

Disabling Practice? Enabling Nurses

Disability Network Newsletter

Number 6. May Edition 2001

Letter from the Editor

I would like to begin by drawing your attention to the next 'Disabling Practice? Enabling Nurses' Conference, this time to be held in Stafford. I also wish to highlight the new Internet Information service, news of which can be found on page 7, that will greatly aid nurses and allied medical professionals. At the present time, typing in the word 'disability' offers over eighty different sites.

Please note that my e-mail address has now changed to: Rae.Spain@btinternet.com. ___ and I would welcome any articles sharing new, or existing, initiatives, requests for information or general feedback.

Rachael Spain

"Disabling Practice? Enabling Nurses"

Staffordshire Disability Awareness

Advance notice of a One Day Conference, in the series, to be held

On: 24th September 2001

At: Post Graduate Medical Centre
Staffordshire General Hospital
Weston Road, Stafford.

This conference will be run along the lines of last year's event in Bodmin and aims to review progress and good practice in providing for the needs of disabled service users in the light of recent policy initiatives and the unfolding provisions of the Disability Discrimination Act. Speakers include nationally recognised figures giving emphasis to the perspectives of disabled people as service users. Locally there have been a number of changes and improvements in the light of feedback from the Hospital User Group and this conference will highlight good practice in this important area of patient care.

This Conference is jointly organised by Philip Scullion, Disability Education Adviser RCN and Mandy Gibbs, Quality Assurance Co-ordinator Mid Staffordshire General Hospitals NHS Trust.

More details and a booking form will be included with the next edition of this newsletter. Interest levels are high so you are invited to express your interest in attending this conference by sending

E-mail to:

MANDY.GIBBS@msg-h-tr.wmids.nhs.uk

and further details will then be sent directly to you in due course.

Launch of the Disability Conciliation Service

Disability Rights Commission

'Disabled people have around £40 million a year to spend - a fact that businesses and service providers need to bear in mind. Yet we know from the thousands of calls to our helpline that disabled people get a raw deal on a daily basis as customers,' says Bert Massie, Chair of the Disability Rights Commission.

The newly launched Disability Conciliation Service will help disabled people to challenge the discrimination they face on a daily basis - in shops, cafes, bars, cinemas, buying services over the phone - in so many aspects of daily life.

It will also help businesses and service providers to put their point of view in disputes - and will help them to avoid situations where discrimination occurs.

The Disability Conciliation Service will be run by Mediation UK, on behalf of the DRC. It will provide a totally independent conciliation service for disabled people and goods and service providers.

If a disabled person has a complaint against a company or service they can contact the DRC helpline on 08457 622 633. If their complaint is likely to fall within Part III (goods and services) of the DDA, their case may be referred to the Conciliation Service. Businesses and services

can also seek help from the DRC about best practice on providing goods and services.

'The service will conciliate between both parties to try and ensure a satisfactory outcome. For example, where the disabled person receives compensation or an appropriate apology for the discrimination they receive, and the business or service receives advice about how to ensure that other disabled customers are not discriminated against,' says Nick O'Brien, Director of Legal Services at the DRC. 'What we're aiming for is a win-win situation.'

'It's really important to ensure that disabled people have the same access to goods and services enjoyed by other members of society. Ensuring that people aren't discriminated against in employment is vital - which is why it's been given so much emphasis in the past - but we can't have an equal society unless everyone can participate in the everyday things in life.'

'If you can't go to a café with your friends or buy a paper when you want one, you're missing out on basic things that other people take for granted. The new Disability Conciliation Service is a much-awaited service.'

Details of the Disability Conciliation Service is given in the DRC's new leaflet: *The Disability Conciliation Service: A Brief Guide*. To obtain copies contact the DRC's helpline:
Tel: 08457 622 633
Textphone: 08457 622 644
Fax: 0845 778 878
Email: enquiry@drc-gb.org
Post: DRC Helpline, FREEPOST MID 02164, Stratford upon Avon, CV37 9BR
<http://www.drcgb.org/drc/Campaigns/Page421.asp>

The Disability Discrimination Act 1995: new requirements to make goods, facilities and services more accessible to disabled people from 2004.

On 1 October 2004 the final stage of the goods, facilities and services provisions of Part III of the Disability Discrimination Act (DDA) will come into force. The new duties will apply to businesses and to other providers of services to the public where physical features make access

to their services impossible or unreasonably difficult for disabled people. They are a further important step towards ensuring that disabled people have access to services at others take for granted.

Last year the DRC consulted on a new Code of Practice giving guidance on these new duties. Over 600 responses were received to this consultation and a DRC Working Group analysed the responses. The Working Group subsequently revised the Code of Practice and this has now been sent to the Secretary of State for his consideration. It will then be laid before Parliament along with the Regulations, which the Government are producing to underpin these duties. The DRC would hope to publish the Code later in the summer.

Launch of DRC Advertising Campaign Disability Rights Commission

'If the world were like this, how quickly would non-disabled people complain?' This is the caption for the adverts, which will be appearing in supermarket car parks and in disabled people's toilets. It shows car parking spaces where each space displays the yellow wheelchair symbol and there is only one space without it.

Aimed to raise awareness among non-disabled people of the everyday problems disabled people experience, this hard-hitting advert also gives details of the DRC's helpline services and bears the new slogan 'Discrimination won't go away unless we all fight it.'

Also appearing in the national and local press will be a series of classified adverts telling disabled people how they can get help from the DRC if they have been discriminated against:

'If any business refuses to cater for your disability, don't put up with it.'
and

'If you're turned down for any job because of a disability, don't put up with it.'

Call the Disability Rights Commission on 08457 622633 or text phone 08457 622644.
www.drc-gb.org

The DRC's helpline can be contacted on 08457 622 633 or text phone 08457 622 644.
<http://www.drc-gb.org/drc/default.asp>

New Learning Disabilities Strategy Aims To Increase Opportunities and To Revolutionise Care

Health Secretary Alan Milburn unveiled the first major new strategy aimed at radically improving the life chances of people with learning disabilities for 30 years.

Announcing the publication of the White Paper Valuing People: A new strategy for learning disability for the 21st Century Mr Milburn outlined a series of key initiatives designed to tackle the social exclusion and discrimination experienced by many people with learning disabilities and their families.

Mr Milburn said: "People learning disabilities have for too long had their needs ignored. For 30 years forgotten generations of people with learning disabilities have lost out. That must change.

"A revolution in care is needed to increase opportunities for thousands of people, their carers and families. Alongside better services there will be a new drive to improve education and employment opportunities. Our ambition as a government is to create a society where there genuinely are opportunities for all.

"A fair, inclusive society must include those with learning disabilities. We can now do this because of the extra investment we are making in services in the NHS and social services, and the employment opportunities we are creating in our growing economy.

"We want people with learning disabilities to have as much choice and control as possible over their lives and the services and support they receive. Helping people with learning disabilities to live as independently as possible within their local communities is key to improving people's lives."

Four key principles of civil rights, independence, choice and inclusion lie at the heart of the Government's new proposals, which have cross-government backing and takes a lifelong look at peoples needs. It will impact on the work of a large number of local agencies including: social services, health, education, housing,

employment, the Benefits Agency and the independent and voluntary sectors.

The key initiatives backing these principles are:

- A new Learning Disability Development Fund of up to £100m over the next two years
- An end to long stay hospitals by helping people move to more appropriate accommodation in the community
- Specialist local services for people with severe challenging behaviour and developing integrated facilities for children with severe disabilities and complex needs
- A five year programme to modernise local council day services
- A new £6m Implementation Support Fund over the next three years to fund new advocacy developments and a national learning disability information centre and helpline in partnership with Mencap
- A £2m learning disability research initiative
- The first ever National Objectives for services for people with learning disabilities, supported by new targets and performance indicators
- More choice and control for people with learning disabilities by extending eligibility to direct payments, establishing a National Citizen Advocacy Network and increasing funding for self-advocacy organisations, in partnership with the voluntary sector
- A new national forum for people with learning disabilities
- The creation of a Learning Disability Task Force
- A Learning Disability Awards Framework to provide a new qualification route for care workers

Lord Rix, President of Mencap said: "Thirty years ago, when my daughter Shelley was a young woman, we had to fight for every bit of support. Now, with the Government's Learning Disability White Paper, we have a real opportunity to build services fit for the 21st century that offer genuine choice and independence for people with a learning disability. Mencap looks forward to working with Government to bring about real change."

Su Sayer OBE, Chief Executive of national charity United Response, added: "It is time for society to move on from treating people with learning difficulties as if they were unable to work, to participate in everyday activities and have full rights as citizens. They have been excluded too much, for too long."

"Employers are missing out on a very valuable workforce. What our employees have achieved with Fulham FC - and all the organisations we work with - is greater confidence, new relationships and their own money. We have encouraged many employers to see things differently, and the White Paper can push this further."

The White Paper also outlines support for carers. Caring for a family member with a learning disability is a lifelong commitment. To help carers, £750,000 over the next three years is being made available to help develop a national learning disability information centre and helpline in partnership with Mencap.

People with learning disabilities also have greater health needs than the majority of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. The White Paper proposals aim to enable people with learning disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.

1. There are approximately 210,000 people with severe learning disabilities (children, adults and older people), who are long-term users of health and social services. There are around 1.2 million people with mild/moderate learning disabilities who will be intermittent users of health and social care services.

2. Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), along with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development. The presence of a low IQ, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. 'Learning disability' does not include all those who have a 'learning difficulty', which is more broadly defined in education legislation.

3. The White Paper Valuing People: A new strategy for learning disability for the 21st Century applies to England only. It has been developed in consultation with people with learning disabilities. The last White Paper, Better Services for the Mentally Handicapped, was published in 1971.

4. Under proposals in the White Paper, disabled children will become a priority group under the Quality Protects programme with £60 million over the next three years earmarked to provide better support. The Schools Access Initiative will provide funds to improve accessibility of mainstream schools and the Standards Fund will be used to improve provision for children with special educational needs

5. UR in Business is a unique firm that competes for facility maintenance contracts and employs people with learning difficulties. The company has cleaning contracts with Fulham FC, Manchester City FC, Stockport County FC, Leeds United FC, and The Lowry in Salford.

6. Copies of the White Paper Valuing People are available from

<http://www.doh.gov.uk/learningdisabilities>.

It is available from The Stationery Office priced at £15.90, ISBN number 010150862X

£25 Million is to be spent on Identifying and Tackling Learning Difficulties in Young Children

Education and Employment Secretary, David Blunkett, announced today a £25 million package to identify and tackle learning difficulties in young children to ensure they get the right help and the best possible start in their

education. He also announced a Government-sponsored working group to develop practical guidance on how to identify special educational needs (SEN) in very young children (under two).

The package will include:

- £11 million to train early years and childcare special educational needs specialists workers, including up to 850 area specialists who will be working with every registered early years and childcare setting by 2004;
- £3 million to set up a regional network of special educational needs experts to work with local authorities; and
- £11 million to fund services to help young children with special educational needs.

The extra boost for identifying SEN in the early years will form part of a continuous process of monitoring and review of children's learning needs and will contribute to school-based baseline assessment. Baseline assessment is now an important element of early identification of problems in all schools.

Speaking in the House of Commons at the second reading of the Special Educational Needs and Disability Bill, Mr Blunkett said: "All children have a right to a high quality education. If a child has a special educational need that isn't identified and tackled early, they can fall behind other children and lose out. We cannot allow this to happen and we must maximise the life chances of all our children. That's why I'm announcing a further £25 million to improve local special educational needs provision for young children and make the vision set out in our recent Green Paper, Schools: Building on Success, a reality.

"The early years and childcare special educational needs specialists we are creating will support staff working in nurseries to ensure special educational needs are identified early and that appropriate support is given. We need to start training all those with special educational needs responsibilities now - and £11 million will be made available to do that.

"And to ensure resources are used to the best benefit of local communities, the network of

regional special educational needs experts will work with local authorities to make sure that the 17,000 childcare and early years settings across England are visited on a regular basis and that no child loses out.

"I also want to help local authorities improve and extend their existing activities. That is why we are devoting a further £11 million to helping improve access to specialist services and developing better resources for helping young children who have challenging needs, such as deafness. Instead of taking children to these specialist services, many will come to the child, over the doorstep and into the home. And I am also announcing £100,000 for further research by the Defence Evaluation and Research Agency, Farnborough and others into the development of an early diagnostic aid for childhood dyslexia using jet pilot technology."

"I am also pleased to confirm the commitment already made recently by Baroness Blackstone in the Lords to establish a multi-agency working group to develop practical guidance for professionals supporting children under two with special educational needs. These measures, together with the historic Special Educational Needs and Disability Bill which received its second reading in the Commons today, will mean that children and adults of all ages will have the best possible access to high quality education - regardless of disability or special educational needs.

20 March 2001

A Life in the Day of a Special Needs Trainer and Advisor.

Gill Dixon, MA, BHSc(Hons), RGN.

When I was asked to write this article I was not really sure where to start. I am an independent special needs advisor and trainer, but to simply describe that role without including the path I followed to become what I am, would be like allowing you only one slice of a very rich and tasty cake.

For fourteen years I was a full time practising nurse both in England and overseas. I loved the job, but the arrival of my two children made shift work very difficult and so I decided to diversify and took a teaching qualification. I, therefore,

have a grounding in both health and educational institutions, and an awareness of the pressures and pleasures of both.

I had never given any great thought to disability/special needs other than in a purely medical model context dictated by the hospital culture of which I was a part for so long. It was the discovery of my own child's very complex and subtle hidden disabilities, which took me, head on into a world of frustration, discrimination and misunderstanding. I began to wonder if a label being assigned to one of their members equally disrupted other families. I started a support group and single handily ran a busy help line from home for four years. I heard horror story after horror story and began to research, question and enquire into the area of disability. Suddenly I found I had a whole host of resources and knowledge that others were hungry for, and I was asked to speak as a parent of a child with special needs at a professional conference. A whole new world opened and I found a place within in, somewhere I could share the realities, inform the 'professionals', and in some way shape their practice.

However, my passion remains with the individuals affected by a disability and my role on a voluntary basis as an advocate, and advisor to individuals and families is something that takes up a great deal of my time. That role may simply be directing someone to a source of information, a local support group or purely to listen and not judge whatever it is they are experiencing. It may be to assist in writing letters or in attending meetings with teachers and other professionals to ensure that they are adhering to current educational law.

I do though, also run study days and training sessions around the country and offer a whole range of disability related subjects to interested parties.

Last year, however, I completed a master's degree in Disability Studies, and the study required for that course was a profound experience, sometimes enlightening, sometimes distressing, always meaningful. Many of my fellow students were disabled people and in listening to them and their experiences I was able to really dig deep within myself and challenge my own beliefs and practices. I now see the challenging of attitudes as a very important part of my role. So many of us are unaware of how a

very negative culture surrounding disability has been able to percolate through our pores, resulting in an unconscious anxiety about disability, a fear of the people who don't fit the social 'norm'.

On reflection, I guess I am fortunate in that I am able to constantly develop and challenge my own practice. However, to call myself an expert would be both naïve and fallacious. It is true that I feel I have something worth sharing, but there are always more questions than answers.

To contact Gill e-mail:

gill@joemax.screaming.net

Screening for cystic fibrosis is to be extended to all newborn babies in England.

Cystic fibrosis is an inherited disease which affects vital organs in the body, clogging them with a thick, sticky mucous. The disease affects more than 7,500 British children and sufferers have a life expectancy of 31.

Research in the United States has shown that screening for the disease can help diagnosis, treatment and quality of life for sufferers. At the moment, only 20% of the country's babies have access to screening. Health minister Yvette Cooper announced that the screening programme would now be extended to all children in England.

A network of counsellors will be set up to provide support to expectant parents about all ante-natal screening and tests on newborns. Pilot schemes for testing the hearing of newborn babies are also being extended to 20 sites across the country.

Ms Cooper said: "It is important that every child gets the best start in life and every parent gets proper information about what health checks are available for newborns and in pregnancy.

"Evidence shows that screening newborn babies for hearing problems and cystic fibrosis can make a big difference to the treatment and support they receive and can significantly improve their health and development."

30th April 2001

The UK's first specialist Royal College of Nursing Resource was launched by Assembly Minister for Education and Lifelong Learning Jane Davidson.

The centre, at the Llynfi Training Centre in Hensol Hospital, will specialise in information about learning disabilities. It is designed to be used by nursing staff, people with learning disabilities and their carers.

Jane Davidson said: "Lifelong learning is one of the Assembly's top priorities. Our vision is to make Wales a truly learning country in which everyone can enjoy high standards of education and training and are given real opportunities to learn throughout their lives.

"This centre will be somewhere where everyone will be encouraged to acquire new skills and knowledge and to make full use of the resources available to them.

"It will play a key role in stimulating interest among nursing staff and improving access to high quality learning through the use of information technologies.

"It is also an excellent example of inclusiveness as it is intended also for the use of those with disabilities, their carers and families. This is a clear endorsement of the principles underpinning the existing strategy for people with learning difficulties which centres round the recognition that everyone benefits from lifelong learning.

Websites Warned over Access

Scottish companies have been warned they could face prosecution if their websites are not accessible by the deaf and the visually impaired. Inadequate design means many of those who have eyesight problems cannot "read" websites using special browser software.

The Royal National Institute for the Blind says few companies realise they might be breaking anti-discrimination laws - and the charity is looking for a high-profile test case.

Technology like speech recognition or special touch facilities make computers much more accessible. The Internet potentially offers a door to all kinds of services and information, but poor design can render it a useless resource.

Dr Nick Fiddes from Scotweb is leading the campaign to make companies aware of the problem. He said that, although many websites appear to be acting in breach of anti-discrimination legislation, no company has yet been brought to court.

An example of just how bad the problem can be emerged during the winter's train delays. All the rail companies urged people to go to their websites for the latest information, however Dr Fiddes said ScotRail's site was unreadable.

A piece of software called Bobby, which can be easily accessed over the Internet, identifies those sites, which can and cannot be accessed by disabled people. The tourist board, Glasgow City Council and Dumfries and Galloway Council all failed the test.

But Edinburgh, Aberdeen and Highland councils' sites would allow people with special browsers to access them.

To explore Bobby on the Internet visit:

<http://www.cast.org/Bobby/Bobby311.cfm>

and

<http://www.cast.org/bobby/index.cfm?i=1504>

If you want to use Bobby, you'll need to read both pages.

Useful publications

Lee H, Scullion P (2001) De-medicalising disability. *Primary Health Care*. 11 (4) 29-32.

Scullion P (2001) Models of disability. *Primary Health Care*. 11 (4). 28-29.

Thomas S, Eathorne V (2001) Access denied in primary care. *Primary Health Care*. 11 (4) 25-27.

'NMAP goes live!'

Nursing and allied health communities collaborate on new Internet service

Are you looking for high quality Internet resources in nursing, midwifery and allied health?

Then head to NMAP <http://nmap.ac.uk>

NMAP is the new free gateway to evaluated, quality Internet resources in nursing, midwifery and the allied health professions. Aimed at students, researchers, academics and

practitioners, it enables users to get quick and efficient access to reliable health information. NMAP has been developed by a core team of information specialists and subject experts from the Universities of Nottingham and Sheffield and the Royal College of Nursing. Joined by other key organisations throughout the UK and further a field, NMAP is an integral component of OMNI (Organising Medical Networked Information), a well-established service that has been serving the UK health and medical communities since 1994.

NMAP provides more specialised information for the nursing and allied health communities, focusing on information of relevance to nurses, midwives, physiotherapists, occupational therapists, dieticians, health visitors, podiatrists, chiropodists, speech therapists, theatre practitioners and radiographers.

Based at Nottingham University, OMNI and NMAP form part of BIOME, the health and life science hub of the national Resource Discovery Network (RDN).

Professor Betty Kershaw DBE The Dean of the School of Nursing and Midwifery at Sheffield University commented:

"The internet can be a great source of information. It can also be a nightmare to find good quality resources.

I am sure that NMAP will provide students, teachers, researchers and clinicians with an excellent source of high quality resources, which will enhance teaching and learning and, most importantly, patient care".

This UK-focused collection uses published evaluation criteria to filter through the plethora of information on the Internet for the UK health communities. The quality assurance process put into practice by subject and information organisation specialists ensures only the best of results from the Internet, listed with concise reviews of each site.

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