



# Link-Upp (Birmingham)

## Networking for Parent/Carer Groups

www.link-upp.org.uk

Issue 57

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# PICNIC IN THE PARK '09



Link-Upp steering Group members Lin and Pat lend a hand with the balloons.

This year the sun shone down on us as we celebrated Contact a Family's 30th birthday. Entertainment was provided by Rags the clown, there was a drumming workshop and mask making courtesy of "Talking Drums", not to mention face painting, parachute games, magic and even a little impromptu karaoke! A record number of families then went onto the Nature Centre. Many thanks to all who turned up for making the day a resounding success.



## Link-Upp Activity Plan

Firstly we would like to apologise for the non-appearance of the promised "Growing Upp" workshop advertised in the last newsletter, Unfortunately we had difficulty getting the trainer we wanted. This workshop is only postponed, we appreciate that the issues surrounding awareness of sexual issues in young people with additional needs is one that can worry parents, and we will do our very best to facilitate this workshop soon.

### Resilient Parenting Workshop:

Tuesday 6th October at Sutton Coldfield Library

OR

Friday 6th November at "The Hub" Kings Heath.

See enclosed flyer for more details.

## Contribute to a new Special Needs Handbook

If you are a parent of a child with special needs and have a tip you would like to share with other parents and professionals, you can contribute to a new Special Needs Handbook which is being compiled.

The Special Needs Handbook will be available freely over the internet and will contain useful tips, ideas and solutions for day-to-day problems encountered by people living with, or supporting a child or adult with a disability or special needs.

To send your tips or for more information about this project e-mail:  
[mail@specialneedshandbook.com](mailto:mail@specialneedshandbook.com)



Link-Upp's constitution states that we cater for the parents and carers of children and young people (up to the age of 25) that have a disability. At the moment we receive the majority of our funding from Children, Young People & Families, Birmingham City Council. As reported in an earlier newsletter, we had applied for additional funding from "Adults & Communities" to specifically support the parents of older children going through the "transition to adulthood" stage. Unfortunately, despite being initially successful, following a judicial review of all applications, we were turned down. Please be reassured that we are pursuing alternative funding that will allow us to support you, if you fall into this category. In the meantime all our events are open to all our members.



Link-Upp group directory

Part of Link-Upp's service level agreement with Birmingham City Council is to compile and maintain a list of Parent Carer Support Groups in the city. Please contact us if you belong to a group that we do not list on our website. Thank you.



# Parent Views Count



The next two open meetings will be:

Tuesday 20th October from 7pm-9pm.

Wednesday 21st October from 10am-12.30pm.

The content is the same at both meetings. In October the speaker will be Chris Bush (Head of Transition Services) who will be updating the meeting on the City's progress in this area.

At each meeting there is also a chance to speak with representatives from SENAS, The Family Information Service and Social workers from the Disabled Children's team. A crèche is now available at both meetings.

For more information about Parent Views Count:

Phone Sue on: 01676 533 565 or e-mail: ParentViewsCount@aol.com.

*Watch out for the launch of the new Parent Views Count website in December!*

**national transition support team**  
working together to improve transition  
for disabled young people

### Online discussion forum on transition

The National Transition Support Team website includes an online discussion forum for people to discuss the Transition Support Programme and issues to do with transition. It is easy to register and add posts and is open to anyone with an interest in issues affecting disabled young people.

For more information visit

[www.transitionsupportprogramme.org.uk](http://www.transitionsupportprogramme.org.uk)

## face2face

Parents supporting Parents of Disabled Children

Face2Face is a network of trained, volunteer befrienders who help parents make positive adjustments to the news that their child has a disability. Every Face2Face befriender is a parent too, someone whose own child has a disability. They know what it's like to cope with a new diagnosis and can offer support parent-to-parent. Face2Face is free and confidential. We support parents of children with any type of disability.

In Birmingham your local Face2Face scheme is managed by Link-Upp Birmingham.

To find out more about our local scheme call 07827 472 659 or e-mail: [face2face-birmingham@live.co.uk](mailto:face2face-birmingham@live.co.uk)

If you prefer you can access online or telephone befriending by filling out a form on the network website:

[www.face2facenetwork.org.uk](http://www.face2facenetwork.org.uk)



**Young people  
send mental  
health  
manifesto to  
all MPs**



Mental health charity **YoungMinds** is putting pressure on the government to improve mental health services for the young with a manifesto created by a panel of young people. The manifesto is being sent to all MPs calling on them to sign up to an early day motion supporting the manifesto and ensuring that policy documents such as the CAMHS (Child and Adolescent Mental Health Services) Review are fully implemented. Liberal Democrat MP Lynne Featherstone is tabling the motion. A panel of 250 young people with mental health problems has contributed to the document, which is written in their own words. Its recommendations include better training in primary and secondary schools to recognise and tackle problems, shorter waiting lists for CAHMS, and better services post-18.

For more information visit

[www.youngminds.org.uk/](http://www.youngminds.org.uk/)



Website  
of the  
Month

Council for  
Disabled  
Children

This is quite an awkward site to find, but if you are interested in national policies that impact upon disabled children and children with special educational needs (SEN) and their families, it's worth the effort!

To get there first visit the National Children's Bureau website at: <http://www.ncb.org.uk/> & put CDC in the search box, this then takes you to a link to the CDC website.

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. They aim to promote the active participation of disabled children and young people, making sure their voices and success stories are heard.

#### CDC News Digest

The CDC news digest is a quarterly round-up of all the essential policy and practice news involving disabled children and young people, and their families. Visit the site to activate an e-mail alert as each digest is published.



## 30 Not Out

### Contact a Family celebrates its 30th anniversary

For the last three decades Contact a Family 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. They 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 their work continues to be as vital now as it was 30 years ago.

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

#### **FOR EXAMPLE:**

##### Campaign to change benefit rules

Contact a Family is looking for families whose children have had their Disability Living Allowance (DLA) suspended once they have been in hospital for a certain amount of time.

At present, DLA regulations state that if a child under 16 is in hospital for more than 12 weeks their DLA payments are suspended. For young people aged 16 and over, the payments are suspended after only four weeks.

This can impact on a parent's entitlement to continue getting Carers Allowance.

Contact a Family thinks this is wrong and they are gathering evidence from families about the effect of this benefits rule, to highlight the issue and push for change.

Claire Pimm, Director of Policy and Communications, said: "Children who have long-term health needs are often in and out of hospital and this puts tremendous pressure on their families. It is wrong that they are financially penalised at such a difficult time.

If your child's DLA has been suspended after a stay in hospital, please do get in touch. Contact a Family would like to gather as much evidence as possible so that they can highlight this issue and encourage change in the regulations."

Tel: Elaine Bennett, 020 7608 8741

or e-mail: [elaine.bennett@cafamily.org.uk](mailto:elaine.bennett@cafamily.org.uk)



30 years of  
strengthening  
families with  
disabled children



[www.link-upp.org.uk](http://www.link-upp.org.uk)

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### Disclaimer

The editor retains the right to omit, include or edit any contributions. The views and suggestions in this newsletter are those of individual contributors and not necessarily supported by Link-Upp. Link-Upp cannot accept responsibility for any goods or services mentioned in, or enclosed in, this newsletter.

### Acknowledgment

We are grateful to Children, Young People & Families, Birmingham City Council, for funding the work of Link-Upp.



First in a new series of Link-Upp "cut out & keep" guides.

## THE BLUE BADGE SCHEME

[www.birmingham.gov.uk/blue-badge-scheme](http://www.birmingham.gov.uk/blue-badge-scheme)



The Blue Badge Scheme gives parking concessions for people with severe walking difficulties who travel as either drivers or passengers, registered blind people and also people with severe upper limb disabilities who regularly drive a vehicle but cannot turn the steering wheel by hand.

The Scheme is meant to help only those people with very severe, permanent disabilities. People with temporary or intermittent difficulties, such as a broken leg, will not qualify for the scheme.

The information below refers only to the conditions affecting disabled children. For information regarding disabled adults please visit the website.

### How do I qualify for a Blue Badge?

You will only qualify for a badge if the child on whose behalf you are applying receives the higher rate of the mobility component of the Disability Living Allowance or is registered blind.

Some people may also be eligible if they are more than two years old and have a permanent and substantial disability which means they cannot walk, or which makes walking very difficult.

### Special Rules for Children under two

A parent of a child who is less than two years old may apply for a badge for their parent if their child has a specific medical condition which means that they must always be accompanied by bulky medical equipment which cannot be carried around without great difficulty, or if they need to be kept near a vehicle at all times, so that they can if necessary, be treated in the vehicle, or quickly driven to place where they can be treated, such as a hospital.

### How to apply for a Blue Badge

Blue Badges are issued over the counter at 27 local Post Offices.

Application forms are not available at the Post Office but can be obtained from:

### **Older Peoples Access Service (OPAS)**

Tamebridge House  
Aldridge Road  
Perry Barr  
Birmingham B42 2TY

Telephone: 0121 303 1234

e-mail: [OlderPeoplesAccessService@birmingham.gov.uk](mailto:OlderPeoplesAccessService@birmingham.gov.uk)



[workingfamilies.org.uk](http://workingfamilies.org.uk)

## Working Families' Survey on Summer Holiday Care for Disabled Children

Nearly 70% of parents of disabled children surveyed by

Working Families said that finding appropriate childcare during the summer holidays was a barrier to their paid work. Working Families, the national charity which, uniquely, helps parents balance their work commitments and their home responsibilities, carried out a survey this summer. They asked members of their *Waving not drowning* network of parents of disabled children who work or wish to work about their experiences of finding and using summer holiday care for their disabled children. Parents felt that the childcare available did not meet their children's needs. It was difficult to find out what was available. It was too far from their homes, didn't cover the hours they needed to enable them to work and cost too much. Parents need to work for financial reasons. It costs three times as much to raise a disabled child as a non-disabled child. A disproportionate number of families with disabled children live in poverty. Also parents wish to work for reasons of self esteem, to socialise and to be good role models to all their children. But the care they need is not there. As well as providing a free newsletter, publications and a helpline to advise parents about their rights in the workplace Working Families campaigns for a better deal for working parents and their children. The survey has shown the great need for a campaign for appropriate summer holiday care for disabled children and easy access to information about what is available.

To learn more visit the website or contact Janet Mearns, Disability Adviser, Working Families.

[Janet.mearns@workingfamilies.org.uk](mailto:Janet.mearns@workingfamilies.org.uk)

