



Learning Disability Psychiatry

Newsletter of the Faculty of the Psychiatry of Learning Disability

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Letter from the Chair

Professor Greg O'Brien

“Letters from Somewhere Else”

“If you really want to learn what it’s like here, go somewhere else.” This was one of the more memorable pieces of advice I picked up from the one major management course I went on, some years ago. It was quite a good course. The highlight of it was a month full-time in residential business school, on what was then supposed to be the first module of the MBA I never did. The greatest insight the course afforded me was the realisation that I didn’t want to train further as a manager. The most powerful message they kept emphasising to us was to learn to live with messy services, and to avoid even trying to set up

“business-like” structures: which “business”, of course, ditched decades ago. But what I remember most vividly were the reflections on the importance of taking time out in different places, because of the major benefits it brings to one’s insight into one’s own situation.

This may sound like a desperate attempt to rationalise a major spell of globetrotting. (It certainly does to my wife. No amount of insight into one’s own situation is quite on the scale of being around to calm warring children at home.) But my most recent set of jaunts has put me firmly into pensive mode, particularly regarding the state of our own services, and where we might go from here.

Hence the following “letters”, which reflect my most recent trips – to San Francisco, and the Ukraine.

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Editorial board:
Dr Roger Banks (editor-in-chief)
Dr Geraldine Holt
Dr Philip Dodd

The Chair,
The Convocation of Psychiatrists Prescribing for Persons with Mental Retardation,
The American Psychiatric Association.

Dear Doctor

It was a pleasure to join you and your colleagues at the round table discussion in San Francisco at this year’s APA. As this was the first time I had met your group, I came away with a set of strong messages.

I guess my starting point is to reflect on the similarities and differences between our respective situations. I had long believed that our system over on this side of the pond is unique, in that we have a national training programme geared specifically towards learning disability psychiatry. It was therefore interesting to meet those senior trainees at your meeting who are actively considering taking up residency training posts in certain States, in mental retardation psychiatry. As far as I could make out this is not common in the USA, but it may be a growing trend, based on a perceived need.

cont. overleaf

That there is such a "perceived need" is interesting in itself. Over the course of your meeting, I heard a lot of points which rung bells with me, having heard them often in various settings here. In common with yourselves, we are keenly aware of the need for a specialist approach to prescribing for our patient group, where dosage regimes, side-effect occurrence, choice of medication and other principles of prescribing are somewhat different from those which apply to the normally intellectually endowed population. These principles, and the need to develop the evidence base which underlies them, are clearly concerns we share, and which may well form the basis for some important projects. I am confident that our Faculty and your Convocation can do some really good work together.

Looking back now, what struck me most about the discussion was the account of the pressures and restrictions under which you and your colleagues are now working. Pressures and restrictions which, as I learned over the course of the APA meeting, are shared with all psychiatrists, but which do seem to be hitting you especially hard. Before I came to your meeting, I had no idea that you are facing such massive cutbacks in service, and that so many specialist services are being closed down, on a finance-driven, unplanned basis. It sounds like the kind of thing that happened to us here some years ago, and from the effects of which we are still reeling. Unlike some States of the USA, in the UK we no longer have large long-stay institutions. Certain consequences of the cuts in your service budgets are therefore not something we would share. But one consequence I certainly recognise, and fear: managerial limits being arbitrarily set on the medical care of individual cases, without consultation, and against specialist medical advice. How best should one carry out clinical practice in such difficult circumstances?

In this regard, I was intrigued to learn that you, as the chair of "The Convocation of Psychiatrists Persons for People with Mental Retardation" do not, in fact prescribe for this group at all. As I understand it, by choice, your contract does not allow you to prescribe drugs. Instead, you operate as a source of advice. As a consultant, I guess.

Maybe we should go down this route. I don't know. In some ways, it's a logical next step for us as we develop joint working. I'd be fascinated if you could drop me a note, saying something about how this has worked out, perhaps comparing it to any other contract you have had, where you were "a prescribing psychiatrist".

Yours, Greg O'Brien

*The Minister for Child and Family Health
Kiev
Ukraine*

Dear Minister

It was a great pleasure to meet you on the occasion of my recent visit to the Ukraine, as part of our development project with UNICEF, on the health care of young people with severe disabilities in the new independent nations of Eastern Europe. It was especially kind of you to be so very frank in your account of the challenges your country has had to face, in moving on from the health and social care systems which were in place under the Soviet regime. We learned that the principle of "defectology" had meant that people with severe disabilities who could not contribute to society were effectively removed from society under that regime. It was fascinating to learn that the first piece of major legislation your government had passed had effectively revised this, as part of a wider move towards the assertion of the individual's rights of all Ukrainian citizens. I do not underestimate the challenges you still face. Because you were so careful to explain your funding limitations, I hardly could. But the people we met were clearly full of energy, especially the recently established non-government agencies with whom UNICEF is collaborating in your country.

As you are aware, we are planning a major meeting in Kiev next year, to be hosted by the British Council. We look forward to seeing you there, along with representatives from other new independent eastern European nations.

One closing thought - the more I think about it, the more I think that "defectology" didn't just operate in the USSR. And it may still be operating, not so far from here.

Yours, Greg O'Brien

Adolescents with learning disability and a mental health problem: can we get it right?

A Hassiotis*, J Turk, C Katona

Since the Isle of Wight study (Rutter et al, 1970), it has been established beyond doubt that a third to more than two-thirds of children and young persons with learning disabilities have mental health problems, depending on the type of assessment used, sample ascertainment and level of learning disability (Molteno et al, 2001; Cormack et al, 2000; Stromme & Diseth, 2000; Linna et al, 1999; Einfeld & Togue, 1996). The prevalence of such disorders is increased when compared with rates of psychiatric disorders in children and young persons of average intellectual ability (Emerson, 2003).

Interest in the mental health problems of young persons with LD has been rekindled in the UK as a result of "Valuing People" (DoH, 2001). One of the groups that has been singled out as most likely to suffer from social exclusion and lack of service support is that of older adolescents at the time of transition to adulthood, and consequently to adult specialist learning disability services. Only a few studies have specifically investigated the prevalence of psychiatric problems in the group of young people with LD aged 12 to 19. The first one by Gillberg et al (1986) found that over half of 13-to-17-year-olds with mild LD and up to 64% with severe LD had mainly "autism-like" psychotic behaviour. A recent study of 12-to-19-year-olds in one catchment area (Hassiotis, in preparation) found that 50.7% of parents who completed the Developmental Behaviour Checklist reported their children as having sufficiently severe behavioural problems to require further psychiatric assessment and/or management. Male adolescents were twice as likely to be reported as cases with more prominent anti-social, disruptive and anxious behaviours. Low levels of daily living skills and socialisation were symptoms significantly rated by parents as contributory factors.

In addition, adolescents with autism were more likely to be reported as cases. 44 out of 75 (total number) adolescents were identified as approaching or being in transition (15 to 19 years old). They appeared to have significantly lower scores in daily living skills, but no other differences were identified in terms of level of LD, DBCL scores, gender or social class. Level of LD, socialisation scores (Vineland Adaptive Behaviour Scale) and family history of mental illness contributed significantly to reports of caseness.

Services - at least in their conventional format of social care (allocated social worker) and health care

(Child Development Teams, Child and Family Consultation Services or even Specialist Learning Disability Services) - do appear to be available and accessed. As many as half of the participating parents said that they visited their GPs often (at least once a month) to seek help for the young person's behavioural problems. Overall, however, there appeared to be fragmentation of provision, little emphasis on after-school activities and occupation and limited respite choices.

Although these findings may represent a local situation, it does not appear to be very different from what happens elsewhere in the UK, though there are a few notable exceptions. While the current focus is on those in transition, it is abundantly clear that psychological problems have been present for several years. Our research indicates that it is the diminishing ability of the young person to cope with increasingly challenging tasks and the lack of co-ordination between services that brings transition into the spotlight. A care manager and transition worker in a service described her frustration with the Social Services for children with special needs at the point of transition as "now cutting care packages to the quick".

Tackling problems only at the point of transition will have already delayed the opportunities of young persons with LD to lead an ordinary life, especially as many may have already experienced exclusion from the education system with continuing difficulties in re-integration. Young persons with LD also access GPs a lot less than their peers of normal intelligence because of difficulties in communication, knowledge about services and diminished ability to seek help (Howells, 1986). Increasing awareness of the psychological difficulties earlier in the lives of the young persons, the offer of appropriate treatment options and mental health promotion are the first necessary steps in achieving good mental health and social inclusion. Several reports, for example "Count Us In" (2002), in addition to "Valuing People", have argued persuasively for the need to develop streamlined and inclusive services for adolescents with LD with clear protocols and care pathways. However, this is still far from today's reality. More cuts in social care budgets as well as other service priorities will hinder still further the much-needed improvements in this field.

(contact: a.hassiotis@ucl.ac.uk)

References

1. Department of Health (2001). *Valuing People: A new strategy for Learning Disability for the 21st century*. UK
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Count Us In:

The report of the committee of inquiry into meeting the mental health needs of young people with learning disabilities

Mary Lindsey

This report by the Foundation for People with Learning Disabilities is based on the work of a year-long inquiry. A variety of approaches was used to obtain evidence from as many sources as possible. These include focus groups with people with learning disabilities and with carers, literature reviews, visits and written and oral evidence. Young people were defined as 13 to 25 years of age. The inquiry was UK-wide and so recommendations had to take a lot of diversity into account and to focus on the factors that underpin good practice. These cover:

- Inclusion and rights
- Research
- Information
- Promoting emotional well-being
- Services for young people with learning disabilities and mental health problems
- Education
- Workforce development

Those particularly relevant to psychiatric services relate to:

- a) planning – local agencies should map existing services and audit the skill levels of staff working in services for young people with learning disabilities and mental health problems
- b) clear protocols for referrals and/or care pathways with the roles and responsibilities of services set out so that holistic treatment can be delivered
- c) access for those from minority ethnic communities should be monitored to determine whether action should be taken to avoid discrimination
- d) within mainstream mental health services for both adults and children there should be a lead person to ensure that needs are being met and that there is professional development of staff
- e) agencies responsible for strategic planning should identify a lead person to ensure that there is coherent planning to meet the needs of the young people with the most complex needs and to support maximum inclusion in mainstream services using specialist services as appropriate

Chapter 6 of the report covers the commissioning and provision of services and there are a number of

key messages that include the issues of transition; the need for a range of services, both generic and specialist; the needs of those involved with the criminal justice system and abuse. It is also suggested that inter-disciplinary training should be explored including at a postgraduate level. The need for further research is also clearly identified.

Further information is available from:

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Jill Davies - Research Programme Manager
 Foundation for People with Learning Disabilities
 83 Victoria Street
 London SW1 0HW - UK
 Tel: +0044 207 802 0300
 Fax: +0044 207 802 0301
 E - mail: fpld@fpld.org.uk
www.learningdisabilities.org.uk

and the report can be purchased from the Mental Health Foundation at the above address price £27.50 for professionals (£12.00 for carers).

The National Autism Plan for Children (NAPC)

Tom Berney

The level and style of provision for autistic spectrum disorders (ASD) vary greatly from area to area as does the degree of co-ordination between the various agencies – health, education, social services and the private/voluntary sector. Children with ASD present the inclusion policy with one of its greatest challenges.

The National Autism Plan for Children initiative, aiming to plan better and more consistent services, came jointly from our College, the RCPCH, the All-Party Parliamentary Group on Autism and the National Autistic Society. Called the National Initiative for Autism (Screening and Assessment) (NIASA), it was led by a child psychiatrist (Ann Le Couteur) and a developmental paediatrician (Gillian Baird). It included representatives from a number of other bodies (the British Psychological Society, the Royal College of Speech and Language Therapists, the Health Visitor Association, Educational Psychology, the Special Educational Needs Regional Partnership, General Practitioners, the British Association for Community Child Health, a parent and observers from the DoH and the DfES). The panel of 15 members met monthly for a year, reviewed literature and heard evidence from a variety of experts about services, investigations and assessments.

The model was a USA committee that two years earlier had produced a set of guidelines for the early identification of autism (Filipek, 1999). These suggested that diagnosis might be approached at two levels:

- 1) *Routine developmental surveillance with*
 - a) Indicators for immediate evaluation
 - b) The use of autism-specific screeners whenever there is cause for concern
 - c) Level One laboratory investigations (particularly audiology if doubt about language or hearing.)
- 2) *Diagnosis and evaluation of autism*
 - a) Formal diagnostic procedures using standardised instruments.
 - b) Expanded medical and neurological assessment to pick up any underlying brain pathology or the conditions that are commonly co-morbid with ASD.
 - c) Specific evaluations of the developmental profile that include assessments of IQ and levels of functioning.
 - d) Assessments of family functioning and resources.
 - e) Expanded laboratory investigation where there are indications for it – e.g. genetic testing (routine EEGs were not recommended except extended EEG in children showing regression).

The UK has its own particular issues, not just in service provision but also the increasing number of organic anomalies open to investigation that might be followed by corrective treatment. An even development of minimum clinical standards across the UK was needed urgently. The study focused on the problem of early diagnosis since, although the average age is steadily decreasing, there remains great regional variation with long delays between a parent's first concern and the final diagnosis. The themes running through the UK plan are:

- early identification
- a clear pathway for referral and early intervention
- multi-agency assessment and joined-up provision
- support and clear information for parents
- greater awareness and skills among relevant staff

It complements a report produced by the West Midlands Partnership as well as good practice guidance produced earlier by the DoH and the DfES.

The elements of the plan are:

Identification – universal screening is not recommended but there should be widespread training of professional in “alerting” signals indicating the possible presence of ASD. Routine

developmental checks (about 1, 2 and 4 years) would give parents the opportunity to discuss their child's progress. There should be clear referral pathways and a system of auditing the age and type of referrals.

Assessment:

Stage 1 – A General Developmental Assessment (GDA) should be available locally for any child with a possible developmental problem. Referrals should be responded to within 6 weeks and the GDA within 13 weeks with immediate feedback to the family (even if there is no clear diagnosis).

Stage 2 – A Multi-Agency Assessment (MAA) by a local team which includes an educational specialist, an ASD family support worker and ASD-trained lead clinician(s). It includes ASD specific interviews and observation in more than one setting as well as intellectual and functional assessments, particularly of speech and language as well as of family resources and needs. Physical investigations should only be carried out where there is clinical evidence for them. This assessment should be completed within 13 weeks and fed back to the family within a further 4 weeks. The family should have a written report for discussion that includes an agreed account of their child's needs and a Family Care Plan (FCP) to meet them.

Stage 3 – Tertiary ASD assessment where there is need for a second opinion because of diagnostic doubt, the complexity of the case or specific advice about treatment/management.

Interventions

A co-ordinated care plan should be produced within 6 weeks of the MAA supported by a key worker and regularly reviewed with the family who should get information about local parent groups. The pre-school child should get 15hrs/week of ASD specific programmes in addition to input for any other problems that might need to be addressed by, for example, the CAMHS/LD services. Family Care Plans (FCP) and Individual Educational Plans (IEP) should include clear ASD strategies and opportunities – every local area should have an ASD trained teacher who can visit any school and advise and set up the IEP within 6 weeks.

Resources

This plan makes a big claim for resources – key workers, care managers and a variety of professionals will need to be trained and employed. Schools will need to provide not just for the child with florid autism, but also for the more able child with Asperger's syndrome. The report will not produce these resources but will make the shortfall more obvious. The aim should be the development of a co-ordinated, local, multi-agency service that is clear to the families, works within the set timescales and audits what is happening.

ASD is a major element of our work and training and experience in autism has always been part of the LD syllabus; it will now become more explicit. The financial consequences are huge and thus professionals are more likely to find their opinions and methodology questioned.

A CPD programme might include training in some of the various formal assessments that are emerging – for example:

- the Diagnostic Instrument for Social and Communication Disorders (DISCO)
- the Autism Diagnostic Interview (ADI)
- the Autism Diagnostic Observation Schedule (ADOS)
- the Family History Interview (currently in development)
- The Childhood Autism Rating Scale (CARS)

The political emphasis at present is on early diagnosis, especially problematic in more able and older people. This plan deals with young children and points out that we have to go on to review the provision for adolescents and adults; something that the College is beginning to consider in order to give its psychiatrists the necessary training and support. Both “Valuing People” and a College working group (on the interface with general psychiatry) have picked out people with Asperger’s syndrome as the exception to the proposed intellectual divide between mainstream and LD psychiatry. There is a flurry of national meetings and an informal SIG is emerging.

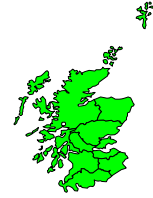
The increasing numbers of people that have been identified with ASD is moving the spotlight towards the implications for management and treatment and psychiatry’s part in this. Parents, with access to a large amount of internet information, are becoming experts on aspects of physiology, pathology and education. Some of the most convincing material has little foundation other than its intellectual coherence. An exciting world in which we must run faster to keep up.



News from Scotland

Susan Miller

Chair of Learning Disability
Section of Scottish Division



The situation for people in Scotland with learning disabilities and for those providing their services has been in a state of change both in the way the services are provided and the legislation.

Legislative Changes

The Adults with Incapacity Act was implemented in Scotland in the year 2000 and in general has been felt to be a major step forward for people with learning disabilities. However, we are still all becoming familiar with Guardianship under the new Act and the use of Part 5, which deals with medical treatment and research. There have been some difficulties with the use of Part 5 and the Code of Practice is already being reviewed with input from the Learning Disability Section, through its Executive.

The Mental Health Scotland Bill is now through Scottish Parliament and awaiting Royal Assent. The implementation date appears to be slipping, currently back to October 2004. The Scottish Division of the Royal College of Psychiatrists has a working group looking at all aspects of the change of the Mental Health Act and Dr Pauline Robertson, from the Learning Disability Section, is involved in this.

The Same As You

Most of the service changes follow on from the introduction of the “The Same As You” (2000). One of the main thrusts of the document was that all long-stay hospitals for people with learning disabilities should be closed by 2005, so those areas which have not closed long-stay hospitals are actively involved in large resettlement programmes. There are a number of implementation sub-groups, including one on hospital closure and its consequences in which the Section has been involved. Professor Anna Cooper has carried out a review of assessment and treatment in-patient services for adults with learning disabilities recently on behalf of the Hospital Closure sub-group which confirms the suspicion of many in the field; 25% of all assessment / treatment beds are currently blocked and the lack of capacity in other community

WANTED!

Bright, enthusiastic specialist registrar to join dynamic and creative editorial board for this faculty newsletter. An excellent opportunity to focus your literary and communication skills, to promote issues of interest and concern to fellow trainees and to saunter nonchalantly through the corridors of power.

The Editorial Board aims to meet face-to-face four times a year but operates day-to-day in “virtual e-space”. Assistance with travel expenses is provided.

Please forward a brief CV to the Editor in Chief at: Roger Banks@ed.ty.wales.nhs.uk

resources accounts for some of these issues. There is a concern that demand already outstrips resource, even though hospital closure programmes are not completed.

The impact of an ageing learning disabilities population also has not been taken into account. Other documents influence the way community care will be delivered, such as "Joint Futures" leading to joint working between health and social work and the introduction of joint assessments.

**Public Health Institute for Scotland (PHIS)
Learning Disability Health Needs Assessment**

Professor Anna Cooper and Dr Neill Simpson have been very active in this but other members of the Section have been involved. The needs assessment has the remit for addressing all health needs of children and adults with disabilities in Scotland and is multi-disciplinary. Neill Simpson chaired the Mental Health Working Group and members of the Section have been asked to be involved in the Expert and Consensus Group and a panel of international experts that will comment on the data and help to formulate the final report.

Joint Working

The Section has been having monthly joint meetings with the Association of Directors of Social Workers in Scotland, looking at areas where there is difficulty in the provision of care e.g. challenging behaviour and forensic services. The joint groups are drawing up reports to submit to the "The Same As You" Implementation Group to help inform future planning and practice.

Workforce Planning

SpR recruitment to Learning Disability Psychiatry is good at present. Training is centred in three regions: West of Scotland, East of Scotland and Tayside. There are, however, consultant vacancies in some areas of the country. We are represented in discussions about workforce planning via the Scottish Division. Services for children and adolescents with learning disability within Scotland are particularly patchy. This reflects the near-crisis point of consultant staffing in child and adolescent services in Scotland in general.

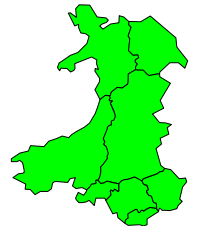
Scottish Learning Disability Section

The Section would see itself as friendly and inclusive and is fairly active. There are quarterly business/executive committee meetings plus twice-yearly, well attended academic meetings. We encourage the trainees to get together Scotland-wide periodically. We are represented via the Chair on the Faculty for Learning Disability Executive and also on the Scottish Division of the Royal College of Psychiatrists. We have recently drawn up a list of mentors to new consultants to try and encourage retention within the specialty and support new colleagues.

Research interest in learning disability psychiatry is strong in Scotland. Readers will be well aware of Professor Anna Cooper's contributions to the field from the University in Glasgow. Walter Muir has a strong department in Edinburgh and there is also considerable research from Dundee. Trainees in particular have benefited from the quality of research supervision available.

I hope this whistle-stop tour of where things are at in learning disability psychiatry in Scotland is of interest.

**Newyddion o Gymru
(News from Wales)**



Ray Jacques
Secretary, Learning Disability Section
of Welsh Division

The past few years have seen a number of fundamental organisational and governmental changes in Wales, which have altered the context in which learning disability services are being developed (hopefully!) and planned (possibly?). Political devolution in Wales, as in Scotland, has led to divergence, brought home to us when we meet colleagues from across the United Kingdom. Where the issues may remain the same, the opportunities and obstacles to development may not be so. It may be helpful to point out the major organisational changes which affect Wales and not other areas in the United Kingdom.

Devolution in Wales produced the National Assembly of Wales. The Assembly lacks the full legislative powers of the Scottish Parliament but it assumes responsibility for health and social services within the Principality. Guidance and policies from Westminster usually go through a process of "cymrification"! At times this can lead to differences of emphasis or even a more radical departure from guidance from the Department of Health.

Re-organisation within the National Health Service in Wales has also occurred. Five health authorities responsible for commissioning services in Wales were disbanded in March 2003 and replaced with 22 local health boards, co-terminous with the local authorities. Theoretically, these boards are responsible for the commissioning of learning disability services, but it is becoming apparent that another tier of "secondary" commissioning will be developed. To increase the complexity even further, there is an all-Wales body that is responsible, among other things, for medium and high-secure services for people with learning disabilities. Specialist learning disability health services sit within large mixed trusts managing both acute and community-

based services (Wales has no such beasts as primary care trusts).

I suspect that the problem of change is the same everywhere, and experience of trying to learn which elements of the new organisational structures are open to influence or indeed have influence will take some time. When I asked my trust representative on our local health board what might be the future direction for commissioning of learning disability services, she explained that they are still trying to work out their parking arrangements!

Learning disability services have been influenced greatly by the All Wales Strategy (1983). Although all organisational remnants of this have now gone, the principles and values of the strategy remain ingrained. The title of the advisory report to the Welsh Assembly Government, "Fulfilling the Promises", alludes to the work still needing to be done to fulfil the aspirations of the strategy. An implementation group for the report has recently started to meet; in what form central guidance will be issued is, however, still unclear. Even less clear is whether additional resources will be made available.

Recruitment and retention of psychiatrists in learning disability across Wales has historically been quite good. In this respect the influence of Bill Fraser in raising the profile of psychiatry in learning disabilities in Wales and attracting people to work here cannot be overestimated. The appointment of Mike Kerr to the Professorial Chair is very welcome and I am sure will maintain the development of the academic profile of Welsh psychiatry in learning disabilities internationally.

In the consultant body, recruitment issues vary from area to area. In recent years, there has been development in west Wales with the appointment of Helen Matthews and Bill Thompson as consultants. There is a vacancy in Pembrokeshire (a very beautiful part of the country with excellent work/life balance opportunities!). The situation in North Wales is more difficult, with vacated posts not being re-advertised.

The Welsh Section of the Faculty meets three times a year, alternating between north, mid and south Wales. As a Section, we are trying to influence development of policy and ensure representation for the psychiatry of learning disability on the various groups. We are hoping to develop links with the psychotherapy section and also with psychology services in Wales. We have a working group looking at out-of-area placements, some areas of Wales being 'importers' from the rest of the United Kingdom, and others being 'exporters'. It is hoped that we will be able to get a clearer picture of the numbers of people involved. Work is also being undertaken on development of care pathways for people with Alzheimer's disease and epilepsy.

In summary, not everything in the Welsh garden is sunshine and roses and the process of organisational change and development of services can be frustrating. Despite this, there are still very significant rewards, even if you do have to put up with the singing and getting beaten by the English (and Italians and French and Irish etc.....) at the national game.

Hwyl Fawr!

2004 Burden Research Prize

The Burden Research Prize is awarded by the Burden Trust every three years for outstanding research work in the field of learning disabilities. In 2001 the prize 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.

The Burden Trust now invites applications for the 2004 Burden Research Prize. The prize, which consists of an award of £1000, is open to all registered medical practitioners, the greater part of whose time is spent working in the field of learning disabilities in the United Kingdom or the Republic of Ireland. The prize is awarded for outstanding research work, which has either been published, accepted for publication or presented as a paper to a learned society during the three year period ending 31 December 2003.

An application form and further details may be obtained from:

Dr Oliver Russell,
Norah Fry Research Centre,
University of Bristol,
3 Priory Road,
Bristol,
BS8 1TX
(Tel: 0117 923 8137).

The closing date for submissions is 31st December 2003.

New Council Report on Psychotherapy and Learning Disability!

Maria McGinnity

Chair of Joint Faculty Working Group

Everyone who works with people with learning disability needs a copy of this new Council Report, which is to be published in the Autumn. At least that's what the members of the Joint Faculty Working Group which produced it and everyone we consulted over the past three years will say! I hope that you will already be aware of this work, since part of our strategy has been to engage and learn from our own membership and as many other disciplines and interested parties as possible. Indeed, since I know that you are going to read the report as soon as it is available, I am going to concentrate here on the process of how a working group actually can achieve the ultimate aim of influencing College policy, through publication of a Council Report.

A word of caution to begin with; remember that if you put forward a proposal for work to be undertaken, it's a fair bet that you will be expected to chair the group! Then begins a steep learning curve on how the College committee structures work. Most executive committee members know only slightly more than the average member about this and the College staff (Gill Gibbins in particular) provide a reassuring and guiding hand. Since many policy areas involve more than one faculty they must each accept and support the proposal, the membership, working methods and likely expenses. Only after approval from the Public Policy Committee (PPC) and the Executive and Finance Committee (E&F) can the work even begin. There are now Guidelines for Chairs of working groups, unfortunately I didn't have them until the work was complete!

We knew at the outset that we must have representation from other major disciplines involved in providing psychotherapy for people with LD on our group and this has been a great strength. Ultimately, it also influenced the focus of our report, leading to a broadening of the interpretation of our remit, which was initially psychiatry-based, and gave us a significant advantage in the consultation process. In fact the consultation process began before the group was established, at the Spring Faculty Meeting in 2000, when I held a consultation workshop to shape the remit of the group and to establish useful contacts.

When we began the work we found we were in virgin territory. Although there is a small literature on applying psychotherapeutic methods of working to this population, there was nothing describing the present position in the UK and thus we carried out our own survey in January 2001. This served a useful purpose in making direct contact with members in the LD, Psychotherapy and Child and

Adolescent Faculties and psychologists in the Learning Disability Faculty of the British Psychological Society. Our approach then developed into a combination of formal consultation, informal networking, engaging with parallel developments and a mixture of awareness-raising and education, all of these feeding into and building on each other. This evolutionary process allowed us to not only gather together information which had not previously been collated about service development and training, but also to describe, for the first time to our knowledge, the application of a range of different therapeutic approaches in working with people with LD. It also allowed us to develop a vision for the future, with immediate and longer-term recommendations for policy, services and training for all disciplines.

The draft report gained enthusiastic approval from our parent faculties and was submitted to PPC and E&F for approval. It was here that the extent and breadth of our consultation paid dividends. I was able to present examples of internal consultation e.g. workshops within meetings of the faculties and at an Annual Meeting of the College over the three-year period, external consultation with other professional bodies and agencies, government policy advisors, user-group representation, training institutes etc. With only minimal amendments recommended by each of these committees, we were able to place the report before Council to be approved within three months of starting the process. Publication now brings another phase of the work in which we need to ensure that the Report is distributed and targeted in order to have maximum impact on policy-makers, service developers and training bodies. In many respects, the really hard work is only just about to begin!



Clare Thomas

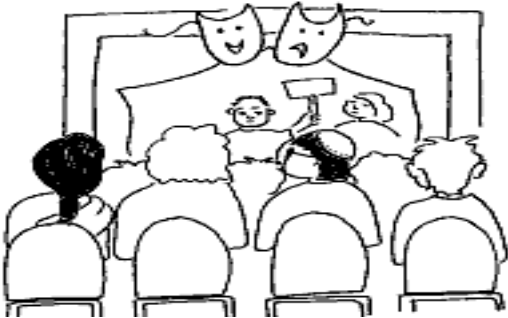
Heart 'n Soul is a dynamic arts organisation working with artists and audiences with learning disabilities. It offers a complementary programme of workshops, training courses, music/theatre performances and nightclub events that provide a ladder of opportunity to its members.

Heart 'n Soul has its roots in a music and drama workshop that Director Mark Williams, then a freelance music tutor, set up sixteen years ago. Pino Frumiento, a co-founder of the organisation takes up the story. "A man came and asked if we wanted to do a music workshop. Now believe it or not, the day

centre didn't agree with it. So he came again, and we said all right we'll give it a go and we've been running ever since, since 1986." With further co-founder and drama tutor Alix Parker, the Original Company, as it became known, began to develop its own aesthetic - a very bold and dynamic brand of original music, theatre that has a universal message, but that speaks very directly to people with learning disabilities.

The Original Company has received much critical acclaim and along the way has forged a path for other developing Heart 'n Soul performance companies and indeed other ensembles of performers with learning disabilities in the UK and abroad. Heart 'n Soul's Original Company has performed in Germany, Holland, Portugal, Greece, Italy, France (to name a few) and at high-profile venues and events in the UK such as the Glastonbury Festival and the West Yorkshire Playhouse. They have also produced two albums that are available on CD and a half-hour long film called *Breaking The Rules*.

Heart 'n Soul now works with over 80 learning disabled artists every week, and welcomes up to 10,000 members of the public to its events every year. Alongside the Original Company there are now six other distinct workshop groups that meet each week at three London venues. The organisation has also inspired a number of spin-off groups in London and the UK, which form an emerging network of cultural opportunities for artists and audiences with learning disabilities nation-wide.



The methodology is simple - Heart 'n Soul is based upon the empowerment of people with learning disabilities to make choices and to access a cultural life. Each of the performance workshop groups is tutored by non-directive professional practitioners who act as facilitators of the group's creative process. Experienced Heart 'n Soul members with learning disabilities are emerging as co-tutors, offering peer mentoring to less experienced artists whilst continuing their own professional development. There is a representative from each of these workshop groups on the organisation's governing Council of Management.

For audiences, the centre of the Heart 'n Soul world is the Beautiful Octopus Club. This is a cabaret nightclub established in 1996 to offer a platform for performance to the Heart 'n Soul artists, and to counteract the prejudice that had excluded people with learning disabilities from accessing mainstream events. The club has a unique blend of live performance and DJs, together with a web and gaming zone, massage and the legendary Open Mic slot. Clubbers come in the hundreds to what the *Guardian* branded "the best club in London". All of the Heart 'n Soul DJs have learning disabilities, as do the Octopus Crew who have received technical theatre skills training within the organisation to empower them to work as stage managers, lighting operators and front-of-house staff at the events. The Beautiful Octopus Club has spread its tentacles to the four corners of London, and in 2002 went on tour to Telford and to Leeds. Heart 'n Soul runs around ten clubs per year including three Squidz Clubs which are geared up for under 25s.



The ladder of opportunity that Heart 'n Soul offers really has changed lives. From the person attending a Beautiful Octopus Club and socialising with people other than those at the day centre for the first time, to the Octopus Crew trainee who at first did not speak but who now is a very eloquent co-tutor. Or the Original Company Member spotted performing at the Open Mic who last year represented Heart 'n Soul when she met Nelson Mandela and who is dreaming of a MOBO award. Each individual sets their own path and makes their own choices, and leaves a trail of opportunity and enlightenment behind them for someone else to follow.



Heart 'n Soul is based in Deptford, South-East London, and tours nationally and internationally. For more information or to get involved please look at our website www.heartnsoul.co.uk or contact the office on 020 8694 1632 (telephone) or 020 8694 1532 (fax).

In conversation:**Professor Bill Fraser reflects on retirement**

Philip Dodd (Interviewer)

Professor Bill Fraser qualified in Glasgow in 1963:FAMed.Sci., FRCPsych., FRP (Edin.), MD.

He was Director of Mental Handicap Services, Fife (1974-78); Consultant Psychiatrist, Lothian Health Board (1979-88); Honorary Senior Lecturer, Dept. of Psychology, University of St Andrew's (1974-78) and part-time Senior Lecturer, Dept. of Rehabilitation Studies, University of Edinburgh (1978-89), before coming to Cardiff to take up post as Professor (Learning Disability) in the University of Wales College of Medicine (1989).

Prior to his recent retirement, he was Clinical Director of the Neuropsychiatry Department at Whitchurch Hospital, which specialises in head injury rehabilitation. He was also Co-Director of the Welsh Centre for Learning Disabilities in Cardiff. He has been Editor of the Journal of Intellectual Disability Research since 1981.

He is author of over 110 papers and 3 books on developmental medicine and learning disability. He was Burden Research Medallist in 1989, and in 1997 was awarded the Distinguished Achievement Award for Scientific Literature by the IASSID in Helsinki. In 1998, he was awarded the CBE.

He is a Trustee of Autism Wales, The Bailey Thomas Trust, and is on the Child and Adolescent Committee of the PPP Charitable Trust.

PD: Professor Fraser, how are you enjoying your retirement?

BF: Well, mixed really. I am enjoying the extra time that I now have for sailing and also to be with my family. I am also still involved in a number of work projects. On the negative side, I do miss being part of a professional team, and in particular miss the associated resources especially my secretary. I now find that, in order to complete a particular task, I have to do all of the parts, including learning how to put a stamp on an envelope! I also find that I have to use my own resources to take part in CPD activities, attending conferences etc. I also have to make extra efforts to maintain my clinical quality, in the absence of colleague audit.

PD: Describe your average week:

BF: I continually relish the fact that I don't work on a Monday! So on Monday, I try to walk or sail, weather permitting (there is a lot of rain in Wales!). On Tuesday and Wednesday, I do clinical work in the private sector, work which has grown somewhat since my retirement. I spend Thursday doing work for Charitable Trusts. I also deal with my own correspondence, primarily by email. I'm about to get broadband internet access which I hope will prove more efficient than my current irritating and intermittent access. On Friday, I do work for the Mental Health Review Tribunals.

PD: What, in your opinion are the important issues currently facing learning disability psychiatry?

BF: I feel that many learning disability psychiatrists are surrendering some very important territory, for example, work with autism. More and more of these children are being looked after by child and adolescent psychiatrists and psychologists who indeed have specialist training to work with these children.

I also think that learning disability psychiatry lacks wide research credibility. This has been a problem for some time, and is clearly illustrated by the absence of MRC and Wellcome Grants given to LD psychiatry research projects. In general, Academic Psychiatry of Learning Disability needs a stronger foundation. There are really only a handful of people in LD psychiatry with research credibility.

PD: And the important issues facing the College?

BF: There is a general problem with the Government taking on medical advice. I think the College suffers from this general problem - we can be so easily sidelined.

We really need people, like our current President, who are lucid spokespersons of stature and charisma for the College.

PD: What do you think is the single most important thing that you have done for LD psychiatry?

BF: I do think I have helped make the *Journal of Intellectual Disability Research* a high-impact journal, in addition to it being highly profitable.

PD: Looking back, if you could change one thing in your career, what would it be?

BF: This is difficult. I think that to be really successful, and effective, one must, early on, carefully plan one's future, and try to stick to that plan. While I always saw myself in academic psychiatry, I spent ten years of my early career working "peripherally", and I missed an opportunity to work in the USA in a major research centre. While I did enjoy the clinical work at this time, I missed a chance to do more important research in famous centres at an earlier stage in my life, and yes, I suppose I regret this.



From Mary Staines, Chair of PLDSAC

Please note that the document describing core competences for higher psychiatric training is to be available on the College website for a 6-month period of consultation.

All trainers are encouraged to download the document, to use it and to feed back comments to the College via the Chair of PLDSAC.

mary.staines@stewartshospital.com

Conferences & Meetings

5th International Congress, NADD, Boston, USA, March 17th- 20th, 2004.

“ Evidence based practices/Practice based evidence in mental health and developmental disabilities”.
www.thenadd.org



12th IASSID World Congress, Montpellier, France, June 14th- 19th, 2004.

“ Towards Mutual Understanding: Person, Environment, Community”.
www.iassid.org



4th European Congress, European Association for Mental Health in Mental Retardation, Rome, Italy, September 17th- 20th, 2003.

“Mental Health and Mental Retardation: A Lifespan Multidisciplinary Approach”.
www.sanraffaele.it
www.sirmonline.it



‘Services for Adults with Asperger’s Syndrome and Autism’, One-day Conference, Barnet, 13th November 2003

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Royal College of Psychiatrists Faculty of the Psychiatry of Learning Disability Annual Residential Conference of Specialist Registrars in Learning Disability **Autism**

Thursday 10th July and Friday 11th July 2003
The Marriott Hotel, Marble Arch, London

This conference is organised by specialist registrars in learning disability. The conference will focus on various aspects of autism including assessment, management, recent developments and future directions for further research. Specialist registrars and consultants from the field of learning disability and child psychiatry should benefit by attending the conference. The conference will take place at Marriott Hotel, which boasts good conference facilities, is situated near Oxford Street in London and is easily accessible.

For further information and registration contact:
Gloria Challis, St Peters House, 3rd floor, 2 Bricket Road, St Albans, Hertfordshire, AL1 3JW, Tel: 01727 829806, Fax: 01727 834785
E-mail: Gloria.Challis@hpt.nhs.uk
For informal enquiries please contact Sujeet Jaydeokar on 07930570905.

Reading List and Website

I continue to welcome any suggestions for articles and books and websites to recommend. The only requirement is that you do not recommend your own! Please contact me with any ideas on:

peter.carpenter@bristol.ac.uk

From the Editor:

I am delighted, if a little daunted, to take over as editor-in-chief of the newsletter from Professor Anna Cooper who, together with the Editorial Board has previously carried out this role with enviable efficiency and creativity. We hope to change the face of the newsletter over the coming months, both in format and in the breadth of content. As always, we welcome articles of relevance to the field of learning disability and we hope to broaden the perspective to include items from the arts and media as well as other related issues. I hope that the newsletter will continue to develop as an informative and entertaining forum for communication between the membership as a whole; more the style of a club newsletter than the “Team Brief” with which we are all no doubt familiar in our employing organisations! I would like to encourage you therefore to submit articles and/or correspondence to myself. Comments on the newsletter are also welcome.

Contributions should be submitted in a recognisable Windows format by email or on a 3.5” disk. The editors reserve the right to edit contributions as deemed necessary. Please limit contributions to a maximum of 700 words unless agreed beforehand. Letters should not exceed 200 words. Opinions expressed in the newsletter are those of the authors and not of the College, unless expressly stated. Each article remains the copyright of its author but the College reserves the right to reproduce the article on the faculty website pages.

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