

# Learning Disabilities Psychiatry

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## Message from the Chair

Dr. Mary Lindsey

The Faculty Annual Residential Conference in Cork this year was a great success and many thanks to our hosts in the beautiful country of Ireland. The conference was particularly well attended and the standard of the presentations was very high. The conference dinner was popular and most enjoyable with an entertaining after dinner speech from Dr. Jonty Calvert, Chair of the Irish Division.

At the conference Dr. Leila Cooke gave a moving tribute to Dr. Jose Jancar, who had been so active in the College not only as Chair of the Learning Disability section and as Vice-President but also in many other ways. He will be greatly missed and his Memorial Lecture will be the keynote presentation at future conferences.

Congratulations to the winners of the Alex Shapiro Prize: Dr. Mhairi Duff for her presentation on "Helicobacter Pylori – has the Killer Escaped from the Institutions?" and Dr. Fabian Haut for his poster on "Theory of Mind in Learning Disabled Sex Offenders".

The membership was updated on current events at the Business meeting:

- The College Research Unit is hoping to establish a National Quality Network to facilitate the process of clinical governance in learning disability services. The emphasis will be on involving and supporting members. It will initially focus on in-patient learning disability services. It will be further discussed at the Clinical Audit in Learning Disability Conference in December.
- The response to the survey of learning disability psychiatric

The Newsletter of the Faculty for the Psychiatry of Learning Disability of the Royal College of Psychiatrists

Faculty Chair: Dr. Mary



### Editorial Board:

**Prof. S.A Cooper, Dr. N Simpson**

*We welcome articles or correspondence to inform, debate, and invite a response, for future editions of this bulletin. Their content should be less than 700 words and may be related to clinical care, management, personal opinions, continuing professional development, research, teaching, policy or general information.*

*Please send articles (a hard copy and disc) to Prof. SA. Cooper, Department of Psychological Medicine, University of Glasgow, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH, or e-mail: SACooper@clinmed.gla.ac.uk*

- The response to the survey of learning disability psychiatric services and the mapping exercise has elicited a good response with forms returned from over 120 consultants. This is currently being analysed.
- Dr Maria McGinnity is undertaking a survey in relation to psychotherapy and learning disability and a good response is again very important.
- Dr Shoumi Deb leads the group on evidence-based medicine and a scoping exercise on the use of neuroleptics is planned as well as a national audit of the management of violence in learning disability in-patient settings.
- Dr Meera Roy is taking the lead in setting up a working group to review Council Report 56 "Meeting the Mental Health Needs of people with Mild Learning Disabilities".
- The Faculty is working with the Faculty for Child and Adolescent Psychiatry to address the issue of specialist training in child and adolescent learning disability psychiatry.
- The College website that includes a description of the work of the Faculty is currently being updated and should go live early 2001.

This is a short summary of just some of the recent activity within the Faculty. Please keep in touch with your Regional Representative to ensure that we are aware of your concerns and views and to keep you up to date with any new developments. We are always pleased to hear from you.

Dr. Mary Lindsey,  
Chair of the Faculty for the Psychiatry of Learning Disability, Royal College of Psychiatrists,  
17 Belgrave Square, London SW1X 8PG.

Contents:  
See Back Page

# The Human Rights Act 1998: The Lion That Snored?

Dr. Simon Halstead

The Human Rights Act 1998 (HRA), incorporating the European Convention on Human Rights (ECHR), came into force throughout the UK on 2 October 2000. A flurry of press speculation predicted the far reaching consequences which this legislation would bring in its wake. Three months on it is still early days but the world is still pretty much as it was on 1 October. Even the premature hope that we would no longer have to incriminate ourselves when caught by speed traps and traffic wardens has been overturned. A quick review of the 221 articles on the HRA registered in The Times archive ([www.the-times.co.uk](http://www.the-times.co.uk)) revealed a surprising number of cases, decided or pending, and decisions made by public bodies. These included life sentences ('two strikes' and Hindley), sentencing juveniles (Bulger), confiscations of property, conduct of magistrates' courts, 'mercy killings', planning laws (Sting and the MoD), unlawful DNA samples used as evidence, privacy (Douglas and Zeta-Jones), Rastafarian religious use of cannabis, dress code at work, nationality laws, secure accommodation orders, sex in independent schools and fairness of conviction (Guinness case). The most bizarre (though not to be dismissed lightly) was the decision of a council to ban parents from filming a nativity play. Not a lot on mental health, however.

Personally, I am not surprised to see such a patchwork of apparently unconnected matters. I will try to explain why, by reviewing the history of the legislation and what it actually does in practice.

The Universal Declaration of Human Rights was adopted by the United Nations on 10 December 1948. The timing was no coincidence and it was an attempt to prevent a repetition of the horrors of World War 2. We can look back on the failures of the international community to prevent genocide in Cambodia and Rwanda with some

justified cynicism but, and it is a significant 'but', human rights law is the only source of international law which allows external scrutiny of policies and practices within a sovereign country. Previously, international law had mainly concerned itself with the relations between states.

The Council of Europe (the European Union's forebear, the European Coal and Steel Community, had not yet been formed) approved the European Convention for the Protection of Human Rights and Fundamental Freedoms in Rome on 4 November 1950 in order to incorporate the spirit of the UN declaration within European law. With modifications, reservations (education) and derogations (Prevention of Terrorism Act) it is this convention which has now become part of UK law.

***“The Human Rights Act 1998 came into force throughout the UK on***

### **To whom does the HRA apply?**

The HRA applies to public bodies, including companies, carrying out a public function. Applicants can be individuals or bodies, such as companies. The courts will balance rights of applicant and respondent. An applicant must be a 'victim', but a body such as a trades union can take action on behalf of a victim. A public body such as a council or hospital cannot be a victim. Someone at risk of being directly affected may also be considered a victim.

### **Are Convention rights absolute?**

Some Convention rights such as freedom from torture are absolute. Others, including rights to liberty are 'limited' which means that there are defined exceptions (e.g. warfare). 'Qualified' rights (freedom of religion, expression, education, property) may be subject to domestic law.

### **'Proportionality'**

**'Proportionality'**

Proportionality measures which might infringe Convention rights, such as those to combat crime, must not be arbitrary or unfair.

**'Living instrument'**

This means that neither the domestic courts nor the European Court are bound by precedent in the interpretation of the Convention. In this sense it is unlike English law. An example is the evolving attitude towards sexuality and human relationships.

***“the Convention protects freedoms from... rather***

**'Declaration of incompatibility'**

Judges cannot strike down statute (contrast the USA) but they can overrule regulations. The HRA makes it unlawful for a public authority to act incompatibly with Convention rights. However the public authority will not have acted unlawfully if it could not have acted differently under current statute. The court may issue a '*declaration of incompatibility*' which permits ministers to amend the law by statutory instrument without reference to parliament.

**Which articles are most applicable to mental health?*****Article 3: Prohibition of torture and inhuman and degrading treatment***

There is a debate about whether there needs to be a single, outrageous incident to justify a finding of inhuman or degrading treatment or whether the totality of a person's care can be taken into consideration.

***Article 5: Right to liberty and security***

This is the only article which refers specifically to unsoundness of mind, which must be established by '*objective medical expertise*'. Historically, the European Court has tended to interpret medical treatment liberally to an extent which would shock the UK practitioner. If the UK courts apply a similar standard then there is little hope for major change from the point of view of patients.

Detention in the community, for instance, may not even come within the remit of Article 5. Public protection has also been accepted as grounds for detention of a person of unsound mind in the Scottish courts.

***Article 6: Right to a fair hearing***

This may have a major impact on mental health review tribunals, hospital managers, post-incident enquiries and professional conduct hearings. The restricted rights of detained patients to bring civil litigation against those treating them may also be vulnerable to review.

***Article 8: Right to respect for private and family life***

The European Commission (a lower body, now incorporated into the European Court) has already established that UK mental health law is in contravention to this article in that a patient may not change the nearest relative.

**Areas not covered**

The convention guarantees negative rights, namely the freedom from certain abuses. It does not provide positive rights to services, and those which are covered (such as access to education) are subject to resources. Also not covered are Freedom of information, children's rights, and access to a fair trial in deportation or extradition hearings. Perhaps of greatest significance in the UK, common law rights and responsibilities are outside the convention. Therefore those duties which we carry out under our '*common law duty of care*' (e.g. Bournemouth) may be exempt (as indeed they are from *habeas corpus* and judicial review).

**Recent developments**

The UK government has refused to sign let alone ratify Protocol 12 which establishes a right to equality of treatment (aside from race, sex etc.) under the Convention.

Continued on Page 5

**Conclusions**

Because the Convention protects

## Consultation: Reconfiguration of Trusts - Implications for Learning Disability Services

Dr. Jane McCarthy

A consultation working group took place at the Faculty meeting in Cork in October 2000. The aim of the working group was to seek the opinion of Faculty members on the implications for Learning Disability services with pending changes to the reconfiguration of Trusts throughout the country. The workshop was led by Dr. Jane McCarthy. Consultation is now sought more widely with the Faculty membership via this Bulletin.

### Workshop summary: issues to date

The first part of the workshop was a brief presentation of issues to date relating to the development of Learning Disability services. The group were reminded of both legislation and policy documents over the past 30 years, such as *Better Services for the Mentally Handicapped*, 1971 and *Signposts for Success*, 1998. These documents have directed providers of learning disability services in the following direction:

- Development of community services.
- Improved access to both mainstream and specialist services for people with learning disability.
- Inter-agency working.
- Better support for carers.

The five points of the NHS plan were highlighted i.e. patient access, patient power, partnership, professions and performance.

Consideration was then given to *Facing the Facts - Services for People with Learning Disability*; a survey of 24 Local Authorities across England to inform the development of the *National Strategy for Learning Disability*. The key findings were highlighted under the three P's of:

- Partnership:
  - Work of Community Teams for Learning Disabilities is positive across a range of settings.
  - There are good examples of interagency collaboration in

many Authorities.

- Patient access:
  - For those with complex health needs there is a diversity of services with variation in access.
  - Only a third of Authorities reported adequate access to forensic/mental health services.
  - No agreed eligibility criteria for access to primary, specialist and continuing health care is available.
- Performance:
  - There is little evidence of agreed standards and assessment of performances.

*“There is great diversity in what psychiatrists in this field are*

### Workshop summary: SWOT analyses

The workshop was a mixed group of Consultants, Non-Consultant Career Grades and trainees, all working in different settings. We undertook the brain storming exercise as a whole group. This consisted of a SWOT (strengths, weaknesses, opportunities and threats) analysis looking at different types of Trusts, asking questions about their abilities or not to deliver mental health / specialist care for people with learning disability. We considered four types of Trusts:

- Primary Care Trusts.
- Specialist Learning Disability Trusts.
- Partnership Trusts - Joint Learning Disability and Social Services.
- Partnership Trusts - Joint Learning Disability and Mental Health Services (& Social Services).

It was agreed that primary health care for people with learning disability should be provided by Primary Care Trusts. Members of the group were well informed of the issues but may have little influence on local outcomes. Also there is great diversity in what psychiatrists in this field are providing in the form of secondary and tertiary care, for example to patients with epilepsy, developmental and neuropsychiatric disorders.

in the form of secondary and tertiary care, for example to patients with epilepsy, developmental and neuro-psychiatric disorders.

#### Consultation with the Faculty membership

Following on from this workshop we are consulting all members of the Faculty through the newsletter. Members are asked to send their views to Dr. Jane McCarthy, at the address below or by e-mail. We ask that members put comments under the following headings:

#### *What is your opinion on the reconfiguration*

- Experience of Trust recon-figuration and impact on your local Learning Disability Services in providing:
  - Mental health/specialist health care.
  - Continuing health care.
- Experience of Trust reconfiguration on professional working and development.
- Any other comments.

Your comments will be summarised and be passed on to the Executive Committee of the Faculty for the Psychiatry of Learning Disability.

#### Further Reading

Hassiotis, A., Barron, P., O'Hara J. (2000) Mental Health Services for People with Learning Disabilities. *British Medical Journal*, **321**, 583-584.  
O'Hara, J. (2000) Learning Disabilities Services: Primary Care or Mental Health Trust? *Psychiatric Bulletin*, **24**, 368 – 369.

*A full list of references is available on request from the author.*

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The Martyn Long Centre, 78 Crawley Road, Horsham, West Sussex RH12 4HN.  
E-mail:  
jmccarth@sghms.ac.uk

#### Further reading

- For a full discussion see Gostin L

## The Lion That Snored

### Conclusions

Because the Convention protects 'freedoms from...' rather than 'rights to...', case law must develop according to the mishaps of the minority rather than the needs of the majority. The future will be therefore unpredictable. Mental health legislation must be HRA compliant and this may well bring welcome improvements in the transparency and accountability of the process of detention in hospital, if not in the community.

Governments in power lose the zeal for reform which they display in opposition. Perhaps the refusal to sign Protocol 12 signals the end of this modest revolution. At least the HRA gives the individual mouse the chance to have his roar.

However, whether the Rastafarian, freed from a life sentence, and allowed to smoke cannabis for religious purposes, in his home protected from a compulsory purchase order, will also be able to film his daughter's nativity play, in privacy, remains to be determined.

### Further reading

- For a full discussion see Gostin, L. (2000) *International Journal of Law and Psychiatry*, **23**, 125-159.
- Home Office website, especially [www.homeoffice.gov.uk/hract/hrcgpa.htm](http://www.homeoffice.gov.uk/hract/hrcgpa.htm)
- The Times archive op cit.
- Council of Europe website [www.coe.fr/](http://www.coe.fr/) contains the Convention and all recent cases.

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## Setting the Boundaries: Reforming the Law on Sex Offences

Dr. Leila B. Cooke

A summary report on *Setting the Boundaries*, and recommendations issued by the Home Office, July 2000 were out for consultation until 1 March 2001. This consultation paper represents the completion of the first stage of a review of legislation on sex offences. One of the principles of the proposed legislation is that the law must make special provision for those who are too young or otherwise not able to look after themselves, and offer greater protection to children and vulnerable people. It is therefore recommended that those who cannot understand the nature or potential consequences of sexual activity should not be able to consent to sex, and that a definition of *capacity to consent* be set out in law. It also recommends that sexual activity with a person without capacity to consent should be an offence and the seriousness of this offence should be reflected in the sentence available.

### Proposed definition of capacity to consent

It is recommended that there is a statutory definition of capacity to consent as proposed by the Law Commission:

#### 4.5.8 The Law Commission

### Institute for Psychotherapy and Disability: Call for Members

The newly formed *Institute for Psychotherapy and Disability* is now inviting applications for membership from psychiatrists and other mental health professionals working in learning disability. For further information about the criteria for membership please contact the membership secretary, Nicola Chadd, at Specialist Psychotherapy Service, Woodlands Road Clinic, Middlesbrough TS1 3BL, or E-mail: nicola@chadds.freerve.co.uk

recommends that, for the purpose of any non-consensual sexual offence:

- a person should be regarded as lacking capacity to consent if at the material time:
  - the person is by reason of mental disability unable to make a decision for themselves on the matter in question, or
  - the person is unable to communicate their decision on that matter because they are unconscious or for any other reason.
- a person should be regarded as being unable to make a decision on whether to consent to an act if:
  - he or she is unable to understand the nature and reasonably foreseeable consequences of the act; and the implications of the act and its reasonably foreseeable consequences, or
  - being able so to understand, he or she is nonetheless unable to make a decision.
- mental disability should mean a disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning.

*“A statutory  
definition of  
capacity to  
consent is*

Comments were invited on whether this definition should be adopted and whether it will deliver the necessary balance between protection and the right to a private life.

### Breach of a relationship of care

The other proposal aimed at protecting vulnerable people is that of a new offence of a *breach of a relationship of care*. It recommends a revised offence to prohibit sexual relations between those receiving treatment at hospital (whether as an in-patient or out-patient) or in residential care, and members of staff (whether paid or unpaid) of those establishments. It also recommends a new offence to prohibit sexual relations

establishments. It also recommends a new offence to prohibit sexual relations between those in the community who are in receipt of certain care services and people providing that care; and also a further new offence to prohibit sexual relations between medical practitioners, or any other who provides medical or therapeutic services, and a patient or client in their care.

Comments were invited on the scope of community services which should be included, the scope of sexual activity which should be included and whether special attention needs to be paid to those providing intimate physical care.

#### **Familial sexual abuse**

Thirdly, an offence of *familial sexual abuse* will reflect the looser structure of modern families which will replace and extend the existing offences of incest.

#### **Commentary**

Generally, I feel all these proposals are very welcome and, if adopted, will represent a major step forward in the protection of vulnerable people. Copies of the executive summary or the full report are available from:

Haydee Scarsbrook  
Sex Offences Review  
Sentencing & Offences Unit  
50 Queen Anne's Gate  
London SW1H 9AT  
Telephone: 020 7273 3443

Dr. Leila B. Cooke,  
Consultant Psychiatrist in Learning Disability, Bath and West Community NHS Trust;  
Faculty Lead on Legislation,  
Bristol Central Community Learning Difficulty Team, New Friends Hall,  
Heath House Lane, Stapleton, Bristol BS16 1EQ.



Discussion of Distinction  
Awards, Cork, 4.10.00

A meeting was held to which Award Holders, Regional Representatives and Executive Committee Members were invited. This was to discuss and agree the process for forwarding nominations for distinction awards in England and Wales, and to agree membership of the committee that finally decides the shortlist. The meeting was chaired by Dr Mary Lindsey, Chair of the Executive, on the 4.10.00 at Jury's Hotel, Cork.

#### **The following was agreed:**

As soon as the call for CVs and instructions how to complete them goes out, Dr Lindsey will write to all Regional Representatives with the information. She will ask the Regional Representative to invite all eligible consultants to send a completed CV to both the Regional Representative and herself. She will enclose the details of the appropriate President's Regional Adviser.

The Regional Representative will encourage suitable candidates to apply, if necessary.

The Regional Representative will liaise with the President's Regional Adviser, so that each is aware of suitable candidates (applications are more likely to be successful if supported by the Region and the College).

The CVs will be sent for independent scoring by an agreed system to the Faculty Distinction Award Committee (all chosen by picking their names out of a hat) comprising 4 members of the Executive, 4 Regional Representatives, 4 A Award Holders plus the Chair and Honorary Secretary of the Executive.

The Committee met in December to decide the final shortlist to be forwarded to the President.

Dr. Geraldine Holt,  
Honorary Secretary of the Faculty for the Psychiatry of Learning Disability.

***“If adopted, these proposals will represent a major step forward in the protection of vulnerable***

## Psychiatrists in Learning Disabilities: Stressed or Satisfied?

Dr. Shamim Dinani

The NHS has its workforce as its main asset, and maintaining morale and thus enhancing quality of clinical care is clearly important. Psychiatrists in learning disability have for a long time informally complained they suffer from professional isolation, difficulty in recruitment, lack of resources, financial cutbacks, adverse publicity and unreasonable demands by the government. These complaints are perennial and chronic. It seems important to ascertain what issues are of particular relevance to learning disabilities, in terms of stress factors, as well as positive aspects of the work. For all the complaints and stresses, many psychiatrists clearly find it rewarding to work in this field.

### Survey summary

A postal survey was carried out for psychiatrists in the South and West Region. The questionnaire comprised of direct closed questions, as well as open questions, about stress factors and positive aspects of their work. A response rate of 65% was achieved.

Part time Consultants and Specialist Registrars reported being content most of the time and stressed very rarely. The majority of Consultants and half of the Specialist Registrars felt stressed sometimes. Only one Consultant felt stressed most of the time and rarely content. All the Specialist Registrars and the large majority of Consultants felt that stress levels have risen in recent years.

***“The majority of  
Consultants felt  
stressed***

### Guidance on the Use of Methylphenidate in ADHD

The National Institute of Clinical Excellence (NICE) has recently published guidance on the use of Methylphenidate in ADHD. This suggests that only child and adolescent psychiatrists and paediatricians have the necessary competence to initiate this medication for children. Following correspondence with the Chair of the group that drew up the guidelines for NICE it has been recommended that Consultants with responsibility for children with learning disability should discuss their position with their Chief Executive or through the Clinical Governance arrangements in their Trusts to seek agreement that the said Consultants can take responsibility for prescribing methylphenidate to children in their care. So long as they can demonstrate that they have competence in this area and are following the NICE guidelines then this should be sufficient. However we will be taking this further through correspondence with NICE.

The sources of enjoyment were related to:

- The actual job content (satisfaction from clinical work, the variety, holistic approach, lifespan, family work, diagnostic and therapeutic challenge).
- Multi-disciplinary working in close collaboration with other agencies.
- Work setting and service context (community orientation, stimulating academic and research potential, supportive and enthusiastic colleagues).

The sources of stress are related to:

- Work demand.
- Role ambiguity.
- Role conflict.
- Poor support.
- Lack of feedback.
- Lack of influence.
- Having to compromise standards.
- Poor working conditions.

Work demand and lack of feedback scored the highest (93% and 53% respectively).

Stress factors pertaining to learning disabilities were in 3 categories:

- Related to the client group:

***“It is important to recognise work related stress and address the issues***

Stress factors pertaining to learning disabilities were in three categories:

- Related to the client group: complex clinical situations with much sadness, dealing with people with aggressive behaviours, patients who are oppressed, ignored, abused and abandoned.
- Human resource issues: difficulty in recruiting medical staff, inadequate paramedical and specialist nursing staff.
- Service related issues: poor recognition of the speciality by other medical colleagues, by other staff, managers, purchasers etc.

Many felt their service was marginalised and had limited resources.

Suggestions were made by participants on how to reduce stress.

- Reducing workload: by having good administrative support, other staff being mental health orientated, less travelling, more doctors and less paperwork.
- Professional support: need for informal time with colleagues as well as formal feedback. Regional meetings of psychiatrists were viewed very positively by everyone replying. The meetings give an opportunity to meet colleagues and develop networks for peer support, as well as for information exchange and academic and personal development activities.
- Service related suggestions: increased awareness by others, particularly managers, of pressures; increased awareness and understanding of the role of psychiatrists in learning disability. Many made pleas for stability and consistent understanding of priorities, and the division between managerial and clinical responsibility to be clearly defined.

**Commentary**

The results show a speciality *not* in a state of high psychological stress or crisis but reasonably content and

**Book Announcement**

Drs. Meera Roy, David Clarke and Ashok Roy (book editors) have taken advantage of the internet to publish the textbook “*An Introduction to Learning Disability Psychiatry*”. This textbook is aimed at members of the multidisciplinary team, general practitioners, medical students, psychiatric trainees and carers. It is written in jargon-free language to make it accessible to this varied readership. The book editors would welcome comments and suggestions to constantly upgrade and improve the book. The book can be found at: [www.ldbook.co.uk](http://www.ldbook.co.uk)

## Activities of the Evidence-based Practice Group Dr. Shoumitro Deb

### Management of violence

The Research Unit at the Royal College of Psychiatrists (CRU) will conduct a "National Audit of the Management of Violence in Services for People with Learning Disabilities" in 2001. In 2000 they conducted a similar national audit based on their "Clinical Practice Guidelines for the Management of Imminent Violence" in psychiatric settings. The CRU has asked our "Evidence-based Practice" group to help them in developing guidelines for use in learning disability settings. These guidelines will be adapted from the CRU's existing guidelines as mentioned above. It was recognised that in order to achieve this goal it is necessary to systematically review the existing evidence on this subject. Our group, in collaboration with the Department of Information Services at the University of Wales College of Medicine, is now doing this. We anticipate producing our first draft on this by January/February 2001. We shall seek comments on the draft document from members of our Faculty and other relevant people, and wish to produce the final document by April/May 2001.

### Use of medication with adults with

### DC-LD [Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities]

The diagnostic manual DC-LD is currently "in press" with Gaskell, the Royal College of Psychiatrists, and will soon be available. It will be launched at the Faculty's Spring meeting, London, 25 April 2001. Copies will be available for inspection or purchase on that day. The manual has been developed specifically for use with adults with learning disabilities, and can be used in a complementary way to ICD-10. It also cross-references to DSM-IV. Many thanks to all of you who contributed to its development.

### behavioural problems

The "Evidence-based Practice" group is also involved in developing "Clinical Practice Guidelines for the Use of Medication in adults who have Learning Disability and show Behavioural Problems". We have held our first scoping exercise, meeting at the new office of the CRU in London, involving as many stakeholders as possible. We had representation from MENCAP, a Social Services Department, a Pharmacist, a parent, a carer, a Forensic Psychiatrist, and the CRU. Although invited, a GP, a nurse and a Clinical Psychologist were unable to attend the meeting but have agreed to remain involved in the project. In this meeting we have ratified various topic areas on which guidelines are needed. Because of the existence of the international guidelines and reviews (including a Cochrane review) on this subject, it was decided no systematic review of evidence is needed at present. The next step is to seek external funding to collate the existing information and guidelines on the subject and incorporate them in a series of stakeholders' focus group meetings in order to develop the guidelines. We expect the whole process to take 12 to 18 months.

### Welsh Health Evidence Bulletin

Although not a part of our "Evidence-based Practice" group's activities, it is relevant to mention here that in Wales we are developing the "Health Evidence Bulletin in Learning Disability". We have finished the critical review of evidence and writing up of "statements" based on those evidences. An "Internal group" of experts from the field of psychiatry, psychology, social services, and voluntary sector, has reviewed the Bulletin. At present an "External group" of experts with equal diversity is reviewing the draft Bulletin. The Bulletin should be published soon. This Bulletin will be available in the Internet

***"Clinical practice guidelines for the use of medication for problem behaviours should be available in***

reviewing the draft Bulletin. The Bulletin will be published soon. This Bulletin will be available on the Internet, through the National Electronic Library and also at: <http://heb.w.uwcm.ac.uk>.

**EAMHMR Practice Guidelines for Mental Illness**

I have also been asked by the "European Association for Mental Health in Mental Retardation" (EAMHMR) to lead the production of consensus - as well as evidence-based - practice guidelines for the diagnosis of mental illness in adults who have learning disability. Other authors involved in this project are Professor Nick Bouras, Dr. Geraldine Holt and Dr. Tim Matthews. The idea is to develop a set of user friendly guidelines that could be used not only by psychiatrists but also by other professionals and carers working with adults who have learning disability. We hope to launch this document in Berlin in September 2001 during the next meeting of the EAMHMR.

Dr Shoumitro Deb,  
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E-mail: [Deb@Cardiff.ac.uk](mailto:Deb@Cardiff.ac.uk)

***The "Welsh Health Evidence Bulletin" and the "EAMHMR Practice Guidelines" should soon both***



The webpage of the Royal College of Psychiatrists now includes a learning disabilities web guide, thanks to Dr. Craig Melville. Check it out at: [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)



**Data Protection Act**

I have recently taken advice from the College solicitor on the changes to the Data Protection Act. We sent our solicitor an example of a questionnaire sent from the College. Can I draw your attention to the requirement that we now add a Rider to every questionnaire stating:

- "I consent to the processing by the College of the information contained in this questionnaire, by any means, and to the release of such information to \*Officers and Committees within the College, and to third parties approved by the Registrar, for the purposes and subject to the limitations specified".

(\*Officers includes Honorary Officers and Chairmen and Honorary Secretaries of Divisions, Faculties, Sections and Special Interest Groups).

*For further information, please contact the College.*

Ms. Vanessa Cameron,  
The Secretary, Royal College of Psychiatrists,  
17 Belgrave Square, London SW1X 8PG.

**Scottish News**

An announcement is expected from the Scottish Executive in early March, outlining details of the award of the grant to establish and run the Scottish Development Centre for Learning Disabilities. The intention to develop such a centre was outlined in "The Same As You?". Hopefully the new centre will play a key role in providing information, training and getting research into practice.



# Mitochondrial Disorders, Deafness, Learning Disability and Mental Health

Dr. Clive Timehin

## Introduction

Mitochondrial disorders are common and frequently affect the central nervous system. The prevalence of the MELAS (Mitochondrial Encephalopathy with Lactic Acidosis and Stroke like episodes) mutation is 16.3 per 100,000. However, it is associated with deafness and its prevalence is 2% in adults with hearing loss requiring a hearing aid, and 7% of patients with matrilineal sensori-neural hearing loss. (Majamaa, et al 1998). Mitochondrial disorders are associated with learning disability so they are probably more prevalent in adults with learning disability than in the general population.

## Mitochondria and their DNA

Mitochondrial DNA encodes 13 polypeptides that are integral components of the mitochondrial respiratory chain essential for aerobic metabolism. The mitochondria produce ATP via the electron transport chain and oxidative phosphorylation.

Gross structural rearrangements or point mutations in the mitochondrial DNA cause mitochondrial phenotypes. The mitochondria replicate, transcribe and translate their DNA semi-autonomously of nuclear DNA. Mitochondria are inherited from the mother and mutations behave like X-

linked disorders. Mutations in the nuclear DNA presenting as mitochondrial disorders may have an autosomal or recessive pattern of inheritance.

Normal and mutated mitochondrial DNA can co-exist in cells (heteroplasmy). In MELAS and MERRF (Myoclonic Epilepsy with Ragged Red Fibres), there is a correlation between the frequency of clinical features and levels of mutant mitochondrial DNA in muscle.

## Mitochondrial disorders

The striking feature of mitochondrial disorders is their clinical heterogeneity. Unfortunately patients do not often present with recognised syndromes but rather with

clusters of symptoms which are suggestive, or with unusual clinical presentations. (Chinnery and Turnbull, 1997). Mitochondrial disorders mimic a number of neurological and systemic disorders. Some conditions have been proposed as "red flags" which when in combination should alert the physician to the possibility of a mitochondrial disease (Leonard and Schapira, 2000). Red flag conditions include central nervous system disorders, myopathy, deafness, eye signs (pigmentary retinopathy, optic atrophy, ptosis, external ophthalmoplegia), short stature, cardiomyopathy and diabetes.

***“Mitochondrial disorders are common and associated with learning disabilities and mental health***

## Scottish News

The SIGN guidelines for epilepsy are currently under revision. The learning disabilities input to this work is being coordinated by Dr. Pauline Robertson.



## Psychiatric complications

Psychiatric disorders are common and can be the predominant manifestation of mitochondrial disorders. Psychosis occurs, possibly only if there is CNS involvement and cognitive deficits, but there are only isolated reports in the literature (Fadic and Johns, 1996). A clinical autopsy report of a 47 year old woman with MELAS revealed she had a history of schizophrenia, peptic ulcer disease, constipation, migraines, deafness and left temporal lobe infarct (Pryson and Wang 1998)

history of schizophrenia, peptic ulcer disease, constipation, migraines, deafness and left temporal lobe infarct (Pryson and Wang, 1998).

Depression may be a reaction to chronic illness made as a misdiagnosis, or is phenotypic. A high level of somatic anxiety occurs. Cases of severe depression and attempted suicide before diagnosis is made have been reported. (Chinnery and Turnbull, 1997). Depression may be phenotypic. Soumalainen et al, 1997, described a family with autosomal dominant progressive external ophthalmoplegia (adPEO). Second and third generation family members were interviewed using structured interview schedules (SADS and SCID). The authors postulated a link between adPEO and avoidant personality disorder and depression.

*So...how many people on your case-load possibly have a mitochondrial*

#### **Cognitive impairments**

Global and focal cognitive deficits are common in mitochondrial disorders. Independent research done by Petty, Kartsounis and Turconi reveal variable focal deficits. Impairment with short-term memory and visuo-spatial skills and associated abnormality in EEGs, CT and SPECT scans have been found.

#### **Learning disability**

Mitochondrial disorders are associated with learning disability. In childhood it presents as non-specific failure to thrive, developmental delay and regression.

A high index of suspicion is appropriate when there is a family history of neurological disease and a history of recurrent abortions or early neonatal death, which may suggest mitochondrial disease.

MELAS may present with gradual development of delayed motor and developmental milestones, short stature and seizures. The course is punctuated with episodes of hemiparesis, hemianopia, cortical blindness; vomiting and progressive dementia due to multiple strokes.

The Kaerne-Sayre syndrome has an

## 4th Annual Learning Disabilities Trainees Conference, 11-12 May 2000 Dr. Gillian Bell, Dr. Steve Wilkinson

Our thanks go to Drs. Fergus Douds and John Russell for organising this year's Learning Disabilities Trainees Conference, which was held in the MacDonald Holyrood Hotel, Edinburgh. The conference was highly successful, with a combination of excellent speakers and a first-rate venue. This year's theme was "genetics" and John and Fergus drew on both local talent and a few imported Sassenachs for a highly informative and enjoyable conference.

The conference began with a lively debate around the motion "Innovations in clinical genetics will provide the most significant advance for people with learning disability in the new millennium". Proposing the motion was Dr. Pauline Robertson and opposing was Dr. Neill Simpson. The forum felt that although genetics would bring significant advances to people with learning disability, that advances in health and social care would also be equally significant. The motion was not passed but Dr Robertson saw an increase in support after a stimulating debate.

Friday was attended by about 40 SHOs and SpRs and was chaired by Professor Sally-Ann Cooper. Sessions included: genetic advances in learning disability by Dr. Walter Muir; foetal anticonvulsant syndromes by Dr. Jill Clayton-Smith (Consultant Clinical Geneticist and Senior Lecturer); paediatric genetics by Dr. David Fitzpatrick (Senior Clinical Scientist and Honorary Consultant Clinical Geneticist); and behavioural phenotypes by Dr. Tony Holland. We would like to reiterate our thanks to everyone who gave their time to speak at the conference.

At the business meeting the main topics of debate were dual training and the difficulties some trainees have utilising their research time. Dr. Ken Courtney stood down as CTC representative to concentrate on

research activities. Ken has held the post for 2 years and has put in a lot of hard work ensuring that trainees views are represented at the College, the Faculty Executive and PLDSAC. He has also developed a national register of trainees. We would like to thank Ken again for all his efforts and look forward to seeing his name more in the scientific press. Dr. Gill Bell was elected as the new Trainee representative and will take over from Ken at the October meeting.

It was pleasing to see that a number of Regions were interested in hosting successive conferences. Newcastle upon Tyne was voted as the venue for next year's conference and the theme will be Child Psychiatry and pervasive developmental disorder. Dr. Steve Wilkinson was elected Chair and Dr. Andrew Richardson the new secretary. Both are Northern Region Trainees.

Our thanks also go to all the pharmaceutical companies whose generosity helped make the conference such a success.

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***The next Trainees  
Conference will  
be held on 7 - 8  
Jun 2001, at the  
Cophthorne Hotel,***

## Continuing Professional Development Dates

Key forthcoming diary dates for continuing professional development include:

### **Clinical Excellence in Mental Health, 2001: Making it Happen**

(This is the sixth annual conference organised by the Clinical Governance Support Service at the Royal College of Psychiatrists.)

Wed 4 Apr 2001.  
Church House, London SW1.

*The aim of this one day meeting is to look at the work of NICE, CHI, and the National Service Frameworks initiatives, and how they are affecting, and will affect, the work of mental health services.*

### **The Spring Meeting of the Faculty for the Psychiatry of Learning Disability of the Royal College of Psychiatrists**

Wed 25 Apr 2001.  
Kensington Town Hall, London.

*The DC-LD diagnostic manual specifically developed for use with adults with learning disabilities who have psychiatric disorders will be launched at this one day meeting.*

### **The Annual General Meeting of the Royal College of Psychiatrists, 2001: A Mind Odyssey - Science and Caring**

Mon 9 - Fri 13 Jul 2001.  
Queen Elizabeth II Conference Centre, London.

*The Blake Marsh Lecture will be distinguished on this occasion by delivery by Dr. Oliver Russell. The Blake Marsh reception and supper will also be held at this event. Trainees should please note the financial advantage of early booking!*

## Contents

Message from the Chair Dr. Mary Lindsey	1
The Human Rights Act 1998: The Lion That Snored? Dr. Simon Halstead	2
Consultation: Reconfiguration of Trusts - Implications for Learning Disability Services Dr. Jane McCarthy	4
Setting the Boundaries: Reforming the Law on Sex Offences Dr. Leila B. Cooke	6
Institute for Psychotherapy and Disability: Call for Members	6
Discussion of Distinction Awards, Cork, 4.10.00 Dr. Geraldine Holt	7
Psychiatrists in Learning Disabilities: Stressed or Satisfied? Dr. Shamim Dinani	8
Guidance on the Use of Methylphenidate in ADHD	8
Book Announcement	9
Activities of the Evidence-based Practice Group Dr. Shoumitro Deb	10
DC-LD [Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities]	10
Announcement: Data Protection Act Ms. Vanessa Cameron	11
Mitochondrial Disorders, Deafness, Learning Disability and Mental Health Dr. Clive Timehin	12
4th Annual Learning Disabilities Trainees Conference, 11 - 12 May 2000 Dr. Gill Bell and Dr. Steve Wilkinson	14
Continuing Professional Development Dates	15