



The Princess Royal Trust  
for Carers

# eBulletin for Learning Disabilities & Family Carers in England

**CROSS  
ROADS  
CARE**

Produced in partnership with The Princess Royal Trust for Carers  
and Crossroads Care

ISSUE 1

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**Welcome** to the first 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.

I'm Cath Baker, Policy and Development Officer (Learning Disabilities). My post is jointly held 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.

I work on England policy issues affecting family carers of people with learning disabilities, carers with learning disabilities and mutual carers. I am responsible for promoting access to existing resources, identifying and developing best practice, developing new networks and strengthening existing networks with external statutory and voluntary sector partners, and promoting better public and professional understanding of these groups of carers.

The eBulletin is England focused, but all information can be useful for the rest of the UK.

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

## What resources are available?

We have been working alongside Inspired Services and the Foundation for People with Learning Disabilities and the Sharing Caring Project at Sheffield Mencap, to produce the following resources which can be found on TrustNet.

If you do not have access to TrustNet, please contact Sam Butler, Online Editor, at [sbutler@carers.org](mailto:sbutler@carers.org).

### ***Directory of Learning Disability Carers Services***

Based on research carried out in 2009, there remain some gaps in this body of work. If you are aware of any services offered by The Princess Royal Trust Carers' Centres or by Crossroads Care Schemes which are not included, please do contact me.

This Directory is also accompanied by the research report, Sharing the Caring, and is available at <http://www.carers.org/trustnet/articles/learning-difficulties-and-mutual-carers,3019,CA.html> .

### ***Guidance for Learning Disability Partnership Boards***

Written by Christine Towers and Hazel Morgan, Foundation for People with Learning Disabilities, and Dalia Magrill, Sharing Caring Project at Sheffield Mencap, this booklet offers guidance to learning disability partnership boards to help them ensure that carers of people with learning disabilities are supported in their own right and are involved in local service developments which affect their lives and those of the people they care for.

Topics covered include:

- key facts about people with learning disabilities;
- what the National Carers Strategy is and how it relates to the work of learning disability partnership boards;
- the responsibilities of learning disability partnership boards to ensure that the aims of the National Carers Strategy are fulfilled for carers of people with learning disabilities and carers with a learning disability;
- important questions to be asked by learning disability partnership boards in reviewing, devising and implementing services for people with learning disabilities and their carers to ensure that the needs of carers are taken into account;
- links to resources to support learning disability partnership boards' ongoing work with carers.

Supporting Learning Disability Partnership Boards to Implement the National Carers Strategy is available at <http://www.carers.org/trustnet/articles/learning-difficulties-and-mutual-carers,3019,CA.html>

### ***Good Learning Disability Partnership Boards: Making it happen for everyone***

This resource was launched by the Valuing People Now team at the National Adult and Children's Services Conference 2009 held 21<sup>st</sup> October. It provides best practice examples from around England and proposed ways of working, and is available from the Department of Health's website:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_107385](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107385)

## **Literature Review and Resource Pack**

Produced by the Foundation for people with Learning Disabilities and the Sharing Caring Project at Sheffield Mencap, this resource helps workers and volunteers within The Princess Royal Trust Carers' Centres and Crossroad Care Schemes to develop and provide the best information and support to family carers of people with learning disabilities. It is available to download from <http://www.carers.org/trustnet/articles/learning-difficulties-and-mutual-carers,3019,CA.html>.

## **What's happening next?**

We are planning a series of *How to...* guides, including:

- *How to...affect policy locally*  
Key meetings to attend so as to influence services for people with learning disabilities and their carers, their powers and the benefits of involvement.
- *How to...make services accessible to people with learning disabilities, including carers*  
planning group activities for people with learning disabilities, care planning for family carer breaks, cultural competence and working with people along the autistic spectrum (ASC);
- *How to...reach out to 'seldom heard' groups of carers of people with learning difficulties*  
Focusing particularly on older carers, mutual carers and carers who have learning disabilities themselves.

# **Policy issues and consultations**

## **Valuing People Now implementation**

The Valuing People Now website is undergoing some construction, however it is being updated constantly. Please pay particular attention to the *Resources* section at <http://www.valuingpeople.gov.uk/dynamic/valuingpeople59.jsp>.

## **The Autism Bill**

On 22<sup>nd</sup> October 2009, the Autism Bill reached the final parliamentary stage to become the Autism Act, the first disability-specific law in England, guaranteeing the introduction of the first ever adult autism strategy (further information below). The Bill was backed by a coalition of 16 autism organisations and had overwhelming parliamentary support from all the main political parties.

Further information is available from The National Autistic Society, <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=2534>.

## **A Better Future: a consultation on a future strategy for adults with autistic spectrum conditions**

Consultation on the forthcoming strategy for adults with autism has been completed and identifies five key themes: social inclusion, health, choice and control, awareness raising and training, and access to training and employment. The consultation document is available from the Department of Health at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_098707](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098707). It can also be downloaded, along with the consultation response, from the National Autistic Society at <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1380&a=20446>.

The Princess Royal Trust for Carers' response is available on TrustNet at <http://www.carers.org/trustnet/articles/learning-disabilities-national-policies,5389,CA.html>.

### **The National Valuing Families Forum**

The National Valuing Families Forum consists of family carers representing each region in England. The Forum meets quarterly and representatives feed into the National Learning Disability Programme Board, chaired by Phil Hope MP (Minister for Care Services) and David Behan (Director General for Social Care in the Department of Health).

Further information on how this forum influences national policy will be available soon.

## **Campaigns**

### ***Don't write me off***

The National Autistic Society's new campaign, *Don't write me off*, launched on 13<sup>th</sup> October 2009, aims to make the system of benefits and support in employment fairer for adults with autism.

The campaign's results show that, out of a group of adults asked about their experience of work and applying for benefits:

- just 15% have a full-time job;
- one-third are currently without a job or access to benefits;
- 79% of those on Incapacity Benefit want to work.

Changes in the system to allow more adults with autism to work will have an impact on their family carers. The National Autistic Society is encouraging people to write to their MP asking them to pledge their support for the campaign. Pledge cards and email contact details for MPs are available on the campaign website, <http://www.dontwritemeoff.org.uk/>.

### ***Living in fear***

The inquest following the death of Fiona Pilkington and daughter Francecca Hardwick has now been completed. Campaigners hope that this will be a turning point in the fight against disability hate crime.

Mencap is calling for people with learning disabilities and their carers to share their experience of disability hate crime as part of its new campaign, *Living in Fear*, which can be found at <http://www.mencap.org.uk/case.asp?id=11930&menuId=51&pageno>.

## **Publications**

### **The Foundation for People with Learning Disabilities**

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, a national charity, and operates as a directorate within the charity.

The Foundation produces a range of publications, including reports, briefings and information booklets, most of which can be downloaded free of charge from their website, [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk).

#### *My Kind of a Future (September 2009)*

An easy read workbook to help young people with learning disabilities to plan their own lives independently and think about their future. The workbook covers a range of topics including staying healthy, getting around and getting ready for work.

[http://www.learningdisabilities.org.uk/publications/?esctl526505\\_entryid5=33639&esctl544701\\_entryid5=33639&p=2&char=M](http://www.learningdisabilities.org.uk/publications/?esctl526505_entryid5=33639&esctl544701_entryid5=33639&p=2&char=M)

#### *Prepared for the Future? (September 2009)*

This booklet contains information to prepare parents, siblings and other family members to help a young relative to lead a fulfilling life after leaving school or college. It covers a wide range of topics, including getting support, different opportunities available after school, moving from the family home, health, and getting support in the caring role.

[http://www.learningdisabilities.org.uk/publications/?esctl526505\\_entryid5=33640&esctl544701\\_entryid5=33640&char=P](http://www.learningdisabilities.org.uk/publications/?esctl526505_entryid5=33640&esctl544701_entryid5=33640&char=P)

#### *Recognising Fathers: Need2Know Briefing (June 2009)*

This briefing for policy makers, commissioners and services, based on a national survey of fathers of children with learning disabilities, includes sections on encouraging and supporting fathers, the importance of fathers to family life, fathers' involvement with their children, services involving fathers, balancing paid work and caring responsibilities and keeping healthy.

<http://www.learningdisabilities.org.uk/publications/?entryid5=32897>

### **Mencap**

#### *New Diagnosis Booklet*

Following consultation with parents and carers, Mencap has produced a new booklet for parents who have just received a diagnosis of learning disability for their son or daughter. It was produced using feedback from visitors to the Mencap website who took part in our online questionnaire earlier this year and shared their experiences of receiving a diagnosis.

<http://www.mencap.org.uk/document.asp?id=11062>

### **The National Autistic Society**

#### *Supporting Adults with Autism - A Good Practice Guide for NHS and Local Authorities (2009)*

Valuing People Now has identified autism as one of four priority groups requiring better support services. This guide provides commissioners with examples of good local practice and recommendations, such as the implementation of local autism planning groups which should include family carer representatives.

<http://www.nas.org.uk/content/1/c6/02/04/83/Good%20practice%20in%20support%20adults%20with%20autism.pdf>

## **Other news**

### **The Care Quality Commission's Learning Disability Advisory Board**

The National Family Carer Network is looking for at least two family carers who can represent other families on the Care Quality Commission's Learning Disability Advisory Board. They will be

working alongside service users, representing the perspectives and interests of families that already embrace personalisation and those who feel cautious because they have lived through lots of change, and will feed back to the National Family Carer Network. Further information is available from

<http://www.familycarers.org.uk/Libraries/Local/866/Docs/News/Invitation%20for%20CQC%20Report%202009.pdf>.

## Employment

Real Roles is a new web resource for people with learning disabilities, containing blogs, case studies of people with learning disabilities who have gained employment and an expert forum, as well as further information.

The website is looking for a parent or carer to become an expert on the forum, which would involve logging on to the forum three times a week to respond to questions.

Real Roles would also like to hear from organisations that have employed someone with a learning disability, and to hear a carer's perspective of the impact that finding employment can have on the lives of people with learning disabilities.

If you know of any carers who might be interested, please contact the website administrator through the website, <http://www.realroles.co.uk/contact.html>.

## Finally...

In future issues of the *eBulletin for Learning Disabilities and Family Carers*, particular areas of learning disabilities and carers' issues will be focused upon. The next issue, to come out in February 2010, will look at older people and mutual carers. In future issues, we also hope to include information on transition and young carers.

This is your ebulletin and so please do pass on your comments and ideas. We would like to include more information on good practice currently taking place in The Princess Royal Trust Carers' Centres and Crossroads Care Schemes, and if you have any good news stories relating to learning disabilities, please contact [cbaker@carers.org](mailto:cbaker@carers.org) or call 01568 760027.