

Disabling Practice Enabling Nurses? Disability Network Newsletter

Number 12 Autumn 2002 Edition

Letter from the Editor

Thank you to all of you, who have sent me material for inclusion in the newsletter, and have commented on previous issues. I have dedicated this edition to reports on the Conference held in July, and to education it is a 'hot' topic at the moment with the Disability Discrimination Act currently being extended into education. I hope this does not disappoint too many people, but there will be another newsletter next month as I have enough information for at least further newsletter. I apologise that this one is later than I intended but I have been on 'sick leave' so it had to go on hold for a while. Please continue sending me information, the network is thriving thanks to your help.

Rachael Spain

Conference report: Enabling Practice: the disability rights agenda

This year's event, part of a series, put Cavendish Square, RCN's London headquarters, to the test since a good number of both delegates and speakers had different access needs. And, thanks to many colleagues, led by Jane Edey who is an RCN events organiser, these differing needs were largely met though we had to acknowledge that it was a steep learning curve. WING reported in their recent newsletter [summer 2002] Congress Report, that there is support at the top of the RCN in the persons of Dr Beverly Malone, General Secretary and Roswyn Hakesley-Brown, RCN President. Perhaps soon nobody will turn their heads at the thought of nurses who happen to also be disabled people!

Of course I cannot give an unbiased account of this event as organiser, chair of morning sessions and concluding speaker. However I aim to present key points in this summary, will refer to the delegates' evaluations and I am delighted that we have an account from one of the delegates, Tom Clarke, who identifies himself as a disabled person and nurse.

Roswyn Hakesley-Brown, the president set the scene for the day by posing and beginning to answer the question 'Do health professionals have a role in promoting disability rights?' She referred to Nikki Heazell who was recently featured on the Disability Rights Commission web site. Nikki had faced some considerable barriers in trying to gain access to nurse education but now works as a staff nurse in Birmingham.

(see http://www.drc-gb.org/drc/InformationAndLegislation/NewsRelease_020514.asp for interview with Nikki).

Michael Brothers, Special Projects Manager, Disability Rights Commission gave an overview of DRC achievements in its first two years, outlined legislation and gave details of some discrimination cases it has dealt with.

The telephone help-line has dealt with a total 143,000 calls since it opened.

He presented the DRC's goal: "Equal and fair treatment of disabled people in health and social care services – as customers, patients and employees" and proceeded to give details of the following specific issues

- Quality of Life – "Do Not Resuscitate" notices
- Maximising Participation – Direct Payment
- Manual Handling and Lifting!

He explained that the DRC's legal advice questions the legality of 'no lifting policies' and described how many care agencies are imposing such restriction on staff activities with serious implication for some disabled people.

Extract from His speech

"The DRC, working in partnership with the National Centre for Independent Living (CIL), has successfully negotiated a number of changes to the Health and Safety Executive (HSE) guidance concerning the manual lifting and handling of disabled people. This includes a clear statement to the effect that, the HSE does not advocate "no lifting" policies and there is no justification for any unreasonable restrictions on support provided to disabled people"

The DRC is involved in a judicial review, due to be heard in September 2002, relating to a case centered around such policies. The full text of his speech is available on the DRC web site <http://www.drc-gb.org/drc/InformationAndLegislation/Page391i.asp>

Michael sought to gain a commitment to disability equality and challenged delegates and organisations represented to respond to the DRC's current public consultation on disability law, since one of its key functions is to keep this under review and advise government as necessary. Details about this consultation can also be found on [http://www.drc-gb.org/drc/InformationAndLegislation/NewsRelease_020520\(2\).asp](http://www.drc-gb.org/drc/InformationAndLegislation/NewsRelease_020520(2).asp)

Sally French, Senior Lecturer, Department of Management and Social Sciences, King Alfred's College of Higher Education, Winchester, presented a paper entitled 'Disabled people as health professionals - the physiotherapy experience'.

She presented key finding from her research, which was recently published (and reviewed in issue 11 of this newsletter) concerning the experiences of visually impaired physiotherapists. Their accounts varied with some facing many barriers especially after qualifying and attempting to access continuing professional education opportunities, which took little account of their special needs.

Sally gave a history of visually impaired people within physiotherapy and showed how they provide a valuable service. Community roles were found to be especially challenging but she gave an account of one senior physiotherapist who, after putting a business case to managers, was provided with a personal assistant to enable his skills to be fully utilised in clinical and other roles. In spite of some barriers, what became clear is that visually impaired people can take on challenging roles in various health related professions. Incidentally the RNIB continue to play an enabling role in some education settings (more details next issue).

Clare Taylor, Principal Lecturer, Occupational Therapy, School of Health and Social Sciences, Coventry University gave an amusing and gripping paper entitled 'Rights, independence and empowerment - the place of professional education' during which time delegates themselves became active participants.

The concepts rights, empowerment and independence were first examined before presenting selected findings from her recent research. A fascinating account was given concerning how different OT students coped with a patient who did not wish to get dressed; approaches ranged from 'the patient must get dressed to be normal;' to 'so what does it really matter? It's the patient's priorities that should be important'. Clare advocated the notion, found in the literature, that independence is not so much an ability to do but an ability to choose and she offered the following definition-

"If it takes me 4 hours to get dressed and undressed but only 20 minutes to do so with help, then I'd rather get help so I can go out and spend the rest of the 4 hours with friends. Independence to me is not the ability to get dressed on my own, but being able to participate in living"

Some of her findings have been published [*M Clare Taylor (2001) Independence and Empowerment: Evidence from the Student Perspective. British Journal of Occupational Therapy. 64, 5, 245-252.*]

Rachael Spain, Disability Consultant, editor of various newsletters and service user, presented 'What does it all mean to me? A disabled person as patient perspective' from her vantage point as nurse, disabled person and recent health service user. The medicalised ideas common among health professionals was aptly illustrated by something she had recently seen while she was serving time as an in-patient. An elderly person, fellow patient, who happens to be Deaf and a life long member of the Deaf community was deemed, by doctors, to be in need of a hearing aid! With apparently no consultation, arrangements were made for her to be seen in a distant audiology department. Rachael saw this as fairly typical of the health service, "when disabled people become in-patients medics cannot resist having a go at other bits of them!" In the case outlined there was deep offence since the person concerned managed with her first language, British Sign Language, for more than three score years and ten.

She explained, with illustrations, how a little forethought could make hospital admissions, or care in the community, easier for people with disabilities.

The afternoon consisted of four workshops which allowed for delegates to select just one from the following-

Rehabilitation in the workplace

Nicola Lee, Adviser for Work Injured and Disabled Nurses, Royal College of Nursing, Nurseline, London.

A Trusts response to DDA and user involvement

Janet Fox, Disability Discrimination Act Manager, South Birmingham Primary Care Trust, Birmingham.

Barbara McCaffrey Volunteer worker, Leonard Cheshire

Disability training

Steve M Tyrell, Consultant for SMT Disability Training Services, Lincolnshire.

Enabling practices in mental health

Mervyn Morris, Centre for Community Mental Health, University of Central England, Birmingham

Philip Scullion, Disability Education Adviser, Professional Nursing Department, Royal College of Nursing, London had the final session after workshop groups had fed back. 'Hearing their voices, seeing the vision: beyond reasonable steps. Health professionals *with* disabled people'. The sometimes thorny question of who has the legitimate voice of disabled people was explored in this session concluding that 'they' include-

- Marginalized groups
- People with epilepsy
- Those with MS
- Mental health survivors
- People with learning disabilities
- V.I.P.s - the Deaf community
- Clients and staff
- Ourselves

Delegates were urged to act to ensure that good policy becomes good practice as there are numerous official statements that are very positive. These include a document expected soon from the Department of Health, which suggests that the NHS should be very positive about employing people with a history of mental health problems. Reasonable adjustments by employers (required by the DDA 1995) of health professionals who acquire an impairment or people who are considering such a career should be viewed as merely '*reasonable adjustment.*'

Evaluations

Apart from the evaluation forms quite a number of delegates took the trouble to contact us in the week after the conference with useful feedback and mainly very positive comment on the event.

Impressions of a One-Day RCN Disability Nursing Conference: Enabling practice: the disability rights agenda NHS: 3rd July, 2002

A View from a Wheelchair

I arrived at Cavendish Square to find a plush new ramped entrance. However, the large heavy swing doors in to the building tended to remove the edge! But once inside, I met a lovely receptionist whose approach was most refreshing; she was kind enough to direct me to the conference room where I duly identified myself and signed in.

The group of people who were there were enjoying assorted refreshments prior to the start of the day's conference; we nodded to each as we thought we recognised each other and then began to talk and realise that we didn't know each other, but it was very agreeable to simply exchange greetings.

The conference room itself was large, airy and comfortable and I duly took my place at the rear looking forward to hearing the speakers in due course. Throughout the morning various speakers were introduced and gave their presentations. Apart from the representative from the DRC, they seemed to indicate the way ahead in how people with disability would like to be dealt with in hospital; both as members of staff, visitors and patients. One of the problems encountered when dealing with the DRC is their reluctance to deal directly with difficulties, preferring instead to merely talk about them.

An excellent, simple buffet lunch was provided and we had the chance to mix and chat with each other; I personally met lovely ladies from Edinburgh, Sheffield and London and Birmingham. They were in agreement with the basic statement that disabled people should at no time be discriminated against but that there should be a very positive element of awareness to particular needs and services. It is important to realise that no two people with disability have

identical requirements. This is often very difficult for non-disabled people whether they are members of the nursing professional or not to understand.

In the afternoon I thoroughly enjoyed a first class presentation by a young lady by the name of Janet Fox. Although a non-disabled person herself, she displayed a wonderfully appreciative understanding of the needs of disabled people; having, as she does, the gift of being able to accurately perceive the individual differences in the needs of disabled people. After her talk there was an opportunity to join various workshops and I joined a group who were supposed to be speaking of how they dealt with the question of disability rights and how they implemented this in their departments, hospitals and organisations.

There was some feeling within the group that the Leonard Cheshire Foundation could proudly be held up as having been a prime mover in the setting up of the independent living facility for disabled people. However, there are very many pioneers of the independent living movement who are far better qualified than I to speak on these matters: they would be able to correct this misunderstanding of the history and background surrounding the independent living movement and the part played by the Leonard Cheshire Foundation.

Seemingly like-minded members of this group, which comprised senior tutors and health care managers, were also at great pains to explain how they dealt with the disabled problem especially those who were wheel chair bound or confined to a wheel chair. I well recall attending management meetings in the late 60's/early 70's and listening to the same uninformed statements and attitudes. It was painfully apparent, certainly to me, that these people had a long way to travel along the path of disability awareness before they could even understand the phrase, "disability rights" far less be able to come to terms with putting it into practice! I feel sad for such staff, as, in the main, they are pleasant people. But it is a fact of life that the further away you get from direct and hands-on nursing practice the more difficult it is for you to come to terms with the immediate patient day to day needs.

I commend all of the people concerned to a detailed perusal of Janet Fox's presentation, begging them to remember that the year is 2002,

not 1902! In spite of my experience with the workshop, I thoroughly enjoyed my conference. Sadly, as I had to leave promptly at four o'clock, I lost the opportunity of speaking to some more of the delegates. I did in fact come away with one main thought: that is, in spite of all the literature and all the work that has taken place since the late 60's, through the 70's, 80's and 90's, we still have many, many miles to go before disability rights become an integral part of our professional, public and social life.

Many thanks both to Philip Scullion and his team for a thought-provoking programme and to all those members of the college staff who made my visit so enjoyable.

Tom Clark

Changes in Disability Law - Education

From September 2002 the first provisions of the Special Education and Disability Act 2001 [SENDA] takes effect. SENDA amends part 4 of Disability Discrimination Act 1995 to fully embrace education. This change covers all types of education institutions and the Disability Rights Commission has produced two Codes of good practice, one for schools and the other for post-16 education covering Further and Higher education.

The Disability Discrimination Act 1995, which places requirements on employers and service providers not to discriminate against disabled people, did not originally include similar requirements for the provision of education. The new post-16 sections of the Disability Discrimination Act deal specifically with post-16 education and training and with related services such as, in England and Wales, the statutory youth service. From the implementation of this legislation, bodies responsible for the provision of education and other related services are required not to discriminate against disabled students and other disabled people. A responsible body is usually deemed to be the Governing Body of the school or college etc.

Within schools it will be unlawful to discriminate, without justification, against disabled pupils and prospective pupils, in all aspects of school life. The principle behind this legislation is that wherever possible disabled people should have the same opportunities as non-disabled people in their access to education.

These codes are available as follows

Codes of Practice for schools:

<http://www.drc-gb.org/drc/Documents/schoolscop2.doc>

Codes of Practice for post-16 education and related services:

<http://www.drc-gb.org/drc/Documents/post16cop2.doc>

Copies are available free-of-charge from the DRC Helpline:

Telephone - 08457 622633

Textphone - 08457 622644

Email - enquiry@drc-gb.org

<mailto:enquiry@drc-gb.org>

What has this got to do with nursing?

We are very familiar with the notion of life long learning within nursing and this legislation will doubtless impact on many of our clients and of course some nurses themselves. Health visitors dealing with families with children with special needs will wish to become familiar with the legislation as they will be well aware that barriers to education in such circumstances can be intolerable. The definition of disabled person used will be that within the DDA

A disabled person is someone who has a physical or mental impairment, which has an adverse effect on his or her ability to carry out normal day-to-day activities. That effect must be substantial (that is, more than minor or trivial); and long-term (that is, has lasted or is likely to last for at least 12 months or for the rest of the life of the person affected.

And currently this definition excludes people with HIV or Cancer unless or until the above criteria apply.

Paediatric nurses and school nurses will obviously need to be aware of the legislation so that they can ensure their own organisations are not in breach of these duties. More importantly they are likely to have a key role in advising teachers and other colleagues about the specific duty to make 'reasonable adjustments' for a given pupil. In some institutions teachers or 'carers' do take on the role of administration of medication for children while within education establishments and health professionals may be called upon to educate staff concerning this aspect of care.

In some adult nursing settings; care homes, rehabilitation or intermediate care facilities for

instance, some of the patients or clients will themselves have come from education settings or may well wish to resume courses or take up new education opportunities such as evening classes or degree courses. Nurses will appreciate the potential benefits of engaging in education of some kind and wish to support these clients. A working knowledge of the legislation will therefore enable them to be enablers for these patients.

Nurse Education

Those involved in nurse education, largely based in universities should be aware of this legislation and may well have had staff seminars to update them on SENDA since it applies to most university courses. Professional courses leading to registration with the Nursing and Midwifery Council rely on some form of joint validation, are excluded at present. There are however some courses, e.g. some Post registration degree courses in nursing studies which are not subject to such validation requirements, in essence they are simply university courses. They will not be excluded from SENDA requirements.

On a related point, bursaried NHS students will become eligible for Disabled Students Allowance in September 2002, which ends the current discrepancy, which excludes them. It is anticipated that nursing students who have been assessed and found to have dyslexia are likely to be the biggest beneficiaries. The provision of amplified stethoscopes, for student nurses with a hearing impairment may also come from this fund, which is administered, via local education authorities.

Disabled Students Allowance for Diploma Level Nursing and Midwifery Students

Note: this is a guide to the new DSA rules and not meant to be a complete outline of the regulations. To obtain full information regarding this allowance see Financial Help for Health Care Students (Useful contacts below).

The Government announced, earlier this year, that there would be Disabled Students Allowance made available to nursing and midwifery students undertaking courses which attracted a non-means tested bursary (Diploma and Advanced Diploma courses).

Since September 1st 2002 students, who receive non-means tested bursaries, may be eligible for a Disabled Students Allowance (DSA). The NHS Student Grant Unit (SGU see useful contacts below) is responsible for administering the allowance. The process for applying for this DSA mirrors that for degree students. This DSA is not subject to means testing. In summary:

The SGU are required to consider all cases where extra costs are incurred in studying because of a physical or learning disability. The DSA should:

- ÿ Be in respect of expenditure not covered elsewhere in the NHS Bursary Scheme, and must arise from attendance at the course as well as a disability.
- ÿ Not be made for disability-related expenditure which the student would incur irrespective of whether or not they were a student; and
- ÿ Not be made for expenditure relating to services that can be reasonably be expected to be provided for by the students institution.

To be eligible for DSA the student needs to have a disability or special need identified along with the impact upon the student's ability to participate in the course and any applicable specialist equipment or other help to be identified.

The student needs to let the University (or College) know as soon as possible if they have a special need/disability, and what extra help or equipment they need to enable them to complete the course.

Evidence of the nature and severity of special needs/disability, with a recent assessment (within the last two years). The student is expected to meet the cost of establishing the disability.

For most DSA applicants, there should be little difficulty in establishing their eligibility – this is often known and documented. Applicants will need to provide documented evidence of their special needs/disability.

In cases of dyslexia, the assessment should be carried out by a qualified psychologist experienced with working with adults with dyslexia, or someone from a professional training course involved in the assessment of adults with dyslexia (e.g. RSA Diploma in Specific Learning Difficulties).

Once established, the level of support needed to enable the student to undertake their studies needs to be identified. Most Universities will refer the student for an Assessment of Needs from a person with specialist experience at an independent centre. This assessment will identify such things as the type of specialist equipment needed, whether a non-medical helper is required, how much this will cost and where to get the equipment/help from. The report will also include training needs for using specialist equipment.

Where an applicant does not have documented evidence, it will be necessary for them to be assessed by an appropriately qualified person or body. This assessment should clearly determine if the student would be obliged to incur additional expenditure to attend the course as a direct result of the special need/disability.

Application for DSA should be supported by the student's academic institution and normally for the claim to be made via the University (usually the Disability Co-ordinator).

DSA is made up of three elements to cover different areas of need:

Specialist equipment allowance: to help buy major items of equipment. It can also be used to pay for repairs, technical support, insurance or extended warranty, as well as for training to use the equipment. If rented equipment is more economical SGU would consider paying for this. This is a one off payment up to a maximum of £4,355 (for 2002/3) for the full three years of training.

Non-medical helpers allowance: to help pay for helpers such as lip-speakers, note takers and other non-medical assistants. This is an annual payment up a maximum of £11,015 (for 2002/3).

General disabled students allowance: to help towards general expenditure. It can be used to pay for minor items such as tapes, Braille paper or to top up the other two allowances. This is an

annual payment up to a maximum of £1,445 (for 2002/3).

Additional allowance: reasonable and necessary travel costs incurred because of special needs/disability are reimbursable. Payment is made direct to the student's bank account (although this may change in the future). Therefore the student is responsible for ensuring that the money is spent appropriately. Students on existing courses are able to make a claim where they meet the criteria.

The DSA is **NOT** intended to be used towards funding infrastructure, general administration and pastoral costs of the academic institution.

DSA should **NOT** be used to fund a disabled person's support, counselling or tutorial services which are made available to all students.

DSA is **NOT** intended for the costs of extra academic tuition or support in the main subject areas being studied.

Useful contacts:

The NHS Student Grants Unit
22 Plymouth Road Blackpool
Lancashire FY3 7JS
Tel: 01253 655655
Fax: 01253 655660
Email: nhs-sgu@ukonline.co.uk

Financial Help for Health Care Students
<http://www.doh.gov.uk/hcsmain.htm>
Printed copies from:
Department of Health PO Box 777
London SE1 6XH
Email doh@prologistics.co.uk
Fax: 01623 724 524
Ref 24557(As of 3 Sept. 2002 this is version four and does not include information about this new allowance)

Skill:
National Bureau for Students with Disabilities
Chapter House 18-20 Crucifix Lane
London SE1 3JW
Tel(voice/text): 020 7450 0620
Fax: 020 7450 0650
Information Service:
(voice) 0800 328 5050 (text) 0800 068 2422
Monday – Thursday 1:30pm to 4:30pm
E-mail: info@skill.org.uk
Website: www.skill.org.uk

DEAF EDUCATION THROUGH LISTENING AND TALKING (DELTA)

DELTA is a nationwide support group of teachers and parents of deaf children, providing support, information and advice to guide parents in helping their children develop normal speech and to live independently within a hearing society. There are regional branches which hold regular meetings and events. DELTA also runs conferences and courses for professionals, parents and families, including summer schools for parents with hearing-impaired children; while the children enjoy themselves, their parents attend lectures, workshops and discussion groups. They can provide: general information; leaflets/booklets; videos; posters; training courses; speakers.

DELTA

Wendy Barnes, National Director
P O Box 20 Haverhill Suffolk CB9 7BD
Tel: 01440 783689 Fax: 01440 783689

TYMES TRUSTCARD

Tymes Trust, a national charity supporting children with the disabling neurological illness known as ME or Chronic Fatigue Syndrome, have recently launched a 'pass card' to special support in school, with the support of the Secondary Heads Association.

Jane Colby, Executive Director of the Trust and co-author of the largest study of ME in schoolchildren ever published, explains: "We are launching the Tymes Trustcard to protect the health of children with ME whilst in school. If children with ME have to expend precious energy explaining why they feel ill, this makes them even more ill. At the moment they are often sadly refused the help they need, due to misunderstandings. Schools and teachers who have not been given training in ME can unwittingly be a key cause of relapse in children. This is confirmed by experienced paediatricians."

The Secondary Heads Association states in its newsletter to Head teachers:

"Deterioration after a latent period of 2/3 days may follow even minimal effort. Use of the Trustcard will assist the school to comply with DFES statutory guidance Access to Education for children and young people with Medical Needs".

ME is thought to affect up to 25,000 children and young people in the UK. It is the biggest cause of Long-term Sickness Absence from school. Tymes Trust provides training and information for teachers and educational professionals.

The Tymes Trustcard information is written simply for children and explains:

Maybe you can recall needing a snack in class because you felt ill? This can be due to low blood sugar and is remedied by eating something. But most schools won't allow that. Have you ever felt that by the time you had done explaining, you would feel even worse? We know of young people who have simply decided not to ask for the support they're entitled to, or who have given up in the middle of explaining, just to save energy and avoid attracting attention. We know how you feel. The Tymes Trustcard can help.

How does a child get a Tymes Trustcard? The child (or the parents) sends a stamped, addressed envelope to Tymes Trust to obtain an application form. Or they can ring the charity on the number below. Membership is not required.

What else comes with the card? There is information and a personal letter for the Head Teacher so that he or she understands the child's requirements and can instruct staff.

What does it look like? The card is small and can be discreetly carried in the child's wallet or bag. It is laminated to protect it from creasing or damp, and carries a photograph.

Lord Clement-Jones CBE, Liberal-Democrat House of Lords Spokesman on Health commented:

"I sincerely hope that all Head teachers will support this excellent initiative, and I would encourage any young person with ME to consider carrying the card."

For information and student application forms, families and schools should contact Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE. Tel: 01245 401080. Information is also on the Trust's partner website: www.youngactiononline.com.

Contacts

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

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

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