

South West London Clinical Commissioning Group Transforming care – focus group and workshop

Five parent/carers from our steering group took part in a focus group hosted on behalf of the SWL CCG by Sally Warren from Paradigm. This was to share their views on the support their children and young people have with a diagnosis of ASD and/or a learning disability.

The aim of the workshop was all about making sure that people who have a learning disability and/or autism and behaviours that challenge, receive the right care and support to live good lives in the communities.

It was interesting to listen to and meet other families. A person and another family having first hand experience of these issues were able to feed back directly to the commissioners who were also attending this workshop. The aim of all the work the commissioners are preparing will be reviewed to improve services within the south west London trust as part of a national project called Transforming Care.

As well as this focus group, SWL CCG also invited 'one to one' discussions with parent/carers

and others. This information will also prove invaluable for our future services.

For more information about Transforming care, visit the following weblink:
<https://www.england.nhs.uk/learning-disabilities/care/>



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

PPA Newsletter

Winter/Spring 2017



Positive
Parent
Action

for disabled children and young people in Wandsworth



HAPPY NEW YEAR!!!

Welcome to Positive Parent Action's latest newsletter!

We have had a busy few months and our aim for the new year is to reach out to as many parents and carers in Wandsworth. We are Wandsworth's parent/carer forum and pride ourselves on confidently expressing parent/carer views and experiences within every strategic meeting we are invited to and attend.

We have managed to maintain a good relationship with Wandsworth Borough council's special educational needs officers and are building good working relationships with health professionals.

Our ongoing work relating to the SEND reforms has meant that professionals working in Wandsworth are constantly reminded by our forum and the focus of the SEND reform is child/young person and family.

Now that SEND reform implementations are reaching the end date (March 2018) we have already been asking 'What happens post March 2018?' We are fully aware that all local authorities across the country are under pressure to complete EHCP transfers within the relevant time frame.

All additional funding given to local authority's will stop even if conversion is not completed in time. Families will also lose the EHCP support from the Independent Supporters which could massively affect those at the tail end of EHCP transfers and we are still unsure of the legal implications for those who may still be on statements.

We cannot express enough the importance of parent/carers speaking out.

Positive Parent Action are here to enable you ALL to do this, whether:

- you would like to attend our monthly meetings
- attend meetings with professionals
- or
- call or email us

Your SEND related issues will be put forward to the local authority or relevant health professionals.

Every parent/carer of a child young person (0-25) with special educational needs and or a disability living in Wandsworth are welcome to join us. You can be involved as much or as little as you want! For more detail please contact us by email at: positiveparentaction@yahoo.co.uk

A REMINDER OF WHO PPA ARE

Positive Parent Action are Wandsworth's forum for parents and carers.

Our aim is to reach out to as many families across the Borough who have a child or young person with a disability or special need. We meet every month during school term time and undertake activities that are aimed to enable parent/carers make the most of local services.

Anyone with a child or young with a disability and or a special educational need are welcome to be part of our forum. Please remember, there is no commitment too big or small, all are welcome!

If you are interested in being a more active member of our forum, ie, representing the PPA, by attending meetings with the Local Authority/Health etc, please do contact Erica.

Save the Dates

1st February 2018

Nandini Ganesh for Contact will be giving a workshop on SEN support in mainstream for those without EHCP. More details will be sent out soon.

28th February 2018

GET SET GO 3 Event

For more information please contact Erica Spink at:
positiveparentaction@yahoo.co.uk
Phone: 020 8947 5260

Positive Parent Action 1 Siward Road, London SW17 0LA

Web: www.positiveparentaction.org.uk • Email: positiveparentaction@yahoo.co.uk • Facebook: www.facebook.com/PositiveParentAction

GET SET GO 3

Following on from the success of our 2016 and 2017 Get Set Go events, we are delighted to confirm we are holding a third, "Get Set Go 3" – Next steps into Adulthood for young people, aged 14-25 with special needs and disabilities (SEND).

We are once again doing this jointly with South Thames College and with new funding from Wandsworth Ambitions Careers Cluster.

This free event is aimed at young people aged 14 to 25, with special needs, their parents/carers, other service providers, and professionals.

We are broadening the remit this year, based on feedback requesting more information about Health, Housing and Social Activities.

The event will be on:

Wednesday 28 February 2018,
at the Civic Suite, Wandsworth
High Street, SW18 2PU.

It will run from 10.30am until
2.30pm.

This is a great opportunity for parent/carers and young people to find out about the widening range of options for them in education, employment, training, independent

living, independent travel, benefits, health support and more. They can meet and talk to providers, try out technology, ask about how each provider works, discover new ideas and develop new aspirations. We are planning interactive workshops, dance displays and with lots of interesting exhibitors, some of whom may be offering small items to buy, so please bring cash too.

PPA Steering Group Training October 2017

PPA's steering group arranged and attended a Governance workshop. Currently our steering group does not have appointed officers, due to parent/carer changes. The aim of the workshop was to look at different Steering Group Models and decide for the future what kind of structure would best for us. This will be achieved by building on our strengths and maximising our local links and skills to be the best we can possibly be. We will then effectively represent all SEND parent/carers and families.

We had lots of fun with the starting icebreaker where we were put into four groups to create the tallest tower from the floor up, made from only newspaper and tape. As you can see from the picture our forum members are very creative!

Overall it was a great session and helped us to bond as a group, confirmed we do all share the same values and appreciate how well we do work as a team, supporting each other with the same goal to empower parent/carers to share their experiences.

Moving forward we have agreed to



continue meeting on a monthly basis. The role of PPA chair will be rotated on a monthly basis to enable everyone within the steering group to be able to chair meetings, but of course, only if they feel comfortable doing so.

We hope you will bring students from Year 9 upwards, so they can see what is out there for them. A light lunch as well as tea and coffee will be provided to help you keep going! So we can make sure we order enough, please book your place as soon as you can.

If you are interested in attending this FREE event which includes lunch, go straight to the Eventbrite page here:

<https://www.eventbrite.com/e/get-set-go-3-tickets-38653674180>

Or, if you need more information please do not hesitate to email us directly at:

getsetgo@wandsworth.gov.uk

For the latest information, please visit the Local Offer website:

<https://goo.gl/8Pc4n3>

where we are adding exhibitors, workshops and more as they are booked to attend.

Youth Legal Training

How the Children's and Families Act & Care Act work for Young People

On 6th October we held a workshop run by Valerie Clark from Youth Legal and Resource Centre. Over 20 parent/carers attended, and it was a very interesting session.

Programme:

- Introduction regarding: Children & Family Act/Care Act
- Information & advice/the local offer
- Assessments
- Eligibility criteria
- EHC plan –
- Social care plan – Joint working
- Transition to adulthood
- Independent advocacy support
- Young carers (Transition) and carers

Lastly, Valerie handed out case studies and the group worked through them together. It was great, and as a team everyone learnt a lot.

For more information about Youth Legal, see their website:

<http://youthlegal.org.uk/>

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CAMHS



Mental Health in Learning Disability & Autism Conference

We were very lucky to be able to attend the fully booked conference in November hosted by Denise Gentry, Clinical lead for LD and ASD.

Anne Webster clinical lead and Carl Shaw learning disability advisor from NHS England attended and spoke to us about the new care and treatment review process for those with SL and ASD who are potential in patients. Currently, of the 1000's of care treatment reviews that have been carried out, up to 75% of community CTRS have resulted in not admitting the person and support and treatment provided with in their community!

The new approach will be a person-centred review process to discharge and check that people are safe and have good care and treatment before admitting as an in-patient or before being referred to be admitted into a hospital. These care treatments reviews will be done by independent experts.

The refreshed policy of March 2017 means a greater focus on quality. Measurable and national standards will play their part for people who are ASD as well as those with learning disabilities.

The care review treatment panel will be a key line of enquiry. They must also:

- Be evidence-based.
- Talking to people not just looking at reports.
- Having clear responsibilities in a checklist for providers, before, during, and after the care treatment review.
- Knowing who is responsible for speaking to the person and their family.
- Making sure that there is a clear link to the EHCP.

For more information about CTRs please follow the weblink below:

<https://www.england.nhs.uk/learning-disabilities/care/ctr/>

National Network of Parent Carer Forums

Positive Parent Action is part of the National Network of Parent Carer Forum's South London Cluster group and we regularly meet with the other forums from this region.

We last met on Monday 16th October 2017 and Positive Parent Action (Wandsworth) hosted. These meetings are always a good opportunity to hear the highs and lows from each of the represented forums and interestingly there are a lot of similarities between all the forums SEND issues within their own local authorities.

We were also lucky enough to have representatives from the department of education attend this meeting. Each forum was able to feedback directly to Daniel Edwards and Andre Imich (SEND Team - DFE) and they both thanked the forums for presenting such a rich picture of the work they are doing.

Members of



National Network of Parent Carer Forums
'Our Strength is our Shared Experience'
www.nnpcf.org.uk

We support

STOMP

Stopping over-medication of people with a learning disability, autism or both

Members of our PPA forum recently attended a conference given by STOMP regarding the effects of over medicating those with learning disabilities and autism.

Between 30,000 to 35,000 adults with severe learning difficulties and or ASD are wrongly taking or are prescribed antipsychotic/antidepressants or both – psychotropic drugs.

Risks include:

- weight gain
- organ failure
- premature death

The Goals of STOMP

- To improve quality of life.
- Receive drugs for the right reason.
- Improve understanding of known on-drug treatments such as Positive Behavioural Support.
- Improve working relationships with doctors and the people who support when changing treatments.
- Regular reviews.

STOMP plan

- Pledges
- Education
- Alternatives – Positive Behavioural Support
- Research
- Empowering people
- Tool for measuring
- Publications

What should professionals do for you?

- Always check/review/question.
- Make sure information given to person and family.
- Always raise awareness.
- Alter medication as needed.
- Empower people to speak up.
- Help the person and family know to know the difference between concern and complaint.

For more information about STOMP please click for weblink below:

<https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

Overall it was a very interesting conference, lunch was fantastic, and we were very pleased to have attended.