

# Disabling Practice Enabling Nurses? Disability Network Newsletter

Number 7 Summer Edition

## Letter from the Editor

People have been very busy since the last edition. There was a fringe event at this year's RCN Congress, in Harrogate, and we welcome new subscribers from there. Victoria Eathorne has held her second Conference Day in Cornwall, and her report starts on the bottom of this page.

There are more Conferences being arranged, so may I bring to your attention the next one, which is in Stafford.

I would welcome any articles relating to disability issues, also the sharing of good practice in your area, be it innovative or long-term. Please also contact me if you would like a particular aspect of disability highlighted, as an exchange of information is also important.

If you would like to contact me my contact details can be found on page 7 of this newsletter together with the details of other people who are happy to be contacted regarding disability issues.

Rachael Spain

**Stop Press Stop Press Stop Press**

**Major Disability Awareness  
Conference  
Monday September 24, 2001**

## Major Disability Awareness Conference

This nationally important conference brings together service users, researchers, nurses, estates personnel and others to highlight 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. Mid Staffordshire General Hospitals NHS Trust, which is jointly organising the event with the RCN, has made commendable changes and improvements, largely based on user-group involvement and taking the DDA seriously.

New research into the quality of services provided for disabled people in out-patients departments will be reported on. National and local speakers, many of whom are disabled people themselves and are highly sought after, will cover topics such as service user's perspectives, implementing the DDA in the NHS, education and training, disability models.

There will also be an opportunity to view exhibition stands and meet colleagues in a very spacious and accessible environment. Further details and booking form are found at the end of this issue of the newsletter.

## Health and Social Care Disability Awareness Conference

The Health and Social Care Disability Awareness Conference was held on 18 June at the Hall for Cornwall, Truro. It was jointly organised between Cornwall Healthcare NHS Trust, Cornwall Social Services and the Royal College of Nursing.

Almost 400 delegates attended from a wide range of organisations, including Disability organisations voluntary groups, Health Service, trade unions and the Employment Service, there was also an impressive turnout of Social Workers and Care managers and senior managers from Cornwall Healthcare Trust and Cornwall Social Services. The conference was aimed at a broad range of people who come into contact with people with a disability, recognising that there is a duty to ensure equality at every level in society, including employment and recreation. The conference emphasised the need to promote a positive attitude of individuals

towards disability and the responsibility of organisations to change their policies, practices and procedures to reduce the barriers, which exist, or appear to exist.

The Director of Social Services and the Director of Nursing for Cornwall Healthcare NHS Trust set the scene for the day confirming the commitment of both organisations to this event.

Keynote speaker was Philip Scullion the Disability Education Adviser from the Royal College of Nursing who reported In our climate of service user involvement in health and social care provisions it is perhaps timely to consider the extent to which our clients or patients would give us a tick of approval. Our policies and public commitment to serving and indeed employing disabled people, within the fields of both social care and health, are beginning to suggest that we are positive about disabled people. Yet the research tends to paint a slightly gloomier picture though I doubt that any of it was conducted in Cornwall!

This presentation took evidence from two key sources, each providing evidence on the extent to which disabled people, as service users, found social and health care provisions to be appropriate, sensitive and non-discriminatory. A report by Muscle-Power, an organisation of disabled of people entitled Bureaucratic Barriers to Normal day-to-day Activities, showed how the systems, policies and administrative arrangements often left people frustrated by the inflexibility and hurdles of red-tape. This research focussed on people with neuromuscular impairments, such people by virtue of their impairment, may have very limited reserves of physical energies to overcome these barriers. Health services fared little better when it comes to implementing the provisions of the Disability Discrimination Act (Freeney et al). Within the NHS, a massive organisation regularly dealing with people who have chronic illness, temporary and long-term impairments of various kinds, one may reasonably expect an environment, which is particularly user-friendly for disabled people. Yet this research showed that many barriers remained, the biggest of which is negative staff attitudes.

There is not only the need to improve our services but in the light of moves towards integrated health and social care the need to ensure that disabled people do not 'fall between

the cracks' or gulf that sometimes exists between the services.

Philip pointed out that the employment services scheme, using the 'Two Ticks' symbol, might represent just two ticks; a badge or symbol to shows a theoretical commitment to disabled people that may not be borne out in practice. He posed the question 'Do our services match our symbols?' and highlighted the real potential that providers of health and social care have in employing and serving disabled people where the need arises and spearheading a genuine positive about disabled people culture. He urged delegates to adopt such a commitment at both personal and corporate levels.

Sonya Davey (Cornish Disability Forum) emphasised that effective consultation is effective communication and how it needs to be well planned and to involve service users at all stages in the process not just at the end. Chris Cox assistant director of legal services from the Royal College of Nursing discussed the implications of the Human Rights Act for service provider's employers and employees. Michael Brothers, Special Projects and Co-ordination Manager gave an overview of the work of the Disability Rights Commission first year of activity and looked ahead to some strategic challenges including the development of exemplary services and legal reform.

Peter White the BBC Disability correspondent gave a very human perspective on living and working in a high profile job as a person with a disability, in summing up on his ambitions for his job: "To explain to the general public why disabled people need rights not favours and how this will increase everyone's dignity, not just ours."

Lynn Waddell Disability Nurse Specialist for Forth Valley Primary Care NHS Trust and PC Mike Matthewson of Central Scotland Police gave the Scottish perspective on 'Partnership Working' between both these services. This has been achieved through effective interdisciplinary education and practice, based on mutual respect for individual values and experiences. The presentation itself highlighted many of the initiatives that have been developed within Central Scotland to enable disabled people to access these services. This was reflected in the Disability Departments Philosophy, which stated

“ Meeting a disabled person’s needs should be seen as normal practice rather than a problem to overcome.”

Victoria Eathorne, Disability Advisor to Cornwall Healthcare Trust outlined the Cornish experience and stated that everyone in the NHS has a responsibility to ensure disability issues are addressed effectively throughout the Trust. She spoke of how the latest section of the Disability Discrimination introduced in October 1999 was placing a greater emphasis on the Health Service to re-evaluate their policies practices and procedures which make it impossible or unreasonably difficult for disabled people to access a service (Thomas S, Eathorne V).

#### **Key references**

Freney M et-al (1999) Working in partnership to Implement Section 21 of the Disability Discrimination Act 1995 Across the National Health Service. NHS Executive  
Maynard Campbell S, Maynard Lupton A (2000) Bureaucratic Barriers to Normal Day-to-Day Activities. Derby. ‘Muscle Power!’  
Thomas S, Eathorne V (2001) Access Denied in Primary Care. Primary Health Care Vol. 11, (4) 25-27

#### **“Actions Speak Louder Than Words”**

What is it all about?  
“Actions Speak Louder Than Words” is the Disability Rights Commission's first major campaign.

The campaign is a call on leaders in the world of business, entertainment, sport and politics to make a practical, long lasting commitment, which will enable disabled people to participate fully in society.

We hope these actions will act as the catalyst for positive change in the wider community - we want to see individuals and organisations go beyond a simple fulfilment of their legal duties. This is crucial to ensure that disabled people have the opportunity to participate fully in our society. Leading voluntary organisations and individuals representing disabled people supports the DRC’s campaign, and is being project managed by the RNID.

The DRC is already working closely with businesses to provide examples of organisations' commitment to change. Organisations such as the TUC, Lloyds, TSB and Arriva have already pledged their support. They are working on a range of commitments to support the campaign and increase participation of disabled people.

Details of their commitments are available on this website.

<http://www.drcgb.org/drc/Campaigns/CampaignsMenu.asp>

Clear commitments from business leaders and opinion formers will demonstrate that actions, not just words, make a positive difference to disabled people and society at large - helping put an end to discrimination.

Our campaign film, 'Talk', is an exciting piece of work, which we hope will become a talking point and help challenge some pre-conceptions of disability. Details are available on the website on the Video page.

#### **Campaign Partners**

Lead Body - Disability Rights Commission (DRC)  
Project Manager - The Royal National Institute for Deaf People (RNID)  
Capability Scotland, Enable,  
Guide Dogs for the Blind  
Leonard Cheshire Foundation  
Leonard Cheshire Scotland  
Mencap, Mind, the Mental Health Charity  
RADAR, RNIB, SAMH (The Scottish Association for Mental Health)  
Scope

#### **Social Skills For People with Asperger’s Syndrome**

An intensive four-week course is teaching people with a rare form of autism the basic rules of everyday behaviour.

The course, based in Islington, north London, is designed to help people who have Asperger’s Syndrome find a job. People with the syndrome have difficulty communicating with others and understanding what the rest of us take for granted - body language, making friends and talking to people. As a result they tend to be isolated and confused and suffer from very low self-esteem.

## **Don't Stereotype People with Profound Disabilities**

Will Rogers observed, "It's not what you don't know that hurts you; it's what you do know that ain't so". A reasonable policy to overcome social exclusion or to promote human rights cannot succeed without an accurate view of the lives and possibilities of the people who are excluded and oppressed by stereotypes.

People with severe and profound disabilities in communication, movement and learning too often suffer the consequences of stereotypes held by experts and carers. These certainties about "what ain't so" grossly underestimate their potential and lead to expensive help that locks them into a narrow, separate world where they remain strangers to their fellow citizens.

Research on the everyday experience of people with disabilities who live in residential care highlights a persistent pattern of disadvantage. Obviously, so the thinking goes, differences in people's bodies and brains explain differences in people's lives. It is just this certainty that five local projects, sponsored by the Foundation for People with Learning Disabilities, have challenged. Significant impairments in communication, mobility and learning need not pose insurmountable barriers to making friends, making choices, and making contributions as volunteer workers. What does make the difference is the way that people are seen and supported.

When people close to project participants chose to find new ways to listen and to discover new ways to assist communication, lives changed in important ways. By stepping outside the certainty that labels like "profound learning disabilities" or "autism" or "severe cerebral palsy" told a complete and certain story about people's potential, they joined a growing number of people around the world in exploding unnecessarily limiting ways of understanding significant disability.

Anne McDonald uses her alternative communication system to describe this movement for inclusion. "Every person with severe communication impairments believes in miracles. I am one of the few who has experienced one. I was given a voice through augmentative communication and came out of an

institution for people with learning disabilities to graduate from university. I did it by learning to read and to spell at the age of 16. Nothing else about me changed."

Anne's experience, and that of many other people whose gifts have been professionally misunderstood, add up to a clear call for a number of radical changes in policy and practice.

Policy and practice need to recognise the centrality of personal relationships in human development. Urie Bronfenbrenner summed up a lifetime of research in developmental psychology like this: "No one flourishes unless at least one other person is irrationally attached to them".

People with severe disabilities need access to technologies that support communication, learning, and mobility. These technologies do not "cure" disability; they augment different abilities to offer people new ways to connect with and extend their world. Implementation of the Human Rights Act should stimulate action to provide people with the assistance they need to exercise their responsibilities as citizens.

Also, ordinary people need to find reasonable and creative ways to accommodate people's differences in movement, communication, and learning. A little goodwill, imagination, and teamwork go a long way to opening new opportunities.

Finally, experts need the humility to admit how little certainty there is in predicting human potential. They need joyfully to give up their certainties and explore new ways to help people and their families make the most of their gifts. Then, and only then, can we say that we are truly enabling people with severe and multiple learning disabilities to make choices.

John O'Brien. From a talk given to the Foundation for People with Learning Disabilities by the lecturer at Syracuse University, New York

## **SPECIAL EDUCATIONAL NEEDS AND DISABILITY BILL RECEIVES ROYAL ASSENT**

The Special Educational Needs (SEN) and Disability Bill has received Royal Assent. The Act makes changes to the existing framework for children with SEN. It also places new anti-

discrimination duties on schools, colleges, universities and providers of adult education - removing the exemption of education from the Disability Discrimination Act (1995).

Part 1 of the Act:

- \* strengthens the right of children with SEN to be educated in mainstream schools where parents wish it and where the interests of other children can be protected;

- \* requires Local Education Authorities (LEAs) to ensure parents of children with SEN are provided with advice and information and a means of resolving disputes with schools and Local Education Authorities;

- \* requires Local Education Authorities to comply, within prescribed periods, with orders of the Special Educational Needs Tribunal (SENT), and makes other technical changes in support of the SENT appeals process and statementing process; and

- \* requires schools to inform parents where they are making SEN provision for their child and allow schools to request a statutory assessment of a pupil's SEN.

Part 2 of the Act amends the Disability Discrimination Act (1995) by placing new duties on providers of school and post-16 education. In school education there are new duties on Local Education Authorities and schools (including independent and non-maintained special schools) in England and Wales and on Local Authorities (LAs), independent schools, self-governing schools and grant-aided schools in Scotland.

In England, Scotland and Wales there are new duties:

- \* not to treat disabled pupils less favourably, without justification, for a reason which relates to their disability; and

- \* to make reasonable adjustments so that disabled pupils are not put at a substantial disadvantage to pupils who are not disabled (but there is no duty to remove or alter physical features or provide auxiliary aids and services).

In England and Wales only there is also a new duty to plan strategically and make progress in increasing accessibility to schools' premises and to the curriculum, and in improving the ways in which written information provided to pupils who are not disabled is provided to disabled pupils.

In post-16 education in England, Scotland and Wales there are new duties on further education institutions, higher education institutions, Local Education Authorities and Local Authorities in respect of adult education and youth services provision secured by them. The duties are:

- \* not to treat disabled students less favourably, without justification, for a reason which relates to their disability; and

- \* to make reasonable adjustments to ensure that people who are disabled are not put at a substantial disadvantage compared to people who are not disabled in accessing further, higher and Local Education Authority-secured education.

The Bill was introduced into the House of Lords on 7 December 2000. It passed into the House of Commons on 5 March 2001.

Copies of the Act and the accompanying explanatory notes are available from: The Stationery Office (0870 600 5522 or <http://www.legislation.hmso.gov.uk/acts/acts2001.htm>)

### **Where to Find Support for Disabled Parents**

**Disability, Pregnancy and Parenthood International (DPPi)** offers information and advice from an extensive UK database and fosters international links for parents and professionals. Their site has an archive of article titles from the DPPi journal. National Centre for Disabled Parents, Unit F9, 89/93 Fonthill Road, London, N4 3JH Freephone information service: (UK) 0800 018 4730 Fax: 0207 2636399 Textphone: 0207 272 7764 Admin: 0207 263 3088 email [dppi@eotw.co.uk](mailto:dppi@eotw.co.uk) Website <http://freespace.virgin.net/disabled.parents>

**The Disabled Parent's Network** works to improve services to support people who have disabilities in pregnancy and parenting (UK), operates a contact network for parents and others, offers training resources for professionals and others including 'Righting the Picture', an exhibition of positive photographic images. PO Box 5876, Towcester, NN12 7ZN Tel: 0870 241 0450 [emailinformation@disabledparentsnetwork.org.uk](mailto:emailinformation@disabledparentsnetwork.org.uk) Website [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

## **Learning is a Sharing Thing**

On Thursday afternoons Veronica Thomas does art. Like most adult education classes, hers is weekly and lasts a couple of hours. The difference is, it comes to her home - or at least one of her fellow students pops in to pass on what she has just learned.

Veronica is housebound. At 54, severe arthritis prevents her getting out. A disabled friend introduced her to a charity called Housebound Learners where volunteers take adult education courses and then visit housebound people to share what they have learned.

It is refreshingly defiant of e-learning and recognises that adult education has so much more to offer than just further study. Tuition is free for volunteers and their students.

"It's literally changed my life," Thomas said. "I've always wanted to go to college to do something else to keep the brain ticking over, but I'm unable to get out. Since I was introduced to Housebound Learners I have done so many of the things that I wanted to do."

The classes she has taken include aromatherapy, ceramics, photography, nature studies and watercolours, in which she has excelled. Without them she feels she would have sunk into depression. "I would just be vegetating to be honest. I was getting to be very negative; because when you're in pain everything gets to you.

"But having the tutor come and do a course with you makes you feel brilliant - you don't think of the pain, you don't think of your disability, you just get on with it, and that's what I was lacking. It's given me back my positivity."

Her "tutor" is Sharan Singh, who gets a double satisfaction from learning a new skill herself and then passing it on to someone else.

"You get a sense of achievement when you see them happy. It is very worthwhile. A lot of students are very severely disabled."

And it's not just about learning, says the charity's director, Hilary Nightingale. "Housebound Learners really addresses something that isn't being dealt with - how to get people included that can't come to the classes. It's the human contact that makes it special. We're looking at

social inclusion as much as the provision of education. Being housebound damages confidence, learning isn't easy and your self-esteem plummets."

For some long-term sick and disabled people, Housebound Learners can be the first step back into the world, she says. "It's not about having a visiting expert telling you something, but somebody who's going to share things with you, who wants to know what you think."

Tutors are trained in how to establish a relationship with the person at home and pass on the information in a successful and interesting way. Volunteers are usually just one step ahead of their home students. "Sometimes Veronica knows more about something and she tells me," Sharan says.

The charity offers a number of tailor-made courses, such as The History of Advertising, The Mitford Family, Charlotte Brontë, Creative Writing, and Tile Decoration, for students to choose from. Or they can select from wider curricula offered by local adult education.

Housebound Learners is based in Putney, south London. Most of the 82 learners over the past year live in the borough of Wandsworth. There are a further 25 on the waiting list.

But with two new part-time staff on board, funded by the National Lottery, Hilary Nightingale now wants to establish links with other colleges across London, the south-east and nationwide. "My vision is that we are an umbrella organisation that can enable other smaller providers to set up. We've been doing it for over 12 years now and we've really got the expertise."

Housebound Learners: 020-8780 1162, email: [hbl@ukgateway.net](mailto:hbl@ukgateway.net)

By Melissa Viney, The Guardian 29/5/2000

## **Recent Publications**

Scullion P (2001) Home treatment service. Primary Health Care. 11 (5).21-22.

Barlow J, Scullion P (2001) Self-management for 'expert-patients'. British Journal of Therapy and Rehabilitation. 8;7, 245

Scullion P (2001) 'The system': relating consumers' views to power and bureaucracy. British Journal of Therapy and Rehabilitation. 8;6, 205

## **Book lets blind 'touch' distant galaxies**

A new book has been published which translates images taken by the Hubble Space Telescope into illustrations that blind people can touch.

Braille and large-print text descriptions accompany each of the book's 14 images. Up to 400 copies of the volume could soon be made available for specialist libraries and schools across the US.

Bernhard Beck-Winchatz, an astronomer at Chicago's DePaul University, created the book with fellow expert Noreen Grice. Touch the Universe: A Nasa Braille Book of Astronomy has just been launched at the American Astronomical Society in California. It begins with a Hubble image of Earth and then moves outward into the universe, showing everything from Jupiter to the Eskimo Nebula and ends with a view of dozens of galaxies, billions of light-years away.

Grice said: "We can take people on a journey of discovery, starting at the Earth and to some of the deepest places seen."

Features are reproduced for touch by using patterns or textures. Rings are illustrated with dotted lines and curved ones show gas currents. Grice explained: "This is the only way to touch something that is so distant."

6<sup>th</sup> June 2001

## **New Web Site for Disabled People**

Recently a new Web site for Disabled people has been launched. It is called **4dp.com** and the URL is: [www.4dp.com](http://www.4dp.com)

4dp.com offers a mixture of disability products ranging from adapted items for the home, and accessible holiday destinations to chat rooms for disabled people and their carers. It also has a wealth of shopping sites for all occasions.

Registration is optional, but if you do, there is a regular e-mail newsletter to alert you to the latest additions to the site. It is developing daily and so well worth a visit.

## **Contacts**

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

### **Sue Thomas**

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### **Rachael Spain**

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E-mail: [rae.spain@btinternet.com](mailto:rae.spain@btinternet.com)

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

### **Philip Scullion**

Senior Lecturer. Coventry University  
E-mail: [philip.scullion@rcn.org.uk](mailto:philip.scullion@rcn.org.uk)

### **Ruth Northway**

Senior lecturer. University of Mid Glamorgan.  
Wales.  
E-mail: [rnorthway@glam.ac.uk](mailto:rnorthway@glam.ac.uk)

### **Sally Davis**

Senior Lecturer. Oxford Brookes University.  
Oxford  
E-mail: [smdavis@brookes.ac.uk](mailto:smdavis@brookes.ac.uk)

### **Dave Thompson**

Disability Advisor. Warrington Community Health.  
E-mail: [dave.thompson@warrchc-tr.nwest.nhs.uk](mailto:dave.thompson@warrchc-tr.nwest.nhs.uk)

### **Vicky Eathorne**

Disability Advisor. Cornwall.  
E-mail: [Victoria.Eathorne@chct.swest.nhs.uk](mailto:Victoria.Eathorne@chct.swest.nhs.uk)

### **David Wright**

Special Advisor for Dyslexic and Deaf Students  
E-mail: [d.j.wright@sheffield.ac.uk](mailto:d.j.wright@sheffield.ac.uk)

# Disabling Practice: Enabling Nursing

A conference in association with

Mid Staffordshire General Hospitals  and  
NHSTrust



This important conference emphasises positive responses to disability law and policy. It will enable health professionals and others to ensure that disabled people are able to access the full range of health services and are not disabled by our practices, policies or procedures. It represents real partnerships and collaboration between service providers and disabled service users, an NHS Trust, which has an excellent track record in serving disabled people, and the Royal College of Nursing, which is working towards de-medicalising disability.

The high profile range of speakers includes nationally acclaimed figures and local representatives of disabled people. The event brings together researchers, health professionals, authors, academics, service users and actors, many of whom are disabled people themselves.

## Who should attend?

Health professionals, managers, education & training advisers, estates personnel and those interested in capturing local service users' feedback.

## Programme

- 09:00 Registration and coffee
- 09:30 Introduction: Mrs Jan Harry, Director of Nursing & Quality Assurance, MSGH
- 09:45 Chair's Opening Remarks: Tamar Thompson, Assistant Regional Director, West Midlands
- 10:00 Nursing & Disability-the RCN's position: Philip Scullion, Disability Education Adviser, RCN
- 10:15 Developing local services: Mandy Gibbs, Quality Assurance Co-ordinator, MSGH
- 10:30 From a local perspective: Ken Crewe, Local Service User
- 11:00 Coffee
- 11:30 Disability Discrimination from a user perspective: Alan Martin, Service User
- 12:15 Conceptualisation and models of disability: Ruth Norway, Senior Lecturer, University of Glamorgan, Wales
- 13:00 Lunch and Exhibition
- 14:00 Chair's Afternoon Opening Remarks: Tamar Thompson
- 14:10 Disability Discrimination Act and the NHS: Michael Freeney, Disability Matters Ltd.
- 15:10 Enabling Education: Philip Scullion, Disability Education Adviser, RCN
- 15:40 A Short Play: The Really Disabled Theatre Company
- 16:00 Chair's Closing Remarks: Tamar Thompson

## Conference Booking Form

**Disabling Practice: Enabling Nursing**  
**Monday September 24, 2001 09:00-16:30**

Send booking form and cheque to:  
Mandy Gibbs, Quality Assurance Co-ordinator  
Staffordshire General Hospital  
Weston Road, Stafford ST16 3SA

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
\_\_\_\_\_  
Phone: \_\_\_\_\_

Phone: 01785 782734  
Fax: 01785 782722

Special Dietary Requirements:  
Access Requirements:

Email: [mandy.gibbs@msgh-tr.wmids.nhs.uk](mailto:mandy.gibbs@msgh-tr.wmids.nhs.uk)

**Cost £65** to include conference pack and lunch 8

**Cheques made payable to: Mid Staffs Hospitals Charity to accompany booking form by August 24 2001.**

