

# eBulletin

for Learning Disabilities  
& Family Carers in England



The Princess Royal Trust  
*for Carers*

**CROSS  
ROADS  
CARE**

a positive partnership between and The Princess Royal Trust for Carers and Crossroads Care

ISSUE 4

November 2010

## Contents

- 1 The online resource bank
- 2 Caring for someone with autistic spectrum disorder
- 3 Policy issues and consultations
- 4 Campaigns
- 5 Publications
- 6 Other news
- 7 Finally...

**Welcome** to the fourth issue of the *eBulletin for Learning Disabilities and Family Carers*; the quarterly update for all staff working with family carers of people with learning disabilities, containing new legislation and developments, advice and help, and good practice examples.

The eBulletin is produced by Cath Baker, Policy and Development Officer (Learning Disabilities). This is a joint post between The Princess Royal Trust for Carers and Crossroads Care, and is funded by the Department of Health as part of Valuing People Now, a cross-government three-year strategy for people with learning disabilities. Cath works on England policy issues affecting family carers of people with learning disabilities, carers with learning disabilities and mutual carers. This eBulletin is England-focused, but all the information can be useful for the rest of the UK.

This issue of the eBulletin contains a special section on caring for someone with an autistic spectrum condition, with links to the latest information and resources to help Carers' Centres and Crossroads Care schemes work with carers experiencing these issues.

We would like to receive your feedback on any of the items that you read in the following bulletin. Please send your comments and any suggestions and contributions to [cbaker@carers.org](mailto:cbaker@carers.org) or call 01568 760027.

© The Princess Royal Trust for Carers

**CONTACT:** Cath Baker, Policy and Development Officer (Learning Disabilities)  
at [cbaker@carers.org](mailto:cbaker@carers.org) or 0844 800 4361

[www.carers.org](http://www.carers.org)  
[www.youngcarers.net](http://www.youngcarers.net)

Registered charity number SC015975

## 1. The online resource bank

The online resource bank is available to all The Princess Royal Trust Carers' Centres on TrustNet at <http://tinyurl.com/34sl8w5> and to all Crossroads Care Schemes on CCIID at <http://tinyurl.com/36pttx9>. For access to TrustNet, please contact Fiza Asar, Online Editor at [fasar@carers.org](mailto:fasar@carers.org). For access to CCIID, please contact Sarah Capstick, Information and Communications Officer, at [communications@crossroads.org.uk](mailto:communications@crossroads.org.uk). For other organisations, some of the resources are also publicly available at <http://tinyurl.com/39rugxg>.

### Good practice examples

We are trying to collect carers' stories and examples of good practice and service models from The Princess Royal Trust for Carers' Centres and Crossroads Care providers. Please contact Cath on [cbaker@carers.org](mailto:cbaker@carers.org) if you have any examples of innovative work with family carers of people with learning disabilities or with carers who have learning disabilities.

---

## 2. Caring for someone with autistic spectrum disorder

There are over half a million people in the UK with some form of autism. Of these approximately 50% will also have a learning disability. The National Autistic Society offers help to parents and carers including respite support and further help and training at <http://tinyurl.com/3yrwqdv> and a directory of autism services <http://tinyurl.com/3xyfoj7>.

### ACT now

A new group called 'Autism Campaigners Together' has launched ACT NOW, a campaign reflecting shared concerns about the proposed benefit cuts and medical assessments which will begin in 2013. Further information is available from <http://tinyurl.com/38hwh5j>.

### Autism diagnosed from brain scans?

The Independent has reported that autism could in future be diagnosed in 15 minutes from a brain scan. Scientists using facial recognition software have devised a method which can distinguish the autistic brain from the normal brain with 90 per cent accuracy. The method

could lead to the introduction of screening for the disorder in children. The full article is available at <http://tinyurl.com/26ymwqy>.

### **Statutory Guidance on Fulfilling and Rewarding Lives (The Autism Strategy)**

The consultation period on the statutory guidance for Implementing Fulfilling and Rewarding Lives finished earlier this month. The Princess Royal Trust for Carers and Crossroads Care produced a response which is available for Carers' Centres and Crossroads Schemes only on TrustNet and CCIID.

### **ATT – the Autistic spectrum disorder transition toolkit**

Although this site is relatively old there are some good resources here to help with the transition from primary school to secondary school for children with autism and their parents. The toolkit is available at <http://www.autismtoolkit.com/>.

---

## **3. Policy issues and consultations**

### **New Care Commission**

The Government has established an independent commission, the Commission on the Funding of Care and Support. The Commission will make recommendations on how to achieve an affordable and sustainable funding system for care and support, for all adults in England, both in the home and other settings. The commission is going to build upon the large body of evidence available on this issue. Further information is available from <http://tinyurl.com/3xjqxt5>.

### **Improving health and social care support for carers from black and minority ethnic communities**

This briefing paper draws attention to the experience of black and minority ethnic carers in the context of mainstream service provision and recent policy developments such as the National Carers Strategy, service user and carer involvement and the personalisation agenda. It acknowledges that marginalisation is often a consequence of lack of support for both carers and black and minority ethnic communities in health and social care. The paper highlights the diversity of carers from these ethnic backgrounds and the multifaceted impact of discrimination. These can be downloaded at <http://tinyurl.com/37jdfk4>.

## Guides to the Equalities Act

The new Equalities Act came into force on 1 October. The Government has produced a number of different guides to the act, including a guide for carers and an Easy Read guide. These can be downloaded at <http://tinyurl.com/36dgn7o>.

---

## 4. Campaigns

### Learning Disability Coalition launches Protect the Frontline campaign

The Learning Disability Coalition (LDC) has launched its campaign to *Protect the Frontline*, on the steps outside HM Treasury in London. The *Protect the Frontline* campaign calls on Central Government and local authorities to recognise that despite the tough financial climate, funding for learning disability services must be protected against any cuts. Further information is available at <http://tinyurl.com/34kex6m>.

### Counting the Costs 2010 - Families with disabled children struggle to afford food and heating

*Counting the Costs 2010*, a survey and report from Contact a Family, found that families with disabled children are going without essentials such as food and heating. The survey asked over 1,100 UK parents caring for a disabled child about their current financial situation. The full report can be found at <http://tinyurl.com/35oznz7>.

### Needless deaths continue - the Department of Health highlights continuing failures in care for people with a learning disability

The Department of Health has published its findings on the progress of *Six Lives* – last year's report containing evidence that hospitals are failing to provide proper healthcare to people with a learning disability. It's available at <http://tinyurl.com/3554fav>.

*Six Lives* was published by the health ombudsman in March 2009, in response to Mencap's *Death by Indifference* campaign. It revealed 'significant and distressing failures' in health and social care services and that people with a learning disability experienced 'prolonged suffering and poor care'.

Mencap is calling on all health trusts to sign up to and implement its nine-point 'Getting it right' charter - see <http://tinyurl.com/2u5vdnt>. It is also asking the health ombudsman to publish a follow up report on NHS Trusts' progress in 2012.

## 5. Publications

### Social care in crisis report

The Learning Disability Coalition has published a new report, *Social Care in Crisis*, which is a survey of all the local authority areas in England, to ascertain what funding cuts have already taken place, how cuts are affecting services for people with learning disabilities and the funding pressures faced by local authorities. The report is available at <http://tinyurl.com/38s7qzb>.

### Approaching your local partnership board

Mencap has produced some Valuing People factsheets which give an overview of each topic addressed by *Valuing People Now* and a set of questions you can ask your local Learning Disability Partnership Board to make sure changes are taking place. The factsheets are available at <http://tinyurl.com/3xl7muz>.

### All about us CD-ROM wins two awards

A CD-ROM, *All about us*, aims to help the personal development and knowledge of people with learning disabilities around sex, sexuality and relationships. It won the Disability category at the Charity Awards 2010, and it received a Silver Award for Excellence in the E-learning Awards 2009. This resource is a self-study learning tool that can be used by someone with learning disabilities on their own, or with support from professionals and/or family carers. The CD rom is available from <http://tinyurl.com/3a7ecj3> and a demo can be seen at <http://tinyurl.com/33yhk6j>.

### The Improving Health and Lives Learning Disabilities Observatory

The aim of the new *Improving Health and Lives Learning Disabilities Observatory* is to keep watch on the health of people with learning disabilities and the health care they receive. Their new website provides information on their learning disabilities and health projects. Further information is available at [www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk) or [www.ihal.org.uk](http://www.ihal.org.uk).

### Health inequalities and people with learning disabilities

People with learning disabilities are much more likely to have poor health than other people. The Improving Health and Lives Learning Disabilities Observatory has produced a report which will be useful to people who commission or provide services for people with learning disabilities. The report will be updated annually and is available at <http://tinyurl.com/38agdpg>. A summary for professionals and family carers can be found at <http://tinyurl.com/38vkyhl>.

## 6. Other news

### Cerebra

Cerebra is a UK children's disabilities charity providing practical help, information and support to parents and carers of children up to the age of 16 who have a brain related disability. Cerebra is set up to help improve the lives of children with disabilities through researching, giving information, and face to face support to children and their carers.

Cerebra provides a range of free services to members including specialist advice via the Regional Parent Support Team (who can advocate for families and are able to provide face to face support and advice related to Cerebra services and other help through home visits or clinics) or through the Helpline, a Stress Counselling Helpline, publications, fact sheets, a step by step guide to completing the DLA claim form, a grants scheme, voucher schemes for Speech and Language Therapy, voucher schemes for Wills and Trusts, E-learning courses for parents, Sleep Counselling service, a Postal Lending Library of toys and literature, Holiday Home, and a Personal Portfolio (or talking book) service.

For more details see [www.cerebra.org.uk](http://www.cerebra.org.uk), or call the helpline on 0800 328 1159 or the stress counselling helpline on 0800 043 9385.

### 'Mate Crime'

ARC is running a three-year project, Safety Net, funded by the Department of Health, investigating 'Mate Crime'. The project aims to prevent the exploitation of people with learning disabilities, by those claiming to be their friends. Further information from the 'Safety Net' website: <http://www.arcsafety.net/>.

Media coverage of learning disability mate crime can be found at <http://tinyurl.com/2f292vh> and <http://tinyurl.com/2bdhevd>.

### New learning disability website pools expertise of parents and professionals

Netbuddy is the first online resource of its kind offering hundreds of simple, yet ingenious solutions to everyday issues encountered by parents, carers, teachers and therapists working with learning disability. From creating calm before bedtime to preventing panic attacks on the bus, Netbuddy lists over 700 practical tips and suggestions from people with first-hand experience of special needs.

People visiting Netbuddy can use the site in several ways: they can either search for tips in areas such as 'routines' or 'sleep' or they can offer their own ideas. They can download videos and talk to other people on the interactive forum, or search for practical help in the information packs. Further information is available at [www.Netbuddy.org.uk](http://www.Netbuddy.org.uk).



## Giving Us A Voice

The Giving Us A Voice project aims to bring together Black, Asian and ethnic minority family carers and people who have learning disabilities with those who provide and commission services. The project is being run jointly by ARC, Mencap and BILD. There will be nine regional meetings where there will be a full discussion on delivering good social care services in times of change, and these will lead to the production of a national charter for inclusion. It is hoped that many BME family carers will attend these meetings. Please contact [pam.smith@arcuk.org.uk](mailto:pam.smith@arcuk.org.uk) for further information, or see <http://givingusavoice.org.uk/>.

---

## 7. And finally...

The next eBulletin will be published shortly after Christmas. If you have any information that would be useful to those working with family carers of people with learning disabilities, please contact Cath Baker on [cbaker@carers.org](mailto:cbaker@carers.org). Articles should be brief (approximately 100 words) and contain a web link.