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# Learning Disability Psychiatry

Newsletter of the Faculty of the Psychiatry of Learning Disability

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## Editorial Board

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### *A view from the Chair*

#### *Highs and lows of 2005*

*Professor Gregory O'Brien*



*Professor Gregory O'Brien*

The turn of 2005/2006 has been an interesting time in the national media. All authorities – including the Queen – have been commenting upon the extent to which 2005 was a year of highs and lows; national and international disasters alternating with good news such as major positive

breakthroughs in international initiatives. Writing at the beginning of January 2006, and still in a New Year sort of mood, it is worth considering the highs and lows the last year has brought to us in the faculty and our wider work.

One of the most striking initiatives, and one which I am sure is going to have very far-reaching consequences, is the extent to which the Healthcare Commission has turned its attention towards learning disability. I think there are real possibilities here, for the more the Commission considers our services and the situation of our service users, the more opportunity there is for investment at a time when there are significant concerns that there has been disinvestment in some parts of the country. There are already signs that the Commission is highlighting some problem areas in our services. None the less, some see the Commission's close scrutiny of our services as threatening and I understand why. I am sure most would agree, however, that the Healthcare Commission turning its attention towards learning disability is definitely more of a high than a low.

mentation of new legislation in Scotland over the past year. In England we have been particularly impressed by the spirit of the wording of the new legislation, seeing this is as a high ideal at which to aim. There have also been some 'lows' in the implementation, though, and I do know that there are real challenges here. Certainly, there are lessons to be learned for the rest of the UK as we work on our new legislation.

Many initiatives of the faculty over the past year have definitely been highs:

- We have been making good progress in working in partnership with the British Psychological Society, including a joint report on challenging behaviour – and here Roger Banks' energetic contributions have been pivotal.
- National concern regarding 'out of area' treatments remains high profile – consequently the paper that has just been prepared by John Morgan and his group is going to be of great interest to the faculty and beyond.

- Our increasing partnership with colleagues who work in old age psychiatry is looking very promising; Sab Bhaumik's initiatives here are successfully driving things forward.
- Other strides are being taken with initiatives in the area of liaison psychiatry and substance misuse, where Helen Miller is making a dynamic contribution.
- Shoumitro Deb's work on developing consensus guidelines for drug treatment of behaviour is proving to be very interesting, again, with far-reaching consequences.
- I would particularly like to highlight the progress that has been made in inclusive practice, wherein Ray Jacques is leading a very interesting initiative concerning the involvement of people with learning disabilities in the work of the executive committee.

These are only a few snapshots of some of the work on which the Faculty has been leading, and I am sure that we all agree that these represent a very positive set of initiatives.

I now come to what was, without doubt, the low point of our year – an horrific event that we learned about on the evening of our faculty Spring Meeting. The meeting itself was successful and the subsequent dinner at the College, where we were meeting to celebrate the enormous strides

we are taking in partnership with Mencap and other key participants on behalf of the Mental Health Alliance, was a personal high point. The then President, Mike Shooter, was there, as was Lord Rix and other key participants in the field of mental health law. We were nearing the end of the meal when Sheila Hollins received a 'phone call, with the devastating and tragic news of the attack on her daughter Abigail.

Since that awful time, Abigail has progressed well, for which we have all been gratified and thankful. This has coincided with the commencement of Sheila's period as College President, which itself was a great high for us as a faculty, and was an immense personal triumph for her. Incidentally, earlier last year she had been awarded a special Fellowship by the Psychiatric Association of South Africa in recognition of her contributions there – a mark of the immense esteem in which she is held internationally.

Highs and lows, positive progress and events that make you feel that 'ordinary' everyday happenings are quite extraordinary. So what will 2006 bring? For one thing, there will be a new Chair of the faculty; this letter has been something of a retrospective for myself, which explains the brief overview of faculty progress earlier. Therefore, to close in retrospective mood, I would repeat the sentiment that Mike Shooter made at the end of his closing presidential address in Edinburgh this Summer: 'I wouldn't have missed a minute of it'. ■

## Erratum

In the last edition of the newsletter, Vol. 7 Issue 1 March 2005, authorship of the article 'New SpR post in psychotherapy and learning disability' was erroneously attributed to Georgina McNaughton. This should have been Georgina Parkes. We apologise to the author and our readers for the mistake.

# Does health promotion decrease or exacerbate health inequalities?

## A case for people with learning disabilities

*Natalia Perez Achiaga*

Research evidence on the health of people with learning disabilities (Hollins *et al*, 1998) has shown an increased risk of early death compared with the general population. Mortality rates increase with the severity of mental impairment (Ouellette-Kuntz *et al*, 2005). The distribution for different types of cancer differs from that of the general population, for example people with learning disabilities have proportionally higher rates of gastrointestinal cancer than the general population. The higher risk of tumours of the gastrointestinal tract is reportedly linked to the higher prevalence of treatable but under-treated conditions such as gallstones and oesophageal reflux. The same applies to respiratory diseases, the leading cause of death in this population. Women with learning disabilities are less likely to undergo cervical smear tests and receive invitations to undergo mammography (Djuretic *et al*, 1999) and to engage in breast cancer screening (Pearson *et al*, 1998).

With the move from hospital to community care came warnings by health professionals of 'community chaos' (Aspray *et al*, 1994). Indeed one of the fundamental aspects of living in the community – access to primary care – has not as yet been fully realised. Difficulties encountered include registration with GPs, lack of regular health checks and not receiving any health-promoting intervention in the community. Updated policy guidance was issued to assist primary care providers during this crucial period of change until the much-awaited White Paper for England, *Valuing People* (Department of Health, 2001). This set out some key actions in an attempt to deal with obvious barriers to health access; for instance, 'registration with a GP' and 'identification of all people with learning disabilities registered with the practice', by June 2004.

A survey of 215 GPs found that 75% had received no training to help them treat people with learning disabilities. Furthermore, 90% felt that a patient's learning disability had made it more difficult for them to make a diagnosis, which may translate to a less favourable outcome (Taylor Nelson Sofres, 2004). Treat me Right, a public campaign recently launched by Mencap, aims to achieve better healthcare for this group of patients (Mencap, 2004). The campaign is a direct consequence of the results from a survey of 1000 people with learning disabilities, which highlighted some of the main barriers encountered, including stereotyped personal assumptions and negative attitudes by healthcare

professionals and institutions. The report states that all these obstacles lead to discrimination when people with learning disabilities try to use mainstream services.

*Valuing People* put forward the development and implementation of health action plans and health facilitators to tackle some of these problems. In my view, these new interventions never originated as a part of a clear strategy to influence specific health determinants in this population. Unless outcome is closely monitored and the fulfilment of targets a key priority (with financial and other means for their enforcement) it remains nothing but another declaration of good will. Surprisingly, important 'key actions' proposed in *Valuing People* were merely *recommendations* and not mandatory targets. Reservations were promptly reported by some professionals in the field, who drew attention to the fact that this was not a National Service Framework with accountable targets and clear standards. It has not surprised anybody that recent research into the matter found all essential targets had not yet been achieved. Further guidance on how to meet the targets set in *Valuing People* has been published in more recent documents such as *Access to Health Care for People with Learning Disabilities* (National Coordinating Centre for NHS Service Delivery and Organisation, 2004) and *Tackling Health Inequalities: A Programme for Action* (Department of Health, 2003).

Accountable targets are needed if the government is committed to reducing health inequalities in this already disadvantaged group. Although there have been major improvements on some essential health outcomes for people with learning disabilities, such as an increase in survival rates in relative terms, this increase (life expectancy) is much lower compared with the general population. Generally, health policies intend to deal with health inequalities and try to overcome or reduce differences in population health outcomes. The disparities are usually accounted for by measurable factors of health interventions. A more recent example of this was the introduction of National Service Frameworks to end the so-called postcode lottery in healthcare provision. However, current public health initiatives may widen rather than close the health inequality gap (Cooper *et al*, 2004). In the current model of healthcare for people with learning disabilities, priority is given to the use of mainstream services. The assumption is that through this they will gain better access to health promotion campaigns and that even though the care interventions were primarily designed for the general population they can have a positive impact on the health outcomes in this group. It is possible therefore, if not likely, that the current model of care will exacerbate rather than reduce health inequalities.

What has been your experience? What examples are you aware of that can illustrate either an improvement in or worsening of health inequalities? Please write to the editor to contribute to this debate. ■

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## Useful links

[http://www.intellectualdisability.info/mental\\_phys\\_health/cancer\\_id.htm](http://www.intellectualdisability.info/mental_phys_health/cancer_id.htm)

[http://www.drc-gb.org/newsroom/easyreaddownloads/DLOADevidence\\_FINAL.doc](http://www.drc-gb.org/newsroom/easyreaddownloads/DLOADevidence_FINAL.doc)

## 'Towards equity and access'?

### The best practice guidance from NIMHE and Department of Health on mental health and deafness ignores people with learning disabilities

*Helen Miller & Ken Courtenay, National Deaf Services London UK*

People who experience significant hearing impairments from early in life have a more visual perspective of the world. They have common deficits in spoken language acquisition, and in incidental learning, that impact on intelligence and social behaviour. They prefer visual communication to spoken language.

We often hear people say, 'I have never met a person with a learning disability who uses sign language' (British Sign Language; BSL). In fact, many learning-disabled people with hearing impairment do use sign language. Their language ability varies according to their level of learning disability and exposure to language. Many use a mix of communication systems (BSL, Makaton, etc.). Community learning disability teams, however, at best have few professionals with even rudimentary signing skills; rarely do they have deaf professionals working in their teams and seldom do they know much about 'deaf culture' and how to help deaf people with learning disabilities gain access to it. When did your team last have 'deaf awareness' training? In diagnosing abnormalities in behaviour in deaf people, it is necessary to be confident about normal behaviour in a deaf person. Deaf people with learning disabilities are often cut off from their language, other deaf people and their culture.

Deafness is common in people with learning disabilities: 10% have significant hearing impairment or deafness, a prevalence 100 times that of the general population. This increases to 40% in people with severe learning disabilities (Yeates, 1991). Prevalence among people with autism is increased with mild to moderate hearing impairment in 7.9% and deafness in 3.5% (Rosenhall, 1999). Despite this, people with learning disabilities have difficulty gaining access to audiological services and health services in general (RNID, <http://rnid.org>; Mencap), 30% having never had a hearing assessment (Timehin & Timehin, 2004). Emotional and behavioural problems are common in deaf people with learning disabilities (62% of deaf adults in the community; Timehin & Timehin, 2004), with an increased prevalence of psychosis in people with congenital rubella. Additional disabilities, particularly visual problems, are also common.

In 2000 an independent inquiry report (Merton Sutton and Wandsworth Health Authority & Lambeth Southwark and Lewisham Health Authority, 2000) stated that there was no

national strategy in the UK for the mental health of deaf people. It recommended that their needs be given higher priority. The Department of Health produced *Sign of the Times* in 2002, a consultation document on modernising mental health services for people who are deaf. It used Deaf with a capital 'D' to emphasise its focus on the pre-verbally deaf and thus excluded the population of people who have hearing impairment but who may have similar issues to deaf people.

The consultation group for *Sign of the Times* expressed concern that in mentioning deafness and learning disability together, the 'disability' in deafness is played down and thus the importance of deafness in people with learning disabilities is under-reported.

It mentioned, in parts I and II, developmental delays as a possible pathway to mental ill health and that learning 'difficulties' may be comorbid with deafness, 'though this may be more a feature of limited educational opportunity – a case of being disabled by the learning environment rather than being learning disabled'.

In part III the seven standards in the National Service Framework were used as a template for deaf people of all ages as a way of looking systematically at their needs and how to meet them. In 'Standard 1: Mental Health Promotion', there is mention of a need for multi-agency approaches with deaf children to counteract 'delays in some cognitive and social-cognitive processes'; there is no further mention of people with learning disabilities.

People with learning disabilities who are deaf or have hearing impairment often have multiple complex needs and local services may struggle to meet them. *Valuing People* does not offer guidance, failing to mention them except to suggest that health action plans should include details of the need for health intervention, including for hearing, and recommendations for communication policies, the emphasis being on the most severely disabled. It fails to acknowledge how complex the communication needs can be of an adult who is pre-verbally deaf or has hearing impairment regardless of their level of learning disability, especially if they have additional problems such as visual impairments or mental illness. There is no acknowledgement of the cultural differences between people who are pre-verbally deaf and the general population, or of the right of an adult with learning disability who is deaf to participate in deaf culture.

Our Faculty responded to *Sign of the Times*, emphasising the existence of the deaf population with learning disabilities and the need for 'specialist responses' to meet their 'complex needs'.

In 2005 the Department of Health and NIMHE published 'best practice guidance' in mental health and deafness,

*Towards Equity and Access*. It purports to 'show how mental health services for deaf people can be improved' using the template of the NSF for mental health and to focus on the needs of a group of people whose 'access to services have, for too long, been fraught with difficulty'. It does not mention people with learning disabilities who are deaf and thus fails in its purpose. Meanwhile people with learning disabilities who are deaf or have hearing impairment, and the services trying to meet their needs, are left without guidance while changes in commissioning arrangements have made it difficult for them to gain access to highly specialist mental health services for deaf people.

The UK Council on Deafness, the umbrella organisation for deaf charities, is collecting information on instances where deaf people have difficulty in gaining access to a service (e-mail [j.isaac@deafcouncil.org.uk](mailto:j.isaac@deafcouncil.org.uk)). The Disability Rights Commission is conducting a formal investigation into the physical health inequalities experienced by people with mental health problems and/or learning disabilities in England and Wales (contact Joanna Owen at [healthfi@drc-gb.org](mailto:healthfi@drc-gb.org)). If you are interested in being part of a College Special Interest Group on mental health and deafness contact Helen Miller ([helen.miller@swlstg-tr.nhs.uk](mailto:helen.miller@swlstg-tr.nhs.uk)). ■

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## Useful links

<http://www.dh.gov.uk/assetRoot/04/10/40/05/>

# Changes to the unfitness to plead legislation 2004

*Caryl Morgan & Harm Boer*

Over the last decade there has been a change in society's attitude to individuals who are mentally unwell and offend. In part this has been influenced by high-profile incidents involving the mentally unwell, such as the Zito and Clunis enquiries. In response to increasing public concern, the government has developed legislation in order to respond to, and deal with, the perceived risk from mentally disordered offenders.

One development is the Amendments to the Criminal Procedure Insanity Act (CPI) 1964. This act was amended in 2004, in the Domestic Violence Crime and Victims Act, enacted 1 April 2005.

Changes in the way that mentally disordered offenders are dealt with are important to professionals working with people with learning disabilities, as more individuals with mild learning disability are thought to have culpability and are appearing before the courts. Prosecution of suspected offenders is, at times, considered helpful by healthcare professionals in that it can help in negating offending-related cognitive distortions and giving motivation to change offending behaviour, two key cornerstones in treatment success in the field of forensic learning disability.

The criteria set forward in the Pritchard case in 1836 are still relied upon to define the very subjective areas of ability that an individual requires in order to have an equitable trial (see Fig. 1).

The original 1964 CPI act was amended in 1991. The major amendments were the introduction of a trial of the facts and the removal of mandatory hospital disposal (equivalent to a hospital order with a restriction order). This gave the court the discretion of a hospital disposal (with or without a restriction order), a supervision order or an absolute

discharge. Previously CPI disposals were not commonly sought owing to the inevitable hospital order with restriction without a trial of the facts. Since 1991 there has been a perceived increase in cases dealt with under the CPI, although no figures are available.

What are the new 2004 changes? From a clinical point of view the major change is in the powers of disposal. In the original act the judge had absolute power of disposal without seeking medical opinion. Technically this was the Home Secretary's power of direction but the Home Office rarely intervened against the judge's advice. In the amended Act the procedure is similar to the requirements of a hospital order under section 37 of the Mental Health Act 1983, in that it needs two medical recommendations that admission is appropriate. The judge, however, retains the right to direct the managers to admit the individual without confirmation of availability of a placement.

From a legal point of view the major change in the 2004 act is that it removes the need for a jury trial of fitness to plead if this arises before arraignment (point of entering a plea) and the issue is now tried by a judge. If a defendant is found unfit to plead, a trial of the facts is then heard by the jury. This negates the previous need to have two juries, one to hear the issue of fitness to plead and one to hear the issue of the facts.

When the fitness to plead issue arises during the trial the current law remains in place in that the one jury will hear both issues. If fitness to plead is questioned by the defence or judge, the basis of the decision is on 'balance of probabilities' but if questioned by the prosecution it is decided on the basis of 'beyond reasonable doubt', an issue that needs to be borne in mind when preparing reports.

During discussions in parliament on the new amendments, it was stated by Vera Baird MP QC that there was an agreement level of 90% between the two medical opinions on a person's unfitness to plead, only 10% of cases having medical disagreement.

The Supervision Order powers of the 1991 amendments have also been changed. Supervision orders will now be possible in those with physical as well as mental disorders although, as before, there remains no compulsion or sanctions on an individual complying with supervision, an order remaining effectively a framework for treatment only. The legislation does not, however, state who will be the 'supervising officer or person'.

## **Pritchard case – R. v Pritchard (1836) 7 C & P 303**

- Capacity to plead
- Ability to follow the trial
- Ability to challenge a juror
- Ability to question the evidence
- Ability to instruct counsel

*Fig 1.*

Overall it appears that in the new amendments the government has separated the issues of responsibility and treatability from the previous legislation. If someone does not have any criminal responsibility then it is not equitable that they should be punished by receiving a sentence, so an alternative to a criminal justice disposal needs to exist. If the individual is medically treatable they should receive treatment in order to keep the public safe. This will still leave the problem of those who are not responsible for their actions but are not medically treatable, which the government still needs to solve. ■

## Useful links

<http://www.opsi.gov.uk>

## From the Editorial Board

Articles and correspondence are more than welcomed!

We would greatly appreciate feedback on the newsletter contents and format.

Contributions should be submitted in a recognisable Windows format by email or on a 3.5" disk. The editors reserve the right to edit contributions as deemed necessary. Please limit contributions to a maximum of 700 words unless agreed beforehand. We would be pleased to receive relevant digital photographs, please contact the editor for details of format etc.

Opinions expressed in the newsletter are those of the authors and not of the College, unless expressly stated. Each article remains the copyright of its author but the College reserves the right to reproduce the article on the faculty website pages.

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## PMETB

### Coming to a training scheme near you!

*Jennifer Dolman*

We have eventually emerged on the far side of the Christmas and New Year season with the mandatory accompaniment of big-budget blockbuster films in the cinema, on the TV and in your DVD. And the relevance to PMETB? Well, like all well-hyped movies, PMETB:

- seemed to have been talked about forever but nobody actually knew what it was really about (including those who were lucky enough to have had a sneak preview)
- had a release date that nobody was sure they were going to make – but did
- once seen is a big disappointment with glaring gaps in the storyline.

Unlike the movies, the PMETB budget is not being wasted on pointless special effects since, with a budget that has been cut by 97% from the original amount allocated, there isn't money available for the essential scenery let alone special effects!

PMETB stands for the Postgraduate Medical Education and Training Board and it 'went live' on 30 September 2005. It will be the body responsible for the training of all doctors, in all Colleges, except for Year 1 of the foundation programme (see below), which will remain the responsibility of the GMC. The individual Colleges found it very difficult to finalise the details of their new training schemes because PMETB was constantly moving the goalposts. The RCPsych website should be consulted for the most up-to-date information.

PMETB is responsible for the regulation of the following major changes in the structure and process of postgraduate medical training.

### 1. Two-year foundation programme

Rather than the usual PRHO year there will be six 4-month placements, enabling trainees to experience more specialties at the beginning of their professional career.



During the foundation programme, trainees will undergo four core assessments by their educational supervisor, all workplace-based.

### **I. Mini-CEX (clinical examination)**

Observation of the trainee carrying out four simple procedures, e.g. consent for ECT, giving feedback to a family.

### **II. Case-based discussion (CbD)**

Structured questioning of a trainee about their case notes, chosen at random by the supervisor. The aim of this is to understand a trainee's decision-making process.

### **III. Mini-PAT (multi-source feedback)**

At least three people will be asked for feedback on the trainee using a structured interview.

### **IV. Direct observation (DOPS)**

The supervisor will sit in on a trainee's clinic.

## **2. Trainees' portfolio**

From Foundation Year 2, trainees will establish and maintain a portfolio, which will form the basis of their exit assessment (equivalent to a very rigorous final RITA). The portfolio, which will be regularly reviewed by the educational supervisor, will determine the trainee's educational needs and training placements.

## **3. Specialist training years**

From Year 3 of a doctor's career they will enter specialist training, consisting of a 'single training grade', i.e. no separate SHO and SpR schemes, so once in specialist training the next interview will be for a consultant post. Entry criteria are up to individual Colleges. Those being considered by the RCPsych are communication skills and previous interest in psychiatry, such as electives or research. Duration of training is not fixed for any specialty and will depend on the rate at which each individual doctor can demonstrate competencies, being about 6 years for psychiatry. Essentially Years 1–3 will be the equivalent of current SHO training and Year's 4–6 equivalent to that of current SpRs. It is envisaged that during Years 1–3, placements will be 3–4 months in length instead of the usual 6, enabling trainees to gain greater experience. In addition, as the trainee will be in the same training scheme for the entire time, the RCPsych is encouraging schemes to give trainees opportunities to follow-up patients for the full 6 years, e.g. psychotherapy, rehabilitation.

Assessments during specialist training in psychiatry have not been finalised. Current ideas are:

- a. at the end of Year 1: a knowledge-based assessment;
- b. at the end of Year 3: OSCEs;

- c. as already mentioned, a rigorous RITA with portfolio at the end of Year 6, which may lead to Fellowship of the RCPsych.

For doctors undecided on their future career at the end of the foundation programme there is the option of a generic Year 1 in specialist training. However, Colleges have been grouped together in four or five specialties and so the generic training is only limited to that group; psychiatry is grouped with general practice, paediatrics and obstetrics and gynaecology. The trainee would spend a year between these four specialties, at the end of which they could choose which of these four they wished to pursue.

There is no guidance for individuals or Colleges about trainees who wish to move to a different specialty after entering Year 1 of specialist training, or on where PLAB trainees would enter the system. As duration of training is not fixed, flexible trainees will no longer have to do the equivalent time to a full-time trainee, instead moving through training as their educational needs dictate and as they develop the appropriate competencies.

## **5. CCT**

All hospital doctors and general practitioners will now obtain a CCT. The number of different psychiatry CCTs is currently six (child and adolescent, forensic, general adult, learning disability and psychotherapy) but the College may rethink this in the future. If a doctor wishes to 'super-specialise', the extra training will need to be agreed between the doctor, trust and deanery on appointment as a consultant.

## **6. Scheme approval visits**

These will change substantially from March 2006; PMETB will assume responsibility for approval visits. The visits will be deanery-wide and cross-specialty, rather than visits to individual schemes and individual specialties as occurs at present. In addition, they will include users and carers.

## **7. Time scale and crossover**

The foundation programme began in August 2005. The first cohort to enter specialist training will do so in August 2007. There has been much discussion about time-scale and crossover, e.g. people who have MRCPsych at the time of specialty training coming in are expected to be slotted in at one of the higher levels of specialty training. Watch for the Dean's newsletter on the RCPsych website for the next production – 'PMETB – the sequel'. ■

## **Useful links**

- <http://www.rcpsych.ac.uk/traindev/postgrad/index.htm>  
<http://www.pmetb.org.uk>



## Involving carers in the training of psychiatrists

*Helen Miller & Roger Banks*

The Royal College of Psychiatrists together with the Princess Royal Trust for Carers, ran the highly successful 'Partners in Care' campaign that was launched in January 2004. Its aim was to highlight the problems faced by carers of all ages of people with different mental health problems and learning disabilities and to encourage true partnerships between carers, patients and professionals. The involvement of carers in the training of psychiatrists has been one of the significant outcomes of this campaign and one that the current President is keen to promote. The Royal College of Psychiatrists made this a mandatory part of training from June 2005 and it is likely to be a requirement of PMETB. On her first attendance in her new Presidential role at the faculty executive meeting in September 2005, Sheila Hollins asked for examples of innovative ways in which carers were being involved in training in the psychiatry of learning disability. Executive member Dr Helen Miller, carried out a brief survey of faculty members asking both for models of good practice and for possible stumbling blocks to progress.

### The current picture

In general, involving carers in training still seems to be at a discussion stage. Learning disability psychiatrists are thinking through how best to implement this with their learning disability colleagues and more widely with other psychiatric specialties across their trusts. Responses from retired learning disability psychiatrists remind us that our specialty has a long history of involving users and carers in training. This has been achieved through family therapy work, work within the multidisciplinary team, networking with carers organisations and organising training sessions for carers. Learning disability training has always included the development of skills in balancing an understanding of the carer's perspective with still allowing the user space and autonomy.

Currently there is some user and carer involvement in under- and postgraduate teaching programmes. This may be through users or carers leading sessions or through the use of video material. Interestingly, respondents were generally unsure if video work constituted 'involvement' but reported that users and carers enjoyed making the videos that were used. Most programmes encourage medical students to visit carers at home and some use training psychiatrists to facilitate this, ensuring that they also learn from the

undergraduates' experiences. Most postgraduate psychiatrists will visit carers at home as part of their clinical work but will not formally record or recognise this as a teaching opportunity. In general, people feel that they could be doing more to achieve routine and systematic carer involvement in teaching.

### Problems and obstacles

Not surprisingly, the lack of funding to cover payment for carers' time and travel costs, and lack of people and time to organise the initiative, were prominent. Some respondents also said that their training programmes were already full and it would be difficult to fit more in. People felt there was a need for clear clinical and training objectives for carer involvement rather than simply ticking off a 'PC' item on a checklist! Interestingly, concerns were raised about the role of the facilitator and how they could effectively facilitate training sessions without 'taking over'.

### Positive practice ideas

- Two-year project established with local carers' centre. The manager and a trained carer visit once a term to go through the Princess Royal Training Pack.
- Service-user groups present at academic meetings, with facilitation by the speech and language therapist who runs the group.
- Trainees are encouraged to attend meetings organised by support groups, e.g. Down's Syndrome, Mencap, National Autistic Society.
- Trained carers present at undergraduate and post-graduate academic meetings: in this case carers are from the Scottish Consortium for Learning Disabilities.
- Users and carers form part of hospital inspection visits (NHSQIS) in Scotland.
- Primary Care Division NHS Greater Glasgow has provided a grant to run training events for a group of service users and healthcare professionals about working together to deliver learning opportunities and training in learning disabilities.
- Trainee psychiatrists (SPRs and SHOs) are involved in organising undergraduate carers' visits.
- Carers making videotaped interviews to use in training.
- Involving users and carers in all clinical teaching sessions in academic programme – get their feedback and allow them to participate in question and answer session afterwards.
- Read *A New Kind of Trainer* (RCPsych; see back page) and the *Partners in Care Training Resource* (RCPsych; see [http://www.rcpsych.ac.uk/publications/gaskell/128\\_4.htm](http://www.rcpsych.ac.uk/publications/gaskell/128_4.htm)).

## Suggestions for the future

- Carer involvement in learning disability faculty meetings – initially a workshop at a faculty meeting could be set up, inviting some of the people who are involved in the above initiatives.
- A regular slot in our newsletter for positive practice ideas – regions could be invited on a rotating basis to say what they are doing.

Please send any comments or ideas to Dr Helen Miller (helen.miller@swlstg-tr.nhs.uk) or to the faculty Executive (c/o roger.banks@cd-tr.wales.nhs.uk).

### Thanks to:

Barbara Easby, Elspeth McCue, Carolyn Greenwood, Reena Sungum-Paliwal, Sunil Manawadu, Gertrude Barton, Pauline Waters (nee Stephenson), Maria McGinnity, Harm Boer, Sean Gravestock, Caroline Marriott, Satheesh Gangadharan, Jo Jones, Susan Miller, Craig Melville, Peter Cutajar, Jane McCarthy, Ken Checinski (Addictions), Angela Hassiotis, Margaret Graham, Ian Hall. ■

## OLDER PEOPLE WITH LEARNING DISABILITIES

**Thursday 23 March 2006**  
**The TechnoCentre, Coventry**

### **Speakers include:**

Professor Matthew P. Janicki  
Professor Sally-Ann Cooper  
Dr Vee Prasher  
Dr Andre Strydom  
Dr Angela Hassiotis

This conference has been organised by Coventry Teaching Primary Care Trust's Services for people with Learning Disabilities and aims to highlight the needs of older people with learning disabilities. Population size, population projections, mental and physical health needs, effective service models and possible solutions will be discussed.

This conference is aimed at:

- Learning Disability care professionals
- Primary care professionals
- Commissioners and managers of services
- Professional staff in learning disability, mental health and primary care services
- Strategic Health Authority representatives
- Academic staff

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Following the College's successful 'Partners in Care' campaign, the faculty continues to look at ways in which we develop collaborative working partnerships with families and carers. This article, submitted by Dr Maurice Brook, a member of the College's Special Committee of Patients and Carers, is the first in a series of articles addressing the family and carer perspective. I hope that it will stimulate readers to suggest or submit articles or letters in response; the views of Faculty members who are also carers would be most welcome. (Ed.)

## Half a century of caring and campaigning

*Dr Maurice Brook*

From our son Andrew's difficult breech birth in 1952 onwards, he developed much more slowly than did his twin sister, or his brother, 2 years older. As young parents, we began tentatively to question professional reassurances that our expressed anxieties were unfounded. Eventually, at out-patients, with three little ones in tow, my wife was told by a paediatrician, 'Well mother, you must understand that this child will never be more than a pet around the house.' Sadly, families can still experience similar insensitivity.

Support was absent until a health visitor suggested placement in a local day nursery when 4 years old. This welcome relief was short-lived; Andrew was too disruptive and unmanageable. In the head's opinion, no family should have been expected to cope with this alone.

Andrew's demands certainly dominated our lives; his brother and sister were suffering in all kinds of ways – he would nip and bite and pull hair, jealous of anyone else getting our attention. We saw that family survival depended on Andrew's removal; how and where we knew not. We campaigned with anyone likely to have influence or authority and in response the County Medical Officer of Health offered a place, only a few miles away, in a small hospital for 'mentally defective children' in an elegant country house with large grounds.

The admitting officer was unsympathetic to our insistence that we were not rejecting Andrew but seeking a workable, although difficult, compromise in still wanting him to be part of the family through, for example, having weekends at home. The professional staff were unsympathetic, implying that we should leave Andrew to them and that our actions were not in his best interest. We persisted in our view and grew confident that our policy was right and that professionals were wrong. Abandonment of some mentally handicapped

people admitted to long-stay hospitals arose from families accepting the professional view of the time.

Around 1954 we learned of Judy Fryd, a mother who had recently created the National Society for Backward Children, which became The National Society for Mentally Handicapped Children, now Royal Mencap. We helped to develop a local Mencap society and I became chairman. It started one of the first Gateway social clubs in the country and subsequently a day 'occupation' centre for children, then classified 'ineducable' and excluded from the education system. The authorities said there were few such children in the area, yet the centre was quickly oversubscribed and a year later we publicly shamed the local authority into assuming responsibility by threatening to close it.

The 1970 Education Act gave education authorities responsibility for those children previously classified as 'ineducable'. Generally, families have benefited, most problems now occurring at the stage of transition from school and beyond, although the fetish for mainstream integration is harmful to some severely handicapped children.

For years we have been subjected to waves of ideologies, promoting fine-sounding but inadequately tested policies with missionary zeal, mainly through social services: normalisation, integration, community care, person-centred planning. Objectively, the quality of life of many people with mental handicap has scarcely improved, particularly those with severe and profound handicap.

The results of studies by the Medical Research Council (Wing, 1990) and the London School of Economics (Korman & Glennerster, 1990) on the closure of Darenth Park Hospital have been disregarded. Approximately one-third of residents had a better quality of life when they moved from hospital to community provision. For another one-third no measurable difference was found, whereas the remainder had a lower quality of life.

The National Society for Children and Adults with Learning Disabilities and their Families (RESCARE) was founded in 1984 by a parent, Richard Jackson MBE, and is largely run by unpaid family volunteers who advise and support other families. Parliamentary liaison and lobbying have been used to press the case for family choice, based on surveys of family wishes. A survey of over 2000 families in 1994/5 showed that half wanted access to village-style residential communities. A quarter of families whose relative was already living in conventional, ordinary street, community care felt that a village would be a better place for them (Cox & Pearson, 1995; Brook, 2000).

Through RESCARE, my knowledge of family stress has increased. Twice, I have met adults, with normal mental

capacity, who had been placed in care as children because their parents concluded that a severely mentally handicapped sibling demanded full parental attention. There are several examples of parents killing a severely handicapped son or daughter, two sons in one instance, after years of official indifference to their plight. Less extreme stressful experiences of some families have been recorded (Jackson, 1996).

*Valuing People* recognised family aspirations; its underlying message was 'Authorities must promote choice not frustrate it'. I believe that families generally are experiencing increasing frustration from decreasing services despite promises of better things to come. For some individuals who are most difficult to manage, admission to acute psychiatric wards occupied by drug misusers or commitment to prison is a consequence of inappropriate placement in community housing, usually against family wishes.

As parents in our eighties, our inability to make arrangements for our son that we believe will ensure his satisfactory lifelong care casts a dark shadow over our lives and we find the need to go on campaigning exhausting and dispiriting. Our experience, shared by others, has destroyed our trust in statutory authorities and their manipulation and misrepresentation of facts.

Despite *Valuing People*, choice in most areas has become more limited and many initiatives have only short-term funding. We feel sad that The Royal College of Psychiatrists now seems to have little influence or, perhaps, interest. The adoption of terminology ('learning disability') set by a government department that is contrary to International Classifications illustrates my point. ■

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John Hillery is President of the Medical Council (the equivalent body in Ireland to the GMC in the UK). His family background is in medicine and politics, his parents are both doctors and his father left general practice to become a minister in the Irish Government and eventually President of Ireland. John trained at the Royal College of Surgeons in Ireland and initially started postgraduate training in general practice before deciding to follow a career in psychiatry.

John first experienced the psychiatry of learning disability during his child and adolescent psychiatry placement and was drawn by the mix of organic psychiatry with psychodynamic and family issues. While training as a senior registrar, John was awarded a scholarship from the Kennedy Foundation, which he used to travel throughout the USA looking at services for people with learning disabilities. Following this, John set up the Centre for Disability Studies at University College Dublin, a multidisciplinary teaching and research centre, in which he has remained closely involved. He is a former member of the Board of IASSID and of MHMR Europe.

He is on the editorial board of the *Journal of Intellectual Disability Research*. A founding member of the Fragile-X Society in Ireland he was responsible for bringing the Society for the Study of Behavioural Phenotypes' annual meeting to Dublin in 1996. He was appointed consultant psychiatrist at Stewart's Hospital and the St John of God services in Dublin, working with people with learning disabilities, in 1998.

Having been first elected to the Medical Council of Ireland in 1999 and having initially served as Vice-President, John was re-elected to the Council and elected President in 2004.

## *In Conversation: Dr John Hillery*

### *President, Irish Medical Council*

*Philip Dodd: Interviewer*

**PD:** What first drew you to the work of the Medical Council?

**JH:** My training in psychiatry and especially in learning disability fostered my interest in medical ethics. I have always been interested in the doctor's role, and training as a psychiatrist in learning disability leads one to question and formulate one's ideas on that. Doctors are privileged in society, and part of that is the profession being allowed to self-regulate. To maintain this privilege the Medical Council has to be at the centre of the evolution of the doctor's role, working with doctors but also working with advocates and families.

**PD:** What are the key challenges facing the Council at this time?

**JH:** As in the UK, self-regulation of the profession is being called into question. It is a watershed time for the profession in Ireland; we must show that self-regulation works to the benefit of patients. The whole way in which the Council functions is currently under review and a new Medical Practitioners Act is currently being developed. The current Act is nearly 30 years old and makes our approach to patients and doctors rigid, legalistic and reactive. We have been developing systems to change and advocating for the legislative power to implement them.

**PD:** How will this work?

**JH:** Up to now, the profession has been poor at dealing with sick or under-performing doctors; we tend to protect patients but not confront colleagues. In a few high-profile cases where a doctor's practice caused harm to patients, the Council hasn't been able to get involved until, what has been perceived as, a late stage. Questions have been asked about the Council's actions but also about the lack of action by the profession as a whole, who seemed to stand idly by while patients suffered. Patients feel that their rights aren't being defended by the current system. The other side of this coin is that doctors in such cases are only being dealt with when it is too late for remediation.

In the new proposed structures, we will be looking to reach out to doctors, trainees and medical students. We will be establishing competence assurance structures that will

require fully trained doctors in independent practice to demonstrate that they are maintaining their competence on a regular basis. Doctors who give cause for concern will be subject to more intensive and intrusive review. This will promote competence and allow for remediation if doctors are falling behind. We also aim to build on our current voluntary health procedures to promote health in students, trainees and fully trained doctors and to support those who have problems. All these will be underpinned by the core value of patient safety.

**PD:** What are the key components of the competence assurance structures?

**JH:** We first have to change the mindset of doctors. We must take responsibility for ourselves and for colleagues who may be in danger of falling behind. This should be part of what we are as individual practitioners but must be encouraged by the regulator having a structure of competence review. In Ireland, we already have a process of CPD-recording in place, although this is not mandatory. In addition, we need to set up structured audit work for all doctors to examine their practice, augmented by a process of regular peer review. In cases where there is cause for concern, more intrusive measures are necessary. How an individual's clinical performance is examined is open to debate. One model we are looking at is a 360-degree process where an individual's practice is examined from many different perspectives. The way in which a doctor is chosen for examination may be at random, or may be in response to public or professional queries of practice. We need a new Medical Practitioners Act to make all of this legally possible.

**PD:** Will there be changes in regulation for doctors in training?

**JH:** We are considering setting up a register for medical students, which will define certain rights and responsibilities. Despite their access to patients they are not seen as different from other students, and are particularly vulnerable if they become sick themselves. For trainees we have emphasised the need to protect educational experience from service demands. We will be starting a process of accrediting training bodies using the criteria of the World Federation on Medical Education. Registration as a trainee will only apply to properly formulated training posts; the days of young doctors working in educationally poor, service-heavy posts must end.

**PD:** Are there any particular challenges regarding competence assurance for psychiatrists working with people with learning disabilities?

**JH:** Like all specialist doctors, trying to establish a peer group when the numbers of colleagues are low and geographically dispersed can be very challenging. People need to be very innovative, using video-conferencing, etc.

More challenging is the fact that we all work in different clinical settings – some psychiatrists working in older style institutions, others working in less restrictive community settings. It can be difficult to set standards of care across these different service types. As a specialty we need to continue to delineate the skills and knowledge required of us.

**PD:** How can the psychiatry of learning disability respond to these difficulties?

**JH:** Ideally by continuing to develop along the lines of general adult psychiatry, with a continuum of treatment options – in-patient/day hospital places, community services, assertive outreach teams, etc. This remains uneven in the Republic of Ireland. However, I believe that the work done by the trainers through the Irish Psychiatric Training Committee on training needs, and by the Learning Disability Faculty of the Irish College in service planning and CPD provision, will change this. Such development can only improve quality and minimise polarisation in clinical practice, so improving standards for patients.

**PD:** How do you divide up your working week?

**JH:** I work at least half my week in clinical practice; I am grateful for the support of my colleagues when they are increasingly busy themselves. I think it is very important for doctors in my position to do this, otherwise we can be perceived as being out of touch with the pressures of daily clinical practice. The rest of the week is very varied and includes committees and meetings with stakeholders. One has to be available to members of the profession and the public and interaction with the media is an important part of this. I find face-to-face meetings with representatives of the public or the profession challenging but productive. If we are to continue to self-regulate then we must be seen to be putting patients first, but the Council must also be seen by the profession as fair and not seeking to victimise doctors. We are ensuring that doctors are fit to practise and I believe that this can be done in a supportive way while reassuring the public and ensuring patient safety. ■

## Useful links

<http://www.medicalcouncil.ie>

# The Evidence-Based Practice Group

## *Shoumitro Deb*

This faculty working group is involved in the development of two major national projects: 'The guideline for the use of drugs for the management of behaviour disorders among adults who have an intellectual disability' (known as the 'DATABID' project); and 'A guide to the services for adolescents and young adults aged 14–24 years who have learning disabilities and mental health problems including behaviour disorders/challenging behaviour' (known as the 'PYrAMID' project).

## The DATABID project

The first draft for consultation was circulated to all members of the Learning Disability faculty for their comments along with a questionnaire in order to gather consensus on the use of drugs. We also propose to carry out a preliminary multicentre audit to gather evidence on current practice. We hope to publish three versions of the guideline in 2006: a quick-reference guide, a full version and one for service users. We also hope to disseminate the findings of the project by holding road shows during 2006 in six major UK cities.

## The PYrAMID study

This has included a series of stakeholder focus groups including professionals, service-providers and commissioners, carers, and a combined group. Analysis of focus group data, along with evidence gathered from the literature and other sources, helped the guideline development group to define its scope (see below). The scope will provide the framework on which to build the guideline. The work is progressing well and we hope to produce a draft guide within the next few months for wider consultation. The plan is to produce three versions of the guideline in 2006. The project manager will also gather evidence via telephone interviews with partnership board members from various parts of the country and through a literature review.

## Scope

### Definition of the population

Young adults aged 14–24 years who have intellectual disabilities and mental health problems including behaviour disorders, challenging behaviour and autism spectrum disorders.

## Areas for guideline development

### Planning at the local level

- a. Define 'local level'.
- b. Define the organisations involved.
- c. Define the 'population' for which planning is needed.
- d. Describe the mechanism for planning (assessment of local population needs; resource planning; time scale for planning).
- e. Define the geographical boundaries among organisations.
- f. Define the functional boundaries among the organisations (roles, responsibilities, accountabilities, legal positions of the organisations).
- g. Relationship with other strategies and protocol (national and local) (e.g. *Valuing People*, NSF, care pathway, etc.).
- h. How and which organisation(s) take(s) a lead in local planning.
- i. How to facilitate joint-planning (e.g. understanding of different rules and culture within different organisations).
- j. How to use the epidemiological data (e.g. who needs to know and what is done with the data).
- k. Implementation of the planning.
- l. Build up relationship between commissioners and providers (e.g. fact-finding away days, training).
- m. Quality control, monitoring, audit, performance indicators, etc.
- n. Training issues.

### Planning at the person level

- a. Roles, responsibilities, accountability of the agencies.
- b. Roles, responsibilities, accountabilities of the professions in co-ordinating care plans.
- c. Facilitation of joint-working.
- d. Assessments:
  - i. Areas to cover.
  - ii. Time frame.
  - iii. Professional involved.
  - iv. The process involved.
  - v. Existing tools/checklists.
  - vi. Standardise assessment procedure/minimise repetition.
  - vii. Community care assessment, carer assessment, continuing care eligibility, etc.
- e. Sharing information (care plan) among professional, service users and carers.
- f. Overlap with other services such as children's service, adult service, legal system, etc.
- g. Existing protocols and check-lists:
  - i. Care pathway (West Midlands).
  - ii. CPA (and children's equivalent of CPA).
  - iii. Green light toolkit.
  - iv. PCP.
  - v. HAP.

- h. Reconcile different work practice involving different agencies and professions.

**Service-user and carer issues:**

- a. Procedure to ensure service-user and carer involvement and influence on the planning of care at pre-transition, transition and post-transition stages.
- Preparation.
  - Information-sharing regarding resources at local and national levels (local and national databases).
  - Information sharing on eligibility criteria, rights and rules and regulations.
  - Reconcile carers' desires with available resources.
- b. Service-user consent and capacity issues.
- Preparation.
  - Information-sharing.
  - User-friendly way of information-sharing.
  - Reconcile service users', carers' and professionals' views on needs and resource planning.

Learning Disability faculty members: Ashok Roy, Sabyasachi Bhaumik, David Clarke, Gill Bell, Jeremy Turk, Jane McCarthy, Shoumitro Deb, Nick Bouras and Greg O'Brien are currently involved in the above projects. Rivashni Soni is the project manager, Laure Lenotre is the systematic reviewer, Louisa Strain is the administrative assistant and Suzanne Robinson is the health economist involved in the DATABID project. Nick Le Mesurier is the project manager for the PYRAMID study. Both projects have drawn representatives from a wide range of stakeholder groups and organisations to constitute their respective guideline development groups and are consulting with a wide range of stakeholder groups and organisations.

The College Occasional Paper *The Evidence Base for the Management of Imminent Violence in Learning Disability Settings* (OP57, March 2005) has now been published and is available through the College website (<http://www.rcpsych.ac.uk/publications/op/pdf/op57.pdf>).

s.deb@bham.ac.uk ■

## Useful links

<http://www.rcpsych.ac.uk/cru/focus/access/access12b.htm>

## News from SpR representatives

### Karen Poon

Jennifer Dolman and I were elected as the joint SpR representatives in November 2004. In addition we volunteered to organise, along with SpRs from Oxfordshire, the 2005 SpR Learning Disability National Conference. Having attended several of the previous conferences and talking with those who did the job before us we have yet to meet someone who has regretted volunteering for the job or to hear any horror stories.

As SpR reps our first task was to update the SpR database. I am sure there are still trainees out there who may not be included on the mailing list and would be grateful if people could let us know their names and contact details if this is the case. Our second task was to organise ourselves to attend meetings of the Executive Committee of the Faculty of the Psychiatry of Learning Disability and Psychiatry of Learning Disability Specialist Advisory Sub-Committee (PLDSAC) held at the College once every few months. We are grateful for receiving full support from our consultants and trust to allow us time to attend meetings. Sharing the job has certainly made it easier to manage the commitments.

With regard to the SpR conference, the biggest challenge was to find a suitable venue with good transport links to ensure our colleagues from other areas such as Ireland and Scotland could attend the meeting. As if that were not difficult enough, we had also to find a date! It may sound easy but with so many conferences and courses being held in the year, we were left with only one month – December. The conference was held on 1 and 2 December at the Cheltenham Park Hotel in Cheltenham. The theme of the conference was 'Physical health needs of people with learning disabilities, including epilepsy'. We worked hard to secure sponsors, invited speakers from various specialties, and lost sleep over the possibility of snow, but from the feedback we received, most people felt the end result was a big success. We will now look forward to next year's conference in Edinburgh.

It has been a great year for us as SpR reps and we have both enjoyed the experience and opportunity to learn about issues on training and the workings of the College. It took a while, however, to grasp the functions of the different committees in order to represent the views and interests of all trainees! Many congratulations to the newly elected representatives, Bala Raju from Leicester and Indermeet Sawhney from Oxford (CTC rep) and we would like to wish them luck for the challenges that lie ahead in the next year.

Karen Poon: [Karen.poon@glo.nhs.uk](mailto:Karen.poon@glo.nhs.uk)  
Jennifer Dolman: [Jennifer.dolman@glos.nhs.uk](mailto:Jennifer.dolman@glos.nhs.uk)  
SpR representatives 2004–2005 ■

## Letters

### From Dr Peter Carpenter

#### Are we a single team or a multi-professional team?

Locally we have been having a campaign of integration of social services and health professionals into a learning difficulties service. As part of this there was a research review that recommended that our teams were not recognised by users as a team in the same way as, say, the members of the A&E team in *Casualty* and recommended more 'badge-ing' of the team and more common purpose and action.

One of the issues that have come up with integration is a desire by the managers (who usually have a mono-professional, social services background) for the team to have common eligibility criteria and priorities. Social workers refer to the health team to assess people to decide whether they are eligible for the social services learning disability team. Similarly the health team are pressurised not to take someone on the cusp of mainstream services if they are seen as being demanding on the social services budget.

I would be interested to hear of other experiences of this. To me, to insist on common eligibility criteria makes a nonsense of the principles of individual needs-led services and mainstreaming where possible. To claim that the boundaries between a person's needs for specialist occupational therapy in assessing the need for bath aids is the same as that for specialist psychology, psychotherapy or for specialist housing makes no sense.

Another issue is that several of the people referred would not get a service from the mainstream mental health services, yet with work from a learning disability service (for example on treating their ADHD and teaching independence skills) could easily become more independent and outgrow the learning disability service. Yet we are being told that if a person is on the books of the social services learning disability team, it is very difficult for them to graduate to mainstream services if they remain vulnerable.

The nonsense of administrators and budget-holders!

I would welcome comments on this:  
Peter.Carpenter@sglos-pct.nhs.uk ■

### From Dr Sam-Best Ewruje

#### What's in a name – 'learning disability' or 'learning enablement' speciality?

Learning disability in the United Kingdom has come a long way, from patients being tagged as 'imbecile', 'idiot', 'mentally handicapped' to, currently, 'learning disabled'. MacFarlane (2005) further stressed the dilemma of learning disability through the ages with the 30,000 case records from the Nazi euthanasia programme and concluded low interest in learning disability. Learning disability is a recognisable diagnosis in the 10th version of the International Classification of Diseases (ICD-10; World Health Organization, 1993), which is the system adopted in British medicine.

For a speciality involved in the prevention, diagnosis, treatment and research in learning disability, it is obvious that its objective is to offer a new lease of life to patients with learning disability, enabling and empowering them to improve their quality of life rather than disable them. So isn't it time for a change in name?

The speciality of learning disability connotes an aim to make worse or maintain the disability of patients that already have learning disability rather than 'abilify' them, to borrow the language of a recently launched antipsychotic drug. This speciality assesses and monitors mental health and psychosocial needs, enables access to generic services and generally rehabilitates and integrates patients into society; it enables, empowers and facilitates patients to set realistic life goals and choices, achieve them and instil hope. What the speciality does is enablement rather than disablement.

Moreover, the concept of a 'learning enablement' department or speciality is in line with the current worldwide trend of de-medicalisation and empowerment. The International Classification of Functioning Disability and Health (ICIDH2; World Health Organization, 1999) has now replaced the International Classification of Impairment, Disability and Handicap (ICIDH1). The concept of 'disability' in the ICIDH1 becomes activity and 'handicap' becomes 'participation' in the new ICIDH2. Nevertheless the basic concept remains the same in the ICIDH2:

- *Disease* is the pathological process leading to impairment, disability/activity and handicap/participation. For example the 'disease' cerebral thrombosis leads to a set of clinical signs and symptoms, i.e. impairment.
- *Impairment* is damage to an organ or part of the body. It relates to clinical features, signs and symptoms. For example blindness, incontinence, swallowing disorders and hemiplegia are impairments.
- *Restricted activity* is a restriction or limitation of *function* as a consequence of the impairment. This includes inability to dress, eat or walk.

- *Restricted participation* is the disadvantage resulting from impairment and/or disability that prevent fulfilment of a social role. This is closely related to *quality of life*.

Health-related quality of life (HRQL) is now a key concern for policy-makers and clinicians though it inevitably differentiates between health-related and other life experiences that make up an individual's perception of quality of life. Patrick & Erickson (1993) have defined HRQL as 'the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy'.

While I agree with the diagnosis of learning disability, a specialty inclined to improving quality of life, promoting and improving mental, psychological and social well-being, not just the absence of learning disability, should not be labelled as such. There is justification for the current label of 'learning disability unit', department or specialty to be renamed with the term 'disability' replaced with 'enablement' or 'enabling' to reflect the current trend of a more humane model and concept of involvement in the prevention, care and rehabilitation of those with the diagnosis of learning disability. ■

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## One man and his dog need support

My name is Dr Geoff Marston, and I work as a consultant psychiatrist for people with learning disabilities in Coventry.

On 23 April, I am running the 2006 Flora London Marathon, to try and raise £3000 for the Down's Syndrome Association. This group does a lot of valuable work for people with Down's syndrome, their relatives, carers and professionals who support them. I would like to give something back in return.

If you would like to sponsor me, you can do this online by visiting: <http://www.justgiving.com/geoffmarston> or by sending a cheque made payable to the 'Down's Syndrome Association', River House, Gulson Hospital, Coventry CV1 2HR.

Thank you for your help and support.

## *Conferences & meetings*

### **Royal College of Psychiatrists' Faculty of the Psychiatry of Learning Disability**

Spring meeting  
Joint meeting with BPS  
26 April 2006  
Regents College  
London  
sfricker@rcpsych.ac.uk

Annual residential meeting  
5–6 October 2006  
Andels Hotel  
Prague  
sfricker@rcpsych.ac.uk

### **Royal College of Psychiatrists**

Tutors' Annual Conference  
10–12 May 2006  
Newcastle upon Tyne  
lbailey@rcpsych.ac.uk

Annual Meeting  
10–13 July 2006  
Scottish Exhibition and Conference Centre  
Glasgow  
mbraithwaite@rcpsych.ac.uk

### **IASSID**

15th SIRGAID Roundtable  
Ageing impacts on health and quality of life among older  
Persons with Developmental Disabilities  
26–29 April 2006  
Toronto  
Canada  
www.iassid.org

### **NADD**

International Congress VI  
15–18 March 2006  
Visions of the Future of our Field; Intellectual Disability and  
Mental Health  
Boston MA  
USA  
www.thenadd.org

## 2006 Burden Research Prize

The Burden Trust invites applications for the 2006 Burden Research Prize. The prize, which consists of an award of £1000, is open to all registered medical practitioners the greater part of whose time is spent working in the field of learning disabilities in the United Kingdom or the Republic of Ireland. The prize is awarded for outstanding research work, which has been published, accepted for publication or presented as a paper to a learned society during the five-year period ending 31 December 2005.

An application form and further details may be obtained from:

Dr Oliver Russell  
Norah Fry Research Centre  
University of Bristol  
3 Priory Road  
Bristol BS8 1TX  
E-mail: o.russell@bris.ac.uk  
Tel: 0117 923 8137

The closing date for submissions is 31 March 2005

# A New Kind of Trainer

## How to Develop the Training Role for People with Learning Disabilities

By Katherine Owen, Gary Butler and Sheila Hollins. Photographs by Paul Stuart.

- A practical guide to getting a job for people with learning disabilities.
- Advice for potential employers at every stage of the employment process is clearly laid out.

[www.rcpsych.ac.uk/trainer](http://www.rcpsych.ac.uk/trainer)



*A New Kind of Trainer* tells the story of a service user through each stage of obtaining his job as a training adviser at a medical school, and shows how he continues to develop in the role. Inspired by the *Books Beyond Words*\* series, this handsome book is liberally illustrated by black and white photographs.

There is an increasing expectation that service users will be involved in preparing health and social care professionals to work with people with learning disabilities, following a recommendation in the *Valuing People* Government White Paper.

This book provides an introduction and guide for both service users and employers. It is based on over a decade of experience of employing users as trainers at St George's Hospital Medical School. It will assist service users in how to find a job and in developing their role as trainers, providing accessible materials which are easy to understand. It will assist employers by providing

good practice guidance together with many pointers about preparing a disability friendly environment that will help them to employ users with learning disabilities as trainers.

**Nov 2004, Paperback, A4 size, 64 pages, ISBN 1 904671 18 7, Price £10.00**  
(RCPsych members' price: £9.00)

### \**Books Beyond Words*

The stories in this series of around 30 books are all told through colourful pictures. They help people with learning difficulties to understand difficult situations and emotions better.

[www.rcpsych.ac.uk/bbw](http://www.rcpsych.ac.uk/bbw)

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