

# Disabling Practice Enabling Nurses? Disability Network Newsletter

Number 10 Spring Edition

## Letter from the Editor

I would like to bring to your attention two important notes about people on the Contact List. Ruth Northway is now Principal lecturer at the University of Mid-Glamorgan in Wales. Congratulations on your promotion Ruth, sorry it is little belated. Philip Scullion is now working for the Royal College of Nursing four days a week as Disability Education Advisor.

The spring seems to have brought a flurry of activity. Please note the **Stop Press**, with the Study Day details on page 6, and the attached Conference Flyer at the end of the newsletter. I have also had a number of articles sent to me for inclusion. Thank you everyone that has contributed. I look forward to receiving more articles from people, and also, hopefully, meeting some of you at the coming study events.  
Rachael Spain.  
Editor

### **STOP PRESS....STOP PRESS**

#### **Dystonia Nurses Network Study Day.**

22nd March 2002  
Bournemouth

#### **Innovation and Disability Nursing - Challenges of the 21st Century**

Thursday 18th April 2002  
Royal Hospital for Neuro-disability

#### **RCN Disability Nursing conference Enabling practice: the Disability Rights Agenda**

Wednesday 3 July 2002  
Cowdray Hall,  
Royal College of Nursing, London

## DRC- New Code of Practice.

The Disability Rights Commission published the updated Code of Practice on rights of access to goods, facilities, services and premises for disabled people on 26 February 2002. This statutory Code, agreed by Parliament, provides detailed advice on the way the law should work, together with practical examples and good practice suggestions.

All provider organisations, including those involving in nursing and health services, should now be planning to ensure compliance with these new duties on disability access. While they come into force in October 2004 the revised Code works on the principle that good employers will wish to plan and implement changes in advance of the legal deadline.

Some services remain excluded under Part III of the DDA such as education and certain closely related services. However the Special Educational Needs and Disability Act [SENDA] (2001) will alter the DDA in September 2002.

The code 'The Disability Discrimination Act 1995: new requirements to make goods, facilities, services and premises more accessible to disabled people from 2004.' is available for purchase from the Stationery Office or it can be viewed or downloaded from the internet. [<http://www.drc-gb.org/drc>]

## HOUSE OF LORDS

Wednesday 16<sup>th</sup> January 2002

### Disability Rights Commission: Statement on Abortion Act 1967

**Lord Alton of Liverpool** asked Her Majesty's Government:

Further to the Written Answer by the Lord Hunt of Kings Heath on 13 December (WA 69), whether they have met the Disability Rights Commission, the medical professions, and other relevant organisations to discuss the recent statement from the Disability Rights Commission that Section 1(1)(d) of the Abortion Act 1967 (as amended) is incompatible with the principle that disabled and able-bodied people should be treated equally. [HL2153]

**Lord Hunt of Kings Heath:** No meeting has been held yet but the Department of Health is meeting the Disability Rights Commission to discuss a number of issues early this year.

## WHO CARES?

Dr Christine Barton, a disabled woman, has personal experience as a service user. For the past seven years she has worked with public, private and voluntary organisations to influence the development and design of service provision for disabled people. She is committed to a social approach to inclusion and believes that disabled people should be supported in a way that enables them to achieve their human rights and interests. In 2000 her work in services to disabled people and equal opportunities was honoured with an MBE and in 2001 she was appointed as a lay member to the General Social Care Council.

**'Good Health'** - a toast at a special occasion or an expectation that we all share. But just what is good health? The majority of us would agree that when the way our bodies work has gone wrong, and can be put right, it should be. As much as possible there should be freedom from pain and the right to dignity, independence and choice over the factors that affect our lives. The purpose of the National Health System is to make these things possible and largely it does.

However, health doesn't stop there. It is also about the quality of life, prevention, protection and making it possible for everyone, no matter what their physical condition, to actively take part in the life of our society. It is in these areas that the distinctions between health and social care become closely intertwined and impossible to separate from each other. And it is in these areas that many service users including disabled people have experienced discrimination and received a service that does not meet their needs.

Much attention over the past few years has been focused on the problems experienced by our NHS and the recognition that a major injection of resources and reorganisation were essential. Less attention was paid to social care. Only when it all goes wrong is it harshly condemned and brought to the public gaze.

In recent years Central Government's commitment to social care has been evident in its intentions to modernise social services<sup>1</sup>, with the principle of promoting independence and

rehabilitation. The NHS Plan<sup>2</sup> made clear that reform of the NHS system should centre round 'the needs of the patient'. Equally, plans to regulate social care stress the importance of putting service users at the heart of design and delivery. Four bodies, sponsored by the Department of Health have been established in England to turn intention into reality. Similar bodies in Northern Ireland, Scotland and Wales have been set up with the same purpose. All these organisations will co-operate with each other, both within and across countries in the UK

### **1. The National Care Standards Commission (NCSC)**

The NCSC will implement national minimum standards for the provision of social care. It will be independent of all service providers and will regulate, by registration and inspection, a wide range of service providers including statutory, voluntary and private sectors (and relevant parts of the independent healthcare market). It will seek to improve the quality of care services through advice and support to providers and supporting service users. It will report to the Secretary of State on the range and quality of care services in England.

### **2. The General Social Care Council (GSCC)**

The GSCC will regulate the social care workforce through establishing a Code of Practice for employees and a Code of Practice for employers (whose implementation will be monitored by the NCSC in the regulated sector). It will introduce and operate a register of the workforce, beginning with social workers, and it will approve schemes for the provision of social work education and training and promote the development of training for the social care workforce generally.

It will ensure that unsuitable people are not employed or retained within the social care workforce and determine the standards required for registration as a means of driving up quality and levels of training in the workforce.

### **3. Training Organisation for Personal Social Services (TOPSS)**

TOPSS is a National Training Organisation responsible for determining the training needs of the social care workforce, developing a national

training strategy and securing its implementation.

It will deliver action through employers to ensure that key target groups for registration by the GSCC have access to the levels of training required for registration. It will develop workforce planning to identify future recruitment, retention and training strategies

It is an independent employer-led Organisation receiving core financial support from Government, reflecting the importance of social care employers' owning and driving the implementation of the training strategy.

#### 4. Social Care Institute for Excellence (SCIE)

SCIE will be responsible for establishing and disseminating the knowledge base. It will draw on research, the results of inspections and the experience of service users. It will develop and promote guidelines for practitioners and providers and inform the NCSC and GSCC on standards.

It will promote the development of an evidence-based approach to policy, practice and management. It will pioneer the use of electronic means of storing and disseminating information (including good practice) as a part of the e-Government strategy.

The appointment of Jane Campbell MBE, a disabled woman who has a long record of lobbying for disabled people's civil and human rights, as Chair of SCIE together with the appointment of service users as lay members of all four bodies, is welcome evidence of Government recognition of their essential role in improving social care. Jane Campbell says,

*"There is excellent practice out there and it is up to SCIE to turn that practice into accessible 'know how', so all stakeholders can benefit and move forward. I hope my appointment will send out a clear message to everyone involved in social care that service users will not only be welcomed to help shape service delivery but will be expected to participate at every level.*

*My vision for SCIE can only be achieved by this active partnership. A partnership that will draw on the evidence of what works for those who give and receive social care on the ground."*<sup>3</sup>

What all the service users who have been appointed share is a commitment to a social approach to service provision. This means recognising that it is the way we have constructed our society that discriminates against people with impairments. It means identifying the barriers that make people 'disabled', 'vulnerable', 'hard-to-reach', isolated, etc. and working towards dismantling these barriers.

Christine Barton  
January 2002

<sup>1</sup> Modernising Social Services, White Paper, November 1998 HMSO

<sup>2</sup> NHS Plan, Department of Health July 2000

<sup>3</sup> Jane Campbell, December 2001, Social Care Institute for Excellence, London

### **Does Personal Assistance Work for You?**

The following article is reproduced with kind permission of the author who would be grateful if his request could be conveyed to people you may be in contact with, who have personal assistants.

#### **Harvey Cowe, a disabled researcher suspects the experiences of personal assistance users are still not recognised.**

I incurred a high spinal cord injury in 1983, due to a road traffic accident, and so need assistance with most daily living tasks. Although she had little choice, my Partner assisted with my needs for the first five years of my disabled career. I now receive funding from ILF (Independent Living Fund) and Social Services to employ assistants 24/7, although my Partner still continues to contribute with some of my personal care needs.

#### **Finding and recruiting suitable Personal Assistants:**

My own experiences of finding suitable PA's have been mixed, but mostly negative. I advertise in my local 'Free paper', because this is cheapest. Recruiting usually means intuitively filtering scores of people over the telephone. Those managing to pass through my 'feel right' filter are then interviewed at my home, the following week. I sit with a list of interview questions on my lap nervously waiting for my

first interviewee to arrive whilst rehearsing over and over, my script. I sometimes find it difficult to explain about the personal care aspects of the job without sounding apologetic and have, on a number of occasions, not even mentioned it! How do you tell someone that they will have to wash your penis, put on a sheath, clean your bum after using the toilet, every day, without feeling like you want the ground to swallow you up!

### **The relationship between Assistant and Assisted.**

I know that my PA is supposed to assist me with my needs, but I am always confused about which needs I am rightfully able to ask for assistance with. I've heard care agencies and other disabled people say that a PA is like 'your arms and legs' but I never see my assistant this way. If I were suddenly endowed with arms and legs you wouldn't see me for dust. I'd be up there, feather duster in hand, sweeping the cobwebs from my bedroom ceiling, I'd grab a broom and start cleaning the outhouse of the mess that I hate seeing every day, wash and clean the van, trim my sideburns, weed the garden. I'd drive to the beach, meet people, travel to far places, and get up to all sorts of sexual delights. My dreams, aspirations and goals would suddenly seem attainable and I could function to my true, full potential. I would feel liberated and empowered.

But I don't feel at all like this, I feel stifled and frustrated most of the time. I think that I get confused about which way I should be; am I supposed to be thinking and 'acting' the way I would before my accident, as though I have no impairment? I doubt that my PA's would be able to act as my arms and legs, pre-impairment, they would rebel and sulk, join a union, and rightfully so because I would work them till they dropped. I would do this not because I have a sadistic nature but because I've always been industrious and still am -I could never sit still.

So I sit and allow most of my aspirations to float away while thinking of simple short-term tasks for my PA to do. I am not particularly unassertive either; I ran my own business and did not have a problem requesting employees to do things then. I think that because the job involves such personal intimacy, and that my health is sometimes dependent upon my assistant, and the quality of the assistance provided, I don't want to rock the boat or give them any reasons to dislike the job or me.

### **Receiving assistance from family members, friends or Spouses.**

As mentioned, my Partner continues to contribute towards some of my personal care. I can see both positive and negative aspects of such an arrangement and wonder how others feel. I would prefer to receive assistance, especially my personal care, from someone I care about and who cares about me. But because the Independent Living Fund will not allow family members, friends or spouses to be paid, and the extra complications of benefit rules, this is difficult. Even if it would be possible to pay my Partner to do more, how would this affect my relationship? Is it possible for such a relationship to work harmoniously without encroaching on each other's freedom and independence? What happens if you have an argument with the person who you have a personal relationship with, that happens to also be the person who assists you? I am interested to find out whether other people's personal relationships have been affected in similar ways.

I am doing a PhD in 'Disability studies' at Sheffield University focusing on the experiences of disabled people who require assistance with daily living. These are some of the many confusions and issues about relationships involving personal assistance that I want to tackle through my project. I'm sure that others must be in a similar predicament and would be very interested to learn about their experiences. I should make it clear that I do not seek advice on how I could improve my own predicament. I am trying to be open and honest about the extent of my own confusions in this article because I want to people to know that if they do come forward to give information about their situation then I will probably understand if your story is disturbing too.

Equally though, I would like to hear from people who have made successful relationships involving personal assistants as positive experiences will help to show the way forward for improving the situation of others. The intention behind the research is to document our experiences, and the issues that are important to us, with a view to trying to make recommendations for relevant practical and policy changes.

If you feel that you would like to contribute to the research please contact me. All information will be treated as confidential and I would be

very glad to hear from anyone in order to get as many different viewpoints as possible.

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### **National Service Frameworks**

In some circles NSF means National Schizophrenia Fellowship, an important mental health charity, whereas in others they are instruments for ensuring an abolition of post-code health and social care services. National Service Frameworks for Coronary Heart Disease, Older People, Mental Health and Diabetes have been produced; NSFs for renal services and children's services are in preparation. The one announced last year by the Secretary of State Alan Milburn on long-term conditions focusing on neurological conditions will be of particular interest to nurses and readers of this newsletter. The first meeting to establish its scope was held in November 2001.

This NSF, expected for 2004, will include services for people with MS, Epilepsy, Parkinson's disease and other similar conditions. This meeting was addressed by Jacqui Smith, Department of Health Minister and Sarah Mullally, Chief Nursing Officer for England and scores of representatives from a wide range of key organisations including the RCN in the person of Sue Thomas.

It is the early stages of consultation of an NSF with particular relevance to disabled people, and people with some chronic health problems, and it is encouraging to note that user and carer involvement in the development and implementation of the NSF for long term conditions is seen as important. The working group wished to promote the aim of 'improving the quality of life and enabling independent living for everyone with a long-term medical condition'. While millions of disabled people in the UK do not have active medical conditions, this work will be of interest to those who do and the nursing and other staff who regularly work with them.

### **Making church life accessible to everyone**

Through the Roof, incorporating the work of the Disabled Christian Fellowship, is a Christian

charity working to make sure that disabled people have the same chance as everyone else to enjoy all that churches have to offer. This is achieved through a variety of activities, such as:

- Providing accessible holidays
- Sending regular inspirational tapes to disabled people
- Providing churches and other organisations with training and advice to help them to be more inclusive
- Running 'Churches for All', a national campaign to encourage churches to be more accessible
- Providing wheelchairs for disabled people in developing countries who would otherwise have no possibility of receiving one

We would welcome contact with Christian nurses interested in helping us with our work – perhaps by providing a small amount of nursing care at an accessible holiday or by joining a team of medical professionals fitting wheelchairs in developing countries. For more information, contact Through the Roof at 01372 749955, email [info@throughtheroof.org](mailto:info@throughtheroof.org).

### **The National Care Standards Commission Goes Live from April 2002**

Professor Jeremy Cooper is Chief Trainer in Social and Healthcare Law for Wessex Interactive Ltd, a company specialising in training busy professionals on the impact of new legislation on their work. Top of his agenda at present is the **Care Standards Act 2000**, which comes into effect in April 2002. As everybody who works in the residential care sector should by now be aware, the Care Standards Act, together with the Care Homes Regulations 2001, and the National Minimum Standards for Care Homes, will bring about a radical root and branch reform of the entire residential care home sector. No corner of the sector will escape the new regime, which will be regulated by the National Care Standards Commission, whose HQ is in Newcastle. Every care home in England, whether private, voluntary sector, or local authority run, will be obliged to comply with the complex body of rules and regulations that will become effective from April 2002, or they risk prosecution or closure. In contrast to the old regime, where unfitness was a matter for the Inspection units to uncover, the onus under

the Care Standards Act is on the care home managers to satisfy the inspectors from the Commission that their home complies with the new requirements to such a degree that they are fit to be registered. Compliance with regulations and standards will need to be demonstrated against standards and regulations across 7 discrete categories: Choice of Home, Health and Personal Care, Daily Life and Social Activities, Complaints and Protection, the Environment, and Staffing. Wessex Interactive Ltd, provides training and consultancy on all aspects of the new regulatory framework, including internet based courses on their dedicated training [www.clickntrain.co.uk](http://www.clickntrain.co.uk) and can be contacted, by E mail at [wessexlaw@aol.com](mailto:wessexlaw@aol.com), or by telephone on 023 8076 7365. Professor Cooper's **Care Homes Legal Handbook** will be published by Jessica Kingsley Publishers in April (144pp. £15.95).

*Jeremy Cooper is a barrister who also heads the Disability Law and Policy Research Unit at Middlesex University. He is the editor of **Law, Rights and Disability**, published by Jessica Kingsley Publishers in 2000.*

### **Dystonia Nurses Network Study Day.**

Dystonia has been defined as a, "Previously little known, neurological disease of the body's central nervous system and consists of a group of related movement disorders, characterized by involuntary and often painful, prolonged spasms of muscle contractions. It has also been clinically defined as "a syndrome of sustained muscle contractions, frequently causing twisting and repetitive movements, or abnormal postures."

[<http://www.dystonia.co.uk/> accessed 21-2-02]

It has been classified as 'Primary Dystonia', where investigation reveals no identifiable cause or 'Secondary Dystonia', which is associated with a known or assumed cause.

The Dystonia Nurses Network is holding a study day with the aim of sharing knowledge and experience concerning Dystonia. This one-day event in Bournemouth 22nd March 2002 is free.

For more details or to book a place please contact the local organiser Shirley McDonald, Tel 01202 -533244  
e-mail [heidimcd@hotmail.com](mailto:heidimcd@hotmail.com) or [Philip.scullion@rcn.org.uk](mailto:Philip.scullion@rcn.org.uk)

### **Innovation and Disability Nursing - Challenges of the 21st Century**

This event covers psychiatric problems in disability nursing, research reports on compliance and practice developments in nursing people with a wide range of neurological conditions. Other topics covered include Huntington's Disease Case Study and Nursing the Ventilated Patient.

Thursday 18th April 2002

09.00 till 16.00

Cost £60 per delegate (includes refreshments)

Please contact Jo Semlyen, Conference Co-ordinator on 020 8780 4500 ext 5236

Royal Hospital for Neuro-disability

### **A website to Combat Medical Discrimination against People with Down's syndrome and Other Learning Disabilities Launched.**

Health Minister Jacqui Smith is to launch a website which aims to combat medical discrimination against people with Down's syndrome and other learning disabilities.

The site will provide a broad range of information for medical students and health professionals.

It has been created by the Down's Syndrome Association and St George's Hospital Medical School in London. Campaigners say inadvertent medical discrimination is based on ignorance and that improvements to training and information available will be an effective antidote to the problem.

The website - [www.intellectualdisability.info](http://www.intellectualdisability.info) has been partly funded by the Department of Health. Carol Boys, chief executive of the Down's Syndrome Association, said: "We hope that medical schools across the UK will encourage their students to use the site to improve the currently patchy provision of training in this area."

### **Current Research –Saliva's Weapon in Infections War**

A substance found in saliva could help in developing new drugs to treat resistant infections, scientists suggest. It raises hopes for people with diseases like HIV and cystic fibrosis, who regularly develop infections that are difficult to treat with conventional drugs.

Dr Libuse Bobek, who carried out research at the University at Buffalo School of Dental Medicine in New York, said: "There is an increasing need for new antimicrobial agents, especially antifungals. "Because there are only a handful of these drugs, they are used widely and several fungal strains already have developed resistance." This is a particular problem for immuno-compromised patients, such as those with HIV/AIDS, organ transplant patients and chemotherapy patients."

So far, the work has been conducted in the laboratory and has yet to be tested on animals or humans. The saliva chemical has been shown to kill fungal agents like candidiasis, cryptococcosis and aspergillosis that can threaten people whose immune systems are compromised. It has also destroyed several bacteria, including E.coli and P. gingivalis, which respectively cause serious intestinal and oral infections, and S. mutans, which causes dental decay.

Scientists also found the chemical is active at very low concentrations and 10 micrograms per millilitre show little or no toxicity to mammalian cells. The discovery has been welcomed by the Cystic Fibrosis Trust. The organisation's director of research and clinical care, Dr Lorna Layward, said: "It would be good if it could lead to the production of new antimicrobial agents." However, this is very early research and we need to know if these new molecules are safe to use in patients." In cystic fibrosis, the lungs get infected with a range of different micro organisms and anything that can be found to be effective and safe to eradicate lung infections would make a significant difference to people's lives."

The Public Health Laboratory Service (PHLS) is also interested in this development. Dr Alan Johnson from the PHLS said: "Given the increasing prevalence of strains of bacteria resistant to current antibiotics, any new drugs that show antibacterial activity are to be welcomed." An added attraction of the compound reported by Bobek and colleagues is that it also attacks fungi, which commonly cause infections in patients with malfunctioning immune systems."

SOURCE: BBC News Online.

## **Epilepsy 'master gene' found**

Scientists believe they have identified a "master gene" linked to epilepsy and learning difficulties. Although other genes which can help cause epilepsy have already been identified, this gene controls how, where and when other genes work, affecting the way the brain functions. The Australian team behind the research said their discovery was likely to impact most on families and isolated cases with "non-specific" learning difficulties. Until now these could only be diagnosed by delayed development and intellectual impairment. The researchers, from the Women's and Children's Hospital in Adelaide, estimate up to 2% of the population suffers from learning difficulties and the same percentage from epilepsy. Epilepsy and learning difficulties often occur together and frequently have genetic causes.

In the UK, around one in every 130 people has epilepsy, a neurological condition which describes the tendency to have recurrent seizures. The researchers were puzzled that the same mutation in this gene can give rise to a range of conditions. These include epilepsy, West syndrome (a type of epilepsy affecting children), Dystonia (a muscle tone disorder causing muscle contraction) and learning difficulties. But they suggest the way the master gene affects other genes could hold the answer.

### **Genetic mutation**

Researchers obtained genetic material from nine families in Norway, Canada, Belgium, and Australia.

Dr Jozef Gecz, from the hospital's Department of Cytogenetics and Molecular Genetics, led the research.

He said: "This gene is found on the X-chromosome and is one of probably 100 genes on that chromosome, which when mutated, can cause intellectual disability. "The really novel aspect to this gene is its involvement in epilepsy as well as in intellectual disability." He said more work needed to be done to isolate other genes affected by the master gene and to establish why the same mutation could cause different conditions. "It will be very interesting to know the identity of these genes that are under control of this master gene as they may potentially be involved in either epilepsy,

intellectual disability, or both."

A spokesperson for the British Epilepsy Association told BBC News Online: "We view this recent research with considerable interest. "Epilepsy that effects children, such as West Syndrome, can have a considerable impact on families, so anything that could potentially help these families or increase understanding about the condition is to be welcomed." We would certainly like to see further research into genetics and epilepsy because there is still not enough understood about the link between the two."

The research is published on the website of the journal Nature Genetics.

SOURCE: BBC News Online.

#### **Recent Publications of Interest**

Minett RJ (2002) User participation in mental health care: a literature review. British Journal of Therapy and Rehabilitation. 9 (2) 52-55.

Cooper J (2002) Care homes regulations and the national minimum standards 1. Nursing and Residential Care. 4 (1) 36-38

Cooper J (2002) Care homes regulations and the national minimum standards 2. Nursing and Residential Care. 4 (2) 92-94

Brothers M, Eathorne V, Scullion P ( 2002) Disability Law and Employment: What does it mean to staff? Nursing and Residential Care. Vol. 4(2) 60-63

Eathorne V (2002) Health and Social Care Disability Awareness, Journal of Community Nursing, Vol. 16 Issue 1

Scullion P, Brothers M, Eathorne V ( 2002) Education For All. Learning Disability Practice Vol. 5 ( 2) 8-10

#### Contacts

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# RCN EVENTS

RCN Disability Nursing conference

## **Enabling practice: the disability rights agenda**

**This conference aims to examine how the disability rights agenda, encapsulated in the Disability Discrimination Act 1995, is being addressed within healthcare.**

Wednesday 3 July 2002

09.00am – 16.30pm

Cowdray Hall, Royal College of Nursing, London

**Keynote address:**

**Do health professionals have a role in promoting disability rights?**

Roswyn Hakesley-Brown, President, Royal College of Nursing

**Other sessions include:**

Promoting a positive response within health and social care services –The D.R.C 's vision and reality

Disabled people as health professionals –The Physiotherapy experience

Rights, independence and empowerment – the place of professional education

What does it all mean to me? A disabled person as patient perspective

Hearing their voices, seeing the vision; beyond reasonable steps. Health professionals with disabled people

**For further information and a registration form please contact:**

Jane Edey, Assistant Conference and Events Manager, RCN Events

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