

GRAPEVINE

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

March 2008

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Families come together to share their views

Working together to get it right

Representatives from nineteen families came together on Friday 8th February at InSpire to talk about the service they receive from the Children with Disabilities and Complex Needs Team in Southwark. All families who receive domiciliary (in the home) respite through this team were invited to this event hosted by Contact a Family. Lots of very hard work both from the families and from representatives of seven different care agencies resulted in lots of comments, ideas and general sharing of knowledge and experience. The lunch was good too!

William Chatterton, Service Manager for the Children with Disabilities Team, has promised to respond to every point raised in the formal report now being written by Contact a Family. A summary of the report and William's response will be in the next issue of Grapevine. A full report will be sent to everyone who came to the event.

Naomi Gilbert, Manager, Contact a Family Southwark

Grapevine is produced by an editorial team at Contact a Family

contact a family
for families with disabled children

incorporating
The Lady Hoare Trust

Southwark Office
020 7277 4436

News and updates

Southwark Family Information Service

Southwark Children's Information Service has changed its name and also its remit to cover young people up to age 20. Here's an update on what they do.

Southwark Family Information Service (FIS), formerly known as the Children's Information Service (CIS), provides parents and carers with free guidance and advice for children from pre-birth to 20 years.

Southwark Family Information Service provides advice on:

- childcare choices, education, health, leisure, family and parenting support
- keeping children safe
- free early learning for three and four year olds
- balancing childcare, work and training
- parental leave and flexible working
- help towards childcare costs
- working/training in childcare
- signposting to useful contacts

Get information by calling 0800 013 0639, visiting www.southwark.gov.uk/familyinfo or emailing family.info@southwark.gov.uk

Teenagers – Young and Vocal wants you

Young and Vocal is a group of young disabled people aged 13-16. They meet once a month on a Tuesday evening from 5.30 to 7.30 pm at Cambridge House. There are currently spaces as some older members have moved on.

The aim of the group is for young people to have their say on issues that affect them such as school, getting about and things to do. They also have a lot of fun together.



Transport is available to collect young people from home and take them back after the group.

The group is coordinated by Linda Cleverly from Cambridge House Advocacy Team

If you are interested please contact:

Linda Cleverly
Tel: 020 7358 7007
email linda.cleverly@ch1889.org

Turned down for a short break?

Every Disabled Child Matters (EDCM) is a campaign for rights and justice for all disabled children. Contact a Family is a founder member. EDCM believes families with disabled children should have a clear legal right to short breaks (respite) to enable them to keep caring. Legal experts have advised EDCM that a right to breaks may already exist in current law. EDCM is therefore calling on its supporters who have been refused support from their local authority to come forward to bring a series of test cases.

If you have been assessed as needing a short break but have been turned down e.g. on resource grounds, please get in touch via the Contact a Family helpline 0808 808 3555. Families will need to be on a low income to be eligible for legal aid to pay for the costs of the case.

More information at www.cafamily.org.uk

Children's Centres

Contact a Family runs regular information drop ins at Southwark Children's Centres. This means you can come and talk to one of our Family Outreach Workers at a venue close to your home.

Ring the office on 020 7277 4436 or email southwark.office@cafamily.org.uk to find out dates and times for each Children's Centre

Contact a Family news

Successful events at Christmas and New Year



Getting creative at our Festive Night for parents at All Fired Up ceramics café

Pantomime time!

On Saturday 5th January, Contact a Family celebrated the New Year in style with a traditional trip to the pantomime. This year, a big group of 94 parent-carers, children and staff went to Greenwich Theatre to see 'Dick Whittington', a story about a young man trying to find his way in the world with the help of his best friend, a black and white cat!

Pantomime usually involves acting, dancing, singing, outrageous jokes and some spectacular stage effects, and this performance was no exception. The show featured some amazing costumes and songs from 'High School-the musical' that most of the audience sang along to!

It was great to see so many familiar faces on the trip, and lovely to welcome new families along too, some of whom were trying out the theatre for the first time. We hope you all enjoyed it.

Here's what some people had to say:

'I liked the funny bits'

'Thanks for making this trip affordable for my whole family.'

My son was excited, singing along and dancing...it really put a smile on his face.'

Sometimes it can be hard to know whether children will cope with and enjoy new experiences like this, so we work hard to help everyone feel like they can join in, whatever

their level. Several mums and dads said that they were surprised their children sat still for so long, and weren't scared by light effects and noises.

If you think you would need some extra support to come along to an event like this, please get in touch. At the moment we are able to provide some additional support at our events to help your family get the most out of the day.

Hope to see you at an event soon

Emma and Helen

Christina returns

To be honest, I can't believe the last nine months of maternity leave have gone so quickly I have enjoyed accessing children's centre activities such as baby yoga, singing and signing nursery rhymes at the library, holding my son carefully when he had osteopathy at the children's osteopathic centre. Having my own son has given me a closer insight into parents' and carers' experiences and my husband and I got to know London in a different way.

Having said that I love caring for my son, I am also enthusiastic to return back to Contact a Family Southwark part time as family worker at the beginning of March. I have come back into work for 10 days already to get used to being in an office again; so instead of thinking about washing real nappies, cleaning up the baby food thrown from the baby chair and playing peek a boo, I have already attended training and development days and sat at the computer updating my knowledge on services in Southwark. I feel proud of Contact a Family's achievements in the last year and have enjoyed reading Grapevine. I hope to focus on developing support with transition services, to address the needs of families with older children.

Christina Kono, Family Worker

Family focus

Moving on – Sophie’s story

Sophie’s mother writes

Sophie has just had her eighteenth birthday – and had a wonderful weekend of celebration which ended with a disco with a DJ at her College, the National Centre for Young people with Epilepsy (NCYPE). She had a brilliant time, dancing for two hours non-stop, surrounded by a crowd of new friends. Just over a year ago, this would have been very hard to imagine.

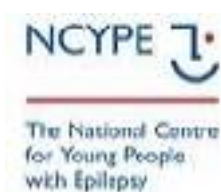
Sophie suffered brain damage at birth through lack of oxygen. This has resulted in learning difficulties, spatial awareness problems, fine and gross motor problems and when she was 12 she developed epilepsy. Sophie was given a statement of special educational needs by the age of 4 and attended local primary and secondary schools with full support. While the special needs staff were excellent, it was never an ideal situation and we became increasingly anxious about her future when she reached the age of 16 and was going to have to move on from The Charter School. We couldn’t find anything suitable within Southwark or, indeed, anywhere, where she would get the support she needed academically and medically. Sophie was becoming more and more aware of her disabilities, very conscious that people thought she was “abnormal” and increasingly socially isolated. What she longed to be was “one of the gang”.

Quite by chance, during a conversation with another parent of a child with special needs, I was told about the NCYPE. I visited their College and boarding houses two days later and decided immediately that we would never find anywhere better for Sophie. I visited again, the following week with Sophie and my husband, and Sophie didn’t want to leave.

Located in Lingfield, Surrey, NCYPE’S 200 acre campus includes St Piers School, St Piers Further Education College and a range of epilepsy diagnostic, assessment and rehabilitation services. The NCYPE is unique

in bringing together specialist teams of teachers, consultants, registrars, nurses, psychologists, therapists, and support staff, all working to ensure that young people living with epilepsy are provided with first rate education, treatment and support. They view each student’s needs as individual and offer a holistic package in order to build and encourage each person to develop new skills. Students work towards achieving realistic targets with staff support. It was perfect for Sophie.

We applied for a place and had to wait for three months, because of their long waiting lists, to have her assessed by the academic and medical teams at the NCYPE before she was offered a residential place.



After visiting the NCYPE, we immediately approached Southwark Education Department to apply for the NCYPE to be named as our choice of provision for Sophie. This was in April 2006 and we were applying for a placement for September that year. All the placements are funded by local authorities or, after the age of 19, by the Learning Skills Council. Sophie’s case went to panel many times. Our first stumbling block was that we had never approached Social Services and, therefore, she was not registered disabled. She, therefore, had to be assessed by Social Services and was subsequently placed on the Disabled Register. However, Southwark Education Department still maintained that they could cater for Sophie’s needs within a mainstream setting in Southwark. This was clearly not feasible – at this time Sophie was having strings of seizures, sometimes several times a day. In any case, they couldn’t actually name a setting. So, in the summer holiday of 2006, Sophie had left The Charter School but we had no idea where she would be going in September – and the Education Department couldn’t tell us either. We had to take the case to Tribunal, a process which would take months. Our Tribunal date was set for mid

Family focus

December. In the meantime, we contacted the Education Department on a weekly basis throughout the holidays trying to get any information from them as to where she was going to go in September. We got great support from many medical departments and local agencies. Contact a Family were marvellous – Abi visited us, wrote a letter supporting Sophie’s case to the Education Department and generally gave good advice and support. We also sought advice from the Camberwell Advisory Service and Tessa Jowell. Everyone we contacted was hugely supportive. However, by September we were no further forward. We were distraught. We had found a College which we thought couldn’t be more perfect for Sophie and now we couldn’t get her in because of lack of funding. The new academic year started and Sophie was still at home.

Eventually, without going to Tribunal, after many meetings with Education, Health and Social Services, they agreed to fund Sophie’s placement. We were all delighted and hugely grateful.

Sophie started College in January 2007 and has had a fantastic year. She has masses of friends. She is now “one of the gang”. She is following a realistic educational programme and is benefiting from the fantastic therapies available on site. The staff are amazed at how she has flourished over the year, as we are too.

Ros Uddin, Sophie’s mother

What Sophie thinks

Grapevine asked Sophie to answer a few questions about her new college.

Why did you want to go to St Piers?

I was the odd one out at my old school, the only one with epilepsy.

How is it different from your old school?

It is not near my parents and I can only see them at weekends.

What's the living accommodation like?

Cory (the hostel) is OK; I find it strange because I call it home as well as my parents’ home.

Were you nervous about being away from home?

I wasn’t expecting it to be this far away, so I was quite nervous about it being a long way away, excited about coming here but still worried.

What kind of courses are you doing?

Drama, art, cooking, film making, computer, and soon to be doing horse riding.

What is there to do after the college day?

Art Club, Disco, Gym Club, Youth Club, Girls’ Brigade and IT Club

Have you made new friends?

Lots of friends on Cory and at college

What are your hopes for the future?

I hope to be a pop star. When I leave I want to go to a college that does dancing and singing which is closer to home

Epilepsy - Did you know...?

- Epilepsy is the most common neurological disorder in childhood
- It affects one in two hundred children. Of these as many as 30 percent continue to have seizures as well as a range of related disabilities including learning, physical and emotional difficulties
- In the UK alone, epilepsy affects over 75,000 children and young people
- It will cost £15 billion to treat the total current UK population of children with epilepsy during their lifetimes. This figure excludes social services and educational costs
- Whilst many can take regular medication to alleviate its effects, there is still a significant number that are affected more severely

Information from NCYPE website

Information and workshops

Resource Room launch

Many Grapevine readers will already have made use of the wonderful new resource room at Contact a Family. We are having an official launch on **Thursday 27th March**

This will be a chance to browse through information, look at displays and chat with Contact a Family staff, parents and professionals

Parent / carer drop in from 10.30 am with some fun activities

Professionals etc come from 11.30 am

12 noon – short opening ceremony followed by refreshments

All welcome – hope to see you!

Workshops at Contact a Family

Toileting Problems and the older child

Facilitated by Dr Margaret Morton, Community Paediatrician

Thursday March 20th

10 am -12.30 pm at Contact a Family, followed by lunch

This workshop is aimed at parents of school aged children with additional needs. If you are wondering if your 9 year old will ever be toilet trained or if your 15 year old will ever stop wetting the bed, this could be the workshop for you.

To book a place, please ring Contact a Family on 020 7277 4436

Joint workshops with SLAM

In May and June, Contact a Family will be running some workshops jointly with Charlotte Fanshawe from SLAM (South London and Maudsley NHS Trust). These will be on general topics relating to having a disabled child in the family.

Full details in the May issue of Grapevine.

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Opportunities for young Deaf people

Deaf Communities Forward is a deaf led organisation based in Croydon that aims provide a range of social development opportunities for the Deaf Community including



- Deaf Camp UK for young Deaf people aged 10-15
- Leaders of Tomorrow for young Deaf adults aged 16-24

for more information see

www.deafcamp.org.uk

<http://dcfprojects.blogspot.com/>

or contact them at

96 Park Lane Croydon CR0 1JB

email: info@deafcamp.org.uk

Yoga for babies with special needs

The organisation Birthlight is running a workshop for baby yoga teachers to help them integrate babies with special needs into what they do.

They are looking for volunteer mums, dads and babies to come to the second day of this workshop for an adapted baby yoga class. This will be free and reasonable travel expenses will be paid. Parents will have a chance to learn specific adapted exercises for their child.

Date: **Friday March 14th**

At: **Yoga Therapy Centre in Islington**

Contact: Carla Thomas

01223 362288 carla@birthlight.com

Information and workshops

Parent Partnership

Southwark Parent Partnership provides independent and confidential support advice and information to parents and carers on issues concerning:

- Special Educational Needs
- Communicating with schools
- Transition to Secondary School

Drop in sessions

Drop in information sessions for parents and carers of children with special educational needs

Come along and meet the Parent Partnership Team and the Special Educational Needs Team at our monthly drop in.



Forthcoming dates:

Wednesday 19th March

Wednesday 23rd April

Wednesday 21st May

All from 10-12 at John Smith House 144 -152 Walworth Road

Autism workshops

Parent Partnership are running a series of workshops for parents/carers of children aged 10 to 16 with a diagnosis of Asperger Syndrome or High Functioning Autism.

Coming up soon:

Travel Training/ Social Stories

Friday 14th March 9.30 - 11.30

Secondary School (what to expect, transition tips)

Friday 16th May 9.30 - 11.30

These sessions will be held in Peckham and will be limited to 20 places. Please ring 020 7525 2886/2866 for more information or to book a place

Southwark Autism Support

Southwark Autism Support, a project of the National Autistic Society, has some group / workshop dates coming up.

Spa Support Group

Spa School
26th March 10am - 12 noon

Dads' Club

InSpire at the crypt, St Peters Church,
Liverpool Grove
24th April 6pm - 8pm

Behaviour Workshop

Learning and Business Centre, Cator St
29th April 10am -12 noon

For more information or to reserve a place, ring Elaine Mulligan on 020 3049 8013 or email: elaine.mulligan@nas.org.uk

Asperger Syndrome Seminar

The Asperger's Syndrome Foundation is running a seminar for Parents, Carers and Professionals on

Practical Strategies for Difficult Moments

Sensory Issues and Anger Management

Presented by Wendy Lawson, Author and adult with AS

Monday 28th April 2008

10am to 3.30pm

at The Royal Institute of British Architects, 66 Portland Place, London, W1B 1AD

Cost £15 for parents and £25 for professionals

Places must be booked. For a booking form ring 020 7610 4050 or download one from: www.aspergerfoundation.org.uk