

Grandparents First

In this issue

- 2 *I wish I could just be grandma*
New Family Fund report
- 3 *Living with autism*
The work of The National Autistic Society
- 6 *A grandparent's story*
"Daniel was excluded from two schools in one year"
- 8 *I can do it!*
Kids Can Achieve



Can you help to spread the word?

Funding for the Grandparents Raising Grandchildren Network comes from the Big Lottery Fund and relies on our membership numbers growing considerably.

If you know any other kinship carers who have not joined the Network yet it would be great if you could encourage them to join too – they can join online at www.grandparentsplus.org.uk or call us on 020 8981 8001. And don't forget the Network is for **all** kinship carers – not just grandparents.

"Hidden army" face unbearable hardship

A new report from the Family Fund has highlighted the enormous financial hardship, health problems, isolation and lack of support faced by grandparents raising disabled grandchildren. Based on surveys completed by 324 grandparents, *I wish I could just be grandma* was launched at an event hosted by Lord Brian Rix at the House of Lords in January.

Continued overleaf...

I wish I could just be grandma

The Family Fund's new report is part of their work to raise awareness of the needs of families with disabled children.

The report found that:

- 99% of respondents were bringing up a disabled child full time.
- More than 60% have a disability or chronic health problem themselves.
- Four out of five said they needed more financial help.
- Over 50% gave up work or reduced hours to care for their grandchild.
- A third say they need a break from caring.

The survey was launched at the House of Lords on 18 January by Lord Brian Rix. Network members Valerie and Joan were among those who attended.

"It was a very interesting day and good to meet other grandparents and MPs," said Valerie, whose story is featured on page six.

"It was a lovely day and really good to meet other grandmas in the same boat and to know I'm not alone," said Joan. "Joseph loved it as well as he had not been to London before – only wished we had had longer there as it was a bit of a rush.

"I also met some lovely and helpful people from the Family Fund and put in an application for some funding, so fingers crossed," said Joan.

The Family Fund provides grants for practical items, like washing machines, money for outings, toys, driving lessons and anything related to the care of the child. They welcome applications from grandparents and other kinship carers so please get in touch to see how they can help.



Continued from cover ...

The report was launched as the Family Fund urged more grandparents caring for disabled grandchildren to come forward to access help.

"Our research shows the extent to which grandparents with disabled children are struggling – many don't get Carer's Allowance, some are disabled themselves, others have had to give up work or reduce working hours – and many feel isolated. However, they are clearly a gutsy group; determined to do the best for their grandchildren," said Clare Kassa, the Family Fund's Network Development Manager.

"These grandparents are not alone – there is help out there for them. The Family Fund is available to help bridge some of the financial shortfall these families face, but it's crucial that there is greater recognition at local and national levels of the vital caring role they play. Without this, these carers will continue to fall beneath the radar and disabled children risk losing the vital care they provide."

"Having to support our grandchildren on our pensions – alongside rising living and heating bills – is virtually impossible and we get no respite."

"Grandparents raising a disabled child save the taxpayer billions of pounds a year in care costs, and for many that caring role won't end when the child reaches 18," said Sam Smethers, Chief Executive of Grandparents Plus. "We are worried about the impact of welfare reform and spending cuts on this group.

"The Family Fund is a lifeline for families in this situation. We urge grandparents and other kinship carers raising disabled children to contact them for help."

For more information on the work of the Family Fund or *I wish I could just be grandma*, please visit www.familyfund.org.uk or call 0845 1304542.

Living with autism



Photo: The National Autistic Society

In 2010 Grandparents Plus' report, *What if we said no?*, found that almost half of the family and friends carers who responded to our survey look after at least one child with a disability or special needs.

Emotional and behavioural problems were found to be the most common, affecting around one in three children, with 7% looking after a child with autism or Asperger syndrome.

According to The National Autistic Society (NAS), there are over 500,000 people with autism in the UK – that's one in 100. One in five children with autism has been excluded from school, with 40% being bullied at school.

The NAS is the UK's leading charity for people with autism, including Asperger syndrome, and their families. The charity provides information, support and pioneering services, and campaigns for a better world for people with autism.

It produces a wide range of information which is available on their website, including:

- How to get a diagnosis for a child, what to expect and how to tell them.
- Advice on education, including details of the six specialist schools the Society runs across the UK.
- Information for siblings, explaining behaviour and outlining how they can help.
- Real life stories.
- Suggested toys, books and games.

The NAS runs an Autism Helpline which receives over 62,000 enquiries a year, and offers information on local support as well as providing information sheets on topics such as behaviour and education. They are also able to give details of benefits and help from social services.

The helpline is open from 10am until 4pm from Monday to Friday on 0845 070 4004. Alternatively, visit www.autism.org.uk to access information on supporting children and young people with autism, ranging from out-of-school clubs to education and befriending schemes.

“I found the Helpline extremely helpful providing information and sensible advice at a time when we were feeling confused and even frightened. Many thanks.”



News & resources...

Giving children and their carers a voice

Exciting new research by the University of Bristol aims to find out more about the lives of families in which a relative or friend is caring for a child long-term because they cannot live with their parents, giving both carers and young people the chance to be heard.

Researchers are looking for young people aged 8–18 to take part in face-to-face interviews to explore their general well-being and find out what it is like being brought up by relatives or friends. They will also interview their carers to discover their experiences, such as how well they are coping, the levels of support they are currently receiving, and the support they would like in the future. Carers and children will each get a £20 voucher as a thank you for taking part.

“Researchers know that when children are brought up by relatives and friends this can work very well. Many children benefit from their high levels of commitment and feel secure and well cared for,” said Professor Elaine Farmer from the University of Bristol. “However, studies in the US have shown that this group may have particular needs but are likely to be missed by local services, and we want to see if this is also the case in the UK. The best way to do this is by asking children and carers how they are getting on.”

Commissioned by Buttle UK and funded by the Big Lottery Fund, findings from the study will provide vital information to government and service providers as to how they can develop policy and practice to meet the needs of these families.

The research team is currently recruiting across the UK and is very keen to hear from carers. If you're interested or would like to find out more, please contact Paula Vaisey on 0117 954 6728/07580 312526, email Paula.Vaisey@bristol.ac.uk, or visit the website at www.yourfamilyyourvoice.com.



In the spotlight

Grandparents Plus is launching a new series of seminars to explore the reasons why grandparents and family members step in to care for children.

The Spotlight Seminars will hear from some of the leading experts in their fields. The first seminar took place on Wednesday 2 February and focussed on alcohol and substance misuse. Hosted by Baroness Massey, the seminar was held in the House of Lords and featured speakers from Adfam, Mentor UK, the Children's Society and Network member Pam Carnegie.

Future seminars will look at issues such as parental imprisonment, abuse and neglect, bereavement and domestic violence.

For more information on any of the seminars please email Campaigns Assistant Ben Wheatley at ben.wheatley@grandparentsplus.org.uk or call 020 8981 8001.

When I'm 65 ...

BBC Radio 4 is producing a landmark new series following a group of people born in 1946, who will be turning 65 this year.

The series will follow a representative group of the UK population and they are keen to speak to grandparents and older kinship carers.

If you would be interested in taking part please contact Beth Eastwood at the BBC on 020 7557 2472 – please let Beth know you heard about the series from Grandparents Plus.

New advice service for Network members

A new advice service is being launched by Grandparents Plus, thanks to funding from the John Ellerman Foundation, the Rayne Foundation and the Mulberry Trust.

The service is being set up following feedback from Network members that many are struggling financially and not getting all the benefits to which they are entitled, with 7% not claiming any benefits or allowances according to our 2010 survey. The service will offer a telephone benefits advice and information line, plus materials will be available online and by post.

“We hope that the service will be of real benefit to our members and will complement existing advice lines run by the Grandparents' Association and Family Rights Group,” said Sam Smethers, Chief Executive of Grandparents Plus. “We also want to use this new service to get information and advice to kinship carers via other advice agencies such as the citizens advice bureaux. We know there are still thousands of families that are not receiving the help they need.”

New staff members Josephine Raine and Maria Bremmers joined Grandparents Plus in January and will be setting up the service ready for launch later this year. More details will follow in our next newsletter.

Conferences for kinship carers

The Family Rights Group has organised two conferences for kinship carers and the professionals who work with them.

Managing contact with parents: for children living in family and friends care placements will be held on 17 February. The conference will launch the first UK research specifically examining the contact which children living in kinship care have with their parents and other family members, including siblings.

Sibling carers: raising brothers and sisters will present new findings about these carers and will also launch new advice materials produced by Family Rights Group specifically for sibling carers. It will take place on 17 March.

Both conferences will feature family and friends carers speaking about their experiences and will be held at NCVO, London N1. A number of free places are available for kinship carers.



Contact the Family Rights Group on 020 7923 2628 or visit www.frg.org.uk for more information.

News since the National Day

Since the Network National Day in October 2010, Grandparents Plus has attended meetings with MPs from all parties.

Chief Executive Sam Smethers and Policy and Research Manager Sarah Wellard have met Ministers Tim Loughton and Steve Webb as well as a number of Liberal Democrat MPs, and have submitted written evidence to the Work and Pensions Select Committee. With the Welfare Reform Bill due in February, it's vital that we make contact with as many MPs as possible - we will be working with our partners in the Kinship Care Alliance to lobby around the bill.



Have you written to your MP yet? It makes a real difference if MPs hear from their constituents. If you haven't been in contact already there's still time – follow the link from our website, www.grandparentsplus.org.uk or, if you receive *Grandparents First* by post, please send off the enclosed letter.

Calling older carers

Thanks to funding from Comic Relief, Grandparents Plus is working on a campaign for older grandparent carers aged 65 and over.

We are looking for families to take part in filming for the project, which will look at the challenges and experiences of older kinship carers.

To take part in the project please call Sarah Wellard on 020 8981 8001 or email sarah.wellard@grandparentsplus.org.uk



Helplines & groups

National

The Grandparents' Association

Tel: 0845 434 9585

www.grandparents-association.org.uk

Family Rights Group

Tel: 0808 801 0366

(10am—3.30pm)

www.frg.org.uk

North West

Harbour Project, Bolton

A voluntary support group for parents, families and friends who are affected by someone's drug and alcohol misuse in Bolton. Contact 01204 62274 for more information.

East England

Northants Grandparent and Kinship Support Group

Meets monthly at Headlands Children's Centre. Contact Roisin O'Hare or Rose French on 01604 237599 or 07921 404501, alternatively email rfrench@northamptonshire.gov.uk for details.

East Midlands

SPODA, Derbyshire

SPODA offers support, advice and group meetings to parents, partners, kinship carers, families and friends affected by someone else's drug use. Visit www.spoda.org.uk or call 0800 068 5718.

A full listing of support groups can be found on our website – www.grandparentsplus.org.uk

Include your details...

If you run a group and would like to include your details please email info@grandparentsplus.org.uk

A grandparent's story:

“Daniel was excluded from two schools in one year”

“My daughter wasn't coping and social services didn't want her to have Daniel any more.”



When her daughter's illness caused her problems in coping with her young son, Valerie was able to provide him with a safe and secure home life.

“My daughter has schizophrenia and when her partner left she couldn't look after her son, Daniel, on her own,” says Valerie. “She would never have hurt him, but she neglected him; he wasn't washed and I dread to think what she was feeding him.”

Valerie tried to help, having Daniel to stay with her and her husband every weekend, but neighbours' concerns for Daniel's welfare meant that social services got involved.

“My daughter wasn't coping and social services didn't want her to have Daniel any more. Either he came to live with us or he would be adopted,” says Valerie. “He was three at the time, very much part of the family, so the only way he would have been adopted was over my dead body.”

With her daughter realising that this would be the best option for the family, Daniel moved in with Valerie and her husband. “I can't fault social services,” says Valerie. “We were very lucky. Our social worker was just out of university and was very sweet, although it was difficult for my daughter and husband as they were hearing things they didn't want to hear.”

Valerie's husband felt reluctant to take Daniel on. He had retired but was helping look after his own father, who had been diagnosed with senile dementia, and was worried about how they would cope. However, Valerie was determined and the family were granted a residence order. They also receive a weekly allowance because Daniel was placed by social services and Valerie was able to continue working full-time as Daniel had a nursery place paid for by social services.

At this stage Daniel's behaviour was quite challenging, although it was blamed on his past situation. "Because I've had four children myself I could see there was something wrong," says Valerie. "I have seven grandchildren, including another grandson who is nine months younger than Daniel, and there was such a difference between them – the younger one was streets ahead, chatting and using lots of words."

Eventually Daniel was diagnosed with ADHD and Asperger syndrome. "The ADHD is more pronounced," says Valerie. "He was excluded from two schools in one year – he wrecked a classroom. He now takes slow release medication to control the ADHD and luckily his third school is fantastic."

Valerie was also fortunate to have a local charity, Kids Can Achieve, which helps children with disabilities to manage their anger and learn how to behave. "The school let Daniel start with half days which were extended," remembers Valerie. "His care worker from Kids Can Achieve went in with him every day for the first term and trained one of the Teaching Assistants to work with him."

Kids Can Achieve also involves the wider family, with a support group which meets regularly. "They are always there," says Valerie. "I couldn't have managed without them. When Daniel was violent and I didn't know how to handle him his care worker would come and take him out, to give me a break. I've become a Trustee as they made such a difference to my life."

Daniel is now preparing to move on to secondary school in September and Kids Can Achieve runs a transition programme to help him cope with the change. Valerie is also in touch with ADHD & Autism Support Harrow, which runs a course for teenagers to help them understand their peers' behaviour which Daniel will eventually take part in.

Daniel sees his mum two or three times a week. "It's very difficult for her – she loves him to bits but just isn't up to looking after him," says Valerie. "She can't control him, he would just do what he wants until he hears my voice." He also sees his dad every fortnight and has just followed in his footsteps to start learning to play the drums.

Valerie separated from her husband around the time Daniel was diagnosed. "He hadn't had much to do with raising our four children and had a very different approach to me, which confused Daniel. He didn't understand his need for routine."

Now 10, Daniel has just been diagnosed with dyslexia. As it runs in the family, Valerie feels she should have done something earlier. "Daniel said: 'You do so much for me – don't worry about it'. He is absolutely gorgeous!"

For information on ADHD & Autism Support Harrow call 020 8426 1719 or visit www.adhdsupportharrow.co.uk.

See page eight for more information about the work of Kids Can Achieve.

"She loves him to bits but just isn't up to looking after him."

Would you like to share your story with other grandparents?

If you are interested in sharing your experiences please call Alison for a chat on 020 8981 8001.

I can do it!

Kids Can Achieve has made a huge difference to the lives of grandparent Valerie and her grandson Daniel, whose story is featured on page six.



Set up in 2002, Kids Can Achieve supports children with special needs and their carers. “I have three children and two of them have ADHD and autism,” says founder and Chief Executive Julie Browne. “I started supporting others from home and was often on the phone to other parents at midnight.”

Julie realised that more support was needed and managed to persuade her local council that Harrow needed a children’s charity to help families like hers. “There were so many families struggling and I knew what it was like,” says Julie. “We were given £16,000 and six months – now, over eight years later, we’ve gone on to be a flourishing organisation.”

Children are referred to the project from around the age of three, although typically they are a bit older, often when they are starting school. Referrals are usually from local schools or social services, or other charities who work in the same field such as ADHD and Autism Support Harrow and HOPE Harrow.

“We run coffee mornings twice a week, which is often the starting point for new families,” says Development Officer Clare Murray. “It gives us a better picture of the support they will need, which will vary from child to child. It depends on why they have been referred to us. Some children will have a particular need, such as anger management, while others will need access to respite services or the after-school club.”

When children are referred they are allocated a key worker, who works with them on a one-to-one basis to put in place a support plan. Within schools the team may help with transition and putting things in place, or may help find a more suitable school when there have been problems.

Kids Can Achieve has also started a youth group which includes a volunteering programme. “Now three young people are pursuing childcare careers and five are supporting younger children at the project,” says Julie.

“When I started I realised I couldn’t change the world but I wanted to change the way the world perceived children with autism and ADHD,” says Julie. “Now I see what our young people are achieving – it’s like my dream is coming true.”



Kids Can Achieve supports families in Harrow, West London. For more information about their work visit www.kidscanachieve.co.uk or call 020 8868 5629.

Written and designed by Alison Blaxland. Cover and page 2 photos - the Family Fund. Printed by Concept Communications.

Grandparents plus

We champion the wider family who care for children

Grandparents Plus
18 Victoria Park Square
Bethnal Green
London E2 9PF
Telephone: 020 8981 8001
Email: info@grandparentsplus.org.uk

www.grandparentsplus.org.uk

The Grandparents Raising Children Network is funded by the Big Lottery Fund



Grandparents Plus co-ordinates the Grandparents Raising Grandchildren Network with the support of:

