

GRAPEVINE

The paper for parents and carers of children with additional needs in Southwark

January 2010

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Christmas Party 2009



We had a great time! The visit from Father Christmas was a wonderful experience and many of the children were keen to meet him. He was a bit hot at times (being used to the North Pole), but did a wonderful job of getting us all in the festive mood. Thanks, Blagoje!

Ricky, the magician, kept the children enthralled with lots of amazing trickery and very inventive balloon 'art' made to request. Mei Si came to visit with her face paints and Dell made sure the hall was decorated and so much more. Thanks to all our volunteers who helped the day go smoothly.

The staff team would like to give a very special thank you to Fare Shares who supplied most of the food and drink and to Greggs, the bakers, who supplied the mince pies.

Wishing everyone a very Happy New Year!

contact a family

for families with disabled children

incorporating

The Lady Hoare Trust

Southwark Office
020 7277 4436

Stop Press Stop Press Stop Press

See www.cafamily.org.uk/cashcounts for useful help and hints on how to manage your finances.

Contact a Family news

Double trouble?

We now have 2 Beckys in the office (on top of an Alice and an Alison) so bear with us whilst we get used to this and try to help us by being clear when you ring the office to speak to either of them. Thanks!

Becky Jones = Events

Becky Skipwith = PCC

Parent Carer Council News

Meet Becky Skipwith



Hello, I'm Becky and I'm delighted to be starting as the PCC's new support worker. I've been working within the voluntary sector for a number of years, both with carers and people with disabilities, supporting

them in self-advocacy and involvement in the development and delivery of services.

I am not a parent, but a very attached aunt to my four-year-old nephew who has ASC. I have lived in Southwark for almost six years, though working in Camden and Bromley, and I am very excited to be involved for the first time in an organisation based within my own community. I look forward to meeting many of you in the coming weeks.

Alison Miles PCC Development Officer gives an update

Becky will be organising meetings and events in the New Year, funded through Aiming High's parent participation fund and details of these will appear on our website:

www.southwarkpcc.org.uk

Since September we have:

- launched our PCC website and e-forum: www.southwarkpcc.org.uk
- commented on a draft leaflet, aimed at parents of children receiving palliative care

-hosted a successful and well-attended parent carer conference

-participated in a national Aiming High conference

-provided parent carer representation for Whippersnappers College Lodge Board

-helped evaluate bids for Aiming High monies, linked to the provision of 'short breaks' and facilities for children with additional needs

-supported a Southwark Parks consultation aimed at children with disabilities + families

-participated in a workshop focusing on examples of successful parent carer participation in service transformation.

Please get in touch via the website, the forum, or give Alison or Becky a ring on 020 7277 4436

Can we TXT you?

New Texting Service

We have a new texting service called GroupCall. When you get a message from us it will say 'GroupCall' followed by 'Contact a Family'. We will now be able to keep you updated about events and remind you when you are booked on to things. Please be sure to give us your up-to-date mobile number so that you don't miss out!

Events Programme – act now

Please respond promptly to get your requests in before the closing date. This helps us to be as fair as we can in allocating places.

Here's a reminder of an event already advertised. Places may still be available.

Pamper Session, Thursday, 28 January 2010 10am – 4pm at the Contact a Family Office

A new year pamper session to help you get over those post Christmas blues! For £3 you can have a wonderful 40 minute massage with a professional. Please call Becky J on 020 7277 4436 to check availability (Crèche places must be booked in advance, please).

News from the borough and beyond

South London Healthcare gets low marks

South London Healthcare has been placed in a low banding in the Dr Foster report into patient safety. It has issued a statement saying, 'We are obviously very disappointed by this and are looking very hard at this report. The report is split into various categories and we have performed well on patient experience, clinical effectiveness, and have good survival rate and infection rate indicators. These also continue to improve. However, we have performed poorly on processes such as data quality and this is where we need to step up.' Letters have been sent to all SLH staff by the medical and nursing directors of South London Healthcare asking for improvements.

Disabled Children's Manifesto for Change

This summer Every Disabled Child Matters was busy working with disabled children and young people to develop a disabled children's manifesto for change. The Manifesto sets out disabled children and young people's recommendations for all political parties on the issues they want to see addressed in party election manifestos. The Manifesto is available in booklet form and as a DVD with disabled young people talking about the issues they face and what they would like to see political parties do on these issues. Please visit:
<http://www.edcm.org.uk/dcmanifesto>

DCSF Anti Bullying DVD

DCSF has launched a DVD for pupils and a new resource pack for schools to help them prevent and tackle bullying of young people with special educational needs (SEN) and disabilities.
http://clients.mediaondemand.net/take1flv/dcsf/send/w_SEND.html

End Child Poverty

Take action now

The Campaign to End Child Poverty has just released a new call to action for children living in the UK. A report, released by the campaign, has shown that as unemployment rises more families are being tipped into poverty. This isn't just happening in deprived areas but in more affluent areas too. It's a reminder that as the recession continues we're all in this together. The report says, 'The government couldn't let the banks fail; so they mustn't fail our children.'

To have your say, please visit:
<http://www.38degrees.org.uk/page/speakout/childpovertyPBR>

Transition

Contact a Family, Southwark has advertised for a Development Officer to try to improve things in the borough for families with a child over 12 years of age. The person appointed will bring services for older children together so that joint planning can be done and a more holistic service provided. For a round up of national transition news please visit
http://www.transitioninonetwork.org.uk/filestore/TIN_392_408905.pdf

Action for Children Launch Report

Action for Children has launched research - 'Backing the Future' - in partnership with nef (new economics foundation) which will provide evidence of how investing early in the wellbeing of children can help achieve a range of policy objectives. See:
<http://www.actionforchildren.org.uk/backingthefuture>

Reports

Olympic Games questionnaire

Help make Games truly inclusive

The London Development Agency has commissioned a very important research study designed to test London's objective to make the Games 'the most accessible and inclusive 'Games' destination.

They need as many disabled people as possible, and their carers to comment on their experiences when visiting London in relation to accessibility issues. A link to the questionnaire is provided below. They are going into a lot of detail which they say has not been explored previously. In case this is too much for you, there is an option within the questionnaire to complete a shorter version. See:

<http://www.arkenford.net/uc/admin/7dfc/?a=24>

Getting ready for winter with Southwark EnergyCare

With the cold weather drawing in, Contact a Family and the Southwark EnergyCare project (managed by Southwark Carers) are offering free energy saving guidance to carers in the borough. This advice included a workshop, held on Thursday 3rd December, which provided attendees with an overview of the measures that can be taken in the average home to save energy and reduce fuel bills. The workshop also highlighted the financial help that is available to carers who wish to improve aspects of their home such as insulation or heating.

Through Southwark EnergyCare, carers in the borough who are in danger of having their gas or electricity disconnected, can also access small grants of up to £200 to help pay off their fuel debt. To find out more about the criteria for these grants or for free advice on any aspect of saving energy in your home, please contact the Southwark EnergyCare project on 020 7708 4506.

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Holiday Report

Susan Elhabti tells us about her family's recent trip to Cornwall

'In the half term holiday, we went to the VITALISE CHURCHTOWN centre near Bodmin, in Cornwall. The centre specialises in holidays for people with disabilities and their carers or with their families. It is very good for people with autism or aspergers syndrome as it has a calm atmosphere as it is not too crowded (there were five families there when we visited) and the plan for the week is displayed on the wall, giving you two alternative options for each day (or you can do your own thing if you choose to) so you know what you are going to be doing and when. It is also very good for people who have disabilities requiring wheelchairs as most of the activities are wheelchair friendly, such as the abseiling facility and a challenge obstacle course which can be done on foot or in a wheelchair. We spent two days doing activities on the centre, which were in small groups with an instructor and volunteers. The activities we did were climbing, abseiling, and the challenge course, canoeing, archery and survival skills. We also went to the onsite farm where the children collected the chicken's eggs and helped feed the animals, and we went swimming several times in the swimming pool at the centre. On other days we went on trips to local attractions in small groups (with Vitalise staff) on the centre's minibuses. We went to Newquay zoo, Watergate bay, the Eden Project, "Screech" owl sanctuary, Jamaica Inn and a shipwreck centre. We also went to a reservoir on the moors where we took it in turns to go on a "wheelie boat" (a small wheelchair accessible boat) on the reservoir, which the children could have a go at driving (with the driver's supervision). All our meals were provided by the centre, including packed lunches for days out, and special diets were also catered for. Our family really enjoyed this holiday and I would recommend it as good place to go for families who have children with disabilities.' *Susan*

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Reports

Asperger Syndrome Conference Report

'A Better Future' by Sarah Semplay,
parent of a 5year old boy with Asperger's.

'The Conference was very full with 11 speakers and 104 delegates from all over Britain, 5 of whom were parents. This was a great opportunity to ask burning questions and to research what could help children like my son have a Brighter Better Future.

All the speakers moved me in their knowledge and passion for the subject. I asked Professor Digby Tantam about the Son-Rise Program which claims to be able to rid a person of Autism in 2hours. He suggests behaviour techniques can help, but explained that a person's quality of life can be marred by emotional difficulties.

Mathew Downie of the National Autistic Society brought tears to our eyes with case studies of ASP people who hadn't received the right kind of support from the beginning. Adults are often not diagnosed until over 40 and are not offered services from their local authorities that match their needs. The Autism Disability Act has placed legal obligations on Primary Care Trusts but needs time to filter down to grassroots level.

In my opinion the most challenging aspect of having an ASP child is the loneliness and isolation of not being able to connect with neurotypicals. It is very hard at weekends and holidays during unstructured time. Our children are out of synchrony with their peers. Lindsay Towns, a Clinical Psychologist, believes they need to be taught friendship skills (Tony Atwood provides a good framework for identifying the different developmental levels of friendship). As our children become older it is often a shared interest that helps friendship develop. They can benefit from mentoring and coaching at college then work. I hope to set up social groups specifically to give my son a sense of interconnection with his peers.

The conference overall really inspired me to adapt and develop the resources already in

place for my son. I feel motivated to attend more Autistic Support Groups and ask questions of professionals with confidence as knowledge empowers me.

Many thanks to Southwark Contact A Family for giving me this challenge.' *Sarah*

Autism Act Passed

The Autism Bill has made it through its final parliamentary stage and will now become the Autism Act. The Act is the first ever disability-specific law in England. The Autism Act will guarantee the introduction of the first-ever adult autism strategy, which will set out how local services should be improved.

The strategy will cover a range of issues including health, social care, employment and training and, crucially, will be accompanied by guidance which places a legal obligation on local authorities and NHS bodies to meet certain requirements. The National Autistic Society are calling on you to help make sure the adult autism strategy is as strong as it can be.

Take action now while this opportunity for change exists. Email your MP today and ask them to support the Don't Write Me Off campaign on: www.dontwritemeoff.org.uk/

Autism Education Trust regional events

The Autism Education Trust is hosting a national conference in London on 28 Jan 2010 as well as a series of regional roadshows. These events are for professionals and parents/carers involved in the education of children and young people on the autism spectrum. The theme is 'Transition: practical steps for moving forward' and each event includes speakers and practical seminars. Attendance at the events is free of charge.

To book a place: 0115 911 3367 or email aetevents@nas.org.uk

<http://www.autismeducationtrust.org.uk/>

Things to do

Southwark Childcare Affordability Pilot launched

The Southwark Childcare Affordability Pilot (CAP09) will help people to remain in employment by helping with the financial costs of childcare when they get a job.

It can help people for up to 12 months after they move into work with the costs of registered childcare. There is a stepped and gradual reduction in the level of the payments over the 12 month period in order to prepare for the time when the financial assistance stops.

You must be a Southwark resident, with a child aged between 0-14 years old, with recourse to public funds and earning less than £20,000 per year as a family income or Lone Parent income.

The maximum CAP09 funding for childcare provision is £215 per week, £43.00 per day and £7.17 per hour (based on a minimum of 6 hours a day).

Contact: Southwark childcare support scheme, Children's Services, Communities, Extended Services and Partnerships
020 7525 5253, 020 7525 5066 or 020 7525 5306
Please note: an answer machine may be used during busy periods.

Access 4 All

Drop in Sessions at Ellen Brown Spa Gardens Adventure playground Mondays, 3.45 – 6.45 in term time

For all children and young people with Autism and related conditions and their families.

Exclusive access to indoor and outdoor facilities at the playground with a snack. Have fun by taking part in exciting free play opportunities that supports social, physical, intellectual, creative and emotional development.

Please note no transport – a responsible adult must stay with the child/ren.

For more information contact:

Peter: 020 7525 1102 or Mary: 020 7358 4834

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Being Dad – make a storybook....free!

**Saturday 13 March at 11am
Crawford Children's Centre,
Crawford Road, SE5 9NF**

Meet the best selling author of 'BabyFather' books, Patrick Augustus and develop a story of your own with your children. This will be placed on a CD for you to keep.

Contact Roksana for details on: 0208 498 7148 or roksana.akhtar@barnardos.org.uk

Camberwell Choir School

**Music Sessions
Every Saturday during term time
St Giles Parish Hall
161 Benhill Road, Camberwell, SE5**

10.30am – 11.00am Mini Music 0-3 year olds – with parent or carer: singing, musical games, storytelling, baby percussion, sound exploration

11.00am – 12.00 noon Music Club 4-6 year olds: singing, drumming, percussion and guitar sessions to choose from followed by whole group singing or playing at the end of the session

12.00 noon – 1.00pm Juniors 7-9 year olds: Every week includes small group lessons in piano, tuned percussion, guitar, violin, brass, drumming or general music (including some music theory)

1.30pm – 2.30pm Seniors 10-16 year olds: Group activities in a wide variety of musical styles for young people who don't already play an instrument or sing regularly or want to try something different, focusing on learning new instruments and developing more advanced musical skills.

There is no audition and no need to book in advance – just turn up at the appropriate time on Saturday to join in the group sessions. Parents must attend.

For further information please telephone: 020 7701 2464.

Things to do

Attention Deficit Hyperactivity Disorder coffee mornings

Friday 15 January 10.30 – 12.30

Thursday 21 January 10.30 – 12.30

Contact a Family is hosting two very informal coffee mornings in January 2010 for all parents and carers of children and young people with Attention Deficit Hyperactivity Disorder (ADHD). There is the possibility that the coffee mornings will develop into something more structured. Come and find out more and meet other parents and carers.

Disability Living Allowance applications workshop

Not your first DLA?

Friday 29 January 10 am

Friday 26 February 10 am

Friday 26 March 10 am

Contact a Family Southwark offices

Come and learn how to make your repeat DLA application by taking part in one of these workshops, and meet other parents. Find out about the new format of the form and how to complete your form on line. Get the answers to some frequently asked questions and feel more confident that you understand the process.

Please contact Alice on 020 277 4436 to book your free place.

Trip to Diggerland



Our family, our future

New Contact a Family report

This report features the stories of 30 UK families whose children are affected by a range of disabilities and rare conditions. The stories were collated by Contact a Family as part of our 30th anniversary celebrations to raise awareness of the issues for families with disabled children and give policy makers and frontline professionals a real sense of what it means to have a disabled child.

Download for free or buy a hard copy for £5 from the website, www.cafamily.org.uk

'Staying positive' facilitator training for young people

18–21 February 2010 in CHESTER

18–21 February 2010 in OXFORD

Young facilitators will ideally be aged 15 – 23 years and be living with a long term health condition.

They will receive training and support to become facilitators and will work in groups of 3 to run workshops for other young people in their local area.

Every facilitator will receive a certificate of achievement once they have successfully completed their first set of workshops and will be paid an honorarium of £40 for each workshop they deliver.

Travel costs to and from the training venue may be paid.

Staying Positive has won a Guardian Public Services Award for long-term conditions

Read more at www.guardian.co.uk/winners-report/common-ground

To refer young people or for more information contact:

Jo Langley on 01225 731324 or email Jo.Langley@eppcic.co.uk or

Cathy McMahan on 01225 731326/07500

093701 or Catherine.McMahon@eppcic.co.uk

Recent Contact a Family events

Makaton Storytelling

We went to experience a special storytime with Whippersnappers talented storytellers at the Cuming Museum at Elephant and Castle. Delivered in Makaton, the stories were accessible to everyone.



Squids Club

This amazing club for the over 14s offers a wide range of activities on top of the 'dance til you drop' disco. It's a great way to meet other young people in a safe environment. Meanwhile, mums and dads can chill out in the quiet area, have a massage, play games and meet up with other parents for a chat.

You don't need to wait for us to organise your own 'club night', but we will be going in a group in April.



See www.heartnsoul.co.uk/squidznext or ring 020 8692 4446 for details

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Please send contributions for the Spring issue to the above address by 24 February 2010 or by email to southwark.office@cafamily.org.uk page 8

We all dug Diggerland!

Our trip to Diggerland proved a huge success. Not only was there lots of fun stuff to do but it was all very positive, building self esteem and confidence. Look out for a repeat visit on offer later in the year.

Boys (and Dads) and their toys



Museums Visit *National History Museum*



The London Eye *Becky and Abiola*

