

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

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

Winter 2009/10

# connected



## Home sweet home

Keeping a smile on his face –  
one mother's fight for housing adaptations

### Housing matters

Grants, adaptations  
and living alone

### Trolley campaign

Fighting for special  
shopping trolleys

### Our family, our future

Exploring the lives  
of 30 families

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Next issue: The Spring edition of *Connected* will be published in February. 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 The deadline is 25 January 2010.

# Getting into festive mood

## Srabani Sen, Contact a Family's Chief Executive, gives an update on events

We may be in the run up to the festive season, but things are not slowing down at Contact a Family.

We know the holiday season can be both a joyful and stressful time, with families seeing support dwindle and an extra strain on finances all round. With this in mind we hope to make life a little easier for you with our new 'Cash counts' online service, developed to help you make the most of your finances and claim everything you're entitled to. Find out more on page 6.

As part of our 30th anniversary, we have been holding a series of events at the parliaments of the four nations. At the time of writing we've held three of them, and at each one, the key government minister attended: Ed Balls at Westminster, Adam Ingram in Scotland, Jane Hutt in Wales. Opposition politicians came too, which is really good news as it suggests there is cross-party support for issues affecting families with disabled children.

We used these parliamentary events to launch our new report and exhibition, *Our family, our future*.

Thirty families with disabled children have shared their hopes, dreams and frustrations, and we have an exhibition of wonderful photos. See pages 4 and 5 to find out more. We are very grateful to all the families who shared their honest and inspirational stories.

Things are hotting up on the political front. In Wales, we gave evidence to the Welsh Assembly inquiry into wheelchairs. In England we have been lobbying to encourage primary care trusts to disclose how they have spent the £340 million, given to the health sector to invest in services for disabled children and their families. In Northern Ireland, we have been responding to a number of consultation documents, and in Scotland, the alliance For Scotland's Disabled Children is going great guns.



*Speaking at the House of Lords launch of Our family, our future.*

As we enter the last six months before a general election, this political activity is crucial to keep the profile of disabled children and their families on the political agenda.

**"We know the holiday can be both a joyful and stressful time..."**

Finally, what would Christmas be without Santa? In the summer a number of women ran a 5K race at Hyde Park to raise money for Contact a Family (hence the embarrassing photo of me on this page looking rather hot and disheveled); well, on 6 December it was the turn of the men. A team of men ran 5K to raise much needed funds to support our work. And, at this close to Christmas you would expect a seasonal theme. You've guessed it. All those taking part were dressed as Santa!

I hope you have a happy and peaceful festive season and wish you all the best from everyone at Contact a Family.

*Srabani Sen*



*In the 5K Hyde Park run.*

# Our family, our future

## The lives of 30 of our families across the UK



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

Contact a Family's latest report highlights that many families with disabled children are missing out on family life due to the bureaucracy and prejudice they face.

*Our family, our future* features the stories of 30 UK families whose children are affected by a range of disabilities and rare conditions. They celebrate family life, acknowledge the challenges and talk about their hopes, dreams and fears for the future.

The stories are written in the parents' own words and are a unique insight into their lives.

All of the families show strength, determination and creativity in overcoming the challenges and pressures they face, and there is a real sense of overwhelming love and pride for their children:

***"Our greatest achievement was being able to bring our little girl home from hospital."*** Natalie Pearson

But there are those at breaking point because of the constant battle to get support and help for their children and themselves, which is preventing them from enjoying family life:

***"Alex has a progressive, degenerative condition and yet, every year the council tries to reduce his care."*** Sara Hunt



Many are worried about the future and what will happen when they are no longer able to care for their child. There is great uncertainty about the support available to those who reach adulthood and this is adding to the pressures that families are under:

***"It is absolutely terrifying thinking about the future. As long as we are here it is fine, but who will look after her when we're gone?"*** Julie Ryan

Others have to live with the heartbreaking knowledge that their children have life threatening conditions:

***"We can't worry about next year, we just have to think about the here and now."*** Clare Lally

And most worry about how society accepts people with disabilities and wish for increased understanding and tolerance:

***"I hope those people whose lives Max touches will become more tolerant and understanding."*** Nicola Reid

*Our family, our future* was published as part of Contact a Family's 30th anniversary celebrations and is accompanied by an exhibition of family photographs. Both were launched across the UK at the House of Lords in Westminster, at Holyrood in Scotland, and the Welsh Assembly in November, with the launch at Stormont in Northern Ireland taking place in December.

The House of Lords event took place on 4 November, and was hosted by Baroness Jill Pitkeathley and attended by Secretary of State for Children, Schools and Families Ed Balls MP.

Ed Balls MP said: "Contact a Family has a fantastic history of supporting families with disabled children and providing them with good quality information at the right time. It is an honour to be here today to mark the launch of *Our family, our future* and I look forward to celebrating Contact a Family's 40th anniversary."

Families who feature in the report were among the many guests to attend this and the other events around the UK. They took the opportunity to meet Ministers, MPs, MSPs, Assembly Members and Members of the Legislative Assembly.

Elaine Bennett, Contact a Family Media and Communications Officer, said: "We wanted to raise awareness of the issues facing families with disabled children, reduce the stigma they face and celebrate their family life and the huge contribution they make to society."



***Pointing out vital sections of the report to Ed Balls MP***

Check out our website for a copy of the report and details of the exhibition which is touring the UK – [www.cafamily.org.uk](http://www.cafamily.org.uk)

## Two of the 30 stories featured in *Our family, our future...*

### The Gurney family's story from Aghadowey, Coleraine, Northern Ireland

It feels like someone pressed the button on a rollercoaster and forgot to stop it.

It frustrates me that professionals always put any problems down to the chromosome disorder, which is so rare there is little information about the prognosis. Rebecca is affected by Hypotonia, Hypermobility, visual impairment, sensory dysfunction and global delay. I am Rebecca's advocate and have to fight for her to receive the best medical treatment.

Last year she screamed seven days a week, had black eyes and head injuries from banging her head and pulling out her hair. Some specialists who assessed her were arrogant and insulting, dismissing our concerns. Eventually a therapist suggested her behaviour was because she was 'sensory seeking'. With appropriate support and equipment, Rebecca's behaviour has improved. We have to



be respectful to all professionals even when they do not treat us the same way.

Recently a neurologist from England was visiting Northern Ireland and assessed her while she was in hospital. She thinks Rebecca may have an underlying neurological condition, not part of her chromosome disorder, and has ordered tests.

Many people lack compassion and over the years some people's attitudes have made my life hell. I was once reduced to tears at a baby and toddler group. People are not tolerant of conditions they cannot see.

Rebecca's life is appointments and hospitals. This affects the whole family. Hannah and Ellie miss out on things, and when my husband and I took Rebecca to the UK for assessments we had to leave them behind.

With the possibility of an additional diagnosis it is difficult to think of the future. Additional problems may shorten her life expectancy. We get a lot of strength from our faith.

The greatest achievement for our family is that we are such a close unit and the children are genuinely happy and loved. All I ever wanted when I was growing up was to be a mum.

### The Brumell family's story from Burnage, Manchester

I could see immediately after Ross was born that something was wrong. He was rushed away and I thought he was going to die. After an agonising wait I saw him on the neo-natal ward, but was scared to touch him in case I hurt him.

Bladder Exstrophy is a rare condition, which causes the bladder to form externally and abnormalities in the pelvic bone and genitalia. Ross needed corrective surgery at seven weeks, and I was led to believe that everything would be normal when he came home. However, a series of health complications followed and Ross spent his first six years in and out of hospital. I never left his side.

One of the hardest things is the constant battle for support. Families whose children have rare conditions just don't fit into government criteria.

When we applied for a grant for an extra bedroom and bathroom for Ross, we were refused because no one understood the condition and its psychological impact around body image. I got legal aid to fight the council using the Convention on the Rights of the Disabled Child. We won, but it was so draining.

I also had a huge battle trying to get Ross into a suitable school. Ross must catheterise at the right time or it can be a life and death situation. The school 10 minutes from where we live has staff experienced in catheterisation, so it's perfect for him. However, the local authority refused him a place because it's outside our catchment area. I fought this, going through the appeals procedure, but lost.

Now Ross attends a school with 2,000 pupils where he struggles with privacy issues and sees a psychologist. Most people don't know about his condition, he knows he's carrying this big secret, which is hard for him emotionally.

As a result of these battles, I had a nervous breakdown last year. A huge scare for everyone and I've had to learn to take care of myself.



# Summer fun and 5K run!

## More 30th anniversary celebrations

As part of our 30th birthday celebrations, we've been encouraging more families with disabled children to get out and about to enjoy leisure time together.

In July, Contact a Family Northern Ireland held a Family Fun Day at Horizon House with puppet shows, magic tricks and a Mad Scientist! Funded by Energy for Children and hosted at the NI Children's Hospice, the day was great fun.

While in Scotland we teamed up with leading visitor attractions to offer families complimentary or discounted passes across the region.

Meanwhile, our 'Big Day Out' to Hyde Park in August was also a huge success. There was music from our resident DJ, a puppet show, circus skills training, face painting, balloon animals, bubbles, jugglers and juggling. To top it off, we finished the day with Bollywood dancing!



### 5K women's run

We also had an amazing turn out for our 5K run, which also took place in Hyde Park in the summer.

We wanted 30 runners to mark our 30th anniversary and, although we didn't quite reach the required number, those that ran, walked or trotted their way to the finishing line did us proud! It was another sunshine day with so many people either taking part or cheering on which created a fantastic atmosphere. I'd thoroughly recommend it!

*Contact a Family runners in the 5K Hyde Park run*



If you are interested in taking part in any fundraising for us, then please contact our fundraising team, e-mail: [fr@cafamily.org.uk](mailto:fr@cafamily.org.uk) Tel: 020 7608 8733 or visit our website for more information.



### Contact a Family Facebook fans top 2,000...

Contact a Family's Facebook fanpage now has over 2,100 fans. Users chat, share advice and information and comment on topical issues and other users' wall postings. To become a fan, visit: [www.facebook.com/contactafamily](http://www.facebook.com/contactafamily)

# Helping make your Cash Count

## Contact a Family's new online financial help with benefits calculator

Contact a Family was given part of the extra £3 million announced by Ed Balls, the Secretary of State for Children, Schools and Families, to provide enhanced services to families being affected by the recession. The money is to be used to provide online support around money issues for families with disabled children.

We have now launched our Cash Counts package of online tools to help families.

These include an online benefits calculator – providing parents with a starting guide to the entitlements they could potentially claim – a top tips guide written by our very own helpline to get parents through the recession,

videos featuring parents' experiences and strategies for how they manage their finances, and a frequently asked questions page. There is also a step-by-step online self-assessment tool.

Check it out for yourself at [www.cafamily.org.uk/cashcounts](http://www.cafamily.org.uk/cashcounts)

# Calling all parents... we need you

## Jo Palmer, our National Volunteer Representatives Manager, looks at how vital parent involvement is to Contact a Family

Our Volunteer Parent Representatives (known as reps) are all parents or carers of disabled children themselves, and provide support to other parents. Parents' involvement is so important that we spent much of the time at our recent residential weekend for volunteers discussing the issues and sharing achievements.

We were very honoured to be invited to a civic reception at the City Chambers by Edinburgh City council in honour of our 30th anniversary, and took some time out from all the hard work to sight-see and shop in the city!

It has been an extremely busy year for parent involvement and participation. With the support of Aiming High for

Disabled Children in England, and with similar work going on in the nations, parent participation is high up on the agenda.

And who better to ask how things are going than our volunteers, many of whom are actively involved in their local parent forums. As a parent-driven organisation, our parent volunteers are very important to us, and we will be using what we have learnt from the weekend to improve our own ways of working and letting local authorities know what parents want.

Local authorities from all over the UK are suddenly discovering that working in partnership with parents is not just good practice, but essential to making the

biggest difference to the lives of disabled children. But one size does not fit all and things are developing in different ways, depending on many factors, such as the size of each local authority, its cultural diversity and its mix across urban and rural communities.

We are currently looking for new parents to join the volunteer team to cover Cumbria, Teesside and Luton and there are likely to be more opportunities in 2010. Keep an eye on our website and Facebook page for updates in your area.

If anyone would like an informal chat about being a parent volunteer with Contact a Family, then you can email me at [jo.palmer@cafamily.org.uk](mailto:jo.palmer@cafamily.org.uk) or call me on 07599 167 561.

*Our Volunteer Parent Representatives are all parents or carers of disabled children themselves.*



## Contact a Family news in brief

### The future of care in England

The 'big debate', the government's consultation on the future of care and support in England, finished in November 2009. Contact a Family welcomed the commitments made in this green paper to the much needed radical reforms to the currently unfair system and a new national care service. But we expressed concerns about the options proposed to fund these reforms. We also think the green paper is a missed opportunity to reinforce better joined up working at transition between children's and adult services. Much more is needed

to reassure parents that their own health and financial wellbeing will not continue to be put at risk due to their caring responsibilities.

### New regional children's centre advisers

Debbie Ravensdale and Karen Robinson have recently joined the children's centre team at Contact a Family. They are offering children's centres and family information services a range of support to help them include families with disabled children. So please get in touch!

Debbie covers Hampshire, Dorset, Wiltshire, Sussex, Bournemouth, Southampton, Portsmouth and the Isle of Wight, Tel: 0148 989 5501 e-mail: [debbie.ravensdale@cafamily.org.uk](mailto:debbie.ravensdale@cafamily.org.uk)

Karen covers the North West of England  
Tel: 01706 220578 e-mail: [karen.robinson@cafamily.org.uk](mailto:karen.robinson@cafamily.org.uk)

Una Summerson continues to support children's centres in other areas. Tel: 020 760 8742 email: [una.summerson@cafamily.org.uk](mailto:una.summerson@cafamily.org.uk)

# More generous Housing Benefit and Council Tax Benefit rules

Our Parent Adviser and financial expert, Derek Sinclair, explains the new benefit rules

On 2 November 2009, new Housing Benefit and Council Tax Benefit rules were introduced which should allow more families than ever before to qualify for help with their rent and council tax.

## What are the new rules?

Housing Benefit and Council Tax Benefit provide help to low and moderate income families with their rent and council tax charges (or rates charges in Northern Ireland). Both benefits are means tested. This means that the amount of income and capital that you have affects how much help you get. But from 2 November 2009, Child Benefit payments have been ignored as income.

This follows a similar change made last year when Child Maintenance payments also became fully ignored as income for Housing Benefit and Council Tax Benefit.

## Who might gain from the new rules?

Families who don't get maximum Housing Benefit or Council Tax Benefit, but who do get some help, should have seen the amount of benefit they get increase from the beginning of November. If this has not happened yet, contact our helpline for further advice.

If you have applied for Housing Benefit or Council Tax Benefit in the past but been told your income was too high, contact our free helpline for further advice. We can check to see whether the new income rules will help you to qualify for Housing Benefit or Council Tax benefit for the first time.

## Income Support and lone parents – new rules

Prior to November 2008, a lone parent was entitled to claim Income Support so long as they had a child aged under 16. In November 2008, new rules tied entitlement to having at least one child aged under 12.



However, from 26 October 2009, this age limit has been further reduced to having a child aged under 10. Many lone parents whose youngest child is aged 10 or above will now be expected to sign on and claim income-based Job Seeker's Allowance instead of Income Support.

However, these rules will not apply to any lone parent who is able to claim Income Support on some alternative grounds. For example, a lone parent who is able to claim Income Support as a carer will not be affected by these rules, regardless of their youngest child's age. In order to claim Income Support as a carer, you do not necessarily need to be getting Carer's Allowance – it is sufficient that you are providing regular and substantial care to someone getting Disability Living Allowance (DLA) care component at the middle or highest rate (or Attendance Allowance at any rate). Sometimes it is also possible to claim Income Support as a carer while you are waiting for a decision on a DLA claim. The new rules also won't apply to certain other lone parents such as those who have health problems which mean they are incapable of work. If you are a lone parent who has been told your Income Support will stop – get further advice from our helpline.

## Direct payments in England – new rules

On 9 November 2009, the government introduced new rules allowing direct payments to be made to the family members of adults who lack mental capacity. Prior to this change, direct payments for a child who lacked mental capacity had to stop when the young person reached the age of 18. Under the new rules, direct payments can now be made to a family member or any other willing and appropriate 'suitable person' to receive and manage the payments on behalf of the adult lacking capacity. The government have updated their guidance on direct payments to reflect this change – this is available along with a user guide at: [www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/DH\\_076522](http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/Directpayments/DH_076522) Paper copies are available from the Department of Health order line on 0300 123 1002 (ref 296235 for guidance and ref 296787 for user guide).

# Lending a helping hand...

## Family Linking Officer, Louise Derbyshire, looks at using volunteers

I volunteered for Contact a Family while studying. This involved attending events supporting families, working with a specific child at workshops, or generally lending a spare pair of hands at the Christmas party or local events. I met some inspirational people and had a sense of making a real difference to the day of that parent, child and family.

Volunteers add a new dimension to the support that groups can offer families and, although unpaid, most are dedicated and enthusiastic.

If you are considering asking for volunteers, it is useful to have a discussion with your committee or the other parents in the group. That way, you are clear about what you want to achieve and the support that can be offered.

A volunteer may need to be shown how to put a newsletter together or how best to use a computer package. If they are going to be answering the phone, it may help to give them guidance. When using volunteers for an event you should brief them on health and safety, and on what level of support you expect them to give families. For example, you may not expect volunteers to take sole responsibility for a child or perform any personal care (such as changing nappies). You should also make families aware of what they can expect from the volunteer.

Whatever you use a volunteer for, it's good practice to discuss confidentiality and child protection issues with them. The national voluntary support organisations listed below have lots of useful information on their websites.

### **Criminal Records Bureau (CRB) checks**

A CRB check is needed for anyone volunteering to regularly support children and vulnerable adults. A new Vetting and Barring Scheme was introduced in October 2009. Contact the CRB or the Independent Safeguarding Authority for further information.

Depending on what activities a volunteer is involved in, and how frequently they will be working with your organisation, you may not need to do a CRB check.

There is a charge to conduct your own CRB checks, but an umbrella body can make checks on your behalf. Checks for volunteers are free, although you may be charged an administration fee.

### **Case study: Prader-Willi Syndrome Association**

This is the only organisation in the UK dedicated to supporting people with Prader-Willi syndrome (PWS), their families, carers and professionals who work with them. Prader-Willi syndrome is a complex genetic disorder present from birth.

In 2006, the Association was awarded a grant to set up and develop a network of volunteer parents to provide listening ear support across the UK. Prospective volunteers had a one-to-one conversation with members of the Association's team, and each volunteer was allocated a member who could support them. Parents in the network take calls on specific issues that they have experience of, and are provided with dedicated mobile phones for this purpose.

The Association considered that CRB checks were not necessary in this situation as they were offering a listening ear by telephone to adults.



### **National voluntary support organisations:**

**Volunteering England** (see their section 'The Good Practice Bank')  
Freephone information line:  
0800 028 3304 (Mon-Fri 10.30am-12.30pm and 2pm-4pm)  
[www.volunteering.org.uk](http://www.volunteering.org.uk)

**Criminal Records Bureau**  
[www.criminalrecordsbureau.co.uk](http://www.criminalrecordsbureau.co.uk)

**Volunteer Development Scotland**  
Tel: 01786 479593  
[www.vds.org.uk](http://www.vds.org.uk)

**Central Registered Body Scotland**  
Tel: 01786 849 777  
[www.crbs.org.uk](http://www.crbs.org.uk)

**Welsh Council for Voluntary Action**  
Tel: 0800 288 8329  
[www.wcva.org.uk/volunteering/index.cfm?sub=3&display\\_sitetextid=103](http://www.wcva.org.uk/volunteering/index.cfm?sub=3&display_sitetextid=103)

**Criminal Records Unit**  
Tel: 0800 019 7391  
[www.wcva-cru.org.uk](http://www.wcva-cru.org.uk)

**Volunteer Development Agency – NI**  
Tel: 028 9023 6100  
[www.volunteering-ni.org](http://www.volunteering-ni.org)

**Access NI**  
Tel: 028 9025 9100  
[www.accessni.gov.uk](http://www.accessni.gov.uk)

**Independent Safeguarding Authority**  
Tel: 0300 123 1111  
[www.isa.gov.org](http://www.isa.gov.org)

# Aiming High for Disabled Children

## Parents and young people participation

Involving parents and young people in shaping services is a key component of Aiming High for Disabled Children. This is a government programme to transform services for families of disabled children in England. One strand of the programme is to improve and increase the number of short breaks available. Below are a couple of examples of how parents, children and young people have been involved, helping to bring about real improvements in families' lives.

### Stoke on Trent: Summer holiday provision

The commissioner responsible for developing short breaks met a group of parents to ask them what type of short breaks they wanted. The parents said holiday times were difficult with their children stuck at home with nothing to do. The parents described the types of activities their children enjoyed and said

they thought special schools were the best place to hold them, as the buildings had the necessary facilities and the children already knew the staff.

Using this information, a range of different activities were organised over the summer holiday at six special schools, which were well attended. Feedback from parents and young people suggests they were very successful. The parents are now consulting with the children and young people who attended to find out which activities were most enjoyed. This information will be used in the planning of future holiday provision.

### Oldham: Fun activities for families with disabled children

A family fun day was organised for the summer half-term to give families with disabled children an opportunity



to try out different sports activities. Children and their parents were able to try out trampolining, a climbing wall, a sensory room, parachute games and accessible bicycles.

The parents and children rated the bikes as the most fun and so some research was done to look into setting up a facility in a local park.

A day was arranged where bicycle providers Wheels for All and Activate came to Oldham with a range of different bicycles. Six schools were asked to send twelve children each at different intervals during the day to try out the bicycles. Transport was arranged to escort the children and staff from school and back. All the children were asked which bicycle they preferred, information that will be used to determine which models to purchase.

The ultimate aim is to have a facility where families can enjoy cycling together, and use bikes suitable for all ages and abilities.

If you have a story about how Aiming High is transforming services, or would like to get involved in parent participation, contact Kate Johnstone at Contact a Family on 020 7608 8783.



*Children try out a range of bikes provided by Wheels for All in Oldham.*

# Contact a Family supports adapted trolley campaign – join our drive!

A mum from Devon has successfully persuaded her local Sainsbury's to purchase a specially adapted trolley seat for disabled toddlers.

She is now calling for every supermarket to stock the adapted trolley and Contact a Family is supporting the campaign.

Julie Evett said: "The experience of going shopping for my daughter Rose is really stimulating. She loves the sounds and smells and the experience helps her development. I think disabled children should be out and about with their parents enjoying life to the maximum, not hidden away and isolated. This trolley has given us a new lease of life and I'd like to see all the major supermarket chains stock at least one."

Julie was determined to take Rose, aged three, shopping and not isolate her from the rest of society. Rose has an undiagnosed brain disorder and can't sit up unaided or support her head. The typical supermarket trolley seats didn't give her enough support and would have been dangerous to use. Julie struggled to push Rose in her wheelchair as well as push a trolley, so often had to leave Rose at home.

Julie approached Sainsbury's in Barnstaple, North Devon, about the difficulties she was experiencing and Customer Services Manager, Katie Southworth, agreed to order a specially adapted trolley.



*Rose in her specially adapted supermarket trolley seat.*



*Rose's mum, Julie Evett and Katie Southworth from Sainsbury's.*

Photos courtesy North Devon Gazette

Julie has set up a Facebook petition group – ***Every supermarket needs this new disabled trolley*** – to support her campaign. Contact a Family is urging families to sign up to the group to help them get out and about doing everyday activities that other families enjoy.

Srabani Sen, Chief Executive of Contact a Family, said: "Families with disabled children are often unfairly isolated."

We campaign to reduce this isolation and help families lead ordinary lives. This adapted trolley is a simple, practical solution to help families with disabled children take part in an everyday activity and we fully support Julie's campaign."

Sign up to ***Every supermarket needs this new disabled trolley***  
[www.facebook.com/group.php?gid=180123000906&ref=ts](http://www.facebook.com/group.php?gid=180123000906&ref=ts)

## Carers Poverty Charter sends clear message to No. 10

Carers UK's Carers Poverty Charter, launched in May on BBC Breakfast, and now signed by 20 major national organisations, including Contact a Family, and over 3,000 members of the public, has been delivered to 10 Downing Street by a delegation of carers.

The Charter calls on the government to set out a timetable of action to improve carers' benefits.



Neil Hunt, Chief Executive of the Alzheimer's Society, said: "Carers save the UK billions of pounds every year..."

If the Government is to stop carer poverty by 2018, as it has pledged, action needs to be taken now."

Mike Hobday, Head of Policy at Macmillan Cancer Support, who supported the Charter said: "It's vital that the rate of Carer's Allowance is increased to stop carers falling into poverty, and that carers are better supported so they can stay in work."

# Housing matters

## Introducing our theme, focusing on housing issues

Home is where the heart is, the saying goes. But for many families with disabled children, it is an uphill struggle to get not only the right housing, but the right adaptations and equipment their child needs. In this edition of *Connected* parents

talk about their experiences of getting help to adapt their home, and highlight why it is so important. We also hear from one mum who's helped her son move on to live independently.

*Julie Marriott  
with Toby*



## What can a DFG do for you?

### Jesslyn Parkes, our Helpline Manager, speaks about the Disabled Facilities Grant (DFG)

We receive lots of calls to our helpline from parents hoping to have their home adapted to their child's needs.

Adaptations can be anything from widening doors and installing ramps or a stair lift to improve access around the home, to building a downstairs bedroom or bathroom, or adapting lighting and heating. In England and Wales, making or improving access to gardens are also classed as adaptations.

The Disabled Facilities Grant (DFG) is the local council grant intended to cover the cost of adaptations, and is not means tested for disabled children. In England, it can be up to £30,000, in Wales, £36,000 and Northern Ireland, £25,000. To qualify for the grant, there has to be an agreement that the adaptations are necessary and appropriate and that the works are reasonable and practicable.

In Scotland, the scheme is called Home Improvement Grants, and new rules have been introduced (see page 18).

Contacting social services or the occupational therapist (OT) with a request for a DFG assessment is not the same as making a formal application. To minimise delays, fill in and submit

the formal grant application form, available from your local authority, before the assessment is carried out. A local authority then has a duty to make a decision within six months of receiving your application.

Julie Marriott, whose son Toby has Cerebral Palsy and is visually impaired, says that the extension, which includes a downstairs bedroom and wet room for Toby, has made an enormous difference to the wellbeing of the whole family.

"Toby couldn't walk until he was seven and now, at the age of almost 11, he still can't navigate stairs. He has no depth perception so it is very dangerous for him. We had to carry Toby in a fireman's lift up and down stairs to use the bathroom and go to bed. This was a strain on us and was undignified for Toby," said Julie.

"We heard about the DFG from Contact a Family's newsletter and contacted the council. They referred us to social services who arranged for an occupational therapist to do an assessment. We then had to fill out an application form we'd received from the council. I would say to any parent that you must sit down and think about

all the reasons why you need the adaptation – the dangers, safety issues – and be prepared to argue your case.

"We were assessed as needing a downstairs bedroom and bathroom, and were granted £25,000 which was the maximum at that time. The extension cost was £32,500 so we had to find the extra. We were very lucky in that we were given £5,000 from Purple Dreams Charitable Foundation."

Unfortunately, the Marriotts were unlucky with a huge delay to building work due to problems with planning permission. This meant the process took four years from start to finish.

"It was a very stressful and tense time, but it was well worth the long hard struggle," said Julie. "Toby can now go to his bedroom when he wants and be supervised rather than depending on someone. The room is entirely adapted to his needs, including light switches at a convenient height, which is a great boost to his independence."

Contact the helpline on 0808 808 3555 for advice on applying for a grant or challenging a decision.

# The waiting game!

## One mum tells her story about getting housing adaptations in Northern Ireland

I live in Ballymena, Northern Ireland. I'm a single mum with two children with disabilities. My six year old girl has a chromosome disorder and mild learning disability and my nine year old boy has autism and moderate learning disability.

Our three storey house was built in the early 1900s, on a very busy main road with no driveway. We haven't been allocated a disabled parking bay as neither of the children qualify for a Blue Badge, so I often have to park some distance from our home.

Because we've no driveway and parking space, I have to get the two children out of the car at the side of a dangerous road, plus shopping or anything else. Neither of my children have an awareness of danger and this is a major worry for me every day. My eldest reacts adversely to loud noises and screams with distress or impulsively darts or bolts directly into traffic.

Among my other worries are a safe and accessible play area so I don't have to be constantly supervising the children and watching for dangers, and a downstairs toilet due to their extra toileting needs.

I found out about the Disabled Facilities Grants scheme and, in May 2008, contacted the local Occupational Therapist (OT) for an assessment for housing adaptations. In Northern Ireland, the Housing Executive will only consider housing adaptation applications that are recommended by an OT, which can take months to arrange.

The OT assessment approved the need for a downstairs toilet and shower and a safe play area. But despite plenty of room for a driveway, this need was not taken onboard or deemed essential.

I got in touch with Karen, Contact a Family's Family Support Officer, and raised my concerns with the OT. Even though the work was well within the grant amount, the OT refused to review her decision.

We called a meeting at my house with the Housing Officer for the Housing Executive, the OT, me and Karen to discuss the plans. Again we raised the issue of the unsafe car parking and lack of driveway and this time the Housing Officer agreed to include it in the adaptations.

**"My eldest reacts adversely to loud noises and screams with distress or impulsively darts or bolts directly into traffic."**

I had plans drawn up by an architect, costing £1,300, which I had to pay up front myself. The cost can be fully reimbursed when the work is completed, providing the architect has indemnity insurance. But many families with disabled children are struggling anyway and can't cover this fee, and there are no grants to help with this hefty outlay.

Nearly 18 months later, there are still ongoing minor details to be ironed out,

I feel I've compromised on some issues, but the schedule of works has been granted by the OT and the architect. I'm now in the process of selecting a builder from the approved Housing Executive list, and planning permission is in progress for the Department of Environment to lower the footpath for access to the new driveway. We then need formal approval from the Housing Executive, which can take up to six months. When this stage is reached, the work schedule should be completed within 12 months.

In the lives of my two disabled children, this is an unbelievable amount of time! By the time the work is complete, the children's needs may be greater. It's a long time to wait for work that can be done privately within several months.

If you're unhappy with the outcome of an application for a grant, or the length of time it's taking, call the Contact a Family helpline on **0808 808 3555**.

Or download our guide 'Aids, equipment and adaptations' for details of how to challenge decisions or make a complaint, available free from [www.cafamily.org.uk/AidsUpdate.pdf](http://www.cafamily.org.uk/AidsUpdate.pdf)



Photo courtesy iStockphoto.com

# Made up with a garden makeover

Alice Cameron, our Senior Family Worker at Contact a Family Southwark, explains how many helping hands make light work

Our office in Southwark offers information, advice and support to parents and carers of children with any aspect of caring for their disabled child, as well as professionals working with families. We help families find information on their child's condition, getting extra help at school, benefit entitlements and can tell them about other organisations who can help.

We received a leaflet from WellChild at the end of last year introducing the organisation and outlining what they do. As well as children's nurses who work with families across the UK, their Helping Hands scheme enlists the support of volunteers from companies and organisations up and down the country to tackle projects in the homes of ill or disabled children. They help in truly practical ways, for example, completing a garden makeover or bedroom refurbishment.

At about the same time, we were supporting a Turkish-speaking family, Mr and Mrs Saglam, who have three children. Their middle son has a condition which causes weakness in his legs and arms. They had been allocated a house with a garden, which was fantastic. But the garden was in a very bad state and needed a lot of work before the children could use it. We explained to the family that we would like to put them forward for a garden makeover and they were keen to take part.

If you think you could benefit from Helping Hands, please call Lee Trunks on 0845 458 8171, email [helpinghands@wellchild.org.uk](mailto:helpinghands@wellchild.org.uk) or visit [www.wellchild.org.uk](http://www.wellchild.org.uk)



*Before and after the makeover organised by WellChild and Contact a Family*



Watch the video on YouTube at [www.youtube.com/cafamily](http://www.youtube.com/cafamily)

I made contact with WellChild in February and spoke to Lee Trunks, the Helping Hands Project Manager. He was very interested in facilitating a garden makeover as it was the right time of the year to start the process. So we took photographs of the garden and sent a little resumé of the family and details of how the makeover would benefit them to WellChild.

In March, we received confirmation that WellChild had decided to take on the project, and a site visit was arranged for May with a start date for the work some time in August.

I contacted the family's Housing Association for permission and to ask for a skip to take away the rubbish. This was done with the minimum of fuss and the Association liaised directly with Lee.

In the meantime, Mr Saglam had started to clear some of the rubbish in the garden and tried to flatten it out a bit. When the volunteer team came from John Lewis in Oxford Street, they spent two days working incredibly hard. When we went back to see the family they were delighted with their brilliant new outdoor space and the opportunities it provides for them to enjoy as a family. They'd started growing their own vegetables so we had the delight of eating home grown tomatoes, which were delicious!

We decided to make a video, as the family wanted a record of the transformation. It also provided a great opportunity to showcase the work of WellChild, and how Contact a Family can help, too.

*Mrs Saglam with her son*



# When it's time to do what will work

Jan Seamer talks about her son's needs and why it was important to find him a home of his own

My son Andrew is a young man of 24. He has a severe learning disability and behaviours described as challenging. He has virtually no spoken language and uses his own signs and photographs to communicate. When he becomes anxious and feels insecure his behaviour, which is how he communicates when things don't make sense, can be difficult to manage. As a result this has led to exclusions.

It was devastating when he was excluded from our local SLD school aged 14½ years (a school for pupils with severe learning difficulties). He was also excluded from a short breaks service.

We travelled the length and breadth of the country to find a school that would be able to meet his needs. I was especially worried at how he'd be supported if he became homesick and sad.

Unfortunately, the only school that seemed to be able to meet his needs was a residential special school more than 200 miles away. For Andrew to have to live so far away was heartbreaking.

My son is a very active, energetic young man who has physical energy to spare. What works is keeping him busy and providing structure and routines that make sense to him.

At the age of 18, Andrew was excluded again! He had no transition plan, no pathway plan and no idea of how his needs would be met by the local authority. He came home to live with me. An agency was contacted at short notice to provide support which was far from ideal.

This was a very difficult time but we continued to be helped by our Circle of Support (friends and family) and arranged for a Person Centred Plan (PCP) to be completed. The plan was pulled together by using stories provided



by our family, Circle of Support and paid staff – in fact anyone who had something to share was invited. It has helped to identify:

- What is important to Andrew and makes sense in his everyday life.
- What doesn't make sense to him and is best avoided.
- How best to support him to lead the lifestyle he chooses.
- And how to enable him to have the things that are important to him whilst ensuring he remains safe and healthy.

By looking in detail at what works and what doesn't leads to success. It really does work!!

Unfortunately, providers failed to see the importance of the detail contained in the PCP, especially where Andrew would need to live. The PCP had identified he needed to live in the village where he was born and had grown up and shared with his extended family. It became clear that to 'get it right' we needed to do it ourselves. So we decided to take the money in the form of a direct payment.

This was a huge commitment. The Circle of Support became a Trust in order to

receive the direct payment. We became employers. We had to recruit and train staff, arrange activities to keep Andrew busy and so on. It was essential that these costs were included in the direct payment as well as the cost of direct care and support. His care plan identified his assessed needs, his PCP identified how these needs would be met.

A home for Andrew needed to be robust with decent door hinges that couldn't be wrecked after an outburst, and away from a busy main road or bend. I found the Housing Options and My Safe Home websites very useful at this time.

Andrew now lives in his own home supported by staff that are selected for their personalities rather than their qualifications.

Amongst other things, he is sharing the same community as his family, and making friends with his neighbours. He's a member of the local leisure centre, is a volunteer in a woodland project and has been supported to develop a small micro-enterprise collecting plastic for recycling. He does a variety of other things and loves going places, especially travelling by bus. Many of the bus drivers now know him well, and will greet him as he boards the bus. His life is busy because it needs to be!

Andrew's needs are complex. His direct payment buys him 2:1 support and 1:1 sleep-in support at night. His support team get a clear induction based on his PCP, followed by further tailored training.

It has been hard work – that I can't deny! But, most importantly, my son is getting a good life. The outcomes couldn't have been better.

Contact the helpline on 0808 808 3555 for more information.

Or visit [www.housingoptions.org.uk](http://www.housingoptions.org.uk) and [www.mysafehome.info/](http://www.mysafehome.info/)

# Home sweet home

Lesley Moore talks about grants and building blunders while making a home fit for her son, Cameron.

Hi, my name is Lesley and my son is Cameron. He's almost 11 and has very complex Cerebral Palsy, which shows itself in fluctuating muscle tone. He alternates between stiff and floppy, constantly. This obviously makes it very difficult for seating and equipment to manage all his movements.

We live in a mortgaged three bedroom house with a downstairs bathroom on the outskirts of a small village in County Durham. I bought the house with a view to what adaptations it would lend itself to in the long term.

My son was assessed for a Smart Chair, which is a powered wheelchair that is worked off a switch and follows an infrared tape on the floor. We managed to get funding for the chair, then had to set into motion the house adaptations to meet the chair's requirements.

The chair was unable to fit in through the front door so first we had to have a lift put on the back of the house outside, and a new back door put in where there was originally a window.

## *Cameron in his Smart Chair*



We had left a through floor lift in our old house, which we were able to use, after an enormous amount of arranging. We were glad that the new occupants of our previous house coped so well with the upheaval of having it removed!

The back door is now an electric door, which opens off push buttons so that Cameron can open it himself. One button is on the top door of the lift, and the other one is loose in the kitchen so we can put it manually in the best place for Cameron to access it.

**“...the wrong size threshold was put on the back door... each time the Smart Chair goes over it, Cameron gets a big jolt.”**

To help Cameron's mobility further, I knocked through a wall to make the sitting room and kitchen one big room. Durham Council then made good the opening.

They also enlarged our very small bathroom by knocking out the walls between the original room and the utility to create one long bathroom. We then put in what I call an 'up and downy' bath and sink. These are electric and can be operated to move up and down.

The same style of sink was to be installed in the kitchen, along with an electronic sensor tap, so that Cameron could work the tap himself. The work started in January this year, but is still not finished. In fact, our building work has been fraught with problems.

## *Cameron enjoys cub camp*



The original builder (who did the bathroom and kitchen) obviously had a different level of finish to the one I was expecting for my son. We had to ask him to come back on three occasions – yet still this was not achieved satisfactorily. A new builder is due to come out to finish the work.

There were things that were obvious, or I felt were obvious, that caused major problems during our adaptations.

For example, the wrong size threshold was put on the new back door, which means that each time the Smart Chair goes over it, Cameron gets a big jolt.

The builder also did not know that the bathroom sink needed to be put onto a strengthened wall. Then the bath was put in before the waterproof floor, tiles and ceiling plastering, so it quickly got covered in plaster!

I have found the whole experience really stressful and the attitude of the builder upsetting. Despite being asked frequently to improve his work, nothing changed. It seems to have gone on for ever and the rest of the house has remained full of boxes from the kitchen and bathroom!

On the plus side, Cameron loves the bath and obviously feels very secure with all the padding and supports. The bath has also been designed to be used as a changing bench, as the side comes down for easy access.

The push buttons for the door have changed my life, never mind Cameron's. When he's in his manual wheelchair, being able to push him out without having to hold the door open at the same time makes life so much easier.

Because I have been very vocal in my disappointment with the standard of building work, a senior manager became involved. It has now been agreed that parents and professionals will come



*Cameron making use of the electronic sensor tap. The kitchen sink is fitted with special wall brackets and a handle so it can be manually moved up and down.*

together to form a focus group to write a booklet.

The booklet will explain the Disabled Facilities Grant to both parents and professionals – what is involved, what is available and useful information such as threshold sill heights and the need to strengthen walls, for example.

My understanding is builders will then get a contract of standards to sign, and they'll have to achieve certain standards if they are to continue winning contracts.

Parents and professionals working together to achieve change and make developments in present practice is beginning to be seen regularly across County Durham, in all areas and services for children with additional needs. It was this knowledge that has enabled me to cope with my experience. I now know that the process will change and will get better.

*Cameron with his cousins, Jacob and Abbie.*



# Housing Improvement Grants

Parent Adviser, Derek Sinclair, explains the new rules for Scotland

If you are an owner-occupier or a private tenant, you may be able to get help from your local council with the costs of adaptations. A new system of financial assistance has been introduced in Scotland – this includes, for the first time, mandatory grants to cover the costs of adapting a property to meet the needs of a disabled person.

## What is different about the new scheme?

Under the previous home improvement scheme, the only grants that were mandatory were those given to provide standard amenities such as baths, showers and toilets. Grants for all other types of work were always at the discretion of local authorities. Under new rules, councils now have to offer grants for any structural adaptations (other than certain extensions) that are assessed as 'essential' in order to meet the needs of a disabled occupant, including a disabled child.

If a mandatory grant is awarded on the basis of disability, it must cover at least 80 per cent of costs. However, where the applicant, or anyone living

with them, is getting Income Support, income-related Employment and Support Allowance, income-based Jobseeker's Allowance or Pension Credit (guarantee credit) it must meet 100 per cent of costs. Where someone does not receive one of these benefits, a council may still decide to give a grant for more than 80 per cent of costs.

## What is the maximum amount of grant I can get?

Under the new rules, there is no longer any fixed upper limit on the amount of a mandatory grant. Instead the grant must cover the costs of the necessary work as identified in the assessment of need.

## How will local councils decide if an adaptation is essential or not?

Councils are only under a duty to offer grants where an adaptation has been assessed as 'essential' to the needs of a disabled person.

## Are there any types of work that a grant will not meet?

The new rules state that councils cannot give a mandatory grant to extend a property in order to provide additional

living accommodation. If an extension provides a standard amenity (such as a bathroom) alongside additional living accommodation, then a grant can only be awarded for that portion of the costs linked to the standard amenity. If an extension solely creates space for a standard amenity and no additional living space is created, then full costs can be met.

## When did the rules come into effect?

Local authorities have until April 2010 before they have to fully implement some discretionary aspects of the new scheme. However, guidance from the Scottish government emphasises that those parts of the new legislation that place legal duties upon local authorities, including the provision of mandatory grants as outlined above, came into force in April 2009.

The Scottish government's booklet, *Help with adaptations to your home – a guide for disabled people in private housing* is free to download at [www.scotland.gov.uk/Resource/Doc/266465/0079748.pdf](http://www.scotland.gov.uk/Resource/Doc/266465/0079748.pdf)

# Get connected

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Parent support groups can receive *Connected* for free. Please call our helpline, tel 0808 808 3555

# A day in the life...

Our Family Workers offer parents one-to-one help and support through times of need. Here Corriena Tomkinson talks about one aspect of her job – podcasting

Working as a Family Worker for Contact a Family means every day is different. I enjoy the variety of my work. Some days I'm working from home responding to telephone and email enquiries, some days I'm out and about visiting families and attending meetings. I've interviewed parents about their experiences of early support, organised family cinema events and run siblings groups.

However, when I was asked to do a podcast I was, to say the least, rather surprised!

I didn't really know what a podcast was and certainly didn't know how to make one. My experiences of recording went back to the 1980s, when I taped the Top 20 on a Sunday evening!

I found out a podcast is a digital media file you can download from a website. Contact a Family got funding to develop this new way of sharing parents' experiences and raise awareness of conditions. The aim is to give parents a voice, inspire others, and reduce feelings of isolation by letting parents hear from others who have children with the same condition as theirs.

Anyway, after a couple of training courses I felt ready to embark on my new venture.

So one morning in August I find myself checking my podcasting equipment: my recorder, microphone and headphones before setting off to record my sixth podcast interview.

This interview is with Sonya, whose 15 year old son, Oliver, has Gorlin syndrome. Gorlin syndrome is an inherited predisposition to the development primarily of multiple basal cell carcinomas (localised skin cancers) and the development of multiple cysts within the jaws. I've never met Sonya before, but have had several telephone conversations with her after being put in touch with her through the Gorlin Syndrome Group.

As I arrive at Sonya's workplace, I feel like an extra from 'Spooks' carrying my recording equipment in a carrier bag! Sonya is very welcoming and we are soon discussing Oliver and his condition and the information that will be covered in the podcast.

Sonya is very generous with the information that she shares with me and I feel privileged to listen to her experiences. After recording the interview, I spend some time with Sonya before she has to return to her work and I pack away my microphone and head home.

On the train journey home, I'm hopeful that the podcasts will be a useful source of information for families and also workers, students, policy makers and politicians. I feel that the podcasts capture an invaluable insight into families' lives.

Once back home, I transfer my recording onto my laptop so that I can begin editing the interview with Sonya. This includes cutting out background noises such as clocks ticking and dogs barking. I've found that I can now identify an 'ummm' by the shape of the sound rather than by hearing it!

For the remainder of the day, I return to my role as a Family Worker rather than Podcaster, making phone calls and replying to emails.

Sonya's interview is now edited and will be on our website soon.

## Local contacts – support

### Volunteer Parent Representatives

Contact a Family has a team of Volunteer Parent Representatives throughout the UK. They are all parents or carers of disabled children themselves, some with complex and rare conditions. So they fully appreciate the impact of caring for these children. The team offers someone to talk to and signposting to local sources of information and support.

### Family Workers

Our team of experienced Family Workers covers different parts

## from Contact a Family

of the UK. Family Workers can help with any of the wide range of issues that families can face when caring for a disabled child, such as claiming benefits, providing information about SEN, through to putting you in touch with local and national sources of support.

### How to find your local contact

Contact our helpline, tel: **0808 808 3555** or check our website, [www.cafamily.org.uk/inyourarea](http://www.cafamily.org.uk/inyourarea) to find out your local Family Worker or Volunteer Parent Representative.





## Getting in contact with us

Contact a Family  
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Tel: 020 7608 8700  
Fax: 020 7608 8701  
e-mail: [info@cafamily.org.uk](mailto:info@cafamily.org.uk)

[www.cafamily.org.uk](http://www.cafamily.org.uk)  
[www.makingcontact.org](http://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.



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