

Last Term's Meetings and Events

In October a couple of us went to a London-wide **Special Educational Needs and Disability conference** attended and organised by all of the main players working on reforms in health, education and social care. It was a very useful day and gave us an insight into what the major changes are and how other boroughs are dealing with some of the challenges.

I-Pad Apps Training

In November, Shelina Mirtha - a specialist speech and language therapist from Linden Lodge School showed a group of about 20 parents basic functions of the I-Pad and how to use communication Apps with children with special needs. She provided some excellent tips and feedback from parents was very positive. **If you would like a list of her recommended Apps, please email us and we will email them back to you.**

We also attended a conference bringing together parent forums and Parent Partnership services from across the South East. One of the parents attending reports:

‘I went to a wonderful conference **‘Together is better’** at the Victoria Plaza Hotel. That was an absolutely amazing experience. I feel privileged to have had an opportunity to attend this conference. There were parents from other forums, representatives from Parent Partnership, Contact A family, National Network of Parent Forums

We also held a well-attended workshop and lunch for parents/carers. **Debbie Rix, Head of the Hearing Impaired Service** explained how to get the most out of meetings with professionals. Her message is: Don't be afraid to ask questions or to say what you want to see happen as a result of your meetings.

and Christine Lenehan, *Director of the Council for Disabled Children.* We did some team building exercises and I learnt that parents and Parent Partnership feel there is still some scope to strengthen understanding between them. Also, I was updated on SEND (Special Educational Needs and Disabilities) reforms. I learned there will be a new NHS Commissioning Board from April 2013, which is made up of our Local GPs. Furthermore, a new Children and Families Bill is following its indicative timetable for legislative reform.’

At the same time, we all need to learn to listen very carefully to what others are saying.

The audience was very impressed by her talk.

One mother said:

‘*Debbie was very interactive and made sure everyone was included. I am really going to take her comments on board.*’



Contact details

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**WE ARE MAKING A DIFFERENCE
and WE DO NEED YOUR INPUT TOO!
PLEASE COME AND JOIN US**



Positive Parent Action (PPA) is Wandsworth's parent forum. We are a group of parents and carers of children (aged 0 to 25 years) aiming to improve provision for all local families, whose children have additional needs.

We are funded by a Department for Education grant, supported by Contact a Family, www.cafamily.org.uk and are part of the National Network of Parent Carer Forums, www.nnpfc.org.uk.

PPA update

Welcome to the first PPA newsletter of 2013.

We had a busy autumn term. As well as taking part in regular Council steering groups, we attended conferences, hosted a South London forums cluster group meeting, ran two parent events, sent out a short breaks survey and continued to meet each month at the EYC. You can read more about some of our activities later . . .

Plans for this term include more training and a parent information event around reforms to the Health system, SEN and social care. We are also having an open PPA meeting to revisit our aims and values and to map out a sustainable future for the forum. If anyone is interested in joining us, please make sure we have your contact details, so we can keep you informed. You may not think PPA is for you, but as our Chair says:

‘If your child is doing well, then the last thing you want to hear about is more disability problems. And if your child is struggling, it's hard enough to deal with their needs, let alone hear about the needs of others.’

And yes, there are a lot of decisions taken at government level or as a result of the economy that we have very little say over. But, and this is a big but, we need to keep banging on about the problems parents of children with additional needs face, such as transition, lack of suitable activities for our children, or the need for increased Occupational Therapy (OT) provision, if these services are to improve. PPA members regularly attend council meetings and consultations with the head of children's services where we make sure the views of our members are heard.’

You don't have to attend meetings or commit lots of time to get involved.

You can join us and add your voice by visiting our website and Facebook pages:
www.positiveparentaction.org.uk
and
www.facebook.com/positiveparentaction

Or call us on
telephone: 020 8947 5260

News & Events

Parent information lunch event 19th March 10.30am - 1.30pm at the Kairos Centre, Mount Angelus Road, Roehampton, London, SW15 4JA

In our previous newsletter we summarised some background on the SEN Green paper and school funding reforms. At the same time there are also significant changes happening in how health services and benefits are provided. All this in a harsh economic climate and with pressure on councils to cut costs - it is more important than ever that we know what is going on and how we can make the most of services. That is why we are running an event on how changes in Education, Health and Social care may affect you.

The aim of the event is to hi-light the SEN changes your families may be facing, ideas on how you can influence the services you receive and your opportunity to ask questions.

We intend to have speakers from Contact a Family and council officers and Parent Partnership will be on hand to answer your questions on local issues.

On 5th March we are having a PPA meeting/lunch where we will review our achievements and plan ways of developing the forum.

This is aimed at forum members, but if you would like to find out more about joining the forum, this may be a good opportunity to do that.

Places will be limited, but if you are keen to join the forum we would love to hear from you.

Places at all our events are free to parents and carers, but need to be booked. Expenses can be reimbursed. Please ring Elizabeth on 020 8947 5260 or email: positiveparentaction@yahoo.co.uk

WE WELCOME NEW MEMBERS

Please get in touch if you would like to come to the next meeting

Positive Parent Action c/o Contact A Family, 1 Siward Road, London SW17 0LA
www.positiveparentaction.org.uk and positiveparentaction@yahoo.co.uk

Local News

Each term our Chair and Facilitator meet Carol Payne (Head of Children with Special Needs and Disabilities service).

They recently discussed:

The Council's protocol on transition to adult services

which is being reviewed and will reflect a new panel process.

PPA is still asking for a commitment to include social workers at Year 9 Annual Reviews for children with complex needs, so that transition arrangements can be understood early in the process.

Transition to adult services support group

A local parent, Jane Delaney and Chris Albury from Mencap, have set up a support group for parents/carers of young people going through the transition process. We understand how stressful this time can be.

Our next meeting is at 11am on 8th March 2013 at Mencap's office: **26 Totterdown Street SW17 8TA, telephone: 020 8767 9911** .

We usually meet on the last Friday of each month. We are all parents going through transition who can support each other.

We have had speakers come to our meetings to give us their advice e.g. Connexions and a speaker about direct payments.

Local News

Wandsworth Transport Services Consultation

The school transport survey report has been published.

427 surveys were sent out and 87 responses received - mainly from children in special schools.

There have not been any significant changes to report, but from December 2012, parents are required to complete a transport request form to access transport services and the annual review question on transport will be more detailed. The Council will be providing more information on

Local News

different travel options and feedback for these new arrangements will go back to committee at the end of the year.

There is an on-line consultation being organised by St George's Hospital around therapy provision.

They want as many parents as possible to respond, so please take a look if your child receives any therapy services e.g. speech therapy, occupational therapy etc.

It can be found at: <http://www.surveymonkey.com/s/L3TQFVW>

There is now a locum OT working to try and relieve some of the back-log on the referrals waiting list.

St George's Hospital A parent's perspective

Having a child in hospital as an in-patient is difficult enough, but when your child has learning difficulties or additional physical or medical needs, the stress can become almost intolerable.

The parent will often repeat their child's medical history, voice their child's needs, arrange their child's usual medication, ensure appropriate feeding, cleaning and toileting measures, all whilst worrying about the condition that landed their child in hospital in the first place.

It is not surprising therefore that difficulties arise that cannot always be resolved with the ward staff.

If this does happen, there are a number of people whose job it is to help you.

Here are St George's Hospital names and numbers:
Telephone: 020 8672 1255

Colin Way ext 2946
Nurse consultant
for high dependency care

Rachael Bolland ext 2058
Nurse consultant
for Acute Paediatrics

Anne Walker ext 2216
Head of Nursing

Maria Hogan ext 2096
Matron for inpatient wards

Carole Kennelly ext 2592
Matron for PICU

Christine Wood ext 2034
Matron for Day Care

Short Breaks

Next year, the Council's Short Breaks budget will be £60k less than this year, so they asked PPA to consult parents on which services they most value.

We sent out over five hundred questionnaires and the top three types of short breaks that families most valued were:

✿ A chance to access events and trips that you could not normally access. **For example:**
Contact a Family outings

✿ A break from caring for your disabled child(ren). **For example:**
Share a Family,
Lady Allen,
special school
holiday schemes

✿ A chance for your disabled child(ren) to enjoy a range of experiences. **For example:**
Specialist
swimming lessons

We have reported the results of the survey to the Council and will keep participating in their Short Breaks steering group.

Thank you very much to all of you who returned the short breaks questionnaire and congratulations to the family in SW18 who won our £50 prize!

**£50
PRIZE
DRAW!**



From the Children with Special Needs & Disabilities Strategy Group

- ✿ Sacred Heart school has a new ASD resource base for 8 children.
- ✿ There is a Specialist Health Visitor to support other Health Visitors in referrals through the Early Years pathway.
- ✿ Housing - if someone has an extra carer, staying 3 nights a week, the carer is entitled to a room themselves.
- ✿ The ADHD service has been temporarily suspended, but is being reopened soon.



Wandsworth have launched the WAND card

This card identifies your child as having special needs and may help you access concessions at the Council's Leisure Centres, libraries and other venues. Sainsbury's in Putney have formally launched it at their store and will be pleased to provide extra help if you need it.

Please ask the Family Information Service if you want to know more about the card, or have any suggestions about where and how it could be used.

They can also tell you more about Short Breaks:
www.wandsworth.gov.uk/fis
or telephone: 020 8871 7899