Learning Disabilities Psychiatry

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A Fly on the Wall – Research Experiences Within the Criminal Justice System

Dr. Jonathan Banes

Looking forward to the summer, as the weather begins to get a little warmer and the climate slowly changes, one major adjustment in our lives will be an increase in unappreciated wildlife.

Research and the Criminal Justice System

Over the past 20 months or so, at times, I have felt very much like a fly; often unwanted and waved away. The reason for this is that I have been conducting research in learning disabilities of which there is very little awareness within the Criminal Justice System (CJS). In this article I am presenting some of the issues regarding this client group, which my work has raised.

When I first started the research I was aware of the problems which have beset research in this area i.e. prevalence rates vary massively between studies, with confounding issues such as varying attitudes, the IQ test administered and the agency involved in testing which all have an impact. The individuals themselves are also notoriously hard to engage in clinical interviewing, with communication deficits, suspiciousness of services, high prevalence of mental health problems and unstable lifestyle and family background as prevailing characteristics.

Identification of people with learning disabilities

Recruitment of individuals presenting with learning disabilities within the CJS relied on professionals who came into contact with them to identify and refer those where suspicions of learning disabilities were aroused. On meeting with professionals within the Police, Courts, Probation Services and Prison Service it became rapidly apparent that almost no one had had training in the definition and identification or the vulnerabilities of offenders with learning disabilities. For instance one Custody Suite Officer when asked for a definition of learning disabilities stated that 'if they were a couple of laps short of the Grand Prix' then his suspicions would be aroused.

The Metropolitan Police have recently introduced a five item questionnaire (Form 57M) asking suspects to self-report any reading, writing, learning difficulty or disability or mental health problems, in order to assess the need to call for an appropriate adult before interviewing. Education in mental health still appears to be the priority to the Police. Results of the responses to this questioning are rarely passed on to the courts or probation officers writing pre-sentence reports; so the information tends to stay within the station.

The courts have been making an effort to improve identification of all mentally disordered offenders. Court Diversion Schemes are now the norm within most Local Magistrate Courts, with each having its own system of partnership and co-ordination with social and health services. As those professionals working on diversion schemes are trained in mental health and not learning disabilities the recognition of learning disabilities offenders is almost incidental.

Working in conjunction with the prison service to recruit offenders with learning disabilities has also been quite an eye-opener. One of the prisons I have been visiting has made no provision to identify individuals with learning

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

Faculty Chair: Dr. Mary Lindsey

Editorial Board:
Prof. S-A Cooper, Dr. G Holt

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. Isobel Hodge, Secretary to Prof. SA. Cooper, Department of Psychological Medicine, University of Glasgow, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH,

Please send 3 hard copies of articles plus a copy on disc to Prof. S-A. Cooper, Department of Psychological Medicine, University of Glasgow, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH, or email: SA-Cooper@clinmed.gla.ac.uk

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disabilities. There is no one even connected to the service available to carry out IQ tests. Initial requests for referral of inmates with learning disabilities was followed by an awareness session, to increase professionals' knowledge of the factors which could lead them to suspect learning disabilities. When the referrals started to come, assessment of the individuals referred aroused further questions as to whether the concept of learning disability had been understood by the prison medical staff and what the motivation to refer was. All those referred were either suicidal or self-harming .

Access to initiatives for offenders

The Offending Behaviour Programmes Unit is currently attempting to address the belief that programmes run through HM Prison Service are not accessible to inmates with IQ levels below 80. This has recently led to an adapted version of the Sex Offender Treatment Programme to be accredited and run in five prisons (HM Prison Service, 1999) and two other programmes to be less formally adapted.

The Probation Service is currently developing initiatives for offenders with dyslexia following a major government initiative to tackle the problem of high prevalence within the offending population (Davis and Byatt, 1998). Working in conjunction with educational support tutors I became aware of the fact that tutors' level of awareness of other forms of learning difficulties / disabilities is negligible. Tutors carrying out assessments were unaware that people with learning disabilities will often manifest signs similar to those who are dyslexic. This begs the question as to how many individuals are wrongly diagnosed with dyslexia, because they have been assessed solely with a dyslexia tool and not fully assessed with an IQ test as well.

The probation officers themselves are also suprisingly ignorant of the issues surrounding learning disabilities. All probation services approached required education in learning disabilities. One senior officer told me that it was generally acknowledged that a substantial proportion of the offenders placed on rehabilitative programmes do not understand the content of the programme. Adaptation of programmes is currently being informally addressed by just one probation service in the country (West Midlands).

During my work I found that the lack of knowledge of professionals assessing and managing offenders with learning disabilities was prevalent. There are few strategies for liaison and information sharing between agencies, meaning, sadly, that the needs of this population are going to be neglected for some time.

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This work was made possible by a Research Fellowship granted by Barking, Havering and Brentwood Health Trust to Dr. Angela Hassiotis and Dr. Philip Barron.

References:

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

"Almost no-one in the Criminal Justice System has any training in learning disabilities"

Burden Research Prize

The Burden Research Prize is awarded by the Burden Trust every three years for outstanding research in the field of learning disabilities. This year the prize of £1,000 was awarded to Dr. Jeremy Turk, Senior Lecturer in Child and Adolescent Psychiatry at St. George's Hospital Medical School, for his research on Fragile X Syndrome.

Job Descriptions

Job descriptions are now available via the College website for key Faculty roles – this can be accessed via http://www.rcpsych.ac.uk.

Report from the Evidence-Based Practice Group

Dr. Shoumitro Deb

The evidence-based practice group is involved currently with two major projects:

- The development of guidelines for the management of violence in adults who have intellectual disability.
- The development of practice guidelines for the use of drugs in the management of behaviour disorders in adults who have intellectual disability.

Look out for the evidence-based consensus practice guidelines for the management of violence.

In summer 2002 we are hoping to publish (under the joint auspices of the College Research Unit and the Faculty) the evidence-based consensus practice guidelines for the management of violence in adults who have intellectual disability. The Faculty has agreed in principle to underwrite the cost of this publication. In the meantime the College Research Unit is carrying out a multi-centre national audit of the management of violence within services for people with learning disability. Twenty seven Trusts representing 46 wards / units have taken part. The project is conducted in three modules. Module one involves using staff and visitor questionnaires, service user questionnaires / interviews / focus groups / observation. Module data collection is completed now and these data are currently being analysed. Module two involves the completion of an environmental audit checklist by two teams of staff; one staff team and one non-staff team. Module two data are being collected at the moment, and data collection will be completed in the end of December 2001. Module three will involve critical analysis of actual violent incidents. Module three is due to start in February 2002, and feedback events will take place in May 2002. We are hoping to present some preliminary data from this audit at the next one-day meeting of the Faculty in 2002 at Kensington Town Hall.

In conjunction with the College Research Unit and MENCAP the Faculty is currently seeking external funding for the development of practice guidelines for the use of drugs in the treatment of behaviour disorders in adults who have intellectual disability. However, we are currently in discussion with the National Institute of Clinical Excellence (NICE) to explore the possibility of NICE endorsing these guidelines.

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Calling all SpRs: A Position on the Editorial Board

Learning Disabilities Psychiatry is seeking to recruit a Specialist Registrar to its editorial board. The appointed SpR will be involved with the production of editions of *Learning Disabilities Psychiatry*, comm- issioning and editing articles, the strategic direction of this Bulletin, and will have special responsibility for issues related to higher training.

If you are interested in this position, please apply in writing to:
Professor S-A. Cooper,
Department of Psychological Medicine,
University of Glasgow,
Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH
SACooper@clinmed.gla.ac.uk

Include three copies of your C.V. and a paragraph (maximum of 300 words) outlining the reason for your interest and the qualities you feel you could bring to this post.

Closing Date : 30.04.02.

A Letter from the Chair

Dr. Mary Lindsey

This report is written at the end of a busy year for our Faculty. We have had two high quality and well attended Faculty conferences – the day conference in London and the residential conference in Chester. The feedback from both was good. Learning disabilities was also well represented in the College annual meeting. The Executive has also been very busy with a number of very active groups addressing specific issues and with a lot of emphasis on communication with the membership through the regional representatives. Evidence-based practice and service user and carer involvement are other important areas. We are also looking at "District of Residence" as it affects psychiatric service providers in areas where many of the clients of specialist residential accommodation originate from outside their catchment area. Dr Val Anness has asked Regional Reps to contact members in their region to find out more about the extent and nature of the problem. We have recently revised the consultant norms, trying to take into account the variety of practice as shown in the recent survey and these should soon be available. We are also working on a document describing the roles and responsibilities of consultants in the psychiatry of learning disabilities. We have established a working group jointly with the Child and Adolescent Faculty to look at the competencies required to work with children with learning disabilities and mental health problems. Abuse of vulnerable adults is another area of concern.

The breadth and specificity of practice in learning disabilities psychiatry continues to be the theme that runs through a number of issues, particularly recent policy guidance from the Department of Health in England (*Valuing People*) and the similar guidance in Scotland (*The Same as You?)* and the draft from Wales. Whilst most of us would agree that inclusion in mainstream health services is essential for most of the health problems encountered by people with learning disabilities, the issue of the future role of specialist mental health services for people with learning disabilities has not been resolved. We need to be very clear in our own thinking about the extent to which people with learning disabilities can be included in mainstream mental health services and the appropriateness of doing so. We also need to consider not only our own practice but that of the teams with which we work. On the one hand there is a strong argument that service users will benefit from services that have specialised sufficiently to really understand their needs and to tailor interventions to take their learning disabilities into account. On the other hand learning disabilities specialist services are in short supply and it may be better to reserve the more specialised skills for those that particularly need them. Indeed some people with mild learning disabilities and mental illness may be better provided for in mainstream primary care and mental health services and may not identify with more disabled peers. For such individuals, facilitating access to mainstream mental health services may be our role. However even this is not easy as many colleagues in general adult mental health services, child and adolescent mental health services and in old age psychiatry, and the teams with whom they work, do not feel willing or able to take on this work particularly when specialist services have previously done this very well. If we are to address this problem I have emphasised to the Executive of the College that it is my opinion that basic training in learning disabilities psychiatry should be mandatory in the future for all psychiatrists. Otherwise the College will have to support us in insisting that only learning disabilities psychiatrists can do this work with the workforce and skill mix issues that this implies.

"The role of specialist mental health services for people with learning disabilities has not been resolved"

This leads into another closely related issue – the future CCSTs. This has come under a lot of scrutiny recently because in Europe there are only two CCSTs in psychiatry – child/ adolescent and adult. There was a proposal that we should do the same but several of the Faculties felt that this would split their membership. There is also concern that it would narrow knowledge and skills so that those working with adults would not have a developmental perspective and those working with children would not have a good understanding of mental illnesses that predominantly affect adults.

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Since April 2001 all career grade psychia-

Feedback on Appraisal

Dr. Peter Carpenter

trists have been expected by the College to develop Personal Development Plans (PDP) supervised by peer groups, for their Continuing Professional Development. From the same time all consultants in the NHS have been required to receive annual appraisal, in accordance with the Department of Health's Advance Letter (MD)5/01 and its associated documentation (see http://www.doh.gov.uk/nhsexec/consultantappraisal and also the BMA website for guidance). This latter appraisal is expected to be the basis of the revalidation process managed by the GMC, and the three processes are likely to maintain a healthy tension bewteen them to ensure the quality of all.

"The CPD Committee tries to encourage and monitor PDP peer groups"

I am the Faculty representative on the College CPD committee. The CPD committee is keen to encourage PDP peer groups and is trying to monitor these when requesting the CPD returns from individuals. However the College is not at present collecting experiences of appraisal. I would be interested to hear of people's experiences of appraisal. I would be grateful if people would contact me after having received appraisal to tell me the following:

- How much time it took to prepare for appraisal (and did it fit into work time)?
- How did you find the preparation process?
- Were you totally free to choose your appraiser?
- Were you appraised by a peer or line manager, and from within the Trust or outside of the Trust?
- How you found appraisal meeting.
- How it could have been improved.

I propose to feedback experiences to the Faculty executive and College. All feedback to the College will be handled in a manner that does not make it possible to identify respondents.

I would prefer some identification so I know how things are progressing around the country, but would rather receive an anonymous reply than none at all!

Please send your experiences to me at the contact details below:

Dr. Peter Carpenter,
Consultant in Learning Disabilities, Bath and North Somerset P.C.T., Kingswood CLDT, Hanham Road, Bristol BS15 8PQ.
peter.carpenter@bristol.ac.uk.

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A Letter from the Chair

This has led to the suggestion that there should be a single CCST in psychiatry that would lead to greater flexibility in training but that there would continue to be a range of subspecialties. Other options have also been proposed including maintenance of the status quo. This is likely to be the subject of a long debate and more information about this will be available on the College website so that full consultation with the membership can take place. So please do give your views.

I wish you all well for the New Year and look forward to meeting you at future conferences and events.

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

Guidance on New Drugs for the treatment of Alzheimer's Disease

A/Professor Vee Prasher

NICE drugs to treat Alzheimer's disease

There can be little doubt that the recent development of drugs to treat Alzheimer's disease (AD) has caused considerable interest and a great deal of anxiety. In January 2001 the National Institute for Clinical Excellence (NICE), published "Guidance on the use of Donepezel, Rivastigmine, and Galantamine for the treatment of Alzheimer's disease", a document which was supposed to clarify the position. The guidance may have clarified the position for the non-learning disabilities population but sadly has appeared to increase confusion for psychiatrists working with people with learning disabilities. There was no representative from the field of learning disabilities on the committee and indeed no evidence was sought from learning disabilities professionals or carers.

The guidance reviewed the role of three acetylcholinesterase inhibitors (Donepezil, Rivastigmine, and Galantamine) for the treatment of AD. The guidance discusses a number of issues relating to the non-learning disabilities population and gives background information regarding what is dementia and how common it is. The article summarises technical information regarding why drugs were developed and how they are effective in people with AD. Acetylcholine is a neuronal transmitter that is metabolised by acetylcholinesterase. The three drugs inhibit acetylcholinesterase thereby increasing the concentration of acetylcholine available for neuro-transmitter actions. As dementia progresses, acetylcholine levels reduce but the drugs appear to preserve acetylcholine thereby maintaining brain function for a longer period. Such an action may be principally associated with mild-moderate AD only.

The guidance discusses the review of 30 randomised-controlled trials and 7 systematic reviews, which demonstrate that all three drugs affect global functioning. All three drugs statistically significantly improve cognition but beneficial effects on behaviour and on quality of life have yet to be established. All three drugs appear to have a significant clinical side-effect profile; commonly nausea, vomiting, diarrhoea and abdominal pain.

Debate continues regarding the cost effectiveness of the drugs but the main benefit appears to be a delay in the transfer to a nursing home of people who are living in the community. The guidance highlights that no appropriate health economics research has been undertaken and many assumptions have been extrapolated from randomised controlled data regarding any costs savings, which may vary from £0 to £30,000 per year.

> ***"Other measures can be used in place of the MMSE"***

Some of the confusion for learning disabilities psychiatry has been the emphasis on the use of the MMSE. The guidance suggests this should be used as the main clinical measure, but does highlight that there are a number of problems on the reliance of the MMSE. The MMSE at times is not applicable for people with learning disabilities. The guidance over-emphasises that the drugs should only be used in individuals with an MMSE score over 12 points on the questionnaire. This excludes many people with learning disabilities. However NICE accepts that other measures such as those of behaviour are important in the decision to use drugs and these could replace the MMSE.

Main NICE recommendations

The main NICE recommendations are as follows:

- All three drugs should be made available on the NHS to treat people with mild to moderate AD.
- The diagnosis of AD should be made by a specialist clinic using standard criteria.
- The assessment should involve cognition, global behaviour and activities of daily living rather than just one specific area of functioning.

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- Compliance should be borne in mind and is an important aspect to inform the decision as to whether to prescribe. Prescribing decisions should be made by specialists, which could include learning disabilities psychiatrists initiating treatment, with GP's continuing prescribing as part of a shared care policy.
- Re-assessment should be undertaken after the first two to four months of the maintenance dose with medication stopped if the assessment shows a decline.

"Drug treatment for Alzheimer's disease should be offered to people with learning disabilities"

Due to the non-mention of learning disabilities and the over-emphasis on the MMSE in the guidance, many colleagues in learning disabilities have been unsure whether such drugs can now be used for the treatment of AD in people with Down's Syndrome. My own view, after personal communication with the NICE committee and having recently finished a double blind placebo controlled trial of the use of Donepezil in the treatment of AD in adults with Down's Syndrome (in press) is that "yes, the drugs can and should be used in the learning disability population if support is available from one's Trust and Health Authority". Appropriate clinical guidelines as suggested above should be followed.

Further Research

A number of areas of further research still remain:

- Are all drugs of similar effectiveness?
- Do the drugs have immediate effect or a cumulative effect?
- What are the adverse effects over time?
- What is the role of the drugs in severe dementia?
- How do the drugs benefit behavioural and non-cognitive symptoms?
- Can the drugs be used in other forms of dementia other than AD?
- What is the outcome for patients when medication is stopped?
- More information is required about cost effectiveness.

I would be more than happy to hear from fellow colleagues of their personal experiences in the use of such drugs in people who have learning disability.

A/Professor Vee Prasher,
Associate Professor of Neuro-developmental Psychiatry, Birmingham Specialist Community Health NHS Trust,
Monyhull Hospital, Monyhull Road, Kings Norton, Birmingham B30 3QQ.

All-Party Parliamentary Group on Autism

The all-party parliamentary group on autism was established in February 2000 under the chairmanship of Dr. Stephen Ladyman MP. It holds regular meetings on subjects chosen by the group and is attended by MPs and peers. Representatives of interested organisations are invited to attend, and I go as a representative of our Faculty. The National Autistic Society supports the group. Speakers are invited to address the group. These have included John Hutton MP, Dr. Tony Holland, Prof. Patricia Howlin and Dr. Simon Baron Cohen. Topics discussed have included the aetiology of autism, its epidemiology, and the availability and suitability of services. The group is generally well attended. Discussions are lively and well informed.

The All-party parliamentary group on disability, chaired by Lord Ashley, also reflects the interest at parliament in autism. At its meeting in July this year Judith Barnard of the National Autistic Society discussed the Society's report 'Ignored or Ineligible?' and a parent discussed his experience of services for his son with autistic spectrum disorder.

In particular both groups have emphasised the need for a clear statement from government as to how the needs of people with autism should be met (i.e. who should be the lead agency, etc) across the IQ spectrum.

Dr. Geraldine Holt,
Secretary to the Faculty of the Psychiatry of Learning Disabilities, Royal College of Psychiatrists,
17 Belgrave Square, London SW1X 8PG.

Department of Health
National Service Framework for Older People

Dr.Val Anness

An aspirational document

The Department of Health's National Service Framework for Older People is one of a series of national frameworks published or in preparation for England.

It is an aspirational document with its main goal being to promote and extend healthy and active lives for older people. The term "older people" covers a very varied group of individuals and in something of a landmark the document specifically identifies the needs of older people with learning disabilities, both in the generality, i.e. having similar needs as other older people, but also their special needs and the specific problems of e.g. dementia in people with Down's syndrome.

The document is very clear in its anti-discriminatory approach and its themes are of universality, comprehensiveness and responsiveness. It is aimed particularly at the NHS but the role of social care was intrinsic to the work of the External Reference Group and specific task groups.

It is intended that the framework should be the key vehicle to ensure that the needs of older people are at the heart of the reform programme for both Health and Social Services in England.

Key Standards

The approach is evidence based and the key standards set include: rooting out age discrimination, person centred care, development of intermediate care, appropriate care in general hospitals, prevention and better management of strokes and falls, access to integrated mental health services and the promotion of active healthy lifestyles.

The issues of discrimination and variation in services for older people will be very familiar to those working in learning disabilities, as will be the aims/standard of treating older people as individuals, respectfully and enabling choice in a person centred service.

Service Improvements

There are proposed remedies to end discrimination and improve skills in working with older people. Service improvements are to include single assessment processes, integrated community equipment and continence services and special attention to the need to communicate appropriately with older people (including specific reference to the needs of people with learning disability). There is to be greater information available to and in a form suitable for older people, enabling greater involvement in decision making, a system of integrated commissioning and thorough multidisciplinary assessment.

> ***"The Framework is very clear in its anti-discrimination approach"***

A new range of acute and rehabilitation services to bridge the gap between acute care and primary and community care is proposed to prevent inappropriate admissions and facilitate earlier discharge. The routes towards this could include rapid response teams, the development of specific intermediate care facilities, additional care at home and respite for carers.

In acute hospital care, it is proposed that specialist multidisciplinary teams ensure that the needs of older people are being appropriately addressed throughout the acute hospital sector. As older people are the greatest users of most acute hospital care, as the document acknowledges, it is remarkable that the document feels the need to state the obvious. It is not only older people who want clean wards, privacy, good nutrition and plentiful, clean, bed linen. What an indictment of our hospital system at the present!

On mental health needs, the document notes the high rates, often undetected, of mental illness in older people and the difficulties in obtaining appropriate care for people with learning disabilities especially if they are dependent on those not alert to their mental health needs.

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Key interventions include promoting good mental health, the early recognition of problems and access to specialist care, although there is no specific mention of specialist care for older people with learning disabilities. Again, the emphasis is on integrated planning and delivery of services.

"There is specific reference to the needs of people with learning disabilities including their special needs and specific problems"

All these initiatives are to be taken forward locally by "champions", by engaging directly with older people, working in partnership, developing inclusive planning with agreed strategic directions. In mental health services HImPs are to be the vehicle for developments of integrated mental health services for older people.

There are to be 5 underpinning programmes in support of the framework covering finance, workforce, research and development, clinical and practice decision support services and an information strategy. Finance will include both targeted and more general resource allocation.

Summary

In summary, this is a document the aspirations of which would be familiar to and have much in common with those in learning disabilities. That it specifically includes the needs of older people with learning disabilities is welcome and its anti-discriminatory stance and approaches if effected could offer a model for other services.

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Regional Representatives
Dr. Val Anness

The Faculty Executive has been anxious to improve links and communication in both directions with the Regional Representatives.

To this end one of the Executive Committee members has been designated as Regional Representative Co-ordinator and following the lead of a number of Faculties, a Regional Representatives Group has been established. The first meeting was held in December, 2001 and further meetings to precede Faculty Executive Committee meetings are planned for 2002 in addition to the usual joint meetings and strategy days.

By this means it is hoped that representatives will feel more closely tied in to the work of the Executive and able to disseminate to colleagues within their region the issues current within the Faculty and the wider College and will feel more able to advise the Executive of local concerns, successes, etc.

At the moment – well as always – some regions are being re-organised, particularly the London and the South East areas and this is causing some confusion. The College is reconsidering the roles of Regional Advisors and Regional Representatives. In a time of such constant change it is certainly hoped that the Regional Representatives will act as extra bridges in the communication network to ensure the Faculty's strength and effectiveness.

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The Role of the Consultant in Learning Disabilities Psychiatry

Should Consultants be responsible for a catchment area, or should they provide a tertiary referral service to general adult psychiatrists? Please send us your opinions on this important topic.

Save Our Patient Records and Archives!

Dr. Peter Carpenter

Many members of the Faculty who read works on the history of mental deficiency will feel that the writer has never examined any of the records of the people actually admitted to hospitals. Ideological dogma appears to have been applied with no attempt to see how it fitted the facts.

> ***"The Department of Health requires that in-patient records are kept for 25 years after discharge"***

Access to the facts is not being helped by the loss of hospital archives. Bristol closed its eight large mental handicap hospitals between 1985 and 2000. During that time managers threw away a lot of material. For example, in April 1846 Miss Charlotte White founded the Bath Idiot and Imbecile Institution, which is generally recognised as the first such institution in England and the inspiration of the large Voluntary Idiot Asylums. Three years ago the hospital catering manager showed me the only known photograph of her, which he had rescued from a hospital rubbish skip because it looked interesting. It had been thrown out despite all Department of Health instructions on the preservation of archives.

Due to my concern about the losses I gained permission from my managers to find the records that I knew were in the basements and sent them to the local Record Office. As my interest became known I was sent other documents and photographs by staff. As a result the Bristol Record Office has a good collection of the history of the local institutions, and I have access to over 2000 images of the old hospitals and life there.

Most hospitals have now been closed and their archives disposed of, but I urge all doctors in the remaining few to make sure that the local record office has sent someone around to see the records, and that managers have somewhere to collect records as they are found. I would also ask that they ensure that records of the last 40 years are saved. I have been intrigued to find that at present it is easier to find records of the local hospitals prior to 1960. Most of the management records of 1974 – 1995 have been thrown out as not important or historical, or because the new manager wanted a clear office. They are now difficult to find, but cover a very important transition in the life of our profession and its clients.

The main purpose of this item though, is to highlight the problem of old patient records. Bristol's records go back to 1909 and last year it was easier to write about the life of patients in 1940 or 1960 than that of ordinary staff who have left no personnel records. The old medical records became a nuisance as the storage facilities in the hospitals closed along with the hospitals. The local Record Office cannot store this volume of notes, though they have taken a small sample. We have been keen to transfer these records to microfilm or digital format, but have hit the lack of interest by our Trust. Because the Trust we were in did not address the issue early on, it finally decided that it would leave the problem to its successor. We are now moving annually between Trusts as Community Trusts, Primary Care Trusts (and Care Trusts) have become the approved host for Learning Disability Services. These have little experience of storing old medical records and as we have transformed so there has been even less interest in doing anything other than destroy the old medical records. Ironically the Department of Health requires that client records for inpatients are kept for 25 years after the completion of treatment (and 8 years after death) (see HSC 1999/053 appendix B1 http://www.doh.gov.uk/nhsexec/appndxb1.htm). The amount of paperwork in records has gone up exponentially in the last 20 years and probably two thirds of the volume of the old inpatient records date from the tenth of patients who were discharged after 1975.

We are now destroying our old records, but others may be interested to know that the British Library, in conjunction with the Wellcome Trust, is interested in applications for the transfer of such old medical records into archives, for example by microfilming. More information can be found at http://www.bl.uk/concord/medical-guidelines.html. The application process takes several months and the information came too late to save our

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Faculty of the Psychiatry of Learning Disability Bursary Fund to Support Specialist Registrar Attendance at College Annual Meetings

The College has, for some time, been concerned about poor attendance at College meetings by trainees and is keen to support initiatives that will encourage greater trainee participation. It is assumed that poor attendance is due, in part, to difficulties in obtaining local funding and full reimbursement of fees, travel and accommodation expenses.

The Faculty of the Psychiatry of Learning Disability has established a bursary fund of £1000 per annum to support Specialist Registrars who wish to attend the College Annual Meeting and who have been unable to obtain alternative or sufficient funding. Awards would be made up to a value of £200 per applicant.

Application for a bursary grant

Specialist Registrars who are having difficulty securing sufficient funding to attend the College Annual Meeting, should, in the first instance, discuss this with their placement Supervisor and Training Programme Director to ensure that attendance at the meeting is a training priority at that time and that all possible sources of funding have been explored.

If it is decided that application for a bursary grant should be made, the Training Programme Director should apply in writing to the Regional Representatives Co-ordinator (currently Dr Val Anness) with copies to their Regional Representative. The application should state the size of the grant required (up to £200) and the reasons why full funding has not been obtained elsewhere.

The Regional Representatives Co-ordinator has the authority to sanction such grants as they think fit after consideration has been given to bursary funds available, previous applications and equanimity across Regions. They will discuss the application with the appropriate Regional Representative in order that a long-term monitoring can be made of funding difficulties within the Regions and subsequent action taken at Regional levels to address this with Trusts and Deaneries.

Should the Bursary fund not be fully used for the College Annual Meeting, grants could be allocated for attendance at Faculty meetings in the remainder of the financial year.

Wherever possible, the most efficient and speedy means of communication (fax, e-mail) should be utilised to avoid unnecessary delay in this process.

The use of the bursary fund will be reviewed annually and adjusted if necessary to reflect demand.

If any Specialist Registrars wish to inquire further about bursary grants, please contact me.

Dr. Roger Banks
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Save Our Archives!

records, but it might save yours, and enable some record of the old patients to survive for posterity.

Another encouragement I would give to anyone is to collect mementoes of life in the hospital, especially of life prior to 1970. The local mental illness hospital has formed such a collection of ‘junk’ (the Glenside Museum) and I am told by the Science Museum and Wellcome Institute that they know of no other collection of hospital life in England. They are now very excited.

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Royal College of General Practitioners Learning Disabilities Working Group

Dr. Glyn Jones

The Royal College of General Practitioners (RCGP), through its council, commissions a number of working groups with the purpose of developing clinical practice and providing expert advice to the College Council.

The Learning Disability Working Group first met in June 1999. It was formed by a group of General Practitioners from across the United Kingdom led by Dr. Graham Martin from Nuneaton. From its inception the group has been augmented by other professionals with a special interest in the primary health care of people with learning disability. Dr. Margaret Flynn, now a member of the academic department of St. George's Hospital Medical School, was then Prince of Wales Fellow at the RCGP. In addition, Dr. Mike Kerr, who has considerable research experience in this area, and myself as another ex-General Practitioner working in the psychiatry of learning disability are also invited members.

The realities of working with a College whose members are, in effect, self-employed, is that face-to-face meetings are difficult to arrange and finance. Since the inaugural meeting, it has become a "virtual" group conducting business largely through quarterly telephone conferencing and by e-mail. Inevitably, these do not have the fruitful dynamics of physical meetings, however, it has been possible to make some progress towards the group's aims:

- To develop practice frameworks for the management of people with learning disability; including equality of access and the means of developing good quality care in the context of the Primary Health Care Team.
- To develop educational materials for practitioners and for those training for general practice.
- To set evidence-based quality standards for the care which people with learning disability and their carers could expect.

In February 2001 the RCGP hosted a conference "to update and inform on clinical education and social policy issues and the delivery of primary care services for people with learning disability". The guest speakers included Mr. John Hutton, Minister of State, Department of Health, as well as Professor Sheila Hollins and Drs. Mike Kerr and David Clark from the Faculty of Learning Disabilities Psychiatry. A subsequent meeting in October 2001 drew together key figures from within the RCGP who have influence on the continuing professional education of GPs and vocational training with educational specialists from the field of psychiatry of learning disability. Professor Sheila Hollins described the comprehensive and integrated model of medical student training at St. George's Hospital Medical School and other education initiatives in the field of learning disability which could be a valuable resource for general practitioners, e.g. a website being developed in collaboration with the Down's Syndrome Association. Professor Nick Bouras described a range of educational initiatives developed in the area of mental health and learning disabilities and this was linked to a presentation by Dr. Jenny Torr (Monash University) on educational initiatives for General Practitioners in Australia including programmes developed in collaboration with Professor Bouras' department. Targets were identified where the Learning Disability Working Group could raise the awareness of current and future General Practitioners in relation to the health needs of individuals with learning disability:

> ***"The RCGP group has the potential to provide a relevant and necessary service"***

- Exploring the potential for questions around learning disability issues in the RCGP exam.
- The regional academic Departments of General Practice and regional general practice vocation course organisers to be approached to raise awareness for the need to be educated in learning disability issues.

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Service Users and Carers Consultation Group

Dr. Jane McCarthy

> **"The Service Users and Carers Consultation Group was formed in 2000 to support the Faculty"**

The service users and carers group was formed in 2000 to support the work of the Executive Committee for the Psychiatry of Learning Disability. The membership includes four members of the Executive Committee, one trainee, one person with learning disability and one carer. We plan to expand the membership to include others involved in national projects to encourage consumer involvement.

Importance of user involvement

The social environment in which medicine is practised has been particularly affected by the growth of consumerism, both in medicine and in society (Lilford et al, 2001).

The reasons for having users involved are many. Firstly, from the human rights perspective there is a right to be a citizen and valued. Secondly, from the aspect of self determination, people with disability should have more control over their lives. Thirdly, to evaluate effectiveness of services, we need to know the impact of services on patients. Finally, public policy such as the English National Strategy for People with Learning Disability, *'Valuing People'* (Department of Health 2001) supports inclusion, and the involvement of consumers in their care.

There is confusion in the area regarding definitions. A user defines a patient, a carer, organisations representing patients' interests and potential recipients of healthcare (Consumers in NHS Research Support Unit, 2000). We are all potential health service consumers and most if not all of us have been. The definition of involvement can be from getting information about your health care, to being consulted to be active participants, to sharing control, to being in charge. That is, the level of involvement is on continuum. The role of users is distinct, but a complementary role to professionals.The involvement of consumers in mental health services has been happening for the past 15 years (Crawford, 2000). The National Service Framework for Mental Health asks for consumers to be involved in the development of services, evaluating the performance of services and the training of professionals (Department of Health, 1999).

The research evidence supporting consumer involvement is minimal. If the aim of consumer involvement is to improve status then there has been a reasonable success, but if to change services the success is small. There tends to be lack of resources in terms of support and training for encouraging consumer involvement.

A commitment to involving users

The Royal College of Psychiatrists is committed to consumer involvement and has the well-established Patients and Carers Liaison Group. This group aims to initiate reform in psychiatric training, practice and policy, to join with the profession in lobbying for the cause of those with mental health problems, and to give a more powerful voice to patients and carers themselves. This group is to become a Special Committee of Council. Brian McGinnis from Mencap and Wendy Perez from St George's Hospital Medical School, London are members. Wendy is also a member of the Learning Disability Faculty Consultation Group.

The Consultation Group within the Learning Disability Faculty aims to complement the Patients and Carers for consumer involvement in Learning Disability Services. A workshop titled 'Involving Users – Really doing it' was held at the Learning Disability Residential Faculty meeting on 11th October 2001. Eight people attended. Most present were 'converted' and actively involved in consumer involvement in various ways. The main theme to emerge was the lack of easily accessible published and training material for those less experienced. Our first task as a group is to produce a handbook on 'How to involve consumers in Learning Disability Services' and hopefully to have follow-on workshops.

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

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Two Yoghurt Cartons and a Piece of String

Dr Roger Banks

The Executive of the Faculty met at the beginning of last year to produce a strategic plan. Surrounded by billowing sheets of flip chart and high on the fumes of board-marker pens, many of us felt somewhat overawed. It was not so much the volume of work that we had been able to generate but the recognition that so much activity takes place not simply within the Executive meetings and throughout the numerous layers and branches of the College structure but on a day to day basis within the membership of the Faculty and College as a whole. The stupefying task at hand was how to try and capture the whole picture, how to co-ordinate the thoughts, creativity, research, experience, opinion, passions and obsessions of those working and training in the Psychiatry of Learning Disability. A further issue was how also to ensure that this was linked in to the activity of the College in a coherent, timely, proactive and efficient manner.

Having suggested that perhaps what we needed was a Communication Strategy, I quickly found myself with my head jutting dramatically above the parapet and thus took on the task of convenor for a Communication Strategy Sub-Group.

A number of pertinent issues were taken from the strategy day itself including:

- The onus of responsibility for providing a Faculty response to College communications (often with little notice) falling chiefly upon the Chair and Honorary Secretary when they may not be best placed in terms of availability, time, area of direct knowledge and expertise to do so.
- Difficulty in sustaining an active dialogue with the Regional Representatives.
- The establishment of other subgroups with particular remits within the overall Faculty strategy.
- Awareness of a need to engage more effectively with the whole membership of the Faculty.

Welcome to the communication strategy subgroup!

The Communication Strategy Sub-Group is comprised of Ms. Gill Gibbins, Dr. Meera Roy, Dr. Jane McCarthy and with assistance from Dr. Val Anness and Dr. Peter Carpenter as required. In consultation and discussion the members of the group spent some considerable time considering the various ways in which we think and talk about 'communication'. It is very easy to be lured into immediate technological solutions of telephones, faxes, e-mail groups, video links and so on. Most of us were acutely aware, however, that despite finding ourselves with an increasing number of such gizmos, we seem to communicate less and less effectively! How many unread or unanswered e-mails do *you* have in your In-Box?! We felt that the fundamental issue was that of the reciprocity of communication; the listening as well as the speaking, the 'learning from' rather than the lecturing to, the psychotherapist's 'facilitatory grunt' as opposed to the symptom checklist. You can shout into an empty yoghurt pot as loud as you like but unless there is a taut piece of string

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RCGP Working Group

- Potential development of a basic education pack for members of the primary healthcare team drawing together information from a variety of relevant sources.

It is recognised that the group will inevitably have limited scope. However, by continuing to raise awareness of learning disability issues within general practice, providing or facilitating availability of relevant educational material and by continuing to lobby on relevant issues, it is felt that the group has the potential to provide a relevant and necessary service.

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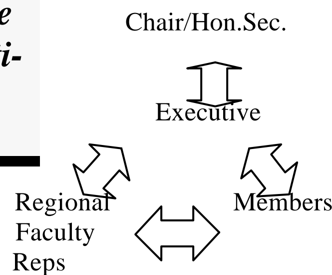
connecting it to another pot and a co-operative friend at the other end, it is a fairly useless device! (Humour me, please.) We felt therefore that our primary aim should be to promote and sustain an *active, proactive* and *reciprocal* network of communication within the Faculty and its membership:

> ***"The membership as a whole will be consulted on pertinent issues"***



A number of preliminary recommendations have been made and ratified by the Executive:

- The Regional Representatives Group will function as a sub-group of the Executive. A Chair and Honorary Secretary should be elected from among this group to serve as co-opted members of the Executive. They should hold 2-3 meetings a year (could take place in College on same day as Exec. Meetings). The Executive officers should meet the Regional Representatives Group before their meetings twice a year.
- A number of sub-groups of the Executive were established or reconfirmed at the Strategy away day. Members were identified to act as convenors of the group. The Chair and Honorary Secretary of the Faculty will be supported in delegating tasks to the convenors to take up and respond as appropriate. Convenors and their sub-groups will be encouraged and feel validated in taking a more proactive approach to their particular remit (while ensuring that the officers and assistant secretary are kept informed or consulted where appropriate).
- A number of Consultation Groups will be established as part of the Faculty meetings at which the membership as a whole will be consulted on pertinent issues decided in advance by the Academic Secretary and the Executive. These issues will be decided in the light of feedback from the Regional Reps of feedback from the Regional Reps Group, from members' communication to Sub-group convenors and via newsletter responses, business meeting questions and possibly the Faculty web page (see below). A summary of the feedback from Consultation Groups will then be given as part of the Faculty business meeting and will go on to form part of future Executive agendas and the work of sub-groups. Convenors will be given copies of the feedback to guide the work of the sub-groups.
- The Faculty web page is potentially an important aid to achieving our aims as set out above. In its present form, although informative, it is not as interactive and encouraging of active involvement of the membership as it could be. A number of amendments are proposed:
  - Details of the Sub-Groups and convenors, and Regional Representatives to be clearly available.
  - The Chair's regular summaries to be on the web page.
  - The establishment of a 'Chat Board'.
  - The Penrose Society to consider establishing a research forum and chat board on the website.
  - Job descriptions for the posts on the Exec. to be available from the website.
- These aspirations do not match up to what is currently available on the College website. Chat Boards and the like require someone to administer them and at present we do not have these resources. Dr Peter Carpenter however continues to take a lead on this and we hope to find ways of establishing a more interactive and lively website. (We may draw the line at a 'jokes' page for fear of indiscretion!)
- The Faculty newsletter is recognised as an important and high-quality asset to the aims of the communication strategy. It is proposed that:
  - The Newsletter should develop closer links with the Faculty website (and perhaps could be downloaded from the site).
  - A trainee will be appointed to the Board.
  - Feedback from CTC meetings should be included.

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Royal College of Psychiatrists Working Group On Psychiatric Treatment within Secure Settings

The Executive and Finance Committee of the College has set up the above Working Group under the chairmanship of Pamela Taylor, with relevant Faculty and regional representation. The terms of reference are as follows:

- To review evidence on the appropriate relationship between custodial and therapeutic provision in physically secure (locked) settings for people who are judged to pose a risk of harm to others and have a mental disorder. For the purposes of the report our constituency encompasses all those people in need of psychiatric treatment in locked hospital units, secure hospitals and other locked settings, including social services units and prisons.
- To provide a report, with recommendat– ions, on maximising safety for those people, their intimates and associates, staff in the settings and the wider public.
- In preparing the report, the Working Group will review published literature, any annual reports or figures on incidents or related issues as may be generated in such settings, and will consult with a range of interested parties.

"Communication between us, patients, families and carers is vital"

The working Group would be most grateful to hear from members with any evidence, experience or advice which would help our deliberations.

The consultation paper is accessible on the College website at: http://www.rcpsych.ac.uk/members/membership/comments.htm.

Responses should be addressed to:
Professor Pamela Taylor, c/o Andrea Woolf, Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG.
awoolf@rcpsych.ac.uk

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Two Yoghurt Cartons

- Future editions may consider publishing the job descriptions for Executive members and officers.
- Future editions may consider appproaching College Officers to provide a series of brief articles describing their role and responsibilities (this has been done in the newsletter of another Faculty).
- More articles describing the work of the Executive should be commissioned.

Since taking on the role of convenor for this group I have also been nominated to sit on the Public Education Committee of the College. It is quite clear to me that in addition to looking at how we talk amongst ourselves, it is vital that we begin to look at how and what is communicated between us and our patients, their families and carers. The next task therefore is to produce a Public Education Strategy for the Executive and I would be most grateful for any thoughts, advice, experience and initiatives that members would wish to contribute. So, yoghurt pots at the ready, tighten your strings and .. Oh for anyone who hasn't got one, here is one I prepared earlier……

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Blake Marsh Lecture, 2003

Do you have any nominations for the Blake Marsh Lecture, 2003? On alternate years an international speaker is invited. The 2002 Lecture will be given by Dr. Oliver Russell from Bristol. If you would like to nominate an international speaker for 2003 please send this to Dr. Mary Lindsey at the Royal College of Psychiatrists together with a citation for consideration by the Executive Committee.

Continuing Professional Development Dates

The Spring Meeting of the Faculty

Wed 24 April 2002
Kensington Town Hall, London
Joint meeting with the British Psychological Society. The main theme is to gain a greater mutual understanding of the two professions' similarities and differences in working with people with learning disabilities. The day will involve presentations of successful joint working, possibilities for closer working and reflective sessions involving legal and ethical issues.
Keynote speakers include: Professor Eric Emerson, Dr. Shoumi Deb, Dr. Dave Allen and Dr. Richard Jones.
Contact: The Conference Office, Royal College of Psychiatrists.

The Annual Residential Meeting of the Royal College of Psychiatrists

Monday 24 – Thursday 27 June 2002
One day will be devoted to evidence-based updates on specific areas in the psychiatry of learning disabilities, dementia, neuropsychiatry of epilepsy, management of challenging behaviour, eating disorders. Tutorials will address implementation into clinical practice. Highlights include the Blake Marsh lecture to be delivered by Dr. Oliver Russell, followed by the Blake Marsh reception and Blake Marsh supper at Cardiff Castle.
Contact: The Conference Office, Royal College of Psychiatrists.

Joint Meeting of the Health/Mental Health SIRGs of IASSID – in collaboration with the Penrose Society and Scottish Section for Learning Disabilities of the Royal College of Psychiatrists

Wednesday 11 – Friday 13 September 2002.
University of Glasgow, Glasgow.
Key themes are research in mental health, mental health associations of epilepsy, health screening and health checks. Abstracts are invited.

Keynote speakers include Dr. Helen Beange, Prof. Patricia Noonan-Walsh, Dr. Mike Kerr, Prof. Matti Sillanpaa, Dr. Tony Holland and Dr. Betsy Benson.
Contact: Isobel Hodge, Secretary to Prof. S-A Cooper, Department of Psychological Medicine, University of Glasgow, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH.
ih51h@clinmed.gla.ac.uk or
www.iassid.org (on-line registration is available)

European Association of Intellectual Disability Medicine (MAMH)

Thursday 6 June – Saturday 8 June 2002.
Debrecen, Hungary.
Contact: Prof. Eva Olah, Congress Convener, Department of Pediatrics
Eva.ola@mamh.net or
MAMH website: www.mamh.net or
Conference website: www.pediatrics.dote.hu.mamh.html.

Faculty of the Psychiatry of Learning Disability of the Royal College of Psychiatrists Annual Meeting

Tuesday 1 October – Wednesday 2 October 2002.
Ramada Plaza Hotel, Bristol.

Alex Shapiro Prize Awards

Congratulations to the winners of the Alex Shapiro Prizes at the Residential Meeting in Chester, 2001. Dr. Farooq Ahmad (North Warwickshire NHS Trust, Dept of Learning Disability Psychiatry, Brooklands, Birmingham) won the prize for best oral presentation, and Dr. Bunny Forsyth (East Gloucestershire NHS Trust) won the prize for best poster presentation. Dr. Jane McCarthy won the Lundbeck Debate at the same meeting.

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