

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

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

Summer 2009

# connected



## School days

How have families with disabled children  
found the education system for them?

### **30 Not Out**

Help us to celebrate  
30<sup>th</sup> anniversary

### **Group support**

How we can help  
your support group

### **Swot up on VAT**

How VAT exemption  
rules could apply to you

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7 **Marathon heroes**



9 **Group support**



12 **School days**

## From our Chief Executive

- 3 **Srabani Sen:** Sights set on summer celebrations

## Contact a Family

- 4 **What makes my family stronger:** New report launched  
5 **Parent participation work heats up:** Encouraging parent engagement  
5 **For Scotland's Disabled Children:** Update on new campaign  
6 **30 Not Out:** Find out how we plan to celebrate our 30<sup>th</sup> anniversary  
6 **Making Contact:** New forums launched on our online linking service  
7 **Our Marathon heroes:** Extending huge thanks to our runners  
8 **Facebook – one year on:** Update on our innovative online project  
8 **New films premiered:** Three new short films

## Support groups

- 9 **A problem shared:** The benefits of support groups and how we can help

## Benefit news

- 10 **Accessing extra money:** VAT exemptions and changes to benefit rules

## Other news

- 11 **Caring with confidence:** New programme to help support carers  
11 **News in brief:** Roundup of the latest news

## School days

- 12 **School days:** Introducing this edition's theme  
13 **A very special place:** Why one mum chose a special school for her son  
14 **Finding solace in a Red Balloon:** Forced to leave school due to bullying  
16 **Desperate for a Statement:** One teacher's story  
17 **Making mainstream work:** One teenager's experiences

## Resources

- 18 **Book review**  
19 **Find your local volunteer parent rep and family worker**

### Connected information

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**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.

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**Next issue:** The autumn edition of Connected will be published in August. We are always interested in stories, especially from parents. If you would like to contribute, please submit articles of up to 750 words. e-mail: [library.team@cafamily.org.uk](mailto:library.team@cafamily.org.uk) The deadline is 14<sup>th</sup> July 2009.



# Sights set on summer celebrations

**Srabani Sen, Chief Executive at Contact a Family, updates us on the recent child health strategy and looks forward to celebrating our 30<sup>th</sup> anniversary**

Welcome to the summer edition of Connected. It's been a busy few months but with the sun coming out and promises of a 'scorcher' on the way, preparations for our 30<sup>th</sup> anniversary are right on track! It's set to be a great summer.

## The child health strategy

First down to business. The long awaited child health strategy *Healthy lives, brighter futures* was published in February, and the government has finally clarified that an additional £340 million has been given to primary care trusts (PCTs) in England for disabled children from 2008-2011. This is a huge success for us. As part of the Every Disabled Child Matters campaign (EDCM), we have been lobbying extremely hard to get the government to say how much money there is and we have been raising this consistently at Aiming High Ministerial Implementation Group meetings.

We now know that a significant portion of the funding from the Department of Health (DH) is expected to go towards short breaks provision to ensure disabled children with complex health needs and their families can enjoy the same opportunities for short breaks.

The money invested equates to 1.23% of the £27,596 million additional resources the DH is making available to PCTs. This is a significant amount but it is not 'ring-fenced', meaning PCTs don't have the same duty as local authorities to spend this money on disabled children, and there is a real danger that it could 'disappear' into the overall PCTs budget. Because of this, Ed Balls, Secretary of State for Children, Schools and Families and Christine Beasley, Chief Nursing Officer at the

DH have both sent out letters to PCT Chairs and Chief Executives setting out clear expectations of the action required by them and reminding them of the new National Indicator for services for disabled children, which will monitor parents' experience of these services. Importantly, it gives you as parents some 'elbow power' with the PCTs and local authorities if you're refused a short break or told there's no money in the budget!

This brings the total government funding for disabled children to £770 million, to be spent on services for disabled children.

## School days

The theme for this edition centres on school days, and education is an issue we hear about from parents frequently. There are some outstanding stories from parents in this issue.

**"This edition centres on school days, and education is an issue we hear about from parents frequently."**

One of the key areas where the Aiming High for Disabled Children agenda is expected to make a difference is encouraging better practice in transition planning for young disabled people. And as part of this, the government is developing a new transition support programme over 2008-2011.

Local area services need to be listening to parents about how this money is spent. In a survey that we did last year with the Family Fund we found that

most families reported that their child did not have a transition plan and 41% of respondents told us that they had never heard of transition.

I'm also delighted to note that Ed Balls has accepted recommendations from the Special Educational Needs (SEN) Information Review, which forms part of the Lamb Inquiry. The government has made a commitment to improve interaction between parents and schools; to strengthen the accountability system and to look at Ofsted's inspection arrangements, with a view to placing a greater focus on SEN and disability.

## 30<sup>th</sup> Anniversary

Now the fun part! This year is Contact a Family's 30<sup>th</sup> anniversary. We would love as many families as possible to celebrate our 30 years of working with and supporting families with disabled children. There will be a series of events, campaigns and most notably our Big Day Out which will be a huge summer party to raise the profile of families with disabled children. See page six for more details. And look out for our '30 Not Out' logo!

And what a fabulous day we had at the Marathon. An amazing number of people turned out with their family and friends to cheer on our 14 runners. As well as our runners looking positively magnificent in their Contact a Family 30<sup>th</sup> Anniversary t-shirts, we all cheered, blew our whistles, and jumped up and down and handed out jelly babies and drinks. A wonderful day, and a huge thank you goes out to our runners who trained so hard, ran so well and raised much needed funds to support the work of Contact a Family.

*Srabani Sen*

# What makes my family stronger

## New report from Contact a Family finds lack of services, attitudes towards disability and lack of support from professionals creates barriers to leading ordinary lives for families with disabled children

To mark the start of Contact a Family's 30<sup>th</sup> anniversary, we have published a new report into the experience of families with disabled children living in 2009.

*What makes my family stronger* will be used to campaign for better lives for all families with disabled children throughout our anniversary year and beyond.

The report is based on the results of an online survey through which we asked families about their social, emotional and practical experiences of raising a child with a disability. As well as gathering statistics, the survey asked families for their comments, which are used to illustrate the reports findings throughout.

The results of the *What makes my family stronger* survey indicate the three main barriers standing in the way of families leading ordinary lives – lack of services, attitudes towards disability, and lack of support from professionals.

Srabani Sen, Chief Executive of Contact a Family, said: "Families with disabled children want to lead ordinary lives. However, they face practical, physical and emotional challenges over and above families with non-disabled children.

"Our research highlights that often the difficulties come from a lack of support from professionals and understanding from society. Most families have to fight for services that should be theirs by right to help their children and themselves overcome daily challenges and lead independent lives."

### Summary of key findings:

- Almost 70% of respondents said that understanding and acceptance of disability from their community or society is poor or unsatisfactory.
- Over 60% of families said they don't feel listened to by professionals.

- Over 60% of families said they don't feel valued by society in their role as carers.
- Over 70% of respondents said their child's access to play and leisure specifically for disabled children is poor or unsatisfactory.
- 50% of families with disabled children said the opportunity to enjoy play and leisure together is poor or unsatisfactory.

Srabani Sen added: "It is shocking that in the UK today, attitudes towards disability from professionals and members of the public are contributing to the difficulties that families face. Families with disabled children have enough hurdles to overcome without having to cope with prejudice and ignorance."

### Families biggest priorities for making them stronger:

- They want more opportunities to enjoy play and leisure and want a real choice in the activities they can take part in.
- They want to see their child reach their full potential.
- They want a support package to meet their child's needs and flexible and regular short breaks.

### Contact a Family is calling for:

- the government to invest in a UK-wide disability public awareness campaign with a focus on children's disability
- everyone working in a public facing role in the UK to be given disability equality training
- disability awareness should be made part of the school curriculum and covered in Citizenship classes.
- the much welcomed and significant investment in short breaks services in England to be sustained and included in the next Comprehensive Spending Review
- fair access to short breaks for all families with disabled children and the use of eligibility criteria should not be used by local authorities as an excuse to limit access. There must be equality of short breaks services across the four nations
- the government to commit to reviewing carers benefits and set a clear timetable for reform
- a reduction in the higher risk of poverty for disabled children. We urge the government to undertake a DLA take-up campaign with a particular focus on ethnic minority families, whose take up of the benefit is particularly low.

### Comments from some families who responded to our survey

*"Me being the person I am makes our family stronger - or more accurately the person I've had to become. Without me, our family would disintegrate. I act as liaison, advocate, secretary, nurse, taxi, Physiotherapist, Occupational Therapist, Speech and Language Therapist, teacher for the blind. And I get no status in society for any of it."*

*"Not having to apologise for having a child with a disability would make us stronger."*

*"We are stronger because we spend so much time together and do everything as a family and don't let anything stand in the way of what we want to do. 'Have wheelchair, will travel' is our motto."*

*"We are stronger because we know what is best for our child and her love and laughter carries us through. If she can get on with it, then so can we."*

*"We are stronger because we understand that she is not disabled by her condition but by the attitudes, policies and the surrounding environment."*

# Parent participation work heats up

## How Contact a Family, as part of Together for Disabled Children, is working to encourage parent group development across England

As you read this phase two of the Aiming High for Disabled Children participation work is just beginning in England.

Parents groups around the country have carried out a huge amount of work during phase one. In some areas this has been starting from scratch and in others where there is already a parent forum, parents have been working to develop this further. Work has included running events to let other parents know about the development of a forum and the opportunity to have a voice in shaping how services are delivered in each area. Groups have also used their grants to pay for training in different aspects of participation work. Some groups have set up websites and e-forums to enable

parents to get involved online and input their views by e-mail.

**“The work has got parents and professionals together and started conversations about how we can work together better.”**

Most importantly the work has got parents and professionals together and started conversations about how we can work together better for the benefit of

disabled children and young people now and for future generations.

This is just the beginning. Phase two will enable much more development to take place. And the goal is having parents' expertise taken into account and seeing it influence the commissioning and delivery of services. The response so far has been hugely positive. As one parent who attended a regional participation event remarked: “Very stimulating – change is a reality not a dream!”

To find out how to get involved in your area, contact the Parent Participation Advisor for your area (details on Web: <http://www.togetherfdc.org>) or contact Kate Johnstone, Tel: 020 7608 8783.

## For Scotland's Disabled Children campaign gets going

### Contact a Family hopes that the newly launched FSDC campaign will have a positive impact on families with disabled children

For Scotland's Disabled Children (FSDC) will launch in June 2009 with a call to action to families with disabled children. Launch activities will aim to raise awareness of FSDC and encourage parents, disabled children, young people, voluntary organisations and support groups to join the campaign.

**“FSDC is committed to ensuring families with disabled children enjoy better lives.”**

FSDC's liaison project, funded for three years by the Scottish Government, is also underway. Its Policy Manager, Kate Higgins, started work in February and the

focus is currently on influencing the bill that amends the Education (Additional Support for Learning) Act. The project is also collating views and experiences from parents and disabled children on “life under Additional Support for Learning” to help shape the review of the Code of Practice which guides local authorities when implementing the Additional Support Needs framework.

Ellenor Anwyl, Director of Contact a Family Scotland and leading member of FSDC commented: “The liaison project has really hit the ground running and already we are making our presence felt with a positive contribution to this bill process. We want to strengthen parents' and children's rights under the Act and ensure that the framework truly enables disabled children in Scotland to fulfil their

educational potential.

“The research and engagement work of the liaison project will enable FSDC to campaign for change on policy and services relating to short breaks, transition periods and childcare. The campaign aims ultimately to translate the good intentions of policy makers into better service design and delivery at local level. FSDC is committed to ensuring the estimated 70,000 families with a disabled child in Scotland enjoy better lives. But we can only do that with the support of families which is why our immediate priority is to recruit members to the FSDC campaign.”

Anyone wishing to join FSDC now should contact Kate Higgins, Tel: 0131 659 2938, or e-mail: [kate.higgins@cafamily.org.uk](mailto:kate.higgins@cafamily.org.uk)

# Celebrating our 30<sup>th</sup> anniversary

## Find out how Contact a Family plans on marking its 30<sup>th</sup>

For the last three decades Contact a Family has been strengthening families with disabled children across the UK. We have provided advice and information to families and have put them in touch with others whose child has the same condition for support. We have also campaigned for better rights for families, but the campaign goes on.

The number of disabled children has risen significantly since the 1970s due to medical advances and increased diagnosis and reporting – between 1975 and 2002 the disabled child population rose 62% whilst the general population

increased by just 7%. And while there have been changes in the support services and entitlements for families with disabled children, there is still much to do to ensure families can lead the lives they choose.

So our work continues to be as vital now as it was 30 years ago.

Throughout our anniversary year we will of course be celebrating our achievements, but we will also take the opportunity to raise awareness of some of the many issues for families with disabled children.

### Timetable of events

#### May

To mark the launch of our anniversary we will be publishing a report, *What Makes My Family Stronger* to raise awareness of what life is like in 2009 raising a child with a disability.

#### August

The Big Day Out – we will be encouraging and facilitating families with disabled children to get out and about to enjoy leisure time together. There will be a toolkit available from June which will give families ideas for fun days out, tips for organising their own party or picnic and will include some Contact a Family anniversary party merchandise. We will also be holding our own celebratory events for families in some parts of the UK.

#### November

*Our Family, Our Future* report will be published, highlighting the hopes, aspirations and fears of families with disabled children living in the UK.

For more information about what is planned and when, visit our website, Web: <http://www.cafamily.org.uk/30notout.html>



**30 years of strengthening families with disabled children**

## Making contact

### Would you like to exchange ideas and information with parents who know how you feel? Louise Derbyshire, Family Linking Officer, explains how we can help

In 2004 Contact a Family launched its award winning website MakingContact.org. This site was ahead of its time in terms of linking people over the internet by e-mail, and currently has over 6,000 people registered. People from all across the UK, and beyond, are registered against a wide range of conditions from ADHD to X-Linked Juvenile Retinoschisis.

Parents can visit MakingContact.org to search for people whose children have the same condition(s) as their child, or find people in the same location as them.

If there is a support group covering the UK, there will be a link to the information which appears in our Directory of rare

disorders and medical conditions. If the condition that your child is affected by is not listed, let us know and we will add it. If you don't have internet access, we can still support you in using this service.

As well as contacting parents whose children have the same condition, we recently added six message boards where you can contact others with questions around the same issues, for example, education. Or just share the good and bad bits of your day.

Some conditions have affected adults registered and this can be invaluable in terms of understanding what the future may hold for your child.

There are different levels of membership depending on which part of the service you wish to use:

- Bronze – forums only;
- Silver – forums and conditions; and,
- Gold – forums, conditions and to e-mail other members.

MakingContact.org is easy to use and confidential.

To use this service go to [www.makingcontact.org](http://www.makingcontact.org) and find out why over 6,000 people are using this service to contact other families, share experiences, exchange knowledge and offer mutual support with others.

# Our Marathon heroes

## Congratulations to all our runners, raising money to help support families with disabled children

On Sunday 26<sup>th</sup> April, 14 intrepid runners took to the streets of the capital to raise vital funds for Contact a Family in this year's Flora London Marathon.

Running 26.2 miles is no mean feat; it takes strength of mind, courage and motivation, as well as fitness.

On top of all the training is the daunting task of raising sponsorship from family, friends, colleagues and anyone else they can persuade to dig in. Fundraising can be hard, but help is always at hand from the Contact a Family fundraising team.

In this year's team, we had three women and 11 men who ran to help families with disabled children and to become part of history — joining the three quarters of a million people to have run the London Marathon since it began in 1981. Massive thanks and huge congratulations go to Nick Breakspear, Peter Cooper, Rachel Dench, Brian East, Alejandro Martinez Fuster, Kate Gardner, Fiona Grist, Matthew Grist, Robin Hindle-Fisher, Jon Morcom, Jason Pascoe, Mike Porter, Mike Sawiki and Jonny Wright. Two of our runners even travelled from as far a field as Germany and Spain to take part. All of our runners put in a fantastic effort, and they are now on target to have raised a staggering £80,000 towards supporting families with disabled children.

British soldier Jason Pascoe, and Jonathan Wright, a striker for Workington

Reds, ran the London Marathon in memory of their brother Richard Wright who died in 2007 at the age of 24. Richard had learning difficulties and Microcephaly, a neurological disorder which affects the size of the brain.

The brothers from Whitehaven in Cumbria said: "We ran the London Marathon to raise awareness about the condition Richard had, but also to raise awareness of all disabilities and the hundreds of thousands of families bringing up disabled children in the UK today.

"Richard was an amazing human being. He never complained about the condition he had and overcame so many challenges, he was an inspiration to us all."

Robin Hindle-Fisher, one of Contact a Family's trustees, set himself a huge personal challenge for his 50<sup>th</sup> birthday of running the London Marathon and raising £50,000 for the charity. Robin who was affected by Thalidomide in the late 1950's completed the course in a very respectable time and looks likely to exceed his fundraising target, which is a tremendous achievement.

Some of our other runners included Jon Morcom, who ran for Contact a Family because of his link with a local support group in Plymouth. He ran with his friend, Mike, a local fireman.



Jonathon, left back, and Jason, far right, with their family afterwards

Nick Breakspear finished in a respectable five hours, seven minutes. He is the son of our Orkney volunteer parent representative, Trudy Marwick and has a brother with autism.

Another runner, Peter Cooper, chose Contact a Family as his charity for the marathon because his sister-in-law's brother has a disability and the family benefited from our support.

If our team has inspired you to take up the 2010 London Marathon challenge, contact our fundraising events officer, Sylvia, Tel: 020 7608 8733, e-mail: sylvia.lee@cafamily.org.uk to get all the details on how to register and fundraising tips.

In the meantime, Contact a Family has guaranteed places in The British London 10K Run, which takes place on Sunday 12<sup>th</sup> July and, to mark our 30<sup>th</sup> anniversary year, we are seeking 30

women to take part in the Hydro Active Women's 5k Challenge, which takes place on Sunday 6<sup>th</sup> September in Hyde Park. We also have places in other events taking place around the UK. Visit our website for more details.



Robin celebrates with his family



Jon Morcom and Mike before the race

# Facebook project goes from strength to strength

Find out how you can link up with other families or contact one of our parent advisers over popular social networking site Facebook

Time flies when you're logging on and a whole year has passed since Contact a Family first ventured into online social networking. Our page on Facebook has grown from a small discussion forum to a buzzing 1,200 plus (and counting) parent community.

Many families find that one of the best forms of support comes from talking with other parents. With people in their millions joining the popular website, we have created a place where parents of disabled children are able to meet others online. They can talk with others to receive support and advice from families who, from experience, understand what it's like to raise a child with additional needs.

Contact a Family on Facebook aims to make getting that support just a little bit more open and accessible – whether it's through family linking, knowing what local days out and workshops are happening in your area, staying on top of disability news or getting one-to-one guidance from our trained parent advisers.

New fans often introduce themselves to the group by telling us a bit about who they are, which condition their child has and why they have joined. Sometimes, parents are looking for condition-specific local support groups or are unsure of which benefits they are entitled to. Our helpline parent advisers are at hand to answer these or any other questions – simply write on the wall and we will respond as soon as possible.

A lot of the time, parents just want to talk to other parents and often do so by finding out who would be good to chat to by reading the parent introductions on the wall. One of our fans said: "It's refreshing to find people who understand. The worst thing is that as a parent with Asperger's (and with children with Asperger's) you think you're alone and my children went through some very strange stages that I'd never dream of talking to other parents as people think you're insane, and then I go onto websites like this and see stories about how "my 5 year old did this"... and that's happened to me – it's so refreshing to talk about your children without being ashamed."

We are always looking for more effective ways to reach families and recent changes in the Facebook layout have allowed us to effortlessly keep parents updated on what's new from Contact a Family. Now, when you become a fan, updates will appear in your news feed whenever we post a new event, news items such as benefits changes, parent story videos or podcast interviews. You can also comment on these updates, allowing you to take part in discussions on the topic at hand.

To become a fan, you'll need to sign up to Facebook if you haven't already at <http://www.facebook.com>, then visit <http://www.cafamily.org.uk/facebook> and click 'Become a Fan' on the left hand side of the page. Once you're a fan, you can interact with the Contact a Family Facebook community, for example by introducing yourself on our wall, or looking through previous wall posts, sharing the page with your other Facebook friends, listen to a podcast, take part in the discussion forums or sign up for an event happening in your area.

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## Contact a Family premieres new films

Tune in to watch our three new short films

Contact a Family is premiering its three new short films about families with disabled children. The videos feature families talking about their experiences raising a child with a disability and the best sources of support they have found.

Elaine Bennett, Media and Communications Officer, said: "Parents always tell us that the best form of support is from other parents. Our new films are a great way for families to get support and information from other people in the same situation, direct from

their computer screen. They are now showing on our YouTube video channel, so tune in.

"We would like to thank all the parents, children and families who took part in the filming and creating such a great form of support for others."

The first film – Contact a Family, supporting families with disabled children – focuses on the support services that we provide and facilitate, and features lots of parents who have

benefited from that support. The second is called Meet the Parents and features families talking about the importance of sharing experiences with other parents and gaining support from each other to reduce isolation. And the third – Meet the Fathers – features two dads talking about their experiences and some of the issues they have come across as dads of disabled children.

To view the films, visit Web: <http://www.youtube.com/user/cafamily>

# A problem shared...

Support groups are an invaluable source of help for families. Louise Derbyshire, Family Linking Officer, gives the low-down on what makes them tick and how we can help them

Support groups come in all shapes and sizes. Some are led by professionals, but many are led by parents. Whatever the make-up of the group, they all have a common drive: to improve the lives of families caring for children with disabilities, raise awareness of a particular condition or issue and educate the public and medical world about disability or rare disorders, as well as the needs of families caring for children with disabilities in the UK.

Some groups are formed to support families whose children have the same disorder (these tend to be national support groups) and others welcome children with any disability. A parent told me she was a member of a national specific condition group which met periodically, but also attended a local multi-disability group: "It makes no difference what disability a child has, the feelings and emotions of having a disabled child are the same."

National groups are more usually run by parents, particularly those supporting very rare disorders. Local groups may be run by parents with support from professionals, entirely run by professionals or entirely run by parents. Some parents prefer professional led

groups: "It takes the pressure off when someone else is organising it," and others prefer a parent led group.

Some groups go from £0 to £45,000 in 12 months, with a media campaign and national conference, whilst others may only support three families. They really do come in all shapes and sizes.

**"Contact a Family is committed to supporting groups."**

### Benefits of support groups

After spending time attending groups and speaking to parents, people might attend a support group for a number of reasons:

- they feel welcome (one parent told me when she attended the support group she did not feel alone and nobody was judging her or her child)
- friendship
- to share information about services, support, treatment or procedures
- to find out what is happening locally
- so their children can interact with other children.

In the last issue of Connected, Patricia Robson explained how and why she had set up a local support group for parents in Aldershot. This is a great example of parents supporting parents. The value this provides to local families is immeasurable.

Contact a Family is committed to supporting groups from small beginnings to achieving, whatever level of service they wish to provide. We work with groups providing local or national support to families, whether around a specific disorder or multi-disability.

### How can Contact a Family help?

We have staff who have been working with support groups for many years. They may not have all the answers, but usually know where to go to get them. We also produce a range of Group Action Pack guides, which cover a number of topics of interest to those running local or national support groups. There are some specifically for local groups and others specifically for national groups. These can be downloaded from Contact a Family's website or can be ordered free by calling Tel: 020 7608 8700. We can also hold details of your group on our database so we can pass it onto any parents who contacts us looking for support. For further information, visit the 'Families' section of our website and click on 'supporting groups'.

### Regular support group feature

We would like to make a regular feature of different topics affecting groups and need your help to do this by telling us your stories. Would you like to share your experiences of setting up or running a group? What were the challenges and how have you resolved them? Did you recently run an event? Contact Louise Derbyshire, e-mail: [louise.derbyshire@cafamily.org.uk](mailto:louise.derbyshire@cafamily.org.uk) or Tel: 020 7608 8715 for more information.



# Benefit news

## Helping families with disabled children to access extra money, from our parent adviser and financial expert, Derek Sinclair

### Simpler rules on backdating extra tax credit payments

If your child is awarded Disability Living Allowance (DLA) or has an existing DLA award increased to the highest rate, this can lead to extra child tax credit payments, known as the disability elements. Following lobbying by Contact a Family and others, the rules on backdating of these payments have been simplified.

Prior to April 2009, any parent who wanted to make sure these disability elements were fully backdated had to notify tax credits both when they claimed DLA and when they got a DLA award. Many parents lost out because they were unaware of the need to tell tax credits that a claim was being made. However, since April 2009 the rules have been simplified. Now you only need to notify DLA once – when you get an award. If you are awarded DLA for your child (or have an existing award increased to the high rate for

personal care) let tax credits know within three months of the DLA decision. So long as you do this, any extra tax credit payments will be backdated in line with the DLA award.

### Some benefits are changing from being paid weekly to fortnightly in arrears

Up until now, lots of benefits have been paid at different times and for different periods. This is now changing. Certain benefits will now all be paid two weeks in arrears and these benefits will now also be paid on the same day. This will apply to Income Support, Jobseekers Allowance, Bereavement Benefits, Incapacity Benefit, SDA and Maternity Allowance. Disability Living Allowance, Carers Allowance, Housing Benefit and Council Tax Benefit are *not* affected.

New claims have been subject to the new rules since April but existing claimants will be transferred to fortnightly payments in arrears between April 2009 and March 2011.

If you are affected by the changes, Jobcentre Plus will notify you in advance by letter, explaining the details of your change and when it is going to happen. Where the change creates a gap in benefit payments, people will be able to claim a loan, recoverable over 12 weeks. In exceptional circumstances Job Centre Plus may agree to continue temporarily paying you weekly in arrears instead.

### DLA high rate mobility to be extended to people with severe visual impairment from 2011

In April the government announced that the high rate mobility component of DLA would be extended to people with a severe visual impairment. This change will come into effect in April 2011. Details of how a severe visual impairment is to be defined have not yet been confirmed.

For further advice on these, or on any other benefits issue, contact the Contact a Family helpline, Tel: 0808 808 3555.

### Getting VAT exemptions

#### VAT exemptions on aids and equipment

Did you know that certain aids and equipment for disabled people are zero-rated for VAT purposes? This means that you do not have to pay any VAT when you buy these goods for the personal use of your disabled child.

#### Are all goods and services for disabled people zero-rated?

No. Zero-rating applies to:

- adjustable beds, chair lifts, hoists and sanitary devices
- auditory training aids
- low vision aids
- certain medical and surgical appliances
- emergency alarm call systems
- some vehicles adapted to meet a disabled person's condition
- any other equipment or appliances

designed solely for the use of disabled people. It is not enough to show that a piece of equipment is one that is often used by disabled people – it must be specifically designed for their use.

You also don't have to pay VAT on any charges made for the installation, repair and maintenance of these goods, or for any spare parts or accessories required by them.

Certain building work may also be zero-rated. This includes work on ramps, doorways and passages; bathrooms, shower rooms, washrooms and lavatories and the installation and repair of a lift. However, the services of an architect, surveyor or consultant cannot be zero-rated.

If you need to have any general purpose goods adapted for a disabled child's use, the extra you pay for the

adaptation should be VAT free, although not the actual goods themselves.

#### How do I go about making sure I do not pay VAT?

In order to avoid paying VAT on the above mentioned goods or services, you will need to provide your supplier with a written declaration that you are entitled to buy these goods without paying VAT. A parent can sign a declaration on behalf of a disabled child. While there is no official form for making a declaration, a suggested declaration can be found at section 10 of VAT Notice 701/7 – available at <http://tinyurl.com/9xr17>

Further information on zero-rating of VAT is in our guide, *Aids, Equipment and Adaptations*, available from our helpline. It also provides information about how to get equipment from statutory sources and help with the costs of housing adaptations.

# Improving life for carers

## How new initiative is aimed at helping you to care with confidence

If you're a carer and you're looking for some support, advice, information or perhaps you want to learn how to manage a bit better in your caring role, a new programme is now available. Free for carers aged 18 and over in England, Caring with Confidence aims to help improve your health and wellbeing and that of the person you care for. Carers can mix and match how they further develop their knowledge and skills – by taking part in one or more free, local group sessions, by using self-study workbooks or by accessing online sessions.

The programme is made up of seven sessions covering different aspects of a carer's role. Everyone is encouraged to start with 'Finding Your Way', which gives you some more information about the programme, helps you look at what matters to you and which other sessions you might want to do.

You can then choose to do one or more of the following sessions: caring and coping, caring and me, caring day-to-day, caring and resources, caring and life, and caring and communicating

One family to have benefitted from Caring with Confidence are the Dryden's from Sunderland. Juliana and her husband look after their three year old son Joshua. Joshua was born with rare chromosome deficiency, 22q 11.2 Deletion Syndrome. This affects Joshua's ability to learn new skills which other children would normally develop naturally. Juliana spends time teaching Joshua about his surroundings and also uses a form of sign language to help communicate things to him in a visual way.

Juliana had heard about Caring with Confidence sessions through her local Carers Centre in Sunderland who encouraged her to come along. Juliana

said: "I always thought as parents we didn't really deserve any help because Joshua is our son and we just got on with looking after him. Caring with Confidence has helped me realise that being a carer is a full time job in itself and made me aware of what help and support is available to us. It's completely changed my perception of what we as carers do."

Caring with Confidence is also developing a number of tailored sessions for specific groups of carers. Contact a Family has been working with Caring with Confidence to help develop one specifically for carers of disabled children. This session is due to be available in the summer but any carer regardless of the condition or relationship to the person they care for can get involved now. Tel: 0800 849 2349 or visit Web: <http://www.caringwithconfidence.net> for more information.

## News in brief

### Budget boost for disabled children and their families

In the 2009 Budget, the government announced that it will pay £100 (£200 for severely disabled children) *per year* into a disabled child's trust fund. Entitlement to these payments will be linked to receipt of Disability Living Allowance (DLA) and payments will start in April 2010.

### KIDS Direct Short Breaks service – coming to your area soon

KIDS is a national charity for disabled children and young people. They are currently developing a 'KIDS Direct Short Break' service. It will use internet and text messaging technology to link families with disabled children to short break workers in their local area who are trained and managed by KIDS. The service aims to put families in control of their short break so they can manage them to fit around work and family life, and be personalised to the

interests and aspirations of the child or young person (up to 25). The service is open to all and is already operational in several parts of the country, expanding on a daily basis. For more information Tel: 0845 453 1000, or see Web: <http://www.directshortbreaks.org.uk>

### Lamb Review calls for local authority accountability in SEN provision

The Special Educational Needs (SEN) Information Review, which forms part of the Lamb Inquiry, has been published, calling for a major shift in the way schools and local authorities work with parents of children who have SEN and disabilities. The review calls for better communication and engagement with parents, fewer and more effective requirements on schools in relation to SEN information, an increased focus on outcomes for disabled pupils and pupils with SEN, and tighter quality assurance and accountability from local authorities. Specifically the review recommends that principles of the 'Core Offer' developed through

'Aiming High for Disabled Children' are extended to provide a framework for engagement by schools and children's services with parents of children with SEN.

### Campaign calls for more consistent delivery of short breaks services

A new report published by campaign group Every Disabled Child Matters (EDCM) finds that good practice on short breaks services for disabled children is emerging, but practice development is far from consistent. The interim report of a three-year short breaks tracking project following two short breaks pathfinder and two non-pathfinder authorities shows that while some good models of practice are beginning to emerge from short breaks pathfinder areas, there is still a long way to go before a consistent, sustainable service is established that works for all disabled children, particularly those with the most complex needs.

# School days

Were they the best years of your life? Many of us thankfully can say yes. In this issue, families and teachers tell us what it's like for them



School days are the best days of your life, so they say. But does this still hold true for children with disabilities? It should do, but we know from speaking to parents that school and education can be a massive issue for many families with disabled children. From the process of getting a statement, to getting the right support recorded on it, finding a suitable school, or dealing with exclusion, discrimination or bullying, school days can be fraught with difficulties.

Since the shift towards inclusion of children with special educational needs into mainstream schools, we have seen many special schools closed down. But all children are different, with differing needs, and one type of school may be more suitable than another. Caroline Hunter, one of our volunteer parent representatives, chose a mainstream secondary school for her son Kevin, who has learning difficulties and is autistic. Whereas Rebecca Suart decided a special school would be best for her son Theodore, who has Down's syndrome. Both children have flourished in their own way, and in environments that work well for them.

It is vital that parents are able to find a suitable school for their children. However, we know from calls to our helpline that not all parents are as fortunate as Caroline and Rebecca in finding the right school for their child.

As many parents know, school days are not just about education. For many children, school is fun. It offers the chance

to make friends, learn to socialise and enjoy time talking and playing. Most of us know someone from our school days who has stayed with us, and it's equally important for children with disabilities, who may spend a lot of time with family or care workers, to have these friends to share their lives with.

We know that some children may find it more difficult to make friends and be accepted, sometimes because their condition makes it difficult, for example they have very little speech or understanding of the world around them. And, of course, some children may only ever be able to communicate in a way their close family understand.

## Bullying

For all, sadly, they can be singled out for what makes them different. Research suggests that disabled children are three times more likely than their peers to be bullied. A survey by Mencap found that a shocking 8 out of 10 children with a learning disability have been bullied. This is hugely upsetting for parents and children alike and potentially dangerous. For children like Charlie, they may be forced to leave school if the bullying becomes extreme. Thankfully, eventually Charlie was able to find security in a school specifically tailored to children who have been bullied, where he has made fantastic progress, as his mum explains on page 14.

To achieve their full potential, children may need additional support at school, recorded on a statement of special educational needs in England, Wales and Northern Ireland or a co-ordinated support plan in Scotland. Extra provision might include things like speech and language therapy, one-to-one support or making adaptations so a wheelchair user can use the school.

In practice, this can be a huge uphill struggle for families, and teachers like Shirley Davies, who on page 16 talks about her experiences of being left without any support for the disabled

children in her primary school classroom. This was recently acknowledged by Ed Balls, Secretary of State for Children, Schools and Families, in a recent speech where he said, "Whenever I talk to parents of children with a special educational needs, they often tell me they have to fight the system to get their child's needs acknowledged, to get a statement for their child and to then get their school or local authority to comply with it."

## Expected changes

In April 2009, Ed Balls accepted several recommendations from the Chair of the Special Educational Needs Consortium, Brian Lamb. These included schools improving communication and engagement with parents, and an increased focus on outcomes for pupils with disabilities or special educational needs. For more information, see Web: <http://www.dcsf.gov.uk/lambinquiry/>

Changes are also due to take place in Scotland, with a bill currently going through the Scottish Parliament to amend the 2004 Act that created the Additional Support Needs framework in Scotland. For Scotland's Disabled Children, a coalition of 28 disability organisations hosted by Contact a Family, have tried to use the bill to remedy other deficiencies in the framework, much of which the Scottish government has listened to positively. To get involved with the campaign, contact Kate Higgins, Tel: 0131 659 2938, or e-mail: [kate.higgins@cafamily.org.uk](mailto:kate.higgins@cafamily.org.uk)

Key changes due to be passed in Scotland this summer include the right to request a school outside your education authority area, clarification on the duties of 'home' and 'host' authorities, increased power for tribunals, and a duty (duties are enforceable in law) on local authorities to make provisions to meet needs outside the classroom.

Contact a Family hopes that changes like these will make the improvements needed, so that all disabled children can enjoy and achieve during their school days.

# A very special place

Rebecca Suart explains why she decided on a special school for her son Theodore, who has Down's syndrome

My son Theodore was born nearly seven years ago with Down's syndrome. It was a huge shock of course, devastating, frankly. That whole period was so bittersweet and ironic. Unlike my first daughter, Hope, which was a very traumatic, long labour, my son's delivery was a straightforward, drug-free and natural birth. I was so proud of myself. Then I saw him, and I knew instantly that he had Down's.

The irony here is that my older brother was born with Down's syndrome 44 years ago. I had grown up with Down's syndrome and couldn't believe that I now had a son of my own with the same syndrome.

From the first day our children arrive, there are so many choices parents have to make. From breast-feeding or bottle-feeding, when to wean, nap times, cotton nappies or disposables? The list is endless. There's no rule book and in the end you just have to trust your instincts, hoping that the decisions you make are going to be the right ones for your child. One of the most important decisions for me was where to educate my son. It was important to find a nursery, and later a school, that was going to cater for all his needs.

Theodore has a severe delay in his speech and language and also moderate



Theodore out on a woodland walk

hearing loss. We were offered a Portage Home Visitor, when he was about six months old. Portage is a home-visiting educational service for pre-school children with additional support needs. The child is taught to achieve small goals in their development by breaking them down into very small stages. So, bit by bit, your child might learn to grasp a toy, hold a cup or stay on task for longer.

**"I felt from Year 2 onwards he would have struggled, not only academically but probably more importantly, socially."**

It was a valuable experience for us both. The Portage teacher suggested a special nursery a few miles away that specialised in taking 50% mainstream children and 50% special needs children. The nursery staff visited me at home, filling me with great confidence. They seemed to have a real understanding of my son's needs.

Theodore spent around a year there, loving every minute of it and achieved so much there. During that time I was thinking long and hard about his primary and secondary education. The word 'inclusion' was running through my mind. However, what exactly does inclusion mean? For me, it is a grey area: it's great in principle, but does it really work? I have always had my doubts about the practical implementation and results.

My brother was educated in a special school. That was a long time ago and things have moved on, but I saw how well he did in that environment, alongside the love, care and teaching excellence he was exposed to. So with an open mind, I explored all the avenues open to me. I visited three mainstream



Theodore with his mum and sister

schools and was impressed with them all and their policies. But there was one nagging thought playing over and over again in my head: "He will be the only boy with Down's syndrome here in a class of 30 children — how will this impact on him?" I believed that my son would probably have 'fitted in' fairly well to start with, but I felt from Year 2 onwards he would have struggled, not only academically but probably more importantly, socially. For Theodore 'inclusion' would have become 'exclusion'.

With this major concern, I went to visit our local special school, which we are lucky enough to live within walking distance of. I knew from the moment I got there that this was going to be the educational haven Theodore needed. Here the staff had plenty of experience not only with Down's kids but with children with a host of complex special needs, from severe Autism to Cerebral Palsy. Here my son would be understood and nurtured in an environment specifically designed and tailor-made to his needs. The school is equipped with a multi-sensory room, soft play room and hydro-therapy pool. The class sizes would be small with Theodore one of 10 children.

Now, three years on, Theodore has gone from strength to strength, exceeding expectations with his academic, personal and social development and I have no doubt that the decision to send him to a special school was the right one for him.

Life with Theodore presents daily challenges but the rewards are enough. Who knows what the future holds, what other choices we have yet to make for our children. All we can do is believe in them, and ourselves.

# Finding solace in a Red Balloon

## How bullying forced Rosie Burrell to remove her son from school

In January 2008, I took the decision to remove my son from school. It was a big step to take, but I had no doubt that I was doing the right thing.

I removed Charlie from school in January following his fourth incidence of concussion and the school's failure or reluctance to carry out his statement.

I had been called to school as I was told there had been an incident and Charlie was "a little unwell." The Deputy tried to prepare me for seeing my son. He looked dazed and confused, but what was alarming were the finger marks of another student burnt into his neck. As we left the school, it became clear that Charlie was extremely confused and he seemed to have severe problems with his short term memory. He has always needed a lot of extra care but he started to need round the clock attention. When I took him to hospital they told me that he had concussion and had been unconscious.

This was the fourth time that Charlie had received a head injury at the hands of another child in a few months.

Charlie had been on the receiving end of bullying throughout school, being called names from an early age. He was ill equipped to deal with the bullying, believing that the things said to him must be true. He came to believe that he was totally useless and worthless. He once told me, "I feel like a scrap of paper that someone has scribbled on, torn up, screwed up and thrown in the bin." He constantly told me that he wanted to die.

Charlie has complex needs and a whole string of diagnoses, including severe difficulties with executive functioning, (when tested his scores placed him at a lower level than someone with learning disabilities), developmental coordination disorder, attention deficit disorder, visual dyspraxia and language processing difficulties. In spite of having a statement of special educational needs, many of his secondary school staff seemed unaware of what his difficulties were.

School had always been difficult for Charlie. When he first started he changed from a happy outgoing little boy into an extremely miserable child with crippling low self-esteem. He had been able to read before starting school but seemed to regress in Reception. Throughout primary he had good teachers who encouraged him in the things he could do instead of focussing on what he couldn't do, but also teachers, who I believe, have caused irreparable damage to him. I remember one teacher, who on reading copies of reports from consultants and the occupational therapist, told me that there was, "nothing wrong with him", and "he was just choosing not to work."

**"This was the fourth time that Charlie had received a head injury at the hands of another child in a few months."**

After taking Charlie out of school, we seemed to be forgotten by the education authority. We looked around many schools in the county but none of them seemed appropriate. I approached some special schools but Charlie did not meet their criteria either. It seemed as if he didn't fit in anywhere. A few months later, Charlie was still out of school. I found this time exhausting, Charlie's needs were huge, he needed 24 hour care.

I'm a single parent and work part time. It was impossible trying to care for my son, hold down a job and find a suitable placement for him. I spent hours on the phone or writing letters to try to get someone to take notice and find a school place for Charlie.

At this time I heard about Contact a Family and met Adele, my local Contact a Family representative.

My research also led me to Red Balloon Learner Centre, a school for children who have been so badly bullied that they are

unable to attend mainstream education but, as it is independent, I did not think the county would fund a place for Charlie there.

With Adele's help, I met with members of the education authority and the wheels were put in motion to get Charlie back into education. It became apparent at this meeting that Charlie would be likely to be placed in a small independent school. It was the middle of July, more than six months after I took Charlie out of school, when we learnt that the county had agreed to fund a place at the Red Balloon for Charlie.

After the summer holidays, in September 2008, Charlie started at his new school. It is a unique learning environment, taking only fifteen students in total and teaching them on a one-to-one basis. It provides an 'intensive care' approach to the education of vulnerable young people. The centre endeavours to be as unlike school as possible and it succeeds. The homeliness starts when students enter Herbert House, a large terraced house in central Cambridge, and take off their shoes. The meeting room has the cosiness of a farmhouse kitchen and students settle down at a



Charlie out on a walk



Charlie playing on his bike

big table to organise their day. Around the outside of the room are squishy sofas the children love to curl up on. There is an ethos of mutual respect and each student is made aware of their own importance in the school. Everyone is on first name terms and it's clear that the children feel at home and at ease. It's heartbreaking to know that at their young age, these children have all known unbearable suffering.

Red Balloon has proved to be hugely beneficial for Charlie and it feels like he is

gradually, piece by piece, being put back together again. Whilst it is not a special school, it's child centred approach has proved to be perfect for Charlie. Every lesson is pitched at his level and the teachers have realistic expectations of him.

There is a close relationship with the staff and all play a part in the rehabilitation of students. The school also makes the most of its central position and there are many strong links with the community, giving the children an enormous range of opportunities. Charlie has particularly enjoyed doing film making courses and working on the sound effects in the theatre where the Christmas play was performed. His report took the form of letters from the teacher to Charlie and their comments brought tears to my eyes.

Little by little his confidence is being rebuilt. He has started to make eye contact and now speaks with greater self-assurance. He even talks about what GCSEs he would like to take – previously he thought he was “too stupid” to do exams. At parents evening I was told that Charlie was working at a level appropriate to his age in Maths – again I was fighting back the tears as I had never been told anything like this before.

For me, as a parent, Red Balloon has been a dream come true. It is great knowing that Charlie will be safe at

school, but more than that he has been given the opportunity to flourish and to believe in himself. He has a long way to go but it is great to know that he is making a journey in the right direction.

**“Red Balloon has proved to be hugely beneficial for Charlie and it feels like he is gradually, piece by piece, being put back together again.”**

I know that he is one of the lucky ones. I am sure that there are many parents out there who will feel as I did, that the education system was doing their child more harm than good. My message to them is don't give in and don't settle for anything that is not right for your child. It is very scary to feel like you are one person against 'the system', but the results for Charlie have been worth the effort.

*There are currently four Red Balloons in England and plans are underway for several more. Visit Web: <http://redballoonlearner.co.uk> for more information and details about their admissions criteria.*

### Bullying at school

It can be hard for all parents to approach their child's school about bullying. Parents of disabled children may find it especially hard as there may be other factors influencing their contact with the school. For example, you may have struggled to get your child a place there, the placement may only just be working out or your child may be experiencing difficulties with other aspects of school life. However, schools do have an obligation to promote and safeguard the welfare of all children and responsibilities regarding bullying and disablist bullying.

All schools should have an anti-bullying policy in place. The policy should set out the steps that will be taken by the

school when incidents of bullying are reported or identified by staff, parents and children. You may find it useful to request a copy of the policy.

#### Letting the school know your concerns

If your child is being bullied at school, let the school know straight away. Some schools have communication systems for parents, like home-school diaries or homework diaries. If your child's school has a similar system, you can use this to tell the school about your concerns.

#### Safe to Learn: Anti-bullying guidance

In England, the Department for Children, Schools and Families (DCSF) has launched a package of anti-bullying guidance called 'Safe to

Learn: embedding anti-bullying work in schools'. This includes guidance dealing with the bullying of children with special educational needs and disabilities. The guidance is aimed at schools, but you may find it useful to have a look at it, especially if the school is struggling to resolve the bullying. It contains information about the legal duties for schools and suggestions on ways schools can prevent and respond to bullying. The guidance is available from Teachernet at Web: <http://tinyurl.com/5m3d4f>

Contact a Family produces *A guide to dealing with bullying for parents of disabled children* with tips on how to deal with the school. Contact our helpline, Tel: 0808 808 3555 for a copy or download from our website.

# Desperate for a statement

## Primary school teacher Shirley Davies shares a typical day with her class, including Ollie and Luke, two boys who both have special educational needs

I recently retired, but still work as a supply teacher at the school where I had worked for 20 years before. During my time as a teacher, I also spent two years teaching at a special school. I'm currently supporting a newly qualified teacher two days a week with taking over a class of seven year olds. It was here that I first got to know Ollie and Luke\*.

Both Ollie and Luke have been diagnosed with Autism. Their behaviour had started to become extremely challenging at the end of Year 1. Their parents were consulted because of the school's concerns. They were very keen for them to be statemented, which is still 'in progress'.

It's Year 3 now. We're still waiting for the statement.

Ollie and Luke are lovely boys but, as a teacher, managing their behaviour, and making sure that they make progress with their education, it can be a real challenge. I can normally tell from the moment they walk through the classroom door what kind of day it's going to be. Some days Ollie and Luke may look reasonably calm and in good humour. However, some days they may already be running around the class yelling (Ollie) or standing in a corner scowling at everyone (Luke).

At the start of the school day, I'll wait for everyone to hang coats up, put lunch boxes away and come to sit on the carpet for registration. My classroom assistant will sort out stragglers, and Ollie and Luke. The class would be impossible to teach without this dedicated assistant and parent helpers.

It's always a good idea to have special jobs for Ollie and Luke, to encourage them to join us on the carpet. Both of them need to be forewarned of the day's schedule. Knowing the order is important, and a change in routine can throw them completely.

It's Luke's job to point the arrow to the appropriate time in the daily activity chart. Once he's done this, he'll usually come join us. With Ollie, I have to get his attention any way I can – getting him to help me in some way – find a book, take a message, anything! They always need to feel 'special' but it's not always possible in a busy classroom of 35 seven year olds. I hope the statement comes soon...

While I take the register, Ollie is bobbing up and down in front of me, pulling at the carpet, looking under my chair, making remarks to other children. I give him his squeezey ball hoping he'll calm down in a minute. He's extremely mathematically able and once set a task he settles down. I have to have lots of activities for him as he always finishes his work well before all the other children.

**“What we really need are the statements. They would give us support for Ollie and Luke and help their behaviour.”**

Once the rest of the class are settled in their activities, I try to engage Luke, trying to ignore his protests of, “I don't want to”, “Why should I”, “You can't make me” or “I hate you!” I start talking about his current interest in space aliens and after a bit, with a promise of listening to him talk about aliens again, he starts the task, aided by my assistant.

Meanwhile, Ollie has finished his challenges and is on the computer. I've delayed this as long as possible because he dominates it and becomes transfixed. He may throw a temper tantrum when asked to share or to stop for assembly or play time. If he becomes so furious, the Head Teacher or Deputy Head will have

to be called to take Ollie to calm down. After such an upset I'll make sure that the class has circle time, so the children can talk about how this affected them. Usually they're sad, scared, and fed up. I feel bad for them and for Ollie. I want all the children included, to feel good and to make friends. Without the skilled, one-to-one support Ollie needs, this isn't a realistic option. We wait, and we hope for the support to come.

As a teacher, I need to be constantly on the look out to pre-empt disruptions. Because lunchtimes can be a problem, my classroom assistant has initiated a social awareness lunchtime group including Ollie and Luke. In a small room a table is set, complete with table cloth, napkins and a vase of flowers. This has been very popular and successful with the class.

Every day is a challenge; keeping a sense of humour is essential. Both Ollie and Luke have a good sense of humour and if I can tap into this it will sometimes diffuse a potentially explosive situation. The school liaise with their parents all the time, and I can imagine how difficult things are at home for them.

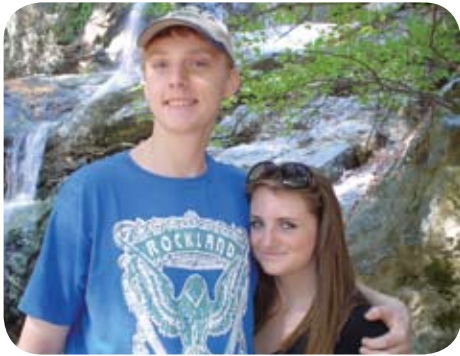
But what we really need are the statements. They would give us support for Ollie and Luke, help their behaviour, quality of life, and allow them to have more positive experiences at school. It can be a frustratingly long and difficult process for parents and teachers alike.

I just wish the powers that be could spend one day in our lovely class, see the children and the potential in them. Maybe then they'd stop haggling over money and dragging their heels. It's heartbreaking to see children like Ollie and Luke let down like this. They need support and they need it now. After all, they only get one chance at their education.

*\*Names have been changed*

# Making mainstream work

Caroline Hunter explains how she was encouraged by the positive experience her son Kevin had at secondary school, as well as the daunting transition to further education



Kevin with his sister Kerry

My son Kevin is 18 years old now. He has Autism, learning difficulties and some challenging behaviour. Together, we live in Surrey with my husband, Alistair, a University lecturer, and our daughter Kerry who is 15.

When he was 12 years old, Kevin started at Thamesmead, one of our local mainstream schools. Kevin had always been in mainstream education but we did look at special schools too. From our point of view, Kevin was making good progress, and most importantly was happy. We felt strongly that the mainstream system would be the best preparation for life later on for Kevin.

Thankfully, he had a statement of special educational needs, so had full cover when he needed it, which for Kevin worked well. He had excellent support assistants, who remain firm friends to this day. They saw Kevin for himself, not for his autism or learning disabilities. They made so much happen by their positive attitude.

At secondary school, Kevin made progress that we had never dreamed possible, and more valuably enjoyed his time there.

He was also completely accepted by his peers, which for many parents like me can be a big worry. Kevin went on to gain four GCSE's, which was a remarkable achievement. He was given a special award at the school leavers assembly for

'Triumph in the face of adversity'. When he went up to collect his trophy, the entire hall were on their feet, clapping and cheering. It was a very emotional moment, and a memory as a family that we will always cherish.

However, Kevin couldn't stay at Thamesmead forever and at his annual review in Year 9 we started to think about the transition process. Fortunately the school had extremely strong links with Brooklands, one of our local further education colleges, which even had a supported learning unit attached to it.

We knew that it was important Kevin felt comfortable in new surroundings, and would be able to cope with the change of routine. We took him to have a look around, and it was suggested that a 'link day' at the college every Friday might be ideal for Kevin. This would start at the beginning of Year 10, and could continue until he left school. This would give Kevin a taster of what it would be like, and a chance to see whether Brooklands might work in the future.

We were really pleased when Kevin decided to start full time at Brooklands in September 2008. He continues to enjoy it, especially sports, and is part of the disability football team. After this year he will still have another two years left there and I'm sure he'll be very sad to leave.

The transition to adult services can be a real struggle, but I feel that the process was made much easier by the 'link day' system.

As a parent, it has been a steep learning curve, particularly in learning to stand back and become less protective. The temptation is to want to know absolutely everything that is going on, but Kevin tells us very little; it just wouldn't occur to him to do so. I've been really pleased to see how much he has grown in independence and he now goes to college by bus every day on his own,

without an escort (though with a fantastic driver who keeps a quiet eye out for him).

As with Thamesmead, I believe that it is working well because of the support from some very special staff, who go way beyond the call of duty to enable Kevin to succeed, and be happy. He has made new friends, learnt new social skills, and his IT skills have come on in leaps and bounds.

**"Kevin had excellent support assistants, who remain firm friends to this day. They saw him for himself, not his autism."**

My advice to other parents in a similar situation is to go with your gut reaction but also to keep your options open. Don't worry about making a nuisance of yourself. Wherever possible, involve your child, and encourage others to do the same.

*Caroline Hunter is one of Contact a Family's Volunteer Parent Representatives*



Kevin with an award for 'Triumph in the face of adversity'



## Helping Children with Complex Needs Bounce Back – Resilient Therapy for Parents and Professionals

Kim Aumann and Angie Hart

Resilient Therapy is a way of working with and strengthening children with complex needs. Kim Aumann is a director of a parent-led voluntary organisation, offering advice and support to parents of children with special educational needs and disabilities, and Angie Hart is a professor in child health who has three children with special needs.

The book is written with great sympathy, warmth and understanding. Because the authors know how it is, their can-do attitude reminds us that no matter how small an achievement is, it can be a springboard to feeling and coping with life's challenges in a different, more positive way. Resilient Therapy pin-points and builds on the little things we can do in our every day life to help build

children's confidence so that they can bounce back.

Written with a healthy dose of humour and honesty about the highs and lows that readers will appreciate, the book has exercises and worksheets, plus ideas and remedies from the authors and other parents who've tried out the techniques. Resilient Therapy offers ways of thinking about your situation and helping your child you may not have thought of before. Although it is written to help children, parents will come away strengthened by the techniques. It may surprise you by affirming how well you are doing already, and suggest new techniques that are helpful to you and your child. Reading it you can't help feeling comforted and surrounded by people who really know what it's like looking after a disabled child.

Karin Beeler  
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Published by Jessica Kingsley Publishers  
ISBN 978 1 84310 948 8  
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**Volunteer Parent Representatives**

Contact a Family has a UK-wide team of Volunteer Parent Representatives who are parents of disabled children providing local information.

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**Family Workers**

Contact a Family has a team of experienced Family Workers, covering different parts of the UK. Our staff help families to access services as well as offering support at times of particular need.

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**South West region & Cornwall**

Contact a Family manages the local Parent Carers Council for Cornwall (PCCC).

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Contact a Family and the PCCC manage the Parent Partnership Service for Cornwall - offering parents information, advice and support with the special educational needs process.

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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.



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