

# GRAPEVINE

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

**July 2008**

## Contents

<b>Aiming High</b>	<b>1</b>
<b>Contact a Family news</b>	<b>2</b>
Information Day at the Grove	
Transition questionnaire report	
Helen leaving	
Urgent benefits and tax credits news	
<b>A Parent's Story</b>	<b>5</b>
Lisa Alexander tells us about preparing for university	
<b>News and updates</b>	<b>6</b>
What's happening at the NAS	
Aiming High and the Parent Carer Council	
<b>What's on in the borough</b>	<b>8</b>
Carnival workshop	
Community events	
<b>Theatre tickets £5 DEADLINE</b>	

## We're Aiming High !



### Aiming High for Disabled Children (AHDC) - what you need to know

This is the government's programme of transformation for services for disabled children. It's big and it will affect you - there is money for short breaks, accessible childcare and to make sure families have a say in how the money is spent and what happens in the future.

Contact a Family and Serco (a large private company) have formed a Partnership, called 'Together for Disabled Children' (TDC) to make sure work on short breaks and family participation in service planning and delivery develop hand in hand.

**contact a family**  
for families with disabled children  
incorporating  
**The Lady Hoare Trust**



Read more inside (page 7).

Southwark Office  
020 7277 4436

# Contact a Family news

## Info Day at The Grove



We invited 80 Camberwell families with children under 5 years old, to an Information Day at The Grove Children and Family Centre on 4<sup>th</sup> June.

### Who came?

There were 9 different stalls and 12 parent carers came to take advantage of having all this information available in one place. Like every good party, there was delicious food and a goodie bag at the end. It was great to see children having their face painted or drawing at the popular Special Needs Oral Health Promoters table. Parent-carers got a chance to talk with each other and be pampered at the Body Shop stand if they chose.

### What families said about the day

Many families wanted to meet more services around education such as SENCOs, SALT, after school clubs etc.

*'I really enjoyed the event, but its hard to ask certain questions - for example talking about financial issues or mental health - in such an open space.'*

*'We met people today I will contact myself when I need to'.*

Thank you to everyone who attended including: Family Information Service, Adult Mental Health team, At Home Care, Child Development Worker, Reed in Partnership and Body Shop at Home.

Christina Kono

## Transition Questionnaire

We'd like to say a big thank you to all the parent-carers who responded to our recent transition questionnaire. We contacted 400 families with children and young people over the age of 12 years old, and over 10% replied. This is a good return rate. Our aim was to consult with parents and gather experiences and views about transition issues.

### What did we find out?

- More parents with young people between the ages of 12-14 yrs replied than young adults over 14 years.
- Many parents didn't know if their children had a transition plan at year 9 at school or not
- Parents' views of transition varied:

*'Choosing options at school and moving into adult working and living environment'*

*'A time of stress'*

*'Independence'*

### What parents said about...

#### Getting about

Parents told us that it is important to them to have either SEN school transport provision for their children at secondary school or college and/or adequate travel training which promotes independence. Parents are concerned about the way young people behave on public transport. They feel that buses are too crowded and that the general public tends to be very judgemental in that environment.

#### Making relationships

Parents would like to know more about activities for young people. Many young people stay at home either watching TV or playing on the computer. Parents genuinely want to learn how to support and prepare teenagers around having relationships, sexual awareness and coping with puberty.

# Contact a Family news

## Coping with bullying

Half of the parents who responded said their children and young people had experienced bullying. A good anti-bullying policy and supportive staff at school seemed to have a big impact and some recommended the anti-bullying group at the Michael Rutter Centre.

## Using the information

There's a lot more information to come from the questionnaire. We will publish a full report and launch a transition pack later in the year. We are also building relationships with other organisations and statutory agencies. We'll keep you posted!

If you missed your chance but would like to contribute your views and experience of transition, please let us know. Email us at [Southwark.office@cafamily.org.uk](mailto:Southwark.office@cafamily.org.uk)

## Helen says Goodbye

As many of you may know, I left Contact a Family Southwark in early July, after 3 years as the project Administrator and then Co-ordinator.

After a nice sunny holiday in Scotland (fingers crossed!) I start work as a fundraiser for a charity supporting homeless people, based up in Bermondsey. I hope I can use lots of the things I have learnt in my new work.

It has been a real pleasure to work with such lovely colleagues over the past years and to get to know so many inspirational families.

I wish Contact a Family Southwark every future success, and I look forward to reading about your progress in Grapevine.

Best wishes

*Helen Fleming*



## Urgent call for families with disabled children to get advice on their benefits and tax credits entitlements

Contact a Family has identified that some families with disabled children could miss out on vital income due to imminent changes in benefit rules.

From 27 October 2008 Incapacity Benefit and income support for people with health problems will be replaced by Employment Support Allowance (ESA).

### Families with a disabled teenager born before 27th October 1992

can either claim the existing benefits now or wait and claim ESA at a later date. Some will be worse off on the new ESA depending on individual circumstances

Sarah Rush, Head of Advice at Contact a Family, said: "We know that families with disabled children face enormous financial challenges with more than half living in poverty. It is therefore vitally important that families get advice now, to find out how these benefits changes will affect them."

### There are 28,000 families in the UK who are missing out on much needed extra income through additional tax credits

Families who have not informed HMRC that they receive Disability Living Allowance could be missing out on this additional income, which is paid in addition to existing tax credits they may already receive.

### Want more information or to check if you are affected?

The Contact a Family freephone helpline - 0808 808 3555 - is staffed by benefits experts and trained parent advisers who can help to maximise your family's income.  
Textphone: 0808 808 3556

# Contact a Family news

## Fill in your contact form

As you will have seen from the enclosed letter we are asking you to update your contact details. We need to do this regularly to make sure that:

- we only keep information on our database that we should
- we have the right information
- we are not wasting money by posting unwanted resources to families

To encourage you to return the contact form we have:

- included a stamped addressed envelope
- decided that **IF YOU DO NOT RETURN IT YOU WILL NOT BE ABLE TO BOOK ON TO EVENTS**

## What if I don't return my form?

We won't update your details on our database, so you won't get sent your personal copy of Grapevine in the post and you won't be allowed to book onto events.

## Let's count you in

We are monitored by our funders on how many families we are in touch with. We need to be able to say honestly how many are part of our 'family'. And we need to feel that 'our families' are happy for us to speak up on their behalf. There are nearly a thousand of you on the database at the moment. *'I need to know I have families' permission to be their voice. I will have much more influence if I can prove that I represent families in Southwark. Getting a clear mandate from families by regularly checking with them will help me represent families fairly and powerfully'*, says Naomi Gilbert, manager of Contact a Family, Southwark.

*The Contact a Family Team*

## The Steering Committee

Your Committee at work!



The committee would like to encourage more parents to join them shaping the work we do in Southwark. Future plans include planning and helping run the conference in October and the Christmas Party, hosting drop-ins and contributing to Grapevine. Contact the office for details of how you can get involved.

## Families' Stories

It won't surprise you to know that real life stories mean much more to the public than facts and figures from an organisation. At a national level, Contact a Family is often asked to comment on a story in the news. It might be about a change in the law or benefits (see the article on page 3) or it might be a development in the treatment of a condition. It is easier to get the attention of the general public if they hear from a real family. The more times we can get the issues that affect families with a disabled child in the media, the more these issues will be discussed in the pub or on the bus. Getting that level of public awareness and debate is one of Contact a Family's aims.

Would you be willing to be one of the families we call on when the media come to us?

At a local level, it really helps us make a good case for funding if we can talk about families' experiences.

If you'd like to know more about how you can help in these ways, please contact us.

# A parent's story

## Returning to Study

### **Lisa Alexander tells us preparing for university**

My name is Lisa Alexander and I am 29 (I don't admit to that often!). I have two children: Monet aged 6 and Junior aged 11.

Junior has Autism and is non-verbal and partially incontinent. I have just completed my first year on a BA degree reading Social Work at Goldsmiths University; I am going to tell you about my journey so far.

### **Why go to university?**

I decided I wanted to return to study to have a career and develop myself. I had been unemployed but worked as a volunteer on the Steering Committee at Contact a Family as well as the Parent Carer Council and as a trustee at Southwark Carers and as a facilitator of the Expert Patients Programme, supporting parents with children with disabilities.

Working with people and empowering them is important to me, helping them to attain the skills and tools needed to improve their quality of life for their children or for themselves. So in essence it was an obvious choice to do social work at university.

### **Where to start?**

My local library gave me information about access courses. An access course provides a re-introduction to education and academic writing in relation to your area of study. I applied to several universities during my access course and on completion I was invited to all of them for interviews.

The access course gave me the confidence and the information needed to know what was required from me in interviews and exam practice for entrance exams. I was offered three places and accepted one at Goldsmiths University.

## Help from the university

You can get prospectuses from universities that will outline your course of study so you can work out what commitment in hours you will need to make.

Most universities have student support officers who can offer advice.

## Do your research

Attend open days and spend time choosing a course that suits you. Talk to students who are currently doing a course that you are considering. Find out about access courses. They will equip you with all that is needed to study and usually last a year.

## How to build a support network

It was important for me to establish a really good support network because without this I would be unable to study; I needed support for myself and for my children.

Whilst studying, I discovered eco-mapping which requires you to draw a map of all your support systems.

I listed all my friends and family that could help with child care if needed and contacted the relevant after school clubs and requested a carer's assessment.

I listed the provisions that support my son, such as weekend respite and then drew up a study plan.

## Thanks!

I owe a great big thank you to all the people that have supported my family and me during my first year of study! It really is possible to return to study as long as it is well planned.

## Lisa's advice

Go for it - anything is possible!

*Lisa Alexander*

# News and updates

## New local NAS branch

A small group of parents of children with an ASD (Autistic Spectrum Disorder) have come together to form a Southwark branch of the National Autistic Society. This is none too soon, as Southwark has approximately 350 diagnosed children with autism.

### Launched with a gift

The launch took place on April 29<sup>th</sup> and was well attended by parents and professionals working in this field. We were delighted to welcome Connor King, a Yr 8 student at Walworth Academy, with a group of his school friends. Connor and his team won a school competition by researching and making a presentation on autism. The prize was £3,000 donated by The Philanthropic Society and Connor and his friends have donated it to the NAS Southwark Branch! Connor gave a very moving speech about what it is like to have a brother with severe autism. We are so grateful to him and his friends who have enabled us to have this fantastic start.

### Moving forward – help needed

The group is currently meeting to decide how best to move forward. We are looking for:

- more committee members who can offer time, energy, commitment
- venues for a support group
- a venue for a Saturday morning autism specific playclub.
- items for a newsletter with information on activities and services

Plans for the future include increasing the awareness and understanding of autism in schools and autism-specific sibling support.

We are not experts, but parents wanting to get something going in a borough where there is so much need. Thank you.

*Rosie, Teresa, Maureen, Iona, Margaret and Leslyn*

## What's on in your local NAS

*Family support group* (parents/carers only)

Wednesday 16<sup>th</sup> July, 10am-12pm

The Roebuck pub (upstairs) at the corner of Great Dover St and Trinity St, SE1

*Family picnic* (bring your own)

Saturday, July 26<sup>th</sup>, 12-2pm

Peckham Rye Park (in the fenced-off, dog-free picnic area)

For details about either of these events, please email : [southwark@nas.org.uk](mailto:southwark@nas.org.uk)

### Other groups:

*Support*, 16/6 +17/9, 10- 12 at Spa School

*Dad's Club*, 9<sup>th</sup> Sept 6 -8pm at Inspire

Please contact Elaine Mulligan 020 3049 8013 or email: [Elaine.mulligan@nas.org.uk](mailto:Elaine.mulligan@nas.org.uk) for details

## Grant giving Charities online

Turn2us is a new charity providing an online service to help people access information on all benefits and grants available to them from both statutory and voluntary organizations in the UK. In many cases, applications for support can be made directly from the website and people can be kept informed by email or by text to their mobile phone. You can access the service at <http://www.turn2us.org.uk/>

## Feeling isolated?

### New website

A new website and forum has been developed for carers whose domestic situation can often be isolating, and those who work in the care sector for whom unsociable hours and stressful situations may affect their social life.

Membership of the site is free. See: [www.carersconnect.com](http://www.carersconnect.com)

# News and updates

## **Aiming High for the Parent Carer Council (PCC)**

Alison Miles, Development Officer says, *'This is a golden opportunity to take advantage of local authority efforts to tap parent-carer opinions of services and find out what we want'*.

The PCC is a way for parent-carers to participate in the planning and evaluating of services in the borough. It is made up of parents who have offered to be the link between families and the services they use and to represent the views of all parent-carers.

### **Southwark appoints Aiming High developer**

The borough has recently named Roger Weissman as the interim service development manager with the job of implementing Aiming High for Disabled Children (AHDC) in Southwark.

Roger will be inviting parents and their disabled children to take part in some major consultation in preparation for longterm engagement with families in service design, provision, monitoring and evaluation.

### **Short breaks are priority area**

As well as setting up robust systems for gathering families' input, Roger will be tackling the other AHDC priority - short breaks.

### **Contact a Family takes the lead...**

...across England. And we are working very closely with Roger and other partners here in Southwark. The PCC is excellently placed to make sure the AHDC promise of real and meaningful parent-carer development becomes reality for the borough. We are looking for long term improvements in participation which will lead to the development of relevant and sustainable services.

### **First steps**

In preparation for all the AHDC related activity later in the year, we'd like to get

started by inviting you to join a parent-carer forum. This will feed into the PCC and give us a much broader group of parents to contact from time to time about the issues you are particularly interested in.

### **Up, up and away!**

Aiming High is intended to provide a jump start and then enable continued working relationships between families and the services they use. Alison says, *'this is something families have been asking for and it's finally on our doorstep. We've got it; let's use it - not lose it!'*

Watch out for more details as we get them.

Find out more about AHDC at [www.everychildmatters.gov.uk/socialcare/ahdc/](http://www.everychildmatters.gov.uk/socialcare/ahdc/) and don't forget to sign up to the EDCM campaign whilst you are on the web.

For more details about the PCC or how to sign up to be part of the parent forum, contact Alison at the office, 020 7227 4436 Tuesdays to Thursdays or email: [Alison.miles@cafamily.org.uk](mailto:Alison.miles@cafamily.org.uk)

## **Cerebra Speech and Language Therapy (SLT) Voucher Scheme**

Vouchers are worth up to £500 of SLT.

There are new criteria:

1. You will need to fill out an application.
2. Children must be aged 16 and under with a neurological, brain-related condition (eg cerebral palsy, autism, Down's syndrome). If school-age, the child must have an SEN Statement or be on School Action Plus.
3. The child must not have received one on one speech therapy in the last 6 months.
4. A reference must be sent with the application.

For more information please call Alex on 0800 328 1159 or e-mail [alex@cerebra.org.uk](mailto:alex@cerebra.org.uk)

# What's on – family activities

## Southwark Carnival workshop

The following workshops will be held at Bellenden Old School:

Thursday July 17 from 4.30pm - 6.30pm

Every day from Wednesday August 6 to Friday August 15 from 11am - 1pm and 2pm - 4pm

The workshops consist of costume making, stilt walking, carnival dance and music. The age range is 10 -19 years old and the workshops are free. You can register when you first attend.

For further information please contact

**Raj Desai** on 020 7635 6525 or email [raj.desai@southwark.gov.uk](mailto:raj.desai@southwark.gov.uk)

## Community Events

Contact a Family Southwark will be at some of these events – come and say hello!

Activity	Place	Time
Funday 5 <sup>th</sup> July 2008	Crawford Primary, Camberwell	11.30 – 3.30
Funday 30 <sup>th</sup> July 2008	Lordship Lane Estate	11.30 - 3.30
Festival 1st Aug 2008	Sceaux Gardens Estate	2.00– 5.00
Funday 12 <sup>th</sup> Aug 2008	Champion Hill Estate	11.30 – 3.00
Picnic 15 <sup>th</sup> Aug 2008	Dulwich Park, bring Teddies!	11.00 – 2.00
Picnic 22 <sup>nd</sup> Aug 2008	Burgess Park	11.00 – 2.00
Funday 10 <sup>th</sup> Sept 2008	Denmark Hill Estate Community Centre	11.00- 3.00

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Please send contributions for the September issue to the above address by 12<sup>th</sup> September or by email to [southwark.office@cafamily.org.uk](mailto:southwark.office@cafamily.org.uk)

## Free holidays for disabled children

The Newman Trust provides holidays for over 120 disabled children aged 5-16 each year, in various locations around the UK. Due to the high level of skilled care they require or financial circumstances, the children selected for these breaks would not otherwise receive a holiday. The holidays provide a range of fun activities in a safe and supported environment and use a care ratio of one helper to one child at all times. The Trust is an entirely voluntary organisation.

Check out the website to see the criteria and how to apply [www.newmantrust.org](http://www.newmantrust.org)



## Take your family to the theatre for just £5 a ticket!

You can enjoy one of 28 fantastic theatre productions with all tickets just £5. Families can include parents, grandparents, uncles, aunts, guardians and carers but MUST include young people between 4 – 16. Only families who receive a special leaflet can participate and only families who have not been before.

HURRY – tickets are limited and there is a closing date of 18<sup>th</sup> July.

### What you need to do

Ring the office and we'll send you a booklet with full details of the shows on offer and what you have to do. Fill out the application form and send it to Mousetrap Theatre Projects with your cheque or postal order and a large stamped and addressed envelope. All the instructions are on the leaflet but of course we can help.