



Family Voice Peterborough

Registered Charity
1171389

Special points of interest:

- Participation News
- Opportunities to participate
- Activities/ Events/ Support and Training

Inside this issue:

Welcome to latest newsletter!

Welcome to our Summer Newsletter; we have much to update you on and there are participation opportunities to let you know about.

It has been a busy spring term for FVP from the move to a charitable status through to a growing increase in the number of parents participating. There will be updates on the work we have

conducted plus details on how else you can get involved.

There are changes occurring nationally with the NNPCF and locally with parent participation work. FVP will continue working with Pinpoint to enable parent carers to receive information, participation opportunities and support in relation to Emotional health and Wellbeing Services.

The Parent Carer Hub/ Inclusion Surgeries FVP started in partnership with Peterborough City Council and Carers Trust are continuing and have gone from strength to strength with parent carers reporting positively on their involvement.

Read all about this and more in this newsletter.

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

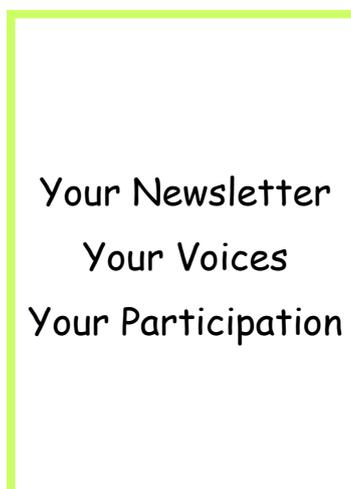
Trustee Update

FVP Transferred to a Charitable Incorporated Organisation (CIO) as of May 2017. The old charity has now been closed.

FVP Trustees are
John Ravenscroft (Chair Person)
Ralph Middlebrook
Wendy Gray

Graham Casey

FVP would also like to thank Sara Rourke for her time as a trustee and look forward to continuing working with her as a Parent Representative leading on Schools, Transport and Personal Budgets.



National and Regional News

Local Area Inspections

A delegation from the joint CQC/Ofsted inspectorate attended our NNPCF steering group meeting on 13 March.

The group also included senior figures from NHS England. The following points were made to them:

We pointed out that Parent Carer Forums are often not invited to the CQC elements of inspections - this has been patchy and relied on the CCG extending us an invite.

They noted our points and thought that these should be run the same way as Ofsted led inspection meetings;

Inspectors emphasised the importance of leadership in LAs that understand what needs to be done and give it real focus. This they commented was perhaps the heart of the inspections;

We asked what the follow on is from an inspection - what happens if a local area is not addressing the points raised in an inspection letter? They said that following an inspection the ball passes to the Department of Education (DfE) to ensure compliance with recommendations.

The DfE said they will follow up as required and welcome input from Parent Carer Forums in this decision making;

They noted our points that forums often feel as they are being inspected. They emphasised that this is not the case - the forum is simply one way of them seeking parent carer engagement;

They too were concerned about how to reach "seldom heard" groups - they asked us how they might access them;

Winter Newsletter Update

Review of the NNPCF and it's steering Group:

In May the NNPCF Steering Group held a second workshop, this time exploring their ongoing communications work including the development of a communication strategy, a work plan and standard templates. We also finalised plans to share the NNPCF priorities with members which are based on our consultations and discussions across the regions. Steering Group Members will be feeding back more in Regional meetings, this is to ensure all member parent carer forums have the opportunity to hear about them

directly and ask questions.

NNPCF Steering Group May Meeting:

Following an invitation to join the Steering Group this month, Dame Christine Lenehan came to update us on the work of the Council for Disabled Children (CDC).

We looked at areas of overlap for CDC and the NNPCF, she also updated us on the current position regarding the Lenehan Review. Lynn Hoppenbrouwers (Strategic Health Lead at Contact a Family), also joined us by invitation to share the work she is doing and to see how we can work together to support parent participation in the health arena. Patrick Aguis from the Department of Education briefly joined us to update us on changes within the Department....

The Steering Group signed off the minutes of the March meeting for publication and they are now available on our website. The NNPCF Steering Group also discussed a briefing paper prepared for us by Amanda Batten (CEO of Contact a Family) on the new Disabled Children's Partnership. There was a discussion about the annual conference, further work needs to be done to secure funding and a large enough venue but we are aiming to agree a

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.

**Together we can
achieve
anything**

National and Regional News Cont.

date as soon as possible so that Parent Carer forums can make their plans.

Transforming Care

Sue North and Anna Webster from NHS England have put together an update on their Transforming Care Programme, it also explains what Care and Treatment Reviews are, what they are used for and how they tie into Care, Treatment and Education Reviews.

There are some children and young people who have learning disabilities, autism (or both) and behaviour that challenges, and who may also have a mental health condition. This group of children and young people and their families often experience real times of crisis. This can happen when services and support do not understand their needs or work well to support the family, or when a child or young person has a mental health crisis, putting them at risk of being admitted to a specialist mental health hospital (or assessment and treatment unit (ATU)).

NHS England have been working hard to support adults and children and young people who are part of this group through the Transforming Care Programme. We know that for some children and young people, going into hospital (or an ATU) is not always the right choice. It can sometimes create even more difficulties, as hospitals are often a long way from home, and from families and friends. It is important to make sure that

every possible option has been considered to see if children and young people can be supported at home, or in their local community, or, if they do need an admission to hospital, that everyone is working towards making sure this is for the shortest time possible.

Care and Treatment Reviews (CTRs)

The Care and Treatment Review Policy was introduced in October 2015 to provide a formalised way of bringing all the right people, including the family, into the room together to look at solutions for the child or young person and family so that they could have a good life with positive outcomes. Led by the responsible commissioner alongside a multi-agency team, the Care and Treatment Review (CTR) meeting;

- ensured the child or young person and their families were central to the review in a person centred way
- looked at how needs could be met locally without admission to hospital
- if an admission was necessary or the CYP were already in a hospital, that there was a clear plan thinking about discharge as soon as possible.

Critically the panel responsible for the review also had two independent experts - one of whom is a clinical expert and one of whom is an expert by experience. The latter would be either adults with a learning disability or autism, or a family member with a lived experience. These members of the panel ensured a strong independent presence where decisions could be robustly reviewed, explored, and

where necessary challenged.

Since September 2016 we have been working with people who have been in hospital, parent carers of children and young people, commissioners, providers, local authorities, the Department for Education, ADCS, and others to review the policy, refresh and amend it.

From CTRs to care, education and treatment reviews (CETRS)

There is now a specific new Annex to the CTR Policy for children and young people. One of the main changes for children and young people is that reviews will now be called Care Education and Treatment Reviews (CETRs). A situation that requires a CETR may be due to a change in a child or young person's education or care provision, or it is likely to lead to some significant changes in their education or care provision. The change of name more accurately reflects the significant role that education plays in the lives of children and young people. The new supporting process for CETRs has a clear expectation that education, health and care will be involved from local areas. It also explains how other elements of the CTR Policy must work for children and young people too including the CCG "At Risk Register."

Local Participation News

Conference Update

FVP had a successful conference with over 70 people in attendance (Both Parents and Professionals reported positively about the speakers, topics and venue). The conference was very busy and it has been decided to hold two follow up sessions in the Autumn Term; Preparing for Adulthood and Schools from SEN Support to EHCp's

Conference Questions

What is the rationale behind the refusal to acknowledge Pathological Demand Avoidance as a diagnosis in Peterborough? Cambs are doing this and it really helps. Pathological Demand Avoidance (PDA) is a term used by some families, professionals and organisations to describe behaviour seen in children with autism and other conditions. This is not universally recognised as a separate diagnosis by health professionals as it is not included in the NICE guidance for autism or international diagnostic manuals like ICD and DSM. In research this title or phrase is used to describe a specific aspect of the autistic child's behaviour and not a diagnosis on itself.

The symptoms described as part of are often explained by autism with associate problems like anxiety, sensory processing difficulties and oppositional defiant disorder. There is no objective measure to define "Pathological" Demand avoidance as all children and children with Autism in particular, will avoid demands that they can not meet due to their inherent developmental difficulties.

There is no specific treatment or intervention for PDA that is significantly different from what

used for Autism. It is much more important to properly assess the difficulties face by children with autism to identify the route cause and then develop individual strategies to meet he needs rather than add another diagnostic label like PDA. The CAMH and Community paediatric professionals from Cambridgeshire and Peterborough met as a group to hear from an expert who is of the view that PDA is a separate diagnosis. The health professionals reached the consensus that there is no significant evidence behind the diagnosis of PDA. This is the view across Cambridgeshire and Peterborough.

We will keep a close eye on research and NICE guidance to make sure that we revise our view if there is change in the national guidance.

Who do we contact for mental health awareness workshops in schools? Hodge Holly on Holly.Hodge@cambridgeshire.gov.uk

Are the co-production standards developed by Rotherham available to share? Delegates can read all about the Rotherham co-production standards here <https://rotherhamcharter.co.uk/>

Participation News

Complaints Exemplars

Parent carers have raised concerns about information on the Local Offer especially in relation to appeals, mediation and complaints. A direct request came to FVP via the Facebook chat room for parent carers to have help with some aspects of making complaints. Taking a you said—we did approach the parents were asked if they would like to co-produce a series of complaints exemplars which would

then be made available via the Local Offer for other parent carers to use. This has been no small task. A focus group has taken place with ideas discussed for the letters and various other examples available via the internet being examined. There were many questions and suggestions raised and a decision was taken for the FVP parent reps to take all this information and draft some exemplars which will be shared in the chat room for other parents to further co-produce. It is hoped the process can be completed by the Autumn Term. A special thanks to the parent carers who have taken part so far and provided such valuable insight and experience in to why these letters are needed.

Early Help

A few participation opportunities have taken part in relation to the Early Help pathway; from a workshop at the annual conference to a breakfast meeting and the opportunity to inform a guide to the pathway for parent carers. The information from these sessions will be used by commissioners to try and improve the way communications about the pathway are shared.

To take part in discussions or provide feedback direct to commissioners please use the feedback function on the Local Offer.

Local Participation News Cont.

Local Offer

The way the Local Offer looks is changing—the local offer is moving over to an IT platform called open objects. Parent carers have consistently reported negatively about the Local Offer since its inception. Parent Carers and Professionals do not like the look, usability or accessibility it offers and these views have been heard. Parent Carers have been asked to provide feedback at two focus groups and via the chat room; if you would like to get involved please do go on the Local Offer and provide some vital feedback.

Participation Opportunities

There are always opportunities for parent carers to get involved in a variety of ways which take them from consultation through to participation and ultimately co-production. Your voice counts and this important both individually and collectively. At FVP we listen and try and put in place participation opportunities based on what parent carers say they want. Following are some upcoming opportunities,

Preparing for Adulthood

Many parents have reported either not knowing what is meant by Preparing for Adulthood or not being ready for Preparing for Adulthood. This is often called PfA. What we really mean is that Young People

are growing up and they are being given as much or as little support as they need to help get ready for being adults. PfA takes in employment and volunteering (from supported internships through to independent living and more). A good website for parent carers and young people to explore is <http://www.preparingforadulthood.org.uk/> Work on PfA generally begins around age 14 or Yr 9. The local colleges, Peterborough City Council and third sector partners have got together and formed a group to try and make sure what is being offered to young people is right for young people. The PfA group really need to hear from and involve parent carers and young people in what they do and how they choose to inform what is on offer. Your help is very much needed. Please contact us via participation@familyvoice.org to find out more.

Cambridgeshire and Peterborough Inclusion Strategy

You may have heard in the press lately Cambridgeshire and Peterborough are moving towards devolution and it was recently announced both authorities are now sharing senior officers. One area FVP and also Pinpoint have been asked to look into involves the development of an County Wide Inclusion Strategy. This will then inform how services for children and young people with SEND are

shaped and commissioned. More information on ways to get involved will be shared soon. To stay informed and get involved email on participation@familyvoice.org.

Schools and Participation

FVP have been working hard to engage with schools and help professionals understand the perspective of parent carers and also to help parent carers understand the pressures faced by professionals in schools. This is not always an easy journey and views can often be quite difficult but the child/ young person is always at the heart of what everyone wants.

SEND Newsletter

There is a new newsletter that has been produced for SEND professionals explaining all that is happening locally and parents can sign up to receive this newsletter too. To view this newsletter use the following link https://gal-lery.mailchimp.com/0b072c914c3ab89211d708285/files/5acdd8eb-1bff-408e-8aa6-494cf9df47ad/SEND_in_PBO_Newsletter_2_Summer_term_2017.01.pdf

"Delivering training is something I love to do and after completing the expert parent programme myself I jumped at the chance to become a trainer when it was offered. I could see the real benefit for parents not just to learn about the health system but about learning communication skills and increased knowledge around the SEND reforms. Parents come away feeling empowered to be the expert about their child and for their child."

Activities/ Events/ Support/ Training

The Following Sessions are all running at The Goldhay Centre, 105 Paynels, PE2 5QP (unless stated otherwise)

Asian Cuisine Day

We are hosting our second Asian Cuisine day with the Aiming High Group

Date: 31st July

Time: 2pm to 5pm

Price: £3.50 per adult and £2.50 per child (Pay on the day or book ahead of time with Ramou on office@familyvoice.org)

Bouncy Castle, Crafting Fun, Face Painting (By Family Action), Big Garden Games

Food included in the price - Home Cooked Asian and Gambian Dishes alternatively Pizza and then Ice cream for the children

Proceeds to go towards the Aiming High Group Coach Trip

Families First

Open Access Play for 5 to 13 year olds. Term Time and Holiday Dates.

Tuesdays 3.15 to 5.15 Term Time and £0.50 for tea.

Tuesday 11am to 2pm, 25th July, 8th, 15th and 22nd August and £1 for lunch or bring a pack up.

Call Ellie Burton on 07927 351605 for further details and also to find out what else Families First is running across Peterborough

FVP Community Cream Tea
Home made Cakes, Scones and assorted sandwiches

Date: Bank Holiday Monday 28th August

Time: 12pm-4pm

Price: £2.50 per person, children free

For further details email FVP on office@familyvoice.org or call 01733 685510

PDDCS Summer Play Scheme

Dates: 1-4 AUG.

Time: 10-3

Year 1-Year 6

£20 Deaf child for week

£10 per day for siblings

Must bring packed lunch

Arts and Crafts, Sport, Games, Party and more!!

Email Amy Fisher on amycasselden@gmail.com for further details

Family Song Signing

This workshop is aimed at parents and carers with children of primary school age. Together we will choose a song (from a list to ensure it is appropriate) and learn how to translate it into sign. Throughout the day we will learn other signs through games and fun activities. If there is time we will sign two songs.

At the end of the day other family members or friends can watch a mini performance of what has been learnt.

7 August 10am - 2pm
performance 2.30pm

British Sign Language & Deaf Awareness Training
Summer Signing Workshops
Family Basic Signing

This workshop is aimed at parents and carers with children of primary school age. It gives you and your family an opportunity to learn useful signs for everyday conversation through games, songs and fun.

You also have the opportunity to ask questions, practice signs and understand how signing can help communication in daily life. There will be plenty of breaks, drinks and biscuits and we are happy for pre-school children to attend and have an outside area for them to use (with a responsible adult) if necessary.

12 August 10am - 3pm

Youth Song Signing

This workshop is for children and young people aged 12 and over. You will work in groups to choose a song and work together to decide how to sign it.

You will design and choreograph a performance for possibly two songs to show to family members at the end of the day.

14 August 10am - 2pm
performance 2.30pm

All sessions

Cost:

- ⇒ 1st Adult £20
- ⇒ 2nd Adult £15
- ⇒ Over 12 £10
- ⇒ Under 12 free

Contact:

mysightuition@mail.com

IPSEA Session

FVP have secured funding to host a bespoke training session

Activities/ Events/ Support/ Training Cont.

run by IPSEA. The session will look at EHCp processes, appeals, mediation and complaints.

Date: Tuesday 19th September
Time: 9.30 to 2.30

Price: Free

Booking: [https://](https://www.surveymonkey.co.uk/r/IPSEA19Sept2017)

www.surveymonkey.co.uk/r/IPSEA19Sept2017

Parent Carer Hub (Inclusion Surgery)

The following information is subject to change and full details will be posted on the FVP website:

18th Sept—SAMS & SEND

16th Oct—EPS & SEND

20th Nov—ADHD & SEND

18th Dec—Sensory/Physical &

SEND

15th Jan—SAMS & SEND

19th Feb—EPS & SEND

19th Mar—ASD/ADHD & SEND

Appointments can be booked between 1pm and 4pm for any of the services listed.

SAMS = Statutory Assessment and Monitoring Service who deal with EHCp requests.

EPS = Educational Psychology Service

SEND = Send Partnership and Independent Support.

FVP is hoping to combine these sessions with Carers Trust and other services on the same day as part of the parent carer hub.

Drop-in sessions will hopefully be taking place between 10 and 12 on the same day and parents can either attend the am or pm session or stop for a light lunch (there will be a small fee) and if staying for lunch booking will be required.

FVP Christmas Fayre and Open Day

Pick up a few xmas gifts and meet your local community groups.

Come and see what's on at the Goldhay Centre.

Date: Saturday 2nd December

Time: 10.30am - 4pm

Caravan News and Bookings

Summer holidays are almost upon us and we only have a few dates left for Haven Caister.

Dates are available for September and October at off peak rate of £25 per night.

Please be aware that if you haven't used our caravan at Caister before that it sleeps 8, has ramped access but is only semi accessible for a wheelchair.

Passes that allow you access into the site for the play area, swimming, the entertainment complex and the shows are also included when you book.

Butlins Skegness is now fully booked for August, though dates

are available for September and October at the off peak rate of £25 per night.

Included with this as always is the wristbands that allows you to access to swimming and everything that Butlins has to offer.

The caravan at Butlins Skegness is ramped and is fully wheelchair accessible throughout the caravan.

There is a wet room in the caravan to make it easy for those requiring their wheelchair and for those that struggle using the facilities normally available

To find out available dates and to

book you can phone the office, send a message through the family voice caravan facebook page or email holidays@familyvoice.org

Please also be aware that certain dates in at Butlins in October are adult only weekends so if you want to book a girly weekend away that would be the perfect time for it.

Please contact the office for more details. For all those who have already booked their holiday in either park, enjoy your holiday.

On a final note feedback is always welcome as is ratings on the caravan page. Thankyou.

Dates to look out for

- ⇒ Asian Cuisine Day
- ⇒ Families First Open Access
- ⇒ PDDCS Summer Play Scheme
- ⇒ Family Sign Sessions
- ⇒ IPSEA Workshop
- ⇒ FVP Community Session
- ⇒ FVP Open day

All About Us

FVP started as group of parent carers who came together to actively seek 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.

The main aim is to be the strategic consultative body within Peterborough for families, providing a liaison point for statutory and voluntary bodies.

FVP also endeavour to bring parents and carers together to have a strong voice ensuring the future for their children and young people is a good one. As well as this FVP arrange national and local trips and activities for the whole family and provide short breaks at the seaside.

FVP 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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facebook.com/FamilyVoiceCaravan

Twitter:

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We're on the Web

@
www.familyvoice.org



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