



Family Voice Peterborough

Registered Charity
1141009

Special points of interest:

- Participation News
- Trustees Update
- Caravan Breaks
- Family Voice Peterborough Our Story

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Welcome to our 6th volume of this newsletter!

Hello and welcome to our latest newsletter; and the first since our AGM

We have much to update you on locally, regionally and nationally in terms of parent participation. Things have been moved ahead at full steam since the introduction of the Children and Families act 2014 and parent participation has become more

recognised and supported.

There will be points of interest in this newsletter relating to work with health, more ways to participate, the move away from the use of Facebook for participation and of course the usual articles on events like the annual conference and access to short breaks through the FVP caravans.

We really hope you enjoy reading and please remember if you don't want to read the newsletter or hang on to it once read please pass on to others who may also want to read it.

Thanks FVP

Don't bin me, pass me on to other parents!

Trustee Update

We would like to update you on who our trustees are since our AGM which was held on 21st April 2015.

We have:

John Ravenscroft (Chair Person)
Mandi Rennie (Treasurer)

Tanya Smith (Secretary)

Also welcome to Tanya our newest trustee.

Your Newsletter
Your Voices
Your Participation

National and Regional News—Direct From NNPCF

Thank-You

A great big thank you to all of the forums who completed the last SEND survey. Your responses go directly to the Department for Education who really value knowing how forums feel the implementation of the reforms is going. It helps to identify particular challenges in local areas and any national themes that may be arising.

We are currently working on collating the results from the February survey and will let forums know when the report is finalised.

We do appreciate it is a very detailed survey that takes some time to complete and that we have not always been able to provide you with a lot of notice about the survey or the deadline, which makes it even more impressive that so many forums have been able to respond.

You don't have to wait for the SEND surveys to let us or the Department know about what is happening in your local areas. You can always fill in our challenges and successes forms.

Opportunities to participate

No voice unheard, no right ignored - a consultation for people with learning disabilities, autism and mental health conditions. This consultation explores options on issues such as how people can:

- be supported to live independently, as part of a community, be assured that their views will be listened to, challenge decisions about them and about their care, exercise control over the support they receive with a Personal Health Budget, expect that different health and local services will organise themselves around their needs and know that professionals are looking out for their physical health needs as well as their mental health needs. The scope of the consultation primarily relates to:

1. Assessment and treatment in mental health hospitals for people (all age) with learning disability or autism;
2. Adult care and support, primarily for those with learning disability but also for

adults with autism (and the links to support for children and young people); and

3. All those to whom those Mental Health Act currently applies (including children and young people);

Closing date for responses is 29 May 2015. .

NNPCF and OFSTED

The NNPCF were asked to provide a response to OFSTED and CQC about the best ways to engage with parent carers as part of the preparation for the creation of an Inspection Framework to inspect authorities implementation of the SEND reforms.

We put out a call on the NNPCF social media in the joint bulletin and on the NNPCF website asking forums what they would want us to include and to contribute to this response.

We produced a short report for Ofsted and CQC including the suggestions of all who contributed.

Articles from NNPCF newsletter

Communication Channels

Facebook

www.facebook.com/fvpcommunity

YouTube

<http://www.youtube.com/user/FamilyVoicePeterboro>

Twitter

@familyvoice1

Website

www.familyvoice.org

Email

participation@familyvoice.org

You can keep informed by linking with us through all these channels of communication.



Parent participation

2014 to 2015

219 parents in total have been involved at some level via face to face meetings/ events

97 professionals have been involved at some level via face to face meetings events

95 respondents have taken surveys via survey monkey - the breakdown of parents/ professionals is not possible due to either surveys being completed anonymously or respondents self-reporting as both parent/ professional

18 parents have taken part in discussions via social media

Two parents have been involved in case study work

Parents have self-reported being members/ attendees at PDDCS, PADSG, LM, NAS, AHG, Shine and Face2Face

Children's/ Young people disabilities have been reported by parents as including Autistic Spectrum Disorders, Learning Disabilities, Tourette's, Mental Health Disorders, Cerebral Palsy, Sensory Impairment, Down Syndrome, Complex Health Needs and Genetic Disorders

Those parents involved have self-reported ethnicity as White British, Pakistani, Portuguese, Albanian and Dutch

Involvement from fathers is much lower than involvement from mothers and tends to be via open meetings/ conference

Reported age of children ranges from 2 to 22

Methods used include open

meetings, a conference, focus groups, social media discussions, on-line surveys, meetings between managers and parents and parent representation

Evidence is both qualitative and quantitative

"I have been a Parent Representative and Volunteer for Family Voice Peterborough for around 2 years now. I attend meetings as often as family allows me to. I do thoroughly enjoy the work I do and feel empowered by being given the opportunity to participate. I have done various different work-strands including Carers Partnership Board, Focus Groups/workshops for Local Offer, meeting with Jonathan Lewis and many more. I have tried anything from filing, to manning stands. I have many roles in the office, admin, reports, creative design and lately lending a hand to Fundraising- wherever help is needed really on the days I can attend"

What is parent participation

Parent participation is about working together collaboratively with parents and professionals to achieve better outcomes for all our children/young people with disabilities and additional needs.

It is about putting aside personal differences and coming together to achieve common goals.

It is about the involvement of parents with a wide range of professionals and local service managers in the planning stages of service delivery. It is underpinned by the following principles:

1. User involvement should be central to policy making, and the design and delivery of services at a

local, regional and national level

2. Parent carer participation is acknowledged as mutually beneficial to service planners and service users

3. Parent carer participation requires support financially at a national, regional and local level

A parents forum's role

A parents forum's role is to be pan-disability and equally involved at all levels it is not about fighting or challenging where that would lead to barriers being created.

It is about working together to break down barriers and challenge positively. A parents forum acts as a critical friend to strategic partners and works to share the positive and negative aspects of services.

We work to find ways together to ultimately co-produce services that meet the needs of all children and young people.

Parents Forum's do NOT

1. Work on one disability ie. ASD, Down Syndrome, Hearing Impairment (this is the work of other charities/ groups)
2. Fight for individual services
3. Provide case work
4. Work with individual families
5. Offer individual support or run support groups

Local Participation News

Parent Representatives

Parent carers act as representatives for FVP and part of their role is to take part in strategic meetings and work; they are representative of parent carers from different backgrounds and with children/ young people with different disabilities/ additional needs.

Parent representatives do not take forward the views of individuals but they do take forward the views of groups of parent carers.

The parent carers acting as reps currently are Tanya Smith, Mandi Rennie, Sarah King, John Ravenscroft, Maxine McCulloch, Gina Yates, Jo Woodhams, Dafne Stoelhorst.

Wheelchairs

Two parent representatives attended a meeting with representatives from Pinpoint, the CCG and Provide to discuss the issues raised in the survey we mentioned in the newsletter from January/ February.

Parents made the following suggestions which were fed back at this meeting:

Use a pre-assessment questionnaire to improve assessments.

Use a follow-up questionnaire after a visit to collect parents' views.

Run an open day drop-in once per year with lots of chairs to look at, leaflets about the chairs, therapists to talk to, etc.

The following actions were agreed:

- 1: To organise a pathway meeting to pick up on pathway issues identified above. meeting, will be on 2nd June,
- 2: to look for guidance on number of

therapists to wheelchair users.

3: finalise leaflet, if still needed.

4: look into Voucher Scheme leaflet.

5: look into national guidance on voucher schemes for contract.

6 look into national guidance on funding wheelchairs.

ASD and ADHD Referrals

FVP and Pinpoint were recently made aware that the local provider for health services CPFT had taken the decision to close their waiting list for referrals for ASD and ADHD assessment.

This caused concern to both forums and work has taken place at a strategic level to raise these concerns. A letter detailing the concerns has been sent to the CCG, CPFT and both Peterborough and Cambridgeshire. The letter asks what support will be made available to families during this time.

Both forums took the decision to also put an announcement out via social media about this issue and the views gathered as a result have been fed back to all parties. Going forward both forums will be involved in developing a suitable pathway for accessing services relating to this.

FVP are also aware that families have been sent discharge letters from local paediatric services delivered by CPFT. This is something we have raised at a strategic level as well.

If anyone has any views they would like to share on any of these issues can they please email participation@familyvoice.org or phone 01733 313184 and ask to speak the participation lead.

Local Offer Focus Groups

Some focus groups have taken place to help inform the development of the Local Offer; these have included the types of information included and the icons that appear on the Local Offer pages. Now that this information has been included in the development of the Local Offer and the Local Offer is live another set of focus groups will take place to look at usability and accessibility.

EHC Process and Documentation

New documents are being developed as part of the work locally on EHC processes and FVP reps have been involved in this.

To make sure that there is not only co-production at design stages by representation but more widely there will be a chance for parent carers to look at the documents during a focus group in June.

One document that has already had some feedback is a new request for statutory assessment form. This received some interesting feedback in part due to confusion over what information would be shared and with who. Some parents felt that other parents may think the information would be shared with organisations like FVP due the logo being at the top of the document alongside the Local Authority logo. In acknowledgement of this

Local Participation News cont.

feedback and confusion and after a suggestion from other parents it has been decided to place all partner logo's including Family Voice Peterborough's at the bottom of documents with the line "document co-produced by ..."

Social Media Use

After much consideration a decision has been reached regarding how and when social media will be used going forward. Twitter and Facebook will be used for information sharing only.

Due to capacity and infrastructure limitations FVP will not be using chat rooms to facilitate participation.

Participation will take place using more traditional methods such as half-termly topic based meetings, focus groups, surveys (which will be available via the website as well as main Facebook page), parent representation and an annual conference; this list of methods provides a sample of methods that may be used.

Support will also be provided to participate through childcare and transport expenses when required which can be discussed with the treasurer. Also timings for meetings will be looked at with some in school time and some after school for parents who work.

"You Said—We Did"

FVP have started using a "you said—We did" format for feeding back what is being achieved by parents participating locally.

1. **You said**—communication is patchy and confusing and you do not know what is happening with transfers to EHC plans
We did—FVP fed this back to the Local Authority and co-produced a letter and timescale document (parent pack) detailing when statements would be transferred to EHC plans and this was sent to every household where a child/ young person has statement.
2. **You said**—the use of the logos was confusing and should be changed.
We did—this was fed back to the LA and the logo position was changed and further information added for clarity
3. **You said**— you did not like the proposed

information on the local offer for appeals, mediation and complaints

We did—this information was given to the LA and the information on the pages was amended and the suggestions made were taken on board.

SEND Awareness Survey

A SEND awareness survey has been conducted twice over the past year and FVP are now re-visiting this. If you want to take the survey please use the link to take you to it.

<https://www.surveymonkey.com/s/SENDawareness2015news>

If you cannot take the survey in this way then get in touch by calling 01733 313184 and a paper copy can be sent out or the survey can be completed over the phone.

Upcoming meetings/ events

Annual Conference

Date: 3rd June 2015

Time: 9:30 to 2:30

Venue: Kingsgate

Free to attend with lunch and refreshments included. Speakers include SBrian Lamb, Wendi-Ogle Welbourne, Jonathan Lewis and Dr

Reddy. Workshops will also take place including topics on funding, health and an open session with Sheelagh Sullivan.

Mental Health and Wellbeing

Date: 25th June

Time 10 to 1.30

Venue: The Fleet

Free to attend with refreshments. This is your opportunity to meet with CAMHs commissioners and providers and comment on early support plans.

Booking essential for all events

Training

Expert Parent Programme

FVP held the first expert parent programme training course for 2015 for parent carers from different ethnic backgrounds. This received positive feedback and all learners reported having an increased understanding of how they could work with health to achieve better outcomes for their children.

The training course took place over two half day sessions and covered

outcomes, understanding the health system and complaints.

After feedback it has been decided to try the course over two sessions again. The next sessions will run on Monday 29th June and Monday 6th July. For booking please call 01733 313184 or use this link to book online.

Working with Pinpoint

FVP have just delivered a train the trainer package for the parent participation and representation course which was well received and will be put in to practice for parent carers in Cambridgeshire in due course.

Caravan News

The two caravans owned by FVP for families with children and young people who have SEND are both nearly booked out for the school holidays.

This has proved a real success with many families benefitting and yet again demand being more than the number of holidays that can be supplied. FVP have introduced a new policy for the caravans to try and make bookings as fair as possible and to ensure as many families as possible benefit.

There is an extra service available for the caravan at Haven in Caister whereby beds can be made up on arrival. Unfortunately this is not available for the

caravan at Butlins Skegness so you will continue to need to take bedding with you.

FVP are continuing to work hard to keep the costs of holidays as low as possible. Generally for families who are eligible the prices continue to be kept as low as possible. Breaks are available for Friday to Friday (7 nights), Monday to Friday (4 nights) and Friday to Monday (3 nights).

There is still availability for both caravans in term time and prices are kept even lower in these times. If you are looking for a late deal then please do get in touch to see what can be offered; this is particularly if you would like a Friday to Monday break. Some

weekends can be offered as late deals at approx. £150.

Both caravans sleep 8 people and the price is per caravan not per person. Also all utilities are included as are wristbands/ entertainment passes.

For further details go to www.facebook.com/FamilyVoiceCaravan or www.familyvoice.org alternatively call 01733 313184.

Short Breaks

Families with children and young people aged between 0 and 25 can access a variety of short breaks; from after school clubs

and youth clubs through to LINK care depending on eligibility. For further details on what is currently available and how to

qualify please check out Peterborough's Local Offer

Family Voice Peterborough — Our Story

2011-2015

We would like to take the opportunity to complete our story which we started in the newsletter from February. Last time we finished at the point when we were first registered as a charity.

Between April 2011 and March 2012 FVP managed to achieve the following: 25 Trips and activity days where over 600 people attended out of the approximate 600 over half were children or young people with a disability or additional need.

Organised 3 separate joint fund raising events and raised over £4000 that was split between the charities involved in each event.

Designed and conducted research that involved 92 families accessing 16 short service provisions.

Held 3 consultations surrounding the SEN green paper

Had 180 new members join the organisation.

Sent 5 parents on Training courses to improve their skill base and better enable them to help the organisation on a voluntary basis

3 Parents stepped forward as representatives for the organisation

2 parents became volunteers for the organisation in fundraising

and training roles respectively.

Between April 2012 and March 2013 as well working on delivering trips and activities and parent participation in a similar way to the previous year FVP branched out slightly in to delivering low cost short breaks for families who have children and young people with SEND. This was made possible after being gifted a caravan sited at Butlins Skegness. FVP also worked hard to ensure that not only would the access to the caravan be low cost it would also include wristbands to access Butlins Resort.

FVP also held some rather unusual fundraising which included a parents nude calendar.

In 2013 to 2014 FVP continued to see growth in the charity and further development of the work of the forum.

FVP were busy working in partnership with Peterborough City Council in relation to the SEND reforms. Due to a successful training programme being designed and implemented by some of the FVP trustees who were also qualified trainers, there was a growth in the number of trained parent representatives.

As in previous years FVP also held activities during the year, for example the Christmas party, activity world and planet

ice private hire. FVP also held a successful network event at the Great Northern Hotel this included FVP's first participation awards to recognise the involvement and support that people had given over the year. We also started a breakfast club that runs about once a month for parents to get together. In 2014 to March this year the charity has grown to the point that there are over 500 households details on the database and moved towards being employers. Also some more security has been achieved through more grant funding from variety of sources.

What all this has shown is how much work needs to be devoted to running a charity and that there are differences between running a charity as opposed to a steering group for a parents forum. For FVP the forum is part of the charity and this has led to some confusion over the different role trustees must take on.

AS FVP continues to grow and develop the current trustees will work hard to ensure that charity compliance is upheld while also working to ensure parent carers continue to have an active voice in shaping services for all our children and young people.

"It's not how much we give but how much love we put into giving."

Mother Teresa

Dates to look out for

Activity World
May 25th

Annual Conference
3rd June 2015

Mental Health and Wellbeing
25th June

Activity World
July 18th

Hunstanton
September 5th

All About Us

We are a group of parents and carers who are on a **voluntary** basis actively seeking to improve services in all areas of the lives of children and young people with disabilities or additional needs between the ages of 0–25 years. We aim to be the strategic consultative body within Peterborough for families, providing a liaison point for statutory and voluntary bodies. We also endeavour to bring parents and carers together to have a strong voice ensuring the future for our children and young people is a good one. As well as this we arrange national and local trips and activities for the whole family.

We are also a registered charity.

**Family Voice
Peterborough**

Together improving services for
children and young people with
disabilities and additional needs



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