

# Campaign for Independent Living in Lewisham



# DISABILITY REVIEW

**September 2009**

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# 'Shaping the Future of Care Together'



**Denise Smith**

**A message from  
Denise Smith,  
Co-ordinator, CILL**

First some good news – CILL has got a small grant from Lewisham Council, lasting until the end of next March, for Disability Review. In the present economic crisis any funding is precious and Lewisham Council has limited resources so we thank the Community Sector for their one-off grant funding. Disability Review now has a 'supported by' statement and this will remain while the funding is in place.

As part of our growing concern to ensure that disabled people and their organisations are kept abreast of modern developments that affect them, the Trustees of CILL have agreed to introduce a

concept of a 'public forum' which will meet three or four times a year to discuss matters of importance to the disability movement. The first public forum is a presentation of a Person-to-Person Support Project managed by Slivers-of-Time Ltd that will take place directly before our AGM on Friday 21<sup>st</sup> August at 3 p.m. at The Bridge Leisure Centre, Kangley Bridge Road, Sydenham SE26. 'Slivers of Time' is a new concept that could enable disabled people to have greater choice and control over their individual/personal budgets, so it is very much part of the changes that are coming to adult social care. Not all councils are considering this concept but I'm very pleased that Lewisham are and they want to know what you think about it.

Last month the Green Paper 'Shaping the Future of Care Together' was published. This is a really important consultation document for everyone. No-one knows if or when they will need care and support services but people are living longer and disabled people are living longer. What we do know is that the system we have now will not be able to cope with either the

financial burden of providing services to the greatly increasing numbers of people who need them or to the expectations those people will have. Changing expectations are being dealt with through 'transformation' also referred to as personalisation or self directed support. Here in Lewisham much work has already been done by Lewisham Council - an individual budget pilot for people with learning disabilities is underway, an advice and information team will be set up later this year, a 'Better Prospects Directory' will be available, a self directed support co-ordinator post is already working, 'slivers of time' a person to person support project is being considered and consultation will continue to fully involve and inform the voluntary and community sector, service users and carers. Last year the Government launched 'The Care Debate' to consider how care and support services could be funded. CILL was one of hundreds of organisations and individuals who took part and the Green Paper is

based on what was said. We think this document is important so to keep you fully aware and informed we have set out below very briefly the main points discussed. Also if you go to <http://careandsupport.direct.gov.uk/greenpaper/> you can download the Green Paper or an easy read version and attached is a Disability Review supplement giving initial responses from various disability organisations.

### Shaping the Future of Care Together

The Government wants to set up a National Care Service providing:

- Prevention Services
- National assessment
- Easy assessment process
- Information
- Personalised care and support
- Fair funding

That sounds great and what we all want but the difficult questions are who should pay for it and also what is the best way of using tax money.

The Green Paper sets out 5 different options for funding:

- **Pay for yourself** – The Government don't think this system would work because many people could not afford to pay and those who did have savings would have to spend everything they had.
- **Partnership** - In this system, everyone who qualified for care and support from the state would be entitled to have a set proportion – for example, a quarter or a third – of their basic care

and support costs paid for by the state. People who were less well-off would have more care and support paid for – for example, two-thirds – while the least well-off people would continue to get all their care and support for free. A 65-year-old in England will need care and support that costs on average £30,000 during their retirement, so someone who got the basic offer of a third or a quarter paid for might need to pay around £20,000 or £22,500. Many people would pay much less. And some people who needed high levels of care and support would pay far more than this, and would need to spend their savings and the value of their homes. This system would work for people of all ages.

- **Insurance** – In this system, everyone would be entitled to have a share of their care and support costs met, just as in the Partnership model. But this system would go further to help people cover the additional costs of their care and support through insurance, if they wanted to. The state could play different roles to enable this. It could work more closely with the private insurance market, so that people could receive a certain level of income should they need care and support. Or the state could create its own insurance scheme. If people decided to pay into the scheme, they would get all their basic care and support free if they needed it. People could pay in several differ-

ent ways, in instalments or as a lump sum, before or after retirement, or after their death if they preferred. Once people had paid their contribution they would get their care and support free when they needed. As an indication of the costs, people might need to pay around £20,000 to £25,000 to be protected under a scheme of this sort, compared with the average cost of care for a 65-year-old which is £30,000. This system would work for people over retirement age. However people paid, the insurance payment would help people to protect their wealth and the value of their homes. Whether they decided to pay during their working life, during their retirement or after they died, people would know that once they had made their contribution and paid for their accommodation, the costs of their care and support would not prevent the rest of their wealth being passed on to their children.

- **Comprehensive** – In this system, everyone over retirement age who had the resources to do so would be required to pay into a state insurance scheme. Everyone who was able to pay would pay their contribution, and then everyone whose needs meant that they qualified for care and support from the state would get all of their basic care and support for free when they needed it. It would be possible to vary how much people had to pay according to what they could afford. The size of

people's contribution could be set according to what savings or assets they had, so that the system was more affordable for people who were less well-off. Alternatively, if people wanted to be able to know exactly how much they would have to pay, most people other than those with lower levels of savings or assets could be required to pay a single, set figure, so that people knew how much they would have to save for. As an indication of the costs, people might need to pay around £17,000 to £20,000 to be protected under a scheme of this sort compared with the average cost of care for a 65-year-old which is £30,000. The cost would be less for people who were over 65 when the scheme was introduced. However people paid, the insurance payment would help people to protect their wealth and the value of their homes. Whether they decided to pay during their working life, during their retirement or after they died, people would know that once they had made their contribution and paid for their accommodation, the costs of their care and support would not prevent the rest of their wealth being passed on to their children.

This system would only work for older people as they reached retirement age so we would also look at having a free care and support system for disabled people of working age alongside this.

- Paid for out of tax money - Everyone gets their care and support for free but to meet the cost everyone would have to pay more tax.

The Government does not think this system could work because there would be fewer working age people paying a lot of tax for a bigger group of older people. They also think it would be unfair as older people are already the richest age group in the country (in the value of their houses). There is also a proposal that 'disability related benefits like Attendance Allowance' are stopped and that money used towards the cost of care services. It is not clear if that extends to Disability Living Allowance (DLA) and the Independent Living Fund (ILF). We now have until mid November to respond to the proposals and following that the Government will decide which option to take forward. Any changes or proposed changes may well be affected by next years general election and in any event will take some years to put in place. CILL is concerned that none of the proposals relate specifically to younger disabled people so we have no clear idea of what we would get. There seems to be an understanding that younger disabled people get free support already and that will continue. This is not true for many – all are means tested and reduced to income support level plus a small 'buffer', those who worked lose their savings, occupational or private pensions, all have to justify what they spend (for example, heating costs), many cannot get the support they need and most are reduced to living in poverty. If DLA and ILF are taken away then more will move into poverty reducing even more our choices and life chances. We will be keeping you in-

formed and involved over the coming months and CILL will be formulating a response but we welcome your views so please contact me at [campaign@fsmail.net](mailto:campaign@fsmail.net)

### **Goldsmiths College Social Worker Training**

The Users and Carers Steering Committee at Goldsmiths College is a diverse group of users and carers that seeks to reflect the complex voices of users and carers. They give advice on recruitment of students, curriculum development in order to maintain and improve the quality of social work training pre and post qualification. CILL has joined the Committee and look forward to working with Goldsmiths.

### **Direct Payments Peer Support**

CILL is a user led organisation (ULO) and we believe that disabled people must control the services they use. Many of you will know that the Direct Payment Support Service is provided by Freewood which is not a ULO. After a lot of thought CILL has offered to be a resource to their users' peer support group so that it might become truly user led. So far we have attended one meeting and very much hope that our knowledge and experience will be helpful to their steering group in developing peer support. If you use Freewood in any way for your Direct Payments why not go along to the next meeting. Details from Ebenezer Ohene, ServiceManager, on 020 8469 9156.

# Scope criticised for not reserving chief executive's post for disabled people

By Kaye Wiggins, Third Sector Online

Disability charities say the organisation should be setting an example in its bid to find a successor to Jon Sparkes. Disability charities have criticised the decision by Scope not to reserve its £140,000-a-year chief executive post for disabled candidates. The charity's current chief executive, Jon Sparkes, announced last month that he will leave in November.

Alice Maynard, chair of the organisation, told *Third Sector*: "We want to invite applications from a diverse talent pool, so we are not saying the role will be open only to disabled people. Our priority is to find the right person for the job, and that person may or may not be disabled.

"Our aim is to create an alliance between disabled people and non-disabled people, so it isn't essential to have a disabled chief executive. But we have asked our recruitment consultants to make sure they think in the broadest possible way and to look in non-obvious places for candidates."

Amarjit Raju, chief executive of user-run disability charity Disability Direct, told *Third Sector*:

"The disability movement is increasingly about disabled people running their own groups, and Scope should be setting an example here.

"Scope has traditionally had business executives running the show, and a tokenistic approach to employing disabled people. It would benefit greatly from a disabled chief executive."

Mary Colley, voluntary coordinator of learning difficulties charity Danda, said she could not understand why Scope would not restrict the role to disabled candidates.

"It would be difficult for a non-disabled chief executive to understand the needs of disabled people," she said.

"There are plenty of very capable disabled people who would do a good job of running the charity.

A spokeswoman for the Equality and Human Rights Commission said positive discrimination was unlawful. But she said there was a caveat in the law that allowed for reserved posts, which would permit Scope to reserve the post of chief executive for disabled candidates.

## MS Society responds to Debbie Purdy ruling

The MS Society has responded to the Law Lords ruling concerning the case of Debbie Purdy, who has sought clarification on the law of assisted suicide.

Debbie, 46, who was diagnosed with Primary Progressive multiple sclerosis (MS) in 1995, wanted to be assured that her husband would not be prosecuted on his return to the UK, if he accompanies her to the Dignitas clinic in Switzerland.

It is now thought that the Law Lords will ask the Director of Public Prosecutions to set out when prosecutions would happen.

Simon Gillespie, Chief Executive of the MS Society, said: "Debbie Purdy's victory has pushed MS into the spotlight but there is far more to living with MS – even in its more severe forms – than planning how to die.

"There are 100,000 people with MS across the UK and most will live about as long as any of us. The key to living well with MS is access to the right care and support, including palliative care when it's needed.

"Most palliative care resources are focused on cancer and cases like this show why the Government's end of life care strategy is so important."

# People from socially deprived communities are around three times more likely to die from a stroke

Statistics included in a new publication reveal that people living in deprived areas are around three times more likely to die from a stroke than those in the least deprived. The findings released by The Stroke Association and British Heart Foundation, show that death rates from stroke vary among areas of different social and economic conditions.

The statistics have been published as part of British Heart Foundation's Heart Statistics series. The Stroke Association and British Heart Foundation have been working together to produce this report which is the first comprehensive collection of national statistics regarding the burden of stroke to the UK.

The stroke mortality rate for men and women of working age (under 65) has fallen consistently since the late 1970s. However the rate has fallen quicker in adults of higher social classes, resulting in an increase in inequalities in stroke death rates.

The social gradient in stroke deaths is clearly demonstrated when mortality rates from areas of differing deprivation are compared. The data shows that stroke mortality

increases with deprivation for both men and women. For premature mortality, the rate in the most deprived twentieth of England and Wales is over three and a half times higher for men, and over two and a half times higher for women.

The statistics also show that people from lower social economic backgrounds are more likely to face major risk factors of stroke.

For example, cigarette smoking is more prevalent among manual social groups and people from households with lower incomes are more likely to be obese. However, it is not just people from lower income households who are at risk of stroke. This document shows that people in managerial and professional jobs are more likely to binge drink and drink alcohol on five or more days a week. People who regularly consume a large amount of alcohol have a three-fold risk of stroke.

Joe Korner, Director of Communications at The Stroke Association said: "We have known for some time that social deprivation increases people's risk of stroke. These shocking statistics show that you are about three times more likely to die of a stroke if you

are poor. Decreasing inequalities in our society will also lessen inequalities in health outcomes. In the meantime there is so much that everyone can do, whatever their social class, to reduce their risk of stroke. Over 40% of strokes can be prevented through the control of high blood pressure. Small lifestyle changes, such as not smoking, drinking in moderation, improving your diet and being active can help reduce your risk of stroke. "

Professor Peter Weissberg, Medical Director at the British Heart Foundation said: "The picture these data on stroke present strongly mirror figures for heart disease, which is also much more common in deprived communities. Many of the risk factors for heart disease and stroke, such as smoking and high blood pressure, are the same and potentially modifiable. The statistics argue for a concerted effort to identify and modify risk factors, by lifestyle and drug interventions, in those communities with the highest risks. We don't underestimate the challenge this poses, but success will save the lives of thousands of people and prevent disability in many more."



## **UK Teenagers Living with HIV to Attend International Conference**

Members of the Children and Young People HIV Network, based at the National Childrens Bureau (NCB), will attend the Seventh Annual Meeting for Young People Affected by HIV in Barcelona from 22-26 July. The Network will accompany 15 young people aged 16 to 24 who are living with or affected by HIV to meet with over 100 young people from around the world, in partnership with Barnardos and Positive Parenting and Children.

The five-day conference will combine sessions on issues such as sexual health, relationships and HIV status disclosure with creative activities including a graffiti workshop. Social events in the evenings will allow the young people to share their experiences with each other in an informal setting. The conference also provides an opportunity for support workers and other professionals to share practice around adolescence and HIV.

Maria Phelan, coordinator of the Children and Young People HIV Network, said: 'This is a great opportunity for young adults living with HIV and practitioners alike to meet with their peers and discuss their experiences and the challenges they face in a safe, comfortable

environment. For many of the young people we are taking this will be the first time they have met with another person living with HIV.'

There were 1,460 children under 19 living with HIV in the UK at end of March 2008, their average age is 12 years old, 52% are female, 50% were born in the UK and Ireland, 97% were infected through mother to baby transmission. The Children and Young People HIV Network is a national policy network that brings together organisations concerned with children, young people and HIV/AIDS. It aims to provide an effective voice for infected and affected children and young people, challenge stigma and discrimination, and build child-centred policy and practice. It is based at NCB.

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## **Young Inspectors to evaluate services**

Sutton is one of 18 areas inviting young people to inspect and evaluate the services they use in order to help improve them, through a new scheme launched earlier this month.

Under the Youth4U Young Inspectors scheme, managed by the Look Listen Change Consortium, Jigsaw4u will be working with the council to recruit, train and support young people to investigate and

assess local services and recommend improvements. Young inspectors will also be given the chance to achieve accredited qualifications through the programme.

Eny Osung, local support worker for Youth4U, who is training five young people aged 16 to 18, said: "The aim of this initiative is for young people to influence services. They are being empowered to visit them and give recommendations."

There will be 12 inspections a year. For each one, young people will receive two days of training before carrying out an inspection and putting together their report. The first inspection will be of Jigsaw4u. Copies will be sent to the Department for Children, Schools and Families and the inspected organisations.

For more information, contact Kerryanne Russell on 020 7843 6085 or [krussell@ncb.org.uk](mailto:krussell@ncb.org.uk).

### **Do you have experience of self-harm?**

SANE has undertaken extensive research into self-harm and the results challenge many common misperceptions about who does it and why. If you have experience of self-harm they would like to hear from you.

SANE. 1st Floor Cityside House. 40 Adler Street. London, E1 1EE. tel. 020 7375 1002, fax. 020 7375 2162, email. [info@sane.org.uk](mailto:info@sane.org.uk)

## The Healthcare BlindArt Permanent Collection makes its home at The Royal National College for the Blind (RNC)

We are delighted to announce that the national BlindArt Collection is making its permanent home at RNC.

Opening to the public during Herefordshire Art Week in September, the Collection is the world's first permanent showcase of visual art accessible to visually impaired people and includes paintings, sculpture, installations and other works of art.

### A feast for the senses

Come and discover the beauty of BlindArt - the collection showcases around 30 exceptional works that appeal to a multitude of senses.



Lolly Gobble Choc Bomb by Stephen Farley

Housed in a dedicated gallery space within RNC's beautiful main building, this stunning collection is a platform for the works of both visually impaired and sighted artists from around the UK.

And, unlike traditional art exhibitions, visitors are encouraged to interpret these diverse and thought provoking pieces through textures, sights, sounds and smells. Audiences are invited to question the nature of artistic perception - is visual ability essential for artistic excellence and aesthetic appreciation?

Works on display include Barnacles by Natasha Lewer, Lolly Gobble Choc Bomb by Stephen Farley, The Laughing Record by Nicola Green and Symphonie des Parfums by Alexandra Conil-Lacoste.

## Jobcentre Plus needs to do more to promote equality

The first formal Assessment carried out by the Equality and Human Rights Commission has found that the Department for Work and Pensions' Jobcentre Plus agency is not meeting all the expectations of its public sector duties on equality. It also found unnecessary duplication between the work of the Department and its agency on equality policies.

The findings are based on a year-long review by the Commission of how the (DWP) and its agency are working together to promote equality. In response to the Assessment, Jobcentre Plus has indicated that it is planning to address all of the concerns raised by the Commission in due course.

Some specific areas of concern were the limited focus of diversity impact assessments (DIAs), a lack of transparency in consultations with stakeholders, prioritising volume of assessments rather than the quality of outcomes, and misconceptions that equal treatment automatically leads to equal outcomes.

A number of examples of good practice were also identified in the Assessment process. In response to criticism that evaluations were not outcome focused, Jobcentre Plus is currently reviewing all of its equality evidence. It will then make better use of this in developing policies that meets the needs of all of its service users and staff.

Susie Uppal, Director of Legal Enforcement for the Equality and Human Rights Commission, said: 'This power allows us to assess performance against the duties in an innovative and constructive way. It seems to be working well in principle with Jobcentre Plus as it is already taking into account many of our recommendations. They now have a year to show that it is working in practice, after which we'll consider if any further action is required.'

The Commission will shortly publish new non-statutory guidance on meeting all three duties in a holistic way, which will replace the separate guidance from the legacy Commissions. This will include EIA guidance and the Commission's EIA audit tool, which public authorities should find useful in understanding what the Commission looks for in effective EIAs.

## Commission's work on proposed Bill of Rights for Britain

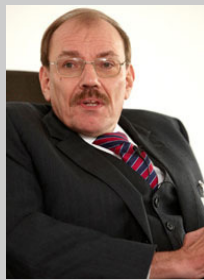
In March 2009 the Government launched a Green Paper to consult with the public on creating a Bill of Rights for Britain. Their proposal is that the Bill of Rights would not amend the nature and extent of protection provided by the Human Rights Act (HRA) but could build on the HRA by including express reference to responsibilities and new rights such as economic and social rights and children's rights. The Government has not set a specific timeframe for the development of a Bill of Rights but has stated that it will not seek to introduce any proposal to Parliament before the next general election which must be held by June 2010.

The Conservatives have also made a series of public statements that have provided some indications on the key elements of their position relating to a Bill. They have stated they will replace the HRA with a British Bill of Rights and Responsibilities which places greater emphasis on responsibilities and that they would amend and reduce the scope of the mechanisms relating to human rights protection. No commitment has been made by the Conservatives to retain the current level of protection and mechanisms under the HRA.

In response to the debate, and looking back both at the experience of the HRA and forward to the election, the The Equality and Human Rights Commission is providing leadership in the Bill of Rights process by developing a set of key principles, ensuring that we actively safeguard the minimum standards provided by the HRA and comply with obligations under international treaties while also promoting a better understanding and ownership of human rights throughout society.

# Where next for the EHRC?

Concerns have been raised over the future of the Equality and Human Rights Commission (EHRC), the government's equality watchdog, after the resignations of several commissioners.



So far, six board members have quit the EHRC, including Sir Bert Massie (pictured), the former chair of the Disability Rights Commission, and disability campaigner Baroness Campbell. Some of those who resigned in the last few weeks have called for the resignation of its chair, Sir Trevor Phillips, who was reappointed on 15 July.

The new commission began work in October 2007, having taken on the work of the Commission for Racial Equality, the Disability Rights Commission and the Equal Opportunities Commission.

This month, the National Audit Office announced that it had not fully signed off the EHRC's accounts, as it had re-employed senior staff from the former Commission for Racial Equality soon after they received redundancy payments, without permission from the Treasury.

And Mark Goldring, chief executive of Mencap, said: "Whilst we were supportive of the Equalities and Human Rights Commission when it was established in 2007 there has been growing concern amongst the disability community that disability has slipped down the agenda in light of the Commission's wider remit.

"We are concerned to see the loss of so many well thought of disability commissioners. The EHRC must have strong leadership if it is to achieve its goal of creating a fairer Britain."

# Equality and Human Rights Commission launches three-year strategic plan

The Equality and Human Rights Commission has published its three-year strategic plan setting out its priorities and work programmes to March 2012. The publication comes the day after the Government announced the reappointment of Commission Chair Trevor Phillips and Deputy Chair Baroness Margaret Prosser for further three year terms.



Mr Phillips commented: 'I am delighted to be offered the opportunity to continue the work that the Commission has begun. As we look to a post-recession world, tackling discrimination and creating a fairer society where everyone is able to fulfil their potential will be key to building a stronger economy, stronger communities and a stronger country. It has been a great adventure to launch this unique body with the first team of Commissioners and our passionately committed staff. I look forward to taking that work on to its next stage.'

The strategic plan outlines how the Commission will work towards its vision of a society built on principles of fairness and respect, in

which everyone has an equal chance to fulfil their potential.

After extensive consultation with nearly 1,000 stakeholders online and at events across England, Wales and Scotland, the Commission has set itself five strategic priorities for the next three years. They are to:

- Secure and implement an effective legislative and regulatory framework for equality and human rights
- Create a fairer Britain, with equal life chances and access to services for all
- Build a society without prejudice, promote good relations and foster a vibrant equality and human rights culture
- Promote understanding and awareness of rights and duties and deliver timely advice and guidance to individuals and bodies
- Build an authoritative and responsive organisation

The Commission has developed a set of Key Performance Indicators to demonstrate how it delivers on these Strategic Plan priorities, including ensuring effective utilisation of resources and delivering on its value for money plan.

Trevor Phillips added:

'Our strategic plan prepares us for a radically changed landscape, with the Commission taking a modern approach to empower people to be their best, help organisations to act fairly and take action against those who do not. We expect the Equality Bill sponsored by Harriet Harman and her team to give the Commission a pragmatic and effective framework to deliver that modern approach.

'Our strategy will provide the blueprint for an organisation that wants to make a real difference to people's lives, whatever their background or make-up. We must ensure that we show real value for money for the public funds we receive – and this plan will help us do that.'

## The Kidz talk shop with Ed Balls MP

This month the Kidz Board met at the Department for Children Schools and Families where the main topic of discussion was a consultation document that the Board are putting together - to poll the opinions and experiences of young disabled people in Schools in England.



Ed Balls MP and Secretary of State for Children Schools and Families came along to discuss how the Department and Whizz-Kidz working together can distribute the consultation effectively and efficiently. This meeting was very productive with lots of encouraging words given by Ed Balls to the Board.

## Alzheimer's Society comment on study that highlights link between healthy heart and healthy brain

Middle aged people who smoke, have high blood pressure or diabetes are more likely to develop dementia in later life.

Neil Hunt, Chief Executive, Alzheimer's Society:

Dementia is one of people's biggest fears in later life but very few people realise that there are things they can do to reduce their risk of developing this devastating condition. This study adds weight to the growing evidence that a healthy heart means a healthy brain. Evidence suggests that the best way to reduce your risk of developing dementia is to keep active, eat a balanced diet, don't smoke and to get your blood pressure and cholesterol checked regularly. Although this study did not find a link between obesity and dementia, other research has found that it is important to keep a healthy weight.

One million people will develop dementia in the next 10 years. We must act now to find a cause, cure and better care for this devastating condition.'

### TAG Calls for Modernisation of Deaf Telephone Services

Deaf people and those wishing to telephone them are being urged to ask their MPs to sign an Early Day Motion (EDM) calling for the modernisation of deaf telephone services.

Within hours of being tabled by the Rt Hon Malcolm Bruce MP, the EDM had gained significant cross-party support.

Ruth Myers, Chair of TAG, which is campaigning for better telecoms services for deaf people, said: "We urge anyone living in the UK to contact their MP asking them to support the motion. An easy way to contact your MP is through the Write To Me website [www.writetothem.com](http://www.writetothem.com)

"We are delighted with the cross-party support that the EDM has quickly attracted and very appreciative of Malcolm Bruce for tabling it."

Led by TAG, a consortium of the UK's main deaf organisations, deaf people are calling for new-style telephone relay services that will enable them to use the phone much more effectively and put them on a more equal footing with hearing people. A series of parliamentary questions asked by supportive MPs has revealed some of the government's thinking on the issue and an Ofcom report earlier this month highlighted many of the issues that TAG is campaigning about.

## Government's initial response on acoustics not good enough

In a letter to NDCS, the Government has said it won't consider introducing mandatory acoustic testing until at least 2013, despite evidence that countless new schools are being built now with poor acoustics.

NDCS is calling for a mandatory and watertight requirement for acoustic testing to guarantee that deaf children are able to listen and learn effectively in the classroom.

In the letter, the Minister recognises that "good acoustics is an essential part of a learning environment for all children and particularly for those with special hearing requirements". The Minister also sets out some of the actions the Government will take in response to our campaign, including:

- Strengthening the recommendation in government guidance that there should be acoustic testing of all new school buildings.
- Introducing a new draft contract for local authorities building new secondary schools that includes a reference to acoustic testing.
- Producing new user friendly guidance on acoustics.
- Conducting post-occupancy evaluations of new school buildings.

None of the above steps would result in acoustic testing of **all** new schools (including primary schools) and NDCS does not believe that 'recommending' testing or suggesting draft contracts is sufficiently watertight. NDCS is therefore calling on the Government to go further. NDCS believes that acoustic testing is needed because poor workmanship and product substitution can lead to inferior acoustics, even where good acoustics have been considered at the design phase.

### Next steps

Baroness Wilkins has called for a change to the law to introduce acoustic testing in new school buildings, which will be debated in the House of Lords in October. This will be a great opportunity to make progress.

In the meantime, NDCS will be continuing to press MPs and the Government for action on this issue.

### Thank you

Over 400 NDCS supporters have contacted their MP to demand action on acoustics - an amazing show of support. Thanks to this, nearly 80 MPs have signed a parliamentary petition on acoustics, whilst 45 MPs came to a parliamentary event on acoustics recently.

You can still support the campaign by contacting your MP if you haven't already. Or why not forward the link to your friends and families and get them involved too!

## CBBC to feature a deaf character in new musical drama series

CBBC is including a deaf character in its major new series *My almost Famous Family*, a comedy drama about a musical family who sing together in a television pop group.

The character, Martha Swann, will be played by eight-year-old newcomer Rachel Brady. The role forms part of CBBC's continued commitment to reflecting its diverse audience within its programming.

Rachel who has deaf parents and whose first language was BSL (British Sign Language) was discovered after a search across 200 organisations and individuals including ethnically diverse deaf associations.

"We looked at *My almost Famous Family* and decided to explore what would happen if eight year old Martha was to be deaf. How would a deaf character interact in the everyday lives of a musical family and overcome the odds that would pose?" said executive producer Steven Andrew.

"Martha is a funny, independent mixed-race deaf girl and we were looking for a feisty young actress who had the comedy timing to bring her to life. Not an easy part to cast! After searching over 200 establishments we found Rachel."

The production team originally planned to cast a deaf actress but upon meeting Rachel, they felt she had the ability and personality to breathe life into the role of Martha, in addition to a personal understanding of the issues that deaf people may face.

The series begins on 12 September

# LETTERS

Dear Colleague

I am the London Development Officer for the Disability Law Service (DLS), an organisation that provides expert legal advice and representation (e.g. in complaints, using the Ombudsman, tribunals and courts) to disabled people, their families and carers. I am writing to let you know about what we do and about how we might be able to collaborate or support your work.

DLS specialises in Welfare Benefits, Community Care, and Disability Discrimination law (in Employment, Access to Goods and Services, the Disability Equality Duty and further and higher education). We employ solicitors and caseworkers to provide **advice and information** by telephone, email etc.

We also publish a range of **factsheets** and produce **training** courses every spring and autumn (if you have not received this email directly please contact me to have your details added to the database of organisations that we contact with information about our courses).

**Outreach** is a major part of my work and I am very interested to work with other organisations and spread our knowledge of disability law; this could involve working with service users or staff (e.g. running outreach clinics, giving talks at events, helping non disability organisations understand disability law or helping disabled people to know their rights).

I regularly make outreach visits to different boroughs and am available to give presentations to groups. We are currently interested in developing awareness of the law relevant to disabled refugees and asylum seekers and we have been developing relevant training materials in this area. We are also interested in improving the accessibility of our service to Deaf clients and people with learning difficulties and are engaging with the move to 'personalised' social care and individual budgets.

All ideas for how we could work with your organisation, in these or any other areas, are welcome. Please contact me with ideas, if you would like me to add your details to our database or if you would like leaflets detailing our services. Please do forward this email through your networks if appropriate.

Kind regards

Nick Clarke, London Development Officer  
Disability Law Service  
DD: 020 7791 9819

You can contact our advice line on 020 7791 9800, [advice@dls.org.uk](mailto:advice@dls.org.uk) and further information and our factsheets are online at [www.dls.org.uk](http://www.dls.org.uk)  
DLS's work in London is funded by London Councils

UK Registered Charity Number 280805, UK Limited Company Registration Number 1408520

Dear Colleague

The Alliance for Inclusive Education would like to hear from any disabled young person who is undergoing an apprenticeship with your organisation or anywhere else. We are aiming to meet the Minister; Lord Young during September to raise the issue that disabled young people can learn a trade without having to get 5 GCSEs. We are arranging the meeting so that young apprentices can share their experiences with the Minister. Additionally we are collecting stories as well so please, we want to hear from you. We will want to present these to Lord Young as well.

The Government has specified the national apprenticeship scheme entry requirements must be for a young person to hold 5 GCSEs or its equivalent in their Apprenticeships, Skills, Children and Learning Bill. We are campaigning to get this removed for disabled people who face big barriers of accessing qualifications.

If you want to know more about ALLFIE's campaign please see our briefings on our website: [www.allfie.org.uk](http://www.allfie.org.uk).

Please contact Simone Aspis (Policy and Campaigns Co-ordinator) on 020 7737 6030 or email: [simone.aspis@allfie.org.uk](mailto:simone.aspis@allfie.org.uk)

## Graduate Talent Pool

Graduate Talent Pool is a new internship programme from the Department for Business, Innovation and Skills (BIS) designed to help employers bring diverse talent into their workplace and provide career opportunities for graduates. From September 2009, employers can post their vacancies on the Graduate Talent Pool website for graduates to search. Graduates are then connected to businesses through a matching service.

Employers can register their interest at [www.dius.gov.uk/graduatetalentpool](http://www.dius.gov.uk/graduatetalentpool) or call **0845 072 7598** for more information.

## Act on official audit, Arthritis Care challenges 'half-hearted' health services

Arthritis Care, the UK's largest support charity for people with arthritis, welcomes the National Audit Office report (published 15 July 2009) into rheumatoid arthritis services and urges health chiefs to implement its recommendations as swiftly as possible.

The audit highlights 'minimal' GP training in rheumatoid arthritis (RA) and poorly co-ordinated services, which the charity says means thousands of people with this devastating disease are failed by the system.

'The NAO report echoes what people with RA have been telling Arthritis Care for years - that it takes too long to get diagnosed. Early diagnosis and referral for suitable treatment is crucial as it can literally stop this debilitating condition in its tracks. We applaud the audit's recommendations that the Department of Health and Primary Care Trusts (PCTs) replace their often scattergun delivery with joined-up services. If actioned, the recommendations in this report should dramatically improve life for people with RA as well as save the country millions of pounds', said Neil Betteridge, Arthritis Care's chief executive.

Arthritis Care believes that the key to addressing the majority of the problems identified by the NAO lies in the proper implementation of the Department of Health's Musculoskeletal Services Framework. The framework, launched in 2006 is a strategy for the delivery of integrated musculoskeletal services for England.

'The Musculoskeletal Services Framework was devised to improve services but any implementation has been intermittent and half-hearted. As the audit says, 73% of PCTs have not even undertaken any assessment to establish the number of people with RA in their areas. Arthritis Care is calling on the government and Strategic Health Authorities, plus every PCT, to respond to the audit by prioritising proper implementation of the framework. We also want to see a National Clinical Director for musculoskeletal services appointed to drive through improvements in services, just in the same way as one exists in the areas of mental health, diabetes and heart disease', says Betteridge.

## Justice system failing victims with mental health problems

A report issued on Thursday 6 August by the House of Commons Justice Committee highlights deep concerns about the treatment of people with mental health problems in the criminal justice system. According to the report, the Crown Prosecution Service is failing victims and witnesses with any history of mental distress by dropping cases before they even get to court (1), and where their mental health is in question, failing to support them to give good evidence even though the support systems are in place.

Mind's Chief Executive Paul Farmer said: "Everyone has a right to seek justice for the crimes committed against them, but people with mental distress are being locked out of the system and denied the same rights to justice as anyone else. The CPS and the criminal justice system as a whole is working on the assumption that any experience of mental distress, from post-natal depression to anxiety attacks 20 years previously, means that your evidence cannot be considered 'reliable'. The blanket assumption that people who have had a mental health problem cannot be trusted in court is ludicrous, and reflects a view of mental health that is out of date and out of touch. Dropping cases on these grounds shouldn't even be an option.

"Where mental health is a consideration in a case, it's vital that prosecutors find out whether mental health is actually going to affect someone's testimony or not, and support them to give their best evidence rather than simply giving up on victims. The measures to support people with mental distress are already in place, but what we are witnessing here is institutional reluctance to treat mental health fairly and appropriately, which is standing in the way of justice.

"The CPS has committed to training prosecutors around mental health, but justice professionals have to be willing to change their long-held stereotypes around mental health, so we can change how people with mental distress are treated by the justice system.



## UK to play lead role in European fight against dementia

A new initiative launched by the European Commission has adopted proposals to tackle Alzheimer's disease, dementias and other neurodegenerative conditions.

The UK is one of ten countries that will lead research aimed at tackling shared health and social care problems. According to the Commission there are over seven million people with Alzheimer's disease and related disorders in Europe and it is predicted that this number will double in the next 20 years.

Today's actions mark new steps both in the Commission's 'Europe for Patients campaign' and the new approach of Joint Programming in research.

Dr Susanne Sorensen, Head of Research, Alzheimer's Society says,

'Building on successful high impact dementia research, the UK will play a critical role in this initiative, leading the fight to defeat dementia. By uniting to find a cause, cure and fund care, we can galvanise our efforts and offer hope to millions of people. 'But while Europe strives forward, the UK government still lags behind the US, Germany and France in providing dementia research funding and there is still no specifically targeted dementia research funding. Yesterday the government promised to develop a strategy for investment in dementia research. It must make good on its promises or we will all pay the price.'

In an open letter to the government, 31 leading dementia researchers united to call for a national plan for dementia research and a tripling of current investment.

The letter coincides with a unique ministerial research summit on dementia which stated the importance of increasing research funding spent on dementia. Experts agree the UK must follow the French model for dementia research which provides a focussed structure to support the full breadth

## Mental health patients neglected and forgotten

- 39% of suicides by hanging took place when the patient was supposed to be subject to observation by staff
- 30% of wards were running at more than 100% occupancy
- Some staff who might be engaged in restraint practices had no training
- On many wards low level harassment was the norm

A shocking report from the Mental Health Act Commission released today (Sunday 19 July) reveals the shameful conditions of many of our mental health wards where poor practice is entrenched, staff are overstretched and often lack the basic skills to prevent tragedies occurring.

Leading mental health charity Mind was alarmed to learn that almost 40 per cent of suicides by hanging took place while patients were supposed to be subject to staff observation. In one appalling case, a patient found hanging was already showing signs of rigor mortis when discovered, despite supposedly being subject to staff observation every 15 minutes.

Mind's Chief Executive Paul Farmer said: "This report highlights some astounding failings in delivering even the most basic level of care. When a ward fails to provide a safe and secure place where people can receive good quality therapeutic treatment, the whole purpose of the ward is thrown into question. They can become a place of neglect rather than recovery.

"It's clear that staff on some wards are stretched to the limit, so much so that it makes patient observation a physical impossibility. There is also a worrying lack of basic training, particularly with restraint procedures, jeopardising patient safety with potentially fatal consequences.

"But it would be wrong to suggest that all wards are performing poorly. There are some shining examples of high quality inpatient care, where innovation and patient involvement ensures that a truly therapeutic service is delivered. The challenge is to make this a reality across the board.

"Later this week the Government will publish New Horizons, its consultation document on the future of mental health services for the next decade and central to this must be a commitment to make quality inpatient care a reality for all who need it. In addition, the new Care Quality Commission must use all its powers to stamp out poor practice and promote the highest levels of safety and care."

# BOOK REVIEW

## **Born on a Blue Day** by Daniel Tammet

- Paperback: 304 pages
- Publisher: Hodder Paperbacks
- Language English
- ISBN-10: 0340899751

### **Amazon Product Description**

'I was born on 31 January 1979 - a Wednesday. I know it was a Wednesday, because the date is blue in my mind and Wednesdays are always blue, like the number nine or the sound of loud voices arguing.'

Like the character Hoffman portrayed, he can perform extraordinary maths in his head, sees numbers as shapes, colours, textures and motions, and can learn to speak a language fluently from scratch in three days. He also has a compulsive need for order and routine. He eats exactly 45 grams of porridge for breakfast and cannot leave the house without counting the number of items of clothing he's wearing. If he gets stressed or unhappy he closes his eyes and counts.

But in some ways Daniel is not all like the Rain Man. He is virtually unique amongst people who have severe autistic disorders in being capable of living a fully-functioning, independent life. It is this incredible self-awareness and ability to communicate what it feels like to live in a totally extraordinary way that makes BORN ON A BLUE DAY so powerful. (20060710)

## **Mencap welcomes SEN changes**

Government commits to new laws

Children's secretary Ed Balls (pictured) has promised to change the way schools support children with special educational needs (SEN).

The announcement comes after the Lamb Inquiry submitted reports on 'The quality and clarity of statements' and 'Inspection, accountability and school improvement'.

The reports were published alongside a series of recommendations including two statutory changes – one allowing parents to appeal a local authority's decision on their child's statement, and another placing a duty on Ofsted to report on the quality of the education provided for disabled children and children with SEN.

Acting on the recommendations, Balls confirmed he will make Ofsted inspections of educational support for children with SEN a legal requirement. He also promised greater rights for parents unhappy with their child's SEN statement.

The Lamb Inquiry was established as part of the government's response to the House of Commons education and skills committee report 'Special educational needs: assessment and funding'. The inquiry will look at ways to increase parental confidence in the SEN assessment process.

Commenting on the planned legislation, David Congdon, head of campaigns and policy at Mencap, said: "All too often parents of children with a learning disability have to fight to get the educational support their child needs. The proposed 'right to appeal' will take a parent's knowledge and understanding of their child into account, strengthening their rights as parents. It is a major step towards addressing the needs of children with a learning disability more accurately and effectively.

"Introducing Ofsted inspections to assess the quality of educational support for children with special educational needs as a legal requirement is a very positive step. We believe this will have a big impact on the lives of children with a learning disability."

A final report from the Lamb Inquiry is due in September

# New project to help people with dementia benefit from self-directed support

## The Mental Health Foundation is seeking pilot sites to participate.

A new piece of work being carried out by the Mental Health Foundation aims to make available and promote different forms of self-directed support, including direct payments, individual budgets, and personal budgets to people living with dementia and their carers.

As a result of the Health & Social Care Act 2008 there will be much greater opportunity for the 580,000

people with dementia in England\* and their carers to benefit from direct payments. Previously, legislation had prevented people who lack mental capacity to benefit from this type of self-directed support.

But the uptake of the different forms of self-directed support for people living with dementia and their carers remains low. Dementia Choices, funded by the Department of Health, will identify the reasons why and recommend solutions, that will be disseminated nationally.

Toby Williamson, Head of Development for the

Mental Health Foundation, said:

“This project aims to improve the lives of people living with dementia and their carers. Whilst eligible for self-directed support, many are still not accessing or benefiting from what’s available. Working with voluntary and statutory groups and organisations we hope to identify and help overcome the barriers.”

Claire Goodchild, National Programme Manager of Dementia Implementation at the Department of

Health, said:

“Dementia Choices will play an important role in improving community personal support, which is a key theme in the Government's National Dementia Strategy. It should accelerate our knowledge and boost our understanding of how we can help people to live well with dementia. We welcome the opportunity to work closely with the Mental Health Foundation on this vital project”.

The Mental Health Foundation is seeking expressions of interest from organisations interested in taking part in the project as a pilot site. Closing

Mental Health Foundation

## Rock the Boat returns

Mencap returns to Proud Camden to host a club night for people with or without a learning disability

Following the triumphant success of the inaugural event held in July, Proud Camden welcomes back Rock the Boat on 9 September, with another stellar line-up including performances from Seb Fontaine and 1st Chancers.

Universally well received and generating huge amounts of press interest, the first event attracted praise indeed from The Sunday Times Style magazine, who said it was the "most fun [they'd] had at an indie night in a long time". The pioneering event has given people with a learning disability the platform to get involved in the entertainment industry, something for which there is a huge appetite, with all profits on the night going to learning disability charity Mencap.

Rock The Boat gives people with a learning disability the opportunity to get involved in every aspect of running a club night, from the door check to the promotion of the event.

Lloyd Page, a spokesperson for Mencap who has a learning disability himself, said "I had a really good night at Rock the Boat night at Proud Camden. I'm really looking forward to the next one, and hope that we will raise lots more money so Mencap can keep supporting people with a learning disability and their families and carers".

Doors: 7.30pm Entry: £5 with all profits on the night going to Mencap

# 100 Changing Places toilets

Thanks to the support of campaigners, there are now 100 Changing Places toilets in the UK

The Tinsley Green Children's Centre in Sheffield this week opened its Changing Places toilet – marking the 100th facility in the UK.

The milestone is welcome news to the Changing Places Consortium which has been calling for Changing Places toilets to be installed in big public places. Throughout this year's Learning Disability Week (22-28 June) Mencap held a series of events to raise awareness and gain support for the campaign.



Changing Places toilets include a hoist, a height-adjustable changing bench and plenty of space. Standard disabled toilets do not meet the needs of nearly quarter of a million people in the UK, including 40,000 people with profound and multiple learning disabilities.

Mencap's campaigns support officer Mark Gale said: "The progress that is being made, especially over recent weeks, is welcome and great news for the thousands of people who are able to enjoy days out with their families as a result.

"However, there are 230,000 people in the UK who would benefit from Changing Places toilets. This means that more Changing Places toilets are still needed, and we will be looking forward to watching the continued growth in the number of toilets as a result of the campaign."

You can still get involved in supporting the campaign by signing the online petition calling for the government to make sure that all new public buildings have a Changing Places toilet. See [www.mencap.org.uk](http://www.mencap.org.uk).

## JFK sister and Special Olympics founder dies

Eunice Kennedy Shriver, the sister of President John F Kennedy, has died aged 88



Ms Shriver organised the first Special Olympic Games in Chicago in 1968. She was reportedly inspired by her sister, Rosemary Kennedy.

Since then, the movement has grown, providing Olympic-style competitions to athletes with a learning disability worldwide.

Special Olympics Great Britain was formed in 1978. Its National Summer Games took place in Leicester at the end of July – more than 2,400 athletes from across Britain competing in 21 sports including judo, football and swimming.

The Special Olympics is recognised as the third Olympic movement, alongside the Olympics and Paralympics.

Brady Lum, president of the Special Olympics, said: "It is an enormous loss, but I know we can rest assured that her legacy will live on through her family, friends, and the millions of people around the world who she touched and transformed."

# Sandra Robinson: Art Saved My Bacon

On Show: 20 August - 2 October 2009

Opening times: Monday to Friday - 9am to 5pm

Entrance: Free

Venue: Together Our Space Gallery,  
12 Old Street, London EC1B 9BE

The first solo exhibition by Jewish artist Sandra Robinson, *Art Saved My Bacon*, is on show at our gallery from 20 August. Life-size sculptures plus paintings and poems map Sandra's journey through her childhood, cultural heritage, and periods of mental illness, to recovery and happiness.

## *Art Saved My Bacon*

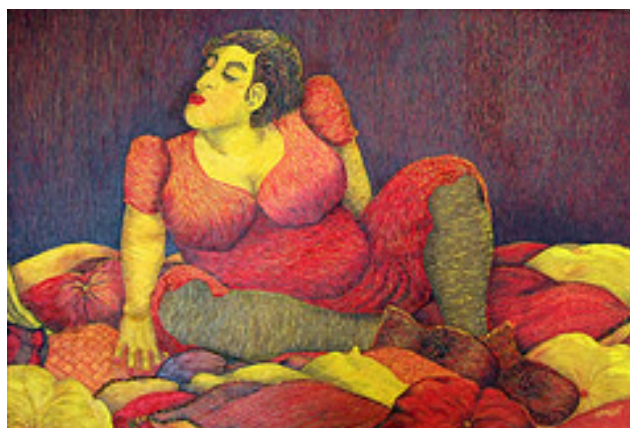


The title of Sandra's exhibition is lifted from a featured work in which building block style letters are laid out to form the sentence, 'As a Jewish woman art saved my bacon'. The letters in the piece group together in odd combinations that make it difficult to decipher meaning, suggesting that it is art rather than words or doctrines that communicate who she is to the world. Sandra comments: "After all these years of being unwell I'm finally able to come out with my first solo exhibition and say: this is me, this is who I am."

After showing much promise and being accepted to art-college a year early (age 17), Sandra dropped out due to periods of depression. Decades later, which included a painful 13 year creative block where she was unable to produce any work, she was diagnosed as being bi-polar. Following a referral from the day hospital she was

attending, Sandra was supported to regain belief in her art by Community Link, a department at Barnet College providing support to adult learners. It is this that has given her the confidence to finally put on her own exhibition, with the support of Together Our Space.

## *Dreaming of Cream Cakes*



Much of the work on display in this exhibition is humorous and powerfully hopeful as it emerges from painful and difficult periods in Sandra's life, to eventual wellbeing. In *Dreaming of Cream Cakes*, the striking image used on the poster for the exhibition, the colours and tone remain stubbornly bright, however Sandra describes the image as, "an expression of my low self-esteem, and the angry feelings I had toward myself at a certain point in my life."

My psychiatrist at the time said I was an 'entertainer'. Like many people I often use humour and jokes to survive bad times."

All enquiries about this exhibition: email Amy McKelvie T. 07875 102 787

# New Horizons Consultation

**Su Sayer, chief executive of United Response**, says of the New Horizons consultation:

"New Horizons, the Department of Health's new consultation on mental health, is a bold and positive step towards reform of mental health services in the UK. Its collaborative approach is particularly welcome: by involving people with mental health needs, the NHS and service providers from the start, the consultation is far more likely to lead to a successful new strategy that reflects and addresses the reality of living with mental health needs in the UK.

"We believe that the paper's focus on commissioning and developing innovative services that are tailored to the individual is entirely correct, such as computer training or reading groups for the over 50s. Our own experience is that good training, which helps a person feel valued and look to the future, can be an essential part of helping people experiencing mental health distress to get better and to recover if possible. Similarly, projects which help people who have experienced mental health problems reflect on their experiences and use them creatively, can help them take control of their lives. The best of these services are flexible and tailored so that they work to the pace of the individual.

"The priority the paper gives to tackling stigma is also very significant: despite the fact that one in six of us experiences a mental health problem at any time, there is still too little understanding of what living with a mental health need is really like, such as in some areas of the media. This can damage people's confidence, increasing their feelings of isolation, and make a difficult situation very much worse.

"Finally, the paper is right to recognise that services must deliver value for money, particularly in these difficult economic times. Providers of mental health services need to be better at demonstrating why they are a good investment, but those that do so must be funded properly as good mental health services save the taxpayer money.

"For example, good employment schemes help people back into work, particularly important economically as mental health is one of the major causes of long-term sickness absence. Early intervention is vital, as statistics show that once

someone has been on incapacity benefit for two years, they are more likely to die or retire than they are to ever work again. Similarly, positive interventions that give people the support they need are absolutely vital in preventing problems from escalating into long term mental and physical health issues which are not only expensive to manage but also incredibly damaging to individuals and those around them.

"Now it's vital that these excellent objectives are put into action. We look forward to playing an active role in this positive and forward-thinking consultation, and ensuring that improved mental health becomes a reality by 2020."

## Rethink's Opinion

Paul Corry, Rethink's director of public affairs, says: "This is a valuable opportunity to set a vision for mental health that could deliver real improvements to people's lives. We particularly welcome the focus on early intervention, personalised services, and recovery. However, this aspirational strategy will be pie in the sky unless it is backed up by adequate resources and dedicated political leadership.

"Stigma and discrimination remain the biggest barriers to the economy over the next ten years. We need the government to commit to long-term funding of initiatives such as Time to Change [see c below] to transform public attitudes. At present we are a long way from achieving the 2020 aim of a society where people accept that mental health problems can affect anyone at any time."

Rethink is pleased to see the government's expectation that by 2020:

- mental health services should be available to all who need them
- stigma will be significantly reduced
- people with mental health problems will no longer be at greater risk of poor physical health
- those who are unable to work will be able to take part in meaningful activities
- physical and mental health will be seen as equal priorities

# Call for nominations: RADAR People of the Year Awards - the "Disability Oscars" 2009

RADAR seeks nominations for the prestigious 2009 People of the Year Awards – the 'Oscars' of the equality and inclusion world - by 1st September. These awards, now in their 43



rd year, celebrate excellence and achievement by both disabled people and those organisations with a commitment to furthering the equality agenda for disabled people and inspire wider change.

In addition to the traditional Person and Young Person of the Year Awards, Media and Lifetime Achievement awards, a raft of new awards have been announced focusing on key areas for disabled people's equality, such as boosting independent living, accessible IT, rights to financial independence and the drive to open up careers and leadership opportunities. These are some of the areas where progress needs to intensify if we are to unlock the talents of disabled people and come out of recession strong.

The winners will receive their coveted awards at the People of the Year Ceremony. This spectacular black tie dinner and show, attended by people from business and the media, celebrities and politicians, will take place at Battersea Evolution on November 30th. The evening will be hosted by Frank Gardner OBE, the BBC broadcaster, who returned to frontline broadcasting from a wheelchair after being shot six times by Al-Qaeda gunmen and undergoing 14 operations.

People can nominate online at [www.radar.org.uk/awards-2009](http://www.radar.org.uk/awards-2009). All nominations must be received by [aidan.hargitt@radar.org.uk](mailto:aidan.hargitt@radar.org.uk) by September 1st.

This year's award categories are:

**Doing Media Differently Awards** - for great programmes, where commissioners, programme makers, the casting agents and/

or disabled actors have broken new ground and have done things differently. There will be two awards in this category: best factual programme and best fictional programme

**Doing IT Differently Award** - for the IT innovation that has really embraced inclusion and opened up the possibilities for disabled people to really participate in society.

**Doing Careers Differently Award** - For the employer or recruitment agency who has pushed the boundaries in enabling disabled people to secure senior posts - doing recruitment and career progression differently

**Doing Money Differently Award** - For the financial institution or organisation which has done the most to help disabled people develop financial independence, access banking or financial advice.

**Doing Access Differently Award** - For the organisation which has really made a difference in access and opened up significant areas to disabled people – or are planning exemplary practice with regard to the Olympics.

**Doing Care and Support Differently Award** – For the organisation that has really increased disabled people's independent living opportunities whether a local policy maker, Social Services Department, Centre for Independent Living or Care Agency

**Disabled Young Person of the Year** - For the disabled young person who has made the most difference this year to disability equality.

**Lifetime Achievement** - For the person who has made an outstanding contribution to ensuring Britain is a just and equal society which embraces human difference.

**Person of the Year** - For the person who has made most difference this year to disability equality.

# Charities seek young scientists to research age-related hearing loss

RNID, the largest charity in the UK representing deaf and hard of hearing people, and Research into Ageing have joined forces to strengthen research into age-related hearing loss.



The charities are inviting applications for a series of co-funded research projects to investigate why hearing declines with age and to advance the development of treatments.

The joint initiative will provide funding for PhD students, encouraging the most promising young scientists to begin a career investigating hearing in an ageing population. The charities hope that by increasing the number of researchers working in this field, faster progress can be made to produce new treatments.

Dr Ralph Holme, Director of Biomedical Research at RNID, said: "Working with Research into Ageing we hope to encourage scientists from other disciplines to get involved with research into hearing loss. We want to attract the best young scientists to this area. Understanding what causes age-related hearing loss is the first step towards finding ways to prevent

it - it doesn't have to be an inevitable part of getting older. "

Professor James Goodwin, of Research into Ageing, the medical research arm of Age Concern and Help the Aged said: "Hearing loss becomes much more common as we age and the impact can be truly devastating for older people. Often it can lead to feelings of frustration, social isolation and loneliness. Therefore we are delighted to be working with RNID in encouraging PhD students to undertake research in this vital area and look forward to

some exciting results in the future."



Hearing loss is the most common disability among older people, affecting one in two people over the age of 60, around 6.5 million people in the UK. Hearing loss affects the quality of life for many, making it difficult for them to communicate with their family and friends, which can lead to social isolation and poor health.



Currently, there is no way of identifying those at risk or preventing the onset of hearing loss.



# Day Conference The Rose

## Review of provision for children and young people with dyslexia: Implications for policy and practice in Local Authorities.

### **When and where is the conference to be held?**

Monday October 12th 2009 The Institute of Education, University of Reading, Bulmershe Court, Woodlands Avenue, Earley, Reading RG6 1HY

### **Who and what is the conference for?**

The conference is designed for those involved at Local Authority level in planning and provision for children and young people with dyslexia. Sir Jim Rose, author of the Rose Review, will provide an opening address to the conference. The conference is intended to help those in responsible positions in Local Authorities to move forward in implementing the recommendations of the Rose Review.

### **How will this be achieved?**

Presentations will bring you up to date with the purposes, evidence base and recommendations of the Rose Review, including the need for such a review, and the Dyslexia Charities' response to its recommendations (see attached provisional programme for details). Workshop sessions will allow you to:

- share your current areas of good practice with others
- learn from their experience
- assess your current provision, in the light of the Rose Review recommendations
- identify the systems, structures and processes necessary to implement the Rose Review recommendations

There will be opportunities throughout the day to discuss emerging issues with representatives from the major dyslexia charities, including:

- Judi Stewart, Chief Executive of the British Dyslexia Association
- Shirley Cramer, Chief Executive of Dyslexia Action
- John Rack, Head of Assessment Services and Evaluation at Dyslexia Action
- Lynn Greenwold, Chief Executive of PATOSS (Professional Association of Teachers of Students with Specific Learning Difficulties).

For any further information or queries, please contact

Tracey Pinchbeck email: [t.i.pinchbeck@reading.ac.uk](mailto:t.i.pinchbeck@reading.ac.uk); tel: 0118378 8838 or Professor

Rhona Stainthorp email: [r.w.stainthorp@reading.ac.uk](mailto:r.w.stainthorp@reading.ac.uk); tel: 0118 378 5935

# Government project brings accessible textbooks for children a step closer

The Royal National Institute of Blind People (RNIB) is celebrating a major milestone in its campaign for accessible school text books. The Department for Children, Schools and Families (DCSF) have announced the appointment of a consortium led by Dolphin Audio Publishing to run a pilot project which aims to transform access to textbooks for blind, partially sighted, dyslexic and other children who cannot read standard print.

Lesley-Anne Alexander, Chief Executive of RNIB said: "Currently blind and



partially sighted children throughout the country risk losing out on their education

because they and their teachers struggle to get hold of text books in a format they can read.

"RNIB is campaigning hard for children's right to read text books. This announcement is an important milestone for all those who have campaigned with us to achieve it. Now RNIB is committed to working alongside this consortium whilst keeping up the pressure on Government, to ensure that this pilot project delivers an efficient solution."

RNIB, with other members of the Right to Read Alliance, have run a long and vocal campaign to highlight the lack of accessible text books, which in March 2007 included the largest ever lobby of Parliament by blind and partially sighted children.

13 year old Rebecca has albinism with nystagmus and needs large print text

books. Currently her teachers try very hard to reproduce the books by enlarging them on a photocopier, but this is time consuming and can disrupt the formatting. Her mum, Michele, is already working with the school to prepare books for next academic year.

Michele says: "Getting textbooks that Rebecca can read is a constant battle for both us and her teachers. We're pleased to hear the Government is finally taking this issue seriously, but we're very anxious to know whether this pilot will find a way of Rebecca getting the textbooks she needs to study for her GCSEs in two years time."

RNIB research (Nov 2006) found that only 12 per cent of maths and 8 per cent of science GCSE text books in England were available in large print or braille. Despite teachers' best efforts, many blind and partially sighted children are still getting some materials later than their sighted classmates.

The pilot project funded by DCSF should transform access to text books for children who cannot read standard print. It will develop and test ways of providing books and other Key Stage 3 and 4 curriculum materials in IT based formats that are accessible to pupils who are blind, partially sighted or dyslexic.

The pilot is expected to run in a number of Local Education Authorities from September 2009, lasting a full academic year. For details of the project and how it is progressing, write to your local MP and ask him or her to keep you informed.

# HISTORICAL STEP AHEAD FOR THE RIGHTS OF DISABLED PEOPLE



President Obama at UN

President Obama keeps his electoral promises: he has just signed the United Nations Convention on the Rights of Persons with Disabilities. Another step forward for the first Human Rights Treaty adopted in almost 20 years and a great signal for its ratification

by all countries around the world.

Yesterday July 30<sup>th</sup>, the United States signed the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This signature represents a policy shift toward enforcing Human Rights obligations putting disability on top of the agenda: this is the first Convention adopted by the United Nations (UN) in 20 years, and. The US has only ratified 3 Conventions in its whole history (the International Covenant on Civil and Political Rights, the Convention against Torture and the International Convention on the Elimination of All Forms of Racial Discrimination) and is traditionally reticent to be bound by International Treaties: President Obama is breaking with tradition: he is signing and seeking Senate ratification of a major Human Rights treaty. "Disability rights are universal rights to be recognized and promoted around the world" said President Obama. He also acknowledged that 650 million people in the world's population live with a disability.

In the European Union, more than 65 million persons have a disability: representing more than 10% of the citizens from 27 countries. Since its entry into force on May

2008, the Convention has been signed by all Member States and by the European Community. The ratification by the European Community is expected by the end of the year and it will be the first time in its history that the Community are going to accede to an international human rights treaty. With 142 signatories and 62 ratifications only just 28 months after opening the Convention for signatures, the UN CRPD sets an unprecedented record of commitment by the International Community.

Carlotta Besozzi, Director of the European Disability Forum (EDF), stressed "President Barack Obama not only fulfilled his campaign promises but he also sent a positive signal to the countries that haven't signed nor ratified the Convention yet." The UNCRPD binds its States Parties to a revision of all existing legislation, policies and programs to ensure they are in compliance with its provisions. Concretely, it will mean actions in many areas such as access to education, employment, access to transport, infrastructures and buildings open to the public, granting right to vote and political participation, ensuring full legal capacity to all persons with disabilities, and a shift from institutions where persons with disabilities live separated from society into community and home based services promoting independent living.

September 2<sup>nd</sup> – 4<sup>th</sup> 2009, EDF will represent the European Disability movement as part of the Civil Society at the historical session of the United Nations Conference of States Parties where legislative measures to implement the Convention on the Rights of Persons with Disabilities will be discussed.

# Lewisham Disability Coalition Response

## AND FINALLY

**At long last we have had a response from Lewisham Disability Coalition (LDC) regarding our comments in this newsheet in June and July. Frankly, I don't understand much of it but it's printed below with our comments to try to clarify our position because in all honesty I'm not sure LDC understand what it is. – Denise Smith**

The Trustees of Lewisham Disability Coalition detail below their response to the recent criticisms from the CIL management committee. They have taken time to consider the criticism levelled at the organisation before responding in order to ensure that the response is measured and appropriate.

***(Firstly our name is CILL (Campaign for Independent Living in Lewisham). A CIL (Centre of Independent Living) is something entirely different. CILL is a registered charity and this means that CILL does not have a management committee, we have a board of Trustees. Last time we checked LDC did not have charity status so I'm unclear as to how they have Trustees. More importantly none of our articles were written as 'criticisms'. We wanted to open up constructive debate and consultation on the way forward for a Centre of Independent Living - our suggestion was for a Federation that would support LDC's vision of a resource centre and enhance their second tier function and strategic role).***

Many of the readers of CIL's newsletters are LDC members and from comments made to us by some of them they are confused and disagree with the picture painted by CIL of Lewisham Disability Coalition. ***(I'm not sure what picture we painted but we hear comments and complaints about lack of communication among other things. I value their welfare benefits service and refer people to them).***

Lewisham Disability Coalition is a user led membership organisation, and like the majority of such disability organisations, including CIL, share common values and aims. Equal citizenship, independent living and inclusion for disabled people.

Our objects are:

- To relieve the needs of disabled people by the provision of services which may help disabled people lead independent lives and participate fully in their community and Society.
- To promote equality for the benefit of disabled people.

***(Given that LDC are funded to provide a second tier umbrella function to Groups and have a strategic role shouldn't there be objects for that?)***

From the start engaging in a constructive way with the CIL management Committee has posed a challenge for us. We have asked to meet with them on a number of occasions but this has not been agreed to.

What has been clear to us since CIL formed is that our two organisations need to work together along with other local and national disability groups and organisations in order to address the needs and aspirations of ordinary disabled people in the borough. No one organisation can represent all disabled people in the borough nor can it meet all of the need for user led independent living services.

***(Frankly I'm confused – I met with Carol Mew (LDC's Director) shortly after she took up her post and we agreed, or at least I thought we agreed, that LDC would let me have specific proposals that I could put to the CILL Trustees for our two organisations to work together. When I heard nothing from them I sent her an email asking for proposals and I also remember explaining why, as far as we were concerned, there was no competition – LDC was a second tier umbrella group with a strategic disability role and CILL was not. Our focus was around supporting and promoting inde-***

*pendent living for individual disabled people. There was no reply but a few weeks later LDC changed their constitution to include independent living for individual disabled people (presumably the current objects) – so much for working together and complimenting each other! Despite that we have really tried to engage with them – I remember a meeting at their office with their Director and Chair (Barbara Britton) at which I outlined the priorities and work set by our Trustees but nothing is ever given back by LDC. Specifically (and with hindsight foolishly) we abandoned our own tender bid for the Direct Payments Support Service to support the LDC bid – a bid they subsequently decided not to make without telling us. They told us they were busy so in the spirit of partnership working we offered to facilitate the Disability Forum for them and we also subsequently offered a designated LDC area in this newsheet for free but got no response. Please forgive my confusion but if they will not give proposals and won't respond to ours just who is refusing to work together? I don't think it's CILL. By the way both proposals are still open so we look forward to LDC's response.)*

The new and proposed developments in health and social care, which LDC and CIL continue to inform their members of, can provide opportunities as well as present risks to a wide range of voluntary organisations and we hope that CIL can see the benefit of working with us and others to the benefit of local disabled people.

*(If LDC feel threatened by these developments I can't comment all I can say is we do not. We are a communication network giving out information, for example as we have done this month on the Green Paper, so why exactly is that a 'present risk'? As for working with others, we already do that and as I explained above LDC won't engage with us.)*

LDC's staff and volunteers are working very hard and continue to be under enormous pressure from local disabled people for ad-

vice and advocacy services but we are also working hard to develop our strategic role. *(I'm sure all of that's true but why is the strategic role (and in our opinion the most important one) only now being 'developed' – this role has been funded for 6 years.)*

We have consistently championed the involvement of disabled people and have raised the profile of their issues and concerns. We have been instrumental and active participants in the development of a number of influential working groups including the LBL Housing and Disability sub group, LBL DDA access group, service user representation on the joint equipment store management board etc.

Sufficient resources are certainly an issue, particularly for small user led organisations such as CIL and LDC but that is even more reason for us to be cooperating and working in partnership.

*(I would expect this from a strategic partner (LBL's phrase) but as a member of LDC I also expect to be kept informed about the strategic work that happens and I'm not. If LDC had take advantage of our offer to have a specific LDC area in Disability Review they could have kept their membership informed every month and saved themselves the costs involved of the recently launched monthly newsletter.)*

We do not deliver holidays or social events; we do give advice and information to clients on those topics. We do advertise the activities of other disability groups and organisations, it appears that this information in our newsletters and informal conversations, have led to CIL drawing the wrong conclusions. We feel that LDC has a deserved reputation for responsive accessible services, we assist over 2000 people a year and our funders get very good value. We generate over £500,000 in income for our service users and each individual who receives DLA or AA counts in increasing the funding to the local authority. We do not just deliver advice on benefits but cover a wide range of issues connected with independent living.

*(If we have made incorrect assumptions I*

*apologise but these were made based on information we had because LDC will not communicate what they do. We get no regular newsletter and despite asking I haven't seen annual accounts or annual reports for three years. I believe accounts have been filed as that is a legal requirement but annual reports are also common practice to keep funders and members aware of what the organisation has done during the previous year and are also needed to support funding applications. I believe they are busy providing advice services and drop-in sessions but isn't the reality that they are using resources (the Director's post?) to do that rather than carry out their funded strategic second tier coalition role?*

*It's a fantastic achievement to have generated over £500,000 for individual disabled people by claiming extra benefits they are entitled to but personally I see the benefit in terms of increasing income and helping to lift disabled people out of poverty – giving them more choices and better life chances - not increasing the amount of charges they can pay. )*

CIL is arguing that LDC cannot play both a strategic role in the borough and deliver services. In fact most other organisations which work for equality for a section of the community do exactly that. Indeed the evidence that can be gathered from service provision can and is fed in to further inform social policy development and give weight to the individual and group voices of disabled people in the borough. We have clear policies on conflict of interest and will source independent advocacy for anyone who needs it.

*(CILL is not saying it can't be done but they have not done it. The reality is they don't have the resources to do everything. The Director's post is too busy running 'drop-ins', advice sessions and advocacy to undertake the strategic second tier coalition role to any worthwhile degree. That is not a criticism of Carol Mew it is about limited resources. We genuinely believed that if CILL took on some of their workload, by facilitating the Disability Forum and providing an easier and cheaper way to communicate with their*

*membership through Disability Review, LDC would be able to develop their strategic second tier coalition function. We know they want to develop a resource centre with services, we agree it's needed, but this alone will not deliver the strategic second tier coalition function. That is why CILL developed the idea of a Disability Federation which would work alongside LDC's resource centre and be a means to strengthening their role. LDC have raised the issue of conflict of interest so perhaps they can explain why a Lewisham councillor sits as a director on their management committee – as they are core funded by Lewisham Council I would have thought this is one.)*

It is true that there is competition between voluntary organisations for scarce resources but if there is genuine dialogue and cooperation, that competition can be transformed into opportunities for joint funding bids and the expansion and development of the user led sector in Lewisham. We have done our best in difficult circumstances and with a difficult inheritance.

*(As I explained above we were never in competition, any competition was introduced by LDC. We have been trying for 3 long years to get some 'genuine dialogue and cooperation' going. Two years ago advocacy groups got together and agreed we needed an advocacy alliance. LDC, as the second tier organisation, wanted to take this forward and it was agreed they would pursue funding. Nothing ever happened but eventually the LDC Director told me that she had been too busy with advocacy and advice to pursue funding. Well she could have asked CILL to do it, we would have looked for an appropriate funder and written up a partnership bid and quite possibly we would now have an advocacy alliance in place that would have set an advocacy strategy.)*

The way in which our organisation works and the methods used for involving members continues to evolve in response to the changing social and political environment and the needs of members but at its heart the driving force is to widen and deepen the involvement

and voice of ordinary disabled people. To this end and in response to a direct request at a Disability Forum meeting smaller local and specialist meetings are held. CIL along with other members are informed of the meetings. We have both individual and organisation members.

We held our first organisation only meeting this June and this will be repeated on a regular basis going forward.

*(LDC knows we support these meetings. We have complained about the way in which disabled people are involved in them, the content and lack of agenda until the meeting starts. We have tried to talk about this but they refuse to listen. At the recent very poorly attended organisation meeting a few people made suggestions about future events – time will tell if LDC takes them on board.)*

Over the next year LDC will build on the success of the Deptford drop in pilot project and will be developing a number of local advice drop in and self advocacy-community involvement groups.

*(Great but what happened to ‘working hard to develop our strategic role’?)*

We continue to work with a range of disability organisations in the borough and are committed to develop that second tier work to improve its effectiveness and responsiveness. This was one of the objectives endorsed by members when they were consulted on the review of our Business Plan.

*(Good news but the big question is how. Also as an LDC member I’m a bit miffed that I wasn’t consulted on the review of the business plan and as I’m also CILL’s Chair that might have been useful to them if as they say they want constructive dialogue.)*

We will not become engaged in a debate over what understanding we have of strategic issues or changes in the disability movement, or even the difference between a resource centre and a Centre for Independent Living, we know what they mean and we also know what our individual members and service users are telling us and we will continue to put the interests of local disabled people at the

core of what we do. We are committed to working closely with and for disability organisations in the borough, particularly user led groups and hope CIL will engage with us in a constructive way to meet both of our organisations aspirations.

*(Finally we get to it – no debate, no consultation, they know what’s best for us and that’s what we’ll have. Our crime has been to dare to suggest that disabled people be given the chance to say what they want and to present proposals that might enable that. Disabled people have spent decades fighting for the right to choice and control in their lives. The very, very least we expect is to have that in our own community, our own organisations. Yet here we have LDC denying that and most frightening of all they use LBL funding to do it. I feel like weeping.)*

## THE LAST WORD

by Denise Smith

This is actually taking up too much time, achieving nothing for disabled people and is presumably boring most people out of their minds – it’s certainly boring me. The truth is that CILL and LDC are very different organisations with very different ethos. Communication, providing information and facilitating debate as a means to supporting citizenship, equality and empowerment is central to what we do. We want and have tried to support strategic and partnership working and have put forward proposals to, we believe, enhance LDC’s strategic second tier coalition role. That has been interpreted as competition, criticism and a refusal to engage. If I’m honest I think the real problem is that we will not be controlled. For now we will continue with our activities and partnership working. Two of our priorities this year will be to continue our call for wide consultation on a centre of independent living and to get an advocacy alliance up and running. We would welcome a partnership with LDC on either. Real partnership working has huge benefits but it is up to LDC to decide if they want that – they know where we are.

**As always this is your  
organisation and your voice  
matters. If you need us we are  
only a phonecall or email away  
so please get in touch:  
Telephone: 020 8776 6967  
Email: [campaign@fsmail.net](mailto:campaign@fsmail.net)**

**"Independent Living  
is not a service,  
it is freedom;  
it is liberation;  
it is equality for  
disabled people."**