

Disabling Practice? Enabling Nurses Disability Network Newsletter

Number 5. Spring Edition 2001

Letter from the Editor

Disability issues appear to be moving up the agenda, in all avenues of life, slowly and surely. This may be attributed to the fact that medical advances mean that many more people are now surviving previously fatal conditions, and swelling the ranks of people who have a disability. It is also true to say that disabled people are more likely to become activists and intent on taking an active place in society rather than living in the margins of life.

UK Legislation is constantly under review and two that are significant to disability issues are the *Special Education and Disability Bill*, currently passing through the House of Lords and the second is the consultation stage of the *Fairer Charging Policies for Home Care and other non-residential Social Services* Guidance from the Department of Health. This latter should prove interesting in the light of the decision of the Scottish Executive to remove all charges for Home Care. Both documents are available, to be studied, on the Internet.

When this newsletter was first conceived one of its objectives was to share good practice. I would be grateful for contributions from people working in the field to that end. I have had a few enquiries about specific conditions, and whilst having a vast resource at my disposal in the Internet, the sharing of real experience is invaluable to all. If people have a query please could they send their information request to me, to be placed in future publications.

I would also like to bring to your attention the addition of a new name on the contact list: David Wright, who specialises supporting students with Dyslexia and Deafness.

Rachael Spain. February 2001

RCN CONGRESS 2001
Sun 20th May – Fri. 25th May
Book Your Place Now

Good Practice in Cornwall

Victoria Eathorne has recently been appointed in the post as Disability Adviser to Cornwall Healthcare Trust. Last year she organised a conference jointly, between the Trust and the Royal College of Nursing, on Disability Awareness. As the conference was so successful, Victoria has been busy, with conference partners Cornwall Healthcare Trust, Cornwall County Council and the Royal College of Nursing, organising this year's follow up. 'Health and Social Care Disability Conference' which will take place on June 18, in Truro, Cornwall.

Based on the theme of good practice in partnership working the conference has already attracted high profile speakers.

The number of disabled people is dramatically increasing for a variety of reasons - an increasing life expectancy for everyone, better medicine, technological improvements, and a higher standard of living. The expectations of everyone in the local community - including disabled people - are increasing in relation to all public services. Government initiatives focusing on helping people to remain living independently in the community increase these expectations - the new NHS plan, Direct Payments legislation, the Disability Discrimination Act (1995) etc. Alone or together these facts have enormous implications for everybody, but especially for staff working in health and social care settings. Disability will affect all health and social care staff - whether meeting the needs of disabled services users: working as, or with disabled staff, or in relation to family or friends with disabilities. It is, therefore vitally important that all employees understand disability issues and people's expectations, in order to improve service provision, meet people's raised expectations and to meet new legislative requirements. This one-day conference will focus on these issues, as well as providing local and national perspectives from highly placed keynote speakers, with views on Consultation,

Rehabilitation, Promoting Independence, and effective Partnership Working.

Victoria can be contacted by:
telephone(01872 272494),
facsimile (01872) 260081
and email Victoria.Eathorne@cht.swest.nhs.uk

The cost of attending the conference is £10. If anyone is interested in displaying information at the conference please contact Victoria to arrange it.

There is a booking form attached to the end of this newsletter.

A Bureaucratic Barriers to Normal Day to Day Activities

A book worth reading sets out to expose how systems, regulations and service providers, set up to support people with neuromuscular impairments, may actually disable them. The book clearly shows that, with current work looking towards creating a seamless service and changing policies, there are a few mountains yet to be moved.

It reports on a project carried out by 'Muscle Power!' an organisation run by people with neuromuscular impairments [NMI] which basically confirms that there are many unnecessary bureaucratic barriers that add tremendous difficulty to the lives of people with NMI

The 14 personal accounts, contained within the report, talk of the impact of bureaucratic barriers on the lives of respondents; give considerable insights into the frustrations which may be unintentionally imposed by rigid administrative systems. They provide rich sources of experience for anyone reviewing their own service or those involved in training.

One respondent outlines the demeaning experience of being assessed for the allocation of community resources; the focus on 'inability' and being embroiled in disputes over which agency would fund the services deemed necessary. They pose the question "Aren't our lives complicated enough without the very services who are supposed to support us making them even more complicated?"

Identified problems include transport, payments, savings rules, the provision of aids and adaptations, lack of back up systems when equipment or systems fail, independent living and disputes over appropriate moving and handling techniques.

Whilst many of the solutions to the problems identified need to be dealt with at policy making levels, the report also offers many solutions that could be more easily implemented. One of these, which will be familiar and of interest to nurses, is the suggestion of a 'personal profile'. This is compiled and held by clients; it may communicate needs and desires and could reduce the number of assessments required by different arms of the health and social care systems. No doubt everyone has felt that 'The System' was working against him or her. This report enables us to see how, in the case of people with NMI and other disabled people, this is a daily experience.

Many nurses find themselves battling within or against 'the system' for their client's rights and independence. This report will strike a chord with them and may help in showing possible solutions to such barriers that are more real than any brick wall.

The report was compiled by Sue Maynard Campbell & Alice Maynard Lupton and is available from 'Muscle Power!' PO Box 5022, Derby DE21 2ZD, price £10

Reviewed by Philip Scullion 24th October 2000

New guidelines for reviving patients

The medical profession has announced its guidelines to end confusion on when it is acceptable not to resuscitate a patient. They call for closer consultation with patients to ensure their wishes are taken into consideration. Age Concern are hailing this as a victory for the UK's elderly who feared they were at risk of not being revived simply because of their age. The joint guidance of the British Medical Association, Royal College of Nursing and Resuscitation Council (UK) hopes to finally end the confusion over do not resuscitate orders (DNR's).

The guidelines follow a string of reports last year when seemingly healthy patients discovered they had "do not resuscitate" or DNR orders written in their medical notes.

Gordon Lishman, Age Concern's director general, said Wednesday's guidelines will offer some reassurance to the elderly population, who were terrified by reports that DNR orders were being written in their medical notes without consultation.

He said: "Age Concern will not rest until the 'writing off' of patients' lives on the basis of their age has been stamped out. "It's vital that the guidelines are fully implemented and monitored,

which means making strenuous efforts to ensure patients and when appropriate, their relatives and carers, are involved in the decision-making process surrounding resuscitation." He said Age Concern was proud to have played "the critical role in bringing about the government's policy change", not only on the issue of 'Not for resuscitation', but also in terms of their "acknowledgement that ageism does exist in the NHS". Mr Lishman added it is vital that elderly people are consulted about resuscitation and asked for their views.

A DNR order means that a doctor is not required to resuscitate a patient if their heart stops and is designed to prevent unnecessary suffering. Last year the government said it wanted all hospitals to draw up a clear policy on DNRs and the joint guidelines will make this easier.

The guidance states that advance decisions not to resuscitate patients should only be made after looking at every aspect of the patient's care and taking into consideration the patient's wishes.

- When is it appropriate not to resuscitate
- When it will not restart the heart or breathing
- When there is no benefit to the patient
- When the benefits are outweighed by the burdens

The guidance calls for medics to work more closely with patients and explain to them the facts about resuscitation.

It also says doctors must clarify in advance where possible whether someone wishes to be resuscitated if their heart stops working.

The guidance also encourages medical staff to sensitively discuss DNRs with patients and to make sure they are aware that resuscitation is very different in reality from the way it is portrayed on medical TV shows.

It says carrying out resuscitation can result in broken ribs; fractures or ruptured spleen, and that patients may need to spend some time in intensive care or could suffer brain damage. But it adds the procedure should be carried out where the benefits outweigh the risks.

Dr Michael Wilkes, chair of the BMA's medical ethics committee, said it is important doctors handle DNR conversations sensitively. He said: "These are difficult conversations which need to be handled sensitively."

Dr Wilkes said it was important that whenever possible consultants and senior doctors take the decisions. "Clear documentation in the medical and nursing notes about any advance decision is essential and junior doctors must be able to

access support from more experienced colleagues," he added.

BBC Online: Wednesday, 28 February, 2001

Simulating age with popcorn

With popcorn in their shoes to simulate bunions and mobility problems the hospital staff at Delancey Hospital in Cheltenham have been learning first hand the difficulties of old age. The "instant ageing" 20-minute training sessions were organised after an audit showed that 52% of all patients at the hospital were over 70 years old and were suffering sight, hearing or mobility problems.

The nurses were also given "simulator spectacles" to reproduce the effects of cataracts, tunnel vision and other impairments.

Some were asked to wear headphones to simulate hearing impairments.

And staff were given an insight into the effects of arthritis after being given special rubber gloves to restrict hand movements. They were then asked to pour drinks or hold cups to show the effect a loss of mobility can have on everyday life for older people.

Anne Edward, ward manager at Delancey said the course had proved invaluable for staff.

She said: "It really does make you think about how difficult life is for the elderly. It really brings it home to you."

Pat Barlow of Gloucester County Association for the Blind said training like this was vital to boost awareness of the disabilities some patients suffer. He said: "This training gives staff an insight which would otherwise be impossible to achieve. "No matter how hard we try to imagine what it must be like to have a visual impairment, we can never really know. Using the simulator spectacles is about as close as most of us will ever get."

BBC Online: Wednesday, 28 February, 2001

Embryo Cloning Trials **'Within Three Years'**

Human trials of embryo cloning could take place within three years after the House of Lords voted to allow it for the first time. Previously licensed research using human embryos was permitted only for strictly limited purposes. These involve studies into infertility treatment, congenital diseases, the causes of miscarriages, contraception techniques and the detection of genetic abnormalities.

The 'therapeutic' cloning of stem, or master, cells from human embryos is expected to help conquer Parkinson's, Alzheimer's, diabetes and cancer. Dr Ian Bogle, chairman of the BMA, wrote to all MPs on the eve of the crucial free vote which decided whether UK scientists can press ahead with stem cell research using human embryos. Like many patient support groups, research charities and scientists, the BMA wants to see the law changed to allow the research.

Under the new law full human cloning will still be illegal.

The move came despite passionate opposition from religious leaders and pro-life groups, who said the legislation had been rushed through. 'Cheapens human life' The anti-abortion groups Life and the Society for the Protection of the Unborn Child have both strongly urged MPs to vote against the proposal saying that cloning human embryos is morally wrong and sets a dangerous precedent.

The Bio-Industry Association said the Lords vote "allows the research to move forward". It predicted the first human trials could take place in three years or so and clinical application of stem cell cloning within five to seven years. The Archbishop of Canterbury, the Roman Catholic archbishops of Glasgow and Westminster, the Chief Rabbi and the President of the Muslim College had issued a joint appeal to the Lords to delay their decision until a select committee had time to consider ethical as well as scientific implications.

But that inquiry will now take place at the same time as research, not before it. The Most Rev Vincent Nichols, the Roman Catholic Archbishop of Birmingham, said the decision "cheapened human life" and was an "affront to human dignity".

Cloning: The facts

To clone, the genetic make-up of something is transferred to an unfertilised egg, which has been stripped of all its genetic material.

Under the new law it will be legal to use stem cells from human embryos under 14 days old - which means taking master cells from the embryo before disposing of it.

Embryonic stem cells are unprogrammed cells with the potential to become any type of tissue. A stem cell can develop into any tissue in the body depending on which chemical signals they are given, and could be used to make replacement tissue for burns victims or victims of Parkinson's and Alzheimer's, as well as overcoming the problems of transplant tissue

rejection.

Adult stem cells, found in bone marrow, umbilical cords and the brain, could also be used to make new tissue.

The new law will make it illegal to produce a human embryo clone and plant it in a woman's womb.

In his letter to MPs, prior to the debate, Dr Bogle said: "The development of tissue for transplantation using stem cells has the potential to benefit vast numbers of people who suffer from disorders that threaten or impede their lives.

"It could potentially offer a means of overcoming the severe shortage of tissue available for transplantation. Furthermore, by generating tissue using the patient's own genetic material, there would be no need for patients to take the strong immuno-suppressive drugs that can be harmful when taken over a long period of time."

A Personal Perspective of Disability

LOSS... by Ria Strong

Write.

Write the grief. Write the pain. Write the anger. Write the tears. Write the doubts. Write the loss.

Write the loss.

Loss. What have I lost? I've lost the person I used to be.

I could, and now I can't. I was, and now I'm not.

Write the loss.

I was on a camp, three and a half years ago. I started fitting, and I didn't stop. Not until two or three days later, when I was finally taken to hospital. I haven't been the same since.

I shouldn't have happened that way, but it did.

They should have acted sooner. Taken me to hospital sooner. Stopped my seizures sooner. They didn't. For some reason— God knows why— they didn't. They just left me fitting. And I haven't been the same since.

Write the loss.

I got my neuropsych report last week. "Ria demonstrates a range of mild to moderately severe cognitive deficits that appear against a background of above average ability. The present results strongly suggest that Ria has indeed suffered deterioration since going into status epilepticus."

Those seizures f*cked up my brain. Permanently.

I didn't need a neuropsych report to tell me that. I worked it out for myself a long time ago.

Write the loss.

There was a time when I could think clearly.
There was a time when I could learn quickly.
There was a time when I could remember properly.

I had a GOOD memory, dammit!

Write the loss.

I was an A student, once. I waggged classes and I almost never did my homework (I had more important things on my mind). I still got As, though. Lots of them.

I won the maths competition in Year 7. And the science competition, several times. I got 95% in VCE Biology. I topped my first year Psychology class at University.

That was all Before.

I tried to study, After.

Second year Psychology— I expected it to be easy. It SHOULD have been easy— but I just fell further and further behind. I didn't even notice until late in the semester. When I saw the sample exam questions. And realised that I couldn't answer any of them.

Write the loss.

I was going to be a teacher— I'd known that since I was 5.

I was going to work with 'special needs' children. Abused children. Deprived children. Children with disabilities. I was going to change their lives.

I never doubted it, Before. There was no reason to— I'd been tutoring and working in recreation programs for years.

Then I went into status, and everything changed.

After, I went on to disability benefits.

For months I spent my time at the local drop-in center. Drinking endless cups of bad coffee. Inhaling other people's cigarette smoke. And talking about trivialities.

I didn't know what else I could do. I wasn't sure if I could do anything at all.

Write the loss.

I was a singer, Before. I joined a choir when I was 8, and started singing solos soon after. Music came naturally to me— as naturally as breathing. I really couldn't imagine life without it.

A couple of months After, I was involved in a big choral festival. A fortnight of rehearsals and performances. It was a disaster. I repeatedly got lost reading the scores— I just couldn't follow my part. When the final concert came, I still didn't know most of the pieces.

I went home crying that day. And I haven't sung much since.

Write the loss.

I used to think I could overcome anything. That I could Triumph Over Adversity, and succeed despite it.

I don't any more.

I go through the motions of rebuilding my life (again). But I can't believe the way I used to.

And sometimes I get tired of struggling.

Write the loss.

Write the loss.

Write the grief. Write the pain. Write the anger. Write the tears. Write the doubts. Write the loss.

Write...

EU Outlaws Disability Discrimination

On 17 October the European Union agreed a directive to its member nations requiring them to introduce laws banning discrimination in employment on the grounds of disability (undefined), age, sexual orientation or religion.

The directive will not require any fundamental alterations to the DDA (Disability Discrimination Act). However, because the directive does not exempt small employers or some particular occupations, it will require the government to extend the DDA to these areas. The Forum welcomes the directive, as it marks an important extension of disabled people's rights across the European Union. It will also provide a level playing field for companies competing in Europe, and is particularly helpful for Forum members with multinational businesses.

It will require a considerable education process in European countries. Up to now, the sole response to disabled people's employment aspirations has been a quota system, an approach fundamentally opposed to the directive's emphasis on removing the practical barriers, which prevent equal access to mainstream employment.

The Forum's concerns - shared by the CBI - about the content of the draft directive seem to have been resolved. The directive will not now require the UK to introduce the concept of 'indirect discrimination' into the DDA; rather, employers can continue to address discrimination by making reasonable adjustments for individuals.

Forum Chief Executive Susan Scott-Parker commented: "We are very pleased that the government has been able to ensure the basic principles which underpin Europe's most effective anti discrimination legislation - the DDA - will continue in place."

Other EU Actions

In May the EC put forward a raft of proposals, beginning a move towards a more rounded approach to disability - promoting equality of opportunities through the removal of artificial, environmental and attitudinal barriers.

At EU level the just announced recent inclusion of non-discrimination provision covering disability in the Treaty of Amsterdam provides the basis for a new rights-based approach to disability.

The EC recognises that its own activities and programmes across all the different policy areas can cause access problems for disabled people. The EC will:

- seek to ensure the participation of people with disabilities in mainstream programmes and provide specific measures in order to meet their particular needs where necessary to ensure true equality of opportunity

- take measures to open employment within European institutions to disabled people

- seek to use EC procurement activities to promote accessible goods and services

- ensure that projects considered for EU funding incorporate approved accessibility standards

The EC also emphasises the need for co-ordinated policy vision across the fields of employment, education and vocational training, transport, the

internal market, information society, new technologies and consumer policy.

This would include the following steps:

Accessible Transport: In 1997 the EC adopted a proposal for a directive which lays down that buses and coaches used for urban services must be accessible to people with limited mobility, including those using wheelchairs. To complement this major step forward, the EC will draw up guidelines on improved provision for disabled people in public and private transport vehicles and transport facilities

Architectural Barriers: The EC will identify areas where it would be appropriate to adopt EU mandatory accessibility standards for the built environment and will encourage every public authority to do so.

The Digital Divide: The EC proposes that all the European institutions and the Member States endorse the existing Web Accessibility Initiative (WAI) guidelines, making the design and content of all public websites accessible to people with disability.

Finally, the EC proposed that 2003 is declared the European Year of Disabled Citizens.

This article has been re-printed from the Autumn 2000 issue of "Update".

The bulletin of the Employers' Forum on Disability, Nutmeg House, 60 Gainsford Street, London SE1 2NY, UK, Tel: 020 7403 3020 / Fax: 020 74030404, website www.employers-forum.co.uk with their kind permission

Holiday Websites

With the holiday season fast approaching, the following website offer useful information on UK holidays for people with a disability and their carers.

Tripscope - information about travel & transport in the UK –

email: tripscope@cablenet.co.uk

website: www.justmobility.co.uk/tripscope

Holiday Care Service - information about accessible accommodation in the UK.

They also produce an information sheet specifically on "Accessible accommodation in London".

Email: holiday.care@virgin.net

Changes at the Royal College Nursing

Sue Thomas, RCN Disability Adviser has won a grant of £80,000 from PPP Healthcare to enable her evaluate the how the Department of Health guidance Best Practice in Continence Services is being implemented in Primary care. Whilst she is undertaking this survey **Philip Scullion**, Senior Lecturer at Coventry University has been seconded to work with with Sue at the RCN to cover her disability commitments during the survey time. This grant is part of the PPP Mid Career Break Scheme. Philip has worked closely with the RCN on disability matters and will work as Disability Education Adviser which will include speaking at conferences and seminars, as well as being a regular contributor to the Disability Awareness Newsletter and other RCN journals.

Nicola Lee joined the staff of the RCN on 26th February 2001 as the new WING Advisor. Nicola has an employment background firmly embedded in disability rights and issues, and had recently come from working at OASIS, the largest staff support service operating within the NHS.

Details of the Disability Awareness Event at Congress

Event: Joint RCN-Leonard Cheshire Disability Awareness Fringe @ Congress 2001.

Date: Tuesday 22 May 2001

Time: 6-8 pm

Venue: The Rose Room

Old Swan Hotel

Swan Road

Harrogate

To register for this event at Congress, please contact:

Felicity Adegbuyi RCN: 0207 647 3739.

Leonard Cheshire staff should contact Angela

Davies at Leonard Cheshire on: 020 7802 8268

Contacts

If you wish to contribute to this newsletter please send you contributions to:

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The following people are our local points of contact for disability.

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**CORNWALL HEALTHCARE NHS TRUST, CORNWALL SOCIAL SERVICES AND THE
ROYAL COLLEGE OF NURSING**

Presents
The first Cornwall-wide conference sharing good practice

**‘RIGHTS AND OPPORTUNITIES FOR PEOPLE WITH DISABILITIES’
DO WE REMOVE BARRIERS OR CREATE THEM?**

Monday 18th June 2001

09.00 - 16.30

at

The Hall for Cornwall, Truro

The numbers of disabled people are dramatically increasing for a variety of reasons - an increasing life expectancy for everyone, better medicine, technological improvements, and a higher standard of living. The expectations of everyone in the local community - including disabled people - are increasing in relation to all public services. Government initiatives focusing on helping people to remain living independently in the community increase these expectations - the new NHS plan, Direct Payments legislation, the Disability Discrimination Act (1995) etc.

Alone or together these facts have enormous implications for everybody, but especially for staff working in health and social care settings. Disability will affect all health and social care staff - whether meeting the needs of disabled service users; working as, or with disabled staff, or in relation to family or friends with disabilities. It is, therefore, vitally important that all employees understand disability issues and people's expectations, in order to improve service provision, meet people's raised expectations, meet new legislative requirements, etc. This one-day conference will focus on these issues, as well as providing local and national perspectives from highly placed keynote speakers, with views on Consultation, Rehabilitation, Promoting Independence, and effective Partnership Working.

Rights & Opportunities for People with Disabilities Conference
Monday 18 th June 2001, 09.00 - 16.30 Venue: The Hall for Cornwall, Truro
Name _____
Job Title _____
Place of Work _____
Mailing Address _____
Telephone _____
RSVP Victoria Eathorne, <i>Disability Advisor</i> 57 Pydar Street, Truro, Cornwall TR1 2SS Phone: 01872 272494 Fax: 01872 260081 or E-Mail: Victoria.Eathorne@cht.swest.nhs.uk
