

in contact

The Contact a Family newsletter

Wales

Inside

30 Not Out	1
Sign up to get our newsletter electronically	2
Take part in one of our workshops	3
Contact a Family and Early Support in Wales	3
What makes my family stronger report	4
Delays in wheelchair provision highlighted	4
Child Trust Fund money	5
Disability Sports Wales	6
Crossroads Care Carers and Employment	7
Order form	8

Local office

Contact a Family Wales

33-35 Cathedral Road
Cardiff
CF11 9HB

Tel: 029 2039 6624
Fax: 029 2039 6625
e-mail: wales.office@cafamily.org.uk
Web: www.cafamily.org.uk
Freephone helpline: 0808 808 3555

30 Not Out – Contact a Family celebrates 30th anniversary

Find out how we are celebrating 30 years of strengthening families with disabled children

We are celebrating our 30th anniversary this year. For the last three decades, we have been strengthening families with disabled children across the UK by providing advice and information and putting 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.

As part of our 30th anniversary celebrations, we will be launching an 'Our Family, Our Future' report and exhibition, highlighting the hopes, aspirations and fears from a wide range of families, including three from Wales. As part of this, we will be holding a Welsh parliamentary event on 17th November at the Welsh Assembly, which we'll be inviting key ministers and local MPs to.



30 years of strengthening families with disabled children

Sign up to get our newsletter electronically

Get our newsletter by e-mail, stay up-to-date and help reduce our costs

Thank you to everyone who has sent us your e-mail addresses to enable us to send you our newsletter and other publications electronically in the future.

By the beginning of 2010 we aim to be sending our newsletter and other publications out in this way to everybody who has access to the

internet, enabling us to decrease our postal costs.

Receiving the newsletter in this way will have no effect on the information you receive and you will still get notified of Contact a Family events and activities. You will also receive updates between newsletters.

Register now

Send an e-mail from your chosen address titled **"EMAIL NEWSLETTER"** to katie.barrett-goode@cafamily.org.uk In the body of the email, please state your **NAME, POSTAL ADDRESS** and the **COUNTY** you live in.

For more information on this service contact Katie, Tel: 029 2039 6624.

Who to contact



Keith Bowen
Wales Manager

- Any matters relating to national policy and campaigning.
- Linking with other voluntary organisations.
- Training for professionals.

e-mail: keith.bowen@cafamily.org.uk
Tel: 01792 390 203



Katie Barrett-Goode
Enquiries and Group Development Officer

- General or individual enquiries relating to a disabled child.
- Local group development.
- Parent guides and publications.
- Anything to do with the Contact a Family Wales newsletter or mailing list.

e-mail: katie.barrett-goode@cafamily.org.uk
Tel: 029 2039 6624



Jill Bartlett
Development Officer and Family Support Worker

- Workshops for parents.
- Family days.
- Events and activities.
- Individual support to families in North Wales.

e-mail: jill.bartlett@cafamily.org.uk
Tel: 01248 670965

Take part in one of our workshops

Book now for our residential weekends, film showings and workshops

Contact a Family Wales provides workshops on a variety of subjects.

We have had a busy start to the year with workshops held on Growing up and sexuality, Makaton training and Wills and trusts.

We are also pleased to report that we have successfully been awarded a grant from Children in Need so we can continue to run workshops in Wales.

This money will help us to provide six free film showings across Wales, with a music workshop running alongside. Further funding has also been given to hold three residential weekends during 2009-10.

Residential weekends

- Wheelchair training weekend at Glanllyn, Bala, North Wales, 20th-21st November 2009 – **BOOKING NOW.**
- Family activity weekend at Llangranog, March 26th-28th 2010
- We hope to have a weekend in Stackpole Centre in Pembrokeshire, during March 2010 (date TBC).

More details of these weekends will follow in the next newsletter.

Free family film showing and music workshop

Please see enclosed flyer for details of when and where the film showings are and to book.

Day workshops

- Growing up and sexuality (two day course), 3rd and 10th November, Wrexham.
- Growing up and sexuality, date TBC, Ceredigion.
- Benefits talks, 22nd October, Mountain Ash; 12th November, Gwynedd, 1st December, Flintshire, 14th January, Pembrokeshire – **BOOKING NOW.**

If you have any questions or wish to book a place please get in touch, e-mail: jill.bartlett@cafamily.org.uk or Tel: 01248670965. We'd like to thank Children in Need and Film Agency Wales who have contributed to make these events possible.

Contact a Family and Early Support in Wales

Early Support is the Welsh Assembly Government's way of making sure that services for young disabled children and their families are better coordinated and more focused on families. It aims to help young children who are disabled or have complex needs to get coordinated services, high quality support and information, child and family-centred approaches, and support that enables them and their families to live ordinary lives.

It is essential that parents and carers are involved in making sure that Early Support happens in Wales. Without parents' and carers' involvement we cannot be confident that Early Support will do what it is supposed to do for families of young disabled

children. Contact a Family is working to involve as many parents and carers as possible from this early stage, and would love to hear from you.

Although Early Support is focussed on services for children under five years old, we understand how valuable parents past experiences are. We are interested in hearing from parents of disabled children of all ages from across Wales.

Ways you can become involved:

- Attending events.
- Sitting on Steering groups.
- Training. If you already have some training experience or if you would like to develop some training skills

then we can offer you training to become an approved trainer for Early Support.

- Reading through or discussing some of the Early Support materials with members of the Early Support team.

At this point, we are also particularly keen to hear from parents who may be interested in co-chairing or taking part in the parent panel at the forthcoming launch in Cardiff (see enclosed flyer).

For more information on this, if you are interested in becoming involved or know someone who is, please contact Katie Barrett-Goode, e-mail: katie.barrett-goode@cafamily.org.uk or Tel: 029 2039 6624.

What makes my family stronger report

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 coincide with our anniversary, Contact a Family has recently published new research based on a survey completed by families on our website.

This research highlights how families still feel stigmatised and shut out from society. The survey was completed by 615 families and found negative attitudes towards disability, coupled with a lack of services are the main barriers preventing families

with disabled children from leading ordinary lives.

Key findings include:

- Almost 70% of families with disabled children 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.

- Vital support services such as short breaks, a key worker and childcare are unavailable to almost half of families.
- Over 60% of families said they don't feel valued by society in their role as carers.
- Half of families with disabled children said the opportunity to enjoy play and leisure together is poor or unsatisfactory.

Contact a Family is calling for:

- The UK government to invest in a UK-wide campaign to raise awareness of the needs of families with disabled children.
- Disability Equality Training for everyone working in a public facing role in the UK.
- A stronger focus on disability awareness in schools.
- The UK government to commit to urgently reviewing carers benefits with a clear timetable for reform.

To read a full copy of the report, please visit Web: <http://www.cafamily.org.uk/pdfs/wmmfs.pdf>

Disabled Children Matter Wales highlights long delays in wheelchair provision

A big thank you to everyone who came along to the Disabled Children Matter Wales event at the Senedd on Wednesday 8th July.

Over 40 people attended to voice

their concerns over the unacceptable delays in providing wheelchairs for disabled children and young people.

The event was held to coincide with a Welsh Conservatives Debate being

held in plenary that afternoon. The transcript of the debate can be read at Web: <http://www.assemblywales.org> or you can watch the debate at Web: <http://www.senedd.tv>

Urgent call to ensure disabled children receive new Child Trust Fund payments

Changes next year will see disabled children gain an extra £100 every year into their Child Trust Fund account, but make sure you are claiming Disability Living Allowance to be eligible

Contact a Family is calling for families with disabled children to seek urgent advice about their benefits entitlements.

From 2010 the Government will contribute £100 every year to the Child Trust Fund accounts of disabled children, with severely disabled children receiving £200 per year. To benefit from these payments a child must receive Disability Living Allowance (DLA) and have been born on or after 1st September 2002. The first payments are due in April 2010 for those in receipt of DLA at any point in 2009-10.

Sarah Rush, Head of Advice at Contact a Family, said: "DLA is the key benefit designed to meet the additional costs of raising a disabled child. Despite this, more than half of families with disabled children are not claiming a potential £119.45 per week. It is crucial that all families with disabled children who are eligible for DLA make a claim.

"For those families whose children are seven and under in September you should make a claim now to ensure your child receives the significant annual payment to their Child Trust Fund."

Families with disabled children face enormous financial challenges and are more likely to be living in poverty than other families. Despite this, many are not claiming the benefits they are entitled to.

Sarah Rush added: "We would urge families to telephone the helpline for advice about claiming DLA and other benefits and maximising your income. We would also urge families already in receipt of DLA to have a full benefits check to ensure you are getting every penny you are entitled to."



Giving young disabled people a sporting chance

Find out how you can get involved with Disability Sports in Wales

Disability Sport Wales

There are many different sports clubs and groups across Wales for disabled people. These may be in a multi disability, disability specific or integrated (disabled and non disabled participants) setting. To find out what sports clubs are available in your area visit the Disability Sport website.

A parent's experience

Alex Elsaesser writes about his, and his family's experiences of disability sport: "In 1998, I was watching the regional news. Up popped a photo of the Welsh ski team at the Special Olympics. I thought, "My daughter Alissa could be on that team one day". I began to enquire. I found other than the Riding for the Disabled Association (RDA), there was not one sport for disabled children in our rural county in West Wales.

"Alissa has now been riding with them for a number years, and, two years ago, for the first time she qualified in the regional

competition to attend the RDA National Championship at Hartpury Equestrian College in Gloucester.

"A few years ago a Development Officer for Disability Sports was here, appointed for our county. With her help, I joined others to start a ski club. I am not a great skier and knew nothing about disabled skiing. We found help from the British Ski Club for the Disabled (BSCD), who ran sessions at dry and artificial snow ski slopes around the UK. With Sportlot funding we were able to buy special adaptive ski equipment from the USA.

"I began taking Alissa and her sister Jessica to a monthly disabled ski session at an artificial ski slope in Pembrey. It was hard work at first but a few winters ago we went on a BSCD ski holiday in France. There were experienced ski guides for each disabled skier and Jessica learned how to be a Helper. It was the best activity holiday ever, except Alissa wanted to adopt her guides to be her new parents!

"At Pembrey Ski Centre we met Harri Jenkins who has cerebral palsy and is a wheelchair user. He is also an accomplished racer, swimmer and boccia player who has won three gold medals for wheelchair racing at the National Athletic Games. Representing Wales, he broke the British Under 15 record. Harri also represented Wales at the National Boccia Championships.

"Ruth, Harri's mum, told me, "Sport has made a huge difference to Harri and his well-being. It has allowed him to be at peace with himself and accept his disability. He thinks he is lucky and that he has done far more, met more interesting people and been to more exciting places than most of his peers".

Get involved with Disability Sport

There are a growing number of disabled sport opportunities for children all over Wales and, for more information on these contact Disability Sport Wales, Web: <http://www.disability-sport-wales.org> or Tel: 0845 846 0021.

Skiing helps promote coordination, balance, movement control and general health and well being. It enables the children to develop their functional abilities and to reach their full potential, so improving their independence and quality of life.

Web: <http://icecoolkids.homestead.com>

Ice Cool Kids

Ice Cool Kids is a local charity covering Neath Port Talbot and Swansea. It's raising money to take a group of local special needs children skiing, both in this country and abroad. These children have a variety of conditions some of which are life limiting. Sessions take place monthly at Pembrey Dry Ski Slope.

The aim is to allow children with disabilities or special needs the opportunity to experience an activity from which they would normally be excluded.

Participating in this therapeutic activity not only allows them to fulfil a dream but also brings a huge sense of fun, enjoyment and achievement.

Crossroads Care Carers and Employment

Let Crossroads Care Wales know what you think on employment issues

Crossroads Care Wales have just started work on a new two year project around carers and employment. This work is supported by The Department for Children Education Lifelong learning and skills (DCELLS) within the Welsh Assembly Government and has a number of key aims:

- To develop partnerships with employers and help them develop strategies for supporting carers in their employment
- To offer awareness raising training to Job Centre Plus staff
- To inform and influence policy development within the Welsh Assembly Government
- To support the development of sustainable local services

for working carers which are flexible, personal and allow carers and those they care for to live independently and with dignity

- To research training needs for carers seeking employment and liaise with training providers.

Crossroads Care Wales is keen to hear from employers, service providers, policy makers and most importantly carers across Wales.

- Are you a parent carer juggling work and care? Or maybe you are not in work at the moment but would like to think about entering or re-entering employment?
- What would help you to get back into work?
- What would make it easier for you to remain in work?

- What services would or do you need?
- What does your employer do well? What more could your employer do?
- Maybe you are an employer? How could we help you to help your employees?

Crossroads Care Wales is interested to hear from you regarding the above issues over the next few months especially if you are living in our pilot areas of North and South East Wales.

For further information or to get involved please contact Cath Bowen, Carers and Employment Project Co-ordinator, Wales via the Crossroads Care Wales office, Tel: 02920 090 087 or e-mail: cath.bowen@crossroads.org.uk

Down's syndrome groups

Central Wales Downs Syndrome Support Group

This group meets monthly for informal family gatherings on a Sunday afternoon at 'Oakwellbarns', four miles outside of Llanidloes, Powys. These gatherings are an opportunity for the whole family to come along, enabling sibling support and friendships to develop between our children (as well as the parents!).

Don't worry if you would like some support but are unable to attend meetings. A lot of families in this area are spread out geographically over large distances,

and, therefore, a lot of the support the group offer can be done via the telephone or e-mail. Everyone is welcome however close or far away they live and however frequently or infrequently they want to come.

HE-DS (Home Education & Downs Syndrome)

New national support group for families who are home educating children with Down's syndrome or who are considering doing so.

This group have a Yahoo information, discussion and support forum where Christine Waterman from Education

Otherwise is available to give legal advice and information of interest. The group also meets for an annual family weekend at 'Oakwellbarns' in Powys, Wales.

For more information on either of these groups please contact Anita, e-mail: anitakolaczynska@yahoo.co.uk or Tel: 01686 413 502

Down's Association

If you would like more information on other Down's Syndrome support groups across Wales, please contact the Down's Syndrome Association, e-mail: wales@downs-syndrome.org.uk or Tel: 029 2052 2511 or 01834 813332.

Contact a Family Wales order form

Name _____ Organisation (if applicable) _____

E-mail _____ County _____

I would like to receive the newsletter electronically via e-mail

Address _____

Post code _____ Tel No: _____

First copies of parent guide are all free although additional copies are charged at 50p each unless otherwise stated.

I would like to be on your mailing list

A number of welsh language parent guides are available on our website, Web: <http://www.cafamily.org.uk/wales>

When your child has additional needs (£1 per additional copy)	
Benefits and Tax Credits Information Pack (contains a number of guides)	
Family Information Pack – siblings – grandparents – fathers – relationships	
About Diagnosis (inc. developmental delay, behaviour, getting or living without a diagnosis, genetics and more)	
Holidays, Play and Leisure	
Preparing for adult life and transition	
Special Educational Needs – Wales	
Education Maintenance Allowance	
The NHS and caring for a disabled child	
About families with disabled children	
Finding and paying for childcare	
Working and caring for a disabled child	
Aids, Equipment and Adaptations	
Disabled Children's Services in England and Wales	
Dealing with debt – England and Wales	
The winter guide: help with fuel bills and keeping warm	
Money when your child reaches 16 years of age	
Getting Direct Payments for your disabled child (England and Wales)	
A guide to dealing with bullying: for parents of disabled children	
Sleeping	
Feeding and Eating	
Toilet/Potty Training	
Sex and Relationship Education for young people with physical disabilities: a booklet for teachers	
Growing up, sex and relationships: a booklet to support parents of young disabled people	
Growing up, sex and relationships: a booklet for young disabled people	
General Contact a Family Wales Information leaflets: workshops, family support service etc.	
Information leaflet: Finding Medical Information on the Internet	
Checklist for parents – a simple explanation of help available to parents	

Please return this form to Contact a Family Wales, 33-35 Cathedral Road, Cardiff CF11 9HB, Tel: 029 2039 6624 or e-mail: katie.barrett-goode@cafamily.org.uk