

Disabling Practice Enabling Nurses? Disability Network Newsletter

Number 11 Summer Edition

Letter from the Editor

The membership of this network has grown considerably since it first started, may I take this opportunity to welcome new members and say I hope you find this edition interesting, and useful to your practice, it contains a number of very different articles. Thank you to those who have contributed. The reason this newsletter came into existence was to give practitioners an opportunity to share good practice and to use it as a forum for airing concerns, so please may I urge you to share your experience in this field. I look forward to hearing from you.

Rachael Spain. Editor
rae.spain@btinternet.com

The Simulation Question

'Everybody's doing it these days, Local Authority Officers, politicians, sports personalities and even radio presenters! They are having a try at what it is like to be disabled for a few hours - sitting in a wheelchair and going around town. Putting on funny glasses or blindfolds, which restrict vision or sticking cotton wool in their ears pretending to be deaf. All in the name of empathy and awareness. The media love it, and it is guaranteed to create a good story. Is it just a bit of good fun? A useful way to make people more aware of the problems we face? A good training tool? Let's look at the issues.

In the educational arena, and in particular in some disability awareness training sessions (run I must admit by the less aware!!!) the popular approach to the training sessions has been predominantly on the medical model - that is, "What do disabled people suffer from?". "What are their problems, and how can we understand what it is like to be disabled?" The discussion - again on the medical model revolves around seeking charity and sympathy based solutions. As well as sympathy and goodwill, this approach may arouse quite strong feelings of pity and a fear of what it is like to become disabled. Everyone is different and simulating an impairment will not convey the degree of diversity encountered by people in that group. I don't think that an understanding of disability

can be imparted by role play or simulation for half an hour or so, as it can never begin to demonstrate the discrimination, oppression and patronisation that we encounter on a daily basis.

Role play trivialises our lives, and these sessions often end up as just "a bit of a laugh" or light relief during a training day. It is also quite degrading for us to be 'mimicked' and our aids and equipment treated as toys. If any group of people were undertaking race awareness training, they would never black up their faces and walk around town. It would also be inappropriate for a man to dress up in women's clothes, and then say he knows what it is like to be a woman.

I fear that this method of training may lead people to think that they are "experts" on disability, and they now know what we require. Planners, political decision makers and service providers need to be consulting directly with us rather than trying to find out what its like to be disabled and then dreaming up their own solutions to our "problems." We need to be demonstrating that it is not our physical difference or the equipment that we use that are "the problem," but quite often it is their reaction to them which disable us. We need to challenge attitudes, not reinforce outdated stereotypes. Written by Linda Durnall

Ldurnall@aol.com

Stimulate learning or simulate disability?

I very much welcome Linda's contribution on an issue that is regularly and hotly debated on e-mail discussion lists and elsewhere. I have written on this topic and discussed it with numerous people who identify themselves as 'disabled' and most agree with Linda that it is unhelpful. Of course in nursing we do use simulation in areas such as CPR, where various cardiac arrhythmia's can be displayed on monitors in a training scenario. Ethical and practical considerations support this method for such vital learning in advance of having to resuscitate someone who has collapsed and I expect no objections. In relation to simulation in disability awareness training my concerns are

that the educational objectives are unrealistic and an unrealistically negative view is gained by 'learners'. However, as research indicates, there may be a skills deficit on qualifying in nursing in areas such as guiding a visually impaired person or wheelchair manoeuvrability. We may wish to call it role-play but there is a need to learn such skills in a safe environment. Readers are invited to comment on this issue. [Philip Scullion]

Higher Standards To Improve Conditions For People with Long Term Illness

Health Minister, Jacqui Smith announced today at the College of Occupational Therapists "Making Waves" Conference that the NSF for Long-term conditions will have a particular focus on the needs of people with neurological conditions and brain and spinal injury, and also address some of the common issues faced by people living with long term conditions.

Speaking at the Conference, Jacqui Smith said: "This NSF will enable us to tackle unacceptable variations in the quality of care across the country for people with neurological conditions and brain and spinal injury. We know that people need help not only in the context of managing their medical condition, but also in the light of their social, educational, employment and family lives. Their views and those of their family and carers are really important in helping to improve their independence and quality of life.

"These are challenging times ahead but occupational therapists have a key role to play in developing and implementing the NSF over the next 10 years. Your expertise in working with patients across health and social care boundaries will be invaluable to this work."

The NSF will build on the NHS Plan principles: aiming to provide good quality, joined-up health and social services along the whole of the patient pathway, with users and carers at the centre of the re-designed services.

The NSF will have a particular focus on services and support for people of working age. For example:

- ◆ User-centred, interdisciplinary health and social care assessment and support including rapid referral for diagnosis;

- ◆ Specialist, community and vocational rehabilitation services;
- ◆ Community equipment services;
- ◆ Help with a range of common symptoms including pain and movement disorders;
- ◆ Information and support for carers and families;
- ◆ Support and services that help people with long term conditions fulfil their own responsibilities as partners, parents and carers; and
- ◆ Developing the concept of the Expert Patient.

The NSF project team has met with and received a number of submissions from key stakeholders including voluntary organisations, clinicians and health and social care professionals regarding their aspirations for this NSF. We are working closely with the Neurological Alliance and the Long-term Medical Conditions Alliance on the development of this NSF.

Further information on National Service Frameworks can be found at

www.doh.uk/nsf.index.htm

Department of Health 12th June 2002

Congress 2002 resolution

At this year's RCN Congress meeting held in Harrogate during April, there was a healthy debate over Disability Living Allowance. It had been suggested by the RCN Forensic Nursing Forum who presented to congress the background in relation to people within psychiatric settings who, after six weeks in hospital, have their DLA reduced to £14.50 per week. Many people spend many weeks beyond their initial six in such places, especially since discharge may be hindered by lack of rehabilitation or other accommodation facilities to meet the needs of such clients. This allowance must pay for toiletries and basic items of clothing and leaves little or none for outings, socialising or even the occasional birthday present for close family members such as children who may be visiting.

Those presenting the resolution linked it to the issue of social inclusion, which had been on the agenda in a fringe meeting at Congress and drew support from the NSF (National Schizophrenia Fellowship) who campaign against such low personal allowances. It was acknowledged that this problem affects more client groups than just those with enduring mental illness.

One nurse from a learning disabilities setting stated that his clients actually receive only £5 pocket money and have to buy their own birthday present from this. Some feared that any increase would be wasted on 'poor' spending choices in the purchase of cigarettes or chocolate. Another nurse asserted that if nurses did not respond then they continue to collude with the oppression of people with mental health difficulties and contributed to their poverty and its harmful consequences.

Congress was reminded that much had been said on the issue of nurses salaries, student bursaries and Continuing Professional Development and the question was raised "what of others?" our clients.

The resolution was put to the vote

That this meeting of the RCN Congress urges the Government to re-introduce the Disability Living Allowance for inpatients in mental health settings

90% of voting members voted in favour

I look forward to being able to report on this as it is taken forward by the RCN over the next year.

Proposed Neuroscience Nurses Forum within RCN

There are an increasing number of people who live with long term medical conditions, many of which are neurological in origin and some of these people require ongoing long-term care. While they may not identify themselves as 'disabled' most will be covered by the provisions of the Disability Discrimination Act 1995. The forthcoming NSF for people long term conditions will have important implications for such people and indeed the health and social care agencies involved.

Nurses in all areas of practice have considerable contact with this portion of the population including those who work outside the NHS, for instance in care homes. It is beginning to be acknowledged that those living with chronic conditions such as Multiple Sclerosis are very knowledgeable about themselves and their own condition such that they are, or should be, afforded 'expert' status. They are able to work with health professionals in monitoring their own condition and articulating the health care support

that they require. Others with neurological conditions will pass through recognised phases leading to increasing dependence on carers and nursing support, such as people with Motor Neurone Disease.

While rehabilitation will feature in the care plan for some of these people at some point in their 'patient careers' this will often represent a small proportion of their life span. Long periods where the impairment remains stable will be experienced after acute and rehabilitation phases, for instance following the onset of Stroke or traumatic brain or spinal cord injury. Other conditions fluctuate unpredictably, such as MS and many such patients undergo long-term treatments involving complex medication regimens as in the case of people with Parkinson's disease. Some conditions are quite rare, such as Dystonia or Myasthenia Gravis requiring a level of specialist professional help, which is not widely available. Many are poorly managed as in the case of epilepsy, which affects around 30,000 people in the UK, a disproportionate amount of whom also have learning difficulties.

The RCN has maintained an active involvement in many of these areas and indeed has been instrumental in developing national documents for specialist nurses in the field of Parkinson's Disease and MS.

The RCN has good links with many nurse consultants, specialists and nurses with a general interest in Neurology nursing. These members are working as specialist nurses in many fields including paediatric, learning disability and general adult settings. Established groups and links include

- Dystonia Nurses Network
- MS Nurses
- MS Research Trust
- Parkinson's Disease specialist Nurses
- Leonard Cheshire nurses
- Stroke nurses
- Motor Neurone Disease nurses
- Epilepsy nurses, [some paediatric specialists]

Members with an interest, those having direct or indirect involvement as specialists or otherwise with clients with long term conditions or experiencing disability are often working in relative isolation. In view of this there is a view

that a new members forum within the RCN is required. There is a database held in Cardiff of members who have expressed an interest in an embryonic forum, titled 'Neuro-sciences Nursing'. Currently 1268 members have registered an interest in this development.

Purpose of the proposed forum

1. Monitor and influence the develop of the NSF for people with long term conditions
2. Promote knowledge and positive attitudes within the RCN (e.g. other forum groups) concerning the special needs of people with long term neurological conditions.
3. Promote the development of specialist nurses in these emerging fields of practice
4. Establish good liaisons with other groups, e.g. forums for Paediatric, Older people, Rehabilitation Nursing groups and WING.
5. Develop a base of expertise available to the college
6. Support for relatively isolated groups of nurses
7. Advance knowledge and skills base for this diverse client group
8. Promote awareness of the legal framework
9. Sharing and promoting good practice in the spirit of mutual support

I am keen to hear of the views of members on this proposal and you are invited to forward these to me at the RCN, 20 Cavendish Square, London, W1M 0AB or via e-mail Philip.scullion@rcn.org.uk.

If you wish to register interest in this forum, which as yet does not exist, you can contact membership services, with your RCN membership number and do so. This will not affect your current membership of other forums. When ringing RCN Direct remember to avoid peak times where possible Tel 0845 772 6100

Community Service Volunteers

Community Service Volunteers is a national volunteering agency and a registered charity. This year we are celebrating our 40th Birthday. CSV was founded in the belief that all young people could make a valuable contribution to the community if they were found the right

opportunity. Over two thousand people volunteer with CSV every year.

CSV has a number of regional and satellite offices throughout the UK including Scotland and Wales.

CSV staff recruit, interview and place volunteers in a wide variety of statutory and voluntary organizations. Through out the UK volunteers are placed on a range of projects supporting a diverse range of people including work with the homeless, young offenders and those at risk of offending, adults and children with physical disabilities, adults with learning disabilities and those with mental health problems.

CSV volunteers can play a variety of roles including mentor support, enabling people to live in their own homes, befriending, enabling people to access leisure activities, assisting with basic personal care, accompanying to appointments, academic and social support and so on.

CSV full time volunteers offer a commitment to volunteer away from home for a period of between 4-12 months. We recruit volunteers 16+ from overseas and within the UK. We have a unique non-rejection policy, which means we accept all volunteers between the ages of 16+ whatever their background or experience. This is because we believe that everyone has something to offer.

In return for the volunteer's commitment and help they receive accommodation, pocket money, food and support from a supervisor based at the project. Volunteering is a great way to gain valuable skills and work experience, play an active part in the community and make a difference to someone's life.

CSV continues to involve volunteers in innovative ways to meet urgent social need. We are always looking for volunteers and to develop innovative volunteering opportunities so if you would like to volunteer or discuss offering a placement opportunity for volunteers then please contact the Birmingham Regional Office on 0121 643 8080 and speak to Sarah Muirhead, Regional Development Manager (smuirhead@csv.org.uk) or Parminder Gill, Marketing Manager (pgill@csv.org.uk).

Classifications

The official launching of the International Classification of Functioning, Disability and Health (ICF) took place on the 15 November 2001. The ICF was endorsed by the World Health Assembly (WHA) in May 2001 as the international standard to describe and measure health and disability. After the WHA endorsement and a seven-year effort involving the active participation of some 65 countries, ICF has now been published simultaneously in all six official WHO languages (Arabic, Chinese, English, French, Russian and Spanish) together with electronic and internet applications.

Dr T. Bedirhan Üstün who is the team coordinator would like to thank all who showed interest in ICF throughout the revision process. "I think ICF will be a good example of creating a common language to describe and measure health and disability between different cultures and various disciplines," he said.

To access ICF on the Internet, please visit the new website:
<http://www.who.int/classification/icf>,
which provides multiple information features on ICF as follows:

- ▼ Online access to the multilingual ICF Browser;
- ▼ Download of the ICF Introduction and Annex Documents, training materials, ICF checklist;
- ▼ Download of WHO Press Release on ICF and WHA resolution on ICF;
- ▼ Download of order forms for ICF Publications, including ICF Book, Pocket version and CD_Rom;
- ▼ Links to the WHO Collaborating Centres for the Family of International Classifications;
- ▼ Regular updates on ICF implementation issues.

Independent Living Design Awards

These awards were announced at a ceremony held on Friday 2nd November at The Park Lane Hotel in Piccadilly hosted by the British Healthcare Trades Association [BHTA].

There were nine awards and an overall winner presented at the event by Dave Prowse, famous as both 'Darth Vader' and the green Cross Code man. He was formerly an Olympic weight lifter and described how he himself had recently become a disabled person. Design awards were presented for the following;

- A two handed eating utensil with Velcro strap, designed by a man with cerebral palsy
- A simple to use electronic water switch called Surestop, helpful for those with mobility of dexterity impairments
- Brown-note, a palm top computer notepad which utilised Soft Braille and speech recognition
- Galaxy plastic frame play ground equipment
- Power-Trike, a wheelchair that converts to a powered tricycle with around 20 miles scope
- E-Motion. Wheelchair with wheel-hub mounted motor drive
- TX-1- A new accessible London Cab, with ramp and conduction loop system for hearing aid users.
- Adjustable height cot with good all round access for high-dependency infant.

The overall winner, judged to offer most potential in enhancing independent living, was the Oxford Voyager. This device is a portable lightweight hoist with portable tracking which may enable users much greater choice in holiday accommodation and other overnight accommodation. It fits into the boot and may well overcome restrictions and accommodate the need to be mindful of minimal lifting policies. This has been designed and developed by Sunrise medical and more details on the Oxford Voyager can be obtained by ringing 01384 446622.

User Participation in Mental Health Care and Education

By Roger Minett, Mental Health Subject Head, Coventry University.

Within the NHS there is increasing importance attached to involving users in a number of ways including planning evaluating and delivering services, conducting research and in the training of professional staff. The desire to involve service users has been articulated by successive governments in numerous policy documents for example (Working in Partnership' DoH 1994; 'The NHS Plan' DoH 2000).

The Care Programme Approach (CPA), which is a feature of the National Service Framework for Mental Health, requires professional workers to develop packages of care for their patients that are agreed with them and their carers. One of the purposes of this is to improve the quality of care offered and subsequently the quality of life for the patient.

Despite these policies it is still evident that users are not fully consulted or involved either in their own care or in the development and management of services. A recent Mind survey, reported in the last edition of this newsletter, found that many patients were given no say in their treatment and that doctors did not inform them about side effects or listen to their concerns.

It becomes even more imperative then that users are fully consulted and involved at all levels within the statutory services as this is the only way that their experience and knowledge can be used to inform practitioners and service development with the ultimate aim of improving care.

Involving users in the education of professionals is now more widespread and as Sayce (1993) has remarked it '*can enable workers to understand more about the implications for users of their actions, their treatments their approaches*'.

Of course user participation in mental health does have its potential problems as some users may become ill during consultation, they may not represent the views of the majority, professional jargon and procedures may be off-putting to some users and there is a danger that some authorities may be tokenistic in their approach and only invite service users to participate when they deem it to be appropriate.

Nevertheless the benefits that can ensue from user participation, of improvements in professional knowledge, professional practice and ultimately improved care and services make user participation worthwhile and indeed imperative for modern mental health services.

Campbell and Lindow (1997) provide a very useful set of guidelines for involving service users that is appropriate for nurses and others working in the field of mental health. Their booklet '*Changing Practice Mental Health Nursing and User Empowerment*' is published by Mind and the Royal College of Nursing.

This topic can be followed up by referring to Minett RJ (2002) User participation in mental health care: a literature review. *British Journal of Therapy and Rehabilitation*. 9 (2) 52-55.

**Every Family in the Land:
Understanding Prejudice and
Discrimination against People with
Mental Illness**

Ed Arthur Crisp

Sir Robert Mond Memorial Trust, Royal Society of Medicine, Royal College of Psychiatrists

ISBN 0 9541314 0 1

Electronic book (pp 464) available free on

www.stigma.org/everyfamily

Also available on CD Rom, £11.75

For details, telephone +44(0)20 7881 9000 or +44(0)20 7235 2351

It was seven years into the HIV epidemic and several thousand deaths before the then president of the United States, Ronald Reagan, could bring himself to use the word AIDS in a speech. Contrast this with the legionnaires' disease outbreak of the early 1970s. This generated several front page headlines, public debate, and a photograph in the *New York Times* showing President Ford holding an emergency cabinet meeting to address the government's response to what was already viewed as a serious public health crisis. And all this within the first two weeks.

If there is one thing the AIDS epidemic must have taught us, it is that stigma, and stigma alone, can have a huge impact on how we respond to public health issues. What opened the public's hearts and the profession's minds to HIV/AIDS? Whatever it was, we need some of that in mental health care, but you can bet it wasn't a CD Rom.

I don't know who reads electronic books. This was my first attempt and I failed. After squinting at the screen for the first chapter, I resorted to a hefty printout provided by the *BMJ*. If you are expecting a multimedia, interactive, virtual learning experience, I'm sorry to disappoint you an e-book is, well, just a book but in your computer. It's easier to carry a CD Rom than a book in your bag. You can print off interesting bits to share with colleagues. But otherwise it's 464 pages of quite small font to scroll through, and without a large screen monitor it's not easy. Why is a book with such a worthy, albeit ambitious, agenda produced in a format that is so

inaccessible? This collection of essays, research, anecdotes, personal accounts, and conference transcripts is another benchmark in the Royal College of Psychiatrists' five year campaign to counter the stigma surrounding mental illness. The campaign began in 1998. As part of my research while reviewing this CD, I asked a team of mental health nurses and junior psychiatrists for their views on the campaign so far. None of them knew that it existed. The well intentioned conferences, cinema advertisements, and leaflets seem to have had little impact.

In the medical profession the stigma around mental illness has rarely been addressed. Observe the esteemed physician on post-intake rounds confronting a patient's agitation with a damning "this isn't medical, *it's psychiatric*," as he waves his team away. Anyone who has experienced countless similar scenarios must surely realise that stigma, fear, and prejudice stand between us and our duty of care. So how do we make the last year of this campaign count? A few high profile celebrities of the calibre that came out fighting for the HIV cause couldn't hurt. You could read some or all of this CD Rom. Then again, although this is less glamorous and certainly less high tech, we could all take a long hard look inside ourselves, and outside at our practices. And perhaps, to quote the late Roy Porter in the first and by far the most readable chapter of this e-book, find the true solution to the problem of stigma: "Acceptance, without shame, of mental disorder. But that would be crying for the moon." Or would it?

Nigel Lester, consultant psychiatrist.
London nlester@onetel.net.uk

A Book Review

Disabled People and Employment.

2001

This recent book is unique in at least two ways. First this book is based largely on research for a PhD thesis and second, it provides a detailed account of the lives of visually impaired people in physiotherapy [which I will refer to as V.I.P.s] from their own perspective. The first of these features may appear off putting since few would choose to read a PhD thesis for pleasure. However the 'methodology' section, which some would find..... 'less interesting', has been surgically excised so but be reassured, it is in fact a very readable book and definitely not bedtime reading to induce sleep! It provides a

rich history of VIPs and blind physiotherapists and, being mainly qualitative research, this represented in their own words. Many of the research participants had experience with the North London School of Physiotherapy for the Visually Handicapped, which closed its doors in 1995. Some respondents expressed concern that this may also mark the closure of physiotherapy to visually impaired and blind people as career choice, since education is no longer available specifically for such people.

An element of comparison between Visually Impaired People and sighted physiotherapists is included and this shows some interesting findings. The sighted group of physiotherapists were more positive about integrating professional education than the VIPs. Flying in the face of common assumptions, "this study shows that visually impaired people can work successfully in, and contribute successfully towards, a profession" in spite of a range of barriers. It provides important evidence for the field of employment and disability, which accounts for the present situation. The range of experiences was vast, some of which, if tested in the courts may now prove to be in breach of the Disability Discrimination Act 1995. Some give accounts of discrimination and lack of support in post basic education and the employment situation. Many VIPs chose to avoid community and ITU area. One reported be so highly valued by his employer that they employed a physiotherapist assistant to make him more efficient and take on some tasks such as administration.

The book comes only in hardback, which unfortunately puts it above the price range of many. Nevertheless, physiotherapy departments and universities will want this for their libraries; researchers, NHS managers, human resources and those charged with implementing obligations to provide reasonable adjustments in the work place will no doubt wish to read it in full. VIPs may soon be contacting the RNIB to get this book translated into Braille.

Sally French 2001 A study of the working lives of visually impaired physiotherapists. Ashgate, 220 pages, ISBN 0 7546 1468 9 Cost £39.95

European Year of People with Disabilities 2003

www.eypd2003.org

The Context

- . Lack of understanding of the barriers facing disabled people
- . Disabled people are not visible in society
- . Need for comprehensive non-discrimination legislation
- . Low level of education and employment, poor social participation
- . Year should be a catalyst with a longer term effect
- . Campaign must be a people's campaign

The Campaign Strategy

- . A people's campaign - run and owned by disabled people
- . EYPD campaign is about rights, not charity
- . A grassroots disability rights movement
- . Focuses on empowerment, visibility, pride, advocacy, ownership, awareness & bridging
- . Commission & Ogilvy will act as the facilitator of this people's campaign
- . Campaign aims to create a climate of change & advancement of disability rights

National campaigns linked into the European Campaign

- . The European Campaign is the sum of the national campaigns, i.e. no European campaign without national campaigns
- . Each member state will focus on national priorities
- . National campaigns must be people's campaigns - run and owned by disabled people
- . National disability organisations will play a key role
- . Campaign must be able to mobilise all players

Campaign Objective

Provide the strategy and the tools for supporting a sustainable grassroots disability rights movement, which will create a climate of change in which disabled people become visible in society, which gives them pride and that achieves measurable change in the fight against discrimination.

Disability is a rights issue, it concerns the whole of society

Contacts

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

Sue Thomas

Nursing Policy and Practice Advisor.
Royal College of Nursing.
20 Cavendish Square
London W1M 0AB
Tel: 020 7647 3743
E-mail: sue.thomas@rcn.org.uk

Rachael Spain

Freelance lecturer (Newsletter Editor). Dorset
E-mail: rae.spain@btinternet.com

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

Philip Scullion

Disability Education Advisor
Royal College of Nursing
E-mail: philip.scullion@rcn.org.uk

Ruth Northway

Principal lecturer.
University of Mid Glamorgan. Wales.
E-mail: rnorthway@glam.ac.uk

Sally Davis

Senior Lecturer. Oxford Brookes University.
Oxford
E-mail: smdavis@brookes.ac.uk

Dave Thompson

Disability Advisor. Warrington Community Health.
E-mail: dave.thompson@warrchc-tr.nwest.nhs.uk

Victoria Eathorne

Disability Advisor. Cornwall.
E-mail: Victoria.Eathorne@chct.swest.nhs.uk

David Wright

Special Advisor for Dyslexic and Deaf Students
E-mail: d.j.wright@sheffield.ac.uk