

The magazine for families with disabled children
and all those who work with them

contact a family
for families with disabled children

Summer 2010

connected



Family and friends

What a difference they make to our lives

Great escapes
Accessible days
out for families

Muriel Gray
The BBC4
radio appeal

Benefit news
Taking a look at the
new Carer's Credit

Contact a Family

209-211 City Road, London EC1V 1JN
Tel: 020 7608 8700, Fax: 020 7608 8701
e-mail: info@cafamily.org.uk

Contact a Family Northern Ireland

The Bridge Community Centre, Railway Street
Lisburn BT28 1XP
Tel/Fax 028 9262 7552
e-mail: nireland.office@cafamily.org.uk

Contact a Family Scotland

Craigmillar Social Enterprise & Arts Centre
11/9 Harewood Road, Edinburgh EH16 4NT
Tel: 0131 659 2930
e-mail: scotland.office@cafamily.org.uk

Contact a Family Cymru

33-35 Cathedral Road, Cardiff CF11 9HB
Tel: 029 2039 6624, Fax: 029 2039 6625
e-mail: wales.office@cafamily.org.uk

Contact a Family North East England Region

The Dene Centre, Castle Farm Road
Newcastle upon Tyne NE3 1PH
Tel/Fax: 0191 213 6300
e-mail: northeast.office@cafamily.org.uk

Contact a Family North West England Region

6th Floor, St. James House
Pendleton Way, Salford M6 5FW
Tel: 0161 743 0700, Fax: 0161 743 0711
e-mail: northwest.office@cafamily.org.uk

Contact a Family West Midlands Region

Prospect Hall, 12 College Walk
Selly Oak, Birmingham B29 6LE
Tel: 0121 415 4624, Fax: 0121 415 4922
e-mail: westmids.office@cafamily.org.uk

Contact a Family Ealing

Room 3, 1st Floor, St. Andrews Church Centre
Mount Park Road, London W5 2RS
Tel: 020 8810 8151
e-mail: ealing.office@cafamily.org.uk

Contact a Family Lambeth

Lambeth Accord, 4th Floor,
336 Brixton Road SW9 7AA
Tel: 020 7326 5270
e-mail: lambeth.office@cafamily.org.uk

Contact a Family Lewisham

Leemore Central Community Hub
Bonfield Road
London SE13 5EU
Tel: 020 8297 8056
e-mail: lewisham.office@cafamily.org.uk

Contact a Family Southall

St. Georges Community Centre
8-12 Lancaster Road, Southall UB1 1NW
Tel: 020 8571 6381, Fax: 020 8571 6400
e-mail: southall.office@cafamily.org.uk

Contact a Family Southwark

54 Camberwell Road, London SE5 0EN
Tel: 020 7277 4436
Fax: 020 7703 6449
e-mail: southwark.office@cafamily.org.uk

Contact a Family Sutton and Merton

Hill House, St Hellier Community Association
Bishopsford Road, Morden SM4 6BL
Tel: 020 8640 5525, Fax: 020 8640 7799
e-mail: suttonmerton.office@cafamily.org.uk

Contact a Family Wandsworth

1 Siward Road, London SW17 0LA
Tel: 020 8947 5260, Fax: 020 8947 9506
e-mail: wandsworth.office@cafamily.org.uk

www.cafamily.org.uk

Freephone helpline: 0808 808 3555



5 Rise to the challenge



8 Time to talk, space to play



16 Don't stop the music

From our Chief Executive

- 3 **Srabani Sen:** New beginnings

Contact a Family

- 4 **West Midlands relaunch party:** Family fun at Birmingham Botanical Gardens
5 **Fundraising news:** Muriel Gray and Contact a Family hit the airwaves
6 **How sharing your experience can help other parents:** How podcasts can reach, teach and connect families around the world
7 **Wheelchairs in Wales:** An opportunity to improve wheelchair policy
7 **News in brief:** The axing of Child Trust Funds and funding for short breaks

Benefit news

- 8 **Caring for your state pension:** What the new Carer's Tax credit means

Other news

- 9 **Great escapes for all the family:** Accessible days out across the UK

Support groups

- 10 **Time to talk and space to play:** Complex Needs Kids Relative Support group (CONKeRS) by Sarah Hillis

Family and friends

- 12 **Hopes and dreams:** Beth Meader on making plans for her brother
13 **'United we stand, divided we fall':** Linking families
14 **'Mum's been there from day one':** How a mother's support matters
15 **The kindness of strangers:** Lesley Moore talks about informal support
16 **Please don't stop the music:** A new after-school club
17 **Family means the world to me:** By grandmother Dorothy Fisher

Resources and local contacts

- 18 **Just Because:** Rebecca Elliott's book inspired by her children
19 **A day in the life:** A typically busy day for Amy Turner

Connected information

Edited by: Nathalie de Broglio, Karin Beeler and Elaine Bennett

e-mail: library.team@cafamily.org.uk Design and layout by: Desiree Blair

Note: Although great care has been taken in the compilation and preparation of this magazine to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions.

© Contact a Family 2010

Next issue: The Autumn edition of *Connected* will focus on transition. We are always interested in your stories, especially if you're a parent. If you would like to contribute, please submit articles up to 750 words. e-mail: library.team@cafamily.org.uk The deadline is 1 August 2010.

New beginnings

Srabani Sen reflects on the new political landscape and the end of our 30th birthday celebrations



Welcome to the summer edition of *Connected*. As we are ushering in a new season of light nights and warm weather, we are also heralding an entirely new political landscape in this country.

On 12 May the Conservatives and Liberal Democrats formed a coalition Government, something that has been unseen for a generation. There are likely to be many changes in the next few months, but what we know at the time of going to print is that the government department with responsibility for families and disabled children has been renamed the Department of Education.

Headed by Michael Gove MP, the Secretary of State for Education, the new department includes Sarah Teather MP, the Minister for Children and Families and Tim Loughton, the Parliamentary Under Secretary of State for Children and Families. We are very much looking forward to meeting with new Ministers and MPs in the coming months. We will continue to champion the rights of families with disabled children and call for a commitment to improving disabled children's services.

And the political excitement doesn't stop there! With elections in each of the nations scheduled for next May, those of us in Scotland, Wales and Northern Ireland are on course for more debates, party broadcasts and campaigning on the doorsteps.

As most of you will know, over the last year Contact a Family celebrated our 30th birthday! That's 30 years of strengthening families with disabled children.

Where did it all begin? In 1974, a group of parents with disabled children in Wandsworth formed a self-help group

to reduce their isolation. They named their group 'Make Children Happy' and organised day activities and evenings out together. In 1979, the group became an official charity and was renamed Contact a Family. The idea of families supporting each other took off on a grand scale and



"Thank you to all our families for making our 30th birthday such a wonderful celebration. Together we can make a difference!"

we now support 300,000 UK families with disabled children each year.

The anniversary's planned events included the London Marathon 2009. A team of 15 intrepid runners took part in one of the most iconic events in the running calendar in aid of Contact a Family on our 30th birthday.

Our 30th anniversary research report *What makes my family stronger* was published in May last year. It found that negative attitudes towards disability

coupled with a lack of services are the main barriers preventing families with disabled children from leading ordinary lives. The report's findings were used to lobby government and all political parties during party conference season.

Last August we held the Contact a Family Big Day Out – and it was a grand day out! Families were encouraged to get out and about and hold celebratory events around the UK, including a picnic party in Hyde Park. In Scotland, we gave out tickets to some of the country's main attractions and in Northern Ireland and the West Midlands, we held parties for families.

To round off our 30th celebrations, Contact a Family Wandsworth recently held an anniversary party. Founding members of the charity attended alongside some of the 600 existing family members of Contact a Family Wandsworth. Justine Greening MP and the Deputy Mayor of Wandsworth, Councillor Jane Cooper also attended. Here you can see them celebrating in style!

Our last report, *Our family, our future*, revealed that many families with disabled children are still missing out on family life due to the bureaucracy and prejudice they face. The stories were accompanied by an exhibition of family photographs. Both were launched at an event at the House of Lords in November. We took the report and exhibition to Scotland, Northern Ireland and Wales, bringing families together with politicians, which was a great success.

I would like to say once again, a huge thank you to all our families for making our 30th birthday such a wonderful celebration. Together we can make a difference! ■

Family fun in Birmingham Botanical Gardens

Contact a Family West Midlands recently celebrated its relaunch with a fun day out for families with children with disabilities.

Families were treated to a great day out with entertainment and activities at the Birmingham Botanical Gardens on 15 April. They enjoyed arts and crafts sessions, including making bookmarks with a nature theme, as well as reading sessions and a balloon modeller. There was also a bug trail for all the family.

Jan Eastwood, Contact a Family West Midlands' Manager, said, "The day was a celebration and an opportunity for families to meet others in the same situation. Everyone had a great day out during the school Easter holidays and found out more about the support that Contact a Family can provide in the region. It was a huge success."

With funding coming from the Big Lottery, two new members of staff are now in post at the Contact a Family office in Sellyoak, Birmingham. They offer up-to-date information, advice and support to families. The new team members also provide workshops, family learning events and training to families



Staff from Contact a Family



Above and left: Families taking part in activities and events

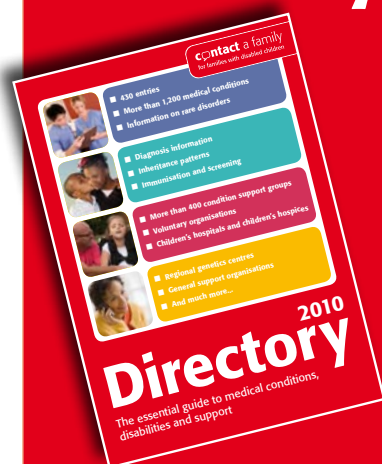
with disabled children and support groups in the West Midlands region.

Jan added, "Families with disabled children are under enormous everyday pressures and can feel isolated. Contact a Family West Midlands provides advice and information and puts families in touch with others for support. We will

be hosting family learning events in the region in the near future so check out the website soon for more details."

If you want more information about the range of support services and events that Contact a Family provides in the West Midlands, just visit the 'in your area' section of the website. ■

Have you got the Contact a Family Directory 2010?



LIMITED OFFER
Order the paperback version now and you'll also get an online subscription for only £5*

If you work with children or adults with disabilities or additional needs, our *Directory 2010* is the vital resource for you.

Contact a Family's *Directory 2010* is available in paperback for £40, or by annual subscription to the online version for £17.25.

Order the Contact a Family *Directory 2010* and get a free copy of our popular wallchart, detailing benefits,

practical help and support available for families with disabled children.

To order The Contact a Family *Directory 2010*, you can pay by card at our shop at www.cafamily.org.uk

Or, to pay by cheque, download a flyer at www.cafamily.org.uk/medicalinformation/subscribe.html or order by calling Natalie Adams on 020 7608 8700.

*£5 online subscription offer only applies when purchased with the paperback version of the Directory 2010, before 9 July 2010. Online subscription valid for one year from date of order (terms and conditions apply – see www.cafamily.org.uk/medicalinformation/subscribe.html for details). Free wallchart available while stocks last.

Take on a challenge

Contact a Family has a number of great running challenges coming up throughout 2010 from 5k runs to marathons. So whether you're a hardened professional runner or a Sunday morning stroller, we have an event for you.

We currently have guaranteed places in the British 10k London Run (Sunday 11 July), Adidas Women's 5k Challenge



Natalie and Paul after the Virgin London Marathon

(Sunday 5 September), the Adidas Silverstone Half Marathon and the Virgin London Marathon in 2011.

Alternatively, if you have your own place in any of the races taking place across the UK, then we would welcome you to join our Contact a Family running squad and fundraise for us.

All our runners receive dedicated fundraiser support, a fundraising pack, running t-shirt, training and nutrition advice and on the day support.

Or perhaps a running challenge isn't for you? No worries, Contact a Family can support you in any fundraising event or activity you venture to do yourself. We can provide fundraising ideas, materials and support to help you in your fundraising venture.

For more information, please contact Lisa Hemsley, Events Fundraiser, on 020 7608 8731 or email fr@cafamily.org.uk. To see our current events, please visit www.cafamily.org.uk/supportus/supportus.html ■

Contact a Family hits the airwaves

Contact a Family were delighted to receive radio air time through the BBC Radio 4 Appeal recently.

Our star presenter was Muriel Gray, Scottish author and broadcaster, who writes for a number of national newspapers and features on the popular BBC programme, *Grumpy Old Women*.

Muriel Gray is a strong and vocal advocate of more support for carers, as her middle daughter, Rowan, has a disability.

She said: "My family is one of hundreds of thousands in the UK, who care for a child with a disability. We have the same hopes and dreams as other families, but we also have enormous challenges. Finding out your child has a disability is always isolating. Gone instantly are all the things other families take for granted."

During the appeal, Muriel described how Contact a Family has been a lifeline to many families with disabled children over the last 30 years and how our work continues to be a vital source of support.

In an interview she gave to Radio 4's Appeal team after the appeal was broadcast, Muriel Gray said: "This charity is so important to me because as the mother of a disabled child.... you often have to cope with social isolation, financial

devastation and a feeling of helplessness so contact with other parents who are experiencing the same is absolutely essential."

The appeal aired on Sunday 2 May and Thursday 6 May but there is still time to listen to the Contact a Family appeal by visiting the BBC Radio 4 website at www.bbc.co.uk/programmes/b00s54d0 to download our podcast.

As well as highlighting the valuable work of Contact a Family, listeners were also encouraged to support our work through donations. To find out more about Contact a Family's Radio 4 Appeal and donating, visit our website at www.cafamily.org.uk/supportus/radio4appeal.html ■



Muriel Gray

Can you help us find sponsors?

We are always delighted to talk to companies who might consider supporting Contact a Family. The more money we receive, the more families we can help.

Do you know someone working for a company who could provide us with the name and job title of the person we should contact for possible 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

How sharing your experience can help other parents

Your story can reach, teach and connect families around the world

For many parents raising a child with a disability can be an anxious and isolating experience. Often, when a child is diagnosed with a rare disorder, their parents are told they are the only child in the world with the condition. Many parents receive limited information about the condition or what the future might hold for their family. Contact a Family is working to help reduce isolation and empower families of disabled children to support each other and share their knowledge.

“Nobody knows what you're going through, or describes it better, than another parent in a similar situation.”

To make information and services accessible to a wide group of parents, Contact a Family is producing a series of podcasts. Podcasts are audio recordings that can be listened to via our website, saved to your computer or put on your music player to listen to whenever and wherever you like.

This is a novel way for parents with children with disabilities to hear other parents' experiences. As well as topics like benefits and education, there are recordings of parents talking about their family life. The recordings enable parents to hear how other families have resolved some of the issues they might also have.

Nobody knows what you're going through – or describes it better – than another parent in a similar situation. The podcast interviews are really important, especially for parents to learn about living with conditions when no support group is available.

On one occasion, Contact a Family received an enquiry from a mum whose child had Coats disease. There is no support group and the mother didn't have internet access, so was unable to listen to the podcast. We recorded the podcast onto a cd and mailed it to her, so she could listen to another parent's experience using a cd player.

Get involved!

We need volunteers to tell their story and pass on words of wisdom to help other parents.

One of Contact a Family's podcast team can arrange to visit you in your home or another quiet, nearby place. We will ask you questions about your experiences around diagnosis, getting information, accessing services, education, the impact of your child's condition on the family or any information you would like to share.

After the recording has been edited, you have listened to it and are happy with the finished recording, the podcast will be put on Contact a Family's website, YouTube, iTunes and Facebook.

Call us now to share your experience. You can't imagine how important it might be to another parent. ■

Visit our website and listen for yourself at www.cafamily.org.uk/news/podcasts.html



Recording a podcast

For more information, or to book a date with the podcast team, just phone Cheryl Lenny on 020 7608 8714 or email cheryl.lenny@cafamily.org.uk

A real opportunity to improve wheelchair services in Wales

A report into the current state of wheelchair services in Wales and how they could be improved to help families with a disabled child was published. The Health, Wellbeing and Local Government Committee's report on its Inquiry into Wheelchair Services in Wales was launched in the Senedd, the Welsh parliament, on 20 May 2010.

The Disabled Children Matter Wales coalition, of which Contact a Family Wales is a member, has urged the Welsh Assembly to act quickly to implement the recommendations.

The Director of Contact a Family Wales, Keith Bowen, commented: "Expectations have now been raised across Wales. We call on the Welsh Assembly Government to respond positively to the recommendations in the Committee's report and identify the additional funding needed to deliver a world-class children and adult wheelchair service in Wales."

The report by the cross-party group thoroughly examined the current system and exposed some real concerns, including considerable delays in waiting times both for assessment and delivery of wheelchairs. Problems with wheelchair maintenance were also raised during the investigation and the report found that there was a lack of accountability.



Evidence to the Committee emphasised how receiving the right equipment at the right time can transform the quality of life of disabled children and their families.

Keith Bowen added that: "The Committee's report and the Health Minister's recent commitment to prioritise work on wheelchair services means that there is now a real opportunity to deliver an improved service which meets the needs of disabled children and adults across Wales."

Other members of Disabled Children Matter Wales include ASBAH Cymru, Bobath Children's Therapy Centre Wales, Barnardo's Cymru, Children In Wales,

Scope Cymru, MS Society Cymru and Whizz-kidz. ■

Workshops in Wales

Contact a Family Wales organises workshops and conferences for parents in Wales, including on wheelchair training, the needs of siblings, transition and negotiation skills.

Please phone 029 2039 6624 or email jill.bartlett@cafamily.org.uk for more information.

Child Trust Funds – government to cease making payments

The government has announced that contributions into Child Trust Fund accounts are to be scrapped from January 2011. It was also said that the government will redirect £20 million from Child Trust Funds for disabled children to additional short breaks.

If you already have a Child Trust Fund for your child, that money will not be affected and you or family and friends will be able to continue making payments into their Trust Fund account. However, once the new rules

come in, your child will get no further contributions from the government.

There will be no changes to Child Trust Funds until the law has been changed. So, between now and August 2010, government contributions are expected to continue as normal.

However, from August this year the amount contributed by government for babies is expected to reduce from £250 to £50 (or from £500 to £100 for low-income families).

The extra payments government makes to children who turn seven are also expected to stop in August 2010. In January 2011, the government plans to stop issuing Child Trust Fund vouchers altogether. The government has also said that an additional disability payment will still be paid for any child who is entitled to DLA during 2010/11. These payments are expected to stop from 2011/12.

For further information, please telephone the Contact a Family freephone helpline on 0808 808 3555. ■

Caring for your state pension

In April 2010, the government introduced a new Carer's Credit to help carers protect their state retirement pensions

Most parents are too busy to think about the amount of pension they are likely to get when they retire. However, if your caring responsibilities mean you're unable to work or can only work a small number of hours and you don't get Carer's Allowance, you may end up with a gap in your national insurance record leading to a reduced pension.

How does the state pension work?

To get a full basic state pension, you must make sufficient National Insurance contributions during your working life. If you're working and earning above a certain amount, you make these contributions by paying National Insurance contributions. If you're unable to work because of caring responsibilities, then in certain circumstances the government will credit contributions to you instead. This protects your state pension entitlement.

What is a Carer's Credit?

The Carer's Credit is a new National Insurance credit available to people who provide 20 hours or more care a week. The credit can also be claimed by anyone who receives Child Benefit for a child aged under 12 (regardless of whether they are disabled) and by approved foster parents. This new credit replaced Home Responsibilities Protection from April 2010.

I get Carer's Allowance. Should I apply for Carer's Credit?

No. Carer's Allowance claimants already automatically get National Insurance credits. The new Carer's Credit is for carers who don't get Carer's Allowance. You might benefit from the new credit if:

- someone else already gets Carer's Allowance for the person you look after
- the person you look after doesn't get a qualifying disability benefit

- you are providing 20 hours or more care to someone whose disability benefit has stopped because they are in hospital or residential accommodation
- you provide at least 20 hours a week care but less than 35 hours and consequently cannot get Carer's Allowance
- you look after several disabled people but cannot get Carer's Allowance because you don't provide 35 hours care to any one individual.

Who can get Carer's Credit?

You will automatically get Carer's Credit without needing to make a claim if:

- you are a parent with a child aged 11 or under for whom you claim Child Benefit. If your partner is the Child Benefit claimant you can opt to get a Carer's Credit instead of them. However, the partner of a Child Benefit claimant needs to apply for a credit – it's not awarded automatically
- you are getting Income Support as a carer.

You can also get this credit if you are a carer who does not fall into one of the above groups. To qualify, you must provide 20 hours or more care a week for one or more people who get a qualifying disability benefit. These are:

- Disability Living Allowance care component at the middle or higher rate
- Attendance Allowance
- constant Attendance Allowance.

If you are not getting any of the above qualifying benefits, it is still possible for you to claim Carer's Credit. To do this, you will need to get a signed care certificate from a health or social care professional confirming that the care you provide is appropriate.

To get Carer's Credit as someone caring for 20 hours or more, you need to make



an application on form CC1. The form is available from the Benefit Enquiry Line on 0800 882200.

The person I look after doesn't get a qualifying disability benefit. Who should I approach to get a certificate confirming the amount of care I provide?

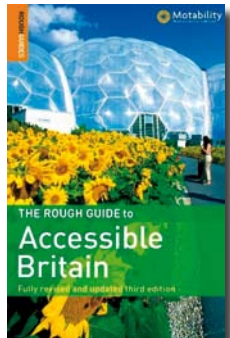
Guidance issued by the Government says that there is no definitive list of who would be an appropriate person to complete a certificate. However, it could be someone who works for the health service (although guidance suggests a GP shouldn't normally be the first choice as providing such certificates is not within their NHS contract) or the local authority. Alternatively, someone employed by a voluntary organisation working closely with your family, or even a local religious leader (for example, a parish priest), may be sufficiently familiar with your child's needs. A care certificate and detailed notes on its completion is available within the Carer's Credit claim pack. ■

If you would like further information about the Carer's Credit, please call Contact a Family's free Helpline on 0808 808 3555 (weekdays 10am-4pm and Monday 5.30pm -7.30pm).

Great escapes for all the family

Accessible days out across the UK

The Rough Guide to Accessible Britain (3rd Edition)



Motability, the leading car scheme for disabled people, and Rough Guides have published a third edition of *The Rough Guide to Accessible Britain*. One of the writers

featured, Lara Masters explains, "I love gallivanting around the UK but as a wheelchair user, I don't enjoy the boring and difficult task of finding out if places are accessible."

Packed with ideas, all the reviews are written by writers with disabilities. The guide contains details of over 180 great days out across the UK for children and adults with disabilities and their families. With plenty of information and advice for those with accessibility requirements, there's also a 'Useful Contacts' section with organisations that will help with accessible travel and days-out around the UK.

From exploring a Garden for the Senses at Alnwick Gardens in Northumberland to a trip to Legoland, there's something for everyone and each of the places featured includes recommendations on accessible places to eat and drink. *The Rough Guide to Accessible Britain* costs £6.99, but is FREE to Blue Badge and Disabled Person's Railcard holders. Download a free audio version from www.accessibleguide.co.uk or call 0800 953 7070 quoting ref: MO256.

The National Trust's *Access Guide 2010* is also out now and free! The National Trust works with national and local disability groups to assess their properties. The *Access Guide 2010* provides detailed information about accessibility at National Trust properties in England, Wales and Northern Ireland.

You can download the guide free from the National Trust website. If you would like to order a hard copy, email accessforall@nationaltrust.org.uk or call 01793 817634 (quote ref. 7330909 or 7331709 for large print). The *Access Guide* is also available free on CD or tape by phoning 01435 862737.

Holidays, play and Leisure

Contact a Family, May 2010



It's that time of year again! For families with disabled children, looking forward to the holiday season can be a mixed blessing. Services close or holiday venues can't accommodate

the whole family. Not to mention the cost of extra facilities and finding travel insurance to cover your child's condition.

Contact a Family's updated guide, *Holidays, play and leisure*, has lots of information about your rights, places to go and things to do, including sporting and cultural activities. You'll find help to pay for holidays, leisure activities and travel insurance. There is also a resources section for professionals with information on children's play and sources of good practice. Get this free guide now by calling our freephone helpline on 0808 808 3555. ■

New Family Fund rules announced

The Family Fund has changed the way it looks at income to help more families on the lowest of incomes

From 1 April 2010, the Family Fund will consider a grant application where a family's total income from all sources, including net income and benefits, is below £25,000 in England and £27,000 in Northern Ireland, Scotland and Wales. Previously, a limit was imposed on working families, whilst families on benefits were automatically eligible for a grant.

Derek Walpole, Chief Executive of the Family Fund, said, "In these tough times, it is our duty to ensure that we

are helping families on the lowest of incomes and being fair to working and non-working families alike.

"Our previous criteria were created with the best of intentions but effectively penalised working families in favour of those on benefit and prevented the Family Fund from helping many families with disabled children who were in greater need.

"Working families have long complained to us that they feel treated unfairly. For

many parents or carers with disabled children, work creates positive mental health and provides a break from caring. It also encourages disabled children's own aspirations for work in the future, which improves their life chances."

These changes to Family fund rules mean that the Family Fund will now be able to help all families with disabled children, whether working or non-working, to the same extent. For more information visit www.familyfund.org.uk or call 01904 621115. ■

Time to talk and space to play

Complex Needs Kids Relative Support group (CONKeRS)

by Sarah Hillis



My name is Sarah. I have had four premature babies. The oldest, Luke, is 10 now and has learning difficulties and autistic spectrum disorder. My son Connor passed away at eight months. Hope, now three, has multiple complex medical needs and cerebral palsy. Imogen, my youngest, is eight months old. She has multiple complications and is currently on home oxygen.

I have been fortunate in that since having Hope, I've made friends with other mothers. One in particular was in a very similar situation as myself, in and

out of hospital on numerous occasions and who shared all the same health-care professionals. We have muddled through together sharing our experiences and complaints on a daily basis. Although her daughter has very different complications to Hope, it has been a blessing that she is always at the end of the phone and understands how I feel.

I realised that there are many parents in similar situations to us who had no one to share their roller coaster ride with. So I decided to set up a support group in my home in Lisburn, Belfast, for parents and carers of children with complex medical and special needs.

The initial response was amazing. I was unsure how many people would turn up, if any, and how willing they would be to share their problems and concerns with complete strangers.

The first meeting was a great success and I currently have about eight families

coming over on the third Wednesday of every month. I am lucky in that I have a large rubber-surfaced, outdoor play area thanks to the Make-A-Wish Foundation as well as lots of multi-sensory toys for the children who come. During term time when some of the children are at school, coming along to the group gives parents a break and a chance to sit down for a few hours and enjoy a coffee!

Everyone's child is completely different yet it's amazing how similar our situations are. I am looking to reach out to as many families as I can. I am hoping that this support group will carry on growing. I want to arrange days out in the summer as well as Halloween and Christmas parties. ■



Join Contact a Family's Local Parent Support Group Network Scheme

Contact a Family was founded on the principle of mutual support for parents and families caring for disabled children. Our Local Parent Support Group Network Scheme offers a flexible service to groups offering support and information to families in their local area. We also consult with groups on policy matters and on issues surrounding their children's welfare.

As a member of the network, your group will be entitled to:

- advice and support from Contact a Family on any matter relating to the setting up and/or management of your support group
- referral of families or individuals who may wish to join, or use the services, of your group

- be consulted on Contact a Family policy and work relating to the support of families and the welfare of disabled children
- our quarterly magazine, *Connected*
- be able to state that your group is part of the Contact a Family Local Parent Support Group Network on all group literature.

Best of all, it's all FREE of charge!

To sign your group up to the Contact a Family Local Parent Support Group Network or for more information, e-mail: adele.meader@cafamily.org.uk

A close-up photograph of a person's neck wearing a gold chain with a heart-shaped pendant. The pendant is engraved with the words 'Who cares?' in a cursive script. The background is a soft-focus image of a person's skin and clothing.

Who
cares?

If you look after someone, who looks after you?

Carers Direct is a free national service.
We offer information, advice and support for
people like you who care for someone else.

Call free on 0808 802 02 02
or go to www.nhs.uk/carersdirect

Carers Direct

Family and friends – what a difference they make!

This edition of *Connected* is dedicated to all the friends and family members who give their time helping parents with disabled children. From children having fun with friends at The Music Club, to finding a whole set of new friends at a support group – sisters, mums and grand mums talk about how proud they are of their families and how much love and joy they bring into their lives.

Hopes and dreams

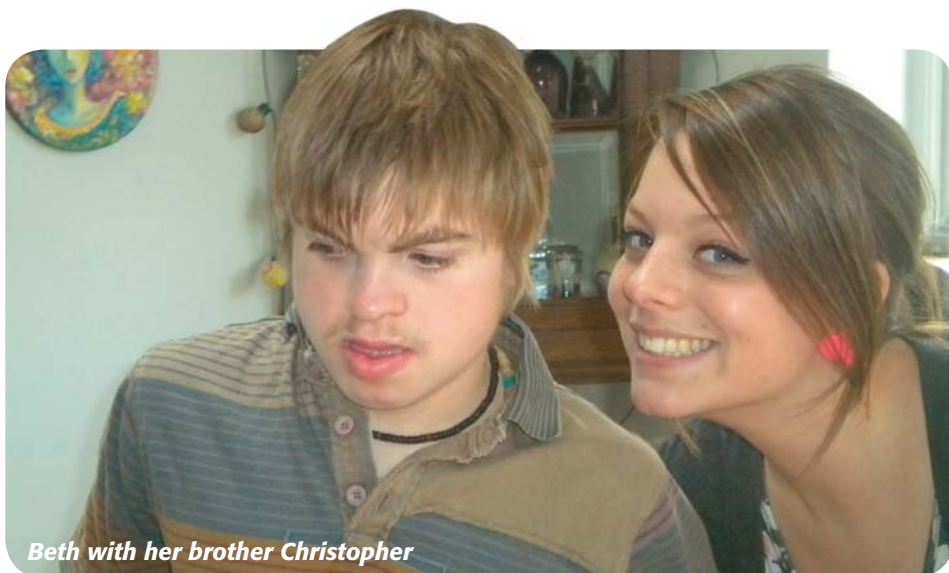
Making plans for my brother at 16 plus, by Beth Meader

My young disabled brother is now dealing with the 'transition process' (preparing for adult life). My Mum hates this terminology and I have noted she has labelled his current file as 'Christopher 16+'. I say he is dealing with it – it's more me, our Mum and our Dad. We are the ones who will be planning for his future. My 16 year old brother doesn't have a care in the world.

All through primary and secondary school, as soon as people found out about his condition the reaction was always the same: a tilt of the head and "Aww – I feel really sorry for him." To which my reply would be, "Why? He loves his life."

"My brother's gift – providing he is in a good mood – is his ability to turn anyone's frown upside-down. Can we write that in his plan? Will it help?"

My brother has severe learning difficulties and the way I normally explain his condition is, "He can walk (although he chooses not to), he can't talk and he is constantly blowing raspberries. The correct term for the condition he has is 9q34.3 deletion syndrome. It's a rare



chromosomal condition in which a tiny piece of genetic data is missing from the tips of chromosome 9."

Recently, a social worker for the children's team delivered a package which Christopher is meant to fill out with his ambitions for the future and all that. As my brother can't speak or write, it's up to us to fill this out.

The first page has four thought bubbles listed as Hopes, Dreams, Fears and Gifts. I would say my brother's hopes and dreams would be an endless supply of food and his own ball pool – the simplest of things to make him happy. After all, my brother Christopher doesn't worry about anything!

Which brings me onto fears! Just what does Christopher have to be afraid of or worried about? A mortgage? He might

be scared living in a place without his family. I wonder, does he even know that at some point he will be leaving? My brother's gift (providing he is in a good mood), is his ability to turn anyone's frown upside-down. Can we write that in his plan? Will it help?

After reading the transition plans, it has really made me think about Christopher's future and just what is going to happen next. I'm glad we have three years to think and plan because we are going to need it.

We have to hope that what we end up choosing is what we believe to be right. I've grown up with my brother and he is very easy to please – just put a pudding in front of him and watch his eyes shine! However, this is a completely different story as it involves his life-long happiness and not the next five minutes. ■

'United we stand, divided we fall'*

Louise Derbyshire, Family Linking Officer at Contact a Family, talks about the values of linking families in similar situations

My work often reminds me of Aesop's fable about four oxen who, when standing together, were able to fend off a lion, but when they separated, the lion was able to pick them off one by one. Once, a mother on a weekend family event told me how comfortable it was to be with other families in the same situation, as her child could socialise without her worrying what other people thought about him and judging her parenting skills. Linking families together reduces isolation, allowing families to gain strength from each other to face the challenges of raising a child with additional needs.

Attending support groups is a proactive way to meet parents. Local groups or coffee mornings provide a great opportunity to network and build relationships with people who live nearby. Whereas national condition specific groups help people meet others affected by the same condition. Some national groups offer one-to-one links by providing members with a list of contacts

"Linking families together reduces isolation, allowing families to gain strength from each other"

and many offer annual conferences or family weekends, giving parents the opportunity to meet others and make their own links.

Linking families is not without its challenges, though. Children with rare disorders can be spread all round the UK and it may not be possible to find a family in the same town with a child of the same age and affected in the same way by a condition. It may take many years to find a suitable link, but that doesn't mean we shouldn't try!



Louise Derbyshire at work

How does Contact a Family link families together?

We have a long history of linking. In fact one of the main drivers when Contact a Family began in 1979 was getting together locally so that families were able to meet others and share the joys and frustrations associated with having a disabled child.

In days of yore, (not quite as far back as Aesop's era), we used to run a contact parent scheme linking parents whose children had the same condition. Many readers may remember being involved. However, as more and more condition groups have developed, less people link in this way. So, today, we first signpost parents to national, specific condition support groups and, if there is no national group available, we can then offer to try and make a one-to-one link.

In 2004, Contact a Family launched its on-line linking service, MakingContact and this is fast becoming the chosen method of finding and linking up with other families. One of the main advantages is that parents can choose when they sit down at the computer. For many, this will be once the children are in bed, when it might be too late to

pick up the phone, or when the children have finished playing on the computer! Additionally, particularly for rare disorders, another parent may be on the other side of the world and the time difference makes it very difficult to pick up the phone and chat.

Now, MakingContact has more than 7,000 people registered. So, why not visit the site today to see if there is someone you would like to share experiences with?

And if you don't have email or computer access, we can help you access this service. One Makingcontact member, Amanda, doesn't have email access, so we manage her profile for her, sending, receiving and forwarding messages by post. Amanda is still in touch with the Mum we put her in contact with in 2007.

If you would like information about local support groups or national rare disorder groups, call our freephone helpline on 0808 808 3555.

For more information about family linking, you can just send an email to louise.derbyshire@cafamily.org.uk or give me a call on 020 7608 8715. ■

*Aesop, circa Sixth Century BC

'Mum's been there from day one'

Liz Reynolds on the constant care and love her mother gives

In April 1996, having recently discovered I was pregnant, I remember going for the first scan with my mum. It was a warm spring day and afterwards we went for a cup of tea and chatted about the fact I'd just discovered I was expecting twins! It was a mixture of shock and excitement, particularly for my mum who took a while to take it all in!

The pregnancy went well with no complications and Victoria and Thomas were born (after 40 very long weeks!) in November 1996. Once again, my mum was one of the first people there. Victoria was confirmed as having Down syndrome within a few days and our future took a very different direction.

The one and only constant source of support during the past 14 years has been my mum. Despite having her own difficulties to overcome (losing my dad a few months before Vicki and Tom were born, and developing arthritis), she also ran her own business. And she was always there to support us. In fact for the first three months of the twins' lives, we actually moved back in with my mum. It was great to have the extra pair of hands!

Shortly after the children were born, it became clear that I needed to be at home. We had the Visiting Teacher Service making regular home visits, physiotherapy and speech therapy to attend and fitting in a job as well just became too much. Once again, my mum was there to help us with some financial support.

Many times my mum would look after Tom whilst I've been at hospital appointments. Vicki has had a number of operations and my mum has always been there to help out with Tom or with school pick ups.

My mum and Tom have a really lovely relationship which has developed through the years due to the amount of time they have spent together. Tom thinks a lot of his Nan, and her dog Pippa which Tom considers partly his dog too!

I have always tried to treat both Vicki and Tom the same, and Tom has been a constant source of support for Vicki. She's always had him around to copy and keep up with. Much of Vicki's brilliant progress is down to Tom being a role model. Having said that, there

"My mum has always been there to help out with Tom or school runs"

have been times when Tom has been held back and I've always been mindful of this. I've always tried to make sure he has the same opportunities as his friends and often it's been Vicki's turn to go to my mum's, so that Tom can have his time out and do those 'regular' things that many just take for granted. With all the planning that has to be put in place just to go to the cinema or swimming baths, it's like a military exercise!

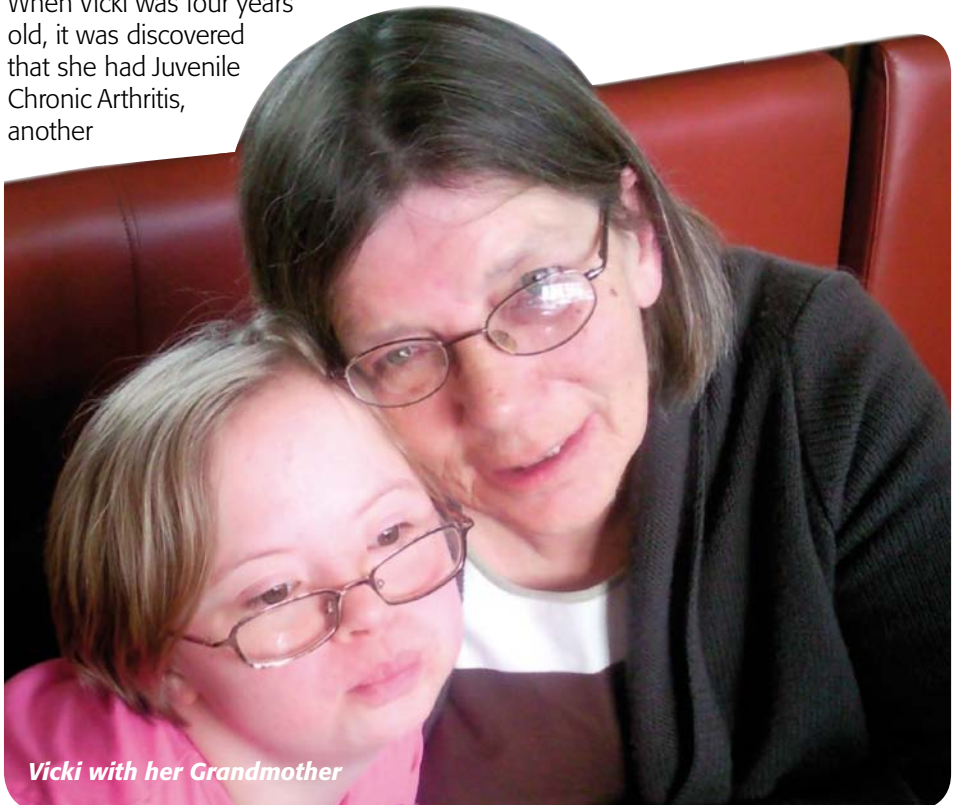
When Vicki was four years old, it was discovered that she had Juvenile Chronic Arthritis, another

huge shock. As with many families of children with disabilities, it took a while to be diagnosed. By that time, her joints, particularly her wrists, had been very damaged by the disease and she now requires support with self help and feeding. As my mum has arthritis too, they will often talk to each other about their 'bad bones' and the splints they have to wear!

This has been an added worry, as I do wonder how Vicki will be able to physically manage as she gets older. However, she is an extremely determined young lady, and lets very little get in her way.

I've had support from a number of people, particularly the local Down syndrome support group where I've made some great friends. And my work colleagues have been brilliant, too.

It's my mum, though, who's been there since day one. Vicki, Tom and I could not have managed as well as we have, if it hadn't been for her. She's been an absolute star! ■



Vicki with her Grandmother

The kindness of strangers

Lesley Moore talks about the informal family support group that's come to include some of her closest friends



Above left: Cameron at Mass Camp

This is my son Cameron. The informal family support group that we have developed has been my biggest support and help through all the stresses and pleasures that parenting a child with additional needs/disabilities brings.

This support started when Cameron and I first attended a School for Parents group at a conductive education school called Percy Hedley near Newcastle. We began to chat during the coffee break and then began to support each other by frequent phone calls and meetings outside of school.

At the same time, a family I knew from my previous life as a teacher started to include Cameron and myself in their family support networks. This really opened my eyes to the value of doing activities together. Your child becomes completely accepted by the group, screams and all. Until we got Cameron's seating sorted, he would scream for hours. It took a lot of support to get through that.

This has developed into an informal support network of people who are

there whenever and for whatever. We make frequent phone calls to each other, pass on any latest information or advice, or just have a good moan about services or a recent negative experience. We often share kit or buy bits of kit for each other as you know what someone's child needs or would find useful.

We go on numerous days out and weekends away in various group formations and every year have a week camping which has now become the annual Mass Camp for whoever can make it, friends and family.

We usually get together to celebrate birthdays and festivals. Although my sister and her children live in the Midlands, they often make it to a number of weekends away and the Mass Camp. Now my sister and her family are meeting up with other members of the group without us being there.

All the children seem to get a lot out of it. Cameron gets to take part in group games and activities and to go off with the other children by himself. This only happens when he is with those that



Group outing to see The Wizard of Oz play in Tamworth



Gateshead Family Sculpture day

really know him well and understand his needs. The able children get to enjoy activities that they would be unlikely to try without being part of a group with disabilities, such as caving and zip wiring at activity centres specifically for people with additional needs.

We have routines and rituals that are particular to the group such as our Golden Plate Awards, artwork sessions such as painting or biscuit decorating and we are frequently to be found on some sort of transport or very near water! All this gives a familiarity and routine to the camps that all the children benefit from and appreciate.

This support group is important for both of us. I've made friends I would want even if I didn't have a child with a disability! I think that's really important. We have a chance to share what we think about having a child with a disability – good and bad – in a completely honest way. And knowing that others know exactly what you mean is a real strength. In many ways, Cameron has a better social life than a number of children his age. ■

Please don't stop the music!

Sophia Nicholls talks about fun and friendship at The Music Club

Waiting in the car for my 11 year old youngest son, CJ, to finish an after school activity at school one day, I started thinking about his 13 year old brother, Matthew, who was sitting waiting in the car with me as he always seems to do.

Matthew has a rare eye condition known as Peter's Anomaly and Anophthalmia. This presents itself as a small eye one side and nothing on the other side! He has severe learning disabilities, and over the past few years he's lost the ability to walk due to an undiagnosed neurological disorder and is now using a wheelchair. Matthew wears a false eye and uses a speech-output device to communicate. He attends a special school 10 miles from home and did not have an after-school club or activity he could go to.

I spoke to another mum whose 13 year old daughter attends the same special school as Matthew. There are activities at the school and in the holidays but there was nothing that our children could access locally after school where they could meet, socialise, make new friends and just have fun like their siblings! We decided to do something about it and discovered that both of our children love playing and listening to music. Music seemed to have a way of engaging Matthew and has been used for a number of years to help him communicate and express his feelings of frustration and overcome his outbursts of aggression. So, we decided to start 'The Music Club'.

The idea of the club was to provide

a space where children and young people with disabilities could meet their friends within the local community and enjoy listening and making music with their carers and siblings. We spoke to other parents, children and teachers at Matthew's school and their positive responses spurred us on to have our first session in February 2010.

"At The Music Club she feels 'just like the other children', she said"

Our group has grown from four children at the first session to 12 by the third session! We meet on the first Monday of the month. The sessions are lead by a variety of specialist music providers who have worked with groups of children both in school and community settings. Carers join in the sessions engaging with their children and learning new skills. Local musicians have shown an interest and will be joining in with our music fun day this summer. Contacts from local shops and businesses have offered to volunteer their time to support the project and some have indicated the possibility of funding!

A mum said how pleased she was to discover the club because it is difficult for her nine year old daughter, who has autism, to fully integrate into

other local clubs and activities. At The Music Club she feels "just like the other children" and her mum does not have to apologise for her daughter's behaviour.

One mum said she really enjoys coming to the club because she meets other parents and can chat about some of the issues she goes through on a daily basis. A father who comes along with his son was really pleased to find the club because he was also finding it difficult to find out of school activities for his 10 year old who is has Asperger's syndrome.

The project is currently funded by donations from a local business, a small charity and funds from the Out of School Liaison (OSLO) budget from Matthew's school whose head teacher recognised the need and potential of the club. The Music Club has given disabled children and their families living in South Oxfordshire an opportunity to have fun together and to meet friends outside of school. It's also provided a space for carers to make local contacts for mutual support and learn new activities that can be used at home with their children.

It's really great to see Matthew and the other children from the local area getting together after school and doing things they really like and enjoy. It's also great to see children making new friends in a safe and non-judgmental environment. One of our newest members asked me, "Why do you only meet once a month? We should have the club every week!" ■



The Music Club in Oxfordshire

'Family means the world to me'

Grandma Dorothy Fisher talks about what family means to her



Family means the world to me. While we've never had much money, we have always had a lot of love and a lot of care in our family.

I am a mum of two and grandma of three children from Gateshead. My daughter Joanne is 37 and has mobility difficulties following two tumours on the brain when she was a child. She has two children, Ross 16 and Sharna 13. Sharna has autism and attends a local special school. They live five minutes away and I see them every day. They lived with me and my late husband Dave for three years when Joanne's marriage broke down, so we have always been incredibly close. I also see my son Michael regularly. He runs his own business and is married to Pat and they have one daughter, Abbey.

When Joanne was 18-months old, she took ill and doctors found a tumour on her brain. She had surgery to remove it, which was traumatic for us all. Joanne was left with a lazy eye but we were told the operation had been successful and were glad to get her home soon after. However, when she was four and half years old, she took bad again, and was rushed to hospital. They removed another tumour and to this day we don't know if it was a new one or if the old one had grown back. We were told the operation had been successful, but the next day Joanne was paralysed.

We were at our wits end. I had never heard of children getting tumours on the brain and felt completely bewildered. I was due to give birth to my son in two weeks, time and I could not have coped without the love, support and strength of my mum, dad and sister.

"I could never have coped without the love, support and strength of my family"

Joanne began to recover over the next couple of days and was given a nine month programme of physiotherapy. The tumours have left her with double vision and poor co-ordination and movement on her left side.

She uses a crutch when she is out and a big walker in the house, so her mobility is restricted and getting ready in the morning is difficult. I have always helped out on daily basis.

When Sharna was a baby, we knew something was wrong and as she grew into a toddler, she started displaying some unusual behaviour. She often tried to run away and we were scared to death that she would come to some

harm. I was at Joanne's constantly because she needed practical help and emotional support. We eventually got a diagnosis of Autism and at first wouldn't believe it. We didn't know anything about the condition and my husband Dave said doctors aren't always right. But after spending time reading a leaflet about Autism and watching Sharna's behaviour, we began to be convinced.

The turning point for us was when Sharna went to Gibside Special School in Whickham. She came on leaps and bounds. The head teacher said she was an ambassador for the school because she was so well behaved and polite.

Now, Sharna and her mum are really good friends. She is so caring and understands her mum's difficulties, so will do the ironing and help out around the house.

We have never treated Sharna any differently to Ross and I think that has helped her to progress in the way she has. She doesn't have tantrums but if things get too much for her, she will go and have some quiet time. I think Sharna was sent to Joanne for a reason.

Sharna now goes to Hilltop Special School, where she enjoys all kinds of activities. She's in three after school clubs and is the goalkeeper for the school's football team. She swims, is in the choir and loves drama. Last year she was the wicked queen in the school pantomime and was the star of the show.

Even though I am at Joanne's every day, I have been able to take a step back. I do some voluntary work at my church, helping in the kitchen at Monday's drop in centre. I love the cross section of people that come in and the sense of community.

Family is central to my life, I love nothing more than being with and supporting my children and grandchildren. It feels like I've been doing it for a long time, but I love to be involved and don't know what I'd do if I wasn't. ■

Just Because by Rebecca Elliott

Rebecca Elliott, author and illustrator of *Just Because*, dreamed of becoming a writer and an artist as a young girl. "This ambition never truly died. It was by a rather scrappy route that I find myself here, though", she says.

"After graduating, I started working in a financial publishing company as their production editor – which was absolutely as dull as it sounds. This only served to fuel my ambition to break into the world of children's illustration. It was hard work – I have a file full of rejection letters to prove it – but I didn't give up and eventually work for mass-market publishers came trickling in. Luckily, I'm married to an extremely supportive husband and a year after graduating, I gave up the dull office job and went full-time freelance."

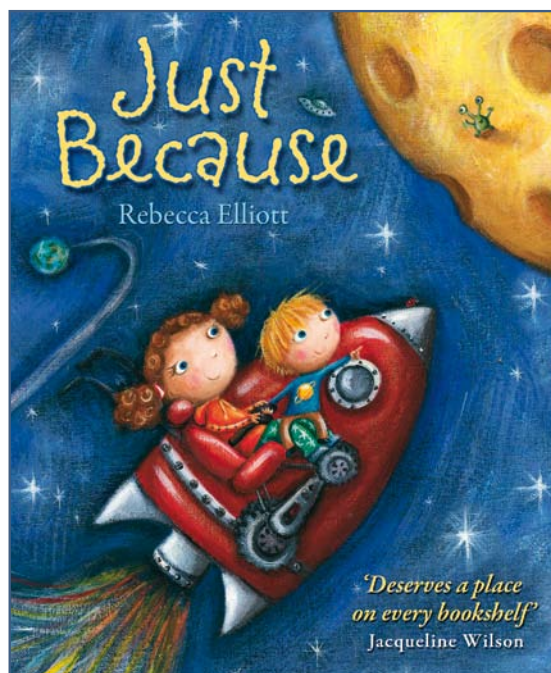
Rebecca's life took an unexpected turn in 2004 when she gave birth to her first child, Clementine, who was born with severe cerebral palsy. "My career took a bit of a break whilst I got to know my little girl and re-adjusted to life with a profoundly disabled child. But as all who meet her will tell you, Clemmie is a true inspiration and I became more determined to get a book of my own published.

"*Just Because* is directly inspired by Clemmie and her little brother Toby, who arrived on the scene last year. I love all my books but this one is particularly close to my heart as it's about my little ones! Thankfully there are more disabled children included in picture books these days, largely thanks to the In the Picture campaign*, but I believe this is the first to star a severely mentally and physically disabled child.

"I didn't write *Just Because* with a view to making a political point or stirring up discussion on the representation of disability in fiction, although I'm happy if this is a side-effect of its publication: I wrote it because I thought it would make for a funny, sweet, life-affirming and heart-warming story that all children could relate to. I'm just

so proud there's going to be a book for sale about my two children."

"In *Just Because* I hope my daughter's character shows that you don't have to do anything – to walk or talk or dance or sing – to achieve anything, to be utterly perfect and loved – just because.



"I wrote it because I thought it would make for a funny, sweet, life-affirming and heart-warming story that all children could relate to"

"*Just Because* isn't due to be published until August this year but already there's been tons of media interest and glowing commendations from incredible people such as former Children's Laureates Michael Rosen and Jacqueline Wilson! It's all quite astonishing and I'm just so excited about its release! I'm also already working on a sequel called, *Sometimes*, so watch this space!"

Just Because is beautifully illustrated with some quirky typographic touches. The pictures include tiny creatures young children love to find and a repeated refrain they can join in with – "just because". The story is told from Toby's point of view. He talks about him and his big sister, Clemmie, describing things he loves about her, the things she likes and doesn't like and the games they play together. Clemmie's disability is not an issue to Toby. He accepts her just the way she is.

"My big sister Clemmie is my best friend. She can't walk, talk, move around much, make macaroni, pilot a plane, juggle or do algebra. I don't know why she doesn't do these things. Just because.

"Clemmie has a great chair. Last Tuesday we went to the moon on it.

"I don't know why we didn't go to Jupiter as well. Just because."

Just Because by Rebecca Elliott (Ages 3-5), paperback, 32pp, ISBN 978-0-7459-6235-1, £5.99, published by Lion Hudson, 20 August 2010. ■

*In the Picture

Scope's In the Picture campaign encourages publishers, illustrators and writers to embrace diversity so that children with disabilities, are included in illustrations and story lines in mainstream books for young readers. The campaign is not an attempt to create a separate strand of children's literature tackling disability issues.

The In the Picture website has a wealth of resources for children and professionals, including stories, positive images of children with disabilities and factsheets.

www.childreninthepicture.org.uk

A day in the life...

of Amy Turner, Family Worker at Contact a Family West Midlands

It's 7.30am and my desk is covered with paper plates, strips of coloured tissue paper and googly eyes. I'm going to be making paper plate jellyfish with my Rainbows later in the week, and I spent yesterday evening experimenting with materials for tentacles. I pile the jellyfish-to-be into a corner out of the way (the googly eyes look distinctly unimpressed) and turn on my laptop to print some maps of where I'm going today.

I'm based in Birmingham but I cover the whole West Midlands region, from Shropshire and Staffordshire in the north to Worcestershire and Herefordshire in the south. This is quite a change from my previous job at Birmingham Carers' Centre, which was tightly focused on Birmingham, and, since joining Contact a Family in September last year, I've been concentrating on familiarising myself with services outside the city. I spend most of my time out and about visiting families and, wherever possible, I use the train to get around. This is partly to be 'green', but I also find it's often quicker and cheaper than driving.

My first stop today is to see a mum whose daughter has undiagnosed learning and behavioural difficulties. She didn't think she could claim DLA until

her daughter was diagnosed but, after calling Contact a Family's helpline, she now has the form and I'm here to help her complete it. She tells me she's been dreading it but, although we need to focus on her daughter's difficulties for the purpose of the form, I make sure we also spend time discussing her achievements. When we've finished, we talk about the other issues the family are facing and I agree some follow-up actions.

My next appointment is only a couple of miles away so I decide to walk, stopping off for a quick sandwich on the way. I'm going to see a family who I've been working with for some time, trying to access support for their four-year-old son who has autism. A social worker is visiting this afternoon to conduct an assessment and the mum has asked me to be present to provide support. I arrive about three quarters of an hour before the social worker's due and we make a list of the issues she wants to raise during the assessment. The mum's quite anxious, but the social worker is supportive and, afterwards, she feels the assessment went well. She's interested in Direct Payments but feels she needs more information, so I explain the options and agree to send some more information by e-mail.



Amy Turner

When I get back, my answering machine's flashing. I've got several messages, mostly from parents who've seen my phone number in the recent West Midlands newsletter. The West Midlands office has just relaunched so it's quite an exciting time, with loads of events being planned for families around the region. I return the calls and arrange some more home visits, then complete the follow-up work for the families I visited today.

Family work can be so frustrating when families face irrational, unjust barriers in accessing basic support. But I finish the day thinking how privileged I am to be able to work alongside families to help them overcome these barriers and ensure they receive the services they are entitled to – and need! Then it's back home to get on with making jellyfish. ■

Local contacts – support from Contact a Family

Volunteer parent representatives

Contact a Family has a team of volunteer parent representatives around the UK. As parents or carers of children with special needs and disabilities themselves, volunteer parent representatives fully appreciate the impact of caring for children with complex needs. Volunteer parent representatives offer parents someone to talk to, provide peer support and will also signpost families to local sources of information and support.

Family workers

Contact a Family's team of experienced family workers covers different parts of the UK. Family workers can help parents with the wide range of issues that families can face when caring for a disabled child.

Whether it's advice on claiming benefits, providing information about special education needs or putting you in touch with local and national sources of support, Contact a Family's

family workers have a wealth of knowledge to share. Family workers also offer support to families in times of particular need and help build parents knowledge and confidence.

How to find local contacts

To find your local family worker or volunteer parent representative, you can phone our freephone helpline on **0808 808 3555** or visit our website www.cafamily.org.uk/inyourarea



Getting in contact with us

Contact a Family
209-211 City Road
London EC1V 1JN
Tel: 020 7608 8700
Fax: 020 7608 8701
e-mail: info@cafamily.org.uk

www.cafamily.org.uk
www.makingcontact.org

Ring the Contact a Family freephone helpline for advice and information on any aspect of caring for a disabled child.

Contact a Family is the only UK charity providing support and advice to parents whatever the medical condition or disability of their child. Our helpline is a 'one-stop-shop' for parents and families whenever they need answers.



Registered Office: 209-211 City Road,
London EC1V 1JN
Registered Charity Number: 284912
Charity registered in Scotland Number: SC039169
Company limited by guarantee
Registered in England and Wales No. 1633333
VAT Registration No. GB 749 3846 82

Freephone helpline:

0808 808 3555

Textphone:

0808 808 3556

Open Mon–Fri 10am–4pm and Mon 5.30–7.30pm