

# contact a family

for families with disabled children

**September 2010  
Summer Activities**



News from the office	2	Meet the Family workers	15
Children's Centre pages	3-4	Relaxation	15
New Family worker	5-6	Parent story	16-17
Meet the Family Workers	7-12	Helpline	18
Events	14	Booking form	19-20

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## News from the office

The summer period is always an exciting time for us here. We enjoy seeing so many of you at our events and at the Fun Mornings at the Early Years' Centre. This year has been no exception - we had a huge response from you all to go on the trips out and have had fantastic feedback. To those of you who were unsuccessful in your application for Legoland, we will be organising another theme park trip soon and you will be first priority to ensure fairness to all. Let's hope it's less soggy next time ☺

### Short Breaks news from Wandsworth:

'Families of children who have a disability are being given the chance to apply for grants to pay for short breaks and adventure trips away.

Wandsworth Council's grants can also be used to pay for an extra pair of hands to support a young person on an outing of their choice or on a family getaway.

Alternatively, organisations can apply for cash to develop their workforce, or provide specialist support for young people to take part in activities.

To find out more call 020 8871 7160, email [hwilliams@wandsworth.gov.uk](mailto:hwilliams@wandsworth.gov.uk) or write to Room 171, Wandsworth Town Hall, London SW18 2PU. '

Those parents who have children with special needs in mainstream settings may or may not be using after school clubs. Please find a questionnaire attached to this mailing and fill out and send to the council in the envelope provided. The council will use the information to improve the provision for children with special needs in clubs and activities. There is a chance to win high street vouchers - so why not spend a few minutes and fill it in?

And finally, our staff team is changing as people move on to new opportunities - we are saying 'Goodbye' to Claire and Alex and 'Hello' to Jan - see inside for more details. We will be resuming workshops for parents as soon as new members of staff have completed their induction and made all the introductory visits to parents and professionals in Wandsworth.

We will continue to offer support to as many families as we can - please bear with us in this time of change as we establish new members of our team of family workers.

Rosie, Jill, Ati, Suzanne, Elizabeth and Jan

## News from the Children's Centres - Tooting Locality

Jill Caterham is available to families in Tooting who have a child under the age of five. Jill works Monday to Friday term times and is able to support on a range of issues from filling in forms, applying for grants to offering a listening ear and giving relevant information and advice. Roxanne is now on maternity leave and Jill will take calls from any of the families who have been working with her. Jill is based at Smallwood Children's Centre and can be contacted on the following numbers:

Mobile: 07508 734 333

Office: 020 8767 3645

## Goodbye from Alex - Roehampton Surestart

As you may all know I have moved on to pastures new.

I have been offered a job working in Southwark as a Portage worker, and start from early September. It has been a pleasure supporting families in Roehampton, and although my time with Contact a Family was short I have many happy memories that will last a life time.



I must say a BIG thank you to all who made me feel so welcome in my role, and I wish everyone the very best for the future!

Best wishes,

Alex

PS We will have a new worker in place as soon as we can. In the meantime, please call the main office on 020 8947 5260 and another family worker will be able to support you

## News from Suzanne - Battersea Locality

Once again I've been kept very busy in the Battersea locality!

It's been great to be in contact with so many families, through 1-1 visits, on the phone, via e-mail, and in our group settings. The majority of our applications for funds for essential household items, holidays and driving lessons have been successful, which has been really great for all the families concerned.

After a short break and a little restructuring, the play sessions at **Somerset Children's Centre** started again at the beginning of the Summer term and were well attended. The group now starts at **11.45am** every **Thursday**. We begin the session with a small lunch, then have some free play time and normally enjoy a singing session at the end! These sessions will start again after the Summer break on **Thursday 16<sup>th</sup> September**. If you live in Battersea and have a child with additional needs who is not yet in a nursery setting in the afternoon, please do call me for further information about joining the group and to check there are still places available. We welcomed some new families this term, but it would be lovely to meet even more!

The Parents/Carers' group was also successful last term. In the Autumn term the group will continue to be held at Katherine Low Settlement, 108 Battersea High Street, London, SW11 3HP. Crèche places are available, but please do contact me in advance in order to arrange a settling-in session and to book a place at each session. The dates for the next groups are:

Friday 10th September	10.00am - 12 Noon
Friday 8th October	10.00am - 12 Noon
Friday 12th November	10.00am - 12 Noon
Friday 10th December	10.00am - 12 Noon

I will send out a flyer with details of the speakers as soon as they are confirmed.

If you would like any information on the above or would like some local support, please do not hesitate to contact me on 07831 725126 or email [suzanne.wilkinson@cafamil.org.uk](mailto:suzanne.wilkinson@cafamil.org.uk)

## Goodbye from Claire

It is 2 years, almost to the day, since I started working at Wandsworth Contact a Family. In some ways it has flown by, but at the same time it feels like much longer.

I have met and worked with so many families and you have all given me some great experience and insight into the issues that families can face. I am now moving on to train as an educational psychologist and am confident that my time at Contact a Family will really enrich my future work with parents, children and professionals. It has been a real privilege to work with you all and fantastic to have seen some positive outcomes for families.

The workshop programme has been very successful and will continue later in the year, we will be co-hosting an autism convention in 2011 so there is lots going on.

I am sad to be saying goodbye, but I am certain that Jan McCarthy will be bringing a fresh and very experienced pair of eyes to the role.

Many thanks to all who I have worked with, I wish you all the best for the future... ☺



## Hello from Jan

I am writing to introduce myself to you as I have taken over from Claire Cox, the autism and family support worker for families of children with disabilities over the age of 5.

To be working at Contact a Family Wandsworth is a bit like coming home. I was a parent member here about 10 years ago and then 'graduated' to being a member of the steering committee. As a parent of a young woman with Asperger's Syndrome, Contact a Family was a lifeline to me and I am sure there are parents out there who feel the same. My daughter is now 25 years old and I had to do something to keep the link with Contact a Family (and get to go on the events) so I am very happy to be doing this job.

I have worked for Contact a Family in Southwark, setting up the Parent/Carer Council and most recently in Special Educational Needs. I have been a member of the National Autistic Society for several years and have been involved as a councillor, a volunteer with their Education Helpline and taking part in information sessions to professionals.

I hope you will take advantage of our workshops, drop-in and information sessions and drop in that are on offer. Not only is this a good way of gaining information and support but meeting other parents and sharing experiences with each other can often put a different perspective on a 'crisis' and help you leave with a smile.

I look forward to meeting up with you and please either ring or email me if there is anything specific I can help you with or to talk about any type of group or workshop you feel would benefit parents.

My contact details are: 020 8947 5260 or mobile 07532 082437.

Best wishes,

Jan McCarthy

## Counting the Costs 2010

Counting the Costs 2010, a survey and report from Contact a Family has just been published.

Key findings include:

- Almost a quarter are going without heating (23%). Up from 16% in 2008.
- One in seven (14%) are going without food. Down from 16% in 2008.
- More than half have borrowed money from family or friends (51%) to keep financially afloat or pay for essentials, such as food and heating. Up from 42% in 2008.
- More than 40% have applied for a charity grant. Up from 25% in 2008.
- Almost three quarters (73%) are going without days out and leisure time with the family. Up from 55% in 2008.

Srabani Sen, Chief Executive of Contact a Family, said:

“Many families with disabled children are in financial dire straits. Everyone has been hit hard by the recession but families with disabled children were already having to cope with a harsh combination of extra living costs and the difficulty of holding down a job and caring. These financial pressures have been worsened by the economic slump and have left many at breaking point.

“In the forthcoming Comprehensive Spending Review we call on the Government to pay particular attention to ensuring that families with disabled children are genuinely protected.”

Many of the parents who responded to Counting the Costs 2010 don't work (60%) due to the difficulties of juggling employment and caring. Many parents wish to return to work, but find the lack of flexible working and the cost of childcare prohibitive, with 45% reporting they pay more for childcare for their disabled child.

Srabani Sen added: “Time and time again research shows that families with disabled children have an above-average risk of living in poverty. Steps must be taken to address this imbalance from the Government, from businesses and employers, from local authorities and the voluntary sector.”

## Fundraising News

### Park Gardens Nursery School

We would like to thank our friends at Park Gardens Nursery School in Wandsworth for raising over £600 for us at their quiz evening in May.

We are always so delighted to get support from the local community and it was lovely to go and meet some of the children there to pick up the cheque. Thanks to you all!



Iona and Harry presenting the cheque to Rosie

### Waitrose

We are also very pleased to receive over £300 from our local Waitrose store in Southside – another indication that local people are offering us their support. In these times of financial uncertainty, every penny counts and we would like to extend our thanks to everyone who works towards increasing our funding.

The money will be put towards our Events programme to ensure we get as many families with disabled children out during the holidays. Many Thanks!

### Help a London Child

Once again we have Help a London Child to thank for their generous support on our summer outing programme.

## Summer Fun

### Under 8's at the Early Years' Centre



Thanks to all the families who joined us on the summer outings – we had some fantastic feedback from parents and children – we especially liked the verdict from one of our children who on going up to bed announced that the Fun Morning had been 'Like Heaven' – can't really beat that!

### Guildford Spectrum Bowling and Ice Skating



## Coalition news.

Extracts from a speech made by Sarah Teather MP speaking at the House of Lords launch of Every Disabled Child Matters campaign: Disabled children: An agenda for the new Government. Full transcript available at:

[www.education.gov.uk/news/speeches/st-edcm](http://www.education.gov.uk/news/speeches/st-edcm)

I've got two key messages for you this afternoon. The first is this: disabled children are right at the heart of what this Government is doing. This is shown by the Childhood and Family Task Force which has recently been announced.

Both the Deputy Prime Minister and the Prime Minister will be taking part in that Task Force, so you can see that there is buy-in at the very highest levels of this Government to support disabled children and their families.

Over the summer I want to work with the voluntary sector, experts on special educational needs and disability, and parents, to make sure that we get the questions to address right.

We'll be looking at things like parental choice. This will mean looking at ending the bias towards mainstreaming, but that does not mean limiting mainstream provision for children with SEN and disabilities.

We will also need to look at educational attainment – how to support children and young people with a broad range of needs to raise their levels of achievement.

There is also the area of transition for young people, where there has been too little work. Finally, we also need to look at assessment of disabled children and address the bureaucratic mess that families face to get their child assessed.

I want to leave you with one final message.

You will all be aware that these are difficult economic times – but I want to assure you that the needs of disabled children will be at the heart of this Government. We are committed to improving choice and experience of families with disabled children.

I know that you will lobby hard and hold us in Government to account for improving the support to disabled children and their families. This is a crucial way in which many of the improvements that have been achieved so far have been realised.

I hope, trust and expect that this will be the start of our conversations as you play a key role in helping to shape the Green Paper over the coming months.

## Internet help and support for parents

**Contact a Family' facebook page:** You can ask questions, take part in discussions, listen to our podcasts and find out more about us. The page is managed by our New Media Adviser, Steve, with help from a Parent Adviser. There is a whole host of information there for families - if you have access to the Internet, take a look: <http://www.facebook.com/contactafamily?ref=ts>

Not forgetting our linking service Making Contact through the following pages: <http://www.makingcontact.org> where you can put in your details and meet up with families in similar situations and swap ideas and offer mutual support.

### **Netbuddy**

A new website launching this summer will offer parents and professionals working with learning disability a unique opportunity to swap handy, practical tips on everything from coping with constipation to planning a birthday celebration. Netbuddy will pool the expertise of parents, carers, teachers and therapists to provide simple, yet ingenious solutions to everyday issues.

Netbuddy organisers are calling for people to come forward and help make the website a success by sharing their tips and ideas. They are looking for tips in all areas of everyday life - routines, sleeping, eating, toilet training, play, behaviour, dressing, family life, support - the list is by no means exhaustive. Netbuddy is a registered charity, and the organisers stress that none of the information compiled will be used for commercial gain. They plan to make the advice they receive available to people who are not on the internet at a later stage.

[emma@netbuddy.org.uk](mailto:emma@netbuddy.org.uk)

### **Change in opening hours for the Contact a Family Helpline.**

We have been working with the Department for Education to see if there are ways in which we can maximise the number of calls that we take on the Helpline. We have had an independent review and some recommendations have emerged that we are putting into place. The Helpline will change its opening hours to 9.30am to 5pm Monday to Friday (to date it has been 10am to 4pm). We will also no longer have the Monday evening opening. We are making these changes immediately and trialling them for 3 months. This may well be a long term change after October 2010. We will let you know.

## News News News

### **Personal health budgets**

The Department of Health in England is piloting a system where people will be given a sum of money or told how much money is available for their NHS care so they can agree the best way to spend it.

For more information go to the Department of Health's website: <http://www.dh.gov.uk> and search for 'Understanding personal health budgets'. You can also view a full list of the pilot areas by visiting their website and searching for 'Personal health budgets pilot programme'.

### **A guide for advocates**

The Challenging Behaviour Foundation have developed a new resource for advocates who find themselves supporting individuals perceived as challenging. This guide is intended for advocates working in England and Wales. It is also a useful resource for family carers acting on behalf of sons and daughters described as having challenging behaviour.

The guide costs £16 for professionals but is free to family carers. For more information contact the Foundation: <http://www.thecbf.org.uk/>

### **Department of Health have launched a National Framework for Children and Young People's Continuing Care**

This framework sets out an equitable, transparent and timely process for assessing, deciding and agreeing bespoke packages of continuing care for those children and young people, under the age of 18, who have continuing care needs that cannot be met by existing universal and specialist services alone. For more information see: <http://tiny.cc/nitht>

### **Cerebra - speech and language therapy voucher scheme**

In 2006 Cerebra ran a scheme offering vouchers to help children access speech and language therapy. The scheme was very effective and they are offering it again this year. To find out more information about the criteria and how to apply visit their website: [http://www.cerebra.org.uk/parent\\_support/support/speech\\_therapy.htm](http://www.cerebra.org.uk/parent_support/support/speech_therapy.htm)

## Exciting International Venture

Rex Yankey - Otoo Foundation is a new Special School, opening September 2010 in Accra, Ghana. The school has been set up by Mr and Mrs Otoo, the parents of an autistic child in partnership with Paddock School. The aim of the school is to provide specialist and up to date teaching facilities using the TEACCH system, for children with the Autistic Spectrum Disorder and also those with severe and complex learning difficulties. Specialist teaching skills and advice will be sought from Paddock School in Wandsworth.



The school's site will also be the main information and training centre for parents, families and the public to learn more about the various disabilities and obtain training and resources to help manage and improve their special need.

For more information go to:

<http://www.sw11.it/devdev/>



Our very best wishes to Hannah Otoo and her family as we wish the project well and hope it brings new sources of support to the families in Ghana. We will keep you updated on the progress of this truly inspirational venture.

## EVENTS!

**Theatre night out for Parents/Carers!** - To celebrate Carers week (which was in June), we are delighted to offer 50 tickets at £12 each to watch the popular West End musical 'Legally Blonde!' There is a **Limit of two tickets per family** - we will draw names out of a hat to decide who will go.

When: Wednesday 10<sup>th</sup> November 2010

Where: Savoy Theatre, London

Time: 7.30pm

For your chance to join us, please apply using the booking form on the back page and send it to us by Monday 11<sup>th</sup> October.

### UNDER 8'S CHRISTMAS CRAFT PARTY



Come and join us at the Under 8's Christmas Craft Party.

Light refreshments will be provided!

When: Tuesday 7<sup>th</sup> December

Where: Early Years Centre, 1 Siward Road

Time: 4.00pm - 6.00pm

If you are interested in joining us please complete the events booking form on the back page and send it to us by Monday 11<sup>th</sup> October. Please remember to bring a wrapped labeled present for each child you bring so that Santa can pass it on!

## IT'S PANTO TIME! - PETER PAN

We are delighted to announce that we have been able to obtain tickets for the annual pantomime at the New Wimbledon Theatre on:

**Sunday 16<sup>th</sup> January 2011 at 5.30pm cost £12 per ticket.**

This year's extravaganza is PETER PAN! Be sure to order yours by emailing us or sending in the booking form on the back page of the newsletter by Monday 11<sup>th</sup> October. As always this is a popular event so we will prioritise people who have not been before and those who missed out last year.

## Meet the Family Workers!

Just a reminder on the first Friday of the month our experienced and friendly team of Family Workers- Jill, Jan, and Suzanne - will be available at the Early Years' Centre to meet with parents and have a cup of coffee and a chat.

These informal meetings are open to all. Individual concerns will not be discussed but we will all share information and advice with each other and you will be able to make an appointment to see the Family Worker at another time.

Friday 1<sup>st</sup> October 10.00am - 12.00pm  
Friday 5<sup>th</sup> November 10.00am - 12.00pm  
Friday 3<sup>rd</sup> December 10.00am - 12.00pm

We will have tea, coffee, fruit and biscuits...so come along!

## Time for you.....

Thanks to the Parenting fund to allow us to continue with the popular Relaxation sessions. We have opened up the diary for the following sessions all between 9.30 and 12.30 and all for 45 minutes.

If you would like to book a session at an unbelievable rate of just £5! Caroline Osland, a registered therapist in head massage, body massage and reflexology comes in on the first Friday of each month and the third Thursday.

The parents who have come to these sessions are always very keen to book again - so be sure to ring and book an appointment for you!

Call us on: **020 8947 5260**

Thursday	16 <sup>th</sup> Sept	9.30am - 1.00pm
Friday	01 <sup>st</sup> Oct	9.30am - 1.00pm
Thursday	21 <sup>st</sup> Oct	9.30am - 1.00pm
Friday	05 <sup>th</sup> Nov	9.30am - 1.00pm
Thursday	18 <sup>th</sup> Nov	9.30am - 1.00pm
Friday	03 <sup>rd</sup> Dec	9.30am - 1.00pm



## A Parent's Story - Living with Cerebral Palsy (with the benefit of hindsight!)

The young man who has Cerebral Palsy (CP) is now in his twenties – this interview took place with his Mum to find out about some key issues in her family life.

*NB the family are based in another London borough.*

*How old was your son when the diagnosis was made, what services were available?*

He was 2 months. Physiotherapy at first, but later other services were offered in addition to this ie portage, hydrotherapy sessions, playgroup with parents' support meetings.

*What was the greatest help during his childhood?*

For about the first year, J's physiotherapist was the greatest help. She was my main, almost only, point of contact with the world of disability. She was an emotional support for me as well as helping me focus on what I could do to help J with his development. This helped give a structure to our day which prevented me from 'drowning!' She also let me know about other services that were available and put me in touch with another mother with a disabled child, so that I did not feel entirely isolated.

*How well did you get on with your paediatrician?*

J's first paediatrician was very experienced in the field of childhood development and we felt we got honest and straightforward answers to our questions. When he retired, the paediatrician who took over had a different style. He was a very kind man who cared a great deal about his patients, but he was much more vague and disorganized in his approach. He tended towards the more optimistic view, which we found less helpful and at times, very frustrating!

*What were the most difficult aspects?*

Emotionally, coming to terms with the enormity of our son's difficulties and the effect that was going to have not just on ourselves, but particularly on his older sister. Early on, I felt hugely guilty on her behalf, as I felt that I had destroyed her life. Also, just not knowing how badly disabled he was going to be and

which areas would be most affected, was very hard to cope with. The most difficult practical aspects were childcare, as J had so many medical appointments and then Conductive Education up to three times a week, plus later on, managing to get his sister to activities such as Nursery School, Ballet, Brownies etc. Actually, even shopping was a nightmare.

*What sort of attitudes have you come across?*

Widely varying attitudes from the general public and professionals. In general, most reactions seem to be sympathetic. However, in the past I encountered a lot of judgmental attitudes mainly arising from ignorance. You have to learn to live with an awful lot of staring and I developed a sort of mental protective shell around myself when out and about. Most health professionals involved with disability were always helpful and positive, but many 'mainstream' health professionals displayed negative or unsympathetic attitudes or on occasion, just downright stupidity.

*What could have been done better?*

That's a big question!! Health professionals, in particular hospital staff from Doctors through to Nurses and all auxiliary staff need to have proper training in understanding and dealing with patients with disabilities, ESPECIALLY Learning Difficulties. Actually, the process which I had to go through in order to have him diagnosed in the first place could also have been better. I felt that my GP and Midwife didn't take my concerns seriously. Only my Health Visitor really listened to me and got the ball rolling. There are lots of individual examples I could name where things could have been handled so much better, if you have the time or inclination!

If you could give three tips to parents of children like your son what would they be?

- REMEMBER you are NOT the only ones going through this experience and find out about support available in your area.
- NEVER be afraid to ask questions and seek alternative opinions if you feel it is necessary.
- MAKE SURE you feel all medical, therapeutic etc appointments are working for you and your child's benefit and not the other way round. If they are not, say so and don't attend them. You need to cut out unnecessary stress where you can.

# contact a family

for families with disabled children

Across the UK, a child is diagnosed with a severe disability every 25 minutes. Although 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 has quickly had to become an expert.

When parents find out that their child is disabled they feel isolated and alone, because usually they don't know anyone else facing the same problems. They want contact with another family who've 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 Contact a Family National Helpline

Freephone 0808 808 3555

9.30am - 17.00pm Mon to Fri

- Give you **information on medical conditions and disabilities** affecting children, including very rare disorders. All the information is written by leading experts in the field, specifically for parents and families.
- Advise you about help which may be available, including **special educational needs assessments**, getting help to have a **holiday**, your rights to **benefits and tax credits**, and **services** for families with disabled children. We have a wide range of **free parent guides** on these issues which you can obtain from the helpline.
- Put you in touch with **UK-wide and local support groups**. Many families like to share experiences with others caring for a disabled child and find the support this can bring invaluable. If your child has a rare disorder and there isn't a group we might be able to **link you with another family** on a one-to-one basis.
- Tell you about any other specialist **voluntary organisations** which may be able to help.
- **Listen** - many parents simply wish to 'tell their story'.

## EVENTS GENERAL TERMS AND CONDITIONS:

- These trips are for Contact a Family members who will be given priority on all trips. If you would like a non-member (i.e. a friend or family member beyond your immediate family) to attend, they will have to pay the full cost and cannot be guaranteed a place.
- Parents and carers are responsible for their children at all times.
- Under no circumstances will staff tolerate verbal or physical abuse from children, parents and carers or other relatives during family outings or other activities organised by Contact a Family.
- The behaviour of children, parents and carers, or other relatives when attending an event or activity should not affect the Health & Safety or wellbeing of others.
- Parents and carers will be responsible for any damage they or their children cause on an event or activity.
- Under no circumstances will Contact a Family tolerate the consumption of alcoholic beverages whilst attending any events unless this is specifically agreed in advance as part of the activity e.g. a carers' meal at a restaurant.
- Please note that Contact a Family cannot be held responsible for any items that have been lost or stolen during an event or activity.
- Under no circumstances will Contact a Family tolerate any acts of criminal conduct of any kind.
- Contact a Family staff, and any organised transport, will not wait for families or individuals who are late and have been informed of the arrival and departure times.
- Under no circumstances should parents and carers behave in a way which could bring the organisation into disrepute.

## EVENT BOOKING FORM

*Please do not send any money with this form Please detach and fax or post this page by Monday 11<sup>th</sup> October. We will contact you to confirm your place and discuss payment.*

Event	Date	Time	Cost	No of Adults	No of Children	Ages of Children Wheelchair y/n
Legally Blonde	Wed 10 <sup>th</sup> Nov 2010	7.30pm	£12.00 per adult		N/A	
Under 8's craft party	Tues 7 <sup>th</sup> Dec 2010	4pm - 6pm	£2 per child			
Panto - Peter Pan	Sun 16 <sup>th</sup> Jan 2011	5.30pm	£12 per ticket			

Adults full name	Children's full name	Contact number / email

Please indicate if you require assistance on the day or if your child is a wheelchair user so that we can accommodate your needs in advance. I agree to abide by the rules set out (above) by Contact a Family, venues and transport and I will be responsible for children's safety at all times.

Signed: \_\_\_\_\_ (parent/carer)

Date: \_\_\_\_\_

Please detach and return the booking form either by post to Contact a Family 1 Siward Road, London SW17 0LA, by fax to 020 8947 9506 or attach to an email and return it to [wandsworth.office@cafamily.org.uk](mailto:wandsworth.office@cafamily.org.uk)

**Closing date for applications: MONDAY 11<sup>th</sup> OCTOBER 2010.**