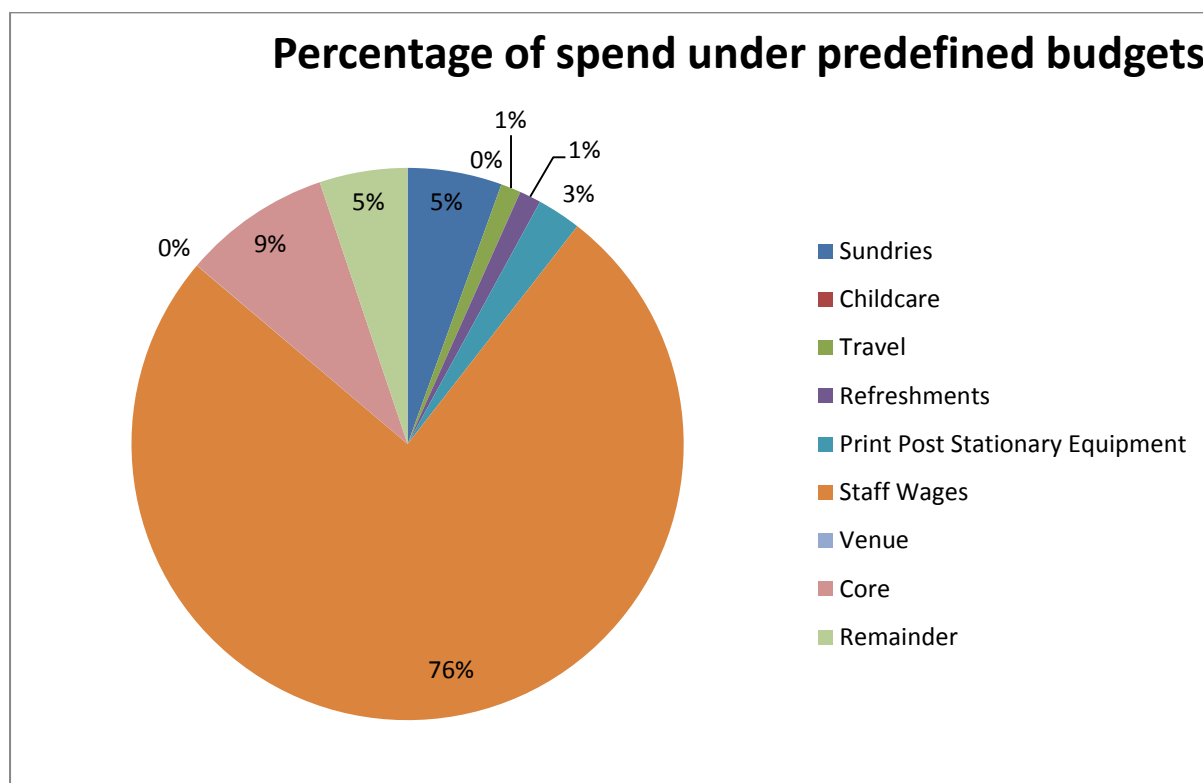


Fig. 2 Overall level of spend across predefined budget headings

The staffing spend for the project appears high, however the staffing has covered an increase in work and the staff members have worked many voluntary members in addition to any paid hours. The staffing also covers use of a consultant for HR/ Premises support and HMRC costs.

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 to embed co-production.	<ul style="list-style-type: none"> • Parent representatives are trained through the Family Voice parent participation training course • Reasonable expenses are met to facilitate parents and carers to attend meetings – childcare travel, etc • Appropriate supervision and support given to participation reps who attend groups/meetings • 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 	<ul style="list-style-type: none"> • Appropriate details of the parent reps given to facilitate planning and Local Authority organisation – scheduling meetings, etc, with acknowledgement of their training, skills, etc • Monthly highlight reports for each work stream, contributed to by the reps attending meetings • Annual report
		<ul style="list-style-type: none"> • There are currently two parent carers who act as reps only, one staff member who is also a parent rep and two trustees who act as parent reps. Some work has taken place to train new reps but due to personal circumstances they were only able to participate for a small amount of time. • A training course has taken place to enable partnership board leads understand what participation and representation is. 	<ul style="list-style-type: none"> • Parent reps complete online feedback reports after meetings and more in-depth reports after running focus groups etc.
2	Strategic representation on various boards including; LDPB, Carers, PDPB, Autism Partnership Board, SEND Transformation	<ul style="list-style-type: none"> • Attendance/representation at strategic meetings • Undertake the planning of workshops with parents, carers and professionals to increase awareness of the current position and next steps • Work alongside partners, including those 	<ul style="list-style-type: none"> • Named, trained, Family Voice trustees who may be attending meetings • Monthly highlight reports for each work stream, contributed to by the reps attending meetings • Annual report

	Board, leads to embedding of participation to promote inclusion across services relevant to children and young people with SEND	in the voluntary sector to share information and good practice	
		<ul style="list-style-type: none"> See section above, have also introduced more hub sessions with carers trust and PCC (SEND/ Inclusion Services) 	<ul style="list-style-type: none"> Various topic specific reports and parent rep meeting reports
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"> Attendance and representation at work stream and task and finish groups 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 services for CYP with SEND 	<ul style="list-style-type: none"> Named, trained, Family Voice trustees who may be attending meetings Monthly highlight reports for each work stream, contributed to by the reps attending meetings Annual report
		<ul style="list-style-type: none"> List of meetings attended in main body of report. Over 192 meetings attended equating to 1100 hours of work 	<ul style="list-style-type: none">
4	Parents and Carers are empowered engage with the Local Authority and their partners	<ul style="list-style-type: none"> Partnership approach through the steps described above, and the provision of themed focus groups – this may include task and finish groups, surveys and involvement through social media Be part of the feedback process for families, to facilitate the understanding of the effectiveness of participation 	<ul style="list-style-type: none"> Parents and carers report positive change in their communications with the Local Authority and their partners Case studies provided

5	Training and Development – an increase in knowledge and skills for local professionals in understanding the role of parent participation across the city	<ul style="list-style-type: none"> • Undertake the planning and delivery of themed workshops, facilitated by Family Voice reps, to raise awareness of parent participation 	<ul style="list-style-type: none"> • Number of workshops provided - target of 6 • Details of workshop content • Number of participants (and their position/post/role) – target of 12 per workshop • Participant feedback
		•	•

Fig. 3 Outcomes Matrix for SEND funding

Focus Groups

There have been 6 Focus groups covering the Local Offer, Complaints Exemplars, Out of Year Group Education and Transport. The focus groups have taken place between April 2017 and March 2018. 20 parent carers overall have attended the focus groups with some of the same parents attended more than one 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 the Complaints Exemplar Session. Full or brief reports have been produced for the focus groups with the information having been shared with commissioning to inform service development. The work has informed the Local Offer, Transport Application processes and Educating Out of Year Group G

On-line Surveys

8 surveys covering topics from Short breaks through to OFSTED readiness 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 277 responses across the surveys; it is not possible to determine the number of unique responders as many complete the surveys anonymously.

Survey Title	Number of complete responses	Number of incomplete responses
Short Breaks	77	11
Pre OFSTED	56	0
Autism Plan	72	0
ASD/ ADHD Pathway	12	0
SEND 2017 to 2018	44	36
Short Breaks Provision	4	
Caravan	11	
Community Groups	5	

Fig. 4 Number of surveys and response rates in 2017 to 2018

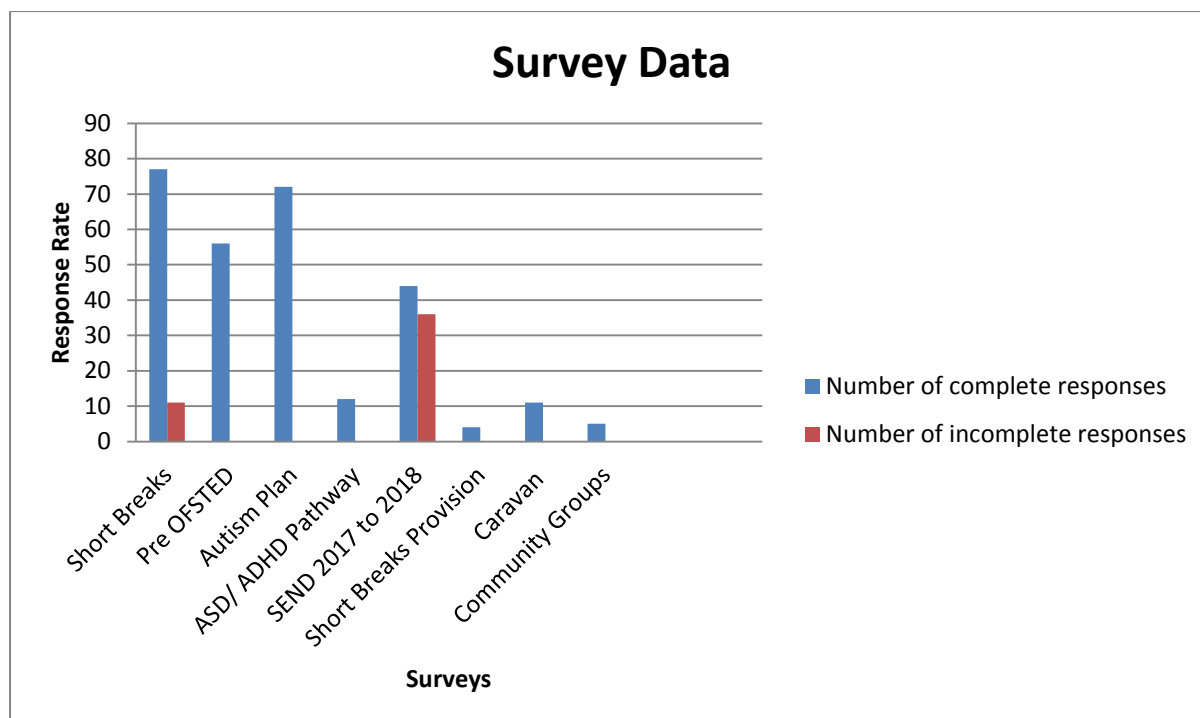


Fig. 5 comparison of survey complete and incomplete responses

The highest response rate occurred on the survey looking at short breaks and the lowest response rate was for the survey on community group provision.

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. 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.

number of CYP	Age	Gender	ethnicity	Setting/ School/FE	Disability
2		M	white British	Primary School	SEN
2		F	white British	Primary School	ASD
1	15	F	white British	Ormiston Bushfields	ASD/ADHD/Dyspraxia
5		M	white British	St Michaels Church School	Golden Har Syndrome
3		F	White British		diagnosed AD
3		F	lithuanian		multiple disability
		F	white/asian	special school	multiple disability
		F	white/asian	special school	multiple disability
1		F	white british	college	Learning disabilities
2	16	M	white british		ASD
	14	M	white british		ASD
1	16	F	white	Stanground Academy	ASD/Dyyspraxia
1	9	M	british	phoenix	complex
5		M	british	COPASS	ASD/ADHD/SPD/anxiety
		M	british	Ormiston Meadows	Moderate Autism
2		F	white british	Ormiston Meadows	ASD
1		M	white british	Abbey College, Ramsey	PDA, ADHD, ASD
3		M			ASD/ADHD/Ehlers Danlos
		F			ASD
		F			Ehlers Danlos
1		M	white british	Wilds Lodge	Sensory
2		M	white british		Aspergers
					ASD, severe learning disability, language disorder
		M	white british	Heltwate	
4		F			chromosomal
3	8	M	English	Welland Academy	Dyslexia, ADHD?, ASD?

Fig. 6 Example of data captured via feedback forms

Aiming High Group (AHG) and Seldom Heard Group Meetings

In the overall report section on the Seldom Heard work of FVP it can be seen that there has been an increase in the number of parent carers participating with a preference for family based activities being the avenue via which participation takes place.

Working Breakfast Sessions

5 Working Breakfast sessions have taken place at which surveys are completed and discussions held where minutes are taken. Themes have included the All About Me documentation, what health information parent carers would like, SEND Visions and Early Help.

Facebook Polls

1. Short Breaks
2. Autism Plan
3. Local Offer Post Card
4. School Contact

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 was the Local Offer Post Card one where 85 parent carers across chatrooms; NAS Peterborough, Little Miracles, FVP and PDDCS took part. The poll looking at the Autism 4 Year Plan was also popular.

An example of a Poll where parent carers have participated that relates to other work was around satisfaction with education services.

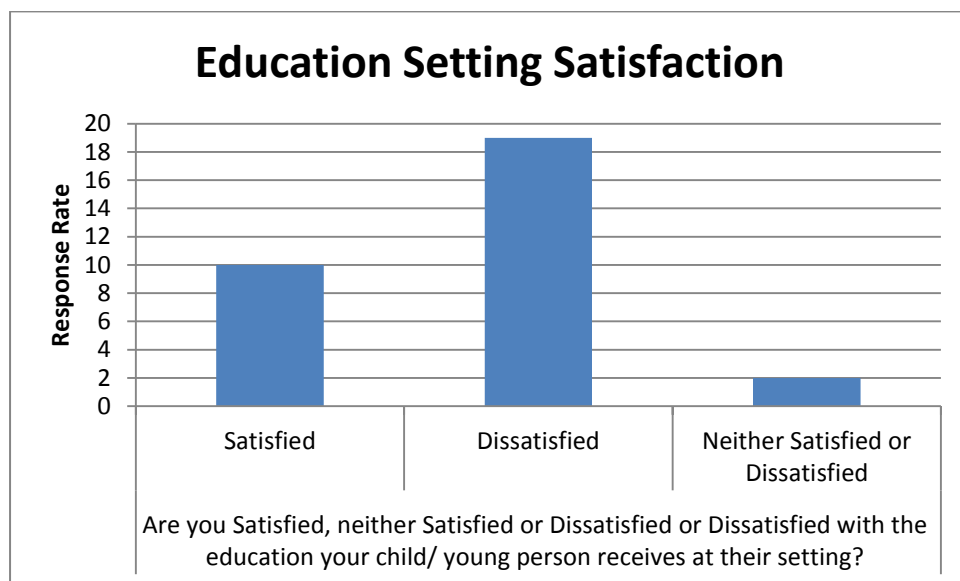


Fig. 7 Facebook Poll data educational setting satisfaction

Facebook Discussions

Facebook also proves beneficial for enabling different parent carers to take part in discussions where time commitments are a factor. Parent carers do not all have to be together at the same time and in the same place. One topic discussed that also relates back to SEND and education was centred on how parent carers are currently experience the system.

I feel education is poor and health is poor, especially mental health. Our experience with both has been a very tough hard journey.

SENCo's and staff in schools have lack of proper training in SEN. SEN Support is being inadequately implemented within most schools. It is very hit and miss, there should be more uniformity. Parents are given lack of proper guidance and information in regards to the Early Help process and how to get the appropriate support for their child

Education is very poor In our schools .I have been fighting for the right sport for past 4 years for my son but not getting any where

Feedback Forms from Trips and Activities

8 Trips/ Activities to places such as Activity World, Hunstanton or London have taken place where information has been gathered on OFSTED Readiness, SEND Visions and Early Help. This is gathered on feedback forms. The forms also give parents the chance to say what further trips/ activities they and their children/ young people would like to see.

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.

PARTICIPANTS (Parent carers)

Demographics

368 parents in total have been involved at some level via face to face meetings/ events/ trips/ Facebook Polls and Discussions up from 206 which is a 78.6% increase. 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. The following methods are used to gather details on CYP needs; feedback forms, database forms and survey questions.

Participation Preference

Participation preference methods are ascertained via attendance records with completed feedback forms, numbers completing online polls and surveys. The most preferred methods appear to be on-line; Facebook Polls/ Discussions and Surveys. Attendance at trips and activities also lends itself to a high level of participation.

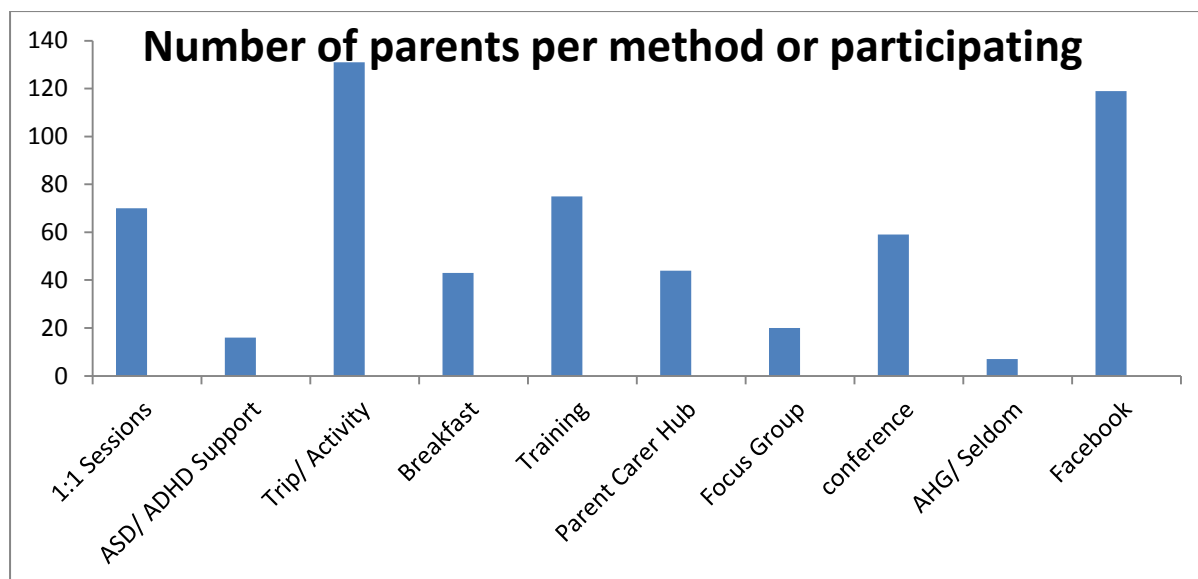


Fig. 8 preferred participation methods based on register information

SEND and Participation Analysis – Survey Data (Written by C. Dias)

1. Population

1.1 This survey report was based on responses from 55 parent carers in Peterborough; representing children/ young people reported as 69 males and 41 female and 1 undetermined gender, with ages between 0-25, attending different education settings, either in part-time or full-time timetables. Although the majority of the young person population had already a formal diagnosis some were on the pathway and expecting to go through a diagnosis process. The range of special needs was varied as the graphic below illustrates.

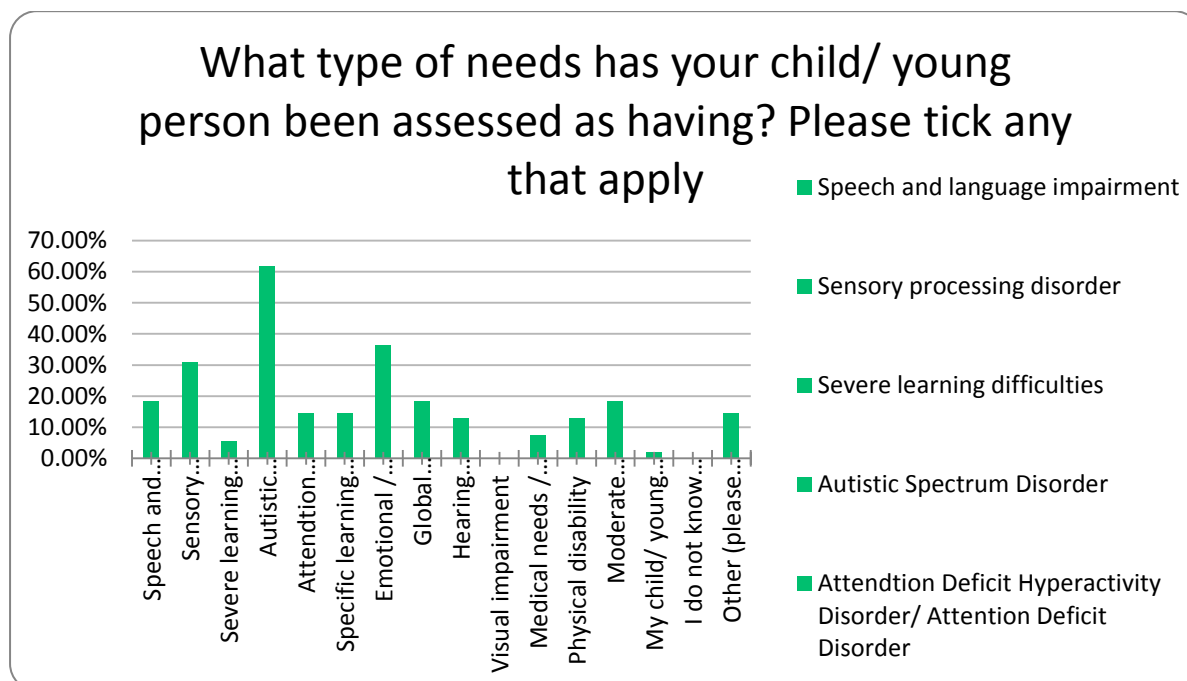


Fig. 9 Variety Special Needs among the poll population

Some of the conditions not mentioned above were Tourette’s syndrome, Obsessive Compulsive Disorder, Severe Anxiety, Epilepsy, and Demand Avoidant Behaviour, and Attachment Disorder. This is a clear indication that education placement need to cater for a growing range of special needs. Training is an imperative at least in most basic areas of SEND, along with coordination and support of health and education services to the young person. The identification of gaps in services is a **must** to ensure a full inclusion of every young person in an education setting. An area for improvement is still the overreliance on specialist services to identify and meet need this is an issue that needs to be address within SEND and education settings. Although none of our population was in an “in care” situation this an area that can be overlooked putting extra demands on foster carers.

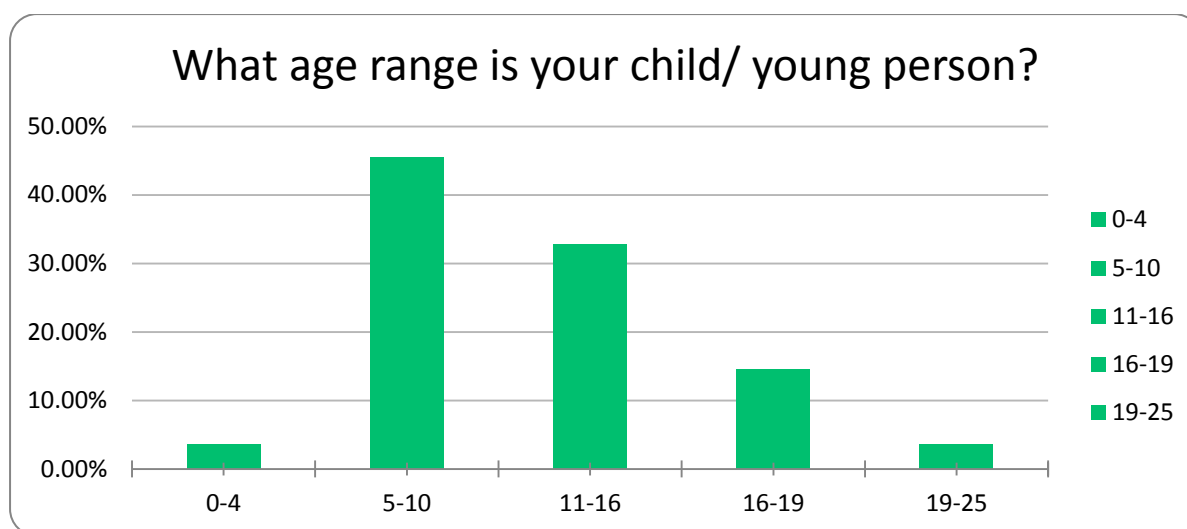


Fig.10 Young Person Population Age Range

The population age range gives a good overview of all the challenges that are still to be addressed by SEND services, from early help to preparing for adulthood. This will be addressed later in this report.

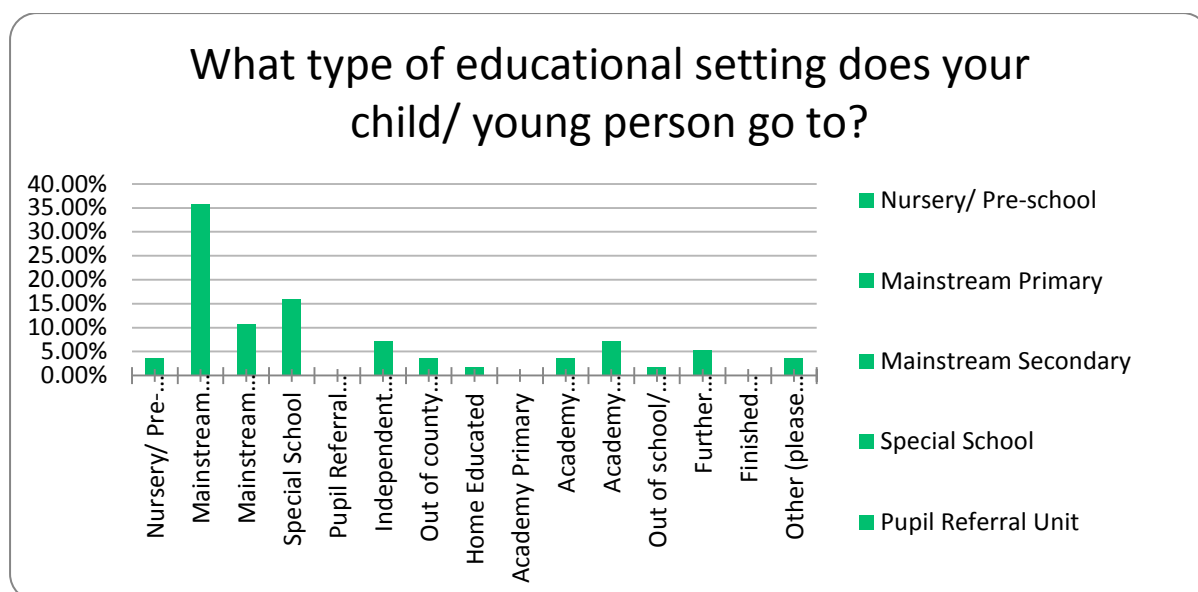


Fig. 11 Overview of SEND Education Settings among the poll population.

This variety of settings comes with its own areas of development. All carers have expressed the need for a more effective way of settings to communicate with them, most feel that although an effort has been made on its lack consistency and transparency. Most parent-carers in special education settings feel that the needs of their child are being met and this includes nursery services. The SEND support offered by mainstream settings remains still an area for improvement especially in the area of SEN support. The EHA is clouded by uncertainty and frustration and therefore the parental confidence in the process remains low. Information, signposting and correct advice to the right services or when services are contacted is still an area for development.

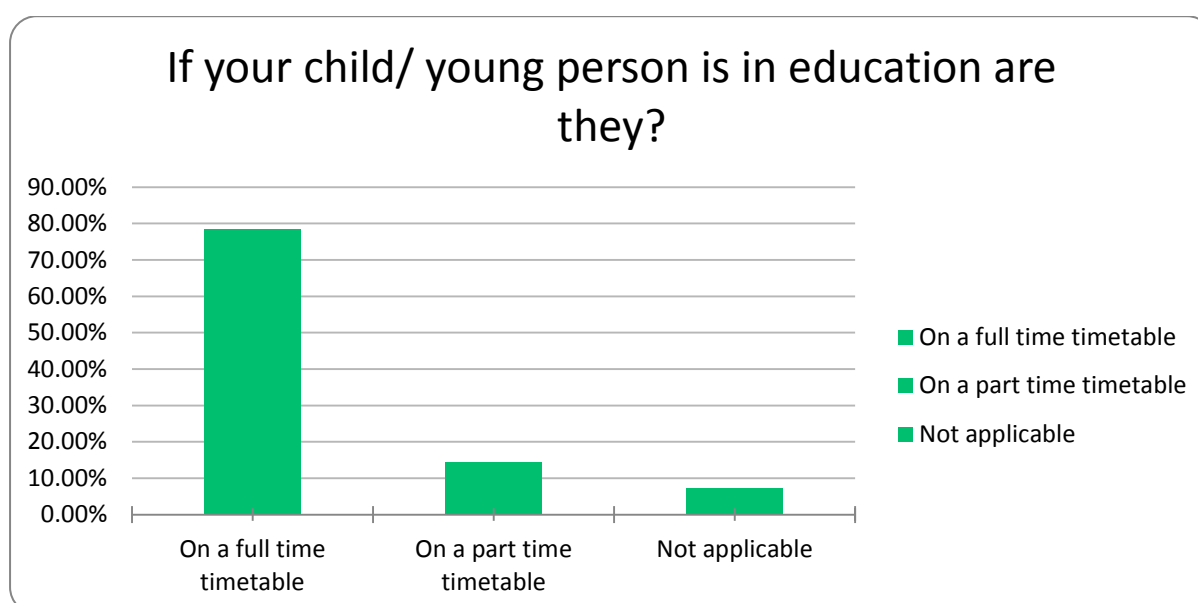


Fig.12 Breakdown of population into Full and Part-time Timetable.

Although it is reassuring to see that nearly 80% of the population is in full-time education still the remain 14.29% in part-time education are a reason to concern as it should not be a long –term solution and can be an indication of need not being met.

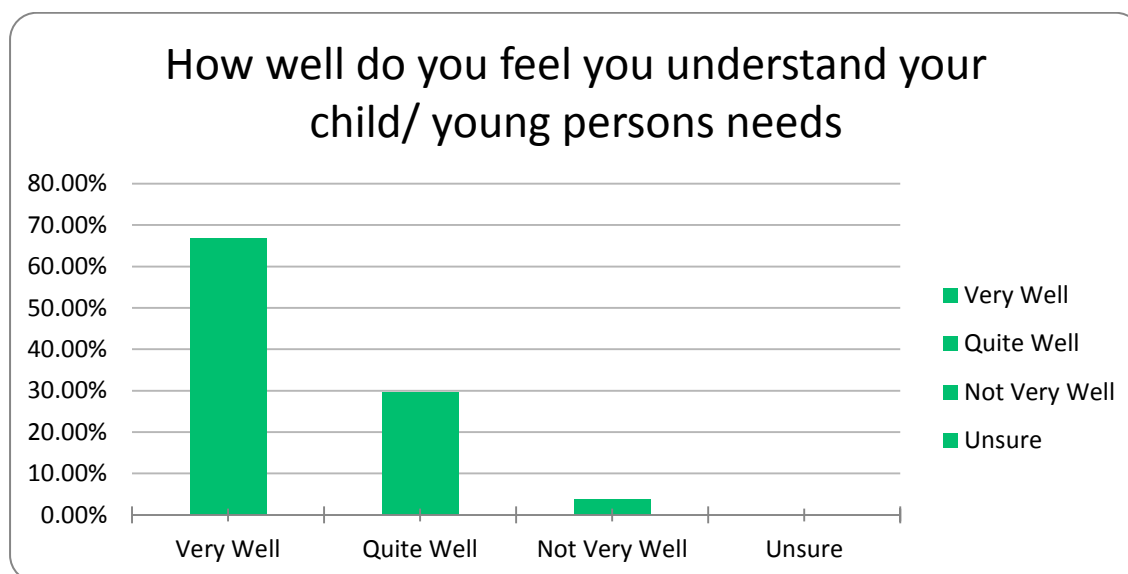


Fig. 13 Parental Resilience

Parental resilience is increasing and that can be assumed a measure of the success rate of the SEND work carried out so far and overall means that services have improved and that parents are feeling more empowered and proactive. If we related this piece of data to the other pieces of information, it may be at cost to families and to parent-carers needs and what now seems to be good progress may be the indication that parents have given up and are taking too much into their own hands putting themselves at being at a high risk of burnt out.

2. Parent Participation

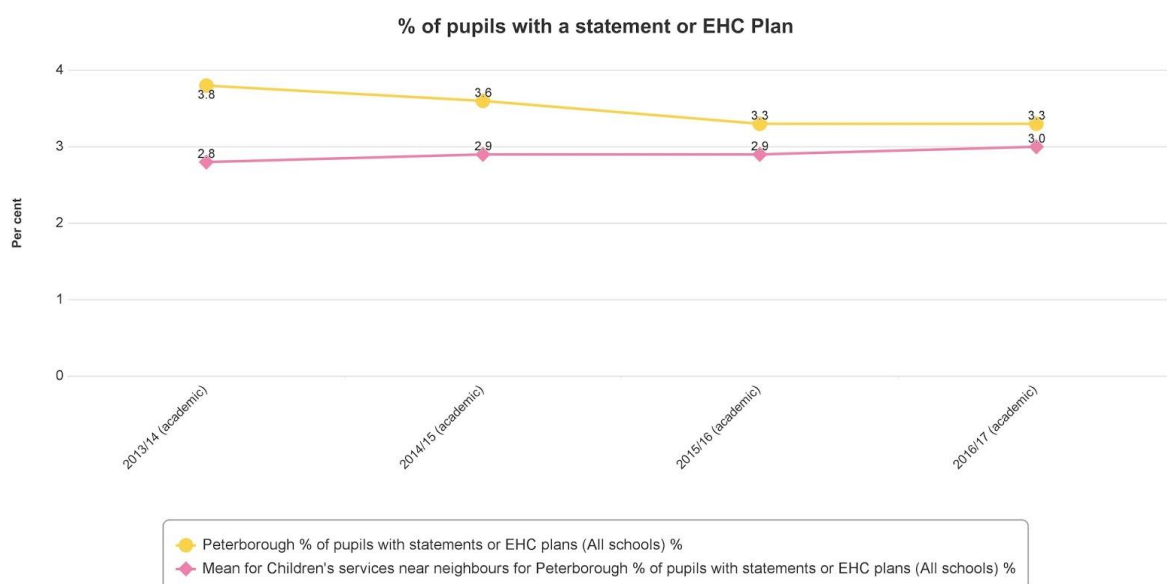
2.1 Effective identification of SEND in Education, Health, and Social Care

All education settings including early years and childcare providers have a responsibility to identify children with special educational needs (SEN), by making sure that support is in place enabling that child to reach the best possible outcomes. The identification of some needs is carried out in the education setting through an Early Help Assessment, where Education, Health and Social Care come together assessing the needs of the young person and family.

Parent carers do seem to point at education as the major source for concern and where they feel that the young person is not receiving the adequate support to theirs needs, followed by Social Care and health. Some of the concerns voiced by parents/carers were the inconsistency of the information provide across services and complaints voices that concerns are taking too long to be actioned by the relevant services; it is not clear what support is being offered, what is being done and what are the processes.

Positive Parenting Courses are one of the most common complaints with families reporting that it stalls/freezes the process until it is finished by the family, in average a positive parenting course can take up to 13 weeks to be completed meaning that time amounts to a delay in the process. This is a default in the process as positive parenting courses were meant to be a paralleled support to families while the process is taking its course.

SEN support still appears an area of doubt to parent-carers, clouded with misinformation and lack of transparency, often parent report being unsure of the support or the amount of support that is offered by the education setting to the young person and how that support is addressing the young person needs. There are also comments shared by parent carers via social media (FVP chatroom) that further evidence this concern, *“My experience with school has been absolutely shocking. They do as they please as like everyone says it's one battle after the next, the complaint procedure is so long that parents just feel mentally exhausted. Feel let down by the whole system”*. It does appear as if there has been an increase in requests for assessment for an EHCP. However from the evidence we have it is not clear why this is and we have no evidence of any correlation between how parents view SEN Support and requests for EHCPs.



Source:
Metric ID: 2213, Department for Education, Special Educational Needs in England

Powered by LG Inform

Fig. 14 Data on pupils with a statement of plan

Peterborough has seen a decline in the numbers of pupils with a statement or EHCP, as part of the overall population. However, our numbers for 2017 (3.3%) remain above the national average of 2.8%.

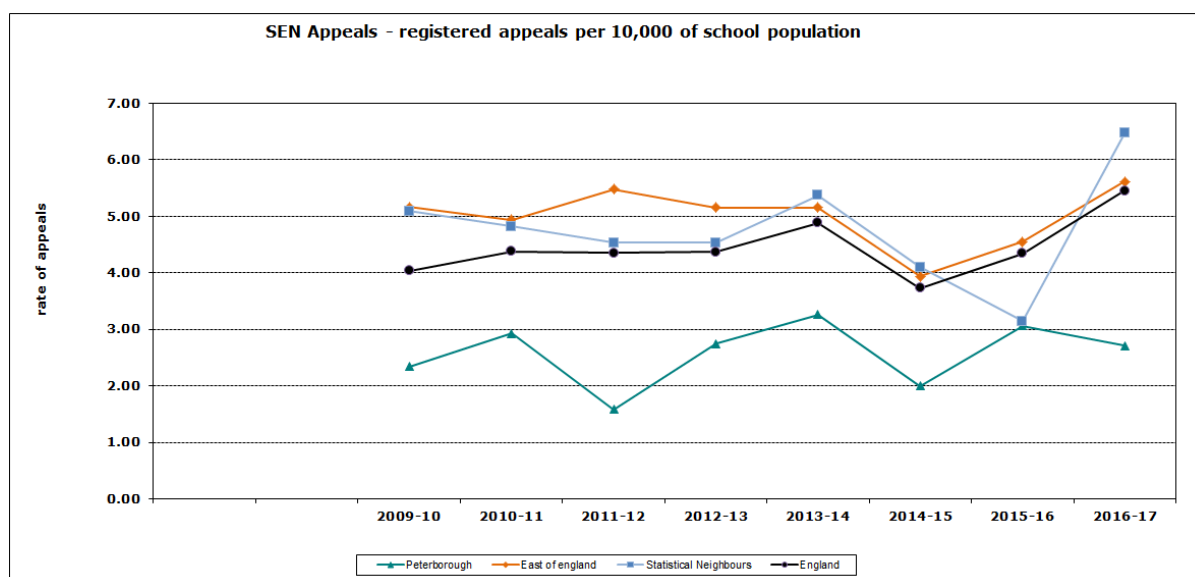


Fig. 15 Number of SEN Appeals

This chart shows Peterborough (the green line at the bottom of the chart) remains well below our statistical and regional neighbours and the national average for registered appeals to SENDIST.

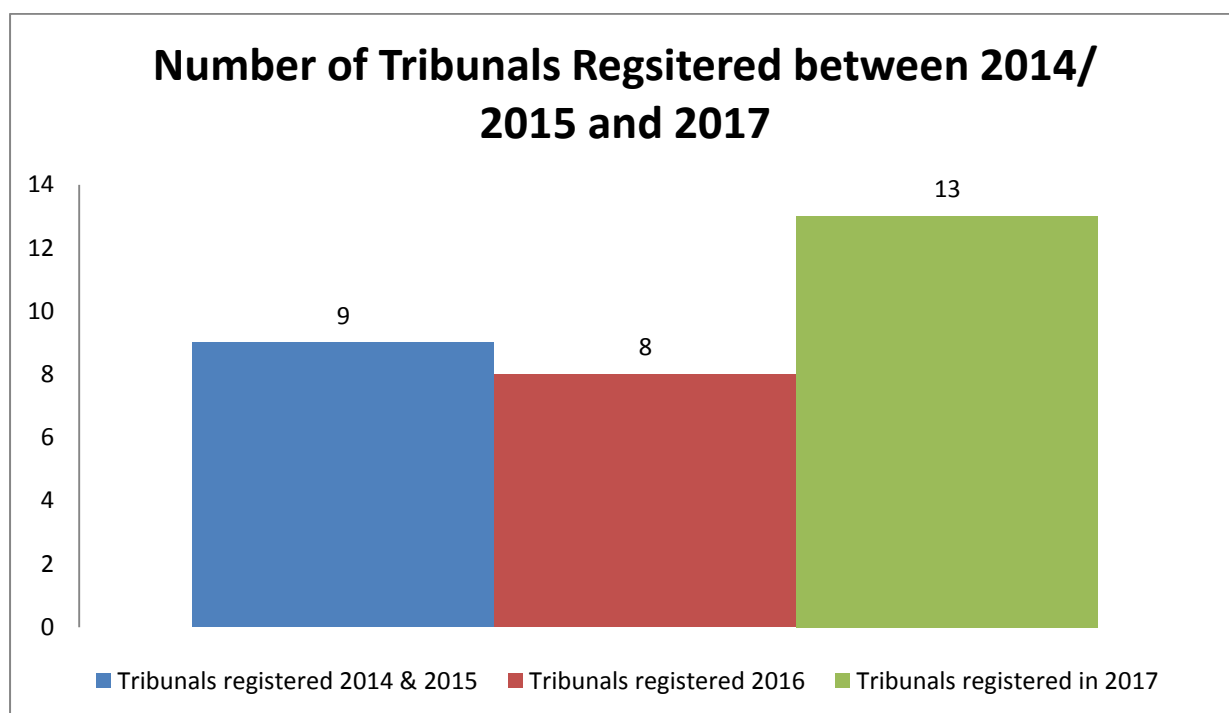


Fig. 16 Year on year comparison of tribunal's registered

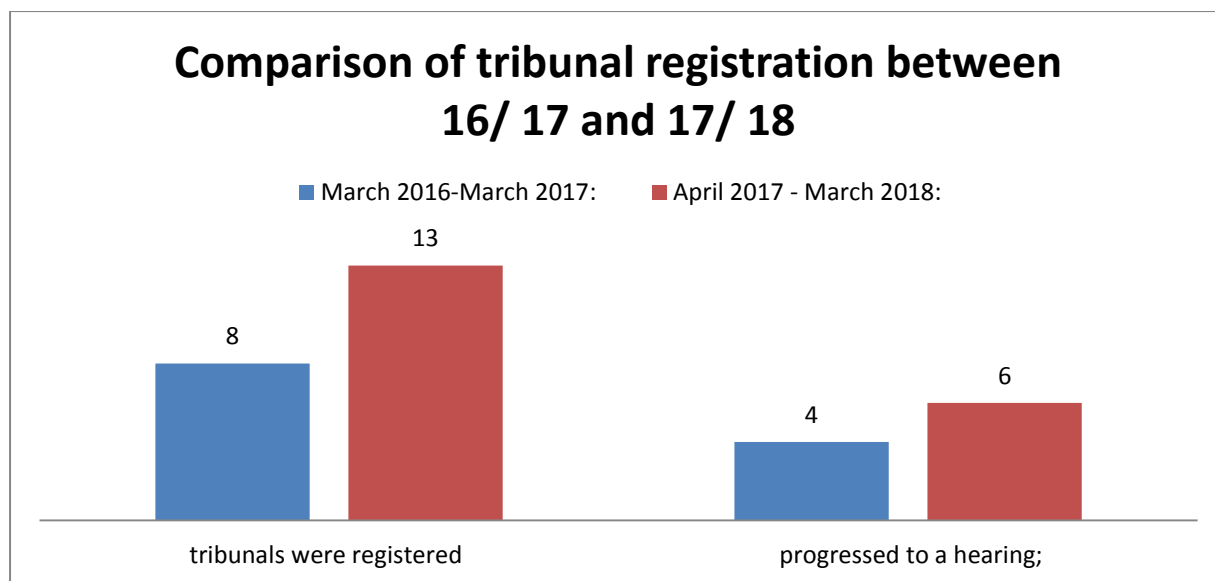


Fig. 17 Comparison of tribunal registration between 16/ 17 and 17/ 18

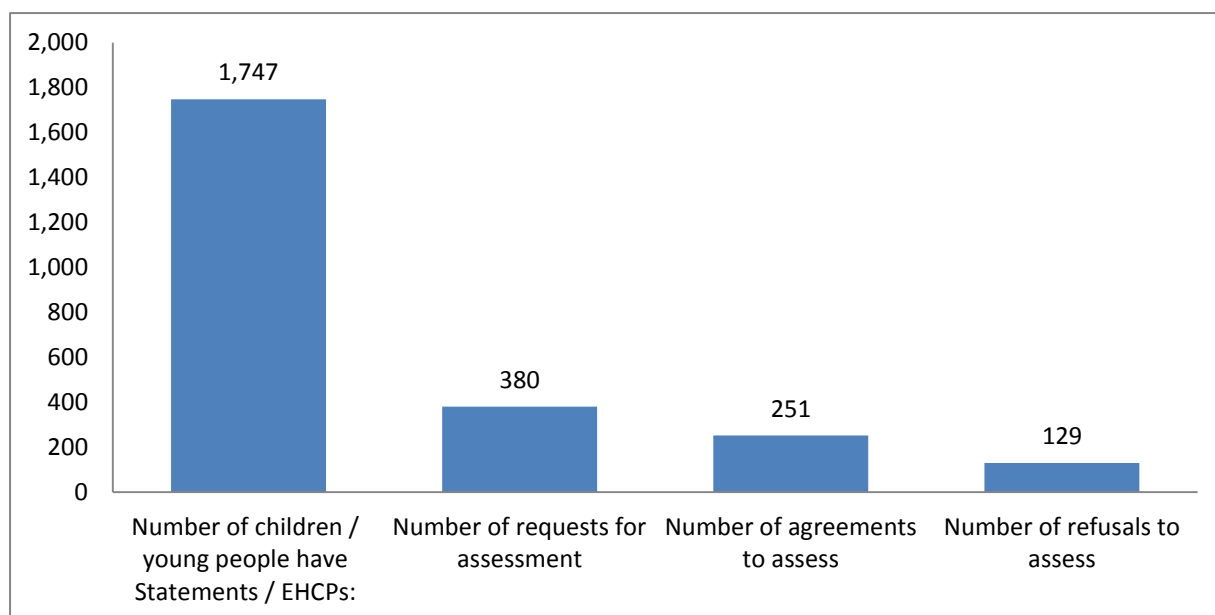


Fig. 18 Data relating to number of EHC/ Statements and EHC Needs Assessment Requests for 2017

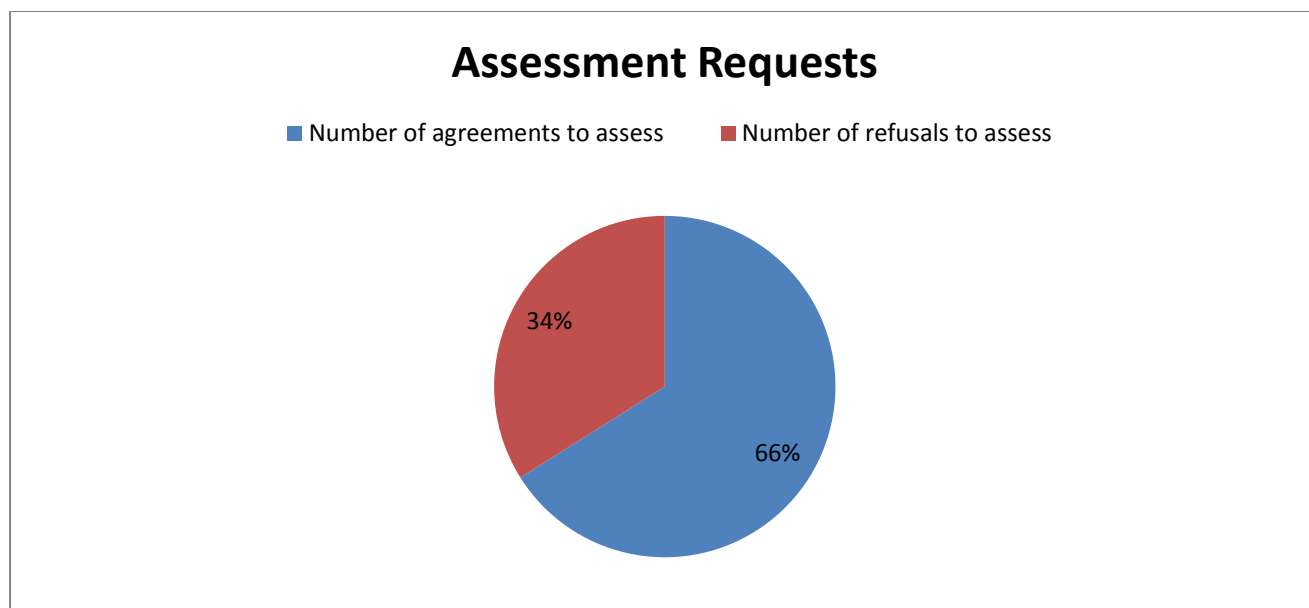


Fig. 19 Percentage of agreement to assess and refusal to assess an overall total of 380 requests

All of the data presented in Fig.14 to Fig.19 needs to be understood in the context of a. population growth and b. Peterborough's position in relation to national, regional and statistical neighbours. The data from Fig.14 to Fig.19 has been provided by Peterborough City Council. To help parent carers understand the context there will be work on sharing of data in a format that is easy to understand. Overall much of the data presented in this part of the report is mixed as information is from a variety of sources some of which can be subjective (face book discussions). No conclusions can be drawn; just an overall picture presented showing an increase in parental concern.

Further on this point is the lack of consistency in health services across all ages is reflected on this piece of data, with certain needs suffering considerable discrepancies leaving families and the young person without or with very little support to deal with the young person's needs. Similar situation is identified in Social care with many not meeting the current criteria for social care, or even when those needs are identified and met with the relevant service; still is not identified on the respective EHCP's.

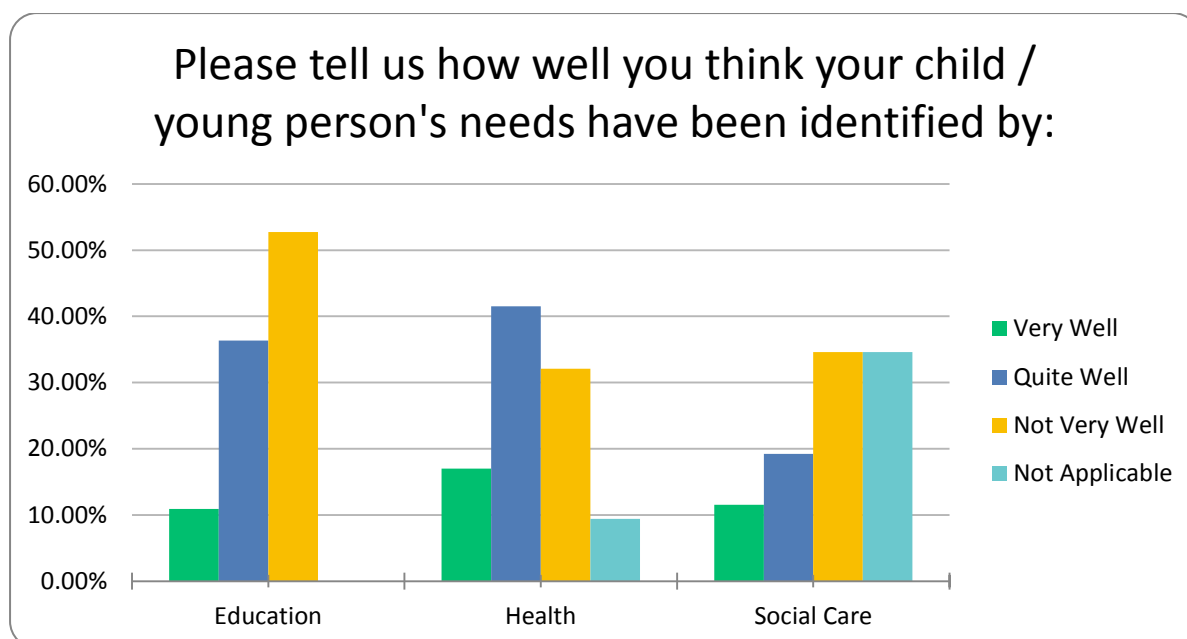


Fig.20 Satisfaction of Identification of need in Education, Health and Social Care

Parent /carers are finding that the identification of need pathway is not straightforward overall, yet the numbers of satisfaction are increasing. The Pathway is a relatively new process and it takes some habituation along with dealing with the high level of frustration from the population is a tricky issue to resolve. FVP has provided extensive feedback to services regarding this issue and it is now being addressed.

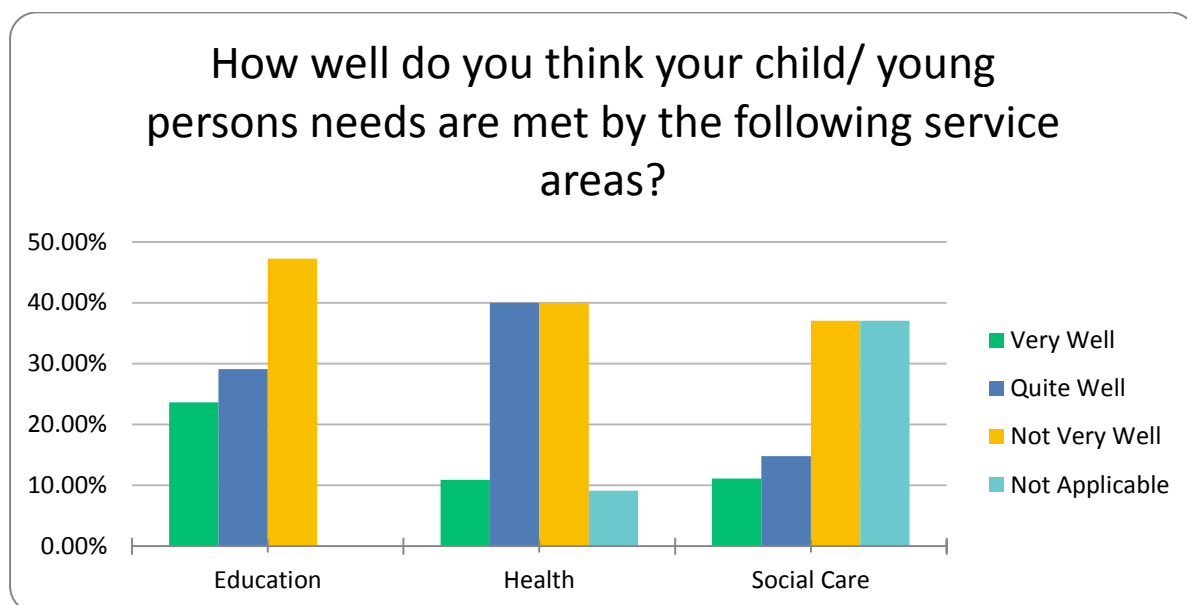


Fig.21 Level of performance by services in meeting young person's needs

This is in part a reflection of the current austerity climate, services are stretched and do not have the capacity to deal long term with certain continuous young person needs, it is required of services to take a consistent and longitudinal support input, therefore consequently parent-carers feel frustrated with services, due to the short-term addressing of need that most

services provided. Peterborough is considered to be a deprived area and school budgets can and are being pushed to the limit due to these factors, therefore it is imperative that school support suffers a clarification of its offer. A higher level of co-production in SEND is needed to offer a more structured approach to ensure that schools are supported on their role as a SEND deliver.

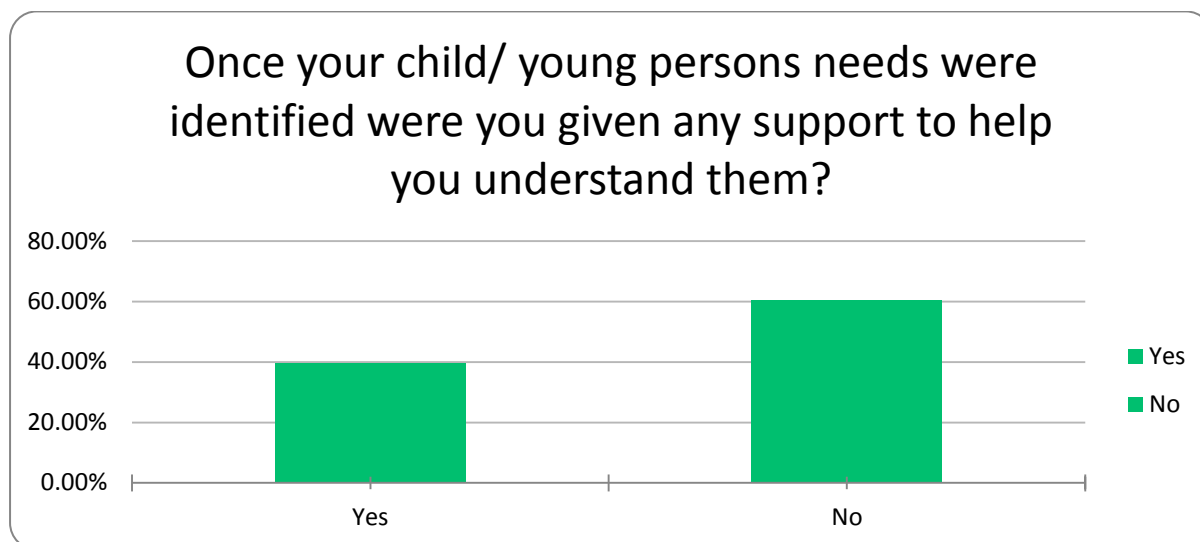


Fig.22 Post diagnosis Support rates among poll population.

The need to inform parent-carers is still as valid as it was in the past but now it is a question of refining the process. Parents have now a wide range of organizations giving information and support strategies yet the rate of satisfaction is low when compared with the amount of information available. This maybe a reflection that information deliverance has to be rethought and possible identification of underlying reasons why it has failed somewhat in the goals that it has tried to achieve is needed.

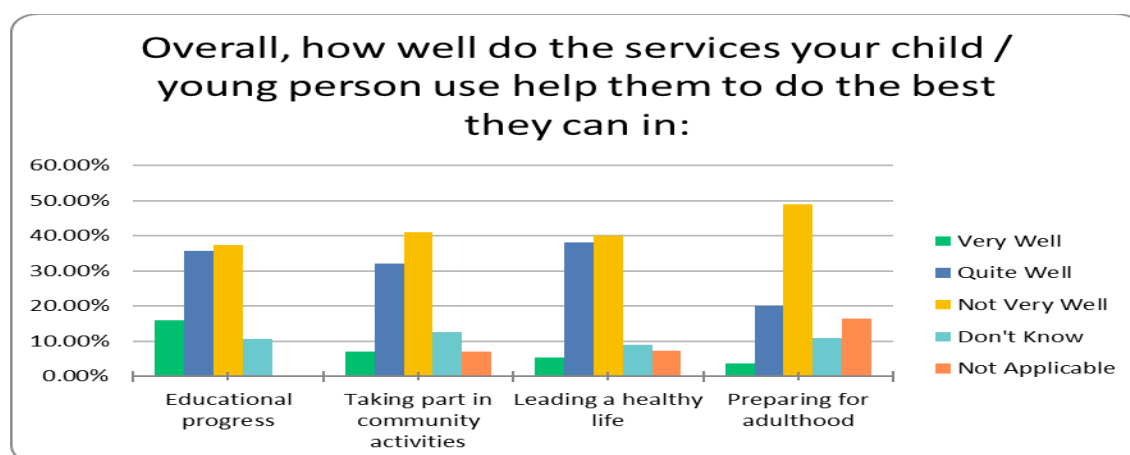


Fig. 23 Identified gaps in support to parent –carers and young person.

The two pieces of legislation that have the greatest influence on support for disabled young people preparing for adulthood are Part 3 of the Children and Families Act 2014, which focuses on Special Educational Needs and Disability, and Part 1 of the Care Act, which

focuses on the care and support of adults with care and support needs. It will support local authorities to identify where processes overlap and to consider how they can be effectively joined up.

The above graphic that although progress has been made in the effective delivery of both legislations outcomes there are still areas that need further input and development, a more fine comb approach is needed to ensure that the SEN population within Peterborough is enjoying a good quality of life and are full included within the community.

Post 16 transitional services are reported as problematic, parent-carers are reporting that they do not feel supported in this part of their young person life as they felt before, investment into employment opportunities and relevant education options are still an area of contention, and the possibility of exclusion and social isolation is a reality that many face when services run out of options to offer.

The idea that post 16 education is an option rather a statutory duty to provide has to be overcome, not just by services but also by parents-carers in order for better outcomes to be reached insuring that wellbeing and inclusion are being fully attained.

2.2 Parent/Carer view of the Process

Part 3 of the Children and Families Act transforms the system for disabled children and young people and those with SEN, so that services consistently support the best outcomes for them. The reforms create a system from birth to 25 through the development of coordinated assessment and single Education, Health And Care Plans; improving cooperation between all services responsible for providing education, health or social care; and giving parents and young people greater choice and control over their support. The SEND reforms focus on the following themes:

- Working towards clearly defined outcomes
- Engagement and participation of parents and young people
- Joint Commissioning and developing a Local Offer of support
- Coordinated assessments and Education, Health and Care Plans
- Personalisation and personal budgets

Preparation for adulthood is a key element of the reforms that cuts across all of these themes. The transformation of the system for disabled young people and those with SEN is intended to ensure that services consistently support the best outcomes for them by making certain children, **young people and their parents have greater choice and control in decisions** and that their needs are properly met.

On the other hand the care act has reformed how the law works, prioritising individual wellbeing for adults with care and support needs over the age of 18, with a particular focus on person-centred practice and outcomes, **putting people in control of their care and support**. The intended outcome of the new legislation is that people's wellbeing, needs and goals are prioritised so that **individuals will no longer feel like they are battling against the system**

to get the care and support they need. It highlights the importance of preventing and reducing needs, putting people in control of their care and support and for the first time, **it puts carers on a par with those for whom they care.**

FVP participation work is not only feedback to services parental views but also ascertain the underlying causes of parent-carers dissatisfaction as service users, so that co-production of future development of services is ensured. Although FVP knows that parents have a high rate of satisfaction when they access services, accessibility and timely accessibility is still an issue, this is reflected on the data collected by our surveys.

Parental involvement on the process is also recurrent issue that has transpired from our raw data either at the identification of need or ensure that those needs are continuously met. Parent-carers do not feel involved in the process or not consistently to their satisfaction neither in health or education. Ad-hoc services and not full understanding of SEND reforms may be the answer along with present austerity measures.

The vulnerability of the parent-carers is being dismissed; lack of information may not just be the root cause of the escalation of situations. The lack of individualised/practical advice, the lack of ongoing support, and prevention measures may the root cause of parental dissatisfaction. It is imperative that the identification of need is accurate and that the service offered is a match to the need, that this identification is not clouded by financial constraints.

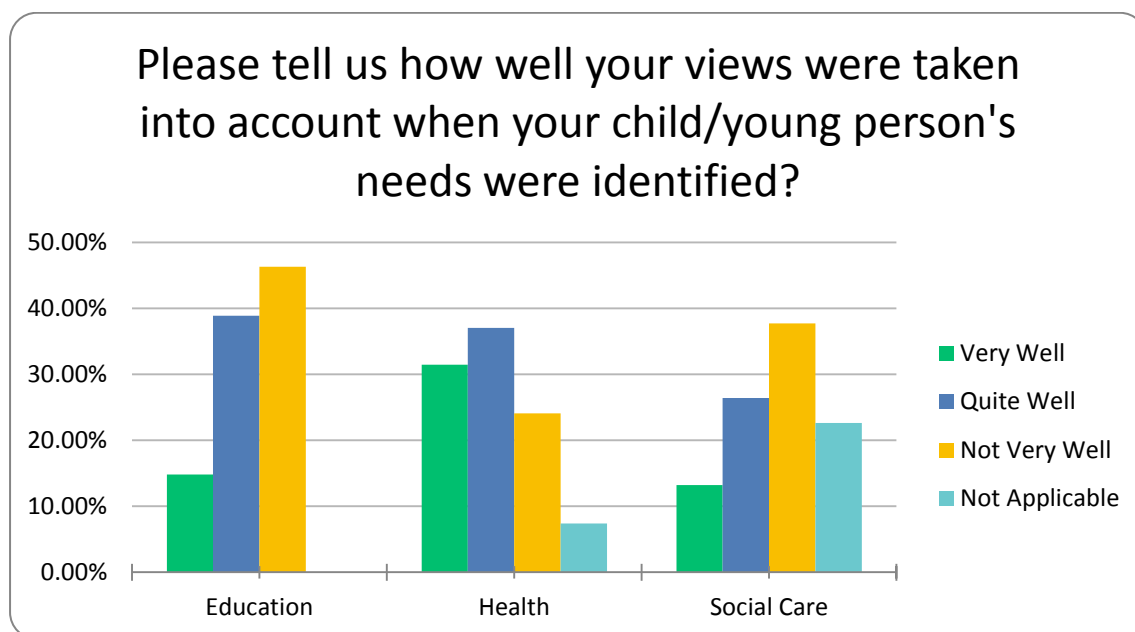


Fig.24 Parental view of the Identification process of need in Education, Health and Social Care

With the new legislation IASS services are statutory, which means that every council must provide them. They are designed to ensure that parents, carers and families of children and young people with SEND have up-to-date information, advice and guidance on matters that allow them to make informed decisions about their child's education as well as in other areas including health and Social care. IAS services should:

- IAS on subjects including local policy and practice, the Local Offer, personalisation, Personal Budgets, the law on SEN and disability, health and social care.
- IAS through the EHC assessment and planning process.
- A phone helpline.
- Confidential and impartial IAS to young people (16+) on their own, if requested.
- Individual casework, representation and support in preparing for and attending meetings.
- Help in filling in forms and writing letters/reports.
- Support on exclusions
- Support in resolving disagreements, including mediation and tribunals.
- Signposting to local or national sources of advice, information and support.
- Links to local parent support groups and forums.
- Training on the law relating to SEN and disability, as it applies to education, health and social care. This training can be provided to early years settings, schools, colleges, statutory and voluntary agencies

It is fundamental that all areas recognise their input in the system and that through communication and transparency address parental concerns in a proactive way. It is imperative that aim to empower parents and families of children with SEND to have the confidence and ability to take an active and informed role in their child's education.

The monitoring of need is an area for improvement the follow up in Education and in Health are particular problematic with parents saying that they do not feel that their child is being offered and reasonable level of follow up. In cases where the child needs change considerable or are also not well identified, the new or emerging level of need take considerably long time to be addressed, living situations to escalate. Prevention and timely intervention seems to be key to address the above issues.

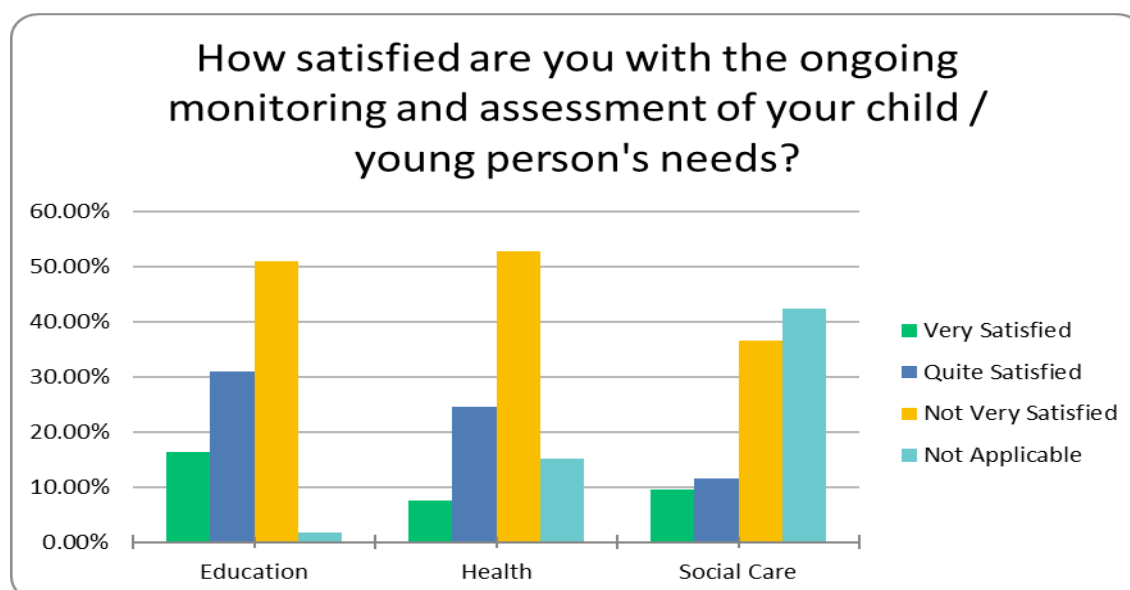


Fig. 25 Level of parental satisfaction with services monitoring of need.

Although a deserved praise should be given to the local Authority for the efforts in addressing parental concerns and the making a positive effort for implementing the SEND reforms in co-production with parents, the austerity is having its weight on monitoring the needs of the population. Services seem to address initial needs expediently and most parent's express a positive opinion, the same is not felt by parents when comes to follow up needs or when those needs change dramatically due to young person special needs. Reassessments of need do not seem to happen despite of parental requests. The same experience is felt in Health. Social Care seem to stir away from that pattern and may be due to the ongoing (every 6 weeks) assessment of need of the young person when under social care services.

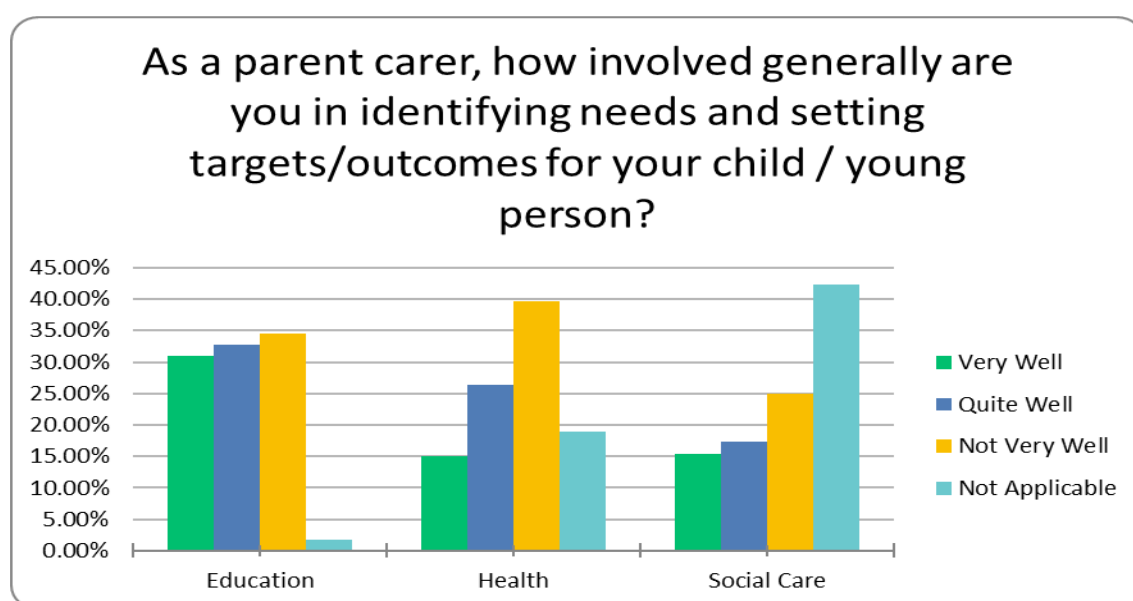


Fig.26 Level of Parental Participation in Young Person Outcomes

The main point in this piece of data is to ascertain what the underlying causes of parental satisfaction are. Are services doing all they can to involve parents in decision making; are all the parts in the SEND process aware of their role and how can they enable the other parts to contribute; Are all parts aware of their barriers to co-production and are they making efforts to reduce it. This are some of the questions that need to be taken forward for the foreseen future.

Accessible, good quality information, advice and support are vital to ensuring good outcomes for young people and their families. The Children and Families Act extends the duty on local authorities to provide information, advice and support on education, health and social care, both to the parents and carers of disabled children and young people and those with SEN and also directly to the children and young people themselves. Local authorities should ensure that the information, advice and support is available through a single point of access.

The Care Act requires local authorities to establish and maintain a service which must provide information and advice relating to care and support for adults and support for carers. The Children and Families Bill also requires every local area to have a Local Offer, which

will include the education, health and care services the local authority expects to be available to support disabled young people and young people with SEN aged from 0-25.

There is a duty for local authorities to consult with young people, parents, schools, colleges and other services when developing the Local Offer. Although there has been an effort of the Local Authority to make the Local Offer known, this effort needs to take another level and explain how everyone can fully participate in the new process and what duties that entails for all, specially schools and health services.

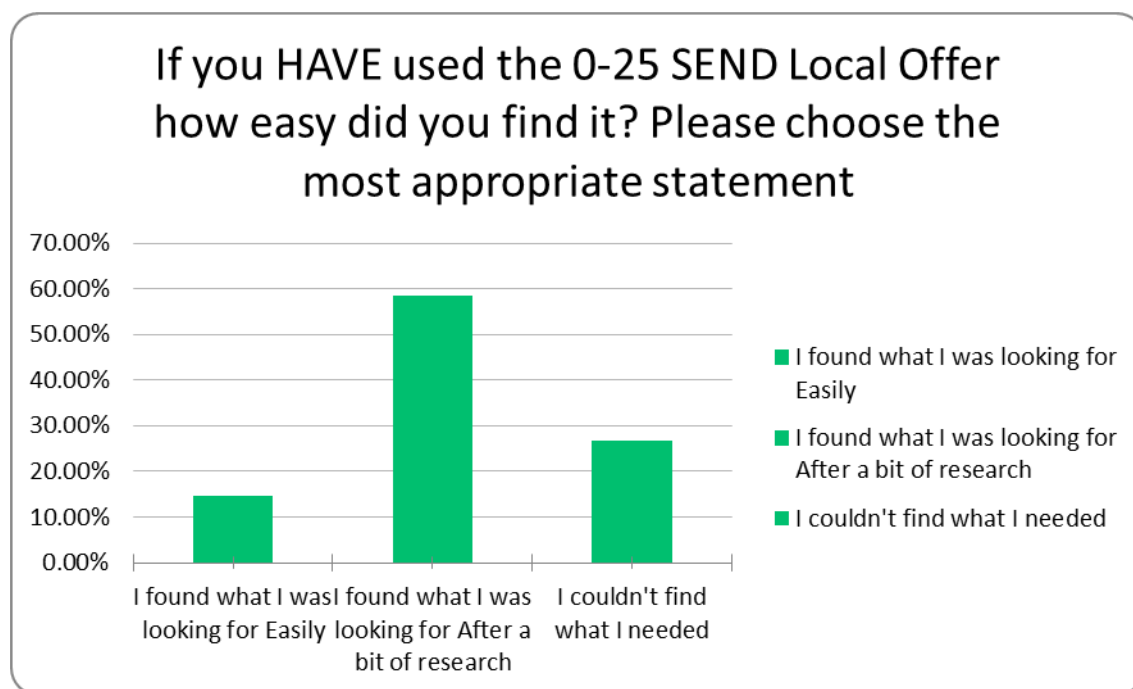


Fig. 27 Local Offer accessibility

Although this data was collected before/during the redesign of the website, and therefore another data collection is need to accurately ascertain accessibility, FVP is also questioning if parents are enabling accessibility and up-to-date with their duty to know where and how now information can be accessed, and what tools are at their disposable.

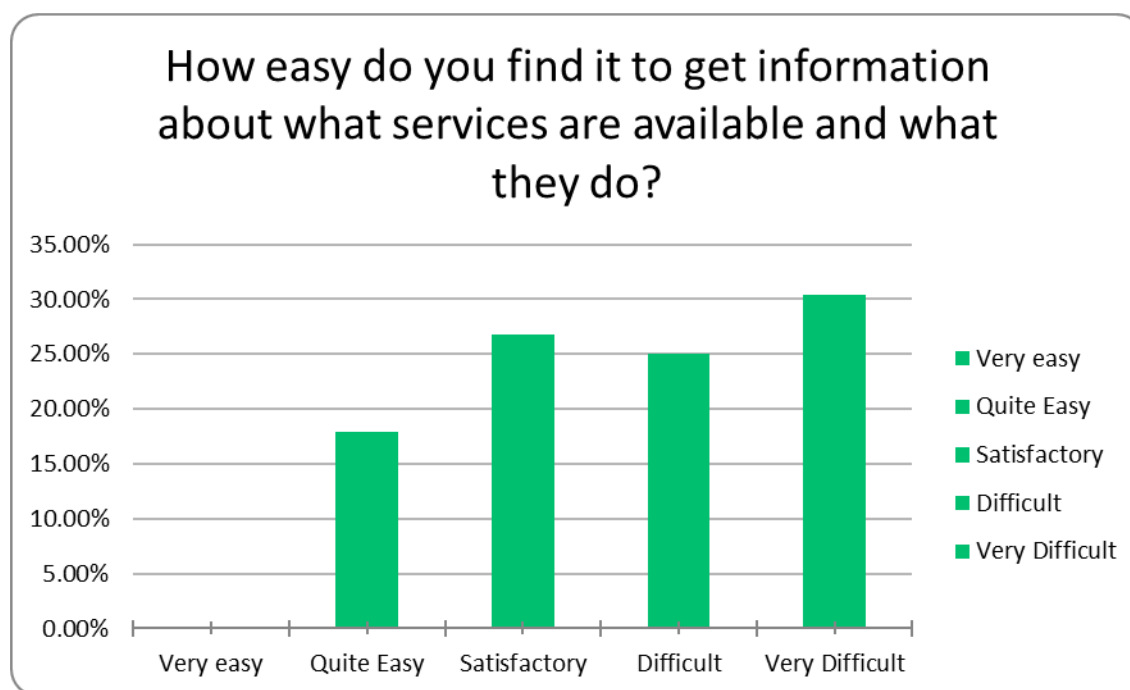


Fig.28 Parental Difficulty in finding Information

This points to the need to look at how information is accessed by parents and how it can be made more accessible. A platform was devised by the new system (Local Offer) as a primary source of information for parents and professionals but is this having in account the characteristics and pitfalls of the local parent-carer population and includes parental disengagement. The above data seem to point to a discrepancy between availability and effective use of such availability from parent-carers.

FVP levels of participation are increasing and this due to a very effective effort to engage parents where they are, logistics is a strong impediment to participation. Time and place are determinant in the success in participation as well as themes discussed. Parents are driven by practicalities, in the moment issue and short terms goals, with many not engaging in long term strategies or not seeing the need of such input.

School and early help groups will be one the main targets for the next Participation year and again is going to where parents are and try to get information as soon as possible to it is easier for them to navigate the new system, which can be overwhelming. The amount of information also will be broken down, we find that parents are now reaching a saturated point where information- freeze is an impediment to successful engagement.

Collaboration with other charities and holding of information sessions is an area to explore and is not trying again for parents to be in more places or spend more time that they can devote to this events. It is essential that groups work towards the same SEND goals and that information is effectively passed on to parents. 1:1 sessions may be also benefit if there is additional needs affecting the parent that can impact on the young person, Peterborough population can be diverse in characteristics and it is important to overcome any impediment to participation.

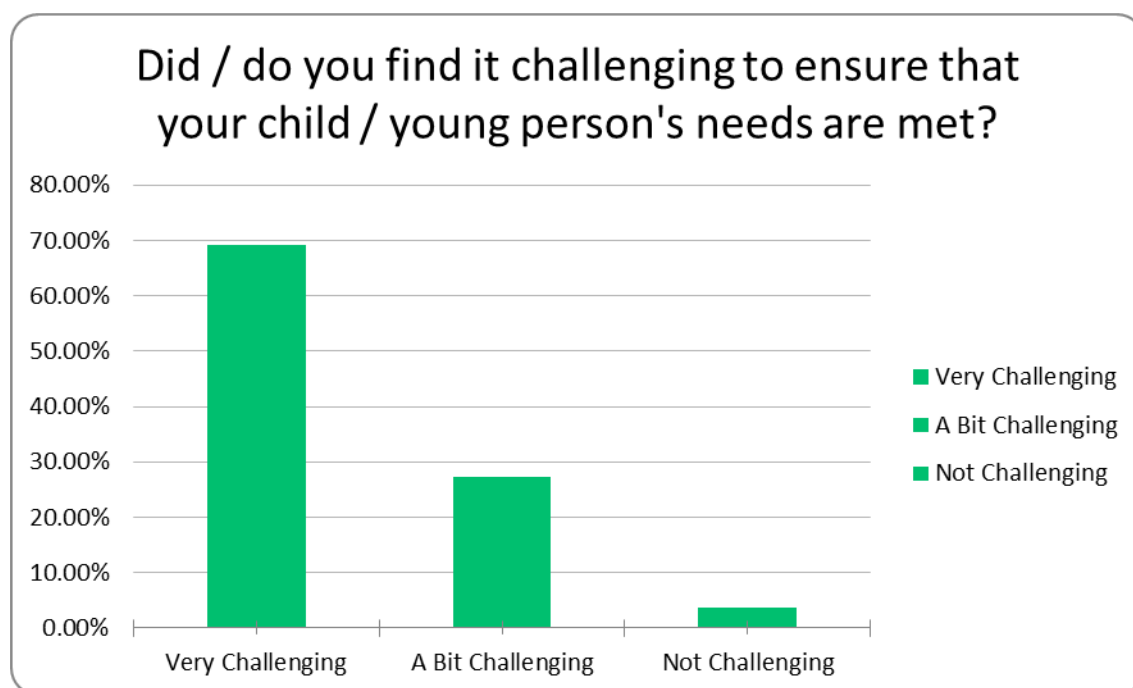


Fig. 29 Parental Perception of Difficulty in Meeting Needs

SEND is not an easy field and comes with many challenges, this piece of data cannot be interpreted without having in account the austerity measures in place, yet that does not invalidate that an internal view of services performance ought to be conducted in an ongoing manner to ensure that the continuous meeting of need in a timely manner is still relevant within the service.

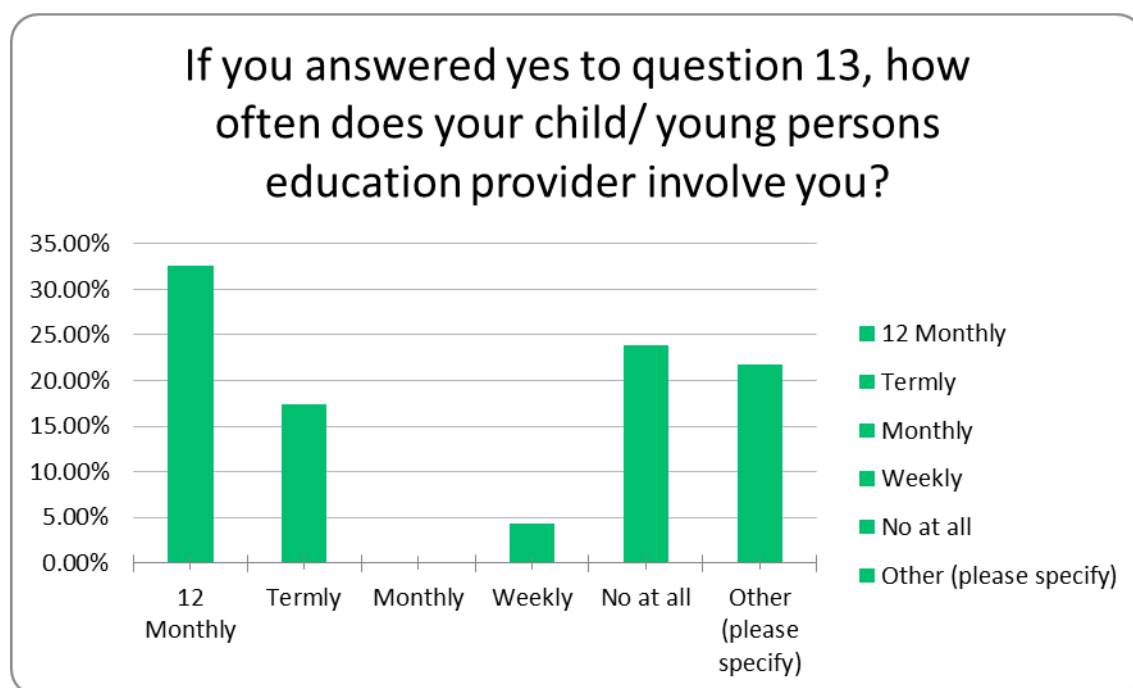


Fig.30 School level of Parental involvement.

This graphic shows that School idea of co-participation is still limited and it differs from establishment to establishment, promoting participation ideas within school settings needs to be prioritise, parents need to have a closer, open and transparent relationship with school as this will enabled the parties to work more proactively in the young person outcomes.

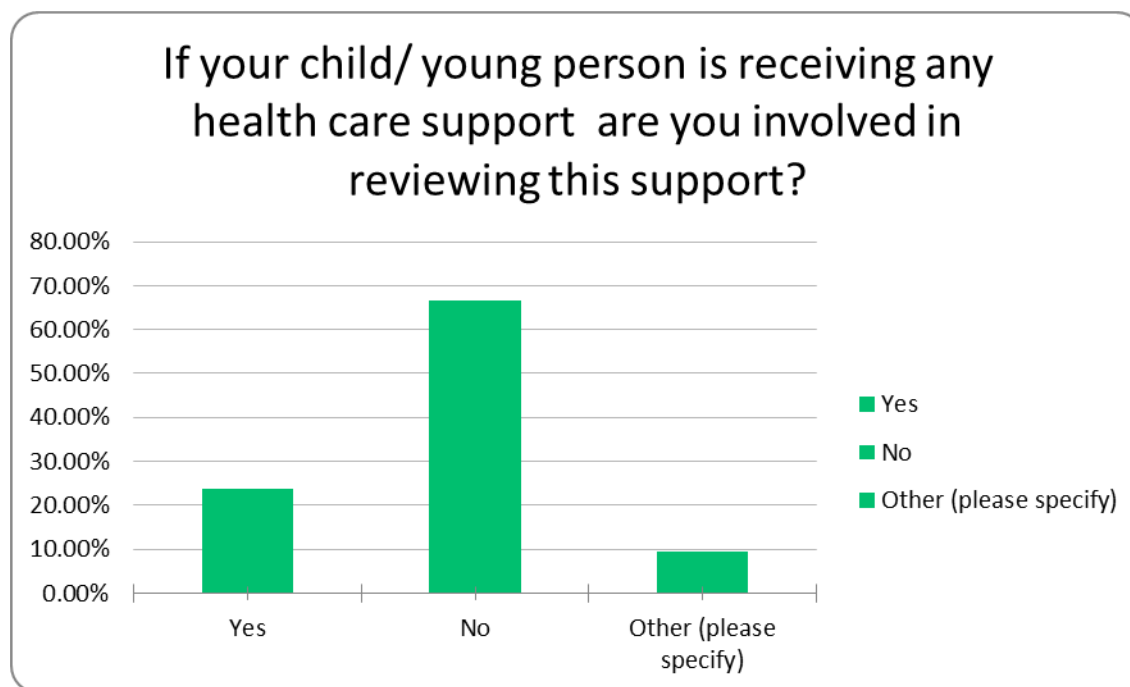


Fig 31 Parental Involvement in Health monitoring of need

Health services need to make a more concerted effort to participate parents in their children decisions, it is not just make a decision of treatment, is also explain why such treatment may not be available for that young person and what are the alternatives and why such alternatives may work to that individual case.

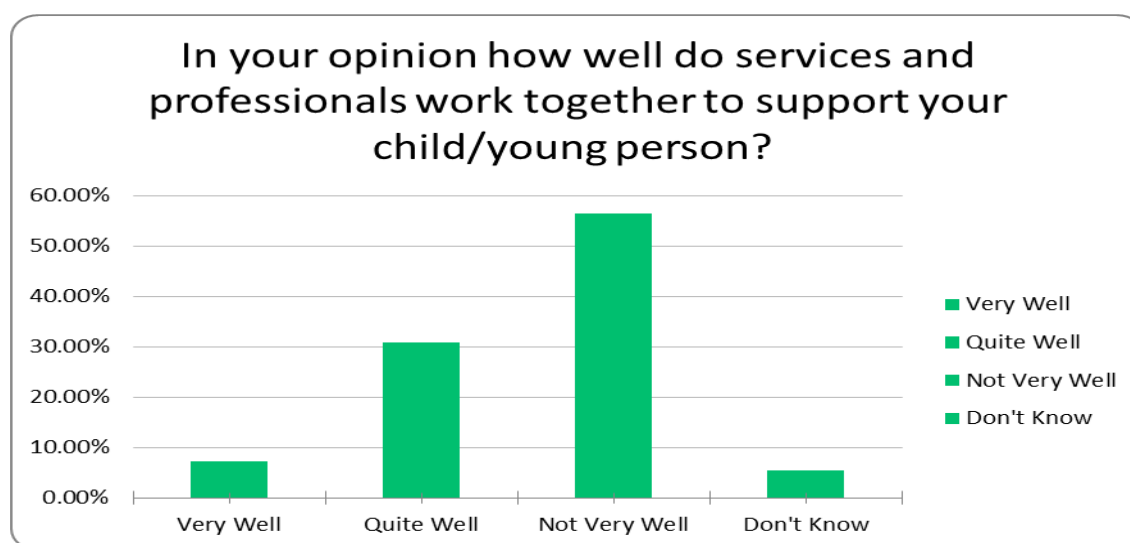


Fig 37 Co- Production/Co –Participation among Health, Education and Social care services

Parents still feel that information is not yet being properly shared that there is a transference of responsibilities rather than a shared view. Signposting is often common used rather the used of shared measures to achieve better outcomes. Co-Production and Co-Participation still is an area that needs further input and professionals need to change the way of addressing population needs.

The overlap between the two Acts around joint commissioning creates an opportunity to explore how pooled budgets across local authorities and health bodies, as well as across children's and adult's services, can lead to more effective use of resources and better outcomes for young people. Partners need to be aware that rules on NHS Continuing Healthcare funding (NHS CHC) come into force at age 18 and some young people with EHC plans will need to be assessed for eligibility. This does not mean that their support must change, except to match their needs. People eligible for NHS CHC have the right to request a personal health budget (and from October 2014 the right to have one in most circumstances).

The Children and Families Act creates a new duty on local authorities and health bodies to jointly commission services across education, health and care. The Care Act includes general duties on local authorities to promote integration and on local authorities and "relevant partners" (including the NHS) to cooperate generally and in relation to individuals. Joint commissioning that encompasses the transition to adult services will need to involve a wider range of partners, such as housing and employment support.

3. SEND Overview and Outcomes

The Children and Families Act focuses on putting children and young people at the heart of planning and decision making through co-production and person-centred practice. It emphasises the importance of engaging young people and their families in all processes from developing and planning, particularly in relation to the Local Offer and Education, Health and Care Plans, and also in the commissioning of services and strategic decision making.

In alignment with this the Care Act focuses on individual wellbeing with an emphasis on outcomes and person-centred practice. And for the first time participation in work has been identified as an outcome for adults with care and support needs. This development should ensure that the focus on young people having employment as they move into adulthood is maintained by adult social care.

Social care professionals are expected to work in partnership with health and education to find creative ways of ensuring that individuals are able to express their views and are supported to engage in decision making, including arranging independent advocacy if required. Developing person-centred, measurable outcomes across different areas of the lives of young people is a challenge that is common to both Acts.

Although most families have a certain degree of satisfaction this feedback from parents illustrates some of the impediments to a more successful experience with services. Parent carers *have stated*:

- *“I also work as a professional with families whose children have SEND so I am very informed as a parent regarding what is available for my child. I would say most families I work with know little of what is available to them and are mainly reliant upon their schools and involved professionals.”*
- *“My experience has been challenging. Firstly, it was a battle with the school to be able to get my son's needs identified and an assessment for a diagnosis of autism. This took, 11 months of fighting to get the school to listen to me that I felt his already identified difficulties didn't explain the full picture. The school actively discouraged me from pursuing an EHCP and told me he would not qualify. When speaking to other professionals who work for the SAMS team about my son, they told me that he needs were great enough to warrant an application. I am currently waiting to hear from the panel to see if my son's EHCP request will go to assessment. My son is almost 7 and cannot read and can barely write, he is not progressing academically and the school cannot meet his complex needs. My son is not currently being educated, he is being managed. In the past academic year I have had to pick my son up on 8 occasions and take him home as they said they could not manage him in school. He has been restrained at least 10 times that I have been informed of. My son needs a full time 1-2-1 in order to have any hope of accessing education as he cannot work independently, this is not always available and this is when my son's behaviour becomes challenging as he finds the environment hard to cope with. I am seriously worried that my son is being denied his right to an education because of the challenges that his autism represents. I fear my son will never find employment and achieve independence as an adult without an education. “*
- *“Teacher of the deaf is fabulous - cannot fault her.”*
- *“OT discharged him with ongoing needs in life/education? Ehcp review NOT done yet and due to start new college in September - not good.”*
- *“Not good very slow process”*

3.1 Assessment of need

The Children and Families Act introduces Education, Health and Care (EHC) plans; a single assessment and planning process for young people with SEN which can potentially continue up to age 25. The Care Act will introduce a new duty on local authorities to carry out Child's Needs Assessments (CNA) for young people who are likely to have needs for care and support after they reach 18.

The purpose of a CNA is to determine what adult social care a young person might be eligible for once they reach 18 so they can make informed choices about their future. Young people or their parents can request a CNA at any time prior to a young person's 18th birthday whether or not they have an EHC plan. In addition, a local authority has a duty to carry out an assessment for anyone where there is “likely to be a need for care and support post-18” whether or not they are eligible needs. The CNA should be carried out at a time when it is of “significant benefit” to a young person's preparation for adulthood and should include an

indicative personal budget so that young people are able to plan what their future support might look like.

The local authority can decide not to carry out an assessment where there is not “likely to be a need for care and support post-18” or because the timing is not of “significant benefit” to the young person’s preparation for adulthood. In these circumstances they must provide reasons for this in writing, and include information and advice on what can be done to prevent or delay the development of needs for care and support. If they do not carry out an assessment because the timing is not of “significant benefit” the local authority should advise when it is likely to be of significant benefit and contact the young person and their family to arrange the assessment at that time. For a young person with an EHC plan a CNA should, as a starting point, be based on a review of the care element of the EHC plan. However it is vital that it fits with and informs the holistic approach across the plan.

This would create the least duplication for professionals, young people and families and provide person-centred information about a young person’s needs, plans and aspirations for their future. It should include clear, short and medium term outcomes which can then be used as the basis for a conversation with the young person, their family, a professional from adults’ services who has a good knowledge of the support options that may be available to them in the future, as well as the other professionals involved in their care and support.

Under the Children and Families Act, EHC plans must clearly set out the care and support which is reasonably required by the young person’s SEN. For people over 18 with a care and support plan, this should be incorporated into the EHC plan rather than developed separately. It will include those elements of their care and support which are directly related to their SEN and also specify other care and support. Elements that are directly related to SEN should be delineated. For young people who do not have an EHC plan, but where they are supported by children’s social care, their existing assessment and plan should form the basis of the CAN.

The key to ensuring that a CNA leads to effective planning is to make sure that the process results in an addition to the care element of the 9 EHC plan, which should include an indicative personal budget, and allows for the needs of young people to feed into the Joint Commissioning Strategy in the appropriate way. The conversation about whether a young person needs a CNA should begin in the Year 9 review as part of the preparation for adulthood planning. The process itself could form part of the review of the EHC plan in order to minimise the repetition of assessments and meetings that many young people and families tell us are stressful for them.

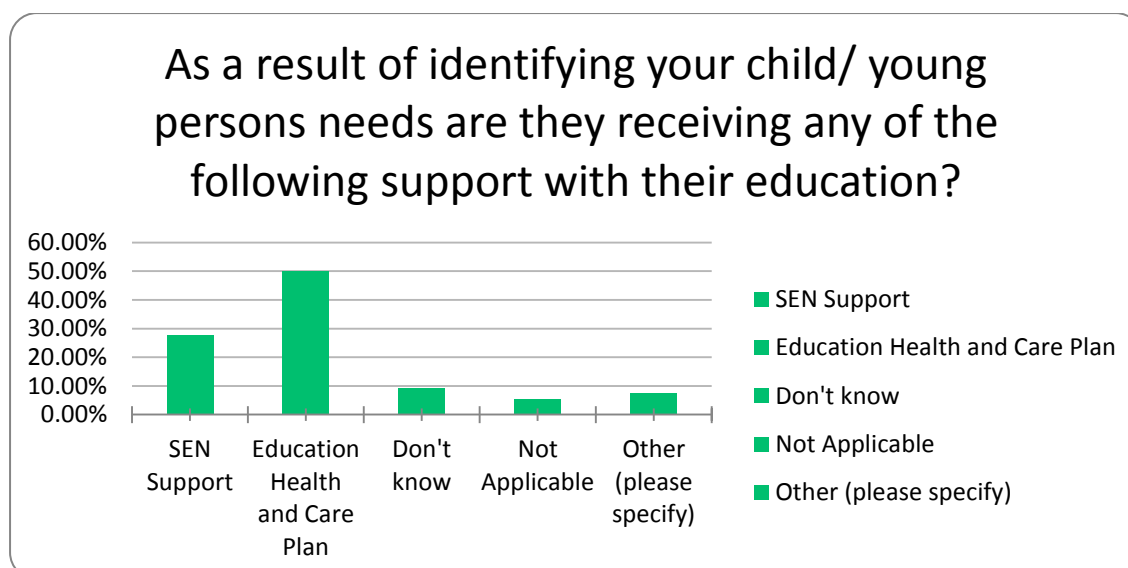


Fig. 38 Assessment of need and SEND Outcomes for the young person

The above data is consistent with Local Authority own data, showing that around 78% (27.78 % SEN support, 50% EHC Plans) of the survey population had a good outcome from a CAN (need assessment).

Please refer to the above Fig. 2, although 35.71% of the survey population is on a mainstream placement, the local Authority shows that at least half of Peterborough SEND population is attending a specialist placement, not only putting a strain on SEND local budget increasing the difficulty of having needs met as this placements will come at a high demand, but also is a clear indication that mainstream may not be doing an effective effort to include SEND and make inclusion as part of their everyday practice. Residential placements are still few and far between which denotes a good address of need in time avoiding escalation of situations.

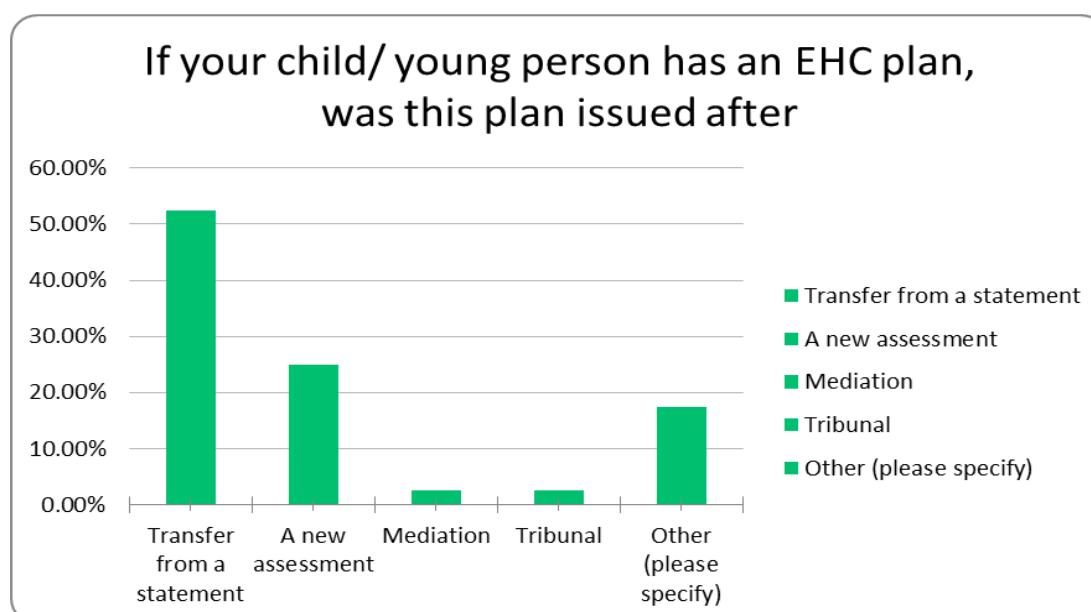


Fig. 39 EHCP issue Process, Conflict and Resolution.

Although our survey shows a good sample, FVP has to congratulate the Local Authority in their effort on conflict resolution, out of a total of 292 initial requests for an EHCP's, and 521 transfers from statements to EHCP's, only 18 cases reached mediation and 3 tribunal stage. This shows that parents are pleased with the outcome reached between the Local Authority and the family SEND offer to meet the need of the young person.

3.2 Reviewing of needs

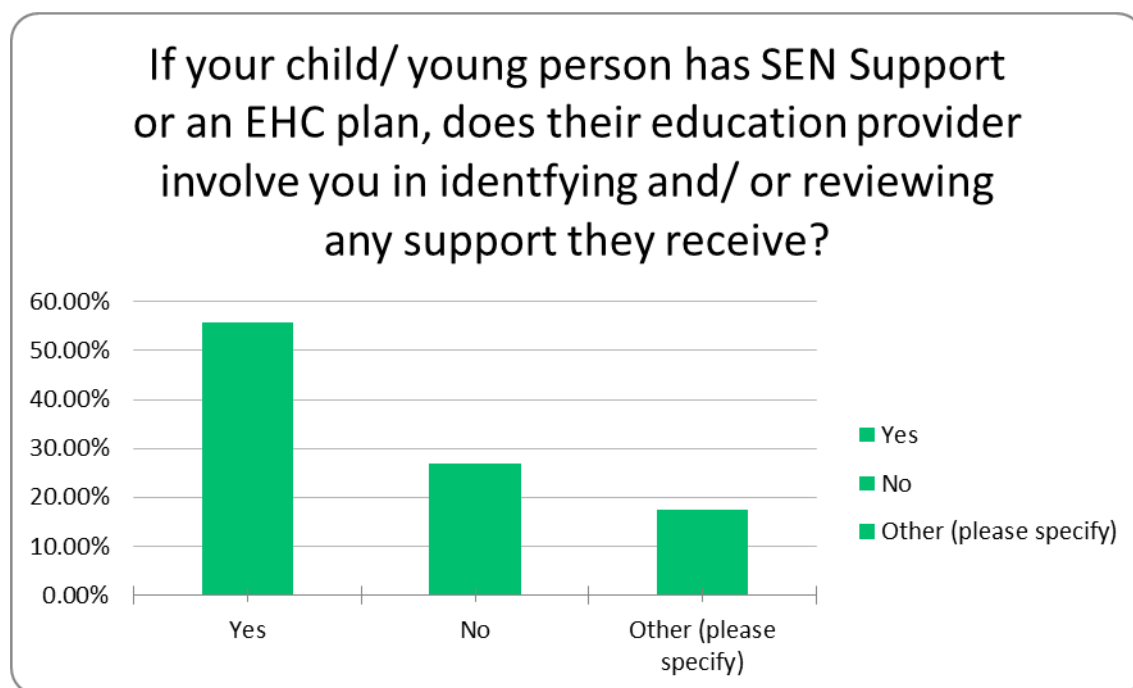


Fig.40 Parental involvement in EHCP's planning.

This graphic data becomes relevant if we relate to the other information on the report. Which means that Annual Reviews have become more collaborative between all the parts and Parents are listened in their concerns and those are addressed within the plan, meaning that SEND is addressed efficiently if the young person has an EHCP but the process is not so successful if other form of support is being offered by the SEND system. This is a reflection of parental concerns that SEND support budgets should be ring fenced as are EHCP's budgets because without a clear allocation of identity/purposed it will fail to reach its intended target. This is an issued that should be considered as a priority to ensure the success of SEN Support as education support. Parental distrust on this form of support is reflected on the number of parental request to assess, with a total of 128 refusals to assess by the Local Authority which means that parents are moving into higher forms of SEND support due to the inefficiency of the way SEN support is being delivered and not because there is an real need for that child to have a higher level of input. On the positive side out of all the assessments done only 1 child was not granted an EHCP which just reinforces the mentioned above.

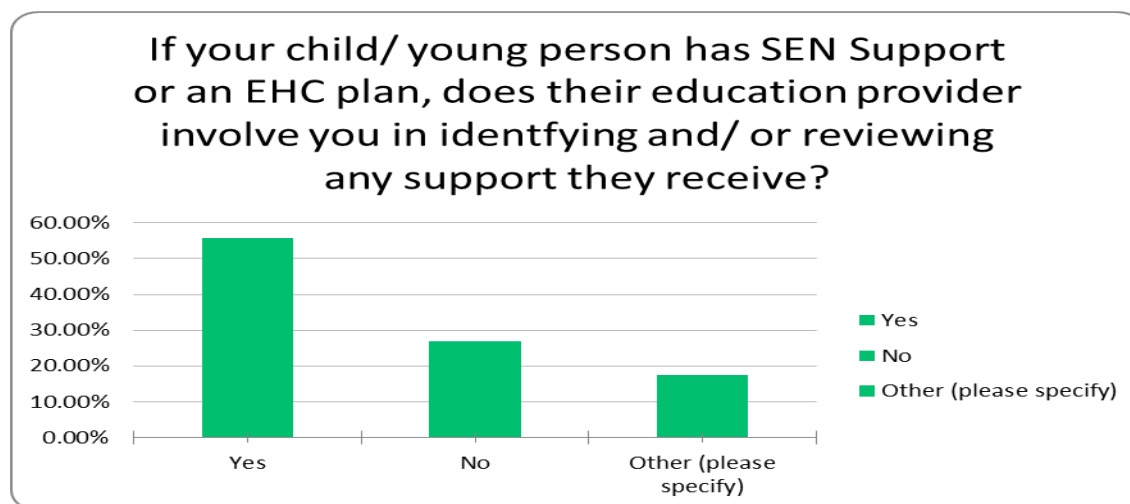


Fig.41 EHCP Parental Participation in identification/Reviewing of need

Although FVP finds very positive this set of data and the fact that parental satisfaction is on the rise, and EHCP's are now effective way of assuring the young person's outcomes and needs, which certainly is a departure from statements as many parents did not view it as an effective tool to secure SEN needs. FVP cannot shy away from areas of concern and those are post 16 education and personal budgets. The Local Authority figures state that only 2 young person's benefit from a personal budget and therefore this is still an area for further clarification, although it is likely to be an area that is falling behind due to financial constraints rather than lack of duty.

Both the Children and Families Act and the Care Act promote better choice and control over care and support for young people and families. The Children and Families Act provides young people and families the right to request a personal budget as part of an EHC plan. The personal budget could be made up of SEN, social care and/or health funding depending on eligibility. The Care Act requires local authorities to include a personal budget in the Care and Support Plan (Care element of an EHC plan) for individuals over the age of 18. Personal budgets and personal health budgets can be taken in a variety of ways to suit the individual and their family (including direct payments), and budget holders should be offered a range of support to make these choices real.

The Local Authority figures support FVP view that Post 16 is still not seen by the system including parents as statutory right and therefore, the number of people supported by the local Authority in colleges is only 19 with no one attending, Apprenticeships, Traineeships, or supported internships, a considerable low number for SEND population in Peterborough leading to the logic conclusion that this placements are not being reached or are failing due to the lack of post 16 SEND support. It is imperative that an effort in preparing for adulthood and towards an independent life has to be made for SEND young adults. Education is the base of future employment and it is there imperative to continue effective support measures to ensure that larger numbers can successfully reach this progression in education.

Educational support can only be effective when the right measures in health and Social Care being put in place, this are areas that enable or impair an young adult to progress. By looking

at the next graphic shows that the health support is not being consistent with many of the survey population stating:” OT 'discharged' for some unknown reason. Has ongoing needs.” or that no support has been given currently as part of an EHCP.

For the young adults receiving support, the question remains if the level of support is the adequate to make enough progress and this includes education and wellbeing and quality of life. SALT and OT services have suffered a restructure and it is yet to be assessed if that restructured has resulted in more positive outcomes for the young person under such health services. The identification of gaps in this services should be ongoing as well as, accessibility and level of service provided to not only ensure the progression of the young person quality of life but also the maintenance of such premise long-term.

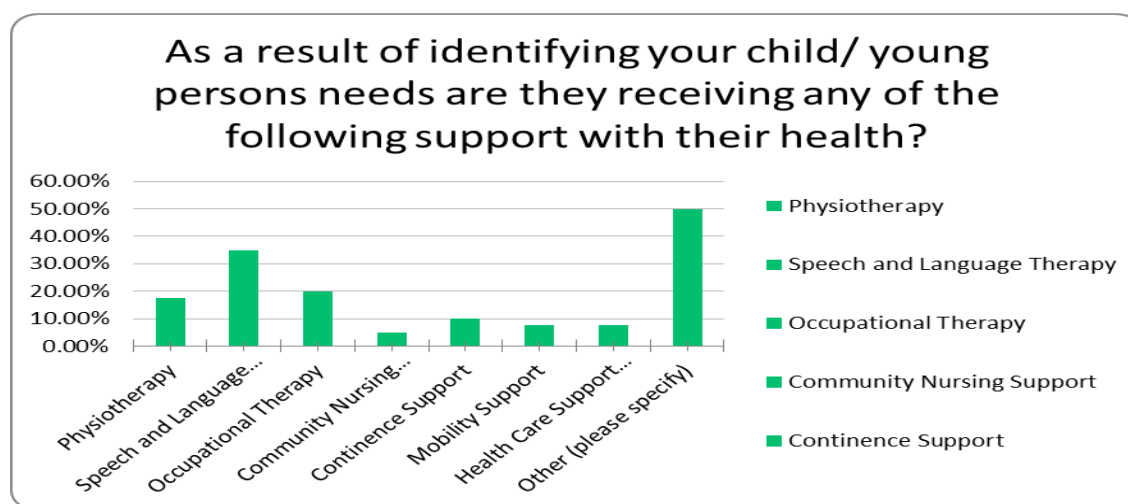


Fig.42 Health Services supporting young person SEND outcomes.

4. Recommendations

4.1 Outcomes and Wellbeing

- Develop a shared vision for Preparing for Adulthood with young people, families and key stakeholders who work with young people aged 14-25;
- Raise awareness of what helps disabled people achieve employment, independent living, community inclusion, and good health, to young people, families and across all agencies;
- Develop capacity and competency in outcome focused support planning across children's and adults' services. Staff and professionals who are developing EHC plans, including Child's Needs Assessments (see Assessment and Planning section) and care and support plans will need to develop common skills in person-centred practice, developing and monitoring outcomes, integrated support plans and personal budgets. Training staff together can lead to efficiencies and a more seamless experience of transition to adulthood;
- Develop a lifespan approach to outcomes. Ensure that professionals at each stage understand their role and responsibilities and how they relate to other stages of a young person's preparation for adulthood.

4.2 Assessment and Planning

- Ensure that there is a representative from adult social care on the local authority's SEND implementation board. Ideally this person would have responsibility for implementing the Care Act locally;
- Ensure that the process for Adults' Needs Assessment and Care and Support plan for young people post-18 are aligned to the assessment and planning process for the care element of an EHC plan;
- Work in partnership with families, young people and other professionals to ensure planning enhances and supports wider aspirations;
- Establish which professional, with good knowledge of adult care and support services, is responsible for CNAs, ensuring they work with those designing the coordinated assessment and EHC planning process;
- From Year 9 ensure young people and families receive information on how to request a CNA. This can be done as part of their Year 9 review. If the young person is likely to be eligible for care and support post-18 it is important that Adult social care are part of transition reviews from Year 9. The local authority should work with schools to identify the best way to achieve this and to inform the preparing for adulthood planning process;
- Develop a process that enables the CNA to produce an indicative personal budget for adult care and support.

4.3 Personal Budgets and Joint Services

- The joint commissioning strategy and Joint Strategic Needs Assessment (JSNA) should be informed by young people, their families, information in a young person's EHC plan and the Local Offer. Young people and families can play a valuable role in quality checking, the results of which should feed back into the strategy;
- Develop a process to allow the information from the EHC plan, including the CNA, and from personal budget holders' choices, to inform the Joint Commissioning Strategy;
- Ensure that the work streams around developing joint commissioning across the 0-25 age group and the Better Care Fund are joined up and that there is a common process being developed;
- Develop the market to ensure that there are quality services, which lead to the intended outcomes of the Children and Families Act and the Care Act, that young people can buy with their personal budget. Local authorities should work with education and training providers, health, social care, employment and housing agencies to develop a range of post-16 support options that lead to better outcomes and more efficient use of resources;
- Explore how personal budgets across education, health and social care (and personal health budgets for young people eligible for NHS Continuing Healthcare

post-18) can be integrated to develop personalised post-16 options and support that lead to better outcomes for young people;

- Ensure that young people and their families have access to good information, advice and support in relation to what is available and how to purchase it;
- Provide young people and their families with opportunities to pool budgets and commission mutually beneficial support.

4.4 Information, Support and Advice

- Develop the Local Offer in partnership with young people, parents, carers and professionals;
- Use the Local Offer to identify gaps in provision and feed into the joint commissioning strategy;
- Use the Local Offer to review the quality and quantity of IAS services for disabled young people and those with SEN and their families (e.g Parent Partnership Services) and for disabled young people 18+ and their families (e.g Disabled people ULOs and other local authority IAS services);
- Ensure there is a strategic approach to developing good IAS for young people moving into adulthood;
- Explore how PPS can be developed to meet the new duties in the Children and Families Act as a single point of access signposting to other services;
- Ensure that professionals responsible for developing the Information and Advice service in the Care Act are working closely with those developing the Local Offer and PPS;
- Consider establishing a joint information and advice offer across all age groups, or across the 0-25 age group.

Local Authority EHC Feedback

Number of cards received:

- January 2018 - 5 (compared to 4 cards in January 2017),
- February 2018 - 6 (compared to 5 cards in February 2017),
- March - 2 (compared to 6 cards in March 2017)

Respondents:

- 13 parents/carers
- 0 children / young people
- 1 unknown

Rating of EHC planning meetings:

- Excellent - 11 (85%)
- Good - 2 (15%)
- No response - 1

Rating of SEN Officers:

- Excellent - 12 (86%)
- Good - 1 (7%)
- No response - 1 (7%)

Do you feel as though you were listened to and included in the EHC planning meeting?

- Yes - 14 (100%)
- No responses - 0 (%)

Were you happy with contribution of professionals at the meeting?

- Yes - 14 (100%)
- No responses - 0 (%)

Comments about how we could improve the process?

all of it
help understanding my daughters' need
It's quite a long process
None - very good

Parent Carer Support and Needs – Survey Analysis

Further to the survey analysis conducted by C. Dias some data was gathered relating more specifically to parent carers as a way of considering the impact of the SEND reforms on families. The section above refers to resilience and parent carer involvement which needs to be supported to ensure an increase in satisfaction and ability to manage. Whilst caring for their children/ young people parent carers also have to learn a new system and navigate an ever changing SEND landscape which impacts on their mental health and wellbeing.

Common Themes/ Concerns/ Experiences

The above section has been placed in this report to demonstrate how information is gathered and that there are some positive areas of work occurring and some negative experiences of system that is struggling to meet the needs of an increasing population. There are a number of common threads occurring across surveys, focus groups, feedback forms and Facebook polls/ discussions that are in more which one area of the overall report:

Information, Advice and Support

One area parent carers have demonstrated needing further assistance relating to Information, Advice and Support Services (IASS). When asked how parent carers access IASS 54 out of 89 who answered the question stated the following:

Sources of IASS

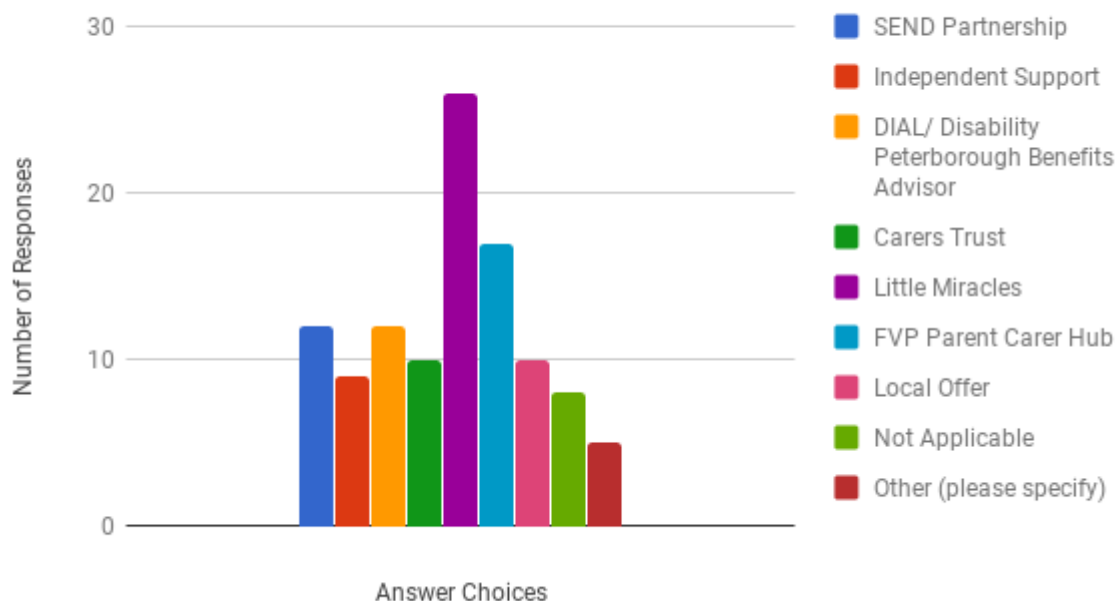


Fig. 43 Preference for IASS sources

A follow-up question asked parent carers why they chose the methods they stated in relation to IASS. 36 parent carers answered the question and presented a variety of reasons

- Early Help Pathway confusion and misinterpretation from parents and professionals
- SEN support is not meeting children/ young person's needs
- Lack of funding for service delivery
- Parent carer mental health and wellbeing – need for support
- When accessing services satisfaction increases and feedback is more positive
- Overall participation is increasing at a collective level with online methods being preferred

Feedback Statements

Education Access Support	Mixed Support/ General Comments	Benefits Advice/ Support
Due to no help from school or other services	Members of groups. Asked for advice through these groups from other parent carers	DIAL/DP – Citizens Advice did not have anyone who could help with filling in the DLA (nor in I main office as I went to the Honeyhill site) who has knowledge of the children's part. CAB printed help information off the DIAL website. I went to DIAL who are helping me with my appeal for DLA. I tried to get their help at MR stage but they did not have availability to see me before the deadline.
Because they are supportive of home education and have a lot to offer	run by parents who do research all the time, and better form of experiences honest experiences	To help to claim benefits and form filling
SEND PP – I was advised by Maxine from Scope as the school were not following an OT report.	DP: Help with Benefits forms. CT: Help for issues other than as a Carer PCH: Where I knew I would be able to see Ms Nichols if I had a query	My community nurse said they would help to fill in the DLA forms as I can't read and write, also they would tell me about benefits I would be entitled to
I was signposted to them by the SENCO at my son's previous school.	Trying to complete EHC plans and claiming benefits	I was referred by my nursery to Disability Peterborough to help me filling in my DLA claim form. I reused them as the adviser was very helpful and helped again with the forms and where else we can go to for help as the school are not supporting my child.
Because I knew they were able to help me at times I needed such as ehc transfer, dla review, school issues etc	I know what they had to offer	
Ehc was organised for my daughter in senior school before college	Used to use for support.	
Met a lovely lady called Nina out and about and got talking and she advised me about Family Voice and through them then SEND where another lovely	I was referred to them as I heard they help parents with disabled children in many ways.	

lady (Marion Deeley) helped us get the school provide our child with the essentials (hopefully)		
To get accurate information about schools responsibility of care for children on sen	Just what ive known. Other parents support too... experiences shared are far more informative ghan advice from LA which seems very poor	
I needed help to change school for my son	Good reliable sources for getting information.	
Attended a workshops training and Facebook page	Was advised by another parent about the group. Don't use it too often though	
	Fvp are an umbrella service so they know about everything!!	
To help gain information for referral for my son for ASD assessment and then to apply for an EHCP for him.	Little miracles have been life changing for my family. Not only have my children received support and made friendship so have us as parents	Support to fill my son dla form
	I've gained numerous qualifications and experience of so many things.	
	To get support, advise and meet other parents with children with send.	
	Little miracles are fabulous, great advice, always welcoming and lots of other parents to talk to that understand and don't judge.	
	I used little miracle I and when I needed any Advice or help with forms they helped me	

Fig. 44 Parent carer comments regards sources of IASS and why they are used and more general SEND experience

The responses demonstrate the types of IASS parent carers are seeking and also show the added pressures they experience as carers especially in relation to education for their children/ young people. Parent carers feel embattled by their experiences and one area that occurs consistently when views are sought relates to SEN support which is further evidenced by the following data:

54 parent carers answered a question relating to their experience of SEN support, the results of which show a 46.3% level dissatisfaction.

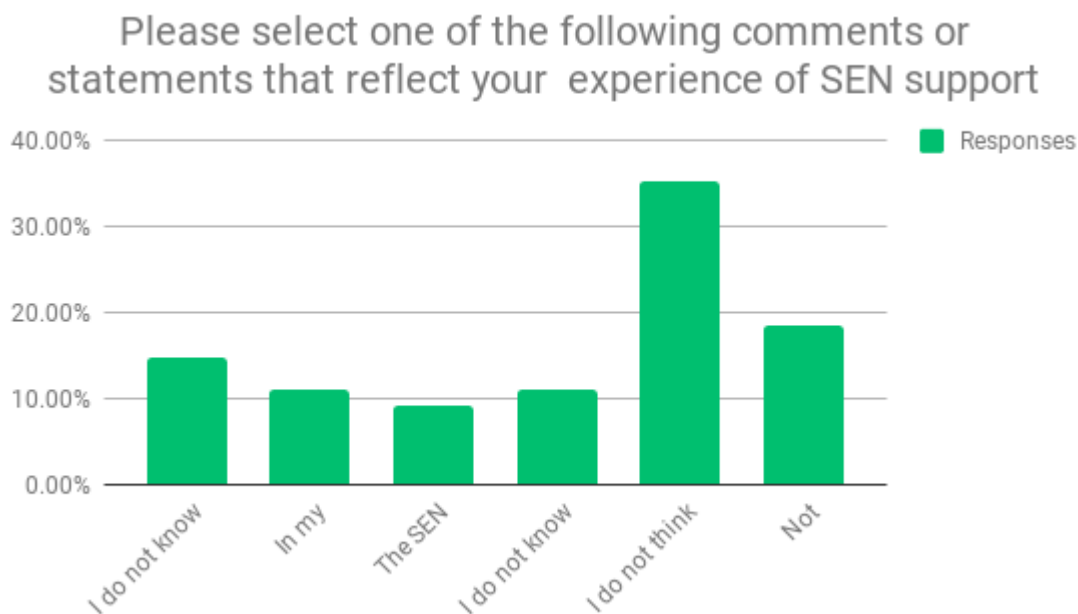


Fig.45 Parent carer experience of SEN support based on predefined catagories

This is further supported by the following comments from four of the parents who opted to provide further information.

The sen support is at a very low standard
They provide as much as they can. The do no have enough TAs so she doesn't get the help needed here.
I find it a murky world and have previously not known if child on sen register or not.
We have had very variable SEN support for our son. Currently his TA at school is excellent and he's making fantastic progress - but this is entirely down to having the correct person as his TA. If that person were to be removed/changed, then the likelihood is that the quality of SEN support would drop significantly. I don't think that the "process" recognises this.

Fig.46 Statements reflecting Parent carer views of SEN support

A further set of questions were asked of parent carers relating more to their own experiences and views in relation to 'carers'. The responses to these questions further evidence the impact the SEND reforms are having on families in conjunction with decreasing budgets to effectively provide the support required to help children and young people achieve the best possible outcomes.

When asked if parents consider themselves as carers 49 who took the survey answered the question. With 77.6% saying yes and 12.24% saying this did not.

SEND and Parent Carer support 2017 to 2018/Do you consider yourself as a Carer

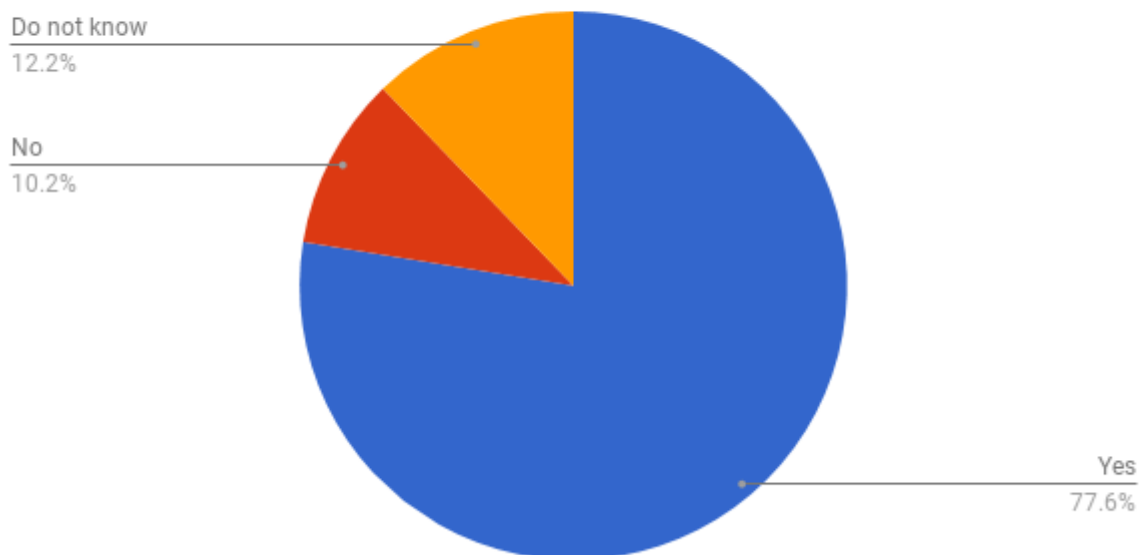


Fig. 47 Parent self-recognition in relation to carer for a SEND child/ young person

For a follow up question relating to being in receipt of carers allowance which could be an indicator of recognition of being a carer 41.67 said they did receive carers allowance. 48 parent carers answered this question.

Do you receive carers allowance

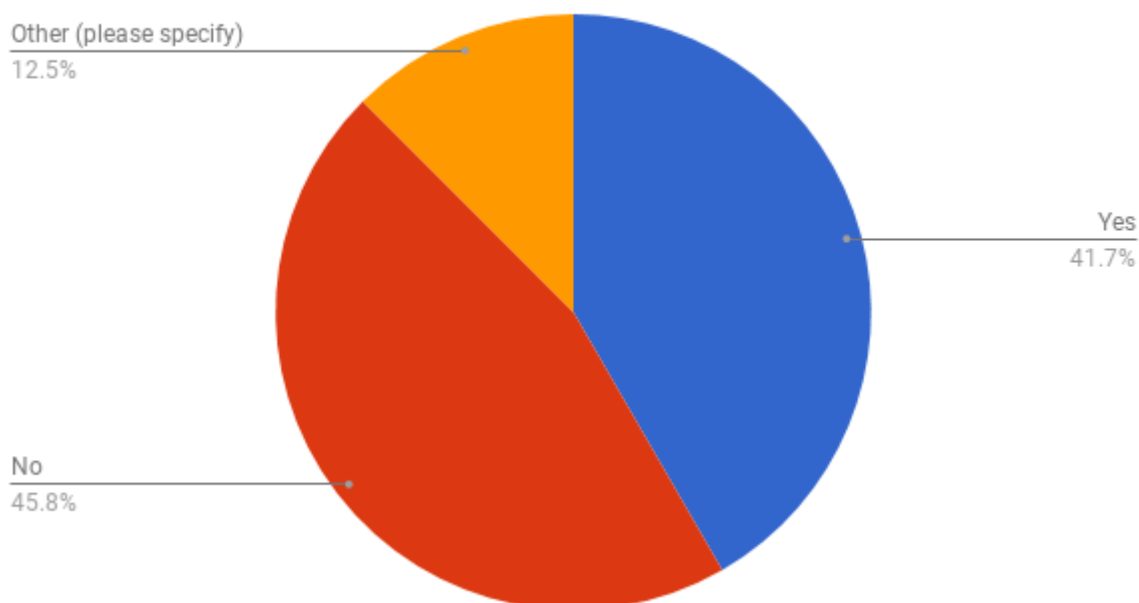


Fig. 48 Number of parent carers in receipt of carers allowance

There are a number of reasons to consider why a parent carer may not get carers allowance; carers allowance is related to other benefits and if these are not received at the right level then it cannot be awarded; parent carers may be working and earning too much.

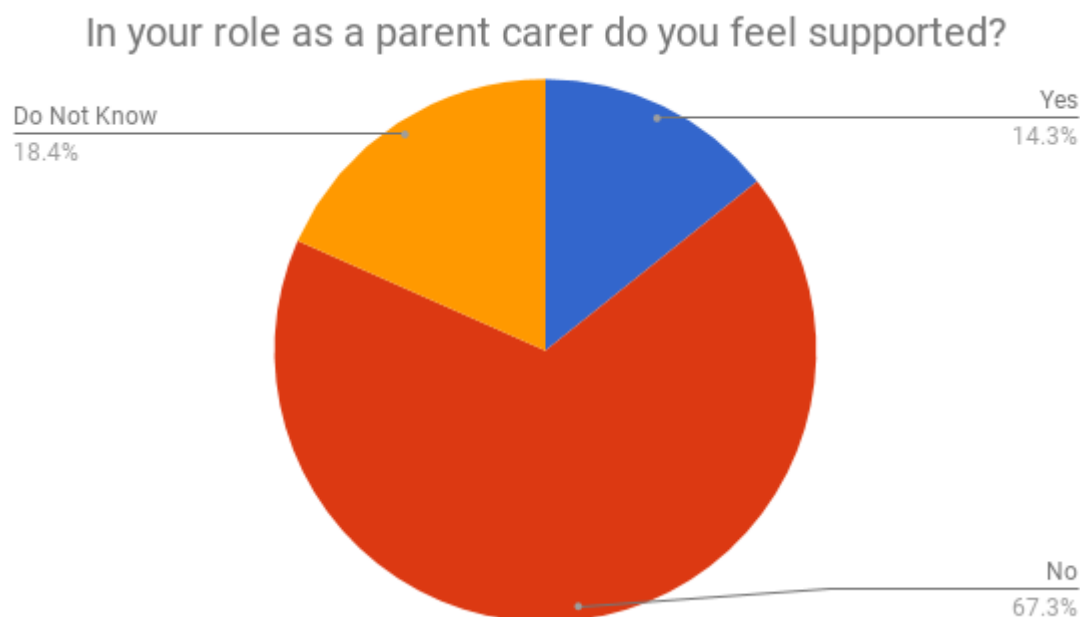


Fig. 49 percentage of parent carers who report feeling unsupported as carers

A large majority of the parent carers who answered the question ‘in your role as apparent carer do you feel supported’, 67.3% said ‘no’ and in a further question ‘does your role as a carer affect your wellbeing?’ a majority of 67.35% felt it did.

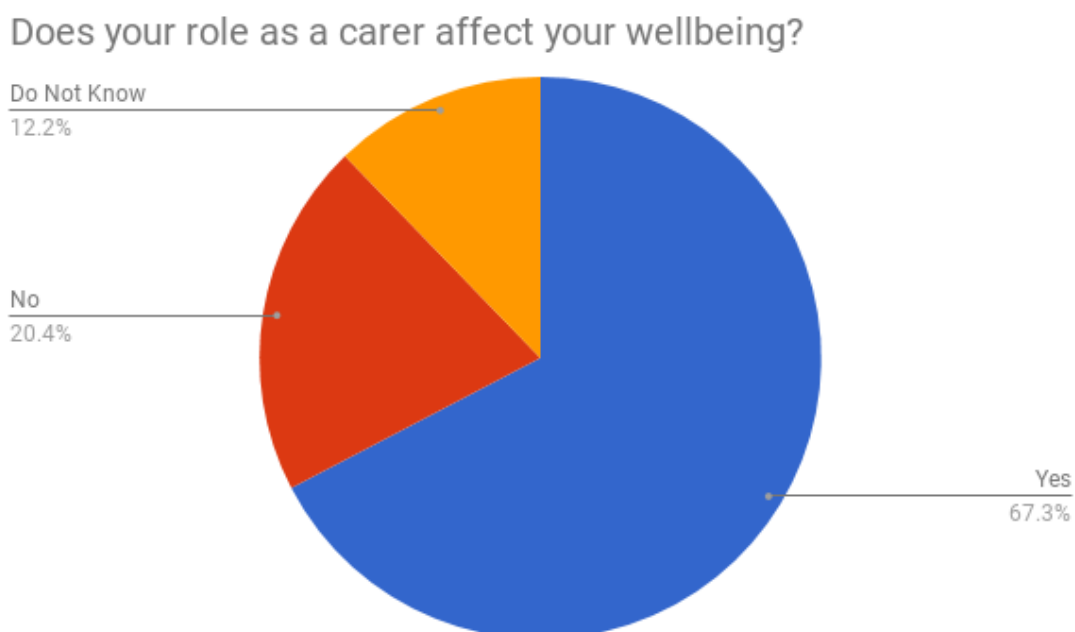


Fig50 Percentage of parent carers reporting that their wellbeing is affected by caring

Two further questions were asked after this relating to having a change to have a social life and being able to go to work with again the majority reporting that caring for a child/ young person with SEND meant this was difficult.

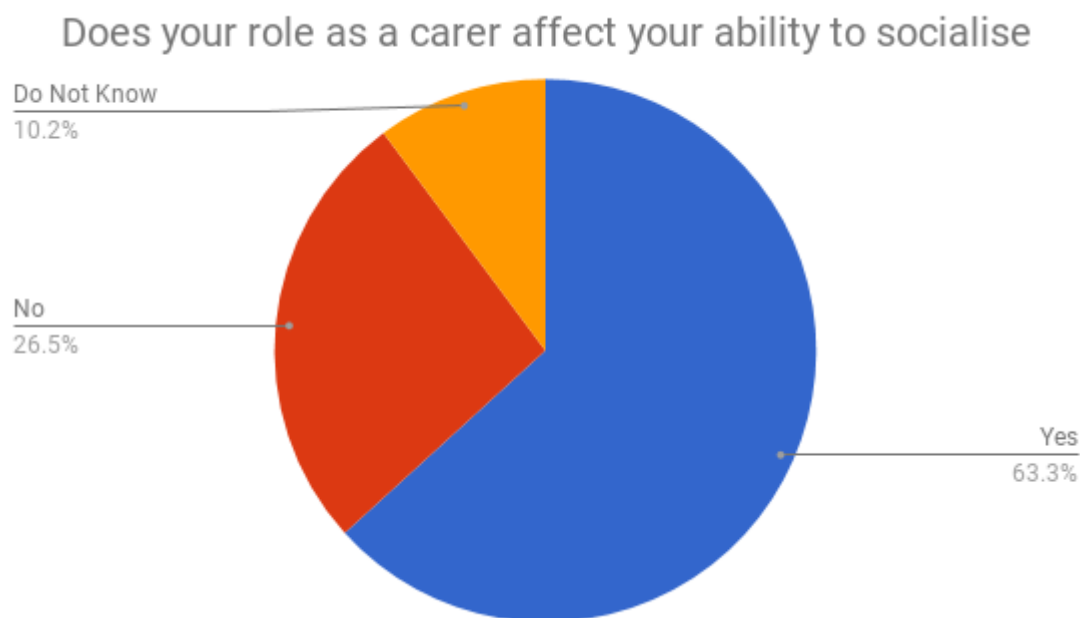


Fig. 51 percentage of parent carers who feel caring impacts on a social life

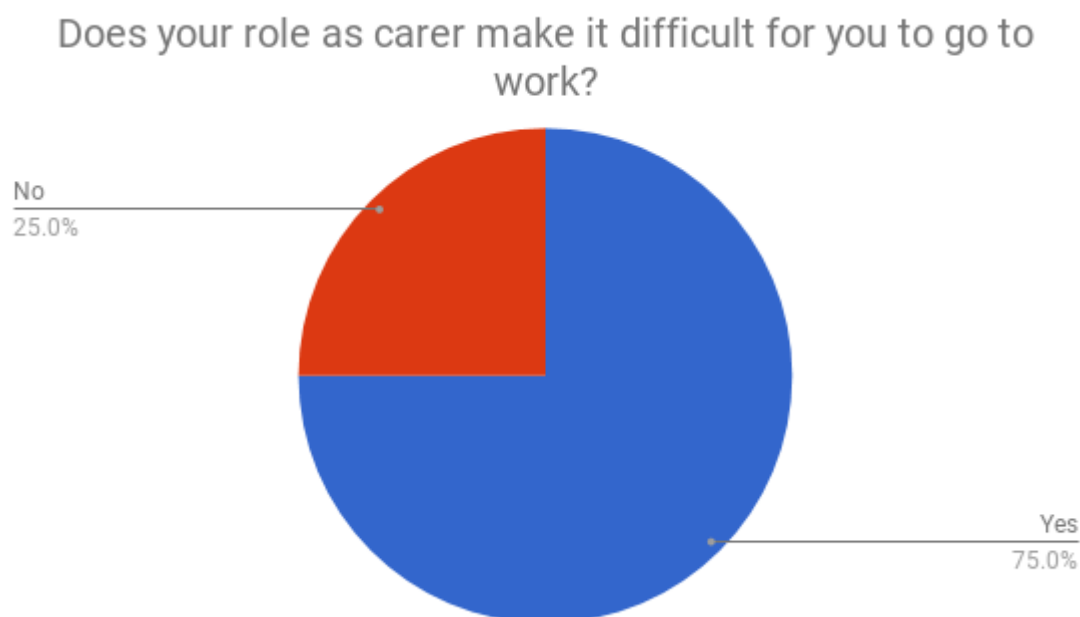


Fig. 52 percentage of parent carers who feel caring impacts on their ability to work

Although the numbers who answered the above questions could be considered low it is concerning that the majority across all areas felt unrecognised, unsupported and unable to work and socialise due to the fact they have a child/ young person with SEND. If parent carers feel unsupported and are unable to go to work the economic burdens they face as families are increased and the less able they are to support their children/ young people to thrive.

So if parent carers feel unsupported and they want support, what would this support look like? What types of support have parent carers been seeking out already?

The following are types of support parent carers tell us they have sought, select any that apply for types of support

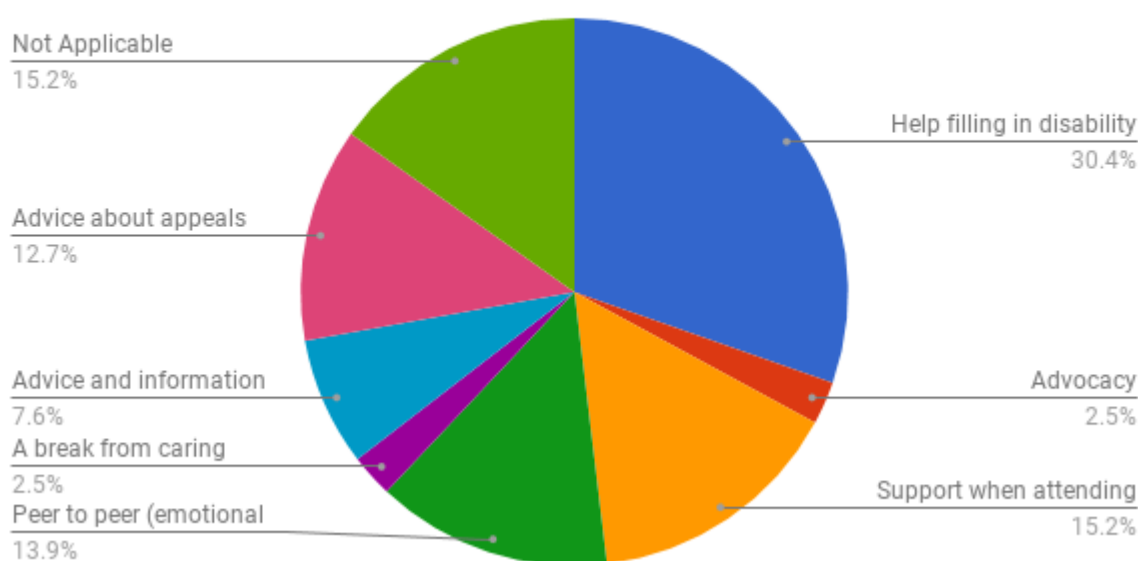


Fig. 53 percentages of types of support parent carers have sought

Parent carers are seeking support to help them navigate the SEND system and manage financially with added burden having a child/ young person with SEND can create

Help filling in disability benefit application forms
Advocacy
Support when attending meetings
Peer to peer (emotional support)
A break from caring
Advice and information about complaints in health, education and social care
Advice about appeals and mediation relating to EHC processes and plans
Not Applicable

Parent carers were given the opportunity to provide any other information they felt relevant and 19 took the opportunity to do so.

I have appreciated the help from DIAL as it is very difficult to see all the negatives or problems in your own child as you are living them everyday. I feel they will help me to put together a better case as they are not involved emotionally and can see the wood from the trees. CAB were not able to help and if DIAL were not able to take my case, then could you advise where else I could have gone for benefits advise that gives me personal support, should they ever have a waiting list again and are not able to help?

Overnight
respite care

Camhs only allocated 10 weeks to 'help' my daughter as they struggled to help her engage with them they discharged her from their services.

I pay for private SaLT and Physio for my son as I do not get help from hospital here

*Children without
EHCPs are suffering
and neglected*

respite is a major concern for a carer not enough and is desperately needed for all carers so can do their role, we get so burnt out and run down which has a negative effect on the rest of the family

There is still (despite legislation including disability discrimination laws etc) an unfair treatment of children with SEN at schools. The complexity of their needs often creates a scenario where teachers/management will opt for a discriminatory route by sanctions or exclusion (whether from school or other activities), simply because it is more convenient for the school than having to find an inclusive solution. This is not in line with the law.

SEN support should be ring fenced as it is clear that it is not used in the appropriate way and not supporting children the way it should be.

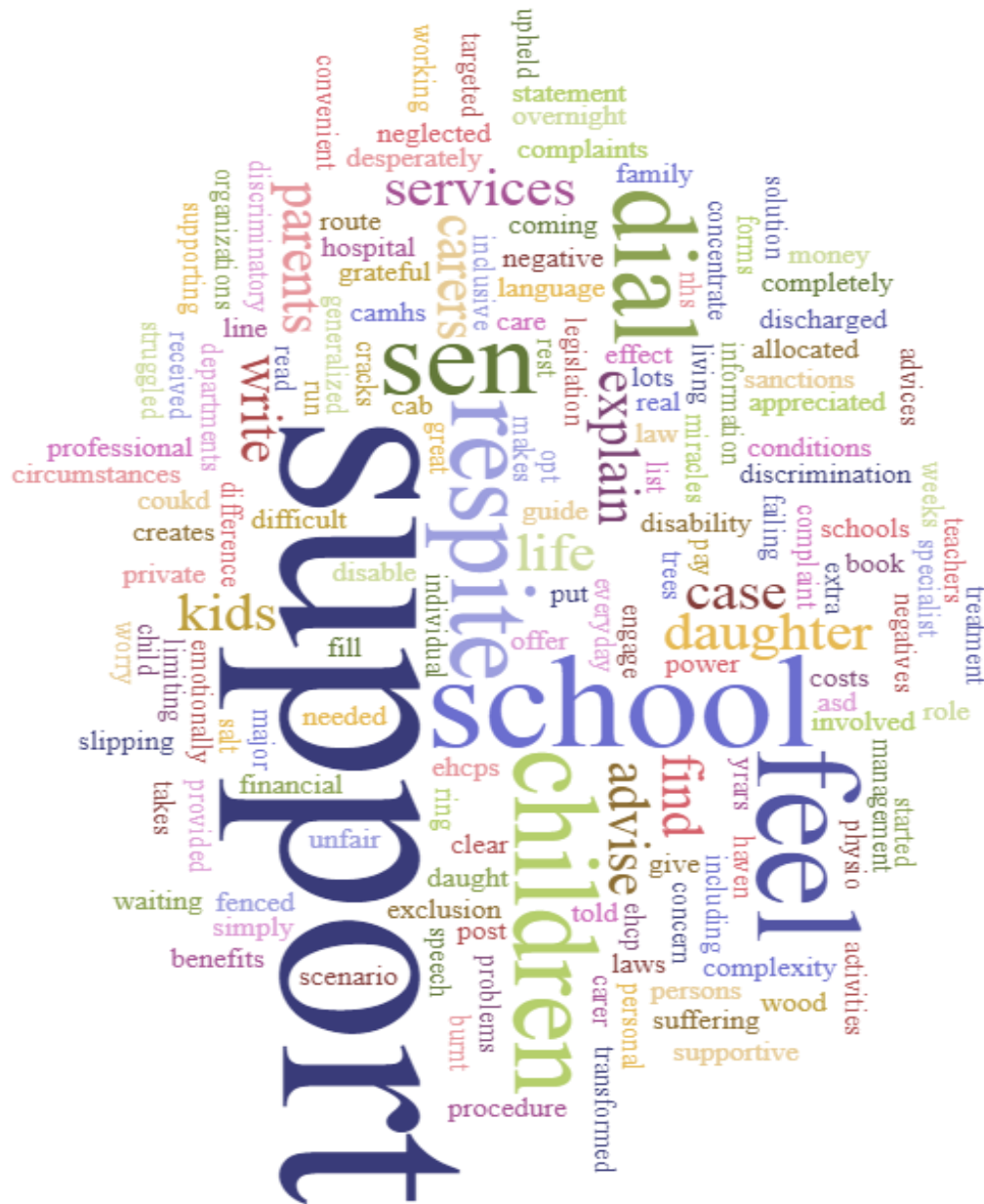


Fig. 54 word cloud generated from open question responses in SEND and Carer Survey

The above word cloud was produced from a series of answers to the questions relating to parent carer support and visually demonstrates the feelings of parent carers around their role. Word clouds are built on word frequency with the most frequent being displayed the most prominently and top is ‘Support’.

A final question asked in this set of surveys related to general views overall of the SEND reforms and services relating to SEND. ‘Do you think any of the SEND Reforms, Services and Support for families who have children/ young people with SEND or other needs are creating barriers to support?’

Barriers to support

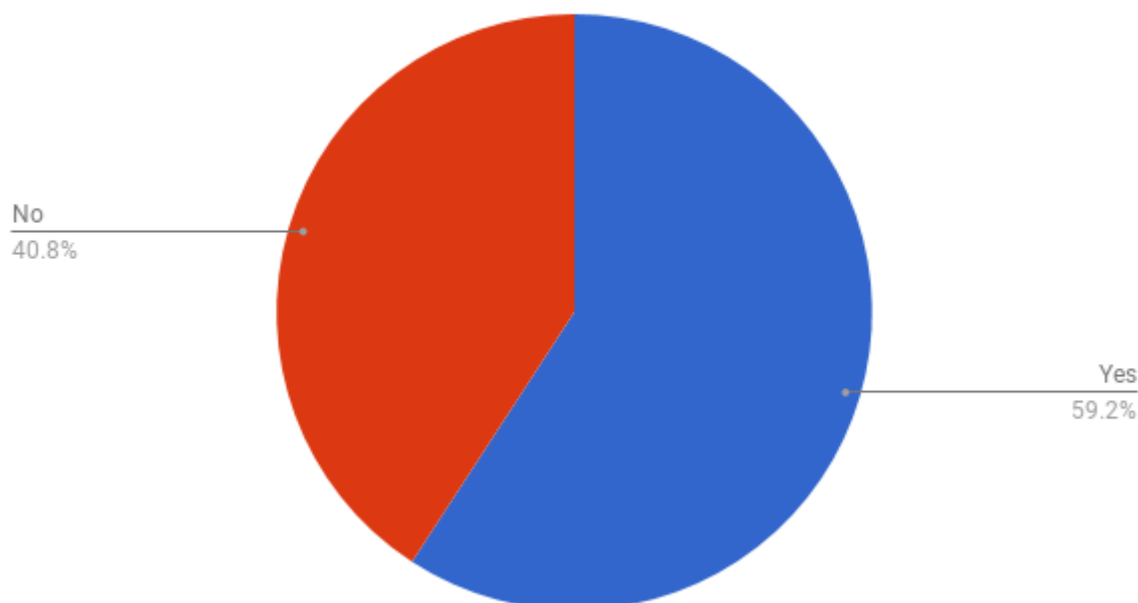


Fig. 55 Parent carers who feel the SEND reforms have or have not created a barrier to gaining support for their child/ young person

- *Everything is so long winded and drawn out to get any support or referrals you need for your child and worse of all to get them assessed because your child has learnt to MASK there are no services that support girls who can MASK*
- *The bar seems to have been raised to be able to get a EHCP compared to the previous way when it was a statement. I hear less children are getting the support. Having to do a parenting course before my son was seen at CAMHS was a way to keep NHS waiting lists down and not a benefit to myself as I knew most of it as I work in the childcare sector.*
- *System is complicated and doesn't work waited 3 years for a paediatrician appointment*
- *i think the parents voice are heard its just not acted on by professionals*
- *Not enough parents understand the changes so are not using the services available to them*
- *The send reforms have made it extremely difficult for families with children with ASD to get support in the areas needed. God forbid your child can add and spell. If so there is no support at all.*
- *Processes are long, convoluted and stressful for parents to navigate.*
- *I find the school is very unhelpful and live in a cloud*
- *I don't know about them and are having difficulties with school SENCo supporting my son*
- *After diagnosis ha E been signed off everything from hospital with no further support only a couple of sensory work shops*

- *I have no idea about a lot of the reforms, but one and that was to take away the option of the mobility scheme away from parents with children with mental disabilities. My life is impossible with no car. My son refuses to walk I can't carry him he is a big lad for his age. But because of he can walk we are deemed as not in need. I am confined to my home most of the time because it is nearly impossible to go anywhere due to meltdowns and refusal to walk. Even getting home from school is a very daunting task it's got to the point that sometimes I have to get a taxi from up the road to get him home, this is no joke!! I think the mobility scheme should be available to people on lower rate mobility too, just means they would have to pay just that little bit extra which I know that people in my situation would more than glad just to pay that little bit extra just to be able to perform normal everyday tasks just every other person.*
- *Once we got EHC plan, SEND support seemed available, more or less*
- *I feel that children without EHCPs are neglected*
- *Children are not being added to waiting lists at the start of the process and parent not listened to.. being made to feel like its their fault. Even when school do not think parenting is the cause .. usually delaying around 6 months*
- *Closure of the Manor and lack of respite care will have a major impact on me as a single mum*
- *I think that while the early assessments and support is available, parents should use it to gain access to further support if needed*
- *No access unless diagnosis and even afterward no information provided that is relevant*
- *I don't feel like the different services communicate enough or look at the child as a whole person. As a parent I also felt excluded from the decisions being made about my son by people that had never even met him.*
- *Apparently I cannot access carer support via gp or carers trust as gp says my youngest child doesn't have asd as they didn't diagnose (it was done via health visitor/early years inclusion office).*



Using a word cloud to visualize responses to a different question again shows the prominence of support for parent carers.

Parent Carer Story

I believe Parent Carers have a lot of challenges to face especially as their children get older.

Take for example, my experience; I have two children with additional needs as well as other children. I am only earner in the family and I work part time. The age of my children means that although two are now adults and one works, they are still not old enough to earn minimum wage and so cannot contribute very much to the household bills, something the government expects them to do.

My oldest child with additional needs is 19 and as her education has finished all benefits have stopped other than pip, although I am entitled to carers allowance because of the amount I earn a week it puts me over the threshold of being able to claim it. My 19 year old is also not old enough or independent enough to be living on her own, managing own bills, income etc although she is getting better at it.

My other child with additional needs is 16 and due to not coping in most social environments is home educated. This in itself presents a problem because as I work he can only be supervised with education on days I am not working as leaving set work with him when I am working often results in him not doing the work or having screaming fits over something he don't understand.

I have tried paying for one to one tutors on certain subjects this can be very expensive and I get no help covering the cost; I have had the experience of the tutors not being able to cope with the outbursts of my son resulting in a refusal to teach him. This leads to me feeling frustrated and that I am not doing enough for my son and who in turn is also frustrated and also that he is a failure which doesn't help his behaviour and attitude in any way.

My 16 year old also struggles with any decision making and so although he has been taught to cook for himself, If I don't give directions in what to have, he won't eat till I get home from work because there is "too much choice". When he goes to the shop he takes over a hour to make a decision in what to get. This leads to many outbursts if going to a supermarket or town as he is frustrated and invariably takes it out on everyone else if they say anything to him.

As both my children with additional needs are not great sleepers this has led to nights where I have had to get up and sort out arguments between them. I am often woken because they have woken up or can't sleep and the 16 year old especially wants help sorting a drink or food or their laptop/ internet etc.

With our economic status being what it is I am left to juggle work, this includes trying to do as many extra hours at work to make ends meet because benefits don't cover it and as my oldest child who is 20 works, benefits are further reduced as they expect him to make up the shortfall in rent etc per week even though he isn't earning enough to do so.

I am also worried that a move to universal credit will result in an expectation to visit the job centre for work interviews and an expectation of finding a full time job or more hours at my current work which because of the nature of the job doesn't always exist.

I am expected to juggle work, increase hours to pay bills, oversee the education of my children as well as be a carer and sort out all the issues that go along with it. Although I have a partner due to some health issues he does not work is limited to the type of work he can do, he also looks after our youngest child who is two. Although he is there to look after all the children's needs when I am working, the 16 year old doesn't interact well with him and I often come home to some argument having erupted and have to deal with the fall out.

As a result I am over tired, often exhausted, frustrated and often angry as I don't feel supported by those around me; juggling to keep a roof over everyone's heads, pay for all the things the family needs and deal with the day to day responsibilities of caring for a family on top of caring for two people with additional needs who are adults or teenagers.

ANALYSIS

FVP have seen a marked increase in the numbers participating this past financial year of 44%. All aspects of FVP work relating to the grant funded work in this report has maintained a participatory element to enable the parent carer voice in any work FVP is involved with. Much of the increase is related to the use of feedback systems on trips/ activities for the whole family and online methodologies (e.g. Facebook and Survey Monkey).

The work relating to SEND more generally and the data gathered in this area is also evidence of an increasing and more diverse group of parent carers choosing to participate. Parent carers have helped inform the continued development of the LO, Short Breaks community based provision, Peterborough and Cambridgeshire's joint SEND Vision and the Early Support Leaflet.

Through Participating in SEND Services (Health/ Education/ Social Care) development, design and delivery and analysing the views of parent carers a number of themes/ trends have been identified:

8. Participation is varied and parent carers are representative of a diverse populace with child/ young person needs varying from ASD through to Complex Health.
9. 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.
10. 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
11. There is an increasing number of parent carers who are considered seldom heard who are becoming informed/ getting involved.
12. The level of dissatisfaction with services is increasing, particularly in relation to SEN support in educational settings and the Early Help pathway.
13. A larger proportion of parent carers report difficulty getting access to support for their child/ young person especially in relation to mental health support and educational support evidenced through Facebook discussions and surveys.
14. Resilience is low amongst parent carers to manage their lives and care for their children/ young people without support and there is increasing risk of more carers requiring more expensive support services.

Overall 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 and 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.

It would also seem from evidence presented in this section and elsewhere in the report more parent carers are feeling unsupported and experiencing difficulties accessing support for their child/ young person which seem to have increased concurrently with increasing budgetary constraints being faced by services. Increasing demand cannot be met by the current level of service available to families. Some views are that children with only the most complex physical/ health needs will get a service and that those with mental health needs/ neurodevelopmental disabilities are being left out.

SECTION FOUR (SELDOM HEARD)



INTRODUCTION

The work relating to seldom heard groups is in its third year and is still ongoing. Traditionally engagement with and involvement from parent Carers from Seldom Heard Groups is lower across the following categories:

1. Muslim, Traveller and Jewish Orthodox faith communities.
2. Polish, Romanian, Somali, Syrian, African, Indian and Pakistani communities.
3. Families experiencing domestic abuse/substance misuse.
4. Families with unsettled ways of life (e.g. former asylum/ recent refugee status).
5. Very low income families or families whose income drops suddenly due to a change in circumstances, self-employed.
6. Home educated children
7. Families with a disabled adult parent carer and particularly all those with learning disabilities or mental health issues.
8. Very young or new parent/carers.
9. New to caring role e.g. grandparent/kinship carers/foster carers.
10. Rare conditions – children with rare condition, family lacking support network/information.
11. Lack of digital skills/engagement/literacy skills and social media awareness.
12. Families with health conditions where disclosing status can have a wide-reaching impact.
13. Families who do not recognise their child as having a disability.
14. Rural or geographically isolated families.

Work has taken place to facilitate engagement with a wider group of parent carers considered Seldom Heard and to build trust in relationships with those who have started to engage over the past couple of years. Time has also been invested in listening to the parent carers to establish how they like to engage, what support they require to engage and what their issues are in relation to SEND services. The report will detail what work has occurred; provide some examples of engagement and data on the numbers engaging and the diversity of those engaging.

GRANT FUNDING

The funding has enabled parent carers from Seldom Heard groups to become empowered to engage with support earlier in the SEND process. Engagement and participating have led to inclusion for the parent carers. Facilitating inclusion fits with the early intervention and prevention agenda.

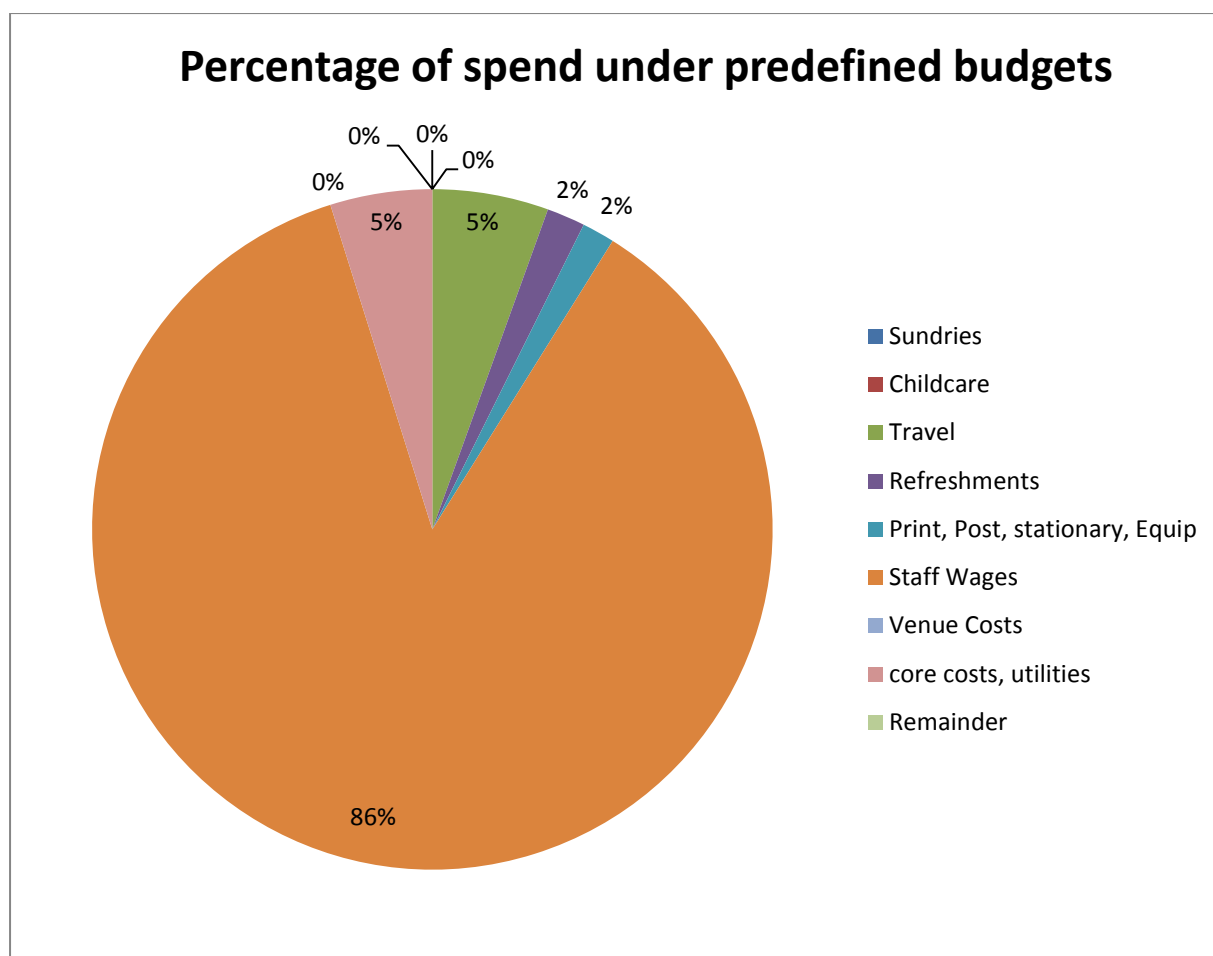


Fig. 1 Percentages of spend under predefined budget headings

The majority of this grant went towards staffing costs which enabled a parent carer to be employed to work closely with parent carers from seldom heard groups. Travel costs were used to enable the parent carers to take part in participation based sessions. Through the work from this project the parent carer has gone on to seek further employment with another organisation delivering direct support and other parent carers have started volunteer positions for various organisations.

The staff member invested approximately 700 paid hours and more voluntary hours in addition to this meeting with parent carers, using different methods to enable them to share their views and working at times to meet their need.

Health engagement/ Early Support

This year time was invested in enabling parent carers to help develop a leaflet about the Early Support Pathway. Sessions were held over breakfast with ladies from the Aiming High Group (AHG) and with an officer from the Local Authority (LA). The sessions were used to gather parent carer ideas, views and input in to the leaflet.

Other work was conducted to see what parent carers felt they needed support with when engaging in health services. The parent carers were supported to share their views via comments written on post-it notes which were then collated.

HIGHLIGHTS

- Greater parent involvement
- Community integration - London / Hunstanton and Activity world Trips
- Asian cuisine day
- Parent Participation Workshop
- Development of the early Support Leaflet

Some Work Conducted

- O-25 Service Facebook Discussion
- Asian Cuisine and Engagement Day
- 4 Breakfast Meetings
- 1 Activity World Session – OFSTED Readiness
- 2 Coach Trips (FVP Self-Funded) – SEND Visions Development
- 1 Parent Participation Workshop

Outcomes and activities for Seldom Heard Participation 2016 to 2017 – Family Voice Peterborough

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"> • Parent representatives are trained through the Family Voice parent participation training course • Reasonable expenses are met to facilitate parents and carers to attend meetings – childcare travel, etc • Appropriate supervision and support given to participation reps who attend groups/meetings • 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 	<ul style="list-style-type: none"> • Appropriate details of the parent reps given to facilitate planning and Local Authority organisation – scheduling meetings, etc, with acknowledgement of their training, skills, etc • Monthly highlight reports for each work stream, contributed to by the reps attending meetings • On-line parent rep feedback form system created and used by parent reps after meetings • Annual report
		<ul style="list-style-type: none"> • One participation workshop took place and two parents expressed interest in parent representation 	<ul style="list-style-type: none"> • Survey Monkey is used to upload parent rep feedback forms
	Improved trust in relationships between parent carers from a range of backgrounds and health, education and social care sectors	<ul style="list-style-type: none"> • Change in self-rating of relationships/ involvement with health sector • Involvement in health, education and social care sector work streams (development of early years guides, a schools directory) • Access to training (Expert parent Programme, Microsoft Basics, Parent Participation) 	<ul style="list-style-type: none"> • On-line questionnaire reports • Case study (at least one) • Co-produced "guide and directory" • At least 10 parent carers from diverse backgrounds have completed the EPP and report positive change
		<ul style="list-style-type: none"> • Parent carers have attended training and been involved in developing an Early Support leaflet and SEND Visions information 	<ul style="list-style-type: none"> • Co-produced leaflet now on Local Offer • Parents from diverse back-grounds in relation to ethnicity and economic position have attended different forms of training including EPP and Parent Participation. Some feedback comments are in the feedback section of this part of the overall report.

2	Operational representation across SEND work streams; LO, PB, EHC Processes, PfA leading to co-production across SEND services	<ul style="list-style-type: none"> Attendance and representation at work stream and task and finish groups 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 	<ul style="list-style-type: none"> Named, trained, Family Voice trustees who may be attending meetings Monthly highlight reports for each work stream, contributed to by the reps attending meetings Annual report
		<ul style="list-style-type: none"> The breakfast meetings have been organised by a parent carer who has been employed as a seldom heard co-ordinator who herself can be considered from one of the seldom heard categories. The breakfast meetings have produced information informing Health and Education commissioning/ services 	<ul style="list-style-type: none">
	Improved participation as a volunteer or parent representative	<ul style="list-style-type: none"> A more diverse range of parent carers acting as parent reps on operational boards Development of champions of participation amongst diverse groups of parent carers FVP support in form of buddying, pre-post meetings, admin support 	<ul style="list-style-type: none"> Registers and feedback forms from a range of opportunities for parent carers to come together, share experience and meet other parent reps Parent reps acting as buddies to parents who want to attend meetings/ focus groups then completing joint reports One parent rep course for parent carers to attend and learn more
		<ul style="list-style-type: none"> Due to family pressures and staffing pressures there has been no change in this area and the same two parent reps from this group are attending strategic meetings. There should be some change in next financial year 	<ul style="list-style-type: none"> An away day was held that facilitated team building which was funded via the DfE grant.
3	Parents and Carers are empowered engage with the Local Authority and their partners	<ul style="list-style-type: none"> Partnership approach through the steps described above, and the provision of themed focus groups – this may include task and finish groups, surveys and involvement through social media Be part of the feedback process for families, 	<ul style="list-style-type: none"> Parents and carers report positive change in their communications with the Local Authority and their partners Case studies provided

		to facilitate the understanding of the effectiveness of participation	
		•	• Parent carers report some positive change in terms of being welcome at meetings and involved in participation but not so positively in terms of accessing services

Fig 2. Outcomes and outputs for Seldom Heard funding

Numbers Participating

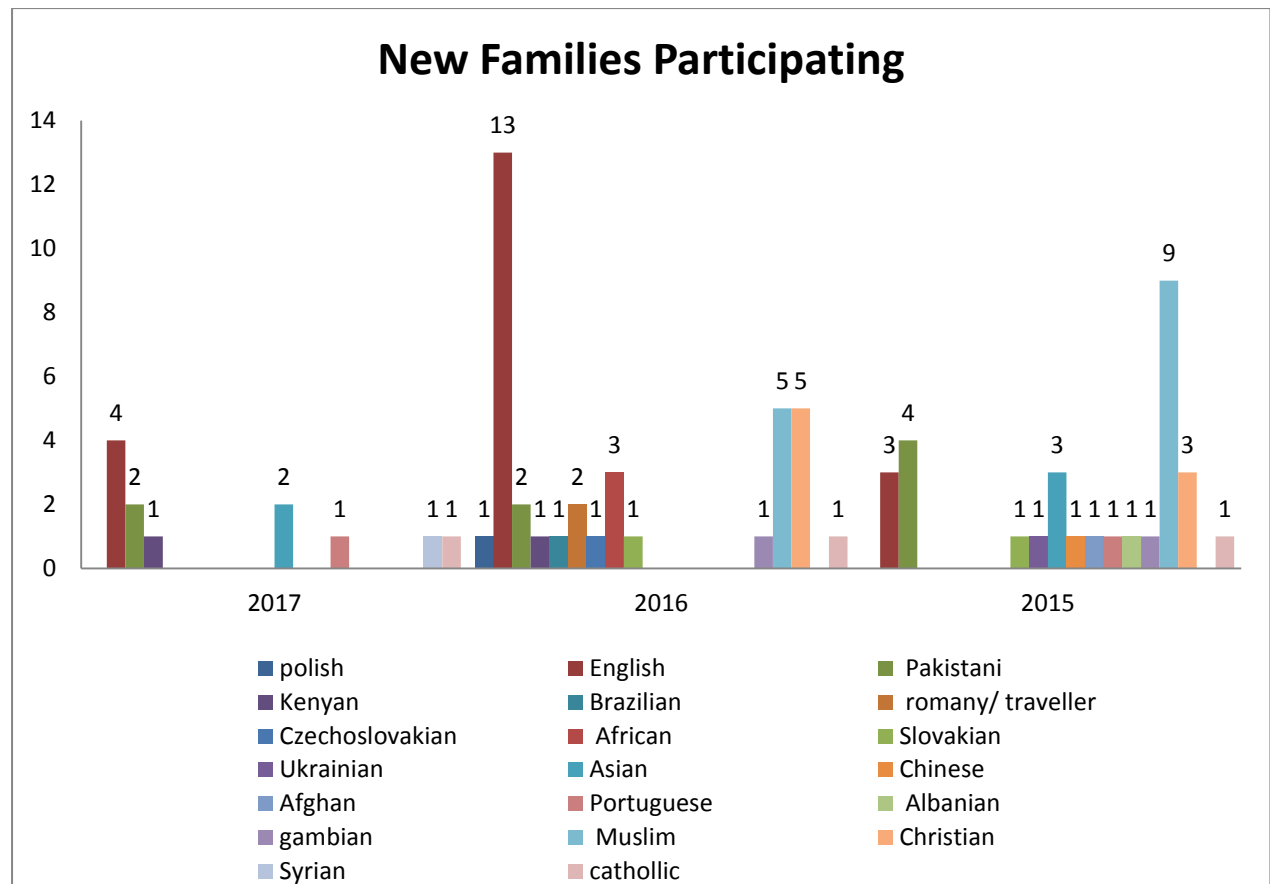


Fig. 3 Comparison of new parent carers from diverse backgrounds engaging with FVP

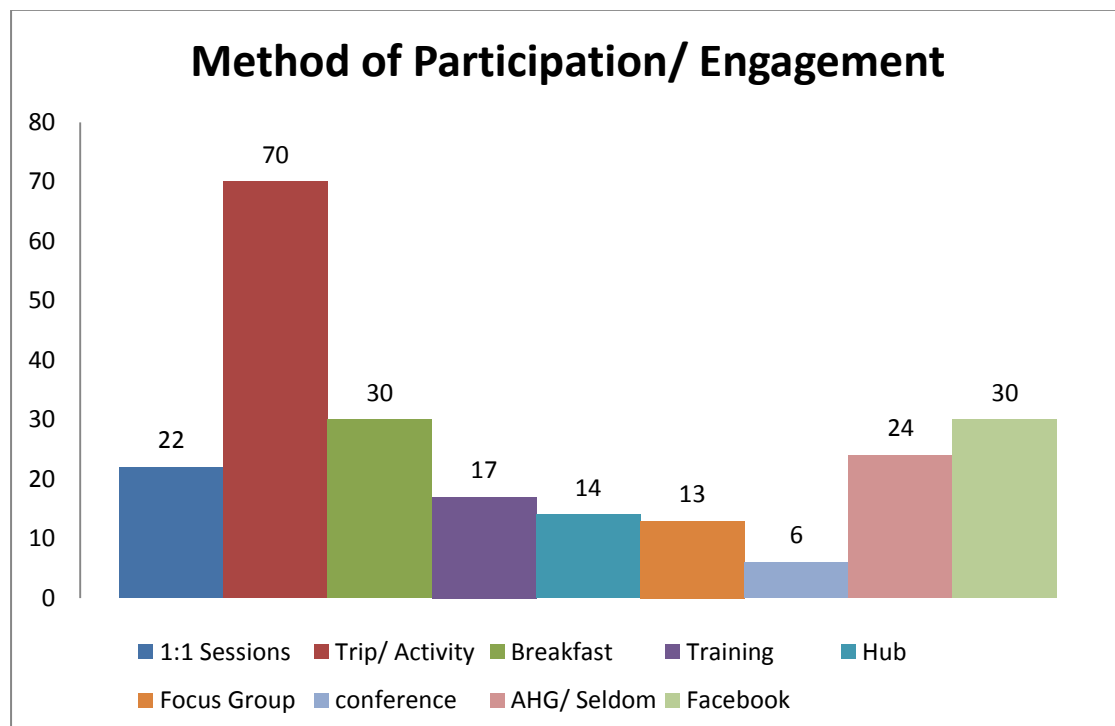


Fig. 4 Numbers of parent carers participating across different methods

Sample Reports From Seldom Heard Work

Asian Cuisine Day

This is the second year that FVP have facilitating this event. After the success of last year's event were FVP sore a turnout of approximately 75 individuals. So this year FVP aimed to build on the success of the previous year and strengthen are relationships with the aiming high group Within Seldom heard communities this gives an opportunity for communities to come together and interaction in a safe environment without fear of prejudice or discrimination whilst also giving other communities the opportunity to learn interact and appreciate the additional challenges that one another face.

The events

This year the turnout was extremely encouraging as there was over a quarter increase with 120 individuals in attendants not including the volunteers. This year FVP linked in with the national citizens (NCS) who support this event as part of their charity week. There were 16 NCS students as well as the supervisors who are supported during the event by serving refreshments, supervising garden games and bouncy castle, selling raffle tickets, providing and doing henna art & glitter face painting, selling tickets & singing people in and out, cleaning, upset or and set down, as well as networking. "This was an amazing encouragement "the lady's from the aiming high group provided all the home-cooked cuisine whit 8 dishes including Biryani, Cheat, Chicken samosa, season chicken wings, Gambian chicken, Indian kebab,

There was great cohesion across lots of different diverse communities, both young and old.

Activities

FVP provided at a variety of activities including

A bouncy castle

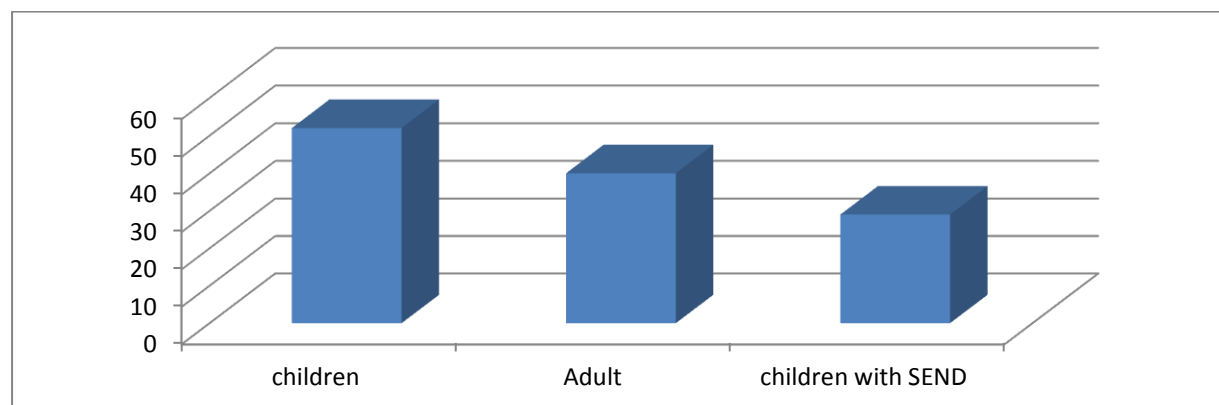
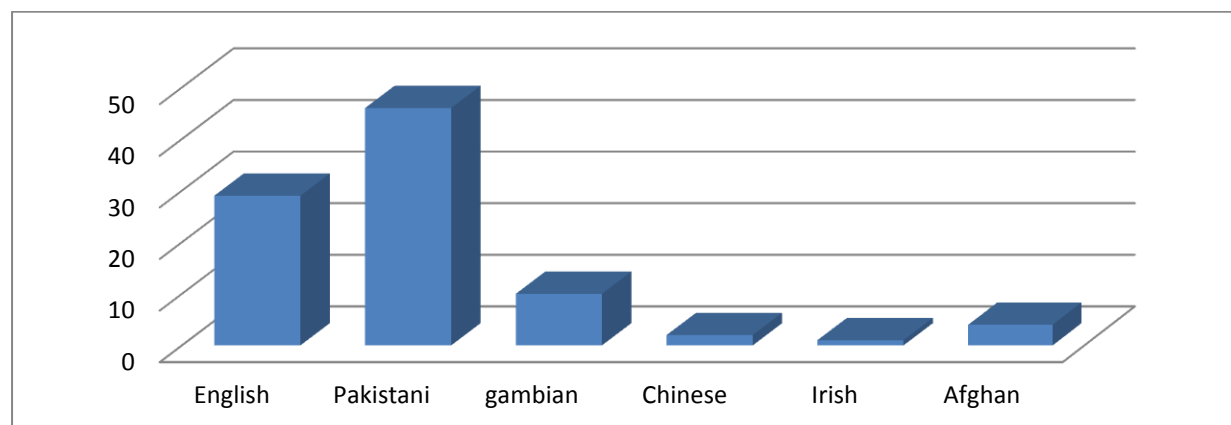
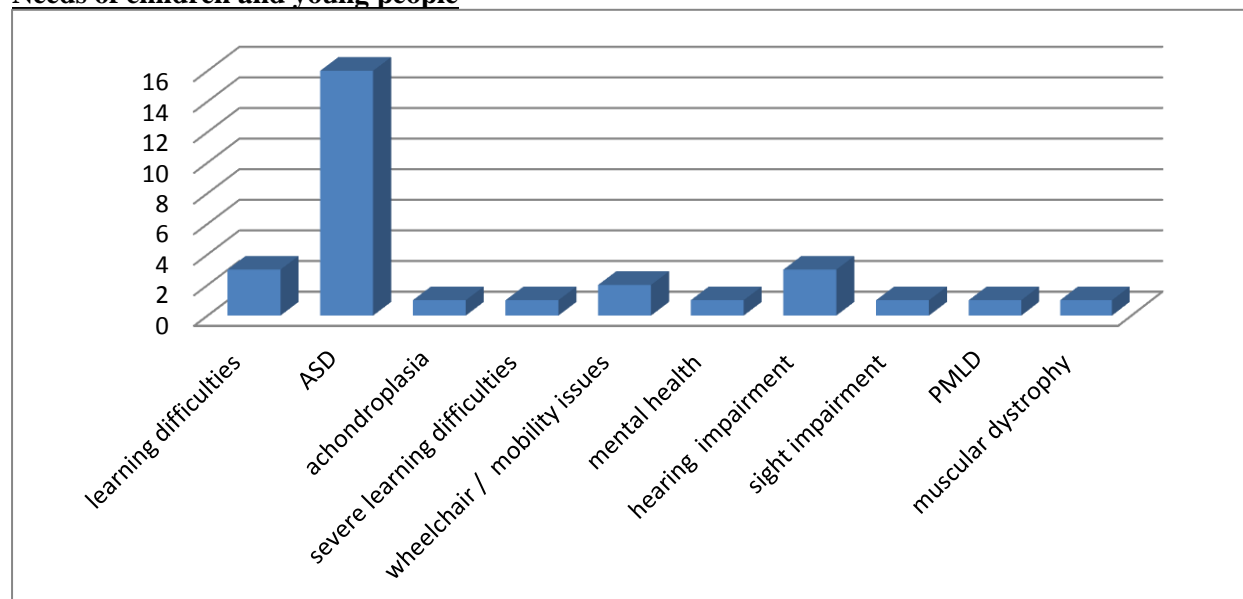
Garden games such as connect 4, giant jenga

Henna art

glitter face painting

Outcome

After over quarter increase on last year with a range of diverse communities, including the seldom heard, aiming high, all of the variety of communities interacted fantastically everyone was positive and said that they'd had a great time and learned lots about each other's communities and found things that they also share in common with one another this was demonstrated particularly well with the young people though play and the activities were there is no barriers for example though, language or disability and believe as play is the international language that all children can relate to and interact with. This is not only a great role model for the next generation but current society too. Where families have the opportunity to come together and learn from one another. As children and young people used play as an international language the adults used the cuisine to bring them together. It was also encouraging to see professionals and parent /carers alike come together and break down barriers in a safe relaxing environment. During this event we had a range of professionals that attended ranging from the head of the local council, members of the commissioning team, head of education as well as partner agencies such as a health watch Peterborough, the national autistic society and family action.

Attendees**Fig. 5 Attendees at Asian Cuisine day****Ethnicity****Fig. 6 Ethnicity of parent carers at Asian Cuisine day****Needs of children and young people****Fig. 7 Needs of children/ young people at Asian Cuisine Day**

A picture says 1000 words





The NCS crew



SEND Visions

The local authority has asked FVP to pull together views from parent carers around communication. However or instead of communicating what is wrong: as there is lots of evidence to say what is wrong. It would be good to hear from parent carers so they can articulate what SUCCESS will look like in practical terms. In that sense our voices are “visionary voices”

The questions the local authority asked were.

(1) What do you want for your child / young person? What do they want? This was facilitated in a pictorial form with suggestions and options.

(2) Are these things you would like to see? Hope for? (Outcomes)

(3) What outcomes would you like for your child / young person?

FVP asked 10 families to answer these questions ranging across a multitude of disabilities

The range of disabilities of the children and young people

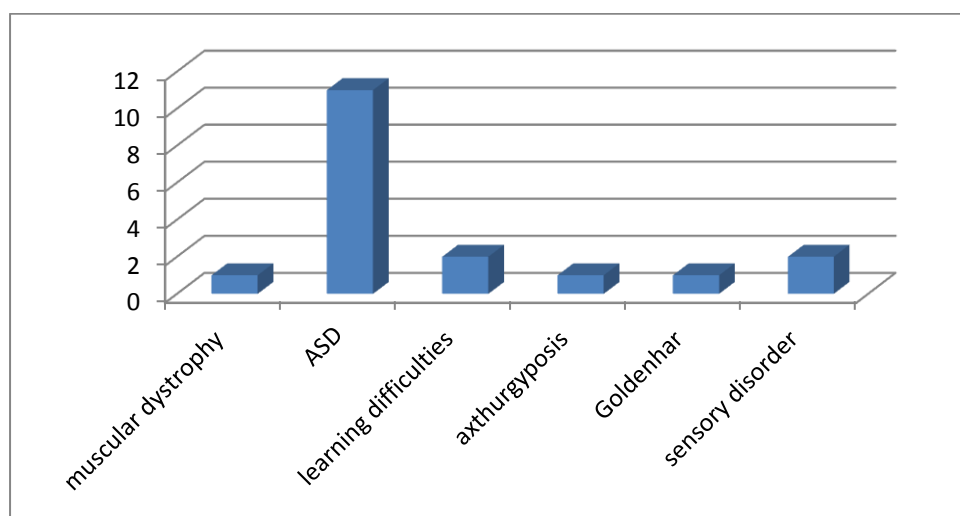


Fig. 8 Data on children of parent carers who participated in SEND Visions work

Outcomes

Q1 Are these things you would like to see? Hope for? (Outcomes)

Per suggestions –

	answered yes to included	not answered	not included
My child is happy	6	3	1
I can see a future for my child	6	0	1
My child is thriving because he/she is happy	3	5	0
My child enjoys life	6	4	0
I can see a future for my child	5	4	0
All the services around my child are listening to us	6	4	0
I feel like I'm a good parent	8	1	1
My child has all that they need to be independent	7	2	0
I know where to go if I need help	7	3	0
I feel like a normal parent	5	5	0
My child has friends	6	3	0
I do not feel that I or my child is a burden	5	5	0
My child will get a job	7	2	0

Fig. 9 Feedback on what parent carers would like to see for their children/ young people

Are these things you would like to see? Hope for ? (outcomes)
"yes"
"yes"
"yes these are the ones were hoping for"
"I hope for my child to have a good group of friends and to have a happy time at school"
" most I hope for, some statements are this and already achieved"
"im doing my best to repair all the non-help she was deprived of in maths all her school life.they thought A numerically a dyslexic but is slowly improving,needs maths in lift
"all these outcomes are taken for above"

Fig. 10 feedback on what hopes

What outcomes would you like to see for your child/ young person?
"all of the above and any training necessary to got a job"
" to attend school full time without being send home, to my son to be happy"
" apply for a collage place for sept 17 ask for ALS and use it when needed acieve a grade that will be useful, socialise out of the house, stay with the new friendship she made at collage 15/16"
" my child to to be able to lern basic skills e.g. read/write/swim/life skills "
"to have an inderpendart and happy life as possible with all support needed to do this in place"
"to live indepenanity by himseif"
"my child to enjoy life"
"heppy, stable, health condiition. Right support, friends,job"
"she is a born leader but must learn to curb this and let others have a say. Want her to be successful but needs to do the work to get the result"

Fig. 11 Feedback on outcomes**Overall summary**

A small number of parents/cares failed to understand the questions being asked of them and had interpretative them in a different way for example some parents/cares had written down as if each suggestion in the first question was a about their children and young people relating to their personal circumstances.

Some of the statistics for quite shocking for example more parent/ carers chose not to include my child is thriving because she/he is happy This suggests that some parent/ carers are after speaking to them that they still feel that they are struggling with positive in case it leads to the loss of provision

Breakfast Meeting October 2017

At this meeting there were 4 parent carers and 3 professionals all from a variety of backgrounds. There were 7 parent carers that had booked and 4 that said they may attend but did not confirm. The ethnicity ranged from African to British and the needs of young people ranged from ASD, SLD, including, genetic blood disorder, dyslexia and sleep apnea however 3 of the young people had ASD which once again seem to be the highest diagnosis across the young people. The ages are various for ranging from 8 – 14. The topic for meeting was to gather parent carer views on the all about me section of the EHCP which has just been redesigned so the local authority wanted feedback from parent carers to see if they felt it was worded friendly and or was it easy to understand and how did they feel about the use of pictures.

All about me

FEEDBACK FROM Focus meeting at Van Hage 3rd Oct

All About Me Form - Child/Young Person's

Child / Young Person's name: _____

Please complete this form to help us learn about you, what you are good at, what you need help with and what you want to achieve in your life. This will help make sure you get the right help or resources for you.

Things I am good at:...

Things I want to get better at:...

Things I like:...

Things I don't like:...

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Fig12. All About Me - Form 1

Parent 1 –

- Needs to be more specific
- Needs a section adding for things the child would like to see happen?
- “Things I like” could read as anything the child would want to know more about?
- Parent wasn’t aware that the schools asked the child their views, need to ensure you ask the questions in the right context to get an accurate answer.

Parent 2 –

- Boxes need to be bigger to fit more information.
- Needs to be age appropriate for the age of the child – teenagers need a more adult version. Maybe set up a draft for children and teenagers.
- Needs a section adding for communication.
- Needs to be simple to look at for a child with sensory issues.

Parent 3 –

- Likes the smiley faces on the form
- Understood it well/simple to use
- Straight to the point
- Boxes need to be bigger for ppl with bigger handwriting and like to write a lot.

Parent 4 –

- Plain boxes would be better with stickers that could be added if a child needs more stimulation.
- Needs to be age appropriate for the child's age, especially if an older child
- Boxes should all be the same shape not different especially for autistic children.

All About Me Form – Child/Young Person's

My hopes, dreams and adventures for my future...

I think I need help to...
(Think about what help you might need to do the things you want in your school, home or community.)

Your signature Your name (in capital letters) Date you finished this form	Please tick which box is correct for you <input type="checkbox"/> I completed this form by myself <input type="checkbox"/> I had help to complete this form
--	---

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Fig. 13 Part of All About Me - Form 2

Parent 1 –

- The hopes and dreams form is overloaded and too busy
- The signature sheet should be on the back of the form
- Needs to be simplified
- Doesn't ask the right questions.

Parent 2 –

- Need straight lines not wavy on the bottom section.
- Signature sheet needs to be moved because it takes up too much space on the page.
- The writing needs to fit inside the bottom box not overlapping.
- Needs to have the writing in a different colour to stand out.

Parent 3 –

- Straight lines plus writing only (simple box)
- Second version for those that need higher mental age with appropriate wording and literature.

Parent 4 –

- Signature sheet needs moving to the back of the form
- Likes the cloud but not the flag shape. Writing does not fit in the middle and too busy.

Fig. 14 Part of Different All About Me - Form

Parent 1 -

- Doesn't like the thought of having their child's picture on the front of the book. Thought it would be nice to have their child own drawing on it instead
- Wouldn't feel happy having their child's name on the front of the cover. Instead use a code or number system.

Parent 2 –

- Liked the idea of it being so personal and having their child's picture and name so it was easily accessible.

Parent 3 –

- Doesn't like the thought of her child's picture being on the front cover. She thought a picture of their child's favourite T.V character or toy would be really good to identify their own book.
- For safety reason she didn't want lots of personal information on show for everyone to see.

Parent 4 –

- Thinks a drawing from their child would be nice and personal instead of a photo.



All About Me Form – Parents

Child / Young Person's name: _____

Your name: _____

Relationship to the child / young person: _____

Please complete this form to help us learn about your child / young person, what they are good at, what they need help with and what you want them to achieve in their life. This will help make sure your EHCP Plan or feedback is about them.

Things they are good at...	Things they want to get better at...
Things they like...	Things they don't like...

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Fig. 15 All About Me Form 4

Parent 1 –

- Very positive wording but would be good to put something like “ changes the child would like to see happen “ ?
- Bigger boxes to fit the information

Parent 2 –

- Parent views need to be about my child and managing their SEND issues
- Bigger boxes
- More details and specific questions asked

Parent 3 –

- Parent views are very important and necessary to the plan
- Needs to be able to be reformatted in case you need more space to write information.
- Instead of early years for background it should read story so far!!
- Needs to incorporate questions like “what my child needs help with? “
- Needs to have on one of the forms the child’s communication method. This is extremely important for behaviour.

Parent 4 –

- Needs bigger boxes to fit info in.
- Looks neat and tidy, but boring for older children.
- More specific questions.

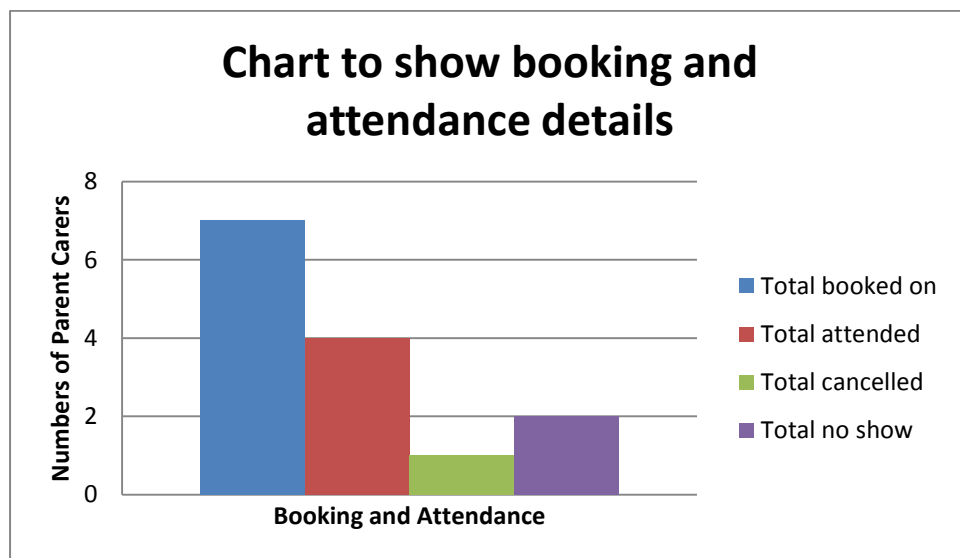


Fig. 16 Attendance at breakfast meeting

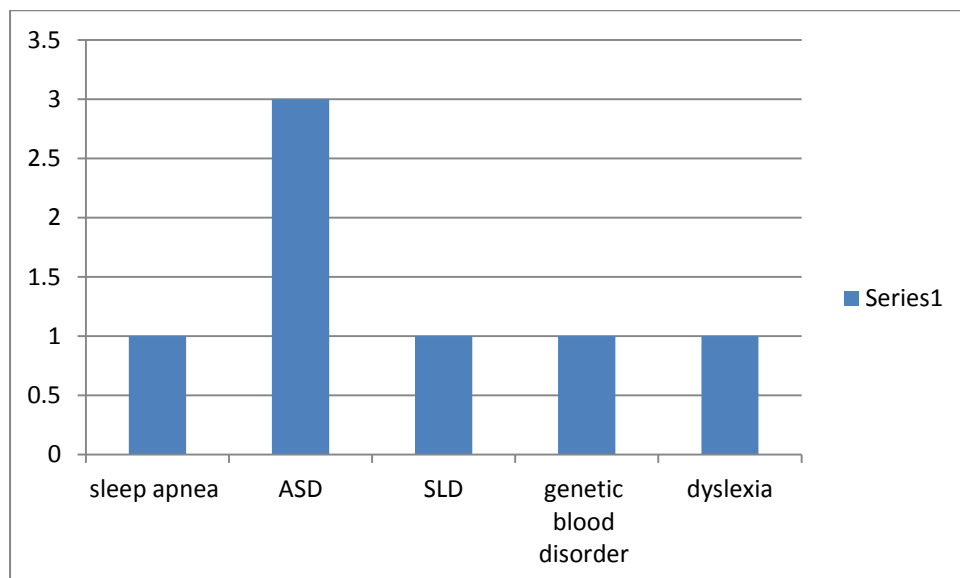


Fig. 17 needs of children/ young people of parent carers who attended

Which parts of the focus group did you find most useful and why	Which parts of the focus group did you find least useful and why?	What could we have done better	Any additional comments
good to give perspective of a parent with regards forms often they are drawn up with specific needs in mind	Difficult have lots of little conversations going on and background was struggling to follow	encouraged to have chats with tables separate ie bit like speed dating	
over looking the all about me and feeding into changes	n/a	n/a	n/a
get information and understanding more what is there	n/a	n/a	na
hate crime	n/a	n/a	thank you

Fig. 18 Sample of feedback after attended breakfast meeting

Participation Coordinator Statement

“I thoroughly enjoyed meeting new families and expanding my knowledge and skills. It was great to see a whole new level of engagement between parent carers and services. Although I am no longer employed by FVP, my time with them is not over as I am still volunteering as their Easter Region Parent Carer Forum Representative helping to ensure the parent carer voice is heard within the region. In my new job for a partner charity I am able to help families directly and refer to FVP as well as work with those sign-posted in my direction.”

ANALYSIS

There has been some organisational change during the financial reporting period of this grant funded work that has impacted on some elements of delivery. Despite this work has still been undertaken to support parent carers who are seldom heard to engage and participate. A fair proportion of time has to be utilised in building relationships with parent carers from seldom heard groups and gaining their trust. Parent carers themselves still report not wanting to talk openly about having a child/ young person with needs for reasons related culture, religion and stigma. A balance has also had to be worked between having 1:1 sessions with parent carers new to the system who have found it difficult to engage and not losing focus in terms of participation.

As with the previous years funding the grant has been used to part fund a participation co-ordinator. The co-ordinator can also herself be considered from a seldom heard group. Time has been spent building trust, and utilising family based sessions to enable engagement to take place. The parent carers from some groups considered seldom heard are more likely to attend family based sessions where participation takes place as opposed to simply take part in participation only activities such as focus groups.

The participation co-ordinator has through the work in this role realised that providing ‘support’ to parent carers is something she enjoys and is good at (feedback from parent carers has been positive). The support comes from parent carers feeling they are being listened to and informed about what is available. However parent carers do have to be informed that FVP cannot do things such as form filling which they would also like support with. Due to this and the conflicting part of working for FVP that means direct support is not necessarily a deliverable for the forum, as well as some other funding factors, the co-ordinator has now moved onto a role in another charity where she can work as a family support worker.

The parent carer hubs have proved particularly beneficial to members of the seldom heard groups that FVP have worked with and on one occasion one parent carer from the AHG provided translation support for another parent carer.

Some key findings are as follows:

4. The way participation and engagement with seldom heard groups is conducted has to be adapted to meet different needs.
5. There has been an increasing in the diversity of the parent carers participating.
6. More parents are attending working breakfast sessions and family based activities and participating in work including the development of the early support leaflet and SEND vision.

SECTION 4 – FAMILY VOICE PETERBOROUGH AS A CHARITY

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

Chairs Forward

The past year has continued to be busy, working with our partners in relation to co-production and strategic involvement. The SEND reforms are almost four years old now and are continuing to be embedded although there is acknowledgement of various issues and things are not always ideal. As the parent carer forum we work “with” partners with the aim of trying to improve things. FVP continue to be involved in various work streams, although we would like more parent carers to become involved at any level. FVP have not provided as much training in the past year as there has been less demand.

We had another well attended conference with over 120 people participating; parent carers and professionals came together to hear from Local Authority and Health about local services from the Early Help Pathway through to The Local Offer. Feedback was always positive.

The Annual Network Dinner/ Participation Awards was attended by over 200 people with Other Charities, The Local Authority, Parent Carers and CPFT being represented. Over £1500 was raised on the night which was shared with National Autistic Society (Peterborough Branch) and the Aiming High Group.

As a charity FVP have also moved towards providing services/ support via the provision of a community premises. Further support is offered to people via the provision of two caravans (one at Butlins Skegness and One at Caister Haven). The Community hall at the Goldhay Centre continues to be well used in the past year by various regular groups and one off booking. The Butlins caravan was upgraded to a fully accessible version at the start of 2017 and has been well utilised in the past year.

As the forum for Peterborough we have also been gathering views on services for parent carers who have children/ young people with SEND and have picked up some recurring themes. One such theme is LA schools VS academies. The LA has very little power in relation to academy schools and looking at how they are providing support including SEN support.

We are going to be busy in the year ahead continuing to make sure the parent/carer voice is heard and be involved in shaping services with not only PCC but also the CCG, there is much more work to do. As a parent carer forum we are proactive and try to gather as many views from parent carers as we can. We need your voice directly by engaging with FVP if you wish it to be included and heard. We are also going to look to recruit more parent representatives and consider how they will be recompensed for their time and support.

Trustees

John Ravenscroft
 Sara Rourke (April 2017 to June 2017)
 Amanda Rennie
 Graham Casey
 Ian Frederick Ralph Middlebrook
 Wendy Gray
 Claudia Dias (joined November 2017)

Declarations of Interest

- An employee of FVP is married to John Ravenscroft.
- Graham Casey is a local ward councillor where the charity premises is based
- Ian Frederick Ralph Middlebrook is a trustee on Goldhay Arts

Governance and Structure

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

Fig. 1 Governance and Structure for FVP

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 code 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, The Aiming High Group 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

As a CIO Family Voice have started the process of moving away from using holding trustees to own/lease/ manage the assets of the charity. Holding Trustees are used to *“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

This will change once asset transfer is complete for the premises at which point the lease will be in the name of the CIO.

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

Staff 2017 to 2018

An operations manager has been employed to oversee all operational elements of the charity, supported by an administrator, two parent forum co-ordinators and a key-holder/ cleaner. No staff member is remunerated over £40,000 and all staff costs are covered through grant funding set specifically for such purposes. The staffing for the charity covers the forum functions of FVP, all administration and management of the assets.

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. As new employers the board have sought advice relating to maternity leave and pay implications and pay and remuneration of employees.

The trustees also had to look at staffing levels due to financial constraints whereby the operations manager was tasked with delivering on a restructure. There has been a high staff

turnover this financial reporting period due to this and other issues around capacity and role suitability.

Volunteers/ Reps 2017 to 2018

The number of registered volunteers/ parent representatives has been low during the past financial year with some of the team going on to paid employment for other organisations and different support based volunteering positions for other charities. The BGL group have supported FVP by enabling some of their staff to give several volunteer days for work on the premises and support as various family based activities.

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 total number of volunteer hours this equates to is 1100. There has also been more strategic involvement in health commissioning and service delivery.

Objectives and Activities

The charitable objects of the CIO are exactly the same as the previous charity due to the old charity changing status to the CIO. 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 access to services for children/ young people with disabilities and additional needs.
- Increased parent participation which can include involvement, engagement, information sharing.
- Increased participation from a more diverse group of parent carers.
- Increased empowerment of parent carers leading to more involvement in the services accessed by their children and increased confidence.
- Increased employment including volunteering.

Measuring Social Impact

To demonstrate social impact of the charity a range of qualitative and quantitative data is gathered. This is used to measure the outcomes and impact of the work of the charity; Some of the methods include activity/ event feedback, survey results, quotes, numbers in attendance, demographic information, changes to services for children/ young people with disabilities through a “you said – we did” approach from the Local Authority and photographs.

1. FVP have seen two parent carers who spent time taking training courses and volunteering with the charity move towards employment with FVP or in other organisations. 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. Some elements of 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. E.g. The Early Support Leaflet, SEND Vision and Principles Documentation, The Local Offer and its advertising, The Early Help Pathway. In the past year 368 parents in total have been involved at some level via face to face meetings/ events/ activities (unique attendance).
3. Through training and workshops 164 parent carers have been supported to gain understanding of specific conditions; gained confidence in managing their children’s needs; gained an increased understanding of SEND issues such as Education, Health and Care plans 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 129 people.

5. Approximately 1600 individuals have benefited from the provision of a community base
6. 53 families have accessed the caravans for a short break and reported positive outcomes in relation to a break from usual life stresses, time together as a family and the opportunity to have a holiday.

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

Information

1. Training sessions in understanding behaviours that challenge related to social communication needs, attentional difficulties and learning difficulties providing parent carers/ family members with basic skills to self-manage and gain resilience.
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. Further to this has been the development of an e-news for parents and partners detailing the work of the charity as a whole.

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 families with opportunities not normally open to them.

Advice

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

Community Premises

1. 475 sessions were provided for the community either for by FVP and other organisations at the Goldhay Centre which is the one of the charity assets.
2. The Goldhay Centre was used to provide sessions for over 55's in the Orton Area run by the Silvertops; Open Access Play for 5 to 14 year olds run by Families First; Deaf Toddler Sessions run by PDDCS; Targeted Youth Provision run by Peterborough City Council Youth Services and Counselling for People with substance misuse by Aspire.
3. A successful community integration days for families from diverse backgrounds who have children and young people with special educational needs and disabilities was attended by over 120 people.

Achievements and Performance

Trips, Family Activity Days & Parent Carer Sessions

Coach Trips

- FVP ran two coach trip in the financial year 2017/ 18 which was funded through monies raised for parent carer and family based activities.
 - The coach trips were to London and Hunstanton both of which took account of accessibility needs by way of hiring of wheelchair accessible coaches.
 - 91 adults and 64 children 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 13 adults and 27 children. The children's needs ranged from Genetic Conditions to ASD and they were aged between 4 and 16
 - Christmas Party attended by 16 adults and 38 children. The children's needs ranged from GDD to Golden Harr Syndrome and the family ethnicity ranged from White British to Polish
 - 1 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

1. 5 Expert Parent Program
2. 4 Challenging Behaviour Sessions
3. 8 Parent Carer Hub
4. 7 Themed Workshops
5. 6 Focus Groups
6. 5 Breakfast Meetings
7. 1 Conference
8. 6 Coffee Mornings

Number of Sessions, Activity Hours, Administration Time, Travel Time, Total Hours...

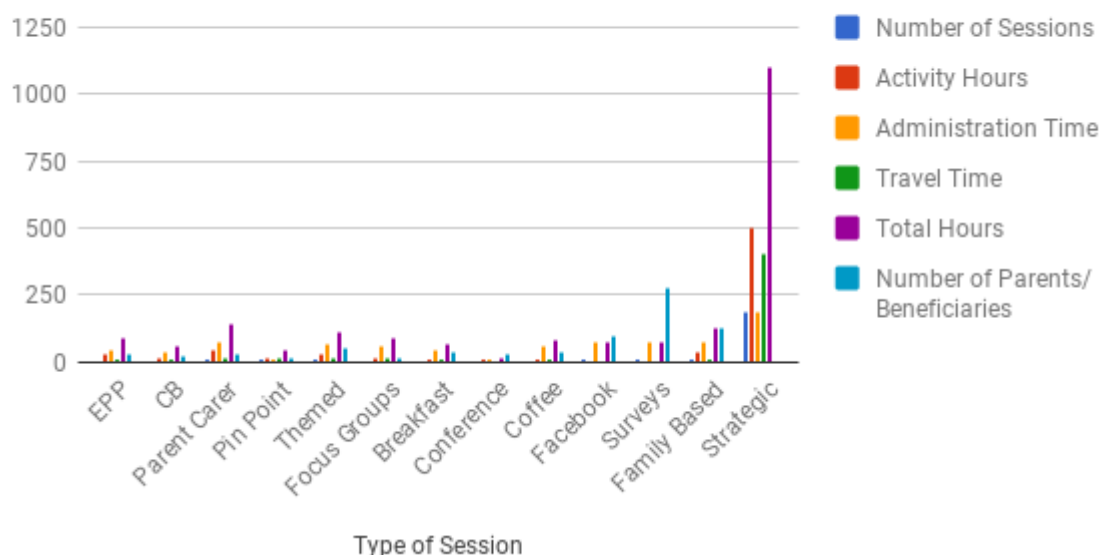


Fig. 2 Overall Hours, Sessions and Beneficiaries across Forum work of FVP

Training

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

- 2 Parent Participation and Representation workshops for parents and professionals
- 1 participation and representation workshop for partnership board leads
- 5 Expert Parent Programme (EPP) – CAMHs Transformation Funded
- 4 Understanding Behaviours that Challenge workshops.

The above training courses/ workshops have resulted in:

- 3 parents have gained an increased understanding of parent participation strategically and operationally.

- 34 Parent carers completing the EPP
- Joint working with Pinpoint (Charity/ Parents Forum) for Cambridgeshire
- 23 parent carers attending and reporting positive outcomes from the understanding conditions workshops

Participation

The financial reporting period this relates to, 2017 to 2018, has seen for FVP an increase of 78.6% in participation compared to 2016 to 2017. Participation methods preferred by parent carers are on-line or via feedback at family based trips and activities. FVP has also seen an increase in requests for parent participation from services across sectors operational and strategically.

There has been some investment by FVP in helping parent carers understand their “right” to be heard on a personal and collective level in the services accessed by their children and young people. 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.

Parent Participation Data

- 368 parents in total have been involved at some level via face to face meetings/ events/ trips/ Facebook Polls and Discussions up from 206 which is a 78.6% increase
- >105 professionals have been involved at some level via face to face meetings/ events/ attending training or co-delivering training.
- 277 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. 28 fathers have been involved which is a 133% increase on the previous year where 12 fathers participated.
- 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 and completed online surveys.

Participation and Engagement Work

Board	Organisation	Designated Rep
Cambridgeshire and Peterborough Mental Health and Emotional Wellbeing Board	PCC, CCC, CCG	J Ravenscroft
Peterborough Children and Families Joint Commissioning Board	PCC	J Ravenscroft/ C Dias
PSHFT Maternity, Children and Young People Programme Board	PSHFT	J Woodhams
0-25 and SEND Transformation Board	PCC	L Ravenscroft
SEND Project	PCC	C Dias
Carers Partnership Board	PCC	C Dias
Learning Disability Partnership Board	PCC	C Dias
Autism Board	PCC	C Dias
Eastern Region Parent Carer Forum	ERPCF	J Woodhams
Diversity and Cohesion	PCC	J Merrill
Multi Agency Forum	PCC	J Woodhams
PfA Sub-Group	PCC	J Merrill

Fig. 3 Some of the strategic meetings attended and the responsible parent rep

Five parent carers acting as representatives have attended 192 strategic meetings investing 1100 hours in terms of administration, travel time and actual meeting attendance. These hours are unpaid as the representative role is voluntary.

Number of Sessions vs Type of Session

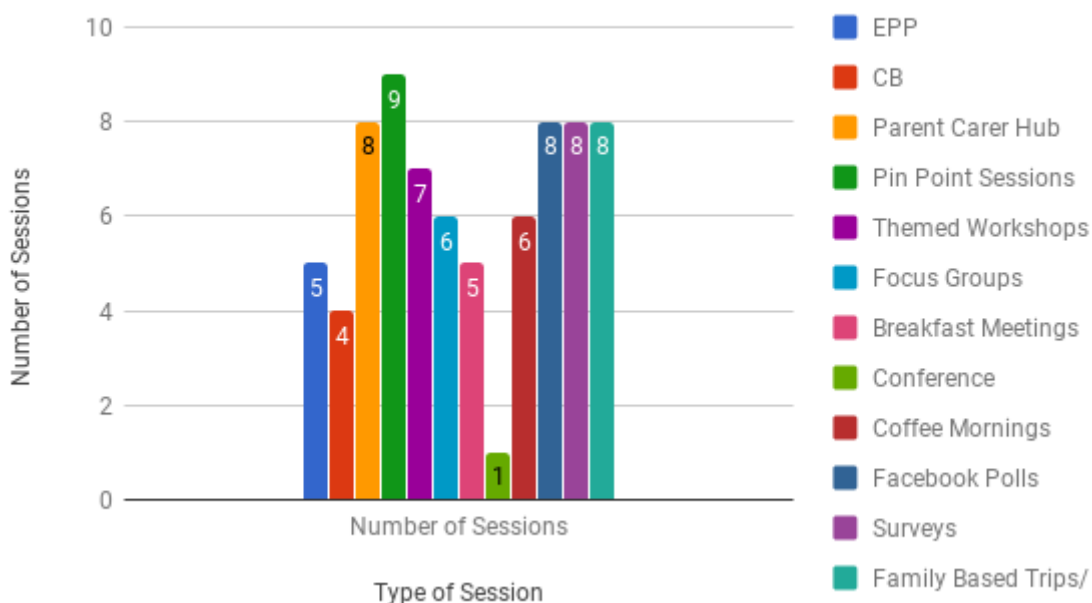


Fig. 4 number and type of participation sessions FVP have conducted

FVP have seen 804 parent carers, some of whom have participated more than once, participate across 75 sessions/ methods. .

NAS Support

‘collaborative working is key to developing services which identify and aim to meet the specific needs of families and individuals, working in partnership enables shared working and it’s a good way of using skills and knowledge’ (Branch Officer, NAS)

CHARITY Assets (Premises)

Premises Details

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

- On one side the community premises comprises, Kitchen, Hall, Accessible WC and WC and outside play space
- The other side is a three storey office area with WC and reception/ admin office on the ground floor, small room/ office and training/ staff room on the middle floor and a small office and larger split office on the top floor.

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 and are in the final stages of asset transfer; a prerequisite of which was FVP becoming a CIO and finding ways to make the premises run cost neutral.

By analysing the financial summary data presented in **fig. 5** it is clear that the running costs of the premises can be secured by hiring out the community hall and kitchen. However this is dependent on FVP securing grants to cover the cost of administration. If administration is factored into running costs then more would need to be charged for hall hire and more bookings would need to be secured to cover the overall costs as seen by **fig. 6**

Income	Month												
	April	May	June	July	August	September	October	November	December	January	February	March	Total
Regular Booking	£ 564.00	£ 1,090.00	£ 786.00	£ 594.00	£ 542.00	£ 852.00	£ 676.00	£ 897.00	£ 637.00	£ 1,092.00	£ 746.75	£ 772.25	£ 9,249.00
Private booking	£ 345.00	£ 225.00	£ -	£ 265.00	£ 190.00	£ 372.00	£ 52.00	£ 225.00	£ 100.00	£ 52.00	£ 136.00	£ 329.00	£ 2,291.00
Donations	£ -	£ 500.00	£ -	£ -	£ -	£ -	£ -	£ 491.00	£ -	£ -	£ -	£ -	£ 991.00
TOTAL	£ 909.00	£ 1,815.00	£ 786.00	£ 859.00	£ 732.00	£ 1,224.00	£ 728.00	£ 1,613.00	£ 737.00	£ 1,144.00	£ 882.75	£ 1,101.25	£ 12,531.00
Outgoing	April	May	June	July	August	September	October	November	December	January	February	March	Total
Cleaner	£ -	£ -	£ -	£ -	£ -	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 2,275.00
Utilities	£ -	£ 1,808.02	£ 42.70	£ 454.85	£ 301.59	£ 107.44	£ 99.39	£ 675.24	£ 309.46	£ 267.00	£ 565.40	£ 100.94	£ 4,732.03
repairs/maintenance	£ -	£ 473.32	£ -	£ 216.00	£ 353.88	£ 565.08	£ 217.20	£ 840.67	£ 213.00	£ 528.00	£ 1,005.00	£ 481.14	£ 4,893.29
Cleaning Supplies/ Waste Disposal	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ 424.22	£ -	£ 59.40	£ -		£ 483.62
Equipment	£ -	£ 36.27	£ 45.98	£ 11.99	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ 94.24
Sundries	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -
TOTAL	£ -	£ 2,317.61	£ 88.68	£ 682.84	£ 655.47	£ 997.52	£ 641.59	£ 2,265.13	£ 847.46	£ 1,179.40	£ 1,895.40	£ 907.08	£ 12,478.18

Fig. 5 General running costs of the FVP premises

Income	Month												
	April	May	June	July	August	September	October	November	December	January	February	March	Total
Regular Booking	£ 564.00	£1,090.00	£ 786.00	£ 594.00	£ 542.00	£ 852.00	£ 676.00	£ 897.00	£ 637.00	£1,092.00	£ 746.75	£ 772.25	£ 9,249.00
Private booking	£ 345.00	£ 225.00	£ -	£ 265.00	£ 190.00	£ 372.00	£ 52.00	£ 225.00	£ 100.00	£ 52.00	£ 136.00	£ 329.00	£ 2,291.00
Donations	£ -	£ 500.00	£ -	£ -	£ -	£ -	£ -	£ 491.00	£ -	£ -	£ -	£ -	£ 991.00
TOTAL	£ 909.00	£1,815.00	£ 786.00	£ 859.00	£ 732.00	£ 1,224.00	£ 728.00	£ 1,613.00	£ 737.00	£1,144.00	£ 882.75	£1,101.25	£12,531.00
Outgoing	Month												
	April	May	June	July	August	September	October	November	December	January	February	March	Total
Cleaner	£ -	£ -	£ -	£ -	£ -	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 325.00	£ 2,275.00
Utilities	£ -	£1,808.02	£ 42.70	£ 454.85	£ 301.59	£ 107.44	£ 99.39	£ 675.24	£ 309.46	£ 267.00	£ 565.40	£ 120.00	£ 4,751.09
repairs/maintenance	£ -	£ 473.32	£ -	£ 216.00	£ 353.88	£ 565.08	£ 217.20	£ 840.67	£ 213.00	£ 528.00	£1,005.00	£ 500.00	£ 4,912.15
Cleaning Supplies/Waste Disposal	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ 424.22	£ -	£ 59.40	£ -	£ 19.80	£ 503.42
Equipment	£ -	£ 36.27	£ 45.98	£ 11.99	£ -	£ -	£ -	£ -	£ -				£ 94.24
Sundries	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -	£ -				£ -
administrator	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 294.60	£ 3,535.20
TOTAL	£ 294.60	£2,612.21	£ 383.28	£ 977.44	£ 950.07	£ 1,292.12	£ 936.19	£ 2,559.73	£ 1,142.06	£1,474.00	£2,190.00	£1,259.40	£16,071.10

Fig. 6 General running costs with administration factored in

FVP have taken approximately £12,531 in fees. The utilities, insurance, building costs, cleaning costs for the Premises have 12,478. demonstrating it is possible for the premises to become cost neutral. 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. Having 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.. Now it is more established, more effort has gone into the promotion of the activities, training and participation opportunities in the centre leading to an increase in regular engagement with parent/carers.
2. FVP staff, parent representatives and parent volunteers are also provided with space and office use to enable them to carry out their duties.
3. Parent carers can attend meetings at the office and seek information, signposting and face to face contact more easily.

Community Opportunities

1. The premises has been provided to the following groups/ organisations for a small fee during 2017 to 2018
 - a. The Silvertops
 - b. Aspire

- c. MySign Tuition
 - d. Two Prayer Groups
 - e. PCC Youth Services
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 continued 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. To make the premises more accessible to members of the Deaf Community, FVP have provided the following; flashing front door bell that can be seen in the hall so those of the deaf community know when to let others in. There are flashing fire exit signs so that anyone who is deaf can see if the fire alarm has gone off. The main hall is carpeted to allow for a dampening of the acoustics in order to better facilitate play and learning sessions. We have also acquired the use of a Juno particularly for the members of the deaf community.

PDDCS had the following to say about our work with them

'PDDCS are very lucky to have had another year of support from Family Voice. The premises are perfect for our parties, Toddler group, signing classes and Play Scheme and they have made the premises Deaf friendly for us too. This especially means that our Sign teacher, who is Deaf herself, can safely work there.'

At Christmas we had to cancel a trip due to the snow so we are now doing an Easter trip to make up for it. Family Voice sourced Easter Eggs for 60 children to make it extra special for all the children that missed out at Xmas.

Family Voice is also there for advice. I often signpost very stressed out parents to Family Voice for help with EHCP, workshops and all manner of things and they Signpost any Deaf to us too.' (A. Fisher, Chair Person)

Overall Usage

Overall hours used and income generated of the community side have enabled an increase in beneficiaries of the charity to receive support.

Hours Overall vs Month

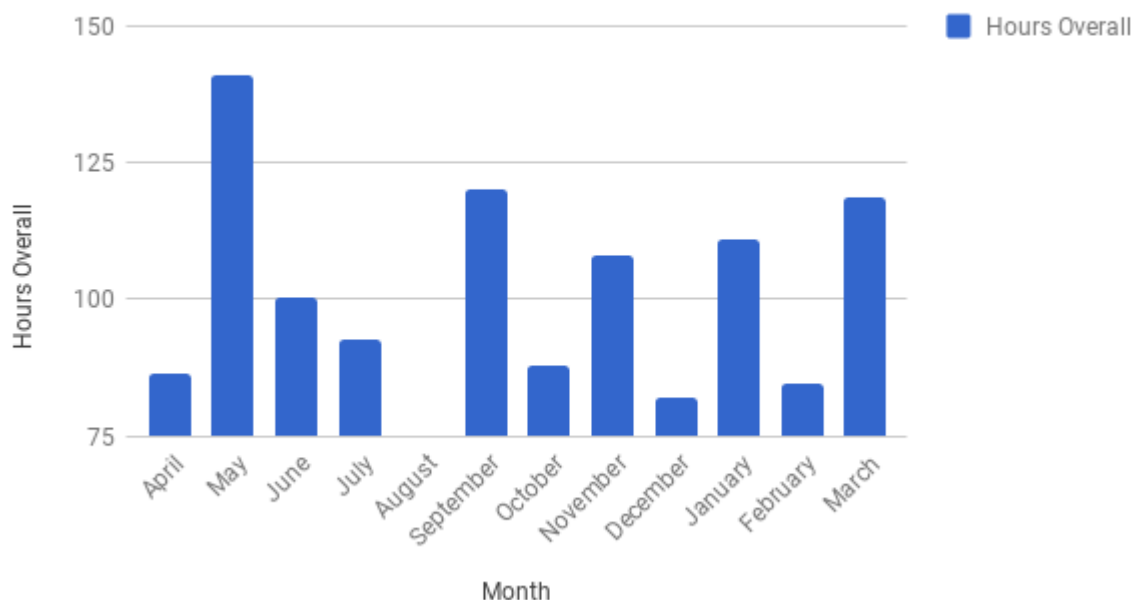


Fig. 7 Overall usage in hours of the community hall per month

Income vs Month

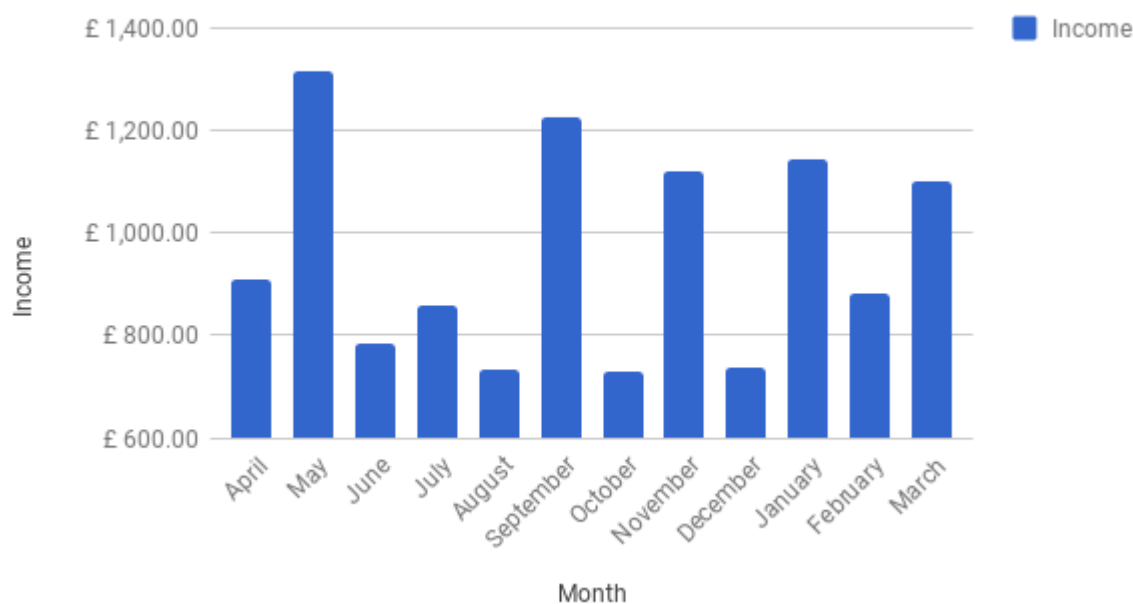


Fig. 8 Overall income per month for the usage of the community hall

Caravan

Management and Structure

The caravans are owned by the CIO and managed by the operations team and the Chair Person is the designated point of contact. Day to day operational decisions are made by the operations team and some information is set down in a hand-book and associated policies and procedures.

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. 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. In 2017 to 2018 the overall income increased and expenditure decreased with an overall shortfall of £329.67

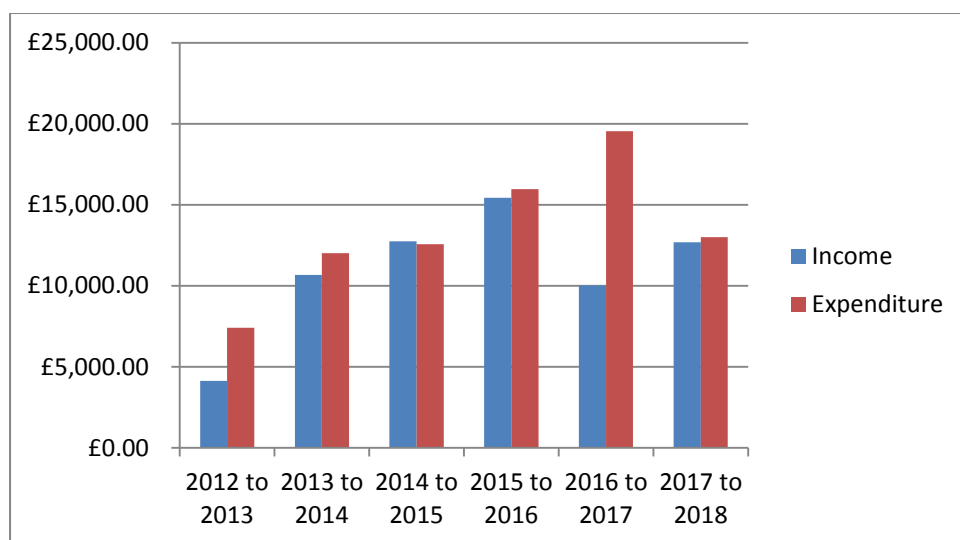


Fig. 9 comparison income and expenditure of the caravans since ownership began

	2012 to 2013	2013 to 2014	2014 to 2015	2015 to 2016	2016 to 2017	2017 to 2018
Income	£4,138.00	£10,671.00	£12,754.00	£15,438.39	£10,011.00	£12,679.15
Expenditure	£7,415.00	£12,015.00	£12,568.00	£15,972.74	£19,544.44	£13,008.82

Fig. 10 yearly overall income and expenditure comparison

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

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

	2012 to 2013	2013 to 2014	2014 to 2015	2015 to 2016	2016 to 2017	2017 to 2018
Number of Bookings	4	28	48	45	42	53

Fig. 11 Overall number of bookings per year

There has been a 20.1% increase in bookings between in 2017 to 2018 from 2016 to 2017 which in part relates to how people are booking breaks at Butlins. Such a difference may be due to the travel time required to reach the Haven caravan.

In a comparison of the number of adults and children who accessed each caravan in the 2016 and 2017 seasons as demonstrated in **fig.12** there was an increase across both cohorts and each caravan in 2017. The biggest increase was for adults which may be due to taking some bookings over the Butlins Adult weekends.

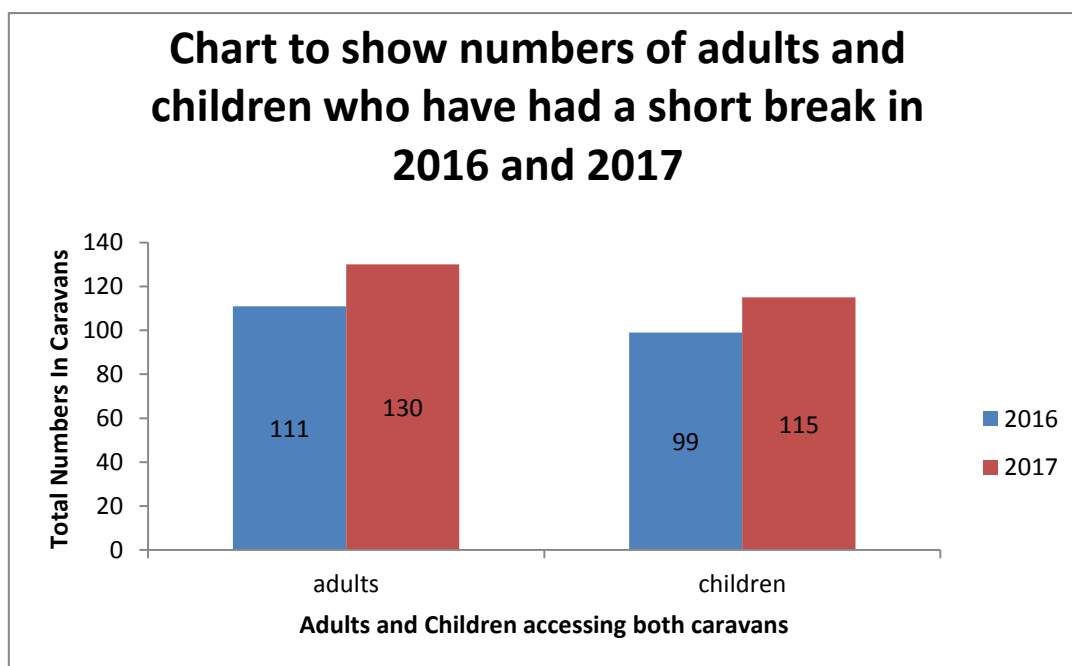


Fig. 12 comparison of number of adults/ children who used each caravan in 2016 and 2017

In **Fig. 13** it is can be seen that more adults and children used the Butlins Caravan in 2017 with Butlins having the biggest difference compared to Haven for the overall number of children.

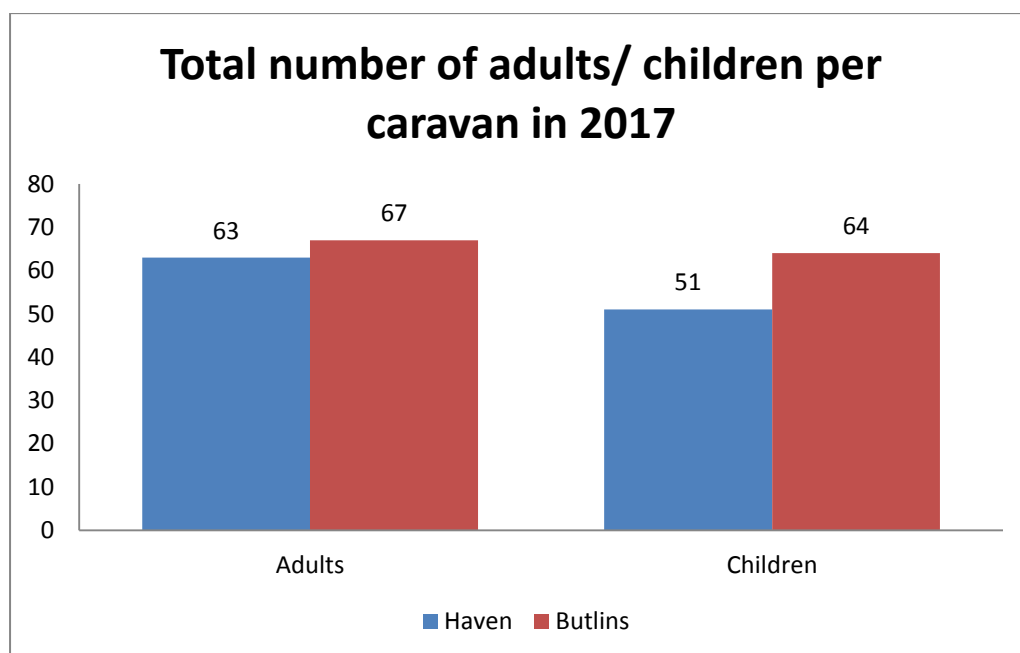


Fig. 13 Number of adults/ children who stayed in caravans in 2016 and 2017

Figures 14 and 15 show that:

- The preferred duration for a break at Haven was three nights with seven night breaks being used during school holiday periods.
- The most popular time to use the caravan was in July to September

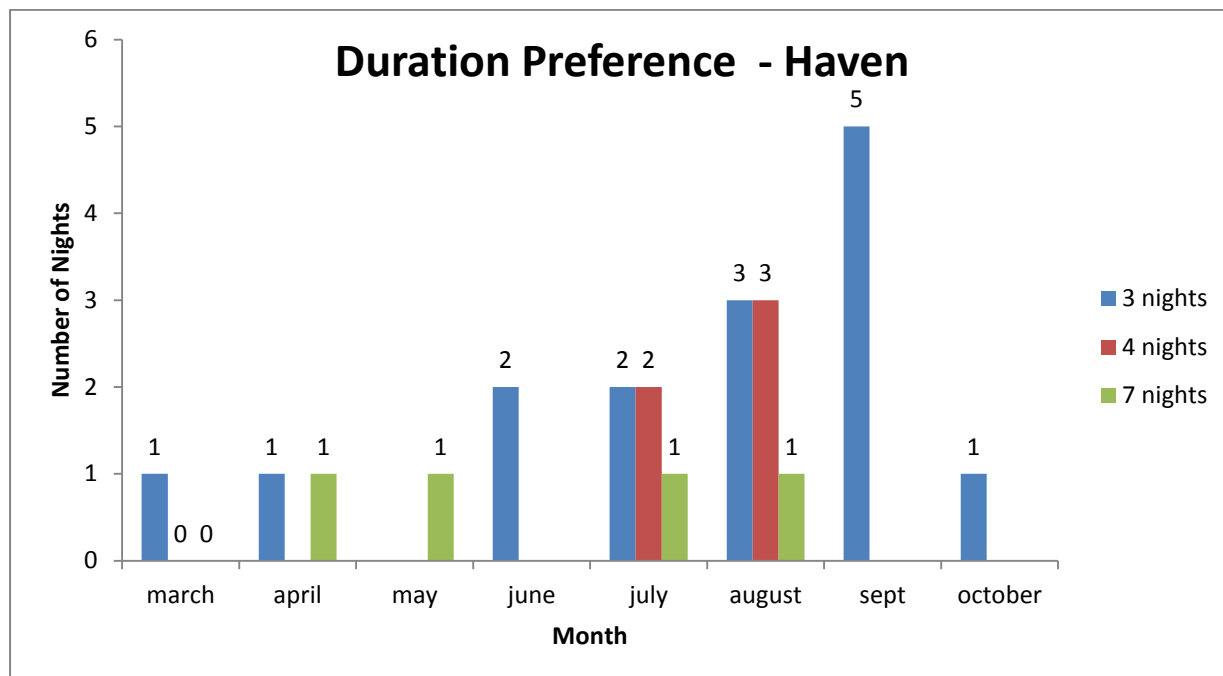


Fig. 14 Short break duration preference for Haven in 2017

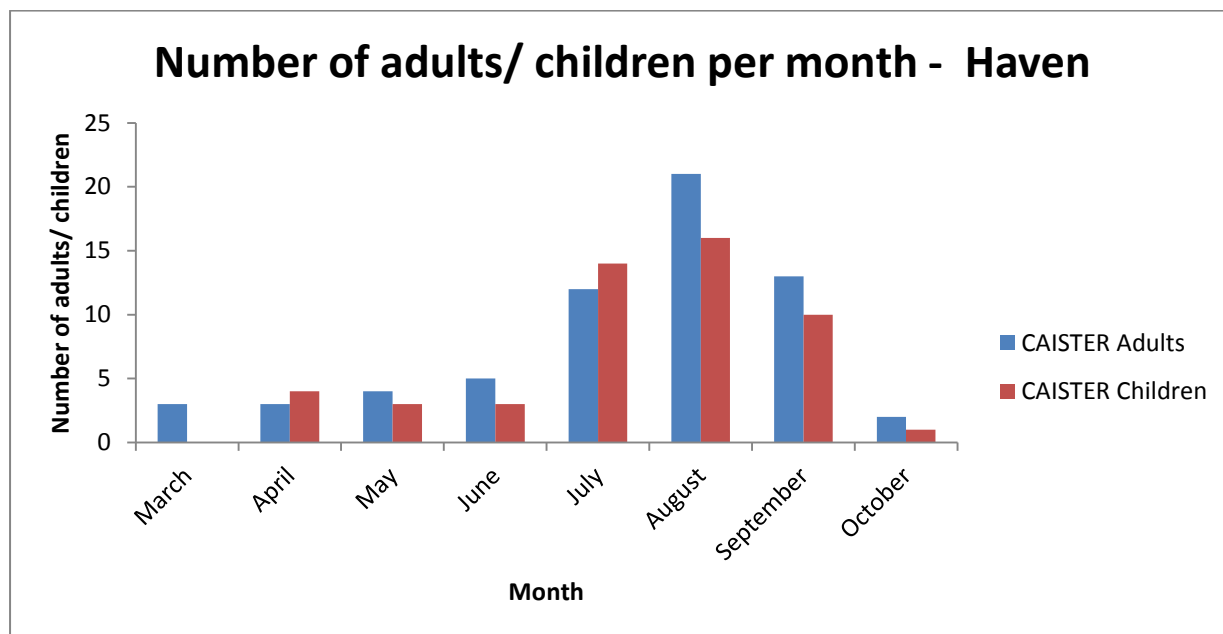


Fig. 15 Total number of adults/ children per month at haven caravan

Figures 16 and 17 show that:

- The preferred duration for a break at Butlins was three nights with seven night breaks being used during school holiday periods.
- The most popular time to use the caravan was in July to September and unlike Haven usage was popular for three night breaks in most months with 19 compared to 15 overall.

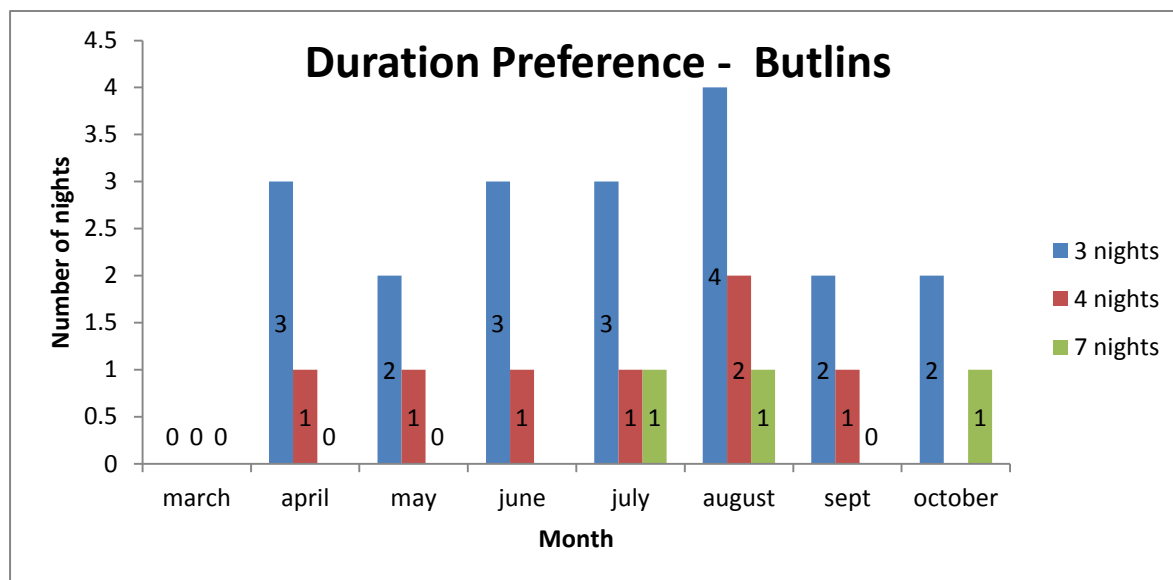


Fig. 16 Short break duration preference at Butlins Caravan

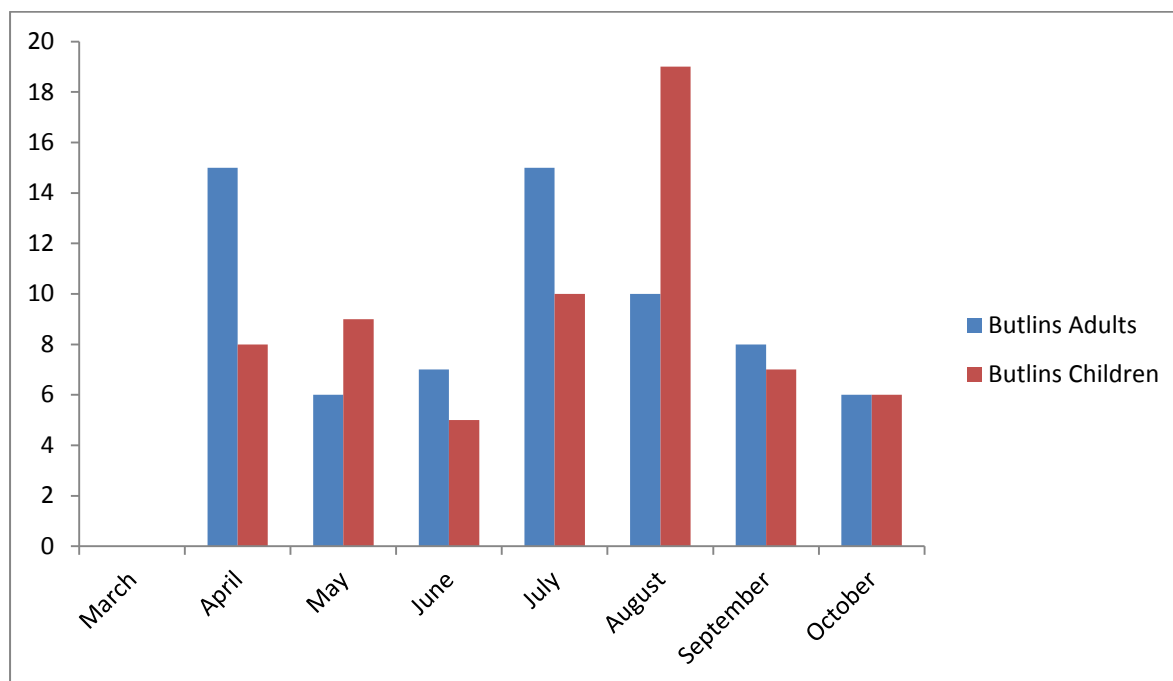


Fig. 17 Number of adults/ children per month staying at Butlins caravan

Financial Review

Reserves Statement

The trustees are continuously working to establish sustainability and good governance for the charity and have developed various policies and procedures including a reserves policy to facilitate this. The policy 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. The charity currently has an equivalent of three 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

The principle source of income for FVP is grant funding which is linked to predefined outcomes. Grants have been allocated by Contact formally 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 44% of the charity's total income and is restricted. The income for 2017 to 2018 also contains funds transferred from the removed charity Family Voice Peterborough (1141009) which was largely restricted grant funding. There is still a level of instability in the income for FVP as it is mainly year on year grant funding.

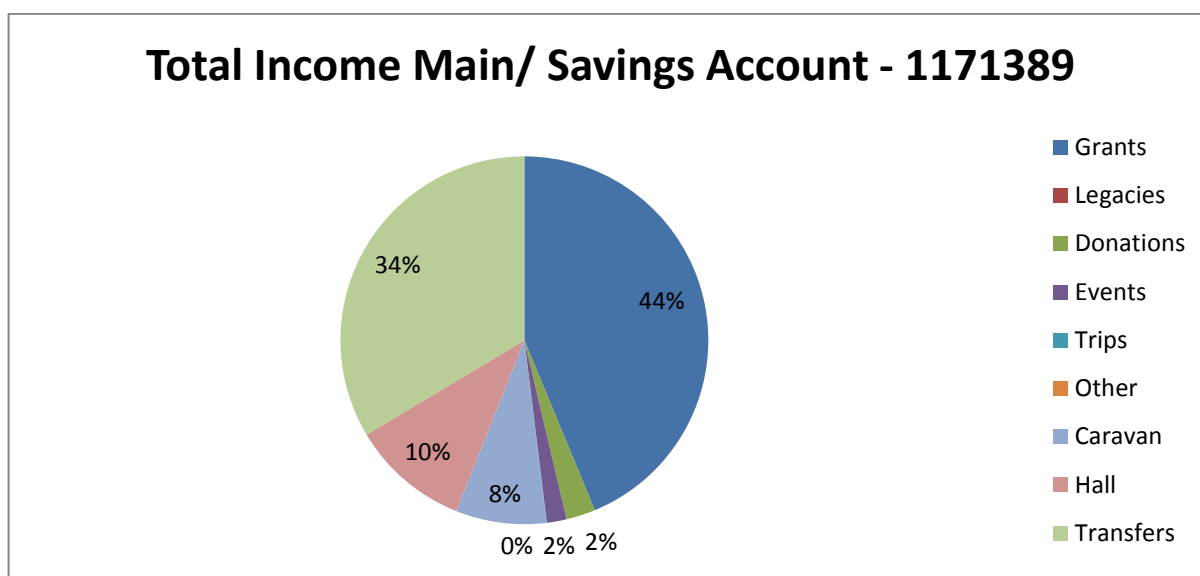


Fig. 18 percentages of different income streams for FVP (1171389)

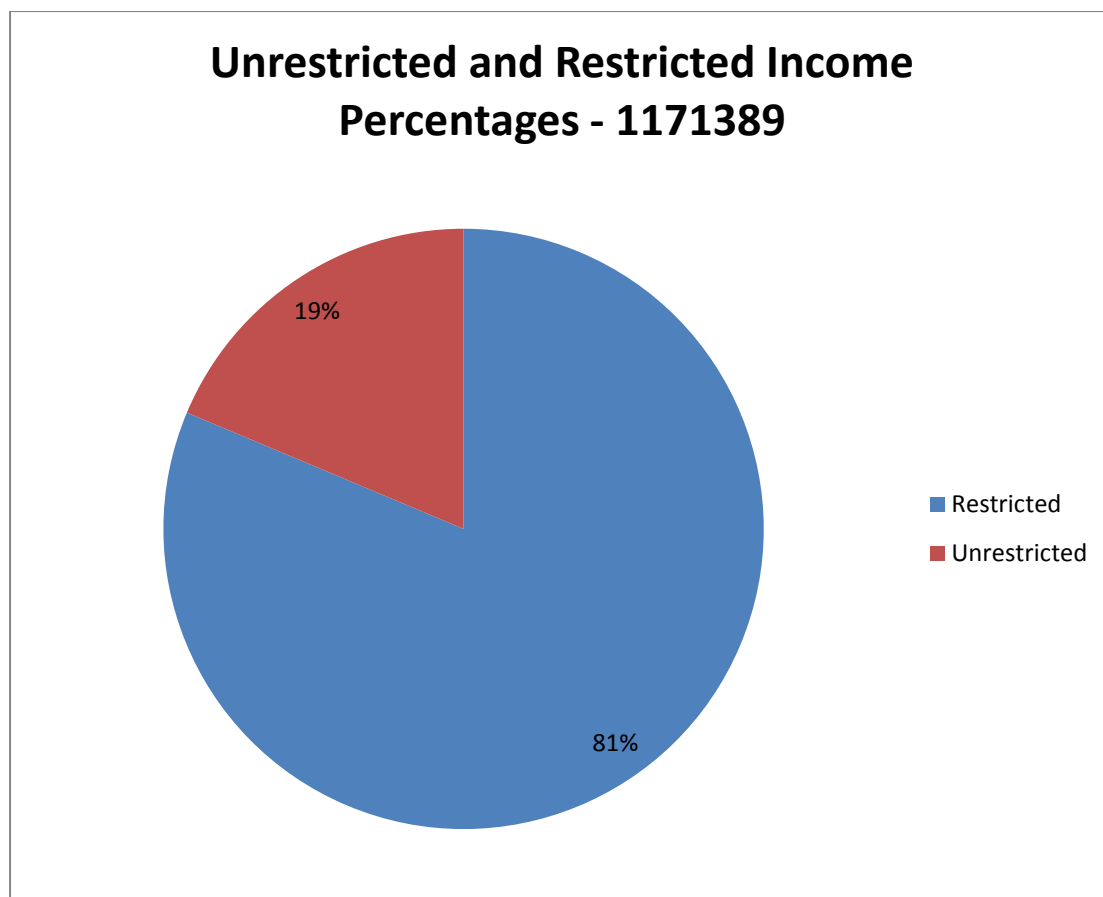


Fig. 19 percentage of income either restricted or unrestricted

FVP have secured income in grants for 2017/8 to 2019 however there has been a significant decrease in the amount of funding that will be available. The Board of Trustees have had to re-evaluate how the funding will be allocated to ensure the work of the charity/ forum can continue. As with the previous year all grant income will be paid in the relevant financial year.

Fundraising and Donations

Through fundraising and donations FVP has generated approximately £9,000 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 event has equated to approximately £4,900. 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 and the FVP premises. Most of the larger donations have been in the form of grants/ in-kind support from BGL.

Network Event and Participation Awards 8th December 2017

FVP hosted the sixth 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 the AHG and NAS 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 £1500 being raised.

Joint Fundraising

As with previous years FVP has endeavoured to work closely with partner charities which lead 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 Key Fest
- Raffle/ Auction at Network Dinner
- Fees and Raffle At Asian Cuisine Day
- Afternoon Tea/Mother's Day event/Christmas and Easter Fayre and Valentines Disco

Expenditure

The majority of the charity expenditure is from restricted funds from grant paid in the financial year this report refers to and from the transferred funds from the removed charity (1141009). Overall 79 % of expenditure was restricted. The majority of core costs fall into restricted funds expenditure with all staffing covered under restricted funds.

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

Trips, activities and caravan expenditure is covered by unrestricted funds that have been designated. This equated for 11% of the expenditure overall. Staffing equated for 50% of the overall expenditure.

Overall Restricted and Unrestricted Expenditure - 1171389

■ Restricted ■ Unrestricted

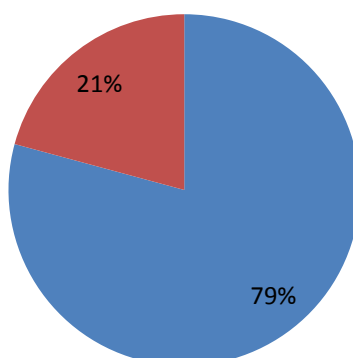


Fig. 20 percentage of expenditure under restricted and unrestricted funds

Expenditure - 1171389

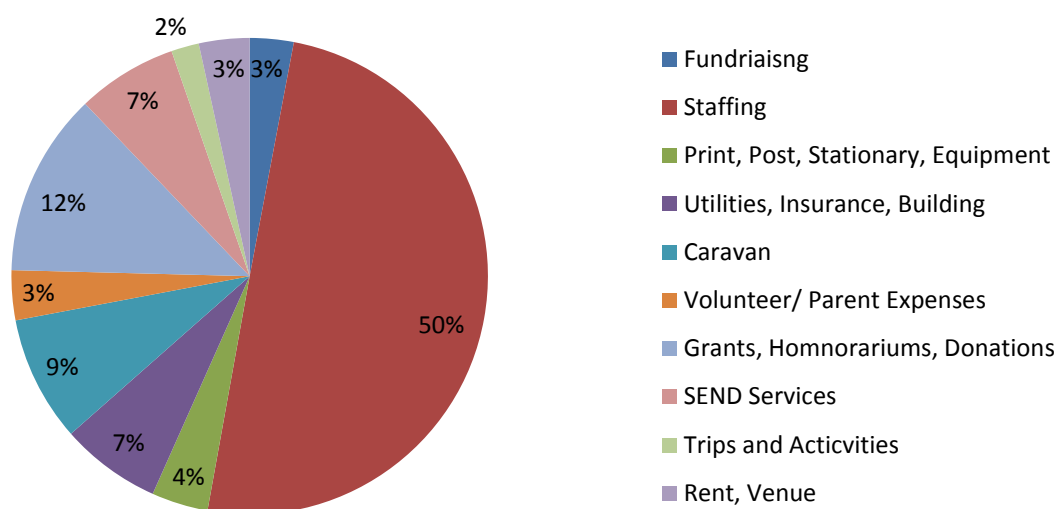


Fig. 21 Overall expenditure across natural payment categories

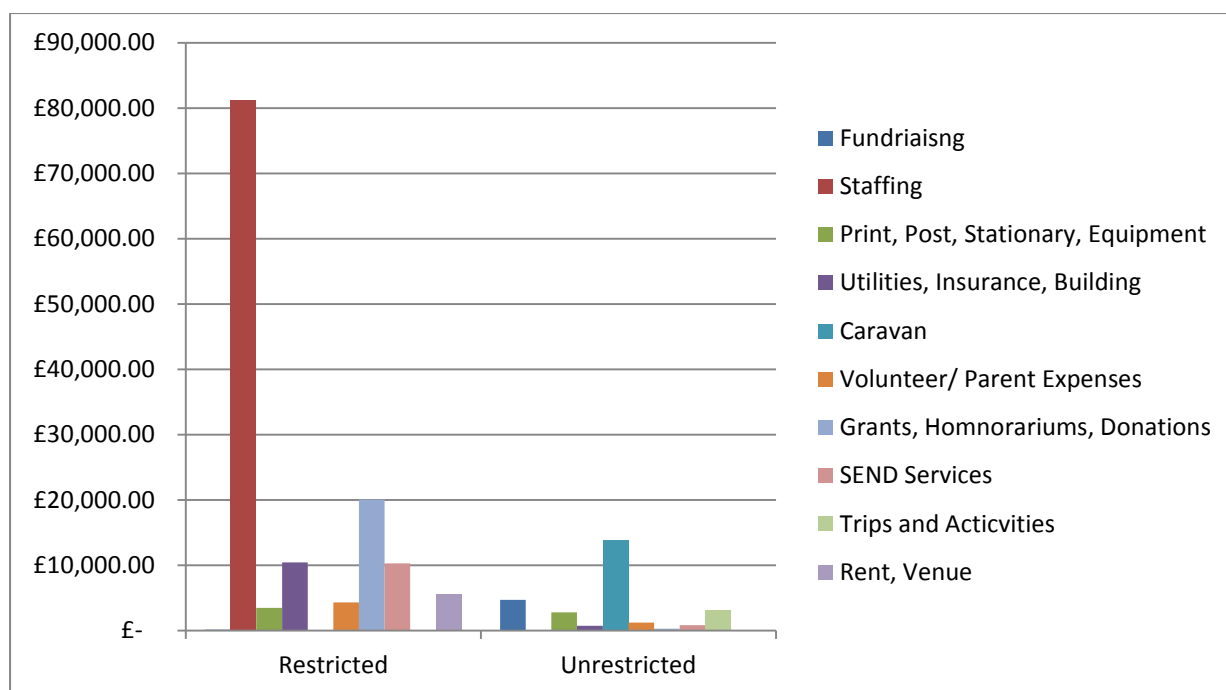


Fig. 22 Expenditure across budgets under restricted and unrestricted funds

Further Details

1. 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.
2. 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
3. There has been a high staff turnover during 2017 to 2018 due to role suitability, an organisational restructure and the changing needs of the charity. The majority of those employed have been parent carers who volunteer extra time to the charity over their contracted hours of employment. All costs relating to employment are linked to grants.

Trustee Remuneration and Expenses

During the financial period 2017 to 2018 no trustees received remuneration for services delivered to the charity. Trustees received reimbursement for reasonable travel and sustenance claims.

Accounts Preparation

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

Statement of Accounts 2017 to 2018 - 1171389

	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations, Legacies and Grants	5,221	89,281	-	94,502	-
Fundraising Events	3,552	-	-	3,552	-
Fees for Charitable Services	71	-	-	71	-
Hire of Community Premises	13,019	-	-	13,019	-
Hire of Caravans	16,239	-	-	16,239	-
Transfer Assets (1141009)	-	68,531	-	68,531	-
Transfer into savings	-	8,168	-	8,168	-
	-	-	-	-	-
Sub total (Gross income for AR)	38,101	165,980	-	204,081	-
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	38,101	165,980	-	204,081	-
A3 Payments					
Cost of Fundraising Events/ Promotion	4,692	156	-	4,848	-
Staffing Costs (wages, pensions, HMRC)	-	81,259	-	81,259	-
Print, Post, Stationary, Equipment	2,762	3,489	-	6,251	-
Utilities, Insurance, Building Costs, Repairs	719	10,406	-	11,125	-
Caravan Running Costs	13,898	-	-	13,898	-
Volunteer and Parent Carers Expenses (childcare, travel, refreshments)	1,207	4,302	-	5,508	-
Grants and donations paid	270	20,050	-	20,320	-
Cost of SEND Services (training fees, delivery costs)	803	10,294	-	11,097	-
Costs of proving trips/ activities (coach hire,, entry fee etc)	3,067	-	-	3,067	-
Rent/ Hire of rooms	-	5,598	-	5,598	-
Transfer to savings	8,168	-	-	8,168	-
	-	-	-	-	-
Sub total	35,585	135,554	-	171,140	-
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	35,585	135,554	-	171,140	-
Net of receipts/(payments)	2,516	30,426	-	32,942	-
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	0	3,055	-	3,055	-
Cash funds this year end	2,516	33,481	-	35,997	-

Forward Plan

Mission

To work together to improve services for children and young people with disabilities and additional needs

To work together with parents/carers and the Local Authority to improve all services accessed by all children with disabilities, additional and complex needs. It is our aim to work in co-operation and co-production to ensure that services around education, health and social care are meeting the needs of all children and young people from the age of 0-25.

We do this by involving parents/carers at the beginning of any proposed changes and reforms. Give them the opportunity to have a say in shaping any changes and reforms by consultation and open discussion, which then is relayed back to the local governing bodies, who then look at how the gathered information can be embedded into any changes and reforms across health, education and social care.

Swot Analysis

Where **FVP** currently are, what's working well, what needs improvement, what opportunities there are available for us to explore and any potential problems the organisation could face in the coming year.

Strengths	Weaknesses
Provides a unique service in that it is the only recognised dfe approved parent forum in Peterborough.	Not enough awareness of who FVP is and what the organisation does.
Has a good reputation with the LA and other professional bodies.	No secure medium term funding, working to short term grants only
Proven track record with participation and already established with connections to both parents and professionals.	Not all parents or professionals understand what the forum aspect of FVP is about and equate this to support.
Strong regional and national links through ERPCF and NNPCF.	Small team leading to capacity issues
Strong dedication to success of the organisation from	Skills, knowledge and experience is limited to individuals within the organisation

Threats	Opportunities
<p>Other groups/ organisations trying to compete in representing the parent carer voice.</p> <p>Very short term funding reliance and risk to staffing</p> <p>Not enough staff to manage the expected workload.</p>	<p>Opportunity to build on resources currently available.</p> <p>Further internal and, where necessary, external training to ensure skills, roles and responsibilities can be covered in absence of individuals.</p> <p>Opportunity to increase resources by way of offering further employment and volunteer roles in all areas needed.</p> <p>Opportunity to build better structure and efficiency throughout organisation supported by designation framework, top level documents, policies, procedures, FVP functions.</p> <p>Opportunity to offer more trips, activities and have an increased presence within the community.</p> <p>Opportunity to market and advertise the organisation in various ways.</p> <p>Opportunity to communicate with our immediate neighbours regarding our visitors, parking, noise and activities</p> <p>Opportunity to positively communicate within organisation, involving all trustees, staff and volunteers, and have regular internal meetings to communicate clearly about ongoing changes.</p> <p>Opportunity to internally and, where necessary, externally communicate the aims and objectives of the organisation.</p>

Long term goals

Over the next two to five years FVP want to:

- Continue with the expansion of engagement work with schools, this will increase understanding, reduce conflict; provide support for school staff, the parents/carers and their children.
- Continue with expansion of engagement work with parents, this will increase the organisational offer to more target groups
- Continue with the marketing and promotion of the organisation to increase membership which will also increase the organisational offer to target groups especially hard to reach groups.
- Explore more sustainable funding options and secure more long term funding that will allow us to expand the forums reach as well as bring on more staff to take the pressure off of existing staff members

Short Term Goals

Over the coming year FVP will;

- Design a marketing plan for the community hall hire, it will review the way the hall is promoted and maximise the usage based on availability. This ensures the community hall is sustainable and continues to be available for the local community.
- Review the viability of the caravans at the end of the season after an extensive promotional and targeted marketing campaign has been followed, this ensures we are offering the best possible facilities to support families to have low cost holidays which increases familial resilience and health and wellbeing.
- Design a marketing strategy which ensures that target groups are aware of all services FVP provide
- Ensure all staff training is up to date and build on the trained trainer capability. This will increase FVP's offer to a wider target group and well and providing increased financial resilience for the organisation.
- Submit lottery funding bid which will increase staff capacity to deliver FVP's offer to their target group, will increase the longevity of the building.
- Identify organisations that we can target for both expansion of our training delivery and provision of our consultancy services. This not only shares knowledge and expertise with in the voluntary sector but provides an increased financial resilience for the organisation.

Action Plan

Activity	Timeframe	Responsibility	Budget	Success indicator
Marketing plan for community hall hire	2/3 months	Trustees in conjunction with COO		Increased regular group usage of hall
Caravan review	October/November	Trustees/ admin for promotion and marketing		Increased bookings of the caravans
Marketing strategy	2/3 months	Trustees in conjunction with CFDO		Increased membership, use of fvp services
Staff training and increased trainer capacity	6 months	C.O.O		Organisation is fully compliant and able to extend its service provision
Lottery funding	2 -9 months	Trustees	500k over 5 year period	Successful bid money in bank
Explore expansion of our training delivery programs	3-6 months			Delivery of training is booked to other voluntary sector organisations

Date of Review**May 2019.**