



The Princess Royal Trust
for Carers

**CROSS
ROADS
CARE**

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

eBulletin

for Learning Disabilities
& Family Carers

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Contents

- 1 The online resource bank
- 2 Panorama documentary on Winterbourne View
- 3 Working with family carers from BME communities
- 4 Policy issues and consultations
- 5 Campaigns
- 6 Publications
- 7 Other news
- 8 Finally...

Welcome to the fifth 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.

This edition contains a special section on working with BME family carers of people with learning disabilities and information for family carers on the recent Panorama documentary on the residential unit Winterbourne View.

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.

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 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://trustnet.carers.org/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>. For access to TrustNet, please contact Fiza Asar, Online Editor at fasar@carers.org. For access to CCIID, please contact Sarah Capstick, Information and Communications Officer, at communications@crossroads.org.uk. For other organisations, some of the resources are also publicly available at <http://professionals.carers.org/social-care/articles/learning-disabilities-and-family-carers.5559,PR.html>.

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 if you have any examples of innovative work with family carers of people with learning disabilities or with carers who have learning disabilities.

Training

Would you like free training on learning disability issues for your staff? We are able to offer free training from a 2 hour session to a whole day, to Carers' Centres and Crossroads Care services. Topics that can be covered include:

- Introduction to working with family carers
- Learning disabilities and dementia
- Older carers, mutual caring and carers with learning disabilities

Other topics may be available - call Cath on 01568 760027 or email cbaker@carers.org to discuss your requirements.

2. Panorama documentary on Winterbourne View

The Panorama documentary about alleged abuse at Winterbourne View, the residential unit for people with learning disabilities run by Castlebeck Care Ltd., has raised many questions and anxieties amongst family carers. The documentary, which was aired on BBC1 on 31 May, is available on BBC iPlayer at http://www.bbc.co.uk/iplayer/episode/b011pwt6/Panorama_Undercover_Care_The_Abuse_Exposed/

The National Challenging Behaviour Strategy Group has produced a charter for people with learning disabilities who are labelled as challenging, which aims to highlight and protect their

human rights and to encourage all sectors of health and social care to provide individualised, high quality, reliable and safe care and support to them and their families. The charter is available at <http://www.thecbf.org.uk/pdf/CompletedCharter.pdf>. Further information about the work of the group can be found at <http://www.thecbf.org.uk/campaigns/campaigns.htm>.

The Challenging Behaviour Foundation has produced a factsheet to help support family carers who are concerned about relatives in residential care. It's available here: <http://www.challengingbehaviour.org.uk/>. The Foundation also provides a family support line on 0845 602 7885.

The Government has since announced that

- The Care Quality Commission (CQC) will investigate all Castlebeck services
- The NHS and Local Authorities will conduct internal inquiries into failings
- The Department of Health will be conducting an investigation and bringing together the findings of the NHS and CQC investigations to learn lessons from this tragic case.

We have been asked by Dame Philippa Russell of the Standing Commission on Carers to help collate family carers' concerns. If you are in touch with family carers of people with learning disabilities, particularly if the person they care for is in residential care, we would be grateful if you could ask the following questions:

1. How do family carers raise any matters of concern about the residential placement, (not easy when you go away and leave your relative with the staff you are criticising)?
2. What do family carers feel about safeguarding?
3. What 'top tips' would they give to parents and other family carers when someone moves out of the family home?
4. Do they have any thoughts about the role of family carers in the residential care and support of their relative?

Please email any responses to cbaker@carers.org

3. Working with family carers from BME communities

Is Information Enough?

This report from Mencap, downloadable from www.mencap.org.uk/isinformationenough examined the information priorities of families of people with a learning disability from Pakistani communities.

Giving us a Voice National Charter launched

Giving us a Voice is a project carried out by ARC, BILD and Mencap. It has written a national Charter for Inclusion for people with learning disabilities and their families from ethnic minority communities. The Charter is available at <http://givingusavoice.org.uk/charter-for-inclusion/>.

ARC guide for services – Supporting disabled young people from black and minority ethnic communities through the transition to adulthood

This guide will help local areas to provide the best support in transition planning for disabled young people from BME communities as they make the transition into adult life. The aim is to provide information, highlight the differences (and often similarities) in planning for disabled young people from BME communities and share examples of good practice from across the country. Available at:

<http://resources.transitionfonetwork.org.uk/media/4970/arc%20guide%20for%20services.pdf>

Half a Million Voices

This new report from Carers UK highlights the additional barriers Black and Minority Ethnic Carers face which adds to the risk they face of experiencing poorer health, poverty and social exclusion. The report includes positive suggestions for mitigating the impact of the additional burden this group faces. Available from

<http://www.carersuk.org/professionals/resources/research-library/item/1958-half-a-million-voices-improving-support-for-bame-carers>

Reaching and Supporting Diverse Communities

This resource will be a useful tool for anyone working in the fields of learning disability, carers, diversity and equality and is based on an audit of BME related work that the Valuing People Team commissioned the Family Carer Support Service at Hft to undertake. The resource is available from http://www.hft.org.uk/Family_Carer_Support/BME_Resource_Guide.

There is a small amount of funding available to update the resource over the next year, and if you have fresh information you think should be included, feedback about the resource or any questions please contact Cath Baker on cbaker@carers.org or Sue Davies, Assistant Family Carer Support Officer, Family Carer Support Service, Hft on susan.davies@hft.org.uk.

4. Policy issues and consultations

SEN and Disability Green Paper

The consultation period on the SEN and Disability green paper ends on 30 June. The Trust and Crossroads Care will be submitting a response. The green paper proposes:

- a new approach to identifying SEN through a single Early Years setting-based category and school-based category of SEN;
- a new single assessment process and Education, Health and Care Plan by 2014;
- local authorities and other services will set out a local offer of all services available;

- the option of a personal budget by 2014 for all families with children with a statement of SEN or a new Education, Health and Care Plan;
- to give parents a real choice of school, either a mainstream or special school; and
- to introduce greater independence to the assessment of children's needs.

The consultation documents are available at

<http://www.education.gov.uk/childrenandyoungpeople/sen/a0075339/sengreenpaper>.

The Autism Strategy

The Government's new autism statutory guidance for health and social care, Implementing Fulfilling and Rewarding Lives was launched in December. The document provides guidance to local authorities, NHS bodies and NHS Foundation Trusts which will help them to develop services that support and meet the locally identified needs of people with autism and their families and carers and enable local transparency and accountability.

The guidance focuses on four important areas where health and social care can practically change the way they support adults with autism:

- increasing understanding of autism amongst staff
- strengthening diagnosis and assessment of needs
- continuing to improve transition support
- ensuring adults with autism are included within local service planning.

It's available at

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847.

5. Campaigns

Cuts to services for people with learning disabilities and their families

A number of organisations are running campaigns to protest about the level and effect of the Government's spending cuts. Some of the major campaigns are:

- **The Learning Disability Coalition** - would like to know about the effects of cuts to local services on people with learning disabilities and their families. Email LDC@learningdisabilitycoalition.org.uk or call them on 020 7696 5574.
- **Mencap** – campaigning to protect the mobility component of DLA and housing cuts: <http://www.mencap.org.uk/campaigns/take-action/dont-cut-us-out>
- **Every Disabled Child Matters** - campaigning to get rights and justice for every disabled child. EDCM campaigns to raise the political profile of disabled children and their

families within central and local government.

http://www.ncb.org.uk/edcm/campaigns_and_policy.aspx

Further information on learning disabilities and spending cuts can be found at
<http://www.carers.org/news/15-million-people-learning-disabilities-suffer-spending-cuts>

Forced marriage

A free easy read booklet and website, www.forcedtomarry.com, has been produced for people with learning disabilities and their families who are concerned about forced marriage. More information is available at

[http://www.respond.org.uk/campaigns/Forced Marriageof People with Learning Disabilities.html](http://www.respond.org.uk/campaigns/Forced_Marriageof_People_with_Learning_Disabilities.html).

Raising our Sights

Learning disability charity Mencap and the PMLD Network have said that the Government's response to Raising our Sights, the report on people with profound and multiple learning disabilities, is extremely disappointing. The response is available at

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_124256.pdf . The Raising our Sights report and DVD can be downloaded from

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

6. Publications

CQC/HealthWatch

The Care Quality Commission has published an "Easy Read" guide to how LINKs will become HealthWatch. The document sets out in straightforward language how the transition will happen with key dates and information about the functions HealthWatch will have. You can read the Easy Read guide to HealthWatch here:

<http://www.westminsterlink.org.uk/sites/westminsterlink.org.uk/files/easyread%20healthwatch.pdf>

NIACE

The following resources for those working with young adult carers with learning disabilities are available for FREE download from NIACE's website - <http://www.niace.org.uk/current-work/young-adult-carers>

- *We are carers and we want to learn* - an Easyread book for young adult carers
- *We are carers and we want to learn* - a short briefing paper for staff
- *Really Useful Book of Learning and Earning for Young Adult Carers 2011 (RUBLE)*

- A staff guidance paper for practitioners to accompany the RUBLE.
- A resource pack for use by managers and practitioners within the FE college sector.

Hard copies of these resources can be requested by contacting emma.brown@niace.org.uk or telephone 0116 2859694.

Employment for people with learning disabilities

New practical tools have now been published to help local partners support more people with learning disabilities into employment. The materials include:

- The business case for Local Authorities to support more people with learning disabilities into work and invest in supported employment, which evidence suggests can save money for social care.
- A 'How To' Guide with learning and practical information from the Valuing People Now employment demonstration sites (including Getting a Life, Jobs First and Project Search).
- A guide for Local Authority Commissioners.
- The Government's new best practice guidelines for supported employment and job coaching.

To access the resources please visit:

<http://www.valuingpeoplenow.dh.gov.uk/content/employment-resources-hub>

National Children's Bureau

Disabled children: a legal handbook is an authoritative yet accessible guide to the legal rights of disabled children and their families in England and Wales. Available at

http://www.ncb.org.uk/cdc/resources/legal_handbook.aspx

Improving Health and Lives

The Learning Disabilities Observatory, Improving Health and Lives, has published reports on:

- Patterns of health inequalities for people with learning disabilities (with guidance for commissioners) -
<http://www.improvinghealthandlives.org.uk/projects/particularhealthproblems>
- Ages and causes of death in people with learning disabilities -
<http://www.improvinghealthandlives.org.uk/projects/deaths>
- The numbers of people with learning disabilities who also have Autism -
<http://www.improvinghealthandlives.org.uk/projects/autism>
- a summary report bringing together a wide range of statistics covering people with learning disabilities in England in 2010 -
<http://www.improvinghealthandlives.org.uk/projects/annualreport>

Hft

Hft publishes a number of resources for family carers including information sheets on personalisation, the Equality Act 2010 and Equality Impact Assessments, and their 2011 holiday guide. All are available at

http://www.hft.org.uk/Family_Carer_Support/Family_Carer_News_and_resources/Family_carer_support_service_resources.htm.

Mencap - Involving families in workforce development

Good practice in involving families in your workforce development was a project to identify good practice of involving family carers of people with a learning disability in workforce development. A report collating seven examples from local authorities, health, training and support providers and identifying common principles of good practice is now available to download from <http://www.mencap.org.uk/page.asp?id=21441>.

Self-advocacy

Staying Strong, the guide for self-advocacy groups published is now available to download from BILD at http://www.bild.org.uk/pdfs/04advocacy/Staying_Strong.pdf.

Progress

Progress is a transition guide for 13 to 25 year olds with special needs, published three times a year by Care Choices and also available as an e-book at: www.progressmagazine.co.uk. Also available is *My Child & Me* – a new magazine for parents of children with special needs which includes in depth guidance on a range of specialist topics. Further information from <http://www.mychildmagazine.com/>

7. Other news

Email Group for Family Carers of People with Down's Syndrome & Dementia

The Down's Syndrome Association has set up an email group for 'Family Carers of People with Down's Syndrome and Dementia'. To join the group, please email stuart.mills@downs-syndrome.org.uk.

8. And finally...

The next eBulletin will be published in the autumn. 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. Articles should be brief (approximately 100 words) and contain a web link.