

Disabling Practice Enabling Nurses? Disability Network Newsletter

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Editorial Autumn 2001

I am writing this, still trying to come to term with the devastating events of September 11th, although a month has past, but with the repercussions still having a marked effect on the lives of so many in this world.

It also highlighted, for me, that people with disability unconsciously, or consciously, accept risks on a daily basis, that they may be in places that mean that their exit is impossible in times of disaster, as, for example, in times of fire, lifts are of no use. Though in the tales of heroism emerging from the aftermath of the Trade Centre attack there is the, verified, story of a man who carried a wheelchair colleague down 100 flights of stairs and they both survived.

I have included a new section in this edition, a letters section, which, at present, I have taken from some correspondence on an academic disability list on the Internet, which I belong to, and with the author's permission. I hope they will stimulate thought and possibly debate. I also welcome any comments on the articles included in the newsletter, articles sharing interests or experiences.

I would also like to bring to you attention the flyer at the end of this newsletter that is seeking mentors for people with disabilities in Higher Education.

Rachael Spain

Disabling Practice? Enabling Nursing- Stafford

This conference held in Stafford in September attracted interest from a wide range of disciplines including architects, students, NHS Trust Board members, local organisations of disabled people, estates department personnel and a police training officer. The local BBC Radio Stoke also showed an interest with the event featuring in their 7am news headlines and breakfast show. Nurses were, of course, well represented and it is encouraging to note a growing interest and commitment to disability as an equality issue.

This was evidenced by attendance at such an event; some delegates travelled considerable distances, and the growing number of senior posts with a specific remit to ensure that disability law is acted upon within health care settings.

The conference was jointly organised by a team at Mid-Staffordshire General Hospitals NHS trust, led by Mandy Gibbs Quality Assurance Co-ordinator, and Philip Scullion from the RCN.

Philip set the scene by outlining what the RCN are doing and explained his 'de-medicalising disability' remit. Mandy gave an overview of local changes and improvements made by listening to disabled people who use the services. These include setting up disability awareness training using 'Welcoming people with disabilities to the NHS', the purchase of a golf buggy and portable loop systems and installation of comfort stops around the hospital sites.

Ken Crewe, one of the local Hospital User Group (HUGs) confirmed their positive commitment to disabled people in his address, which gave an account of his recent experiences as an in-patient. Ken explained that though he is both deaf and blind; the provision of an interpreter and one nurse on the surgical ward who can use the Deaf-Blind finger spelling system made his stay much less frightening. He distributed a simple diagram to delegates, which enabled them, in a very short time, to communicate with him effectively.

Alan Martin, a man who has Cerebral Palsy and is an integrated dance leader and disability consultant spoke on the subject of 'Disability Discrimination from a user perspective'. He explained how the district nursing service in his own area had been accommodating to his needs and had thus enabled him much freedom to enjoy his life. Alan uses a speech synthesiser called a liberator and I feel sure he got Arnold Schwarzenegger to programme it! Amongst other important issues he opened the question of the provision of IT speech aids, which it would

appear, is not always straightforward. His parting words were "I'll be back!"

Ruth Norway, Principle Lecturer, University of Glamorgan, gave an account of conceptualisations and models of disability and illustrated clearly how important these are to practising nurses and their clients. Our personal and professional concepts related to disability will direct our behaviour and attitude to people we come into contact with who may happen to be disabled.

Michael Brothers, director of the Disability Rights Commission, spoke about the Disability Discrimination Act and the NHS and answered a wide range of questions from delegates. He showed the DRC award winning short film Talk, which had a tremendous impact on his audience. Philip Scullion, who is also a nurse lecturer at Coventry University, spoke on 'Enabling Education'. He supported the idea that nursing curricula should be employed in challenging disability discrimination and negative values associated with disability. Nurse education "should aim to positively alter those values in so far as they view disabled people as merely the recipients of care, charity and pity".

The event was timely in placing disability issues back onto the agenda of the NHS and nursing in advance of forthcoming legal requirements and the publication of a code of good practice from the Disability Rights Commission.

If you would like to stage an event in your area please contact Philip.Scullion@rcn.org.uk

Mentally ill 'treated poorly'

Psychiatric patients are given no say in their treatment - particularly if they are from ethnic minority groups - a report by mental health charity Mind says.

A survey of patients' experiences found they feel they are not told about potential side effects and that doctors do not listen when they have concerns. Mind says the situation is "appalling".

Both problems were worse for black and ethnic minority patients. Mind analysed 500 "yellow cards" sent in by people with mental health problems between March and June this year, who had suffered adverse side effects from their drugs. The yellow card scheme, first used by

Mind in 1995, is based on the system doctors and pharmacists use to report side effects to the Medicines Control Agency.

One Black British respondent to the survey said: "Doctors will not listen to, or respect, what the patient says about side effects, which makes it hard to trust them and put your faith in their ability to get it right."

Sixty-one per cent of those who responded to Mind said they had not been given enough information about side effects, rising to 75% of people from ethnic minority groups. Almost two-thirds said they had decided to stop their medication, and 45% reduced their dose, mainly because of unacceptable side effects. There were also examples of doctors continuing to prescribe drugs when they were told they were making people feel worse, and in one case suicidal.

Sixteen per cent of cards were sent in from people from ethnic minorities. Language difficulties in particular were linked with a lack of information about diagnosis and treatment.

People taking the new generation of SSRI and related antidepressants were most likely to suffer anxiety, nausea and suicidal thoughts. They also found the drugs the most difficult to stop taking, and said doctors were unwilling or unable to help them stop or reduce their dose, even if they were suffering from severe side effects.

Although 64% of those who went to their doctor for advice found them helpful, that compared to 80% of people who went to a non-medical source of advice.

Schizophrenia, depression and manic depression were the most common diagnoses.

The most common drugs to be prescribed were older anti-psychotic drugs such as chlorpromazine and haloperidol (22% of all side effects reported), SSRI antidepressants such as fluoxetine and paroxetine, (18%), atypical antipsychotics, such as olanzapine and clozapine (14%) and antimanic drugs such as lithium and carbamazepine (13%).

The most common side effects reported were weight gain (25%), muscle shaking or tremor (15%), loss of energy or lethargy (14%), feeling sick or nauseous (12%) and stiffness, or a stiff neck or jaw (12%).

Mind is calling for more information about the side effects of drugs, and better access to information for people from minority groups. The charity also wants a new Mental Health Act, which stresses the importance of consensual treatment, and more support for people who want to stop taking their drugs.

Richard Brook, Mind's chief executive, said: "It is appalling to see Mind's latest yellow card survey results continue to show the lack of information and choice individuals have using medication. It concerns me particularly that people from black and ethnic minorities find it so hard to obtain appropriate information."

The Royal College of Psychiatrists is currently looking at how to improve services for patients from black and ethnic minorities.

Dr Roger Freeman, a general psychiatrist and spokesman for the college, told BBC News Online it was not surprising people from ethnic minorities felt they received a poorer service. He said doctors needed to try to address language and cultural differences. But he said the drugs doctors had to treat psychiatric illness did have side effects. "Unfortunately we don't have the perfect drugs to treat them and the drugs that we have do have side effects." "I don't want to be too defensive, but doctors do feel they need to encourage people to go on taking their pills." BBC News Online.

Looking at Cultural Needs When providing Services For People with Disabilities

Anthropologist Lilah Pengra, author of *Your Values, My Values: Multicultural Services in Developmental Disabilities* (Baltimore, MD: Paul Brookes Publ. Co., 2000), taught transcultural nursing for South Dakota State University then directed an agency serving adults with developmental disabilities, many of whom were Lakota from the Pine Ridge Indian Reservation in western South Dakota.

She combined these experiences in her book to develop a practical method for recognizing, supporting, and protecting cultural diversity for people receiving services in a service system that is based on Euro-American middle class values.

For example, in chapter five she provides a qualitative assessment tool for readers to identify values that they use in making decisions, then relates these values to cultural differences among several Euro-American groups (Norwegian, German, and Polish Americans) in contrast to Lakota decision-making values. You can see more about the book at

<http://www.amazon.com/exec/obidos/ASIN/155766448X/qid%3D955199443/sr%3D1-1/107-5530136-7680568>

A review by Devva Kasnitz was published online in the *Disability Studies Quarterly* at http://www.cds.hawaii.edu/dsq/issues/2001/summer/html/04_beyond.htm

She says that she believes the methodology described in the book would work in any country but that it would be nice to know whether or not someone from a country other than the US agrees with this. If you are interested in reviewing the book to test the applications in the UK, please contact her at lilah@rapidnet.com

Specialist Nursing in MS – The Way Forward

There are only eighty MS specialist nurses in the UK, yet around 85,000 people with MS who may call upon them for essential support, advice and specialist knowledge and skills. Though few in number they have organised themselves, developed expertise and have recently launched a key guidance document providing a practical framework for developing MS nursing posts. Paul Burstow, MP, who hosted the launch of 'Specialist Nursing in MS - The Way Forward' in April 2001 at the House of Commons, pointed out that GPs "cannot be reasonably expected to gain a high level of understanding of managing MS" since they are unlikely to deal with large numbers of people with MS in their entire careers. MS specialist nurses are filling the gap, acting as consultant and teacher; having their own caseload and direct involvement in clinical governance. This new guidance document sets out the role, development and resources needs, standard setting, measuring outcomes and provides a specimen detailed person specification for the post of MS Specialist nurse.

There is a commitment to interdisciplinary co-operation as expressed at the launch by Sue

Thomas, Royal College of Nursing Adviser, "What counts is the quality of care given by every member of the team. MS nurses play a pivotal role in that care".

Full details of the document are as follows; Multiple Sclerosis Specialist Nurse Association, Royal College of Nursing, MS Research Trust (2001) Specialist nursing in MS- the way forward. The key elements for developing MS specialist nurse services in the UK. Letchworth. MS Research Trust.

ALSO recent publication...

Porter B, Scullion P (2001) Multiple sclerosis specialists: key to better services. British Journal of Therapy and Rehabilitation. 8;9, 325

Help for parents who suspect disability

It can take a long time to work out what's wrong.

A charity for the parents of disabled children is launching a new helpline following a survey which indicated that not enough help and support was available. The Birth Defects Foundation, based in Cannock, Staffordshire, conducted a survey of parent's experiences, entitled Listening to Special Families.

The families who took part all had a child with one of approximately 3,000 birth defects dealt with by the foundation. Findings showed that many parents were forced to wait long periods of time to get a diagnosis for their child. Parents reported first noticing "something wrong" with their child at the average age of 1.2 years. The average age of diagnosis was 3.6 years. Some parents felt obliged to pay privately for professional help such as speech therapy and occupational therapy, and 60% of respondents said that a charity had been an important source of information and support. And many parents who answered the survey had received no help at all from social services.

The report highlighted the detrimental effect that looking after a special child has on the relationships of parents, and on siblings.

Now the charity is extending its "Here to Help" - a free and confidential phone and email service - to cover weekends and after work hours. The charity says its new service will be staffed by

experienced nurses, and will have back-up support from doctors and researchers from its medical research portfolio.

It will give a listening ear to families and promises to take time "to appreciate each family's unique experience and tailor information to help".

Donna Covey, Director of the Association of Community Health Councils for England and Wales said that local CHCs could help parents formulate complaints if they feel their concerns are not being adequately addressed. She said: "If parents feel they need help to make a complaint about the service they are receiving from the NHS they can contact their local CHC for advice on how to go about it. The number of their CHC should be available from their GP or hospital or can be found in the phone book."

The BDF can be contacted on 01543 462777, or by email at enquiries@birthdefects.co.uk
SOURCE: BBC News Online.

Carers' Efforts To Double

Britain's ageing population and lack of community care mean the country is sitting on a demographic time bomb, a study has warned. The number of people caring for the chronically sick or disabled is set to double, with women bearing the brunt of the task, according to Carers UK.

The charity's study It Could Be You said three in five people would be affected with 70 per cent of women and 60 per cent of men taking on a carer role at some point during their lifetime. The need for an extra 3.4 million carers in the UK by 2037 will have a "significant" economic and social impact on the economy, the report said.

Carers UK chief executive Diana Whitworth said carers are forced into poverty and cut back on essentials like food and heating to survive. Without more support, she warned, the community care system will collapse, placing a further burden on the NHS.

"The trends described in this report are startling and the welcome fact people are living longer has to be prepared for," she said. "We are talking about a different kind of society and sadly we are

not prepared for the challenges that will present." A Department of Health spokesperson said the government would increase the carers' grant by £15m next year.

Source: Sky News

Disabled people must starve for security reasons

Formal Response from Enable Enterprises regards new British Airways safety policy changes

British Airways have announced new policy changes which restricted passengers from carried sharp objects including a metal spoon. For disability consultant Simon Stevens (27), managing director of Enable Enterprises, this will seriously affect his ability to fly. Simon has cerebral palsy, which, like many other disabled people, is not able to use aircraft cutlery (Plastic or otherwise). Previously Simon brought his own standard metal spoon, cup and feeding bib. In contacting the airline this morning he was informed any relaxation of the restrictions may require a doctor's note and would be at the discretion of the airline on the day.

'I am extremely concerned that disabled people are becoming worse off than ever before, this over-reactionary approach to 11th September means some disabled people face a hard battle to just have the right to have a meal on a plane and all over a simple spoon!' said Simon. He warns that failing to take into account the needs of specific customer groups in such policy changes will lead to hostility to air travel, causing a further downturn in the already weakened air travel industry, as Simon says 'I been travelling cross Europe by plane for many years and now the train is becoming a serious option as an alternative to be treated like a crazed criminal'.

Simon is an active campaigner and is a founder member of European Human Bridges, who organised a conference on disabled people and travel. 'The conference highlighted how bad air travel already is for disabled people and now it looks like getting worse'. In attempting to resolve the issue directly with British Airways, he was informed that they did not deal with the public directly on these issues.

You can contact Simon Stevens in the following ways;

Standard Email: sjs@simonstevens.com Mobile Email: sjs@sjsmobile.co.uk

Travel Email: sjs@sjstravel.co.uk Laptop Email: sjs@sjslaptop.co.uk

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Friday, 28 September 2001

CIDNY Struggles to Assist New Yorkers With Disabilities

The Centre for Independence of the Disabled of New York, Inc. (CIDNY) is the primary Independent Living Centre in New York City assisting people with disabilities who have been affected by the September 11th bombing of the World Trade Centre. As the Independent Living Centre closest to the World Trade Centre, CIDNY has served as the nexus of information and services for New Yorkers with disabilities during the crisis.

CIDNY is assisting people with disabilities who have been displaced from their homes, whose services have been interrupted, and who are without transportation because New York's para-transit system, Access-A-Ride, is still not running in lower Manhattan. The Centre has distributed emergency food, shelter, and funds from its modest budget.

As downtown neighbourhoods are reopened, some people with disabilities have been able to return home, but cannot get to work, because accessible transport in Manhattan has been halted. Morning weekday traffic entering Manhattan has been restricted to vehicles carrying more than one passenger. Vehicles with disabled parking permits are exempt, but sometimes delayed at checkpoints. In addition this restriction has made it difficult for many home health care providers to reach their clients regularly.

CIDNY assists New Yorkers with disabilities in manoeuvring such obstacles, and helps individuals navigate social service agencies, which are especially pressured at this time of crisis. While individuals have applied for relief funds from FEMA (the Federal Emergency Management Administration) to cover the expenses they have incurred, CIDNY and its

volunteers have served as the direct contacts for more immediate assistance.

The local media and relief agencies have been directing New Yorkers with disabilities in need to CIDNY. The Centre was highlighted on the local news over a number of days, and representatives from FEMA are now filming a segment on CIDNY as well. While it is important to connect isolated people with disabilities to the resources CIDNY provides, this new coverage is resulting in a still greater number of requests for assistance, which will press CIDNY's resources to the limit.

In addition to the needs of people whom already had disabilities of September 11th, it has been projected that an additional 2,500 people have newly acquired disabilities in New York City. They will require assistance from the Independent Living Centres immediately and long-term. CIDNY is in the process of providing for outreach to the newly disabled, through Traumatic Brain Injury counselling and grief counselling. Understandably there is an ever more demanding need for peer counselling, group counselling and career counselling for those who have lost their jobs as a result of the destruction of the World Trade Centre.

Bethany Hoffman. October 02.2001.

Letters

"My daughter was diagnosed with ADHD in 1997. Since then she has been on Ritalin, purely for concentration reasons. She is now 16 and has just finished her GCSE's. She has obtained good results, which have enabled her to start a pre-nursing at the beginning of September at the local Regional College. She is currently spending 3 days a week at the college and 2 days at the local Hospital. She has had to fill in an occupational health form, which has resulted in a various telephone calls asking for additional information. Information was only provided by her consultant, which was seen and approved by us. The occupational Health department at the hospital have now informed us via the college that she will no longer be able to continue as because she may lose concentration when on the ward and consequently put a patient at risk. A doctor who has had no personal contact with my daughter in order to assess her made this decision. Any advice or information that you could provide would be greatly appreciated. In particular we would like to hear from anybody

who has been in the same or similar position, especially if they work in a hospital with ADHD."

Concerned Parent. (name and email supplied, and I will feedback as necessary)

Hi all

I have recently run some workshops for health sciences clinicians who host students on fieldwork. I was able to provide some information about the Australian Anti-Discrimination Act, The Privacy Act, and the University policy on privacy, risk management & duty of care. There were always one or two in these groups who were vocal about their "concern" with taking on students with a disability (in this case arising from mental illness). I am sure its got something to do with maintaining the "standards of their profession" and their inability to see a person who might normally be a "client" as a peer.

In all cases of practitioners being "concerned", there was a concern with the student being able to do everything that they themselves are required to do in their own work role. This, I would say, goes back to the Professional Associations who set the standards that all students must attain within a course accredited by them. I suggest then, that their standards (skills of a practitioner), accreditation standards and thus curriculum is inherently discriminatory if it doesn't have the flexibility to allow a student the

choice of directing their skills toward a particular professional context where their performance will not be hindered by a disability. What if, for instance, a student with Quadriplegia wanted to study physiotherapy, not because they want to practice it but to research it? Shouldn't they be assisted to study what they want? Why is it the business of the Professional associations and practitioners what a student wants to do with their skills and knowledge? Maybe it's the inability to see a person with a disability in any other way than as a client?

Laurence Bathurst

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"I have just had a spell in hospital; from a disability awareness perspective was a complete disaster. On my first night there they tried to take my wheelchair away, to tidy up the ward! I was

promised that they would find me one in the morning when I needed it, and, in case they could not find that particular one (even though it is a lightweight model about as far from the usual hospital types as you can get) they assured me that there plenty of wheelchairs in the hospital! My next obstacle was that there was only one toilet, out of five, that I could get into on the ward, and the bathroom and shower room were also out of bounds for me! This is in a hospital that was built about the mid 1990's and is supposedly a showpiece!

I have written an interesting letter to the management! Sadly there seems that there is a long way to go before disabilities are not exacerbated by the 'social' system."

(Name and address supplied but withheld for confidentiality purposes)

Useful References

Eathorne V. Scullion P (2001). Positive Attitudes. Primary Health Care 11 (7) 18.

Thomas S. (2001) A new approach to disease management in multiple sclerosis. Primary Health Care 11 (7) 22.

Spain R. (2001) Community Care (Direct Payments) Act 1996. Primary Health Care 11 (7) 37-38

Web Resources

The Nursing Standard

The Nursing Stand is now Online. With free access, a fully searchable archive, selected recent articles from RCN journals and the quick assessment guides, self assessment questionnaire, best practice guidelines etc. It can be found at: www.nursing-standard.co.uk

Exceptional Nurse

www.ExceptionalNurse.com is a resource network for nursing students with disabilities and nurses with disabilities. The site originates in the United States, but much of the information could be helpful to nurses worldwide. It contains links to disability-related organizations, financial aid, equipment, technology, employment opportunities and research. The site also offers helpful information for nursing educators and guidance counsellors.

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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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Centre for Research and Policy in Disability

Would you, or an employed (professional) disabled person you know be interested in becoming a mentor to a disabled student?

Beginning October 2001, we are embarked upon an email-based scheme, which pairs mentors, and mentees from all over the country in order to provide students with a positive source of support and advice.

Every year, the number of people with a disability who enter Higher Education and who graduate rises but these figures do not correspond with the number of disabled people who find employment. Disabled graduates are four times less likely to find a job than their peers and those who do, often enter an area of employment, which is not commensurate with their academic background.

We believe that by matching a disabled student with a mentor who may have a disability similar to their own or has chosen a similar career path, there is an opportunity to discuss the challenges surrounding career options and given the advantage of their mentor's knowledge and experience, to improve their job prospects.

If you are able to spend a half hour or so a week replying to emails or know of others who may be interested in our scheme, then please contact-

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