

eBulletin for Learning Disabilities & Family Carers in England



ISSUE 3

July 2010

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Welcome to the third 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 parent carers and transition and siblings, with links to the latest information and resources to help Carers' Centres and Crossroads Care schemes work with carers experiencing these issues.

Please note that due to the recent general election, some of the information in this eBulletin is liable to change.

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://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>. 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://www.carers.org/professionals/social-care/articles/learning-disabilities-and-family-carers,5559,PR.html>.

New Resources

Our consultants, Inspired Services, have produced their final set of resources for network members. Each *How to...* guide is aimed at Carers' Centre and Crossroads Care scheme staff and volunteers, who are intending to improve or develop services for carers of people with learning disabilities and carers with learning disabilities.

The three guides are:

- *Affecting change locally*, which explains the processes by which all family carers (including marginalised groups) can become involved in influencing change at a local level and how their voices can be heard from local to regional and national level.
- *Making services accessible to people with learning disabilities, including family carers*, which is aimed at Crossroads Care schemes providing services for people with learning disabilities to give their carers a break, and for The Princess Royal Trust Carers' Centres and Crossroads Care schemes who provide, or plan to provide, services for family carers who have learning disabilities.
- *Outreach*, which provides 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 has produced a *Training for the trainers pack*, which is a PowerPoint presentation 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.

The '*How to...*' guides and the *Training for the trainers* pack are available to The Princess Royal Trust for Carers' Centres and Crossroads Care Schemes only, in the new learning disabilities resources sections of TrustNet and CCIID.

Good practice examples

We are trying to collect 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.

2. Parent carers and transition

Parent carers of children and young people with learning disabilities often experience some of their most difficult times at transition between children's services and adult services – with finding meaningful activity, including employment and further education, making and

Transition to adulthood – advice from national charity Contact a Family

Leaving school or disabled children's services and moving into adulthood can be a challenging time for young disabled people and their families. Families with disabled children have the same hopes and aspirations as other families. However, many parents are anxious that there will be no support or choice for their child to lead a fulfilling life as they grow up, such as going to college or getting a job.

Srabani Sen, Chief Executive of Contact a Family, said: "The transition process should start early – when a child reaches the age of 13 or 14. Unfortunately this does not always happen and parents tell us that they have to push for help and advice and this adds to the pressures they are often under. Young people and their families should be given timely, comprehensive information and guidance and they should be involved in the decision making. This will help them reach their goals."

Contact a Family provides advice, information and support to families about their rights and entitlements during the transition process and publishes a parent guide:

www.cafamily.org.uk/pdfs/preparing_for_adult_life_web.pdf

National Transition Support Programme

This is a three year national government programme with £19m of funding committed between 2008 and 2011, working on improving practice in every aspect of the transition to adulthood for disabled young people and their families. It is part of the wider government programme, Aiming High for Disabled Children (AHDC). Further information is available at: <http://www.transitionssupportprogramme.org.uk/>.

Getting a Life

Getting A life is a government project for young people with severe learning disabilities. It is about raising aspirations, making changes to the system and creating a clear path to paid employment. There are 12 demonstration sites throughout England which are finding new ways of working at each site so that young people with learning disabilities can leave school, get paid employment and have equal life opportunities. The sites are bringing together organisations working with young people such as Connexions, LSC and post 16 education providers and Job Centre Plus. A map of the demonstration sites can be found at <http://www.gettingalife.org.uk/>. Also available on this site is a good graphic representation of transition pathways: http://www.gettingalife.org.uk/resources/pathway_map.html .

The Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities has a section on its website on transition: <http://www.learningdisabilities.org.uk/information/issues/education-and-employment/transition-from-school-or-college/young-people-and-transition/?locale=en>.

Mencap's resources around transition: Trans-active and Plannet

Mencap have produced two online resources to help family carers and young people with learning disabilities manage issues that they face at transition:

Trans-active is a project in which teenagers with and without severe learning disabilities work together using multimedia to explore and communicate choices they will have when they leave school. The project is about using and giving support, making plans, making friends and having fun. Find out more at <http://www.trans-active.org.uk/index.htm>.

Plannet is a unique interactive and accessible online tool for young people with learning disabilities, offering a tailored package to suit different users to help young people together with their families and supporters to explore, prepare and plan for their future, using multimedia techniques. Available at: <http://www.plannet.org.uk/>.

3. Siblings

Sibs – the charity for siblings

Sibs is the UK organisation for siblings with a brother or sister with a disability or chronic illness, providing information and support, and influencing service provision for siblings throughout the UK.

Sibs' website has sections for parents, adult siblings and young siblings, with information leaflets, tips and a weekly email "Tip for Parents". Parent carers concerned about sibling issues can also access the telephone support session by completing an online enquiry form or calling 01535 645453. More details at http://www.sibs.org.uk/Telephone_support_session/.

Sibs also run workshops, training days for sibling group leaders, and an annual sibling group leader conference. See <http://www.sibs.org.uk/events/> for dates. They will also provide consultation by telephone for anyone planning to start or improve services for siblings and can attend strategy meetings or help with funding applications.

Contact Sibs on 01535 645453 or info@sibs.org.uk or visit the website on www.sibs.org.uk.

4. Policy issues and consultations

Towards 'Fulfilling and rewarding lives': The first year delivery plan for adults with autism in England

The Department of Health has set out further details about how the aims of the adult autism strategy for England will be achieved. Amongst other commitments, the first year delivery plan for the adult autism strategy makes it clear that carers should be involved in the development of regional and local plans on autism services. The first year delivery plan is available at:

<http://www.autism.org.uk/~media/NAS/Beta%20documents/News%20and%20events/Towards%20fulfilling%20and%20rewarding%20lives%20-%20first%20year%20delivery%20plan.ashx>

A briefing paper explaining the plan and what it means for carers will shortly be available.

Workforce development

The Valuing People Now team, National Workforce group and the National Valuing Families Forum want to promote good ways of involving family carers of people with a learning disability in workforce development. This includes:

- Workforce planning and recruitment
- Induction of new workers
- Training of students and professionals
- Development and delivery of training and qualifications
- Staff recruitment, appraisal and assessment

Mencap is gathering examples of good practice in this area. If you involve families in workforce development they would like to hear from you. They would also like to hear from people who are, or know of, family carers who would like to champion an organisation or

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provider who works well with families in developing their workforce. The results will be published later in 2010.

Please send your replies to: workforce.development@mencap.org.uk

4. Campaigns

Inquiry into Disability Hate Crime

Every working day one person on average is charged with a crime against a disabled person, but evidence suggests that many crimes are not being reported and public sector organisations are failing to put preventative measures in place. The Equality and Human Rights Committee is gathering evidence from disabled people, family carers and disability organisations and would like to hear from disabled people and family carers who have experienced hate crime and have tried to get help from public bodies.

The first wave of evidence will be collected until Friday 10 September 2010. It can be given directly to the Commission via its website, <http://www.equalityhumanrights.com/legislative-framework/formal-inquiries/inquiry-into-disability-related-harassment/>, email and helpline (telephone or textphone). There will also be some evidence gathering events which will be publicised locally.

At the end of the Inquiry, councils, the police, schools, social housing and other public bodies, bus and train companies found not to be doing enough to tackle the problem and to protect the human rights of disabled people could face legal action to force them to comply with their legal obligations.

Talk about Autism

On 28 April, national autism education charity TreeHouse launched 'Talk about Autism,' a new national campaign which aims to improve public understanding of autism. Research carried out by TreeHouse revealed the difficulties that children with autism and their families face due to a lack of understanding of autism. A new mini-documentary, *Talking about Autism*, featuring Oscar nominee Nick Hornby can be viewed on www.talkaboutautism.org.uk. The site provides expert information and advice about autism and education, covering key times such as diagnosis, admission to an appropriate school, the statementing process, tribunal and exclusion. It also hosts a moderated online community for all families of children with autism to share experiences, ideas and support.

5. Publications

A practical guide to employing staff with learning disabilities.

'Employing Staff with Learning Disabilities – Guidance for Employers' which is accompanied by a DVD, gives lots of achievable and practical ideas for creating a more inclusive workplace, from developing useful job roles to recruiting and successfully retaining capable staff of all abilities. It's available from CHANGE, at www.changepeople.co.uk.

Parents with Learning Disabilities

The Elfrida Society, in conjunction with the London Network of Parents with Learning Difficulties and the Valuing People Support Team has published The Parenting Toolkit. The Toolkit, which was created by parents in London, aims to help members of local Partnership Boards know what they should be doing to ensure parents get the help they need. Available

The Princess Royal Trust for Carers & Crossroads Care eBulletin for Learning Disabilities & Family Carers in England Issue 3 July 2010 from the website <http://www.bristol.ac.uk/norahfry/right-support/download/parentingtoolkit.pdf>, or from the Elfrida Society direct on 020 7359 7443.

Parent guides on bullying, special educational needs and holidays

Contact a Family produces parent guides on all aspects of raising a disabled child. These are available at:

www.cafamily.org.uk/pdfs/bullying.pdf

www.cafamily.org.uk/pdfs/educatio.pdf

www.cafamily.org.uk/pdfs/holidays.pdf

Mencap's autism resources

Mencap has produced a guide about autism for families which can be found at <http://www.mencap.org.uk/page.asp?id=14351>.

6. Good Practice examples

New system of carer consultation trialled in Bristol

The Princess Royal Trust Carers' Centre for Bristol and South Gloucestershire trialled an innovative approach to the problem of presenting the views of family carers of people with learning disabilities to their local Learning Disability Partnership Board (LDPB). Using volunteers from the Carers' Centre to ring family carers who were particularly isolated, they asked them for their views, collated the issues raised and presented them to the Board. As a result the Board have doubled the amount of time carers have to present and for the first time prompted a written response to a carer report. All carers involved in the consultation were sent the summarised carer report and Board's responses. The team plans to repeat the process for the next few LDPBs to identify common issues.

The full report can be viewed on the learning difficulty pages of The Princess Royal Trust for Carers' Centre for Bristol and South Gloucestershire's website: www.prtcarserscentre.org.uk, or on the good practice pages of TrustNet and CCIID.

7. Other news

Seeability

SeeAbility has launched a new series of easy read factsheets on eye care and vision for people with learning disabilities. Around 1 in 3 people with a learning disability have a sight problem. This factsheet series aims to make it clear how to look after your eyes for people with learning disabilities and their carers. The first factsheets to be released are 'Having an Eye Test' and 'Wearing Glasses'. Each is packed with full colour illustrations and uses clear simple words. Copies of the new factsheets can be downloaded from the 'Easy Read' section of www.lookupinfo.org

8. Finally...

Issue 4 of the *eBulletin for Learning Disabilities and Family Carers* will be published in the autumn and will focus on family carers of people with autistic spectrum conditions.