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Learning Disability Psychiatry

Newsletter of the Faculty of the Psychiatry of Learning Disability

Letter from the Chair

Gregory O'Brien

I was recently interviewed for a nursing journal called *Learning Disability Practice*. A few weeks earlier, I had been misquoted in *The Guardian*, where it said that I was in favour of an expansion of long-term hospital care – hence the questions I was asked in this “email-interview”.

I have recently read it again and although I may have over-egged the pudding in some respects, I stand by what I said. I hope it makes interesting reading:

Has the pendulum swung too far away from in-patient care in favour of community-based approaches?

In a way, it has not gone far enough. We do not have community services that are equipped to cope with certain patients; the issue is not one of moving back to in-patient care but a matter of investment both in expertise and in thinking. We need more emphasis on specialist services in the community, rather than assuming that generic services will cope with all people with learning disabilities, which our clinical work tells us is just not possible. At present, there is an unplanned, rapid, massive expansion in non-NHS residential care for people with learning disabilities. This is happening because community services are unable to cope with “difficult” “challenging” individuals, and there are not in-patient services available. The response should not be to say that we have “swung too far away from in-patient care” but to have



Professor Gregory O'Brien

more substantial investment in expertise at a community level.

Name three steps needed to improve services for people with learning disabilities

Firstly, there is the issue of public acceptance and understanding. We live in a rapid, aspirational society, in which people with learning disabilities (especially those with behavioural problems) are often not well accepted. I am not proposing some naïve move towards the idea that people should be more accepted. It is more in line with the kind of public information campaign SCOPE and MENCAP have recently promoted where they emphasise that people with disabilities have real problems but that it is for all of us to acknowledge these and accept them, rather than deny them, or hide the people away.

Secondly, we need to build on the experience of the implementation of “Valuing People”. This has resulted in greater involvement of people with mild disabilities in mainstream services but has highlighted that people with more severe disabilities are not doing so well. We need to be thinking more about these individuals and developing expertise rather than pretending that there are not problems here.

Thirdly, and in some ways this is my greatest concern at present, there is the current concern regarding the draft Mental Health Bill. This proposes that people with learning disabilities who are "at risk of serious neglect" in the community should be assessed for detention under the Mental Health Act. MENCAP and the Mental Health Alliance have already said that this is not the way we should be going forward. On behalf of the Royal College of Psychiatrists, I can say that we are of one mind with these organisations in this matter. I would propose that the third step which is required to improve services for people with learning disabilities is that we should be seeking to amend the current Bill and that we should be implementing the rather more person-centred mental capacity legislation that is proposed.

How can young doctors be persuaded to enter this field?

I have made a case for the development of expertise and of specialist services. "Young doctors" are more interested in an area that promises to be career-developing and challenging; this is partly through there being an area of expertise and specialism. They are hardly likely to be persuaded to enter into a field where there is not an emphasis on expertise.

What drew you into this field?

I grew up with people with disabilities. My best friend, our next-door neighbour, had twin brothers who were two years younger than me and had cerebral palsy and substantial disabilities. From the outset, I had personal experience that is important to me. As a medical student in Aberdeen University, I used to do volunteer work with the "Caphill Village Community" run by the Rudolph Steiner organisation. This organisation has a philosophy

that is unique, engages and works with people with disabilities including those with autism spectrum disorder and does so successfully. I think this experience was pivotal. Toward the end of my medical degree I did my first research, which was on the development of children who had been abused and reared in care. This gave me a life-long perspective on the development of people with disadvantage. Once I had qualified in psychiatry, an opportunity arose to join the Cambridge University Department of Psychiatry in the field of disability. I'm pleased to say that if given the choice now I would make the same career steps again.

Have you been inspired at work recently?

Yes and perhaps from a source which will surprise some people. I have just come from a meeting with our Trust's Chief Executive. He inspired me because he clearly is committed to both community development and also to in-patient work in certain specialist fields. It is inspiring to find that at every level in our Trust there is commitment to specialist work.

Where did you go for your Summer break and why did you choose that setting?

We had a magnificent three-week holiday holiday, involving a tour from San Francisco up to the mountains in Yosemite, through the desert into Las Vegas, down to San Diego and back home via New York. Having planned this for some time, we chose to do it this year because our teenage children are now at the stage when they can enjoy this kind of thing without regarding their parents as too embarrassing to be seen with! A great holiday but my credit card was well and truly drained. ■

2006 Burden Research Prize

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

An application form and further details may be obtained from:

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

The closing date for submissions is 31 December 2005

The 'Bournewood' Judgement

Tony Holland

On 5 Oct 2004 the European Court ruled in the case of H.L. v. the United Kingdom. The Court disagreed with the House of Lords, ruling that H.L. had been detained without due process and his stay in hospital under common law had been unlawful. The Court stated that the lack of fixed procedural rules meant that arbitrariness in the process could not have been avoided, and there were no ready means, other than by judicial review, whereby the insistence of the consultant psychiatrist that H.L. stayed in hospital, could have been challenged. The right to liberty and security of person (Article 5.1 of the European Convention) and the requirement for due process to enable a speedy challenge to the lawfulness of any detention (Article 5.4 of the European Convention) applies to everyone, including (and perhaps most particularly) those who lack the ability (capacity) to make decisions about such matters as hospital admission and treatment.

The essential facts are well known. Mr H.L. has autism and severe learning disabilities. His admission to hospital came about after he became distressed at the day centre he attended. The staff, unable to contact his carers, asked the hospital staff for help. They subsequently took him to the local casualty department and then to the long-stay hospital. When his carers wanted to take him home, the psychiatrist advised that he needed to stay for further assessment. Although not formally stated, it was clear that Mr H.L. lacked the capacity to consent to his admission. It was said that he was not trying to leave and in effect was assenting to this course of action. It was argued that his stay in hospital was in his best interests.

The carers were ultimately granted a judicial review by the High Court, with subsequent appeal hearings in the Court of Appeal and the House of Lords. Following a ruling by the Appeal Court (later overturned by the House of Lords) that his detention was unlawful, he was placed under a Section of the Mental Health Act (MHA) (1983). His legal advisers obtained a second medical opinion. The psychiatrist concerned advised that he did not meet the criteria necessary for detention under the Act and he was eventually discharged back to his paid carers. The Law Lords in their judgement recognised that this case identified a serious "gap" in English and Welsh law, but ruled that he had not been unlawfully detained.

This judgement by the European Court could not have come at a more opportune time, as two pieces of legislation (for England and Wales), the Mental Capacity and the Mental Health Bills – highly relevant to the Bournewood situation – are currently being considered by Parliament. The former Bill is at committee stage and, with some reservations, has been broadly welcomed by the various



lobby organisations. In contrast, the proposals in the Mental Health Bill have been almost universally criticised, fundamentally because the Government rejected the specific principles put forward by an earlier Government-appointed scoping review, chaired by Professor Geneva Richardson, and has instead produced legislation that is over-inclusive and based on different principles than apply to those with physical disorder; thus, it is discriminatory.

While in the case of Mr H.L. his stay in hospital was finally ended through the appeal mechanism afforded by the present MHA, more generally the issues raised by this case are best resolved through mental capacity legislation. First, because the fact that the Mental Capacity Bill is predicated on the principles of autonomy for those with capacity and acting in the best interests for those without; second, the Bournewood situation could also arise in cases of treatment for a physical disorder; and third, the issues are as pertinent in the community as they are in hospital. The present MHA is solely concerned with treatment for a mental disorder and only operates in hospital. The Mental Capacity Bill, as it stands at present, however, does not have the same level of safeguards as the MHA. Some revision will be necessary to ensure the right to second opinions, advocacy support, and ready access to appeal.

In the absence of mental capacity legislation it is difficult to see how the gap in law can be filled, other than in the narrow context of hospital treatment for mental disorder. What if Mr H.L. had been admitted to a general hospital for treatment of pneumonia and his carers had said they wished to support him at home? Whose view would trump? How could the decision of the doctor be challenged? For those of us with capacity, it is our consent that renders medical treatment lawful. We must seek legislation that balances this principle of respect for autonomy with the need for care and support, it must be enabling rather than restricting, and clinicians will need to change their practice in order to maximise people's capacity and involvement in decision-making. ■

Useful link

www.rcpsych.ac.uk/press/parliament/westminster.htm

History, philosophy and learning disability psychiatry

Neil MacFarlane

We know that within the faculty there is considerable interest in psychotherapy, not only from discussion with colleagues, but also from Roger Banks's survey presented at Chester four years ago, and the well-attended 2002 Oxford SpR conference on the subject. What then of two areas of inquiry which, on the face of it, have considerable affinity with psychotherapy: history and philosophy? Sadly, the College's History Special Interest Group (SIG) is now defunct, but reports of its past activities, and my scanning of the journal *History of Psychiatry*, indicate that interest in learning disability has not been high (with the notable exception of Peter Carpenter's papers on the Bath idiot institutions). There might be a number of reasons for this trend, which seems out of step with the current public popularity of history; perhaps the continuing "trauma" of anti-psychiatry, and the increased professionalisation of medical history.

As for philosophy, I recently attended 'Time, Memory and History', the 7th International Conference on Philosophy, Psychiatry and Psychology, in Heidelberg, Germany. I did not know what to expect, as I had not hitherto played an active part in the College's philosophy SIG, but by the end of this conference I was convinced that in some real sense I had been taken back to the roots of psychiatry. Karl Jaspers wrote his *General Psychopathology* in Heidelberg nearly 100 years ago and many presentations were explicitly in the phenomenological tradition, often with reference to Jaspers' philosophical predecessor, Husserl, or his contemporary, Heidegger. To give a flavour of this approach, a quotation from the abstract of Thomas Fuchs (the conference organiser) on 'The memory of the body': "Whereas explicit or autobiographical remembering is directed back toward the past, the implicit memory of the body unconsciously re-enacts the past in the present; it is our 'lived past'. Thus body memory is the foundation for our being-at-home in the world as well as for our interaction with others."

The whole range of contemporary philosophies was represented in over 120 presentations attended by 280 delegates: Bill Fulford's usual cunning unpacking of "concepts" into both pragmatism and values-in-themselves; the linking, by Harvard's Nassir Ghaemi, of phenomenology, Weber's situational analysis, and recent reflections on US psychiatric practice; plenty of psychoanalysis, especially Lacanian; and even overtly classical references to Aristotle, the stoics, and Catullus. Given the conference theme, there was also straightforward history, not that such a thing can exist for the philosophically-inclined!

A few presenters touched on autism, usually attempting to distinguish it phenomenologically from schizophrenia. I contrived to miss, however, perhaps the most relevant session to learning disability, presented by five Heidelberg psychiatrists undertaking a historical project on 30,000 case records from the Nazi "T4-action", or euthanasia programme, which were discovered in East Berlin after the fall of the Wall in 1990. Some five per cent of those records contain the histories of, and selection procedures for, learning disabled children.

The tone of much of the conference was serious but there were plenty of lighter moments. My suggestion that Nietzsche's positive view of amnesia might be linked to his concept of the Dionysian through the use of alcohol in the "ordeal" of suicide attempts was met with incredulous laughter by Keith Ansell-Pearson, Professor of Continental Philosophy at Warwick University. Perhaps these philosophers could benefit from the being-in-the-world-with an on-call SHO for a session (or ten)? In general, however, I was struck by the number of professional philosophers from all over the world and their open-minded, or at least nuanced, approach to the dilemmas of mental health.

On this evidence the philosophy of psychiatry seems to be pretty healthy. How can learning disability psychiatrists participate and contribute? One obstacle is perhaps the lack of a tradition of involvement, owing to the classical preoccupations of, say, phenomenology, being with aspects of mental disorder that require good verbal ability on the part of the patient; complex delusional systems, or bodily experiences, for example. I have spent some time pondering how my own area of interest in philosophy, the relation of contemporary thought to Karl Popper's social and political philosophy (as distinct from the natural philosophy, which has tended to be distorted within psychiatry in order to dismiss psychoanalysis), could be of relevance to learning disability and have recently "discovered" some direct historical links with deinstitutionalisation and normalisation: Jack Tizard was an undergraduate student of Popper's during the war and later developed "Community care for the mentally handicapped" as an avowedly "Popperian psychologist", as well as having a certain Wolfensberger study with him in London.

For others wanting to explore different approaches, one obvious area might be autism, while another would be to build on the distinctive nature of psychotherapy in learning disability. As for organisational structures, it might be premature to talk of a faculty subgroup developing history and philosophy (and cultural or transcultural studies?), but such an idea has come up in one or two discussions I have had. Please contact me with any comments or suggestions: neil.macfarlane@tgt.sthames.nhs.uk ■

Scottish Consortium for Learning Disability

Lisa Curtice (Director)

“People with learning disabilities are individuals. They should be valued for their differences, respected as citizens, supported to speak for themselves and make their own choices. They should not experience discrimination, abuse, harassment or exclusion from the community, of which they are a full part.”

This statement expresses the thrust of policy in Scotland for people with learning disabilities. *The same as you?*, published by the Scottish Executive in May 2000, set out a direction for change and established a new organisation to support people in Scotland to make that change happen. The Scottish Consortium for Learning Disability (SCLD) brings together 13 partner organisations, largely from the voluntary and academic sectors, to be a centre of excellence in supporting the development of training, information, research, policy and practice in Scotland.

One of the key values of the Consortium is that people with learning disabilities and family carers should be supported to take the lead, working in partnership with professionals. Half of the Consortium’s trustees are people with learning disabilities or family carers. One of the partners, PAMIS, has run successful training courses on mental well-being and people with profound and multiple learning disability, led by family carers. Another partner, Badaguish, runs an annual Leadership course in which people with learning disabilities work alongside others on projects to make a difference to their community. SCLD has developed a network of people with learning disabilities who are co-trainers, contributing to all aspects of the training programme, which is delivered to staff across Scotland; they help to develop and deliver courses and to assess work.

SCLD has also been managing some quite complex partnerships in order to improve the exchange of knowledge and information across Scotland. The eSAY project (SAY is the short name for *The same as you?*) has developed a common national dataset for information about people with learning disabilities. Four pilot areas are already supplying anonymous data and, working with the eCare project, which is developing an infrastructure for information sharing across the whole of community care, eSAY will result in consistent data about the changing use of services across Scotland. Other partners – ENABLE, Capability Scotland, Down’s Syndrome Scotland and PAMIS – have pooled their library resources and created an online library catalogue so that wherever you live in Scotland you can



Craig Whinnett, his mother Jenny Whinnett (a trustee on behalf of PAMIS) and Jan Murdoch, SCLD’s Public Education and Communications Manager at a roadshow event in Aberdeen

search these specialist collections and have a book posted out to you. Just now, the library partners are working in partnership with the Centre for Digital Library Research at the University of Strathclyde on a thesaurus of terms for learning disability, which it is hoped will become a standard.

SCLD is closely involved in practice development. *The same as you?* introduced local area co-ordinators, a new type of workers who work alongside the individual, their family and community to help them access the support and opportunities to lead a fuller life. SCLD has supported the development of these challenging posts and provides continuing professional development by running quarterly action learning sets for all local area co-ordinators in Scotland.

SCLD’s experience of working alongside all those engaged in the lives of people with learning disabilities is being translated into publications and resources, including DVDs and videos. ‘Having our say’ is a DVD in which people with learning disabilities explain the benefits they have gained from participation, including more confidence and a sense of making a difference. ‘Someone on your side’ shows local area co-ordinators in action, explaining the role and how it represents a different way of working with individuals and families. ‘Just Ordinary People’ was created for NHS Education for Scotland as part of their learning materials for nurse education (‘Getting it Right Together’). In the video, people with learning disabilities discuss how they wish to be treated by health professionals. There is an energy and optimism in all these materials that demonstrates the value of enabling people to take charge of their own lives and to tell others how it feels. Professionals who view them should feel heartened by the difference they can make to these lives and the possibilities for all of us to do things even better. ■

Useful link

www.sclد.org.uk

email: administrator@sclد.co.uk

Supporting carers: learning communities to support practice

Tim Bilham

Care and support workers are often disadvantaged in being able to access educational opportunities. Individual carers are generally not well networked and those in organisations are overlooked in plans for personal development training, resources often going to higher profile groups.

Recently the School for Health at the University of Bath has developed and piloted a blended learning programme for care and support staff working with young adults with Asperger's syndrome (AS).

The context for this project was a group of three residential Special Education schools in Frome, Somerset and in the Isle of Man. Dispersal of the care and support staff through different physical locations and over time (shift work), the demands of the role they fulfil and the low occupational status of their work mean that these workers have few opportunities to discuss issues with colleagues or to participate in training. As members of a wider course-development team of parents, professionals and academics, the care and support staff themselves played a pivotal role in crafting their own learning experience by validating the philosophy, structure and approach of the training, then testing and piloting it. Because AS manifests very individualistically, a single one-size-fits-all approach to care or training does not generally work – support requires awareness, understanding, and tailored implementation.

In this case, the solution, which “blends” face-to-face sessions with online activities and resources in a virtual learning environment, is sympathetic to the prevailing care and support culture. The programme runs over 12 weeks with face-to-face sessions limited to four half-days, supported throughout the period by the online environment of rich and topical content, engaging activities, highly relevant cases and lively debate through asynchronous online discussion. The theoretical framework was strongly influenced by insights from theories of adult learning, situated learning and communities of practice. Programme design was based upon a social constructivist model including e-moderating (Salmon, 2003) and the building of learning communities (McMillan, 1996; Wenger, 1998) at a distance (Rovai, 2001). It also drew upon examples of good practice from the Higher Education Academy's Subject Networks, for example in learning communities (the HEA Psychology Network), and it shares the philosophy of the College's 'Partners in Care' campaign.



The online learning process is driven by a series of e-tivities, which build meaningful pathways through the learning materials, and the process is facilitated by e-moderators working with AS tutors who provide subject matter expertise. Authentic final assignments not only generate additional content for the course but are of great value to the care and support community as they encapsulate much tacit knowledge surrounding their work. The course design provides access to information on AS when and where required, enables staff to become independent and adaptive practitioners, disseminates the good practice of experienced staff and facilitates knowledge sharing and support networks. Delivering in an e-learning environment allows inclusivity in participation, gives structure to a potentially chaotic and stressful online environment, is inherently motivating because of the response element and gives time to build mutual respect and trust.

In the first pilot run over the 12-week programme, there were 8068 accesses to the main content areas online (excluding the discussion areas) by the 20 students (over 400 accesses per participant), and a staggering number of 31,427 to all areas, indicating the popularity of the discussion facilities. This was reinforced by the qualitative evaluation, where participants hugely valued the normally rare opportunities for reflection on their own practice and for the sharing of strategies for intervention. The learning community model is the more impressive for the fact that the participants were not familiar e-learners and indicated significant constraints with access to appropriate technology (75%) and provision of sufficient time to do the course (81%).

The “blended learning” approach and the use of e-tivities contributes to the development of a learning community which both mirrors and reinforces the existing care and support community of practice. Hopefully, it offers also a model for the development of care and support staff working in other fields.

The AS course is now being extended into a University Certificate in Special Needs aimed specifically at carers, health professionals and teaching assistants, which will also address ASD, EMD and learning difficulties. Opportunities to extend the resource to allow access to parents are also being explored. ■

Useful link

www.bath.ac.uk/health

Further information from: Tim Bilham, Director, Educational Research & Development, School for Health, University of Bath, t.d.bilham@bath.ac.uk.

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Higher Education Academy Psychology Network <http://www.psychology.heacademy.ac.uk/>

From the Editorial Board

Articles and correspondence are more than welcomed!

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

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

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Conference report

General hospital care for people with learning disabilities

Susie Gibbs

In October last year, 120 people from all over the UK attended a research conference and workshop event at the Royal Infirmary of Edinburgh. This was organised by members of a research group based in Edinburgh and was supported by NHS Lothian. The group is dedicated to improving general hospital care for people with learning disabilities, through encouraging and supporting research and service evaluation. The group formed from a long-standing local interest in these issues, which has resulted in two liaison learning disability nurses being permanently employed in general hospitals in the Lothian area (Brown & MacArthur, 1999). Two fatal accident inquiries, a Scottish Executive report (2002) and an NHS Scotland report (2004) have encouraged service development in Scotland as a whole.

Beginning with talks outlining the evolving evidence base, the day moved through a mapping exercise of present clinical service provision and research and on to developing a practical research agenda. Experienced researchers, clinicians and colleagues from the voluntary sector, facilitated workshops. Delegates were able to draw on the experience of those further ahead in service developments and begin to collaborate on future research and service evaluation.

Lisa Curtice, Director of the Scottish Consortium for Learning Disabilities (see p. 6) chaired the morning session:

- Why are people with learning disabilities high users of secondary health care?
Michael Brown, Nurse Consultant & Teaching Fellow, NHS Lothian & Napier University, Edinburgh
- A user's perspective
Douglas White
- A carer's perspective
Betty Mauchland
- A legal perspective
Liz Craigmyle, Solicitor, Disability Legal Services, Balfour & Manson
- Experiences of adults with learning disabilities and their carers in general hospitals – results of a focus group study
Susie Gibbs, Specialist Registrar, Psychiatry of Learning Disabilities, NHS Lothian

- Lothian Acute Hospital Liaison Project – The service and research developments
Scott Taylor, Liaison Nurse, NHS Lothian & Heather Wilkinson, Reader, University of Northumbria and Senior Research Fellow, Centre for Research on Families and Relationships, University of Edinburgh.

The presentations highlighted the many areas requiring development and improvement. Particularly poignant was the presentation given by Betty Mauchland about her brother Jimmy. His death resulted in a fatal accident inquiry, the results of which have been influential in steering Scottish policy and service provision for people with learning disabilities in general hospitals.

During a series of workshops, delegates undertook a mapping exercise, producing a summary of all the service and research developments known to them. Despite little active research, there are many developments of nursing liaison services into general hospitals across the UK. Different models exist, from provision of dedicated full-time liaison nurses, to community nurses having links into hospitals. While recognising the many negative experiences of users and carers, those present were encouraged to draw on their more positive experiences to advise on practical ways forward.

Professor Ruth Northway from the University of Glamorgan chaired and began the afternoon session by speaking on 'Why research matters for people with learning disabilities'. The results of the morning's mapping exercise had been swiftly amalgamated over lunchtime by Heather Wilkinson, who was able to feed back a summary to delegates. This informed the afternoon workshops, which aimed to help people take forward practical ideas for research, audit and service development. The importance of policy and campaigning was acknowledged, and carer and user input was particularly important in these workshops. Topics were:

- Action research.
- Involving people with learning disabilities in research.
- From policy to practice.
- Setting up a liaison service.
- Clinical Governance.
- Campaigning to influence services.

Feedback from these workshops was followed by the outlining of a research agenda and future directions.

Delegates came from a wide variety of backgrounds – NHS employees, carers and members of voluntary organisations from social services and education. They participated enthusiastically and contributed greatly to the success of the day. We are producing a full conference report, which will be available in early 2005 and is being distributed to all delegates. If you would like a copy of this report (for a small cost) or you are interested in collaborating on research in this important area, please contact us at: *MichaelJ.Brown@lpct.scot.nhs.uk*.

I am interested in the role of doctors (general hospital doctors, psychiatrists of learning disabilities and liaison psychiatrists) in the care of people with learning disabilities in general hospitals. If any readers are interested in this area, please contact me at: *susiegibbs@doctors.org.uk*.

Organising committee:

- Michael Brown, Nurse Consultant & Teaching Fellow, NHS Lothian & Napier University, Edinburgh
- Susie Gibbs, SpR in the Psychiatry of Learning Disabilities, NHS Lothian
- Juliet MacArthur, Senior Nurse – Research, NHS Lothian
- Scott Taylor, Liaison Nurse, NHS Lothian
- Heather Wilkinson, Reader, University of Northumbria and Senior Research Fellow, Centre for Research on Families and Relationships, University of Edinburgh. ■

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New SpR post in psychotherapy and learning disability

Georgina McNaughton

"Psychological services can no longer be regarded as optional" says the recent Department of Health document *Delivering Psychological Therapies* (DH, 2004). Access to current psychotherapy services in England and Wales for people with learning disabilities was found to feature "neither inclusion nor equity" in *Psychotherapy and Learning Disability* (RCPsych, 2004). It describes "very significant barriers to access" and an environment where there is "no specific training or regulation". It points to a definite need for service provision and training structures in this therapeutic area.

My current post was created in July 2004 to redress this imbalance. I work in the Joan Bicknell Centre in Tooting, SW London, named after Professor Joan Bicknell, who was a pioneer of psychodynamic thinking in working with people with learning disabilities. The psychotherapy service is led by Professor Sheila Hollins, who is a consultant psychiatrist in learning disability and in psychotherapy, and by Dr Valerie Sinason, a child psychotherapist and psychoanalyst. I am the only full-time member of the psychotherapy team – the other members are SpRs in special interest sessions, psychotherapists on placements and trainee clinical psychologists. There is an art therapy trainee for nine months of the year, although there is no permanent art, music or drama therapist.

Like other things in the learning disability field, the post is not entirely new – before Calmanisation of medical training there was a dual psychotherapy and learning disability training post in the SW London area. It was a successful scheme producing high-quality local consultants, some of whom work primarily within learning disability with a special interest in psychotherapy, or vice versa.

The current post is not part of a dual training number, but is an overlap year accredited for dual training in psychotherapy and learning disability enabling completion of training in five years.

We take referrals from three London boroughs; most referrals come from within the community learning disability teams.

Patients are most often referred for trauma/abuse, challenging behaviour and depression; combinations of these and other factors are frequent. We also see referrals for personality disorders, bereavement reactions and a small number for sexually inappropriate or offending behaviours. Rates of mental illness are high including all major mental illnesses and most commonly depression.

The treatments offered are group and individual psychodynamic psychotherapy, group and individual assessments and a small amount of art therapy. This service, for which there is high demand, was initially started as group treatment.

My role is to see patients for weekly individual therapy and to act as co-therapist for a group, which currently has eight participants with learning disabilities ranging from mild to severe. I attend the community team meeting in a liaison role and take part in case discussions. I am also part of a weekly work discussion group that is multi-disciplinary and open to all members of the teams in the three boroughs to discuss difficult cases in more depth. The post includes academic sessions in psychotherapy and learning disability, supervision of an SHO and the family therapy service for people with learning disability. While there are opportunities to practice CBT, I do not take this up as it is not advised to try to carry out more than two modes of therapy at once.

I enjoy the opportunity to work in greater depth with patients and feel humbled that they trust me enough to tell me their often traumatic stories, sometimes for the first time. The emotional lives of people with learning disabilities have often been overlooked (Arthur, 2003) – it can be very uncomfortable to actually hear what people are telling you. Transference and counter-transference both within therapy and among colleagues working with people with learning disabilities can centre around profound confusion and uselessness, which often leads the therapist in turn to feel useless. Working through patients' issues often leads to taboos: the disability itself, fear of annihilation, dependency, sexuality and death (Hollins & Sinason, 2000).

I find psychotherapy work immensely satisfying and believe it can, over time, lead to internal changes that can be lasting and really improve a patient's quality of life, however small. It is a mode of therapy that doesn't suit everyone's personality, but I find it rewarding. I hope to become one of the qualified therapists able to supervise and teach others in order to provide lasting psychotherapy services for people with learning disabilities. ■

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In conversation: Lord Rix

Roger Banks (Interviewer)

Brian Rix was an accomplished actor manager and one of the BBC's most successful entertainers with his Whitehall farces. In 1980 he gave this up to become Secretary General, Chairman then life-President of the organisation we know today as The Royal Mencap Society. His commitment to improving the lives of people with learning disabilities has been recognised with numerous awards and honours. In 1992 he was created a life-peer, and it is from this privileged position that he continues to campaign tirelessly for the people he has spent more than 50 years supporting. In addition to active involvement in the Mental Capacity, School Transport, Charities and Disability Discrimination Bills, he is a member of the Joint Parliamentary Scrutiny Committee reviewing the draft Mental Health Bill. Just prior to a meeting at the House of Lords, Lord Rix spoke with Roger Banks.



RB: You recently celebrated your 81st birthday, yet in our conversation the other day it was clear that your diary is busier than mine!

BR: I try to keep my weekends free to catch up with the huge amount of paperwork, with a singular lack of success on many an occasion. I'll show you later the stuff that arrived for the Joint Committee on the Mental Health Bill – it almost gave the postman a hernia! You're supposed to read through these things, but you end up reading the summaries and highlighting the references to learning disabilities.

RB: I'm pleased to hear that's the approved method.

BR: I imagine others have to do the same. I can't believe they can get through all the paper – nobody can. I'm still involved daily with Mencap and I'm also Chancellor of the University of East London. I was on the phone with the banqueting department here this morning organising a lunch for the Rix Centre.

RB: Can you tell me more about that?

BR: It's a great pleasure that it is called the Rix Centre. It will be run initially as a charity within the University and will act as a source of all available information about learning

disability, from grants through to special educational needs, inclusive education, Downs syndrome and autism. It will be the biggest research centre for learning disability in the world, we hope. So I need to arrange a lunch for the rich and the famous to come along and hopefully make a contribution. I am here three and sometimes four days a week, and I have to be here every Wednesday morning for the Mental Health Bill because I am on the Joint Scrutiny Committee.

RB: In the past, you have blended work in the arts and with disability such as the Monitoring Committee for Arts and Disabled People and pioneering 'Lets Go', the first BBC programme for people with learning disabilities. Do you still have time for that?

BR: At the moment I am chairman of Libertas. Liverpool is to be European City of Culture in 2008; we want to find out how people with a learning disability wish to be conducted around the city. We have already produced over 100 audio-tours for learning disabled people. We followed some of the principles from "Let's Go"; I've done commentaries on buildings or pieces of art, in fairly steady speech and repeated three times. Now we think many people with learning disability have moved on and are capable of much more direct questioning and interactive approaches.

My son wrote the Basic Language tour for Westminster Abbey; it was so successful, not just for people with learning disability but with foreign tourists, that he was asked to write the main tour again in the sort of terms in which you would address a learning disability tour.

RB: There are parallels in your current work with legislation – interpreting the issues for people with learning disabilities can lead to greater clarity for all.

BR: Absolutely. You know my complaint about the inclusion of learning disability within the draft Mental Health Bill; the easy-read version doesn't mess around and says mental disorder means "having a mental health problem or illness, this includes having a learning disability". I found this deeply offensive for, in my view, people with a learning disability should only come within the scope of the Bill if they have an allied mental illness.

RB: You were born in Yorkshire and I wondered what that Yorkshire lad would say if he could have known what he would be doing in 2004.

BR: He would be very surprised! I only wanted to be two things – a famous actor or a famous cricketer. I played Yorkshire league for a time but became short-sighted during my early adolescence and batted more by instinct than by visual contact for a long time. It wasn't until I went into the Air Force that they found out I'd been driving illegally for a couple of years because I couldn't read a number plate from

25 yards! I still went on to initial training as a pilot navigator bomb-aimer, with special lenses that fitted inside goggles.

I had planned to be a doctor. My godfather was a successful local GP; he and my father discussed it and the plan was that I would follow the same educational path and then join him in partnership.

When the War came, however, it was clear that I was utterly and absolutely useless; I would never have got through my first MB because I couldn't do physics or chemistry. I was good at English, English literature, history, scripture all the things actors are good at but I was absolutely hopeless at all things scientists or doctors were good at!

RB: When did your acting career begin?

BR: When I was young. My mother was keen on amateur acting and all four kids in the family were swept into amateur theatre. I started as a young, keen stage manager, graduated to the prompt corner and eventually the stage, also playing leading parts at school. At 18, when I should have been going to university, I thought I'd like to be an actor. My sister Sheila, who played the lead in *Emmerdale Farm* for 25 years as Annie Sugden, had already gone into theatre on tour with Donald Wolfitt. I knocked on his dressing room after a matinee and said "Can I follow Sheila?", and I was swept off my feet, simply because I was young and had 10 months deferred service before joining the RAF. After various roles, including playing in the West End, and my time in the RAF, I borrowed a thousand quid from my father and uncle and put together my own company and we played *Ilkley* and *Bridlington*, including pantomime...

RB: When did you meet your wife, Elspet Gray?

BR: I started another company in Margate in 1949. I went for the opening and one of the people I interviewed was Elspet; she had just done some pictures for the Rank Charm School and was told that she ought to go and get some real acting experience. I fell for her the moment she walked in the door and posted her to *Bridlington* where I knew I was going back, and we married six months later.

It was around that time that I got hold of a play called *Reluctant Heroes*, which was very funny, and I thought that this was going to make my fame and fortune. After touring I managed to get the *Whitehall Theatre*, where it was pretty successful and really my first farce. I then did a BBC radio excerpt, only 15 minutes, which kept us going through the Festival of Britain, which emptied most theatres. The BBC then asked me if I'd like to do an excerpt on the telly, which we did in 1952, and the queues went down *Whitehall* for the next three years.

RB: This would have been *live* television.

BR: Live of course and then they said come and do some more farce, but at first they wouldn't let me do it on a Sunday because it wasn't considered appropriate. Then came *ITV* and *Sunday Night at the Palladium*, and in 1956 I started a contract with the BBC which lasted until 1977.

RB: I would never be forgiven if we didn't bring up the subject of trousers, but we could leave it behind very quickly.

BR: Behind is hardly the word!

RB: Does the image of the man who drops his trousers haunt you?

BR: Oh no, no, it doesn't worry me at all – it's said to me all the time.

RB: I'd like to talk more about your family. Your daughter Shelley was born in 1951; I wonder what the impact of having a daughter with a disability was?

BR: Well it was terrible. Terrible of course because there was no support of any kind. The gynaecologist didn't even want to tell us; it was the Sister who said "You've got to tell them". He told me an hour before the curtain went up and he asked me to tell my wife, but I couldn't as I had to go and work. In the morning I went in and burst into tears as I walked through the door and that's how I broke the news, by breaking down. I wrote to the Minister for Health and I got this terrible letter back talking about my "mongol daughter" and then they sent me a list of private residences for "imbeciles" and "idiots", male and female, and it was horrendous.

Eventually we got her to *Normansfield*, which was only across the park from us, and Shelley could come home and we could go and see her easily. She was well treated, but she had to be certified.

We initially joined the Stars' Organisation for Spastics because we hadn't heard of the Association of Parents for Backward Children. We also started the Friends of *Normansfield* and built a school, a hydrotherapy pool, a clubhouse and a magnificent holiday home at *Selsey Bill*. Then the National Society for Mentally Handicapped Children, as it then was, asked if I would chair their fundraising committee. All these associations took a lot of time, work and effort for Elspet and me; people used to cross the road when they saw me coming because they knew I'd be after their pocket books. After 30 years as an actor-manager, I saw an advert in *The Guardian* for the post of Secretary-General of the Royal Society for Mentally Handicapped Children and Adults, as the Association now was. I thought, that's what I want to do. But they turned me down as being an actor who lost his trousers for a living! They engaged somebody else, luckily temporarily, the staff rebelled and I was asked to reconsider.

It was a huge cut in salary; along with Robert Morley I had been the highest paid actor with the BBC, quite apart from my earnings in the theatre.

RB: You must have been convinced that this was the right choice?

BR: I know it sounds awful, but I had a vision of what I could do. I thought I could make this society really change things; having been a popular actor made it easier. I retired when I was 65 and then became Chairman for 10 years and I've been President ever since. My proudest achievement is to have toured the country to persuade the local societies to change the constitution to be more inclusive. Now nearly half the National Assembly are people with a learning disability.

So it's been fantastic, I don't miss the theatre. I stopped on 8 January 1977 and I never really wanted to go back. Occasionally, I get twinges watching a show and think I wouldn't mind that applause or laughter.

RB: I thought I heard someone outside the door.

BR: Elspet hasn't turned up has she? Are you outside the door? No, can't hear anything.

RB: Isn't this the beginning of a Whitehall farce?

BR: Could be...

RB: I hope I've got my best underwear on... ■

Letters

Letter from Dr Keith Ingram on behalf of the Wessex learning disability psychiatrists CPD peer group

Dear Editor,

There is considerable variation in resourcing of learning disability specialist health services, even within a county. From my perspective, it is often the views of those who have better resources that seem to dominate what the Government currently writes about with regard to the proposed new changes for learning disability services. I think it would also be helpful to raise the concerns of the less well-resourced community learning disability specialist health services. I, like other members of the Wessex CPD peer group, work single-handedly covering a large catchment population within a multi-disciplinary team that is well below national average size.

The thrust of Government policy towards joint-working and mainstreaming of learning disabled people places the less well resourced services at particular risk of being lost or absorbed within a Social Services-dominated, integrated service. This may result in us having our already small team split further into those delivering specialist mental health services and those delivering health facilitation and health

action planning. The better-resourced services, with more consultants, medical staff, business managers and time, are in a much better position to define what it is they do and what they can do in terms of the services they provide. The less well-resourced services are not able to offer the whole spectrum of services. As a result, we have a harder job to develop an equitable partnership, a comfort zone with each other's services and a common way of working that fits well together. We are also, sadly, far less able to argue for resources and to meet professional and Government standards. There are examples throughout the country where people have given up and what little they had has been sucked up into other services.

I feel it would be extremely helpful for the Learning Disability Faculty of the Royal College of Psychiatrists to develop a minimum specification for specialist learning disability health services to be used as a template to develop local services countrywide. The Green Light for Mental Health is clearly indicating the need for such a service and the silence from the Department of Health on this issue presents an opportunity to take a lead with this.

I would also like to suggest that the topic for the next Lundbeck debate be "Should learning disability psychiatry be a secondary or a tertiary service?"

Conferences & meetings

Royal College of Psychiatrists Faculty of the Psychiatry of Learning Disability

Spring meeting 20 April 2005, Regents College
(pcornell@rcpsych.ac.uk)

Annual residential meeting 27–28 October 2005, Hôtel de France, Jersey (ecook@rcpsych.ac.uk)

Royal College of Psychiatrists

Annual Meeting 20–23 June 2005, Edinburgh International Conference Centre
(conference@rcpsych.ac.uk)

EAMHMR

Conference 6–8 October 2005, Sitges – Barcelona, Spain
(www.mhmrbarcelona.com)

IASSID

1st Asian-Pacific IASSID congress 12–15 June 2005, Taipei, Taiwan (www.asiapacificiassid.org)

Institute of Psychotherapy and Disability

Annual Conference – *When our bodies fail us: New ventures in psychotherapy and disability*
11 June 2005, London (david.odriscoll@respond.org.uk)

MAMH

European Association of Intellectual Disability Medicine Congress – *Who Cares?*
25–27 August 2005, Lahti, Finland (www.whocares.fin)