

LinkUP

www.rcn.org.uk/learningdisability

Contents

- 2 A change for the better ...
Shaping the future – learning from experts
- 3 Scotland update
Northern Ireland update
- 4 Blue sky thinking ...
- 5 Protection of body shape through postural care
Stimulating simulation!
- 6 Death to indifference? New working group
- 7 Learning disability open meeting
Finding caring solutions
Nursing Standard Learning Disability Nursing Awards 2008
- 8 RNLDs – vital advocates

Further information

Send contributions for the next issue by 9 September 2008 to the editor:

Jim Blair
Email: jblair@hscs.sgul.ac.uk

Letter from the Adviser

Elections, new members, strong voices and renewed determination

RCN Learning Disability Forum Adviser ANN NORMAN rounds up the latest news and takes a peek at what's inside the newsletter.

Dear colleagues,

It gives me great pleasure in letting you know the latest news. Within this issue of *Link Up* you will have an opportunity to read what the forum committee has been up to, together with some really good articles and updates. Here goes:

All change ...

The RCN has undergone significant restructuring in past months, and this includes the Professional Nursing Department. In light of this however, I am pleased to note that learning disability (LD) nursing will have a very strong voice in the future, with an increase in adviser time and a strong forum committee.

We have had two forum committee members leave us in the past year (Martin Bollard and Steve Hardy), with Mandy Dunford handing over to a new member this summer. Jim Blair has kindly agreed to take on the role of newsletter editor for *Link Up* after this issue, so please send any articles to him on email: jblair@hscs.sgul.ac.uk

Congress news

Jim (together with the rest of the LD forum committee) will be at Congress this April and has agreed to run an educational seminar on students day, entitled: 'Has the nursing profession abandoned people with a learning disability?' There will also be a forum fringe event at lunchtime on Tuesday, 29 April on the future of learning disability nursing.

At Congress, as always, there will be resolutions that impact upon people who have a learning disability, directly or indirectly. The forum committee will be joining the debate at every opportunity. Of particular interest is a resolution on 'vulnerable adults', which I shall lead on following Congress.

Future plans

We have a busy few months ahead, bringing

forum committee membership back up to total. Fortunately, we have been approached by a large number of nurses wishing to get more involved, which is great news! There will be elections so if you are interested in finding out more about how to get involved and stand then please contact Sandra Hall email sandra.hall@rcn.org.uk

We will also be busy developing operational plans and making sure we hit all the top priorities in LD nursing on your behalf.

Independent inquiry

In other news, as a panel member on the Independent Inquiry into Access to Healthcare for People with Learning Disabilities, I can tell you that I have been very busy indeed. The team, led by Sir Jonathan Michael, has received a great deal of information in the form of submitted written and oral evidence, together with a full review of national and international research. The Independent Inquiry will be looking forward from its recommendations, which are due out in June 2008.

There will be a report at around the same time from the Parliamentary and Health Services Ombudsman, which has been investigating the six deaths cited within the Mencap report *Death by indifference*.

What's inside ...

Curious about who won the *Nursing Standard* awards last year? Check out page seven, and consider putting yourself forward for next year. Also, we have updates from Scotland and Northern Ireland on page three. Postural care is examined on page five, while page eight features a nursing student's perspective on becoming a learning disability nurse. Happy reading and once again keep up the great work that you ALL do.

Ann Norman

ann.norman@rcn.org.uk

A change for the better ...

Parents with learning disabilities frequently experience prejudice and discrimination. Because of this and lack of good support, many parents have their children taken away. CHANGE is a national organisation that fights for the rights of all people with learning disabilities. Parents with learning disabilities at CHANGE take a leading role in campaigning, training and setting standards in accessible information. FIONA McDONALD reports.

Best practice

In 2005, CHANGE held a national gathering of parents with learning disabilities. This led to a meeting between parents with learning disabilities and officials from the Department of Health, Department for Education and Skills and other government departments that then commissioned the *Good practice guidance on working with parents with a learning disability*. This was written by Jenny Morris in consultation with CHANGE and parents with learning disabilities nationally, as well as professionals who were promoting good practice.

The guidance aims to help services to improve their support for parents with learning disabilities and encourage joint working between children's and adult services so that parents receive the right support to enable them to keep their children. It is very important that professionals who work with parents with learning disabilities are aware of the guidance and put it into practice.

Having information in an easy to understand format is an essential part of providing good support. With this in mind, CHANGE produced an accessible version of the good practice guidance so that parents can get important

HAVING YOUR SAY

'Having good, clear information from day one means parents will know what to do and have more confidence and independence.'

SHAUN WEBSTER – parent with learning disabilities and Parents Training for Change Project Development Worker.

'It's important that a person with learning disabilities has clear and easy information about what happens in pregnancy because a lot of information is confusing and difficult.' BRIAN BOOTH – parent with learning disabilities and Pregnancy Project co-worker.

information about their right to good support.

Books available

The organisation also produces accessible books about parenting, which use easy words and illustrations. *You and your little child, 1–5* gives parents advice about

Shaping the future – learning from experts

JIM BLAIR writes about a new training package that works with parents as educators, improving care for people with learning disabilities who have complex health, educational and social care needs.

Project

Working together to improve staff education to enhance care provision, the Faculty of Health and Social Care Sciences (Enterprise Team) of Kingston University and St. George's University of London have been funded by Wandsworth PCT, Rix Thompson Rathenberg and Baily Thompson (Charitable Trusts) to work together to pilot a 'parents as educators' training package.

The aims of the project are to:

- review current practice
- develop a training programme to prepare parents as educators
- pilot the education delivered by parents to services.

Project phases

- identify learning disability services that involve parents as educators – March/April 2008
- review programmes and educational materials used both to prepare parents for the role and in the educating of staff in learning disability services – March/April 2008
- pilot a 'parents as educators' training programme – May/June 2008
- pilot parents delivering education to staff within local services – July/October 2008
- produce and disseminate findings – December 2008.

Issues

There have been a number of high-profile investigations and reports that have highlighted poor-quality care provision for people with learning disabilities, who often have complex health, educational and social care needs.

These reports highlighted inequalities, abuse and models of care based on service providers' convenience rather than the needs of individuals. Key reasons reported for such findings include the lack of awareness, poor management, specialist knowledge, training and limited insight of staff (Healthcare Commission, 2007). A core concern is the need to involve relatives and their advocates in care planning, as well as the necessity to increase the level of priority given to people with learning disabilities and their families within services.

looking after small children and has over 800 illustrations. This book is a follow-on from the *You and your baby, 0-1* book. Both books were written with the help of parents with learning disabilities and professionals from around the country. The books are also an invaluable resource for many other parents, including parents whose first language is not English, and teenage mums.

CHANGE is launching a new book in easy words and pictures about pregnancy and birth, called *My pregnancy, my choices*, which will be available in summer 2008. We are campaigning for these accessible books to be made available free to all parents with learning disabilities in the same way that books such as *Birth to five* and *The pregnancy book* are provided to all parents at the moment.

Health and social care professionals can support this by asking for accessible resources to be made available for parents with learning disabilities. For any information about CHANGE or the issues raised in this article, please contact Fiona McDonald or Karen Harris, on telephone: 0113 243 0202.

Further reading

- Disability Rights Commission (2006) *Equal treatment: closing the gap*, London: Disability Rights Commission.
- Healthcare Commission (2007), *Investigation into the services for people with learning disabilities provided by Sutton and Merton Primary Care Trust*, London: Healthcare Commission.
- Healthcare Commission (2007) *A life like no other*, London: Healthcare Commission.
- Healthcare Commission (2006) *Joint investigation into the services for people with learning disabilities at Cornwall Partnership NHS Trust*, London: Healthcare Commission.
- Mencap (2007) *Death by indifference*, London: Mencap.

For further information, please contact Project Lead Jim Blair, on email: jblair@hscs.sgul.ac.uk, or on mobile: 07768145283.

UPDATES

Northern Ireland update

MICHAEL GREGORY, forum committee member representing Northern Ireland, writes.

After September 2007's successful Northern Ireland RCN Learning Disability (LD) Nursing Forum event, 'Foetal alcohol – the single most preventable cause of developmental disability?', forum members have generated ongoing interest in the RCN LD Forum (UK).

A date for your diary is 25 June 2008, when the next RCN LD event will be held at RCN Belfast. The day will focus upon challenging behaviour, with the keynote address being given by Dr Roger Banks, Vice President of the Royal College of Psychiatrists, and co-author of the report *Challenging behaviour: a unified approach*, which was published in June 2007. For further information or to book a place, contact RCN Belfast on telephone: 0845 456 7839.

Scotland update

MICHAEL BROWN, forum committee member, reports.

Promoting health, supporting inclusion: five years on

Promoting health, supporting inclusion: the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities was published in 2002 by the Scottish Executive. Now a review of the progress of the implementation of the report recommendations is being undertaken by the government in Scotland. Professor Heather Tierney-Moore, Nurse Director, NHS Lothian, is leading on the work and will be supported by Project Nurse Scott Taylor, who is currently on a part-time secondment from his post as a learning disability liaison nurse in Edinburgh to the Scottish Government.

Fatal accident inquiry

Roderick Donnet was a man with Down's syndrome who died in Ninewells Hospital in Dundee following complications arising from ulcerative colitis. His death was the subject of a fatal accident inquiry and the investigation highlighted system and service failures that contributed to his death. The Fatal Accident Inquiry Determination, published in 2007, calls for changes in practice across local authorities, primary care services, general hospital services and specialist learning disability health services. The Scottish Government has asked for detailed action plans from all NHS boards and local authorities by May 2008.

Quality improvement in Scotland

NHS Quality Improvement Scotland has announced its intention to undertake an inspection of its two learning disability quality indicators relating to general health care services. NHS Quality Improvement Scotland has a remit to review health services across Scotland and undertook a national review of specialist health services against four of the six learning disability indicators and published its findings in 2006. The programme will be undertaken throughout 2008 and a clinical lead is to be appointed to facilitate the work programme across Scotland.

Blue sky thinking ...

The Association for Real Change (ARC) is undertaking a new project, titled 'Clear Thoughts', to develop a mental health in learning disability knowledge centre. Project worker DAVID GRUNDY writes.

People who have a learning disability are more likely than the general population to have mental health problems (Foundation for People with Learning Disabilities, 2002; Emerson and Hutton, 2007) and the mental health needs of these people are often not recognised and are also subject to 'diagnostic overshadowing' (Disability Rights Commission, 2006).

Many family members and front-line supporters are unaware of the steps they can take to promote positive mental health for people who have a learning disability and what to do when they have concerns about an individual.

A new project

The Association for Real Change (ARC) is undertaking a three-year project, funded by the Department of Health, to develop a 'knowledge centre' providing information regarding mental health in learning disability. The centre will provide information for individuals themselves, their families and front-line staff.

The 'Clear Thoughts' project (www.clearthoughts.info) will primarily be a web-based resource – it seeks not to re-invent any wheels but will point interested parties to existing resources, many of which are excellent but not always easy to find for those less proficient in using the Internet.

What's on the website

This website will have passive resources – sharing best practice, offering information, links to relevant organisations and resources and will provide individuals and families with details of what they should expect from services. It will also have an active

aspect – becoming a virtual community and email forum.

It will be a single site that will develop over time. However, the project worker will also become aware of future direction, useful contacts and local and national resources enabling support for interested parties via telephone. The aim is to present information in an accessible style and as simple a format as possible, attempting to ensure ease of access.

The website is 'endorsed' by various organisations and their logo is included on the front page, hopefully increasing confidence in the information given when people log in.

Website aims

The focus of the website will be promoting positive mental health, including the positive roles diet (Sustain/Mental Health Foundation, 2006) and exercise (Mental Health Foundation, 2005). The Clear Thoughts website will direct people to the services, both voluntary and statutory, locally that may be able to assist them.

The essential issues regarding people with a learning disability and their emotional well-being are often not fully recognised. Communication needs, especially non-verbal communication such as 'challenging behaviour', physical health needs, including sensory impairments and self-harm all need to be considered by the Clear Thoughts project, as do ethnicity, stigma and labelling.

Wording and good practice

Agreement about the language used on the website needs to be reached and the project worker will seek views on the

'correct' terms to use on the website. Some people may prefer emotional well-being over positive mental health or emotional distress over mental ill-health, for example. The terms used will have to be discussed and agreed with families and individuals. It may be more sensitive to use the term emotional distress, for example, but it is not useful if people do not understand the term. A questionnaire about the proposed images for the project has also been sent out.

On a positive note, many of the skills, abilities and ways of working that exist in learning disability services are well suited to promoting positive mental health, for example, holistic principles, person-centred planning, and use of advocacy. In many cases, people will already be doing the things highlighted as good practice, therefore offering positive messages to those using the site.

Further information

Another recent project undertaken by ARC is the Candle resource. Candle stands for Child and Adolescent Mental Health Services (CAMHS) and New Directions in Learning Disability and Ethnicity. This is available to download for free from the Clear Thoughts website or can be purchased as a hard copy or on CD. The resource offers front-line staff information, case studies, good practice examples, exercises and handouts about young people, ethnicity, mental health and learning disability.

For more information, to share examples of good practice or order the Candle Resource, please contact the Project Worker David Grundy on email: david.grundy@arcuk.org.uk. Do have a look at the website at: www.clearthoughts.info

What is ARC?

ARC is a national charity that supports providers of learning disability services. It offers a range of services to its members such as criminal record background checks and training opportunities as well as a number of publications and sources of information. For more information about ARC and to see the range of projects it is developing, visit: www.arcuk.org.uk

Protection of body shape through postural care

ANNA GOLDSMITH, Course Manager at the Postural Care Skills Programme explains a bit about this organisation.

Postural care is gentle, respectful and effective at protecting and restoring body shape, muscle tone and quality of life for those people with a movement difficulty. By protecting body shape, we can help to avoid secondary complications for individuals who have movement problems. Through empowering families, personal assistants, and nursing staff, we can protect people from secondary complications such as scoliosis, and respiratory and digestive failure. We mean to challenge the assumption that distortion of body shape is inevitable and we want to raise everyone's expectations for people with complex and continuing health care needs.

The principles of postural care

Out of 8,760 hours of the year, someone with a movement problem will spend approximately 1,140 hours in school or day care (a bit longer if you go to work) and 7,620 hours with the family. Of these, 3,640 hours will be spent in bed. People spend three times longer in bed than they do at school or work, and so it is here that we can really improve people's body shape, muscle tone and quality of life.

At present, people are left in easily avoidable damaging positions that can distort their body. If you are supporting someone at night, whether you are a nurse, a family member, or a personal assistant, you need the right information and skills to successfully self-manage postural care and protect people's body shape. We need to acknowledge that unless we are there at three in the morning, our role is limited. People who need postural care need you!

We have to measure body symmetry to

6 We have to measure body symmetry to ensure that postural care is effective in protecting and restoring body shape, muscle tone and quality of life. 9

ensure that postural care is effective in protecting and restoring body shape, muscle tone and quality of life. The Goldsmith Indices of Body Symmetry are the only validated, objective outcome measures which do this (Physiotherapy, 1992). Through taking the Goldsmith measurements we make sure that we are accountable for protecting body shape and ensure that the approaches we are taking are effective. If we are not measuring body symmetry, how do we know we are being effective?

Coleen Annette's story

We met Coleen when she was six years old and she had a great deal of difficulty in lying straight. This was damaging her chest shape and causing her a number of difficulties. She also had very high muscle tone. Her family began to provide Coleen with postural care at night. With the right skills and knowledge, Coleen's family used ordinary household items to make one extraordinary difference.

Coleen's muscle tone reduced, she got fewer chest infections and she was much more comfortable. Very sadly, Coleen passed away in 2005 but her family are very proud that they were able to reduce

Coleen's muscle tone and improve her quality of life with postural care. They want to share Coleen's story with others so that more people can benefit from postural care.

Avoiding body shape distortion

We now know that distortion of body shape is avoidable and we have a duty to protect people from avoidable risk. This risk can be easily and inexpensively guarded against through training families, personal assistants and nursing staff to self manage this approach. Without action now, the next generation will go through unnecessary complications, such as scoliosis and respiratory and digestive failure, and the invasive treatments that are offered for them, such as surgery and expensive medication.

If we can protect people from these complications in the first place, we protect their quality of life. For more information, please do not hesitate to contact me on email: annagoldsmith@posturalcareskills.com, or telephone: 01827 304 938, mobile: 07812 749 892. Please also visit: www.posturalcareskills.com

Stimulating simulation!

Started at Kingston University and St Georges University of London in 2004, involving people with learning disabilities as simulated patients has proved to be a great success.

Co-ordinated by learning disability nurse lecturers, in partnership with people with learning disabilities and the Baked Bean Theatre Company, the focus is on helping pre-qualifying nurses across the four branches and social care professional students learn about working with people with learning disabilities. For further information, please contact Jim Blair on email: Jblair@hscs.sgul.ac.uk

Death to indifference?

For the first time, a cross-college and cross-agency working group has been set up to tackle the disturbing inadequacies in NHS treatment for people with a learning disability.

The 'Death to indifference' group meeting in November 2007 brought together the Royal Society of Medicine's Intellectual Disability Forum, the royal colleges of General Practitioners, Nursing and Psychiatry, the Equality and Human Rights Commission and learning disability charity Mencap to pledge an end to the poor quality of health care experienced by people with a learning disability.

It was the first time these groups had come together to discuss the issues highlighted in Mencap's *Death by indifference* report and the Disability Rights Commission (now Equality and Human Rights Commission) report *Equal treatment – closing the gap*. Both reports highlighted widespread poor treatment of patients with learning disabilities.

Looking for funding?

Try the Mary Seacole Award

Have you got an idea for a project you want to undertake, or have you seen a course that you'd like to start and the only thing stopping you is the lack of funding?

If your project or course would enhance patient or client-focused care you may be eligible to apply for a Mary Seacole Award.

The Mary Seacole Leadership Awards and the Mary Seacole Development Awards were set up by the Department of Health (England) and provide opportunities for nurses, midwives or health visitors in England to undertake educational or development activity to enhance patient/client-focused care.

Each Mary Seacole Leadership Award is worth up to £12,500, and the Mary Seacole Development Awards, which should benefit the health needs of people from black and minority ethnic communities, are worth up to £6,250 each.

The closing date is 7 May 2008, and application forms with further details are available to download from: www.rcn.org.uk/scholarshipsaward

Time for change

Martin Bollard, chair of the meeting's working party, commented: "Despite more than thirty years of legislation, policy guidance and central directives, it is a scandal that people with learning disabilities are so often treated so shamefully by our health care system.

"Why is it that all the energy, time, effort, planning and countless meetings on this subject hasn't translated into efficient joint planning and commissioning of their health needs? We have been haemorrhaging public money and getting nowhere. And now things have to change."

Those who attended the meeting heard how professional indifference had led to unnecessary deaths – as highlighted in both the above reports.

Becoming accountable

Jim Blair, President of the Royal Society of Medicine's Intellectual Disability Forum, said: "There is a lack of education and training and a lack of accountability and that's why vulnerable people have died. We have seen the same 'institutionalised discrimination' described in the Stephen Lawrence report."

The new working group will meet regularly at the Royal Society of Medicine (RSM). "We want – and demand – better treatment for these users of NHS services, and that means individual accountability of professionals," said Blair. "The RSM and the royal colleges have been around for over 200 years and it's taken us this long to get this far. Let's hope it takes us a fraction of that time to get us working together effectively to improve health care provision to this group."

Further reading

- Disability Rights Commission (2006), *Equal treatment – closing the gap*.
- Mencap (2007) *Death by indifference*, www.mencap.org.uk/deathbyindifference

QUOTES FROM ATTENDEES AT THE DEATH TO INDIFFERENCE MEETING

"I'm fed up of inquiry after inquiry making no difference whatsoever." – attendee with learning disabilities who cares for his brother who also has learning disabilities and a heart condition.

"My daughter was treated as a non-person. She had no name above her bed, no named doctor or named nurse ... she was in hospital for five weeks and lost two stone." – mother of 53-year-old woman with Down's syndrome.

"They say he feels no pain." – mother of 22-year-old son with severe learning disabilities.

What is the group about?

- being action focused
- advise and promote ways of developing practice
- professional reaction to the issues of accountability, training and responsibility among health professionals.

Aims

- access to mainstream health care in an inclusive outcome-focused manner
- maintenance of specialist health services that access and address specific and complex health needs of people with learning disabilities
- challenge professionals to be responsive to the health requirements of people with learning disabilities and those closest to them.

Areas of work to highlight

- responsibility
- accountability
- training
- governance.

Update

The Royal College of Speech and Language Therapists as well as the College of Occupational Therapists have joined the Death to indifference group.

Further, the group is currently working on providing information to guide health practitioners in getting it right for people with learning disabilities.

Learning disability open meeting

The open meeting was created in 2002 for a range of practitioners (covering education, health and social care) to share knowledge and experiences with each other and people with intellectual disabilities and their carers. About 25–45 people regularly attend each of the 5–8 meetings a year. This unique approach to knowledge and skills sharing has led to the development and maintenance of service user, carer and inter-professional partnerships in terms of practice, education and service delivery through altering negative attitudes by breaking down barriers.

The word ‘open’ has come to signify opportunities, partnerships, educating and networking. There have been four evaluations relating to the effectiveness of the meeting and the general feedback is that the meetings have led

to improved relationships by sharing information, developing networks, enhancing leadership, delivering best practice and continuing professional development within all sectors.

The focus on collaborative partnerships related to practice, education and service delivery is enabling members to become more effective leaders, role models and change agents. It is envisaged that this inclusive meeting will be adapted within a variety of health, social and educational settings covering a range of interests and client groups in many countries to improve leadership, practice, education and service delivery.

For more information, contact Jim Blair on email: jblair@hscs.sgul.ac.uk, or on mobile: 07768145283.

Finding caring solutions

‘Parents creating a brighter tomorrow through finding solutions to improve services’ – Jim Blair reports.

LD Caring Solutions was set up in September 2006 to enable parents to share concerns, identify priorities and to form collaborative partnerships with education, health and social care service providers to influence change. It is a supportive environment rather than a support group. The group seeks to drive services forward in partnership with service providers in an action-focused manner. The group, comprising of 12 parents and representing a range of children and adults aged from 3 to 53 with learning disabilities and complex needs, have formulated their governance process and identified key priority areas.

The carers are:

- experts in providing care for people with learning disabilities
- campaigning for better care homes
- highlighting concerns to people involved in strategy development.

They are improving services by:

- meeting with local commissioners
- advising NICE, Nursing and Midwifery Council and the London Network of Learning Disability Nurses

- building partnerships to create solutions
- training the health and social care professionals of tomorrow
- undertaking projects, shaping the future learning from experts and parents as educators supported by Rix Thompson Rathenberg, Wandsworth Teaching Primary Care Trust (PCT), Kingston University and St. George’s University of London, South West London and St. George’s Mental Health Trust
- writing for publication and presenting at conferences.

The group is facilitated by one university lecturer and one director of nursing meeting once a month at St. George’s. By meeting in a ‘neutral’ non-service-based organisation, carers can contribute freely without worrying about whether or not what they say will jeopardise the services they receive.

For more information, contact Jim Blair on email: jblair@hscs.sgul.ac.uk, or on mobile: 07768145283.

Nursing Standard Learning Disability Nursing Award winner

Forum committee member Mandy Dunford reports.

The forum would like to send congratulations to the Nursing Standard Learning Disability Nursing Award nominees Teresa Day, Community Nurse, Isle of Wight Primary Care Trust, for *Understanding the sexual needs of people with learning disabilities*, and Christopher Griffiths, Nurse Consultant, Bro Morgannwg NHS Trust, for *Improving the way people with learning disabilities are treated in hospital*.

And the winner is ... Teresa Day! Judged noted that her project was ‘A very solid project that really stands out from the crowd’. Thanks to Regard Partnership and Choice Support for sponsoring this award.

Start thinking about the 2009 awards – it could be you next year. Keep learning disability nursing on the map!

Did you know you can read this newsletter online?

This and other forum newsletters are available on the RCN website even before they are mailed out to members.

So if you would like to be one of the first to read the next issue log on to **MyRCN** at www.rcn.org.uk/myrcn, or call RCN Direct on **0845 772 6100**, to register your email address and opt in to our email services. You’ll then be sent an email with a link through to the newsletter each time it is published rather than be sent a printed copy.

Help us reduce our carbon footprint and save some trees!

RNLDs – vital advocates

What exactly is the role of the Registered Nurse Learning Disabilities (RNLD) in this modern day of ‘social inclusion’? **KIM THOMAS** offers a nursing student’s perspective.

As a third-year nursing student studying learning disabilities at the University of Glamorgan, I am often asked to discuss the role of the RNLD. This question is often more complex than initially judged – society and the way a person who has a learning disability is viewed is undergoing rapid change, therefore the role of the RNLD should be in direct correlation to this change.

Are the old days behind us?

We often hear about the dark days of institutionalisation, where people who had a learning disability were marginalised by society, banished to the regions of some dark, foreboding mansion house on the outskirts of suburbia. We are told that those days have long gone; society is now ready to understand and embrace such individuals. I wish I could believe this to be true.

It is a fact that enormous strides have been made towards inclusion. However, unfortunately, the marathon has not finished. Just as we turn the bend expecting the downhill homeward run, we see before us as many twists and turns – in fact, the finish line is not even in sight.

Enabling change

Inclusion for a person who has a learning disability must be total; it cannot be a token gesture. Opening the windows to blow away surface dust is not enough – a thorough revamp is necessary to allow for

the creation of a new structure. The role of the RNLD has therefore never been more important than at this particular time in facilitating and enabling the process of total inclusion.

People who have a learning disability may have moved out of the large institutions of the past, the purposive intentional communities have diminished. However, it could be argued that they have been recreated in smaller isolated houses. It is possible that the problems experienced by these individuals have remained the same, however, now it has just been spread around a bit, diluted in society, behind the doors of smaller houses up and down the country.

Improving human rights

The recent paper by the Parliamentary Joint Committee on Human Rights, titled: *A life like any other?* has just been published and discusses the findings of the inquiry into the human rights of adults with learning disabilities. The paper comes to the conclusion that many of the ideals highlighted in *Valuing people* (2001) have not come to fruition, and it stresses that such individuals are still denied many rights that most of us in society take for granted.

People who have a learning disability are often treated in an inhumane way; the need for a specialist advocacy service is therefore paramount and the RNLD has a vital role to play in this advocacy service. The United Nations Declaration of Human

‘Inclusion for a person who has a learning disability must be total; it cannot be a token gesture.’

Rights 1948 stated that everyone has the right to be treated without discrimination on grounds such as race, colour, sex, language, political or other opinion. Today, sixty years on, society still allows such disparagements of justice to occur.

Where does the RNLD fit in?

The role of the RNLD has been called into question – some professionals in society feel that members of social services would be as adequate at the task. I would question this evaluation and feel strongly that to fully understand the complexity of this group of people is an essential prerequisite to becoming their proficient advocate.

The training experienced by the RNLD is by far the most fit for practice for this particular role and should not be phased out or be replaced with a less specific more generic model. I hope to see RNLDs taking up more challenges in their role by becoming nurse practitioners; I believe that their hands-on experience and knowledge is vital to improved quality provision.



This newsletter is published by the Royal College of Nursing,
20 Cavendish Square, London W1G 0RN.

Tel: 0845 772 6100 Website: www.rcn.org.uk

For details of forthcoming
RCNEVENTS go to
www.rcn.org.uk/events