

# Linklines

...using Hampshire's Joint Information Link to bring information to those caring for children with disabilities.

## Ed's Bit

Welcome to the fourteenth edition of our newsletter. This time Linklines brings you news of the Aiming High consultations, some ideas and hints to help the summer school holidays fly by and the usual round up of freebies and money savers, campaigns and sources of support.

Sadly, we had no replies to our two letters asking for help in the last issue, if you have any information then it's still not too late to pass it on!

Kind regards,  
*Fiona Hall*

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<b>Aiming High for Disabled Children – Better Support for Families</b>
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## Key Points Raised by Parents at Consultation Event on 10<sup>th</sup> July 2008

**Christine Lenehan from the Council for Disabled Children agreed to meet with parents to look at the issues that were raised at the series of consultation events held around the county during the spring. We wanted to make sure that parents were happy with the way we had interpreted their views. The points below reflect what parents told us at this event**

1. Can you be clear about charging policies, including the used of DLA
2. Can we have a concerted County approach to families knowing about and being supported to receive DLA
3. Information is critical – all info – all services – all sectors. Currently it is poor and patchy
4. The Children's Information Service doesn't always provide appropriate information to the parents of disabled children
5. We need to review all Universal Services for DDA compliance and publicise the information (this should include improving the attitudes of staff)
6. Parents are tired of fighting – we need a system that is **clear** and that supports parents to understand their rights/entitlements
7. The Direct Payments system is confusing, bureaucratic and inconsistent. Please sort this out. It needs to be developed – brokerage, Personal

- Assistant banks, stop using expensive agency staff and more liaison with other services.
8. Please use the wide range of charities/voluntary sector organisations available. Consider core funding costs of groups which are working well and replicating them across the county.
  9. Sort out in-county and border county boundary issues
  10. Issues of **criteria** are critical – too many children seem to fall off the edges and get offered nothing.
  11. Passporting has dangers – particularly around children in mainstream schools – can we look at higher/middle rate DLA as well.
  12. Can we work towards a clear minimum offer
  13. Workforce worries us! We want:
    - A county-wide recruitment campaign
    - A look at all resources, childminders, school staff etc to look at usage
    - A training programme for staff in universal services
    - To build on student/voluntary initiatives
  14. Ensure basic facilities are in place including changing facilities
  15. Don't reinvent the wheel – use the facilities you have already have, e.g. QE Country Park
  16. Please sort out your relationship with Health
  17. We need a service that is responsive in a **crisis** and year round (e.g. holidays).
  18. Transport is still an issue....

### What Happens Next?

We hope that you and your family can join us for the next phase, to look at how we're going to improve services for disabled children and their families. This event is also open to professionals.

#### **Family and Children's Fun and Participation Workshop**

**Saturday 22<sup>nd</sup> November at the Alton Maltings, 10am – 1pm**

- Briefing on the Commissioning Strategy for Disabled Children's Services
- Fun and games for children of all ages and abilities

Please note this event in your diary. You will receive further details and a booking form in September.

## National News

### Surviving the Summer

Claiming to be the only guide you will need to survive the summer, Netmums Summer Solace Index covers all sort of topics from Local Events and Activities, Holiday Playschemes, Summer Eating, Garden Games, Outdoor Play, Indoor Fun, Swimming Pools to Team Read, Camping and much more.

Local events covers 4,000 free or minimal cost events, holiday playschemes list over 6,000 playschemes and summer camps, 3,000 listings for outdoor play and 4,000 for indoor fun so while not everything will be suitable there should be something there to help make the summer holidays pass more quickly. There are also reviews of some the locations that mothers and children have visited and you can add your own review too.

The link is <http://www.netmums.com/h/n/WHATSON/HOME/ALL/1241//>

Other useful websites to visit for holiday inspiration are:

The Hantsweb site at <http://www3.hants.gov.uk/kids> where you can sign up for the newsletter of events in and around Hampshire.

An award winning search site for things to do with the children is <http://www.ideasforthekids.co.uk/> Just pop in a post code for the area you want to visit and a couple of key words such as 'zoo' or type of event such as 'soft play' and you should get plenty of choices returned. You can narrow the search to only give results within a set number of miles from the post code you entered, there is a map of the location, a list of other attractions nearby, there is a review tab giving the views of others that have used the attraction and a discussion tab where you can ask questions about the venue.

Winchester City Council have a useful children's activities page at: <http://www.winchester.gov.uk/Events/?eventcat=7876&page=3> including details of a concert on Saturday 6<sup>th</sup> September to raise funds for Naomi House.

### Helpline text service

The National Autistic Society Autism Helpline is piloting a text service, following funding from the Financial Service Authority's National Strategy for Financial Capability. Enquirers can text their name, address and the age of person with ASD to the helpline on 07903 200 200 to request an information pack on benefits and finance.

### Contact a Family enters virtual reality

Contact a Family has set up an office in the virtual world of Second Life. The charity is using government funding to create the digital office to support its work giving parents information and mutual support.

Mark Robertson, Contact a Family's head of information, explains: "The first place anybody goes for information these days is the internet. There are issues with accessing support in real life, even popping out to a local advice centre. Online and telephone support is and has been for some time important to parents of disabled children."

Second Life, a virtual reality world where users can adopt new identities (avatars), conduct business and even raise families, may seem an odd place for the charity to reach its audience. Contact a Family insists it is only going where the parents already are. As those caring for disabled children may find it hard to leave the house and get help, many seek refuge in the virtual world and in online communities.

"It's an attractive and new way of reaching parents, we don't have to be open to use the office. It's a bit like an online library " says Robertson.

The office is open online every Wednesday from 10am to 4pm. Parents, represented by their avatars, can stop in for a chat with a staff member. Alternatively, they can come by when the office is closed to browse.

Visitors have included one mother whose son has a rare condition called dyskeratosis congenita, of which there are only 66 known cases in the world. The adviser was able to give her the contact details of a parent support group and the leading medical specialist for the condition. Other parents have dropped by wanting to meet people in the same situation.

"There's been small numbers, but it's really early," says Robertson. "If it's successful it will take time." If enough people do drop by, real world meetups may be on the cards.

Contact a Family also runs support groups on social sites Facebook, MySpace and Bebo, as well as its own network, makingcontact.org. So why not look them up when you're visiting Facebook, MySpace, Bebo and Second Life?

- Contact a Family Facebook Fanpage

Web: <http://www.facebook.com/pages/Contact-a-Family/25040545213>

- Contact a Family MySpace page

Web: <http://www.myspace.com/contactafamily>

- Contact a Family Bebo page

Web: <http://www.bebo.com/contactafamily>

- Contact a Family office on SecondLife

Web: <http://www.secondlife.com>

It has also set up [its own YouTube channel](#).

The charity's online support project was created with funding from the Department of Children, Schools and Families' parent know how initiative, a programme intended to develop new channels to reach parents who are not as well served by traditional sources of support.

**Disability Living Allowance Podcast**

Disability Living Allowance is the main benefit for children and adults with extra care or mobility needs. In keeping with their drive towards new technology methods of distributing information, the podcast from Contact A Family explains the two main parts of the benefit, how you can claim it, and has other helpful information around getting the benefit.

To listen visit Web: <http://www.cafamily.org.uk/news/podcasts.html>

You can also subscribe at no cost on iTunes, simply search for Contact a Family and click 'subscribe'. If you don't have web access you can use their free help line to ask for a paper copy of the podcast on 0808 808 3555

**Help for Visual and Hearing Impairments**

There will be a new drive to improve the experience of children with visual and hearing impairments, Schools Minister Andrew Adonis announced recently.

Two initiatives will seek to:

- Improve resources for children with visual impairments and dyslexia in schools.
- Increase demand for and use of British Sign Language by children;

A pilot will seek to make textbooks accessible to children who can't read standard sized print in textbooks, due to a visual impairment or dyslexia. The pilot will particularly seek to develop schools' access to resources in electronic format, and to end the culture of teachers having to enlarge and re-type sections of texts to produce large print or Braille versions.

A report by the Royal National Institute of Blind People (RNIB), showed that only 12 per cent of maths and 8 per cent of science GCSE textbooks in England, were available in Braille or large print. 96 percent of books for adults and children never make it into a format that a blind or partially sighted person can read.

Organisations are also being invited to bid for a £800,000 project to test ways of improving demand for and use of British Sign Language (BSL).

With less than one qualified interpreter available for every 100 BSL users, RNIB, the UK's largest charity for the deaf and hearing impaired, says that deaf and hard of hearing people in the UK struggle to access basic services and support. The scheme will start off in one or two areas and look at ways of increasing the provision of BSL, and its status amongst families with deaf and hearing impaired children and young people. It will particularly look at raising the profile of BSL amongst the wider school workforce – which in turn will create more demand for courses and qualifications.

Andrew Adonis said:

“It's vital that sensory impairments are not a barrier to learning. Children with hearing difficulties and visual impairments have the same right to a quality education as everyone else. I'm confident that both these projects will be a significant further step down the road to improve the experiences of children with sensory impairments.”

Brian Lamb, Director of Communications, RNID said:

“This investment could have the potential to transform the lives of thousands of young people who use BSL as their first language.

“The shortage of sign language courses and tutors has a major impact on both the education system and deaf people’s communication needs more generally. This represents an important first step in beginning to lay the foundations to address this shortage and identify what else needs to be put in place.”

Richard Orme, Head of Accessibility at RNIB said:

“Despite the best efforts of teachers, blind and partially sighted children throughout the country are currently losing out on their education because they can’t always get hold of textbooks they can read.

“Teachers have told us they need textbooks in electronic formats, and the tools to create accessible versions for pupils who are unable to read standard print. RNIB very much welcomes this announcement and will work alongside the government and other partners to ensure that an efficient solution is found.”

Among the objectives of the BSL project are: increased awareness of BSL amongst families; increased demand for BSL training from the children’s workforce; better availability of BSL tutors and courses, including at higher levels; and learning from centres of excellence, such as schools that already have strong BSL provision.

The accessible resources project will test the best ways of providing texts to schools in electronic format; demand by teachers; pupil preference for various formats; cost benefits and time saving of different materials; and the practicalities of accessing different resources.

### **£10m funding boost for special education teaching**

Funding to the tune of £10 million a year is to be set aside for schools to train Special Educational Needs Coordinators, it was announced today.

The coordinators - Sencos - are the key people responsible for the learning and support of all children with special educational needs in their school.

The money will allow them to undertake new, nationally accredited training. From September, it will be a requirement that all Sencos be qualified teachers and receive additional training. A further £12 million will be put towards training for trainee and existing teachers. The funding is part of a package laid out by schools minister Lord (Andrew) Adonis in his speech to Voice, the union for teaching professionals.

Lord Adonis said: "Improving the life chances of children with special educational needs (SEN) and disabilities is an absolute priority for this Government and equipping teachers with the skills they need is central to this. Overall, funding for SEN provision has risen by more than £1 billion in the last four years. Teachers who take on a specific role in helping children with special needs and disabilities

are an inspirational group, who do an amazing job. It is only right that we meet their commitment by providing them with the professional development they need."

### **SEN performance reports across England.**

The Special Educational Needs (Information) Act became law on 25th July 2008 and requires the government to publish annual reports on how children with special educational needs (SEN) are doing at school in different local areas. It is designed to tackle the wide variations in the way local authorities collect information and to drive up standards.

Contact a Family and the Special Educational Consortium (SEC), two of the four key partners in Every Disabled Child Matters (EDCM), supported the Bill as it progressed through parliament. SEC is a group of organisations that work together to champion the interests of children with special educational needs and disabilities.

To view the Bill, visit the web at <http://services.parliament.uk/bills/2007-08/specialeducationalneedsinformation.html>

Sorry, this website does not give a contact telephone number. Your local support group may be able to help or you can use a computer at your local library for free.

### **Experiences of Dyslexia Wanted**

A website for teachers, parents, young people and others with an interest in dyslexia is being launched by Sir Jim Rose as part of his review into how children with dyslexia learn best.

Sir Jim is asking for personal accounts and experiences as well as details of published research to help inform his development of recommendations to the Secretary of State for Children, Schools and Families. The website will also contain regular updates and information about the review.

Sir Jim Rose said:

"Many years ago I read an article entitled: 'Dyslexics of the world untie.' In those days, the nature of dyslexia was little understood. There were many who believed that dyslexia was not only hard to define but also questioned whether it existed at all. Nowadays we know better. Dyslexia is no joke.

"I am pleased to be asked by Ed Balls to look at the current position on tackling dyslexia and to make recommendations about the identification of this learning difficulty and the teaching needed to overcome it. I am already undertaking a review of the Primary Curriculum, and although I shall also be looking at how children with dyslexia can be most appropriately supported at secondary school, it is often whilst at primary school that children's difficulties should first be identified and addressed. I will be drawing strongly on the help of expert advisers and we will look at other learning difficulties, such as dyscalculia and dyspraxia, which may overlap in some respects with dyslexia.

“I am talking to teachers, children and young people about their experience of tackling dyslexia whilst visiting schools, as well as to representatives of the dyslexia charities. Whilst research evidence is very important I’m eager to hear personal accounts and I would urge parents, teachers, children and young people to have a look at my website and tell me what has worked well, and what has worked less well, to improve the progress made by children with dyslexia.

“I will be visiting schools where there is much to learn from their good practice and the website will provide regular updates on progress. I expect to publish a report, containing my recommendation, by the end of February next year.”  
The website address is: [www.dcsf.gov.uk/jimroseanddyslexia/](http://www.dcsf.gov.uk/jimroseanddyslexia/)

Accounts of experience and details of research evidence can be e-mailed to [dyslexia.jimrose@dcsf.gsi.gov.uk](mailto:dyslexia.jimrose@dcsf.gsi.gov.uk)

The British Dyslexia Association helpline, which provides advice about dyslexia can be contacted on 0845 251 9002.

### Help on the Highways

The Highways Agency is producing road safety guidance for disabled drivers and needs your help. They consulted disabled drivers last year about how their Traffic Officers should assist disabled customers who have broken down on the motorways. Feedback from the disabled people consulted expressed that they wanted more information on how they could keep themselves safe on the road.

The Highways Agency have already produced road safety guidance for motorcyclists, HGV drivers, female drivers, and other groups, and they now want to produce a driver information programme for their disabled customers.

To produce the best possible guidance, they would like to ask you various questions about driving and the problems you may face on the roads. To share your views simply visit the website at: <http://www.highways.gov.uk/knowledge/19292.aspx> or e-mail them at [ha\\_info@highways.gsi.gov.uk](mailto:ha_info@highways.gsi.gov.uk) or telephone 08457 50 40 30 or 0121 335 8300.

### The Snowdon Award Scheme

Students with physical disabilities can apply to the Snowdon Award Scheme for grants ranging from £250 to £2,500. These help cover additional costs, like computers, mobility equipment or human help, that push up the already high costs of being a student or trainee.

Whether they fund a sign language interpreter, a laptop, transportation or something more specific, grants can change people's lives. They provide students with the opportunity to access education or training and enjoy a level of independence that would not otherwise be possible.

Whatever the situation – whether your child is already studying, starting a new course or retraining following an accident or illness – you may be eligible to apply on their behalf for one of the Snowdon awards.

There are conditions which can be found on their website but briefly the main ones are:

- Candidates will have a physical disability
- Students of all nationalities may apply but must be studying at a college or university in the UK.
- A grant will be for a period of one or two years and will not usually exceed the value of £2,000 per year. In exceptional cases, £2,500 may be awarded.
- In the case of two-year grants, the continuation of the grant for the second year will be subject to a satisfactory academic or other appropriate report.
- Candidates will declare all relevant financial and medical information, which will be kept confidential to the panel and administrators of the grants.
- The awarding selection panel usually meets in July and October, with applicants receiving results soon after each meeting. Acceptance of an award must normally be made within two weeks of a funding offer.

The website can be found at: <http://www.snowdonawardscheme.org.uk/index.asp>  
You can also contact the Snowdon Award Scheme at: 22 City Business Centre, 6 Brighton Road, Horsham, West Sussex RH13 5BB Telephone: 01403 211252

### Free Books

Every five-year-old and 11-year-old in England will be given free books by the end of the year. The charity Booktrust has announced it wants to give out more than 2 million free books by Christmas.

The Department for Children, Schools and Families supported project, which has attracted funding of more than £4m, will see reception-aged pupils get a free copy of Harry and the Dinosaurs go to School by Ian Whybrow. Children in Year Seven will be able to choose their own book from a list of 12. All children will also be given free poetry anthologies. The idea is to encourage children to read for fun and pleasure.

Viv Bird, director of Booktrust, said: "These books have been chosen with great care to encourage the simple enjoyment of reading among five- and 11-year-olds when they start at primary and secondary school, which for some can be a stressful time."

### Free resource CD

Potential members of the British Institute of Learning Disabilities (BILD) can find out all about the advantages of BILD membership from a free CD-ROM. It also contains a collection of information resources from BILD's website and elsewhere. If you want a copy then you can request it by e-mailing [p.mazurek@bild.org.uk](mailto:p.mazurek@bild.org.uk) or calling Pam on 01562 723015.

**Free Bug Hunt**

Today, like every other day, at least two children under 5 will contract the devastating meningitis disease in the UK. There is still no vaccine for the most common form and it can kill in under 4 hours. The sooner we find a vaccine to protect against all forms of meningitis, the less chance it will have of affecting someone you know. Meningitis UK are the only UK charity committed to finding a vaccine to prevent meningitis. To help raise funds for their work they are holding a Big Bug Hunt for children up to 5 years of age. You can get a free Resource Pack with Cheeky Bug story sheet, colour templates of the bugs for you to hide, bug colouring-in sheets and free bug stickers for the children. Groups can fund raise for the charity too and will get a free book if they raise over £50.

In September and October they will be running their own Bug Hunt and Obstacle Races at a selection of leisure centres around the UK. These events will be facilitated by play leaders and more details will be published online soon. The website can be found at: <http://www.bigbughunt.org/> their address is Meningitis UK, 25 Cleeve Wood Road, Downend, Bristol BS16 2SF Telephone: 0117 373 73 73 (Mon to Fri 9am to 5pm)

**Sing through Summer Free CD**

Are you one of the countless people wondering how to keep your little ones entertained throughout the long summer break? If so, then help is at hand from Sing Up, the national Singing Programme, which has now launched a new-look family section of their website to keep children singing throughout the summer.

Sing Up is the Music Manifesto National Singing Programme, produced by Youth Music with AMV-BBDO, Faber Music and The Sage Gateshead, supported by Government. Sing Up aims to increase opportunities for primary school-aged children throughout England to enjoy singing every day.

Families can register for a free singing CD-ROM in the new family area - [www.singup.org/families](http://www.singup.org/families) - and will find song lyrics that families can sing together as well as a selection of games and activity packs that can be downloaded to play in the car, or on a rainy day. The CD features songs such as *This little light of mine* and *The animals went in two by two*, that children can sing-a-long to in the car and play on their computer, along with activity sheets and inspiring articles about singing. As well as being great fun for the whole family, scientific studies have proven that singing can have a significant impact on the educational and social development of children, inspiring their imagination, improving their memory and building their confidence. If you don't have access to the web you can write or phone them at Sing Up, One America Street, London SE1 0NE Telephone: 020 7902 2939

**Win a laptop.**

Contact a Family is calling on parents to tell their story of raising a disabled child in a national competition which aims to highlight the many issues they face.

On the theme of 'Me and my disabled child', they would like you to make a short video about the joys and challenges of caring for a disabled child. If you don't have a video camera, or have other creative impulses, you could tell your story in an essay. Alternatively, you could make an audio recording or take a picture.

All entries will be considered in a category alongside those other entries using the same media, with a chance to win a digital camera - and for the over all winner, a laptop. The best clips, pictures and stories will be featured on their website and other online channels such as Youtube, and in their magazine Connected.

Deadline for entries is 30th November 2008 For more information including details of how to enter, visit the website at: <http://tinyurl.com/5aor3y> or telephone the New Media Officer, Louis Yung-Hoi on 020 7608 8727 or e-mail: [louis.yung-hoi@cafamilly.org.uk](mailto:louis.yung-hoi@cafamilly.org.uk).

**Children First**

Children First - a guide to services for disabled children is written for the parents, carers and families of disabled children and aims to provide access to valuable information that may help to improve their quality of life.

The book covers a variety of topics such as health and social services, housing, transport, social security, education, technology and leisure. The information relates to children and young people between 0 and 15 years and briefly covers issues when they are 16+ years. It costs £4.75 including post and packing from the RADAR organisation (they run the National Key Scheme which gives independent access by disabled people to around 7,000 locked public toilets around the country.) You can visit the RADAR website at: <http://radar-shop.org.uk/Default.aspx> or write to them at **RADAR**, 12 City Forum, 250 City Road, London EC1V 8AF or telephone 020 7250 3222 or e-mail: [radar@radar.org.uk](mailto:radar@radar.org.uk)

**Seven million qualify for help to go digital.**

The Help Scheme will help households to make the switchover to digital TV, including providing them with easy-to-use equipment and the help to install it. They can help households where there is a child or adult entitled to Disability Living Allowance and/or are registered blind or partially sighted. Households with someone over 75 will also be eligible. People should be contacted well ahead of switchover in their region with details of how the scheme works and the digital options available.

You can find further details at the website: <http://www.digitaluk.co.uk/en/how/help-scheme.html> or telephone 0845 6 50 50 50.

**Family Fund Extra Launched.**

The Family Fund is launching 'Family Fund Extra' during October and is calling on families with disabled children to register their interest. Family Fund Extra is a separate scheme from their grant making programme and aims to help families make their money go further. It will offer a variety of discounted goods and services like electrical products and holidays. It will also allow supporters of Family Fund to make a difference to disabled children through donations and 'donate as you shop' opportunities.

If you care for a child or young person up to the age of 25 years old and would like to benefit from the discounts and services Family Fund Extra will offer, register now at Web: <http://www.familyfundextra.co.uk> or by writing to Family Fund, 4 Alpha Court, Monks Cross Drive, York YO32 9WN or telephone 0845 130 4542 or 01904 621115

The Family Fund Comet gift card is a first step towards the fully-fledged Family Fund Extra and is already up and running. Web: <http://tinyurl.com/667tbv>

**Parent Petition.**

Kate Thomas from Leicester, is the parent of a child with spina bifida. When she took up a degree place at Northampton University her carers allowance was stopped by the Department of Work and Pensions (DWP) as their rules do not allow for study of more than 21 hours per week. Kate has started a campaign to get the rules changed. You can support the campaign by visiting <http://petitions.pm.gov.uk/Value-Carers/>

**Campaign for more specialist children's nurses.**

In the past children with complex health care needs, including the need for long term ventilation support and other medical interventions, needed to stay in hospital for months (or in some cases years). It's widely recognised now this isn't always necessary and by making specialist care available in the community, many children can go home. Sick children's charity Well Child and the Royal College of Nursing has launched the 'Better at Home' campaign in order to call for more specialist children's nurses to support families in these circumstances. The campaign will be highlighting the issue to government, service providers and the general public.

For more information on how to support the campaign send an e-mail to <mailto:campaign@wellchild.org.uk>

Visit the website at <http://www.wellchild.org.uk/WhatWeDo-Campaigns.asp>

Or telephone 0845 458 8171

**Support the 'End Child Poverty' Campaign**

Contact a Family has announced its support of the biggest event to end child poverty in the UK. The campaign charity End Child Poverty is organising the 'Keep the Promise' event - to be held in Trafalgar Square on Saturday 4th

October 2008. The event is intended to mobilise public support while putting pressure on Government to keep its promise to end child poverty by 2020.

Mark Robertson, Contact a Family's Head of Information and New Media, said: "It costs three times as much to raise a disabled child and many parents struggle to hold down a job due to the pressures of caring. As a national charity supporting families of disabled children, we support Keep the Promise and call on government to make the significant investment necessary to end child poverty."

The event will begin with a short march from Millbank to Trafalgar Square where there will be children's activities, family fun, film and speeches. This will be followed by everyone being asked to make as much noise as possible to show their support to end child poverty.

If you want to attend the event in Trafalgar Square or would like to find out how to support the campaign in other ways visit the website at <http://www.endchildpoverty.org.uk/keepthepromiseevent>  
Or write to - End Child Poverty, 94 White Lion Street, London, N1 9PF  
Or telephone 020 7278 6541

#### **Support for the price of a local call**

Families caring for sons/daughters with severe learning disabilities can now receive individual telephone support around understanding and managing challenging behaviour for the cost of a local call.

Some children (and adults) with severe learning disabilities typically display behaviour which may put themselves or others at risk, or which may prevent the use of community facilities or an ordinary home life. This behaviour may be in the form of aggression, self injury, stereotyped behaviour or disruptive and destructive behaviours.

Whilst anyone may at times display challenging behaviour, the work of the Challenging Behaviour Foundation is aimed at helping those with severe learning disabilities. Severe learning disability (sometimes referred to as severe intellectual disability or severe mental handicap) is a developmental disability and refers to individuals who have either no speech or limited communication and require support with daily living skills such as dressing and eating.

Family carers experiencing these issues can now access individual information and support from the Challenging Behaviour Foundation Family Support Worker on **0845 602 7885**.

Originally started by a parent to provide help and information to other parents, the Challenging Behaviour Foundation's expertise is now recognized by a growing number of learning disability professionals. Email support is also available, and families and professionals are invited to contact [info@thecbf.org.uk](mailto:info@thecbf.org.uk) to find out more about the information, resources and support

available from the Challenging Behaviour Foundation, which specializes in challenging behaviour associated with severe learning disabilities. All information, resources and support free to family carers.

For more information contact: The Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent ME4 6BE, email [info@thecbf.org.uk](mailto:info@thecbf.org.uk) or telephone 01634 838739 (general enquiries) 0845 602 7885 (Family Support Worker)

#### **New Early Support website.**

Early Support is the Government programme to achieve better co-ordinated, family focused services for young disabled children and their families. It's a national programme that is being introduced and used in local authorities, hospitals and community-based health services across England. The programme across England was announced in Aiming High for Disabled Children in May 2007. The programme's website has had a makeover. The 'for families' section explains what Early Support is about to parents and carers and helps those visiting the site for the first time to find their way around. Find the website at: <http://www.earlysupport.org.uk> where among other things you can download information booklets about:

- [People you may meet](#)
- [Childcare](#)
- [Financial help](#)
- [Education](#)
- [Health services](#)
- [Social services](#)
- [Statutory assessment - education](#)
- [Useful contacts and organisations](#)

If you don't have access to the web you can contact Hannah Tramaseur [Hannah.Tramaseur@rnid.org.uk](mailto:Hannah.Tramaseur@rnid.org.uk) 020 7296 8238 or Eileen Strevens [eileen.strevens@rnid.org.uk](mailto:eileen.strevens@rnid.org.uk) 020 7296 8307 for more information.

#### **Help 'Syndromes Without A Name' (SWAN)**

Elizabeth Swingwood set the SWAN group up 11 years ago and has been working tirelessly to improve life for families whose children do not have a diagnosis. This brings a unique set of challenges as families struggle to get the services they are entitled to because they cannot say exactly what condition their child has. Unfortunately, due to ill health, Elizabeth has to step back from carrying the weight of the group and urgently needs assistance particularly in the areas of fundraising, accounts and admin. If she is unable to find assistance she may have to close the group which is very much valued by the families it supports. If you or someone you know would like to get involved contact Louise Derbyshire on telephone 020 7608 8715 or e-mail [mailto:louise.derbyshire@cafamilly.org.uk](mailto:mailto:louise.derbyshire@cafamilly.org.uk)

#### **TummyTrouble - help required.**

Unfortunately, due to a change in circumstances the parent running the above group is no longer able to give time to running the group and is looking for someone to take over. This group provides valuable support to families whose children are affected by Hirschsprungs Disease and other gut motility disorders. If you are interested in finding out more about what would be required please contact Louise Derbyshire on 020 7608 8715 or by e-mail <mailto:louise.derbyshire@cafamily.org.uk>

### **Make silence golden**

As a way of raising awareness, and some income, the Afasic organisation are asking people to get involved with a sponsored silence during the week commencing the 20th October 2008.

They want to encourage as many members, schools, children, parents and businesses to take part to help raise the profile of children and young people with speech, language and communication impairments. They are also attempting to get into the Guinness Book of World Records for “the most people simultaneously performing sign language to a song at different venues”. They hope that you will want to join in with this, and you can incorporate it as part of your sponsored silence.

The record attempt will be on the 22nd October at 9.30am. For more information about either or both of these events, sponsor forms, posters, stickers, and support please contact Mark Thompson at the Afasic central office (phone 020 7490 9410, email [markt@afasic.org.uk](mailto:markt@afasic.org.uk)).

### **Financial victory for families of disabled children.**

Up to 30,000 families with a disabled child will be better off thanks to campaigning by Contact a Family and Every Disabled Child Matters (EDCM).

The charities identified that there were thousands of parents not receiving the child disability element of tax credits because they did not know to tell HM Revenue & Customs (HMRC) they were receiving Disability Living Allowance for their child.

After months of joint work by Contact a Family, EDCM, HMRC and the Department of Work and Pensions, HMRC has now found a way to identify the estimated 30,000 families currently missing out and give them the correct tax credits. Officials have also put measures in place to ensure future claimants receive their full entitlements.

Jill Harrison, External Affairs Director for Contact a Family, said: “We are delighted that those families who were missing out will now get their full benefit entitlements and welcome the government’s commitment to solving this situation. It costs three times as much to raise a disabled child and with fuel and food bills escalating, families are struggling to make ends meet, so every penny counts.”

Families who don’t want to wait for HMRC to check their claim can phone the Contact a Family helpline on 0808 808 3555 and they will check your entitlement.

**Lone parents no longer penalised**

From July 2008 the Child Support Agency (CSA) was replaced by a new body called the Child Maintenance and Enforcement Commission (C-MEC). There will be a gradual series of changes over the next five years. This includes a change in rules that will mean lone parents who are currently receiving a reduced amount of Income Support or income-based Jobseeker's Allowance because they were refused permission to opt out of using the CSA will have their benefit increased to the full amount.

The Child Maintenance Options Helpline provides information to parents about the options available in making a child support arrangement, Tel: 0808 988 0988 (Mon-Fri 8am-8pm, Sat 9am-4pm); Web: <http://www.cmoptions.org/index.htm> or call the Contact a Family Helpline on Tel: 0808 808 3555 for more information.

**Lone parents wrongly told to sign on.**

From November lone parents with a youngest child of 12 years old or over will no longer be entitled to Income Support (IS) - and will be expected to sign on for Jobseeker's Allowance in order to get benefit. **However, this change in the rules should not affect lone parents of a child receiving the middle or highest rate care component of Disability Living Allowance.**

**It should also not affect those who get Carer's Allowance or who are fostering children. Lone parents in any of these circumstances will still be able to claim Income Support.**

Contact a Family's helpline has already had calls from lone parents with disabled children who have wrongly been told by staff at the Department of Work and Pensions (DWP) that their IS will stop in November. Any lone parent caring for a disabled child who is told their IS will stop can contact the Contact A Family free helpline on 0808 808 3555 for advice.

**County News****Action for Blind People**

This is a National charity for visually impaired people, providing supported housing, holiday hotels and employment support, information and advice and a welfare rights service. They also run a grants scheme to help with holidays and assistive technology. Support and assistance is also available to help blind and partially sighted entrepreneurs to set up and develop their business.

They run Actionnaires clubs providing sporting activities for children aged between 8 and 18. Under 8's are welcome as long as they come along with an adult and the adult stays with them during the session. Children are also welcome to bring along a sighted brother, sister or a friend if they wish

They offer multi-sports sessions run by professional coaches for blind and partially sighted children and young people of all abilities. If your child has a favourite sport they want to improve; a new one they want to learn or even if they fancy just coming along to run around and let off a little steam, your local club will have something for them.

Currently in Hampshire there is an Actionnaires club at Southampton, meeting on the second and last Saturday of the month from 9.30am until 12pm at: Chamberlayne Leisure Centre, 150 Weston Lane, Southampton. Among other activities are swimming, martial arts and visits to a local climbing centre. If you have any questions about Southampton Actionnaires give Nicky Holloway a call on 07793527031. Alternatively you can call Ruth on 07731476644, or Helen on 07971804535.

The contact details for the main Action for Blind People organisation are Helpline: 0800 915 4666 e-mail: [info@actionforblindpeople.org.uk](mailto:info@actionforblindpeople.org.uk) Website : [www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk)

#### County Council factsheets

Updated factsheets are available now from Hampshire County Council. They show how the public can put their views forward to the Council, find out more about a particular issue, and how to get in touch with County Council staff.

**Factsheet 1: How we work** offers a user-friendly summary of how Hampshire County Council is organised.

**Factsheet 2: How we listen** explains the deputation procedure and County Council meetings.

**Factsheet 3: How we handle information** provides an introduction to the Data Protection Act, Freedom of Information and explains people's rights to accessing the information we hold.

**Factsheet 4: How to get in touch** describes the County Council's complaints procedure, and gives a link to our online form for members of the public to make their views heard.

**Factsheet 5: How we respond** explains the standards everyone can expect when writing to, telephoning or sending e-mails to our offices.

The factsheets can be found at the website at

<http://www3.hants.gov.uk/factsheets.htm>.

If you would like a printed copy of these factsheets, please send an email to [corporate.communications@hants.gov.uk](mailto:corporate.communications@hants.gov.uk) or call the Contact Centre on 0845 603 5638

#### Checking Car Seats

Hampshire County Council's Road Safety Team is joining forces with Hampshire Fire and Rescue Service (HFRS), offering a series of free child car seat checking events, a move that's supported by the BBC's Real Rescues crew.

And not a moment too soon – the last child car seat checking event in Basingstoke revealed that a staggering 40% of the seats checked were fitted incorrectly, and 39% were not compatible with the car.

A properly fitted child car seat is essential for the safety of young children traveling in vehicles. At just 5mph a child can be thrown forwards and killed. Last year in Hampshire there were 179 reported child vehicle occupant casualties.

Staffed by specialists in child car safety seats, the events will focus on checking that children's car seats are compatible with the vehicle they are in and appropriate for the age and size of the child they are for.

The child car seat checking events will be at Basingstoke Fire Station 20 September, Eastleigh Fire Station 4 October and Alton Fire Station 11 October. (Southampton and Portsmouth are also carrying out checks with HFRS, please contact them for more details).

For further information please contact Charlotte Allison, Senior Road Safety Officer – Publicity telephone: 01962 874603 email: [charlotte.allison2@hants.gov.uk](mailto:charlotte.allison2@hants.gov.uk)

### **The Big Free 'Live Your Dream' Picnic**

As the closing ceremony of the XIXth Olympiad reaches its conclusion in Beijing on August 24<sup>th</sup> and the Olympic Flame is extinguished, the Olympic Handover Flag will be raised simultaneously up and down the UK to mark the official handover and beginning of four years of preparations for London 2012.

Winchester will be celebrating this occasion with a fabulous family fun day. Winchester City Council and Hampshire County Council have teamed up to provide a wide range of sporting and arts taster sessions and activities free of charge, as well as providing a huge TV screen on which to broadcast the final moments. All you need to do is bring your picnic and join in the fun!

In addition to the activities at North Walls, there will be an invigorating procession through the city's streets, with Chinese dragons accompanied by a Samba-style drumming group. The procession will arrive at the Guildhall just in time to see the official Olympic Handover Flag being raised at exactly the same moment the Olympic Flag is lowered in Beijing.

#### **Activities at North Walls Recreation Ground**

Picnic: bring all you need, including something to sit on;  
TV screen: watch the closing moments of the Olympics; Dream Radio  
Roadshow;  
Sports taster sessions: rugby, football, athletics, mini tennis, netball, badminton;  
Orienteering course;  
'Shoot for Goal' inflatable;  
River Park Leisure Centre Mini Olympics; Climbing wall; Trainer wanging;  
Arts activities

Tickets are free and can be obtained by phoning or e-mailing 01962 848 231 or by e-mailing [smoore@winchester.gov.uk](mailto:smoore@winchester.gov.uk) There will also be catering, toilets and first aid facilities at North Walls.

Timetable of Events	
11am	Picnic, TV broadcast, activities and radio roadshow commence
1.15pm	Procession gathers
1.30pm	Procession moves off
2.30pm	Procession arrives at The Broadway
2.45pm	Olympic Handover Flag raised
2.45pm	Recycling of procession instruments
4pm	North Walls activities finish

## Local News

### East Hampshire cycling for all!

The goal of Cycling For All is to enable as many people as possible to enjoy cycling and its many benefits. In East Hampshire the starting point has been to focus on people with disabilities - a group for whom cycling is not often an easy option. A range of adapted bikes and trikes make cycling an accessible activity for many people who would normally not be able to join in. The Cycling for All centre is in the beautiful Alice Holt Forest. Volunteers are being recruiting to help the community to get the most out of cycling. If you would like help to get cycling in East Hampshire, call Clive on 07717 721511 or email [clive.andrews@ctc.org.uk](mailto:clive.andrews@ctc.org.uk).

### Energy bill help in Rushmoor

The ScottishPower Energy People Trust has awarded £75,000 to Rushmoor Healthy Living to deliver a new project over a two year period that will help local residents with their energy bills. An 'Energy Advisor' will be employed to offer one to one advice to residents who have energy bill arrears. As well as advising on energy saving measures and available grants, they will signpost people to debt relief schemes and will supplement the vital work already being carried out by agencies such as Citizens Advice Bureaux. For an appointment or more information telephone 01252 362660 or e-mail [admin@rushmoorhealthyliving.org.uk](mailto:admin@rushmoorhealthyliving.org.uk)

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To send in any news or helpful information that you would like to share via Linklines contact: Fiona Hall, Joint Information Link Co-ordinator, Children's Services, Children & Families Strategic Planning Team, 1<sup>st</sup> floor, Ashburton Court East, Winchester SO23 8UG Phone: 01962 846123  
e-mail: [joint.information.link@hants.gov.uk](mailto:joint.information.link@hants.gov.uk)

**Please remember, if at all possible, to supply your e-mail address for delivery of Linklines as this helps us to save costs and enables us to deliver it to you much more quickly than by post.**

**Thank You!**

**Next issue of Linklines – October 2008**