

20th June

May/ June
2015

2nd Highlight SEND Report 2015/ 16


family voice
peterborough
together improving services
for children and young people with disabilities and additional needs

Introduction

This report is the second highlight report produced to detail what parent participation work is taking place in Peterborough via Family Voice Peterborough (FVP). The report covers May and part of June and refers to some ongoing and new work streams. It will as in previous reports detail parent representation, focus group and other participation methods.

As detailed in the report from April 2015 this report includes more input from parent carers involved in strategic work via qualitative data not just parent rep reports. The “You Said – We Did” method of feedback will also be used again. There will also be a brief analysis on the work involving parent carers to date for this financial year, with numbers included, background and Children and Young Person (CYP) details where known all of which will be in the main body of the report.

Method

Parent Representation

Parent representation has started to increase again especially in relation to preparing for adulthood, personal budgets, Education Health and Care (EHC) processes and Outcomes and Local Offer (LO) Delivery. Parent Representation reports from these work streams and others will be included in the appendix from Dafne Stoelhorst, Claudia Dias, Mandi Rennie, Johanna Woodhams and Tanya Smith.

Parent Representation still needs consideration in holiday periods and also outside of school hours as some meetings have recently been scheduled from 2pm onwards and the majority of those acting as parent representatives have collect young children from school/ nursery 2.30pm onwards.

Facebook Use

Facebook has not been used for discussion on any topics since the decision was taken to shut the FVP chat rooms. Facebook has primarily been used to pass on information and set up event invites for focus groups and meetings.

Conference

The annual conference took place on 3rd June and was held at Kingsgate Conference Centre with extra planning support and funding provided by Peterborough City Council (PCC). The conference was well attended with 125 delegates in total. 35 parents attended and reported their CYP needs as autism, downs syndrome, hearing impairment, mental health needs, Speech and Language needs (SLN) , Learning Difficulties (LD), Behavioural needs, Attention Deficit Hyperactivity Disorder (ADHD) and Genetic Conditions; there were parents from different ethnic backgrounds in attendance with five from the Asian community which is higher than in previous years

Some photos from the day



The keynote speaker was Brian Lamb OBE who presented on the SEND reforms and Local Offer and then hosted two workshops; one on The SEN Report and Local Offer and one on Effective engagement with parents in schools for better outcomes.

Feedback from parent carers who also act as reps has been provided in the following statements:

Sarah King

It highlighted how let down as parents we have been in the past, And the the la and health wont undo those wrongs, it makes you wonder 'what if'.... Would our children be in a better standing if it was realised back then how services were failing them...On the positive side, it was admitted and that means looking forward to making vast improvements. The day itself was well managed, with the personal touch of stories from parents hopefully struck a note with a lot of parents and professionals

Jason Merrill

Another good conference great to hear stories from two different age groups by that I mean from the ages of the children and also what schools get depending on what hours of help the child gets in school and also what they have to find if the child goes out of county maybe there needs to be some work so that children don't have to do that because it seems big schools struggle to cope with some conditions.

Claudia Dias

I found the event well organised , there was a lot of information being given to parents and others professionals who deliver services to families with Special or additional needs throughout the day from the seminars to the workshops, the invitees answered to a lot of parents doubts which was refreshing .The array of stalls scattered was also of excellent quality and also gave a great deal of information and support to parents. All in all a excellent day.

Dafne Stoelhorst

This conference was very well organised and professional. The venue was great, with ample parking facilities and lunch very tasteful. There was a variety of very interesting speakers from different services and having Mr. Lamb speak was a real insight and honour. For me it was a privilege to be on the same stage with these people and tell the story of our journey into support in education. As a parent you often hear the negatives and I hope our families positive outcome gives parents the reassurance that parents and professionals can work together to find the right outcome for their child(ren). The workshops were very diverse and the only negative for me would be that I wanted to have a chance to visit all of them. There was a large variety of information stands with a lot of information for both parents and professionals. All in all a great day and brilliant experience, already looking forward to next years conference

Other feedback gathered on the day was mainly positive with some suggested improvements provided.

"Good - encouraging - lots of opportunity for change. I really enjoying hearing the speakers and the clear hope and commitment to creating positive change in what has been a severely neglected area of society, so long as everyone acts and continues to act in alignment with the changes they wish to create then there is real hope for all."

"Very interesting. As a professional I was slightly disheartened by the 'them and us' attitude that seemed to exist between schools and parents."

"Not have seating plan - would make for a quicker start"

"Make all parents stick to all the rules - no children! Parents personal problems to be done the right way. "

"Cover really well. It open my eye but most of all it has clearly shown that Parent / Carers will have a voice finally. YAY!"

"Meeting parents with experiences to share is valuable and i always try to consider what the things I do would feel like from a family perspective."

"I believe this a tremendous opportunity to address and provide solutions to what is a issue. These children are our future and that always needs to be kept in mind. If it's not dealt with it will be to the detriment of all society - if we succeed it could probably be one of the most amazing transitions in our time."

It was also good to be joined in the Morning by Stewart Jackson MP and Cllr John Holdich Peterborough City Council Leader both showing their support for parent participation and co-production in Peterborough.

A full report is available detailing the day, feedback and data on attendance. In due course this will be uploaded to the Local Offer along with all questions raised and answers provided by Local Authority officers.

Pop Up Shop

FVP facilitated parent carer support and engagement via the use of a Pop up shop again; this time the shop was only open for a two week period from 1st to 15th June which coincided with volunteer's week and carers week.

Support for the shop was provided by PCC Early Years, Carers Trust, SEND partnership, Autism Outreach and Hearing Impairment Services. The Head of Inclusion and SEN also spent some time in the shop.

Attendance was low in the first week but did increase during the second week (carers week). In total about 20 people passed through the shop and a portion of these received direct support from Carers Trust and one parent from Early Years. Three parents from FVP also took the opportunity to update their database records.



Peterborough City Council,
Cambridgeshire and Peterborough
Foundation Trust and Peterborough
MP Stewart Jackson supporting
Carers Week

Parent Carers, Peterborough City
Council, Cambridgeshire and
Peterborough Foundation Trust and
Peterborough MP Stewart Jackson



Focus Groups

Two focus groups have taken place so far and more are planned, the focus groups provide a wider group of parent carers the opportunity to participate and also make it easier to explain what information is required and what the expected outcomes for the sessions are.

Focus groups held

Local Offer Checking

A report will follow once all focus groups in this area have been completed, there are two to three planned as series which will follow a set progression.

Local Offer Actions for focus groups from discussion with Adrian Chapman/ FVP meeting

“Test and Discover”: to test the web site in live time and capture the issues. This session is not to agree the solutions, just to map the problems

“Design Parameters”: to agree what’s in scope to change and influence

“What next”: to agree actions, leads and timescales

The solutions will be worked on in the background, and anything that can’t be resolved this way can be brought back to either meeting 2 or meeting 3.

The first focus group was attended by seven parent carers, the FVP participation lead and two PCC officers during which several search/ information issues were found some are mentioned below.

1. Information is in the wrong place
2. Searches for special schools brought up the incorrect information
3. Translation to other languages is problematic
4. The icons being in green only were felt to be bland

Personal Budgets

A full report will follow and will be produced by the parent rep leading on this work stream. Details provided so far are there were 11 parent carers in attendance and six of these also attended the Local Offer focus group. There is still an issue over understanding of what personal budgets are, what they can be used for and how they can be accessed.

Jason Merrill (taken from basic rep report about what was covered)

The focus group was organised by ourselves (fvp) and representatives from PCC and Parents with children with special needs problems what was discussed what should be in personal budgets and what organisations should be involved

Planned Focus Groups

- A. Emotional Health and Mental Wellbeing and CAMHs
- B. EHC Process Documents
- C. Local Offer Development

Work

Parent Participation Work Streams

Hard to reach groups

There have been monthly Hard to Reach Group (HTRG) and Child Development Centre (CDC) meetings where attendance demographics can be broken down in to the following

Needs of CYP - Autism, Genetic Disorders, Hearing Impairment, Downs Syndrome, Cerebral Palsy, SLN, ADHD

Ethnicity of parent carer - Albanian, Pakistani, Dutch, Portuguese, Canadian, Indian, Polish and British

Issues identified by Participation Officer:

1. Commitments of members to attend also sudden cancellations as all of us are parent carers which is our first priority and responsibility.
2. Finding ways of having access to more members in BMI community as they often even hide within own community.
3. So far time and active participation have been an issue within the group. It is clear from the census that 'white other' population is the fastest growing group within the BMI community. We need those members on board and for this it is vital to meet up with the various international schools and its members. We had this contact in the Polish school, but she has since resigned from her post without making us aware and advising us of her replacement.
4. We have had a few meetings at the Aiming High group but even within their own group attendance is proving to be an issue. These parent carers have a huge responsibility within the family and with the many marriages to organise and religious duties they find it hard to make time to attend support groups. It is not as much a priority for them as it is within other communities.

Outcomes:

1. Outcomes are that several members have attended the expert parenting program and have found this a very positive learning experience. The next one is planned for later in the year as at present no members are willing to commit due to Ramadan and the summer holiday.
2. There is a group of at least six members who are interested in working as volunteers for CPFT at the CDC/CAMHS. Work is taking place to get this organised and for volunteers to start in September 2015.
3. Baseline questionnaires for professionals and parents have been made and responses are coming back from the parents. At the next 'parent story meeting' the professionals will be asked as well to do this questionnaire and also Dr. Reddy will be sent a link for this questionnaire so his staff can fill this in online.

4. A 15 step challenge questionnaire was made for the CDC/CAMHS and passed to Dr. Reddy for approval and use by CPFT.
5. A very successful parent story was told by Gina Yates at the weekly meeting of professionals. We are in the process of organising the next story to be told by Claudia Dias in the next few weeks. A parent will tell their story once a month.
6. The various foreign language schools in Peterborough have advised Jonathan Lewis they want to be involved in the project and we are waiting for their details to arrange a visit.

Child Adolescent Mental Health services (CAMHs)

Pinpoint and FVP are still working jointly on this and as mentioned above a focus group is planned to provide an update and the opportunity to inform pathways and early support. This focus group will mirror a series of network meetings that Pinpoint have held across Cambridgeshire.

Details will be in a separate focus group report when all details have been gathered. The focus group will have input from the Clinical Commissioning Group (CCG), LA and parent carers. The focus group will be hosted by FVP.

Other work streams

The other work streams that are ongoing and which will be detailed in reports over 2015 to 2016 are:

Emotional Health and Wellbeing (Mandi Rennie, John Ravenscroft)

Self-harm

Schools Engagement (Sara Rourke, Eloise Veale and Vanessa Perry)

SEND Strategy (Louise Ravenscroft)

SEND project (Shared)

Personal Budgets (Sara Rourke, Sarah King)

EHC processes and documentation (Johanna Woodhams)

Local offer – web development (focus group based)

Outcomes focussed advice (Johanna Woodhams)

Health engagement with child development centre (Dafne Stoelhorst, Claudia Dias and others)

Carers Partnership Board (Sara Rourke, Sarah King)

Learning Disability Partnership Board (Claudia Dias supported by Sara Rourke)

CCG Maternity, Children and Young People Programme Board (John Ravenscroft)

Peterborough Stamford Hospitals Foundation Trust Maternity, Children and Young People Programme (TBC)

Health Child Programme (Tanya Smith)

Child and Families Joint Commissioning Board (John Ravenscroft)

The names listed by the work streams are the lead reps but other parent carers do join them when they can.

What Is Working Well and Risks/ Concerns

Working Well

1. Increased inclusion from parent carers from different ethnic backgrounds
2. Face to face parent participation via focus groups which affords better understanding and inclusion in discussions
3. Increase LA support from different areas for parent participation

Risks/ Concerns

1. CAMHs remains an area of concern with increase in dissatisfaction of services especially for those who has CYP with a diagnosis of Autism
2. Capacity especially around the Summer break
3. Timings of meetings

You Said – We Did

1. Parents at the conference and LO focus group said the LO is bland and colour may be a problem so the LA have listened and the icons will have colour added to match the icons on the LO postcards and banners
2. Parents at the Local Offer focus group said there needs to be a better mechanism for feedback on the Local Offer and it should not be just an FVP email address so the LA have listened and are developing others methods for feedback which will be available to view and comment on at the next Local Offer focus group
3. Parent carers have commented on the public Facebook page that CYP engagement is not good enough and more needs to be done to include those in mainstream settings and CYP with autism specifically the LA are looking into this and methods of wider engagement are being explored and suggestions will be welcomed via the Local Offer.

Actions

1. Create survey exploring parent carer views of ASD/ ADHD/ Challenging Behaviour (Services, Support, Definitions).
2. Set up meetings between Lou Williams and John Ravenscroft/ Mandi Rennie for Emotional health and Wellbeing Work and Lou Williams and Dafne Stoelhorst for Social Care and HTRG.
3. Plan and conduct focus groups on Emotional Health and Wellbeing, EHC process documents, Local Offer next stages.
4. Explore issues and solutions further for the Aiming High Group who are forming part of the HTRG in relation to attendance and active involvement.

FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Tanya Smith and Dafne Stoelhorst	
Title of Strategic Group	Healthy Child Programme Board	
Date of Meeting:	Tuesday 19 th May 2015	
Agenda Items (relevant to Family Voice):	All	
Brief Summary for feedback at Family Voice meeting/ updating members:	Please see attached meeting paperwork	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	FVP will be involved in all associated work streams going forward.	
Any significant issues to be noted by Family Voice Forum members:	As a parent of multiples I noted that the midwifery system is not set up for multiples. I.e. antenatal classes are done when most have already given birth. I raised concern with the early year's program and who can request this. I think parents can get confused and think it is the EHCP and that needs to be made clear that it isn't.	
Any other comment:	Our involvement is very valued at all levels. We were clearly asked for our opinion and listened to by the professionals.	
Any items to feedback from the Forum to Strategic Planning Group:		
Any Actions for Representative or Forum as a result of meeting:		Responsible Person and Date for/ Of Completion
You Said – We Did		

FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Dafne Stoelhorst	
Title of Strategic Group	Senco	
Date of Meeting:	6 th May, 2015	
Agenda Items (relevant to Family Voice):	Changes to SEND Reform and parent stories	
Brief Summary for feedback at Family Voice meeting/ updating members:	Sheelagh O'sullivan organised an event to discuss the SEND reform changes which have come into place. This event was aimed at all the Senco's in Peterborough to explain to them where the process is now and what has changed since September 2014. From FVP two parents were invited to tell their story/experience with the new EHCP process.	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	That it is recognised that the LA works closely with FVP to make sure the changes are understood by both professionals and parents. The senco's could clearly see that the LA takes the experiences of parents serious as is now expected with the new EHCP process. We are part of this process no longer bystanders and that message was clearly made.	
Any significant issues to be noted by Family Voice Forum members:	Some issues previously were raised about FVP having access to confidential information. This was based on the fact that their logo is on the new form.	
Any other comment:		
Any items to feedback from the Forum to Strategic Planning Group:		
Any Actions for Representative or Forum as a result of meeting:		Responsible Person and Date for/ Of Completion
You Said – We Did		

FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Dafne Stoelhorst	
Title of Strategic Group	Meeting with Aiming High	
Date of Meeting:	11 th May 2015	
Agenda Items (relevant to Family Voice):	Explain what FVP/HTRG can do to empower ladies of aiming high	
Brief Summary for feedback at Family Voice meeting/ updating members:	<p>Spoke about:</p> <ul style="list-style-type: none"> - Training availability and the expert parenting program and how that is important for them to attend. - Six parents signed up to join at the annual conference - Parents wanted to know how to get on Hunstanton trip/Activity world - Will meet again to discuss further and see what we can mean to this group - They were made aware that they can get transport to and from to make it possible for them to attend. 	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	Out of the 8-9 ladies 6 are willing to attend the conference.	
Any significant issues to be noted by Family Voice Forum members:	These parents need a lot of reminding and pushing. We need to make them become aware that if they want to help their children they need to take responsibility and not have a sit back and wait attitude.	
Any other comment:		
Any items to feedback from the Forum to Strategic Planning Group:	This will be a difficult group to get fully on board due to the cultural and language issues. Even within their own community there is frustration about the lack of willingness to empower themselves.	
Any Actions for Representative or Forum as a result of meeting:	Attending next meeting on 11 th of June to discuss what focus groups would they want. I.e. Dial etc to come out an meet them.	Responsible Person and Date for/ Of Completion
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You Said – We Did		

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FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Mandi Rennie	
Title of Strategic Group	SENCo Briefing	
Date of Meeting:	6 th may 2015	
Agenda Items (relevant to Family Voice):	Presentations by MR and DS SENCo Updates	
Brief Summary for feedback at Family Voice meeting/ updating members:	<ul style="list-style-type: none"> • DS and MR attended SENCo briefing to share personal experience of SEND reforms. Focus was on positive impact of being included, informed and individual participation. • Some Key messages shared by PCC included use of co-ordinated plans not being compulsory, timescales for transfers, Produced 16 EHC plans with 175 assessments underway, By June 2015, 60 statements (post-14 year olds) will be converted to EHC Plans, funding re. Personal budgets. 	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	Parents given opportunity to share experiences	
Any significant issues to be noted by Family Voice Forum members:	N/A	
Any other comment:	Both personal experiences of reforms presentations were well received.	
Any items to feedback from the Forum to Strategic Planning Group:	N/A	
Any Actions for Representative or Forum as a result of meeting:	N/A	Responsible Person and Date for/ Of Completion
You Said – We Did	N/A	

FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Louise Ravenscroft	
Title of Strategic Group	LO Delivery	
Date of Meeting:	13 th May	
Agenda Items (relevant to Family Voice):	All	
Brief Summary for feedback at Family Voice meeting/ updating members:	<ol style="list-style-type: none"> 1. The development plan was re-visited. 2. The comms plan was discussed and work will need to take place to put together a case for suitable resources 3. Focus groups to develop LO have been set and will include different parent carers/ disability groups 	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	N/A	
Any significant issues to be noted by Family Voice Forum members:	Comms is still an issue and needs resources to develop further	
Any other comment:	N/A	
Any items to feedback from the Forum to Strategic Planning Group:	N/A	
Any Actions for Representative or Forum as a result of meeting:	N/A	Responsible Person and Date for/ Of Completion
You Said – We Did	<ol style="list-style-type: none"> 1. Key messages for the comms strategy from parent carers have been added. 2. Focus groups have been set up as parent carers have reported issues with searching for information on the LO 	

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FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Claudia Dias	
Title of Strategic Group	Meeting with the Aiming High	
Date of Meeting:	21 th May 2015	
Agenda Items (relevant to Family Voice):	Possible actions from FVP/ HTRG to empower Parents from Aiming High	
Brief Summary for feedback at Family Voice meeting/ updating members:	<p>Discussed:</p> <ul style="list-style-type: none"> -importance of service structure knowledge to make better use of services available / Expert parenting courses offered -Signposting of information about respite and Autism courses available in Peterborough - Further support and discussion of future actions within the group. 	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	Most Ladies were satisfied with the information given and a bond of trust was formed	
Any significant issues to be noted by Family Voice Forum members:	<p>The objective of the group is still not clear, most of the members still struggle with the stigma of the disability within their community, The group work is patchy and most of its members are not aware of the changes in services themselves.</p>	
Any other comment:		
Any items to feedback from the Forum to Strategic Planning Group:	Trust is going to be a long term work; language for some members is also an issue. The group also face internal problems like the lack of commitment of some member's mean that others take too much on board and are not being able to fulfil their work and family commitments or create feelings of frustration among themselves.	
Any Actions for Representative or Forum as a result of meeting:	Attending the meeting on the 11 th June to ascertain group objectives and plan further actions within the community and group itself.	Responsible Person and Date for/ Of Completion
		CD
You Said – We Did		

FVP FEEDBACK FORM
REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Johanna woodhams	
Title of Strategic Group	Outcome focus meeting	
Date of Meeting:	21/5/15	
Agenda Items (relevant to Family Voice):	Draft ehc assessment	
Brief Summary for feedback at Family Voice meeting/ updating members:	Looked at draft for the new ehc assessment	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	<p>The hi light part of the documents are for professionals fill-in and will be in the top</p> <p>We also look at the Portsmouth evidence writers pack and how it can be used here in PETERBOROUGH</p> <p>The draft is almost ready for Singing off one other possible meeting</p>	
Any other comment:	Further notes to follow whit minutes	
Any items to feedback from the Forum to Strategic Planning Group:	No	
Any Actions for Representative or Forum as a result of meeting:		Responsible Person and Date for/ Of Completion
You Said – We Did	N/a	

FVP FEEDBACK FORM

REPRESENTATION ON STRATEGIC PLANNING GROUPS

Name of Representative:	Claudia Dias	
Title of Strategic Group	Meeting with the Aiming High Group	
Date of Meeting:	11 th June 2015	
Agenda Items (relevant to Family Voice):	Discuss possible HTRG strategies and support to Aiming High group / Invite AI to Expert Parent course	
Brief Summary for feedback at Family Voice meeting/ updating members:	<p>Discussed:</p> <ul style="list-style-type: none"> - How service providers are changing their approach to the delivery of services and how that will impact on children and families - Some explanation of certain disabilities basics knowledge - Difficulty in recognising Disability within the group and Asian community - the importance of religion commitments, elders , and large family on Asian community 	
Particular achievements/ outcomes useful to Family Voice as a result of group meeting:	A better knowledge of the Asian community which allow FV to better design and promote awareness of services and disability within the Asian community. Information and Brain storming to redefine Aiming High propose within the Asian community either as an advocate group or as an off load /inter help group an avoid dissolution.	
Any significant issues to be noted by Family Voice Forum members:	Aiming High is a group at the moment with an internal crisis, already existent at the time of first contact and that is continuing. The lack of commitment from some members is the main reason and this may mean that a flexible attendance and less formal purpose may be needed.	
Any other comment:		
Any items to feedback from the Forum to Strategic Planning Group:	<p>It is imperative for Aiming High to define purpose as alternative actions may have to be considered within the Asian community, possible issues to have in consideration:</p> <ul style="list-style-type: none"> - The reluctance in being associated with disability from some Aiming High members - Extensive work in overcoming myths about disability and Pathologies - Thrust is an issue and outside community organisations seen with a certain suspicion, but NHS is well respected and carries a lot of weight (as reported by a member of AI) so in time and if parts are comfortable maybe a relationship FV/CDC can be made public knowledge . 	
Any Actions for Representative or Forum as a result of meeting:	A bond of Trust is starting to emerge and although despite of the reluctance information is being passed on and acted upon, slow but steady progress is being made.	Responsible Person and Date for/ Of Completion
		CD
You Said – We Did		

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