

# eBulletin for Learning Disabilities & Family Carers in England



## ISSUE 2

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**Welcome** to the second 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). 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. I work 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 older families and mutual carers, with links to the latest information and resources to help Carers' Centres and Crossroads Care schemes work with this group.

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.

# 1. The online resource bank

The online resource bank is available to all The Princess Royal Trust Carers' Centres on TrustNet at <http://www.carers.org/trustnet/articles/learning-difficulties-and-mutual-carers,3019,CA.html> and to all Crossroads Care Schemes on CCIID at <http://www.xrds.org.uk/dsweb/View/Collection-1648>.

The resource bank has been expanded to include sections on previous learning disabilities eBulletins, good practice examples and learning disabilities national policies. It also includes the resources produced by Inspired Services and the Foundation for People with Learning Disabilities with the Sharing Caring Project at Sheffield Mencap, as outlined in the last ebulletin. These are publicly available at <http://www.carers.org/professionals/social-care/articles/learning-disabilities-and-family-carers,5559,PR.html>.

For access to TrustNet, please contact Sam Butler, Online Editor at [sbutler@carers.org](mailto:sbutler@carers.org). For access to CCIID, please contact Sarah Capstick, Information and Communications Officer, at [sarah.capstick@crossroads.org.uk](mailto:sarah.capstick@crossroads.org.uk)

## What's happening next?

Our consultants will be producing a final set of resources in the next couple of months for all network members. Inspired Services will produce a series of *How to* guides:

- *How to...affect policy locally* will explain the processes by which all family carers (including marginalised groups) may become involved in influencing change at a local level and how their voices can be heard from local to regional and national level.
- *How to...make services accessible to people with learning disabilities, including carers* will be aimed, primarily, at Crossroads Care schemes providing services for people with learning disabilities to give their carers a break, but may also be relevant to The Princess Royal Trust Carers' Centres if they provide, or plan to provide, these kind of services.
- *How to...reach out* will provide practical advice to The Princess Royal Trust Carers' Centres and Crossroads Care schemes on how to find and promote services and support to 'seldom-heard' groups of family carers of people with learning disabilities.

The Foundation for People with Learning Disabilities will be producing *Training for the trainers packages*, aimed at Carers' Centre and Crossroads Care scheme staff and volunteers who are intending to improve or develop services for family carers of people with learning disabilities and carers with learning disabilities. Full details of how to access the completed toolkit will be provided in the next issue.

# 2. Older families and mutual caring

Older families of people with learning disabilities may find that their needs change as they get older and there may be concerns about the future and a lack of appropriate information and support.

## The Mutual Caring Project

The Foundation for People with Learning Disabilities has set up the Mutual Caring Project to help promote recognition of good practice and develop improved service provision for older families. The project aims to highlight this neglected area and provide evidence of practical approaches that can be used in different settings, particularly in cases where the balance of the

caring relationship between the long-term family carer (often a parent) and the person with learning disabilities (normally an adult son or daughter) has changed.

Publications in this series include *Mutual Caring*, a DVD containing four films featuring older families where mutual caring is happening and five booklets: *Supporting you as an older family carer*; *Supporting you and your family as you grow older together*; *Supporting you to support your family*; *Supporting mutual caring* and *Circles of support and mutual caring*.

The booklets are aimed at older family carers, people with learning disabilities and workers supporting older families that include a person with learning disabilities. Also available are *Need 2 know mutual caring*, a briefing note for policy makers, commissioners and services from the Foundation for People with Learning Disabilities, and *Being a carer and having a carer's assessment*, a pack to help people with a learning disability work out if they are a carer and how to get help. This pack was produced by the Valuing People Support Team and written as part of the Mutual Caring Project.

The resources will be available to download from 11<sup>th</sup> March 2010 from the Foundation for People with Learning Disabilities website [www.learningdisabilities.org.uk/mutual-caring](http://www.learningdisabilities.org.uk/mutual-caring)

### **People with learning disabilities and dementia**

There is no evidence to suggest that dementia affects people with learning disabilities differently to how it affects those without. However, family carers are a vital part of dementia diagnosis, particularly where the person involved does not use words to communicate. This is because the early stages are more likely to be missed or misinterpreted, particularly if several professionals are involved in the person's care. The person may find it hard to express how they feel their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change.

The Alzheimer's Society has produced a factsheet on learning disabilities and dementia, available at <http://alzheimers.org.uk/factsheet/430>. The Royal College of Psychiatrists and the British Psychological Society have produced a booklet *Dementia and people with learning disabilities - Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia*, available at <http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf>

### **Respond Elders Project - A Specialist Helpline for Older Families of People with a Learning Disability**

People with learning disabilities are living longer and finding more opportunities for fulfilled lives. However, this also presents the challenge of preparing for older age, to which some services have been slow to respond and families have found hard to face. The Elders Project at Respond has set up a specialist helpline to support such "hidden families", emotionally and practically in planning for the future. The helpline offers specialist therapeutic support to address these issues; callers can call as many times as they wish and take as long as they need in order to build the emotional capacity needed to face the future and consider options. The helpline worker can then signpost people onto relevant services to support families' further planning.

For further information please contact Michelle Brooks, Elders Therapist/Trainer on 020 7830 8256 or [michelle.brooks@respond.org.uk](mailto:michelle.brooks@respond.org.uk) or visit [www.respond.org.uk](http://www.respond.org.uk).

Further information about the work of the Elders Project is available to download from [http://www.respond.org.uk/assets/files/elders\\_leaflet.pdf](http://www.respond.org.uk/assets/files/elders_leaflet.pdf)

## 3. Policy issues and consultations

### Valuing People Now implementation

Valuing People Now celebrated its first birthday on 19<sup>th</sup> January 2010.

For information on the achievements to date, please see

<http://valuingpeople.gov.uk/dynamic/valuingpeople2.jsp>

### Fulfilling and rewarding lives: the strategy for adults with autism in England

The new adult autism strategy was published on 3<sup>rd</sup> March 2010 and is available at

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369).

Actions in the autism strategy include a new National Autism Programme Board, investment of £500,000 to develop training with health and social care professional bodies, autism awareness training for Jobcentre staff, guidance on making public services accessible, and a clear, consistent pathway for diagnosis.

The National Autistic Society is campaigning for the establishment of specialist autism teams, who will aim to improve access to support for adults with autism in every local area. For further information, please see <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=2608&a=21323>.

Also available from [http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/DH\\_079431](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/DH_079431) is the overarching report of findings from the Adult Autism Strategy consultation activities, and the summary of the submissions received in response to the online consultation. These provide an overview of the key themes which emerged from both the online consultation and the public engagement programme. Family carers were by far the largest group of people who responded with over 350 people contributing.

### Who Cares? Promoting Family Focused Learning Opportunities for Young Adult Carers

NIACE (The National Institute for Adult and Continuing Education) is looking at the learning needs for young adult carers. As part of the 'Who Cares?' project, NIACE would like to conduct informal interviews with young adults (16-25) with learning difficulties who are carers, to find out about their experiences of learning and how these experiences could be improved.

Each young adult will be offered a £15 gift voucher to thank them for their participation. If you are able to offer any expertise around support for young adult carers with a learning difficulty, or if you are in contact with young adult carers who may be interested, please contact Nicola Aylward at NIACE on 0116 2047059 or [nicola.aylward@niace.org.uk](mailto:nicola.aylward@niace.org.uk)

Further information on 'Who Cares?' is available from the NIACE website,

<http://www.niace.org.uk/current-work/young-adult-carers-access-to-education-and-training>

## 4. Campaigns

### Still Waiting for a Break

New research from Mencap has revealed that, despite increased levels of government funding for short breaks, some families with severely disabled children are actually receiving a reduced level of service compared with 2008. *Still waiting for a break* reveals that a £370 million package provided to local councils in 2008 - along with another £270 million for primary care trusts - is failing to meet the needs of many families of children with profound and multiple learning disabilities (PMLD). Six years after the launch of the 'Breaking Point' campaign, the research found that 3 in 10 families with PMLD children are receiving no short breaks or a reduced level

of service compared with 2008, and only 1 in 4 of the families saw an increase in their short breaks in 2009.

Download the report at: <http://www.mencap.org.uk/document.asp?id=12815>. Find out more about Mencap's Breaking Point campaign at: <http://www.mencap.org.uk/case.asp?id=542>

## 5. Publications

### How to make information accessible

A new booklet by Change, the national equal rights organisation led by disabled people, *How to make information accessible*, is available free at <http://www.changepeople.co.uk/productDetails.php?id=2010&type=3>

This can be used by services to ensure their resources are accessible to people with learning disabilities and their families.

### Contact a Family

A new report, *Our family, our future*, features the stories of 30 UK families whose children are affected by a range of disabilities and rare conditions, illustrating how families with disabled children celebrate family life despite facing bureaucracy and prejudice.

*Contact a Family* is calling for:

- the government to invest in a campaign to raise awareness of the needs of families with disabled children;
- stronger focus on disability awareness taught in early years and schools;
- people working in a public facing role to be given disability and equality training, so that they can recognise the unique talents that children bring because of their disability.

*Our family, our future* is accompanied by an exhibition of photographs which will be touring the UK. The report is available at

<http://www.cafamily.org.uk/index.php?module=newsmodule&action=view&id=359&src=@random4864ff40710ee>

## 6. Other news

### Giving us a voice

The Association for Real Change (ARC), the British Institute for Learning Disabilities (BILD) and Mencap are producing a 'Charter for Inclusion' for people with learning disabilities who use services and their family carers from black, Asian and other minority ethnic communities.

Further information on the project is available from the Association for Real Change's website, <http://www.arcuk.org.uk/1000649/default/giving+us+a+voice.html>

### Health checks for people with learning disabilities

People with learning disabilities are more likely to have greater health needs than the general population and experience more barriers to accessing primary care services.

The direct enhanced service with GPs, which entitles adults with learning disabilities to a free annual health check, has been extended until 31<sup>st</sup> March 2011. Further details can be found on the Valuing People website at <http://valuingpeople.gov.uk/dynamic/valuingpeople144.jsp>

## Hft Family Carer News Digest

Hft is a national charity supporting people with learning disabilities and their family carers and produces free *Family Carer News Digests*, written especially for family carers who have a relative with a learning disability and for organisations that support them.

Issue 16 features articles for family members on Valuing People Now, personalisation, the National Carers' Strategy, the housing register, choice-based lettings & tenancies, community connecting, new safeguarding and quality regulators and much more. Copies are available at [http://www.hft.org.uk/Family\\_Carer\\_Support/Family\\_Carer\\_News\\_and\\_resources/Family\\_carer\\_support\\_service\\_resources.htm](http://www.hft.org.uk/Family_Carer_Support/Family_Carer_News_and_resources/Family_carer_support_service_resources.htm)

## Holiday Information 2010

Hft's Family Carer Support Service is encouraging people to take up new holiday opportunities regardless of disability. *Holiday Information 2010* contains places to stay in the UK and abroad and tour operators with experience of providing services to people with learning disabilities (with and without supporters). It also includes advice about what people can do before they book, insurance, benefits issues and financial help.

For more information, please see

[http://www.hft.org.uk/Family\\_Carer\\_Support/Family\\_Carer\\_News\\_and\\_resources/Family\\_carer\\_support\\_service\\_resources.htm](http://www.hft.org.uk/Family_Carer_Support/Family_Carer_News_and_resources/Family_carer_support_service_resources.htm)

## Every vote counts

With the general election due later this year, national disability charity, United Response, has commissioned a website designed to make the political process easier to understand for people with learning disabilities.

The *Making Democracy Accessible Pack*, available on the website, also contains information on how family carers can support people with learning disabilities to vote and is available at <http://www.everyvotecounts.org.uk/pack-content/supporters/index.php>

## Guidance from Valuing People for commissioners and services

Anne Williams, National Director for Learning Disabilities and Scott Watkin, Co-National Director for Learning Disabilities announced two sets of guidance at the 'Learning Disability Today' conference on 25<sup>th</sup> November. These support commissioners and services to address the inequalities faced by people with learning disabilities in accessing support:

- *World class commissioning for the health and wellbeing of people with learning disabilities*  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_109088](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109088)
- *Equal access? A practical guide for the NHS: creating a Single Equality Scheme that includes improving access for people with learning disability*  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_109753](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109753)

## 7. Finally...

Issue 3 of the *eBulletin for Learning Disabilities and Family Carers* will focus on transition, young carers of people with learning disabilities, including siblings, and young carers with learning disabilities.