

# Grapevine

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

## winter 2010

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## Festive greetings to you!



photo by Rod Morris Photography, 2010

The Contact a Family festive party sparkled brightly. With glitter on the arts and crafts table and shimmery face paints, there was fun in every corner. Charlie the clown filled the hall with laughter and he delivered some surprises too. Archie the fluffy bunny was a favourite for all, particularly Carys who really enjoyed the furry cuddles. The family portraits were a hit, and the photos turned out beautifully, not surprising with such stunning families. It's a shame we can't say the same for the Contact a Family staff family!

A huge thank you to everyone who helped with the entertainment, to FareShare for the food donations, Mei Si and Rachel for their stunning face painting and Rod, Heather and Mark for their photography skills. Everyone's talents and hard work contributed to a fabulous festive day!

### Help us!

Text **family** to **70007** and donate £3 to Contact a Family. You will be charged £3 plus one message at your standard network rate.

Contact a Family will receive a minimum of £2.40 from each message sent.

# Contact a Family news

## how Contact a Family supports families' finances

When Annie's son was diagnosed with autism last year, she came to Contact a Family to see what financial support she was entitled to. We completed the DLA form – her son was awarded middle rate care and lower rate mobility (£66.75 per week in total). Getting DLA meant that Annie became entitled to the disabled child element of Child Tax Credits, which made her a further £52.08 a week better off. Annie was also entitled to Carer's Allowance (£53 per week) because her son was awarded DLA at the middle or highest rate and she looks after him more than 35 hours a week. We advised her to call the Helpline, who advised that although her Income Support would come down slightly when she started receiving Carer's Allowance, she would still be better off by £30.05 a week. She came back to Contact a Family Southwark for help completing the form.

Annie's son wets the bed, and she was worried about buying a new mattress and the burden of extra laundry. Annie's Family Worker helped her to complete a Family Fund form, and as a result she was given a £400 Argos voucher to put towards a new bed and washing machine.

Getting the diagnosis of autism was stressful for the whole family, so Annie wanted to make sure her other children weren't missing out. We completed a Merlin's Magic Wand form, which resulted in a family ticket for Thorpe Park worth £104. She also takes the children to the cinema every school holiday, so we supported her in filling in a CEA Cinema Pass card – now she gets in free as her son's carer.

DLA: £66.75 per week (**£3471** per year)  
Child Tax Credit: £52.08 (**£2708.16** per year)  
Carer's Allowance: £30.05 per week (**£1562.60**)  
Family Fund: **£400**  
Merlin's Magic Wand: **£104**  
CEA Card: **£35** over the year

## Stop the DLA Takeaway

Contact a Family are calling for the rules to be scrapped whereby Disability Living Allowance (DLA) is taken away from a child when they spend more than 84 days in hospital. Parents continue to provide high levels of care to very sick children, they are often unable to work, and their expenses increase. The rules are penalising families when they are at their most vulnerable.

Last autumn we appealed to parents to back the campaign. Over 1000 emails of support were received in just one week. These emails were sent on to the Department of Work and Pensions (DWP) as part of their consultation on welfare reform.

In mid-November, Contact a Family and The Children's Trust received a disappointing response from the DWP. In their letter to us, the DWP states that DLA payments are suspended because in a hospital "a patient's needs (are) fully met free of charge". We know this is not the case, and due to the overwhelming support and feedback received from families, we have resolved to press on with the campaign.

We are writing back to the DWP and setting up a meeting with a relevant minister and an affected family. Supporters are continuing to write to their MP to raise awareness of the campaign. We've had one family confirm that she has been asked to meet with her MP on the subject, which is great, and we have secured the support of another MP who will be asking a Parliamentary Question on the subject shortly.

We have written to professional bodies, including the Royal College of Paediatrics and Child Health (RCPCH) and the Royal College of Nursing (RCN) to ask them to support our campaign.

# Contact a Family news

## debt advice in your home

Contact a Family is undertaking a pilot project with Citizens Advice Bureau (CAB) to make face-to-face debt advice available to more families with disabled children. Greater London is one of the pilot areas for the new service.

There are seven workers based in Camden CAB who offer advice and help for families with disabled children anywhere in the Greater London area. They will arrange to visit you at home anywhere in London.

If you would like to make an appointment, please call the Contact a Family helpline on: **0808 808 3555** and we will arrange an appointment for you.

## Can you help us with an introduction?

Many companies want to help charities. It is good for their wellbeing as it can improve staff motivation, supplier and customer support and public relations. However, they receive many requests from charities but can only support a few. The most successful discussions come about with an introduction from an employee.

Do you work for a company or know someone who does? Can you help us with an introduction to the person we should contact for support? If so, please contact **Peter Herbert**, Head of Corporate and Major Donor Fundraising, on **07802 274047** or by email on **peter.herbert@cafamily.org.uk**. We will then approach the company and see what potential there is for support.

Remember: we are the only UK-wide voluntary organisation providing expert, specialised advice, information and support to families caring for children with any kind of disability – no matter what their health condition.

## Derek stars on Moneybox Live



Derek, a valued member of the Contact a Family Helpline, featured on Moneybox Live on Radio 4 in November, as part of a panel of experts answering questions about support for carers. In response to the show, Contact a Family have received an email from a listener who wants to give £500 to caller Emma, towards equipment for her daughter.

Radio 4 also received this email from a parent who's benefited from contacting Derek and the Helpline:

"I contacted the Contact a Family freephone helpline earlier this year to check our entitlement to benefits when our son with disabilities turned 16 this summer. Derek was able to provide a thorough financial check for us and advised us to discontinue our claim for two benefits in favour of a different one and now we're better off as a family to the tune of nearly £100 a month which is obviously really welcome when there is only one wage coming into the house. My comment was to encourage listeners to pick up the phone and call Contact a Family's helpline and make sure they are making the most of welfare benefits they are entitled to. Don't go by what friends and family say because it's a complex system and what's beneficial for one family might not be for another. And to also say thanks to Derek for his advice, it made the process of changing our claims so much easier knowing what I should be saying and doing."

The Helpline is open Monday to Friday 9:30 am to 5:00 pm for any support and advice, including welfare benefits.

**freephone:** 0808 808 3555  
**textphone:** 0808 808 3556

# inside Southwark

## funding update

Contact a Family, like all national charities, is facing cuts to funding which may affect its national activities. These include the Helpline, website and publications. The fundraising team are working hard to minimise the effects of these cuts by finding alternative sources of support.

Government decides each local authority's grant using a formula based on a number of factors, such as the number of people and the level of need. Although the council disagrees with the way the Government has calculated the amount it will give Southwark, it seems that the end result will be a cut of approximately 10%.

Southwark Council has made it clear to locally commissioned services, like Contact a Family Southwark, that final decisions about funding for 2011/2012 will not be made until after their finance meeting in February.

At the moment Contact a Family is commissioned by several different parts of the council and it is hard to have a clear picture about what the whole service might look like from 1 April 2011. Like all other commissioned services we received a letter from the leader of the council, Councillor Peter John, telling us that they are aiming to continue all funding throughout 2011/2012 but there will be a cut which may be 10 to 15%. Subsequent information suggests that the letter only applies to certain funding streams and it is hard to be certain which ones. The letter says that during 2011 decisions will be made about which services will be decommissioned (i.e. stopped), recommissioned (i.e. continued) or newly commissioned for 2012 onwards.

The bottom line is that Contact a Family Southwark won't know until late February, and more likely early March, what funding we will have to offer a service for the rest of 2011.

We will let you know in the next Grapevine.

## BME Advice Network

The Black and Minority Ethnic Advice Network is an integrated network of advice services delivered for and by people from London's migrant refugee communities.

Members provide free and confidential advice on issues such as debt and money, housing, employment, immigration and asylum, health, education, discrimination, family matters and domestic violence.

In Southwark, you can access services at:

### **Afro Asian Advisory Service**

53 Addington Square, 020 7701 0141

### **Multilingual Community Rights Shop**

213 Camberwell Road 020 7703 4442

For a full listing of member organisations, many of which offer services to people across London, visit the Network's new website:

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

## Thames Water Trust Fund

The Thames Water Trust Fund is an independent charitable fund offering financial help to any Thames Water customers who have trouble paying their water charges.

Anyone who lives in a Thames Water area, including homeowners and people in full-time employment, can apply for a grant if their financial situation makes it hard for them to pay their water bill.

You can contact the Trust Fund on:

**0300 123 6001**, or make an application online, at:

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



# inside Southwark

## Makaton workshops in 2011

Henry Mellor is a regional tutor for Makaton in Southwark. He will be running workshops for parents later on this year. This is what Henry told us about what Makaton is, and why it is so important.

Makaton is designed to support a wide range of people with communication needs. It is a unique language programme which may be used as a systematic multimodal approach (e.g. using signs, speech, facial expression, body language, symbols and writing) to teaching communication, language and literacy skills as well as being a source of highly functional vocabulary for a person with communication needs and their interactive partners.

Typical amongst those who use Makaton are people with learning difficulties, autistic spectrum disorder/condition, Down's syndrome, cerebral palsy, articulatory dyspraxia, and challenging behaviours, as well as their interactive partners: parents, family members, carers, siblings, peers, professionals etc. There are also other "fringe users" who may need to use Makaton on a more occasional basis, such as play-scheme volunteers, doctors, A&E staff, receptionists, shopkeepers, bank/post office tellers, etc.

The Makaton Core Vocabulary provides approximately 450 signs with corresponding symbols essential to everyday life that are presented in stages ranging from immediate needs to leisure interests and feelings. In addition, there is a much larger Resource Vocabulary of around 7000 signs with symbols that are topic-based, e.g. National Curriculum, food and drink, animals, transport and vehicles, personal social and health education etc.

Makaton signs and symbols are always used with speech, and the programme is designed to encourage both comprehension and speech no matter how severe the disabling condition experienced by the child or adult.

Makaton has been around for 35 years and is now used in over 40 countries worldwide. Makaton signs in the UK are derived from the naturally occurring signs used by the deaf community. In the UK this is British Sign Language (BSL) and, specifically, the BSL dialect used in the South East of England. This has been chosen so that Makaton signs can be standardised and not subject to regional variation as with BSL. A Makaton user in London, for example, should be able to understand Makaton communication equally well in Manchester, Newcastle or Glasgow. Because Makaton signs and symbols are used with speech, they follow English spoken word order. The aim of this is to encourage speech rather than to replace it.



There is a significant body of research to support the positive effect that Makaton has on the development of speech in people with communication difficulties. For every signed concept there

is a corresponding symbol, which can be used flexibly with signs, speech and writing in order to help develop literacy skills.

The Makaton website ([www.makaton.org](http://www.makaton.org)) is well worth a visit; there is a lot of useful information about the Makaton Language Programme, Makaton workshops and resources as well as research papers.

You really don't have to be good at languages but it is important to get started!

Henry Mellor, November 2010

# our Steering Committee

## Sade

My name is Sade Dawodu. I came to Contact a Family when my son, who is now 12, had lots of borderline diagnoses in many areas, and needed extra support in school. I met other families for support and to share our journeys together in supporting our children and each other. It was a very difficult period for us as a family but we needed to stay strong. My son was eventually diagnosed with specific language impairment. He is now in a mainstream secondary school and he is doing well. He enjoys playing Ice Hockey for the Werewolves of London Special Ice Hockey Club.



I have been involved in education as a School Governor, Early Years Practitioner and a Youth Worker. I have been involved with Contact a Family for many years in different roles and am willing to offer my services in support of the organisation. I hope that my past experience as a mum and my knowledge of special needs will be valuable to other parents.

## Victoria



Hello,

I am Victoria Garrett, Special Needs Health Visitor, based at Sunshine House. I am pleased to be invited to serve again on the Contact a Family Steering Committee. I have had a long association with

Contact a Family Southwark, since I started working with families of children with special needs in 2000.

I value the work of Contact a Family and recommend them to new families that I meet, so am glad to become more involved. I find that I always gain at least as much as I can contribute from the expert knowledge and experience of the parent members.

## Dorchester celebrations



Contact a Family hosted an event at the Dorchester Hotel in November. Steering Committee members, funders, commissioners and staff came together in celebration, to hear parents' stories and to learn about the range of work we do in London. Sarah Teather, Minister of State for Education, joined us briefly, and showed her support for families with a child with a disability.

The beautiful surroundings and the quality of the refreshments helped everyone feel very special. We had financial support from a number of funders and the Dorchester Hotel was especially generous.

Overshadowing everything else, though, were the contributions from three parents, including Ella Baines from Southwark. These parents told their stories eloquently and vividly. All three were hugely positive about their individual situations and very complimentary about how Contact a Family has supported their family on their particular journey.

# Parent Carers' Council



PCC and Forum members at our October meeting

## training for the future

Southwark Parent Carers' Council (PCC) has been funded by the Aiming High for Disabled Children programme since 2009. The funding for this programme ends in March 2011 and with uncertain financial times ahead, the PCC commissioned three sessions of training to help think about how the organisation might continue to operate and grow.

The sessions were planned around three areas:

### local decision-making

The aim of this was to help us understand how the local authority works, who makes the decisions locally and how we can influence them.

### having an impact

This session looked at the priorities we as a group feel are important. Predictably this session produced a long list of potential areas we could focus on in the future, and helped us begin to think about how to prioritise them.

## sustainability

The last session looked at future types of funding and potential funders, and covered restrictions, such as charitable status, on applying for certain grants. We looked at the bare minimum of income the PCC needs, what would be our core priorities if funding was cut, and what we could no longer do. This was

a very interesting and challenging session with no easy answers and lots of difficult decisions. This with the two other sessions helped us work out where the PCC is now and most importantly to see that even in this very difficult financial climate we still have exciting opportunities to grasp and the potential to thrive and grow.

### Heather Tarbuck, PCC member

Southwark Parent Carers' Council is a growing group of parents of children with disabilities or additional needs. We aim to represent the views of local parent carers and work with the local authority and other organisations to improve services for us and our families.

We have an elected PCC membership of 10, and are in touch with a wider forum of over 220 local parent carers. If you'd like to find out more, or join us, get in touch!

020 7277 4436 / 07508 124789  
<http://www.southwarkpcc.org.uk>  
[info@southwarkpcc.org.uk](mailto:info@southwarkpcc.org.uk)

  
**southwarkparentcarers council**

*passionate about our disabled children*

## Marika talks about Felix's new communication aid

Last Christmas, we bought an iPod Touch for our son Felix as he loves music. We loaded his favourite songs (especially from *Oliver!*) and lots of photos onto it and he started using the simple touchscreen really easily. What we didn't realise was that it was going to become an incredibly useful device for his speech and language.

Felix has global development delay, some physical disability, and cannot speak. He uses mainly Makaton to communicate. He also has a communication book with signs and words, that the speech therapist made for him. We had been hoping to get Felix a specialist device for some years but, despite a referral over a year ago, and various attempts to get equipment, we and the speech therapist had not got very far. The cost of equipment, e.g. a Dynavox, can run into thousands so we could not afford to buy it.

There are all sorts of games and educational applications that you can put on an iPod Touch from iTunes, so I looked on the internet to see if there were any applications to help with communication, and found ProLoquo2Go. It's developed in the US but only costs £100 to upload onto an iPod Touch or iPhone.

I bought it straight away as it looked brilliant. Using a grid system (like other devices), you can choose to have up to 16 squares on a page, with words, pictures or symbols on. When you touch the squares, the iPod speaks. The squares can have just one word or a whole sentence. They can also be folders, with more grids inside. Felix has a square called "food and drink", which leads to a page with types of food and drink. So Felix could touch a square saying "I want" then scroll down to a square with "hot chocolate", to tell me what he'd like.

You can edit or customise the programme really easily to make it right for your own child. It uses

text-to-speech voices so any words you choose will be spoken, and it has a vocabulary of 7000 words and symbols.

Felix has a folder called "my news" and every week, I add a sentence and a symbol or photo (you can add your own photos from albums you create on the iPod). For example, we've added a square that says: "I played football" (with a football symbol), and "I had my face painted" (with a photo of Felix with his painted face). Felix can tell anyone his news. He also has squares called "what I like" and "about me". He has photos of his family, teachers and friends with their names, so he can talk about other people. You can make it as simple or complex as you like.

We take the iPod wherever we go. As the speaker isn't very loud, they recommend you buy a portable speaker case for it, so that people can hear the speech more easily. (Felix also plays his music everywhere very loudly!)

The total cost of this communication aid (iPod Touch, Proloquo2go application and speaker case) to us was about £280, which compares brilliantly with specialist communication aids. You can also put the Proloquo2go onto an iPad, where the squares are much bigger, although less portable. We are saving up for one, to help Felix to build up sentences and do literacy work.

For more information about the software, go to [www.proloquo2go.com](http://www.proloquo2go.com).

Anyone interested in asking me about this device can email me on: [marika@tiscali.co.uk](mailto:marika@tiscali.co.uk)



# Contact a Family Southwark survey

## 2010 survey results

A very big thank you to everyone who responded to our survey. A massive 33% of the 400 families active with us completed the survey and 13% of colleagues from other agencies also gave their views.

We are very grateful as always for your suggestions and comments and this summary gives an overview of the results, and responds to some of the issues raised. As all entries were confidential, we are unable to feedback to individuals. All your evaluations and suggestions, along with the contributions of the Steering Committee, are invaluable in planning the service we can offer in Southwark.



### prize draw winner!

The winner of our prize of an iPod was Isabel Wilma Velasquez de Meer.

Congratulations!

## parents' responses

Parents told us we are 'excellent' or 'good' in every part of our work, and particularly like the way we keep them up to date and provide easy to understand information. See the graphs on page 10.

## what the numbers mean

The parents who responded to the survey (135) are representative of the whole group (400) in terms of the information we asked for such as age, diagnosis etc. An administrative error means that we cannot use the ethnicity data. Apologies to all those who were affected by us missing out two choices from the paper version. Points of interest:

- Parents don't see us as helping them to increase their finances. See page 2 for an explanation of how we do this.
- 'Support from other parents' was rated as being the most important to parents by only 18% of respondents; however 67% chose 'social contact and events programme' and as part of this activity families will meet and have the opportunity to link up.

## parents' comments

Forty-one comments were left to explain 'if we have exceeded your expectations, or if you feel we have not provided the service you expected'. The majority (31) were very positive comments:

"When I am down I know their door is always open to me"

"Contact a Family have given me support, encouragement and strength to cope with my son's disability from the outset. They guided me through the maze of information and services to help with his condition. The initial shock was softened by their one-to-one support which was crucial to my wellbeing"

"You have helped with all my questions. I'm in a better position to help my son and my family"

"We have received outstanding support from you"

"Grapevine is fantastic at gathering the info I would not know otherwise. Your events with other families have been amazing – it helps us to feel we are not alone and it helps my son to see others who also have differences about them".

## other comments

Parents expected more from us in terms of activities for families with specific needs. See the next section for a response to that issue. There were three comments which suggest we have not offered a good service. These were:

"Not replying to letters."

**we say:** There is no reason for this and we would like to offer an apology. Please contact us so we can put things right.

"I have visited you a lot of times but none of the problems I needed your help for have been resolved" and "I need respite".

**we say:** We aim to support all families as they tackle the issues they face, but we are limited in what we can control or offer ourselves. We always aim to be honest with parents about what we can and can't do. See the next section for some more details on this point.

# Contact a Family Southwark survey

## your suggestions for improving our service

We had 34 suggestions, some of which followed on from comments in the previous section. Suggestions were made about:

### more activities for

- physically disabled children
- older children
- younger children
- dads
- just more, including out of London!

**we say:** We would love to do more events and offer as many inclusive events as possible. We have put on specific events aimed at all these groups and will do so again. With regard to pre-school age children, we try to encourage families to use universal services on offer at most Children's Centres.

We ask for your feedback in a number of ways and use all this information in our planning. So please keep telling us what you think and give us your suggestions. You should also bear in mind that there is one full-time equivalent post to cover all the activities we run and a very small amount of money to spend on them. The team do a fantastic job of making a little go a long way.

### extending our services to include:

- translation/specific support in other languages
- counselling
- respite

**we say:** These are not things we do or offer. We have been fortunate in having a very diverse staff team with a range of language skills and many families have benefited. However this is not something we can plan for. We will always do our best to source appropriate support with a variety of translation services within the borough.

- evening services

**we say:** We will be trialling this soon, by appointment.

- educating other cultures about disability

**we say:** We take improving awareness of disability and disability issues very seriously and can offer training to other agencies. We network with many other groups through a wide range of forums, influencing, educating and supporting where we can.

## Did you know?

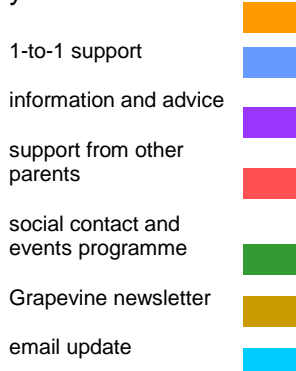
The events team ran 26 events with 821 places in the six months from July to December 2010.

This was with a funded budget of £5000.

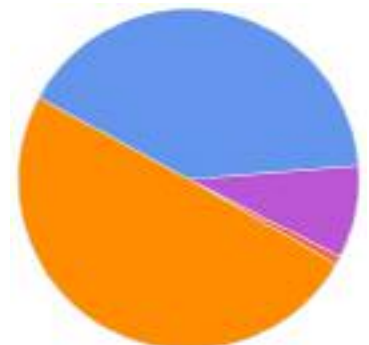
All our events were over-subscribed.

## what you said

Which of our services is the most important to you?



How do you rate the quality of our services?



# Contact a Family Southwark survey

## other suggestions

- supporting families with a new diagnosis

**we say:** We run regular coffee mornings and we will also link people where appropriate.

- supporting a group of parents to meet for emotional support

**we say:** We offer a number of ways for parents to come together. We would be happy to do more – please get in touch.

- having a swap-shop so families can pass on equipment and clothes

**we say:** We would love to facilitate this but we don't have time to run it and we definitely cannot store things. Please get in touch if you would like to advertise 'swaps' in Grapevine.

- more one to one services

**we say:** We offer this to families who really need it. Contact a Family is all about bringing people out to meet others, so we would not want to see everyone individually.

- links with SEN and Parent Partnership (PP).

**we say:** We have close links with PP and have been offering joint information sessions. We refer families to PP as they are the experts in SEN.

- evaluation after events – why bother?

**we say:** We can't respond to individual evaluations as these are usually anonymous but we do use all the feedback to help us plan future activities and we use comments in our monitoring and in funding bids, in the annual review and in reporting in Grapevine.

- the events booking and payment system needs refining

**we say:** We agree and would like your help in finding a better system which will allow us to remain fair in the way we allocate places, deal with payments and let you know whether you have a place or not. Work is in progress. Please let us know your ideas.

## what we can tell from comments

We were delighted to have so many comments from parents. It shows that parents feel able to have their say. Parents are overwhelmingly positive about the service they receive. Everyone wants more – either targeted services to suit their family, or just more!

Many of the comments show that we have not done a good enough job of making clear what we can offer either in terms of what fits with our vision and purpose and/or our funding situation. We can improve on this.

We are also looking closely at comments about the events booking process and would really welcome your help. Please get in touch.

We would love to offer more in terms of support groups, linking, and practical support like the swap-shop idea. We just do not have capacity. So, again, if you would like to get involved – please get in touch!

## non-parent survey

We sent the survey to 147 individuals or services who also receive Grapevine. 82% of respondents said they work with families who use our services in Southwark, 9% said they don't. 68% said they often refer families to us but only 44% said we often refer to them. 85% use Grapevine in a variety of ways with the majority using it to pass information on to families.

The top three rated services were 'support for families', 'information and advice for families' and 'Grapevine'. The email update was unrated. All those who gave us an overall rating for our service to families chose either 'excellent' (25%) or 'good' (60%).

## reflections and thanks

This was the first time we have used an online survey, and we've certainly learnt a lot. It hasn't been possible to share all the results in this edition of Grapevine, but we will present more information and analysis in our next annual review.

We are hugely grateful for the time and effort people put into responding to the questions. We would really like to respond to every comment, particularly those which were critical. Manager, Naomi Gilbert, would like to invite anyone with a burning issue to contact her directly, so she has a chance to make things right, wherever possible.

# what's on at Contact a Family

## drop-ins for parents of older children

Meet other parents with children of a similar age for a chat and to share ideas and experiences.

### parents of 5–11 year olds

Monday 7 February, 10:00–12:00

- taking care of *yourself*

Monday 7 March, 10:00–12:00

- topic tbc

### parents of 12–19 year olds

Tuesday 8 February, 10:00–12:00

- taking care of *yourself*

Thursday 10 March, 10:00–12:00

- topic tbc

drop-ins are at Contact a Family, 54 Camberwell Road, London SE5 0EN.

Call Abi if you'd like to find out more: **020 7277 4436**.

## talk to a family worker

Contact a Family Southwark holds a number of drop-ins at venues around the borough, offering information, advice and support on a range of issues.

### Mondays

9:30–12:00 Crawford Children's Centre  
(during term time)

### Tuesdays

coffee mornings and workshops at the Contact a Family Southwark office  
(call 020 7277 4436 for details)

### Wednesdays

9:30–12:00 Sunshine House

9:30–12:00 Rye Oak Children's Centre  
(during term time)

4:30–6:30 Sunshine House, by appointment

### Thursdays

9:30–12:00 Sunshine House

9:30–12:00 Dulwich Wood Children's Centre  
(second Thursday of the month)

9:30–12:00 Kintore Way Children's Centre  
(during term time)

### Fridays

9:30–12:00 1st Place Children's Centre

Call us for more information or to book an appointment: **020 7277 4436**.

## DLA workshops

We run regular group sessions for people completing their Disability Living Allowance renewal forms. These group sessions help to build confidence for parents in managing their child's benefits. A family worker is on hand to advise and help out, too.

Tuesday 1 February, 10:00–12:00

Tuesday 1 March, 10:00–12:00

Thursday 31 March, 10:00–12:00

DLA renewal workshops are held at Contact a Family, 54 Camberwell Road, London SE5 0EN. To book, call: **020 7277 4436**.

## members' coffee mornings

Contact a Family holds regular informal coffee mornings for members to drop in, chat to each other or to a family worker, and find out more about services locally.

Tuesday 18 January, 10:00–12:00

Tuesday 15 February, 10:00–12:00

54 Camberwell Road, London SE5 0EN  
No need to book – just come along!

# what's on locally

## money advice events

Are you worried about paying your bills, and how the government spending cuts will affect you? Southwark Legal Advice Network are holding two money advice events early in 2011:

### Thursday 27 January

Beormund Community Centre, Abbey Street  
SE1 2AN

### Thursday 10 February

Kingswood Community Centre, Seeley Drive  
SE21 8QR

both 11:00–3:00

You can find out about:

- benefits you may be entitled to
- help with housing costs
- saving energy and money
- staying well and healthy
- getting back into work and training
- what to do if you are in difficulty paying bills
- low-cost credit services
- low-cost insurance

## creative:space



Come and make music, decorate crowns and dance with the charity Create at one of its *creative:space* events on **Sunday 13 March** at the Henry Wood Hall in London.

two sessions:  
11:45–1:00, 2:45–4:00

Henry Wood Hall, Trinity Church Sq., SE1 4HU

For more information, or to book, call Anna, on: **020 7374 8485**, or [anna@createarts.org.uk](mailto:anna@createarts.org.uk)  
<http://www.createarts.org.uk>

## Serious About Art?

Mencap are organising a one-day arts event for anyone with a learning disability.

**Sunday 23 January**  
**10:00–3:30**

Laban Arts Centre  
Deptford, SE8 3DZ

The day will feature singing, dancing, comedy, art and makeup.

Attendance is £3, and a supporter can go along for free.

To find out more, or book a place, contact Caroline Jones, on: **07810 183552**, or email: [caroline.jones@mencap.org.uk](mailto:caroline.jones@mencap.org.uk)



## Squidz

Squidz is a club for young people with learning disabilities (aged 10 to 25 years), and their families and friends. Siblings under 10 are also welcome.

It features young DJs, arts and crafts, digital funfair, dressing up, and a games room, as well as a space for parents to unwind and have a massage.

The next Squidz night is **Friday 18 March**, and costs £5 per person attending.

The Albany  
Douglas Way  
Deptford, SE8 4AG  
**7pm–11pm**

To book, call: **020 8692 4446**

# policy updates

## families' rights to short breaks to be made clear

In April next year, new regulations are going to be introduced to make things a lot clearer for parent carers applying for short breaks. The regulations will place a duty on local authorities to prepare a statement for carers on what services will be available in local areas and exactly who will be eligible to use them.

A recent report by Every Disabled Child Matters (EDCM), "Calling for Clarity", showed that out of 60 local authorities, eight per cent could not produce a set of eligibility criteria for their commissioned short breaks services and 28 per cent had left themselves at risk of legal challenge.

The draft policy also states that local authorities are obliged to provide a range of short breaks services for disabled children within and outside the home and during evenings, weekends and school holidays.

Government will publish guidance for local authorities in producing their statement. The statements themselves must be available by October this year, they must take account of local carers' views and situations, and they must make explicit:

- details of the range of short breaks services provided
- any criteria used to determine a child's eligibility for a service
- how the range of services is designed to meet the needs of local carers.

You can read EDCM's report here:  
<http://www.ncb.org.uk/edcm/ECreport.pdf>

and the full draft regulations here:  
[http://www.opsi.gov.uk/si/si2010/draft/ukdsi\\_9780111503850\\_en\\_1](http://www.opsi.gov.uk/si/si2010/draft/ukdsi_9780111503850_en_1)

## C4EO promotes good practice

The Centre for Excellence and Outcomes in Children's and Young People's Services (C4EO) aims to help those working in children's services improve the life chances of all children and young people, in particular those who are most vulnerable.

Through research and expert Advisory Groups in eight theme areas, one of which is disability, C4EO provides research evidence and examples of good practice in children's services.

For an A-Z of what works for children with a disability, and a resource for parents, visit C4EO's website, <http://www.c4eo.org.uk>, and click on "disability".

## STOP PRESS

### short breaks funding increased

On Saturday 11 December, Sarah Teather MP, Children's Minister, announced that Government will be increasing funding to local authorities to provide short breaks for families with disabled children.

Government will be spending £800 million on short breaks over the next four years, an increase of £22 million per year over Government funding in 2010. There will also be a capital investment of £40 million over the next financial year to improve infrastructure and facilities for short breaks provision.

Government will also be allocating £27 million in the next financial year to the Family Fund to help families with disabled children pay for equipment and essentials to make their life easier and more enjoyable.

# conference reports

## Future of Services for Autistic Children

Two presentations at this conference were of particular value.

Dr Glenys Jones of the University of Birmingham School of Education outlined the most important things when considering the autistic child's needs and services: we **must** have an understanding of autism; we must understand the individual and their specific needs; we must collect really good information about the child; and we must not take research studies for granted.

Dr Jones said there are a number of things we should always consider when making provision for the autistic child. They include thinking about when we make demands on them; the sensory environment; taking the child's perspective; how the neuro-typical (NT) person is reacting to the autistic child; accepting that we (NT people) are far too physical and will cajole autistic children for our own purposes. Autism pervades every area of functioning. So, in schools, communication should be developed throughout the day. Dr Jones' presentation was hugely compelling and a plea to all of us to try and change ourselves to fit the needs of the autistic child.

Alice Stobart, Senior Consultant in Education Support, looked at teaching pupils with ASD in a mainstream school. It is important to recognise anxiety which most often manifests as aggression. Her principles of good ASD practice were to reduce anxiety, enhance motivation and self-esteem, reduce behaviours which inhibit progress, remove distractions, develop an evidence base for effective practice and facilitate independence. Some of the problem areas in classrooms include the child's difficulty in understanding abstract terms, the expectation to express opinions, and large volumes of listening and processing.

**Lisa Soverall**

## Assessment and Services for Disabled Children

I am a mother of a child with a physical disability and recently attended a course on Social and Health Care Legal Framework which I found very informative. I would like to share what I believe are some of the main points listed below:

All Children in Need (CIN) should be assessed in accordance with the Framework for the Assessment of Children in Need and their Families. Children with disabilities and additional needs are seen as CIN.

If your child is not with the Child with Disabilities team then the CIN Team should provide services. Challenges can be made as an individual family via the ombudsman, or as an organisation.

Under Article 8 of the Human Rights Act (1998), the right to private life for disabled people includes dignity and participation in the wider life of the community. However local authorities can interfere with this, but it must be lawful, necessary and proportionate, and in practice balanced.

The Human Rights Act only applies to public authorities. The Act cannot be used against private Care or Health providers. But where there are concerns about residential units the local authority has a duty to investigate. Not all rights are absolute.

Courses like this are useful and any such knowledge is to the benefit of our children. If you are not able to attend courses, you can get a lot of information from the Every Disabled Child Matters website:

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

**Antoinette Harris**

# book review and resources

## Carys's book review

### *Caring for Myself*, by Christy Gast and Jane Krug

We all want our children to grow up to be independent, but for children with additional needs, this journey can be demanding. Some families help to teach their children daily living skills by using social stories. Social stories are designed to help children with learning difficulties understand routines and expectations.

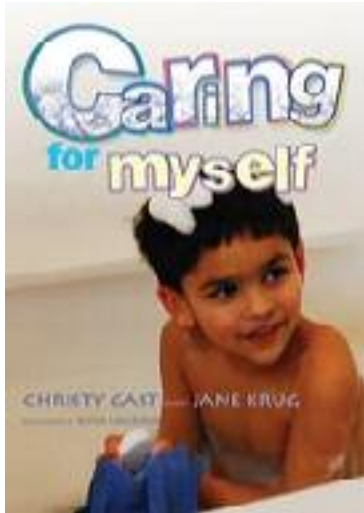
The Contact a Family resource room has several books which contain social stories which you are able to look at, and you can photocopy sections if you need to. The most recent addition to the library is *Caring for Myself* by Christy Gast and Jane Krug.

This book contains the following social stories:

- washing my hands
- getting my hair cut
- taking my bath
- going to my doctor
- brushing my teeth

*Caring for Myself* breaks down these activities into simple steps, with clear language and full-colour pictures. The idea is that you take photos of your own child completing the activities in order to help them learn. You can use the stories directly, or change them slightly to suit your own child or routine.

If you would like to look at this or any other book, come along to our resource room.



## Contact a Family Resource Room



Did you know that we have a Parent and Carer Resource Room at our Camberwell Road office? We keep these area stocked with up-to-date resources that might be useful for our families. Here are some of the things that are available:

**books to borrow:** You are allowed to borrow or photocopy sections of our books. We have books with information about specific conditions, social story books to help your child learn set routines, and books featuring disability which can be helpful for children and siblings.

**parent/carer computer:** Parents and carers are welcome to use our computer to research their child's condition, apply for jobs and grants, contact relatives abroad and anything else that might support your child. If you want to use the computer, please call to book in advance.

**leaflets and factsheets:** We have a wide range of leaflets and factsheets, with information about what's on in Southwark, what to do if you're struggling financially, how to keep warm during winter and how to support your child through early years and transition.

Please feel free to drop in and browse what we have. If you want something specific, please ask – we might be able to help you find it!

# personalisation

## personalisation – a quick guide

Everyone should have access to the right information, advice and advocacy to make good decisions about the support they need. With personalisation, people will have wider choice in how their needs are met and be able to access universal services such as transport, leisure and education, housing, health and have opportunities for employment, regardless of age or disability.

### Who does it affect?

Anyone who gets a service through Adult Social Care. If your child is likely to be eligible for this in the future you should find out more now, so you and your family can prepare.

Eventually, this way of working will extend to those who get a service through Children's Services and Carers' Services. However, personalisation is about giving people much more choice and control over their lives and is much bigger than giving personal budgets to people eligible for council funding.

For example, it includes:

- ensuring that people have access to information, advocacy and advice to make informed decisions about their care and support
- finding new collaborative ways of working (sometimes known as co-production) that support people to actively engage in the design, delivery and evaluation of services
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities
- ensuring all citizens have access to universal community services and resources – a total system response.



### What is happening locally?

Within Adult Services, Southwark Council is working with staff, other providers of services and those who use services in order to get the concept across to people. At the same time they are working on ways to implement personalisation through the use of personal budgets.

Community Action Southwark, which supports the Community and Voluntary Sector (CVS), is also working on ways that the CVS can support individuals, their carers and the services they use to get the best results.

There is no timetable as yet for when personalisation will be implemented in Children's Services.

To read more and to find an Easy Read summary, go to:

<http://www.scie.org.uk/publications/reports/>

# focus on autism

## NAS Southwark



The Southwark Branch of the National Autistic Society runs drop-in support groups for parent carers at **Alfred Salter Primary School**, Quebec Way, Rotherhithe, SE16 and the **Magnolia Pub (the Mag)**, 211 Lordship Lane, SE22.

Dates and times of sessions are as follows:

### **Alfred Salter Primary School**

- third Friday of the month, 10:00–12:00pm

### **The Magnolia**

- last Wednesday of the month, 7.30–9.30pm

Additional drop-ins (supported by NAS Southwark Autism Support) take place at **Spa School**, Monnow Road, SE1 5RN, and a **Dads' Club** meets at **InSpire** at the Crypt, St Peter's Church, Liverpool Grove, SE17 2HH.

For more information about dates and times of meetings, or to join the NAS mailing list and receive news of events and services, call: **07747 768536**, or email: **southwark@nas.org.uk**

## NAS Southwark Christmas party

On a winter's evening the children young and old came excitedly and expectantly to the National Autistic Society Christmas party. At the door welcoming and passing on the festive cheer was Prithvi, a familiar face to most families.

For those that wanted to dance, the floor was set and the music was on to test those dance moves, and on the other side in the quiet room there were sensory toys, duplo, pop-up tents and other activities to occupy those that wanted a quiet moment to enjoy. The children moved excitedly from one room to the other and at the end of the evening, when the last song had played, it was clear that for some the party was not over yet.

## AuKids



AuKids is a quarterly glossy written for parents of kids with an autism spectrum condition. Its editors are Debby Elley, a parent of twins with autism and journalist, and speech and language therapist Tori Houghton, who specialises in autism.

In issue 10, AuKids features an impartial guide to therapeutic techniques – what's out there? How does it work? How do you know whether it's any good? There's also a computer special, including an exclusive chat with Numberjacks creator Chris Ellis.

AuKids' expert panel discusses rigid behaviour and there's news, reviews, hints, tips, competitions and discounts, all written in an easy to read and colourful format.

AuKids is published four times a year and costs £10 for four copies to be delivered, or £8 to download. You can subscribe online, at: **<http://www.aukids.co.uk>** or by post: AuKids, PO Box 259, Cheadle, Cheshire SK8 9BE, enclosing a cheque for £10 made payable to AuKids magazine, with your name and address, age of child and diagnosis written on the back. For more information, contact the team at: **[aukidsmag@googlemail.com](mailto:aukidsmag@googlemail.com)**

# AuKids

## our recent events

### Peckham Pulse swimming course



The first five-day swimming course at Peckham Pulse really was brilliant fun for all those who took part. But it wasn't all splashing about, each session had a half-hour lesson where technique was practised and this was followed by a free play session with floats. Lots of progress was made by all. Many of the families who took part had never been swimming, and the warm waters of the hydro-pool were a perfect introduction. All agreed they would be returning to the pool as soon as possible. Some even signed up for the swimming course starting in January!

### festive party



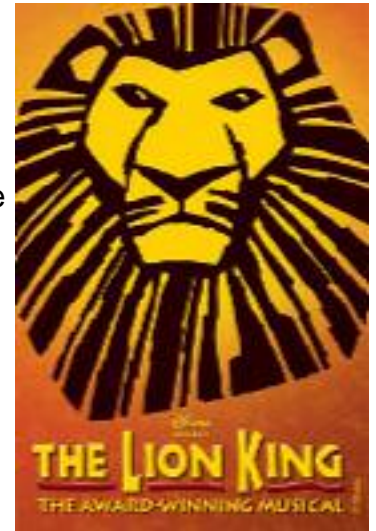
See the front page for details of our fantastic party, thoroughly enjoyed by everyone!

You said:  
"I got to meet a lot of families at the Christmas Party and it was fab!!!"

"Had a really great day and the whole family enjoyed it. Looking forward to next year."  
"What a swell party this is! More please."  
"Party was fun! Magic show was funny. Buffet was good and atmosphere was lively."  
"Lovely party – an opportunity to get out of the house."

### The Lion King

The Lion King event was the result of the huge demand for theatre trips from our families. Even so, no one could have predicted or anticipated the overwhelming demand for this show. Names had to be picked out of a hat.



For those who went, it was a spectacular and colourful show with the music, costumes and everything going on around making you feel you were in the show. Everyone's eyes were glued to the stage, only stopping for a short break to have an ice-cream.

When the show ended the applause was unanimous. You told us it was "wonderful", "fantastic". For some it was Simba who stole the show and for others it was Mufasa. On that there was no agreement.

### pamper day

It was a snowy Thursday morning and as we made the calls to find out if we had any crèche workers coming in or whether therapists would get in despite the snow, it quickly became clear that the parents were coming no matter what.

You said:  
"Amazing massage, I feel 100% relaxed."  
"So glad I made it in despite the snow"  
"As relaxed as if I was sitting in the park in the summer afternoon, and I got a great gift!"

As we closed the door after the last parent that day, we were grateful to Lush for providing gifts and to the resilience of our parents. We will no doubt see them throughout the next year regardless of what's to come!

# about Contact a Family

Across the UK, a child is diagnosed with a severe disability every 25 minutes. While some children need hospital care, 98% of disabled children live at home with a parent or other family member who may not have expected to be in this position, but who quickly has to become an expert.

When parents find out their child is disabled, they feel isolated and alone, usually because they don't know anyone else facing the same problems. They want contact with another family that has been through a similar experience and they want information about their child's disability.

Contact a Family is the only UK-wide charity providing advice, information and support to the parents of all disabled children, no matter what their disability or health condition. We also enable parents to get in contact with other families, both on a local and national basis. Each year we reach at least 275,000 families.

## the helpline

**freephone: 0808 808 3555**

9:30am–5:00pm, Monday to Friday **new opening hours**

for **information**: on disabilities and medical conditions

for **advice**: on assessments, breaks, benefits and finances

for **signposting**: to support groups, organisations and services

for **linking**: to other families

for **listening**

## Contact a Family Southwark

**54 Camberwell Road  
London SE5 0EN**

**tel: 020 7277 4436  
fax: 020 7703 6449**

**southwark.office@cafamily.org.uk**

**contact a family**  
for families with disabled children

registered office:

209–211 City Road  
London EC1V 1JN

**helpline: 0808 808 3555**

**www.cafamily.org.uk**

**reg. charity number: 284912**

**charity registered in Scotland, no: SC039169**

**company no: 1633333**

Data protection: Contact a Family is committed to the confidentiality of your personal information. Personal data will be held and used in accordance with the Data Protection Act 1998 and will not be shared with any third parties for commercial use.

## acknowledgements

Contact a Family Southwark would like to thank –

- Help A London Child



- Rod Morris Photography

- Lush Cosmetics



- Aiming High for Disabled Children



for helping to make our events programme such a success

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