

for children and young people with disabilities and additional needs

Family Voice Peterborough

June 1

This report refers to the organisation known as Family Voice Peterborough (working name FVP). The report details the agenda, attendance, themes and outcomes from the conference held on 26th May 2017which took place in partnership with Peterborough City Council.

Report for FVP 8th Annual Conference

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Introduction

The following information has been included in previous reports and still applies "Family Voice Peterborough (FVP) as well as being a registered charity is also a Parents Forum who provides a collective voice for parents/carers at strategic level with the aim of improving services for children and young people with disabilities and additional needs. One way to meet this aim is through the hosting of open meetings to bring parents/ carers and professionals together."

The open meeting (annual conference) facilitates wider participation in service development with information gathered on the day being fed in to local service design, development and implementation. Wider engagement is possible and key messages can be shared jointly with parents and professionals at the same time.

This year's conference is the 8th formal annual conference FVP have hosted and is the fourth to be held fully in partnership with Peterborough City Council. Partial venue costs and professional input for workshops were provided by Peterborough City Council with speakers as well as including Irwin Mitchell and Jane Friswell, the programme for the day and behind the scene running of the day provided by FVP staff, parent reps and volunteers.

On The Agenda

	Opening	Gethyn Williams		
9:25	Parent Participation – A National Overview	Contact a Family		
	,	Wendi Ogle-Welbourn		
	The Way We Work	Peterborough City Council		
	Growing Up – Our Story, In Our Own Words	Karen Sheen Parent Carer		
10.30	Refreshment Break			
10.45	CAMHs Update	Lee Miller & Nick White CCG and CPFT		
11.00	Workshops	 Appeals, Mediation and Complaints (Irwin Mitchell) PfA (Ellen Atkinson) 		
11.45	Feedback and Q&A	All		
12.00	Lunch & Networking			
12.45	Healthy Child Programme (Children with complex needs) SEN Duties for Mainstream, Academy and Free School settings	Janet Dullaghan Peterborough City Council Jane Friswell		
13.45	Workshops	 Improving the database of providers on the Local Offer (Jacky Cozens) Neurodevelopmental Pathway (Karen Moody, Pam Setterfield) 		
14.15	Feedback and Q&A	All		
14.30	Close			

Attendees

- ❖ Parents/ Carers/ Grandparents
 - > 27 parents/ carers/ Grandparents attended the conference
- **❖** Professionals/ organisations
 - ➤ 44 attendees were professionals/ representatives from across the LA, Health or 3rd Sector.
 - > Irwin Mitchell, Carers Trust, Independent Support (Scope), Healthwatch Cambridgeshire, Carers Choice, Day Opportunities, SENCo Network, Peterborough SEN and Inclusion Service

On The Day

Attendance was virtually the same as the previous year. The conference was held on a Friday the same as the previous year but unlike previous years it was held at the Marriott hotel, where they allowed any parent carer that was booked on to have access to the hotel spa at the end of the conference until 5pm. Gethyn Williams (Director of Development and Engagement), from Contact a Family opened the conference and spoke about parent participation which was well received by all.

There were only two less parent carers in attendance compared to the previous year together with the same amount of professionals in attendance. Out of the attendees about 25% were attending for the first time, this includes both parent carers and professionals.

As with the previous year's conference the highest self-reported areas of SEND from parent carers was Autism Spectrum Disorders (ASD) although other areas of need were also represented.

The most popular workshops were Appeals, Mediation and Complaints with Irwin Mitchell solicitors and the Neurodevelopmental Pathway with Karen Moody and Pam Settafield. All questions asked during the day were captured and recorded and have been fed back to the appropriate person and we are awaiting replies which will be placed on the Local Offer in due course. Due to timing issues throughout the morning, the workshops were cut short which left little time for both presentation and questions.

Work Shop Topics / Notes

Appeals, Mediation and Complaints

This workshop was led by Stephen Baylis, a solicitor from Irwin Mitchell. A presentation was delivered describing what parts of the EHCP can be appealed, legal timings involved in an appeal, who can make the appeal, who holds the decision making power (parent carer or child/young person), capacity of young people with SEND, use of mediation, how a complaint can be made and how you can get funding for an appeal or judicial review.

After the presentation, due to being short on time, questions were asked for but none were offered. 31 people attended this workshop

Preparing for Adulthood (PfA)

This workshop was delivered by Ellen Atkinson who is part of the National Development team for Inclusion commissioned by the Department of education to support the implementation of the "Preparing for Adulthood" strand of the SEND reforms in partnership with the Council for Disabled Children; she is also the national link representative for the East of England and the East Midlands. 20 people attended this workshop

Local Offer

This was led by Jacky Cozens the Customer Feedback Manager at Peterborough City Council (PCC), who current responsibility is the development and maintenance of the Local Offer. 10 people attended this workshop

Neurodevelopmental Pathway

This workshop was led by Karen Moody (Head of Prevention and Early Help Services PCC) and Pam Settafield (Commissioner, Child Health, Communities Directorate, PCC). This was attended by 25 people.

SEN Inclusion 1:1's

This included 1:1's with the following services:

- **Educational Psychlogist**
- Autism Outreach
- Statutory Assessment and Monitoring Service
- Parent Partnership
- Portage
- **Sensory Support**
- Sheelagh Sullivan

In total 13 parents took the chance to have 1:1 with the support services with 4 parents seeing more than one service

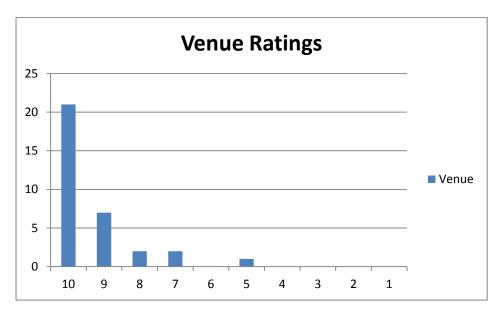
Conference Feedback

Table 1: Children/ Young People Details

number of CYP	Age	Gender	ethnicity	Setting/ School/FE	Disability
2		М	white British	Primary School	SEN
2		F	white British	Primary School	ASD
1			white British	Ormiston Bushfields	ASD/ADHD/Dyspraxia
5		M	white British	St Michaels Church School	
			Willie Birtisii		Coracii i i a con come
3		F	White British		diagnosed AD
3			Willte British		ulagiloseu 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	М	white british		ASD
	14	М	white british		ASD
1	16	F	white	Stanground Academy	ASD/Dyyspraxia
1	9	М	british	phoenix	complex
5		М	british	COPASS	ASD/ADHD/SPD/anxiety
		М	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 Danlo
		F			ASD
		F			Ehlers Danlos
1		M	white british	Wilds Lodge	Sensory
2		M	white british		Aspergers
		M	white british	Heltwate	ASD, severe learning disability, language disorder
4		F			chromosomal
3	8	М	English	Welland Academy	Dyslexia, ADHD?, ASD?

As can be seen in the table above that some information was omitted to be provided on the feedback forms when being completed.

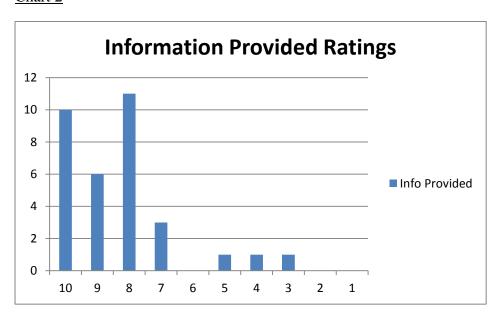
Chart 1



The chart shows how overall attendees rated the conference for the Venue; The conference was rated well out of 34 feedback forms received back with one not rating the venue.

Of the 33 who rated the venue 64% rated the venue as a 10 while only 3% rated the venue as a 5 which was the lowest rating scored

Chart 2

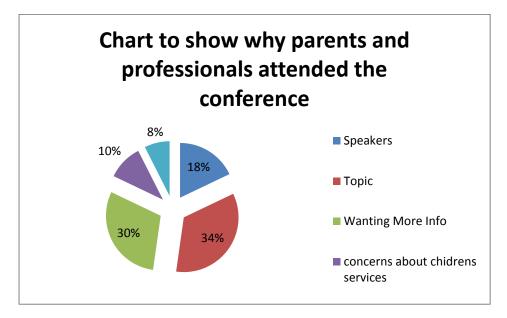


The information provided was also rated by 33 people with one not rating at all.

Of the 33 who rated the venue 30% rated the information provided as a 10 (being the highest) whereas the lowest score of 3 was rated by 3%.

This is a very mixed score rating with not much reason given in the feedback forms as to why. Out of those that scored the information 10, five of these were first time attendees.

Chart 3

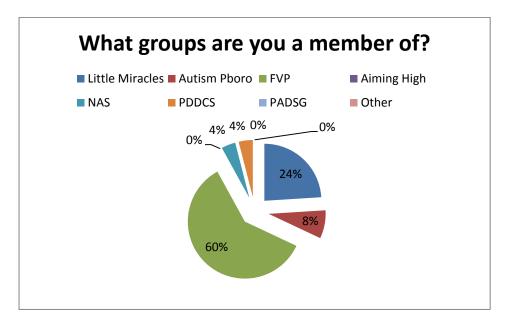


At 34% the most popular reason for attending the conference was recorded as "wanting more information" followed as a close second choice by "topic" which is exactly the same as the previous year

Some attendees provided comments as well as selecting the pre-defined reasons for attendance which are as follows:

- make people aware of our services
- networking opportunities
- visit forum event
- CTP stand
- for general info

Chart 4



To ascertain how many parent carers are being reached in terms of what groups (charities/ organisations/ support groups) they class themselves as members of the feedback form also asks parents to select the groups they attend/ see themselves as members with. Parents could select more than one group and overall FVP was selected the most.

Table 2:

Which parts of the conference did you find most useful?		
Autism information because I am autistic. I have high functional autism		
netowrking and meeting parents		
information relating to current guidelines and future changes being		
planned/worked on		
the knowledge that all the issues I have had, have now started to be addressed and		
changes are happening in CPFT		
pm - speaker Janet Dullaghan pm workshop EHWB quite good		
Jane Friswell's presentation. Mediation presentation. Networking opportunities		
health and the morning		
speakers		
Jane Friswell was fantastic, an inspiration professionally and personally		
1:1 was great, lot of important information and lovely to put faces to names		
speakers were very good and learn lots of how the services work		
all		
education info. Early intervention to get help		
workshops, smaller groups		
I found all of it helpful		
talking through wishes of others		
all		
all		
parent carer speaking and Jane Friswell. Workshop that we ran on LO		
Karen Sheen - 1st person account of parent carer experience		
means to find pathway for information		
all		
having one on ones		
Jane Friswell - intersting, informative and inspirational		
PFA workshop		
PFA and LO workshops		
Jane, networking, having commissioners in the room, knowledge- meeting paretns -		
raissing concerns with the right people		
speakers and networking		
PFA, 1:1 with SAMS team and CAMHs		
contact/awaeness with different organsations		
appointments - EP, Autism outreat very interesting and more info given and helpful		
useful to find out the pathways to follow		
·		

Table 3

what parts of the conference did you find least useful and why?
presentations not professional enough. Hard to see but I could see because I have good
attention to details
Appeals, Mediation and Complaints didn't grab my attention
a late start
joint commissioning
not 'least useful' but would always would be good to encourage higher parent carer attendance
none
none
last main speaker was hard to follow and disappointed
some parts seemed resolved
none
the workshops on appeals and complaints - a bit dry
I found the Neurodevelopmental workshop very confusing and didn't get much out of it
too much information to digest within a short period
none
CAMHs
health pathway as kids have been through and coming other side
CAMHs
time delays but this cant be helped
unclear prior to arrival what the programme was, because 1:1 overlapped with other
presentations it was a bit confusing for first time attendees
timing, some material very dense
Jonathan lewis was listed on original agenda, however, we were not informed that he was no
longer going to presetn on academies and SEND
Benefits - did not understand as missed the start
a lot of complex information to take in, in such as short period

Table 4

child with ASD more choices lots of info to read, consider information to pass to families linking up with other orgnisations info about broader subject to support my child to be the best he can to access information/help providers info good I have gained so much information, thank you more knowledge if who to speak to and more confidence information provided will help me support parents networking and knowledge yes- excellent co-production feedback I am not sure it will. I feel more confused now than before better understanding and means to find appropriate services to signpost helpful information, that will help in decision making gave me knowledge lots of info to assimilate more knowledgeable it will hep with pieces of work that I am doing for FVP further my knowledge learning about the future of peterborough support in going forward post 16 awareness sadly, I havent gained any new knowledge	How will this conference help you as a parent/professional?
knowing there are people to help out there in a very isolating world with a child with ASD more choices lots of info to read, consider information to pass to families linking up with other orgnisations info about broader subject to support my child to be the best he can to access information/help providers info good I have gained so much information, thank you more knowledge if who to speak to and more confidence information provided will help me support parents networking and knowledge yes- excellent co-production feedback I am not sure it will. I feel more confused now than before better understanding and means to find appropriate services to signpost helpful information, that will help in decision making gave me knowledge lots of info to assimilate more knowledgeable it will hep with pieces of work that I am doing for FVP further my knowledge learning about the future of peterborough support in going forward post 16 awareness sadly, I havent gained any new knowledge	more awareness or services and procedures
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support in going forward post 16 awareness sadly, I havent gained any new knowledge	further my knowledge
awareness sadly, I havent gained any new knowledge	learning about the future of peterborough
sadly, I havent gained any new knowledge	support in going forward post 16
	awareness
schol and meetings re son	sadly, I havent gained any new knowledge
5	schol and meetings re son
helps to identify places to signpost people	helps to identify places to signpost people

Table 5

what could we have done better?
started on time
more interative activities
hotel-label food in additional room (couldn't identify
individual dishes)
nothing
10-Oct
start on time (but understand traffic difficulty)
timing! Very rushed
have a separate "preparing for adulthood" conference - a day
long one
larger versions of slides printed as printed size hard to read
make programme long to accommodate everything
nothing
less powerpoint presentations - hard to take it all in
programme available before the day preferably when
better timing, consistency
started on time. It as very annoying to start late
more time. Have private meeting at not the same time as
presentation and workshops
shorter presentations
registration 9.15 before starting at 9.30

Tables 2 to 5 are used to present the answers to feedback form questions:

- 1. Which parts of the conference did you find most useful and why?
- 2. Which parts of the conference did you find least useful and why?
- 3. How will this conference help you as a parent/ professional?
- 4. What could we have done better?

The speakers and topics appear to have been the most popular responses to what was found to be most useful, while specific workshops and speakers were less popular, which contradicts the most popular in part, this will always depend on the level of knowledge the parent/carers and professionals have on the topics being discussed.

Overall when asked how the conference will help you the most popular reason appears to be more informed and knowledgeable about the topics at the end.

When asked for what could be done better a popular suggestion was longer timings for workshops and different timings.

Conference Analysis

The conference was fairly well attended and the themes were popular with attendees from all areas. More time needs to be spent on working towards professionals and parents breaking down barriers to participation together. The SEND reforms are still a work in progress and working together will go some way to make sure children/ young people benefit in relation to individual participation.

The 1:1's with the service providers were very well received from both the parent/ carers and the service providers, that is, except for them overlapping the presentations and workshops. This will be looked at for future events to see if this can be altered.

Generally feedback was positive with some useful suggestions for improvement being provided including; too much information to digest in a short space of time, timings of the day, longer workshops, and to make the conference longer

Appendix 1 – Questions Asked

- 1. What is the rationale behind the refused to acknowledge PDA as a diagnosis in Peterborough? Cambs are doing this and it really helps
- 2. Who do we contact for mental health awareness workshops in schools?
- 3. Are the co-production standards developed by Rotherham available to share? For Gethyn
- 4. You spoke about a gradual transition between child and adult services. How will this work when no services available for adults? No autism service for adults only diagnosis. Annual med review for ADHD. **CAMHs**