



Volume 6 Issue 2, July 2004

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Learning Disability Psychiatry

Newsletter of the Faculty of the Psychiatry of Learning Disability

A view from the Chair

(with an ear to the House)

Professor Gregory O'Brien



Professor Gregory O'Brien

"It was never realistic to close all the long-stay beds by 1 April 2004. It was better to do the job right... we haven't published an overall target for closure now, but a target for each one... the people who remain in hospital now have very complex needs."

Dr Stephen Ladyman MP, Parliamentary Under-Secretary of State for Community with responsibility for Learning Disabilities, Department of Health: extracts from his address to the All Party Parliamentary Group for Learning Disability Meeting, 19 May 2004.

Dr Stephen Ladyman MP has recently taken over from John Hutton as the Minister with responsibility for the health services of people with learning disability in the UK. I was therefore immensely interested to hear what he said in this forum... and struck to hear him make the comments quoted above.

A quick word on what "this forum" is. All Party Parliamentary Groups (APPGs) are relatively informal bodies, which aim to shape and inform government policy and strategy, on some subject or theme. They work in partnership with the respective representative bodies, and members of the public, as part of the UK parliament's policy of accountability and openness to the public. There are APPGs for a host of topics – from football through to each of the emerging African and Eastern European nations. The APPGLD was established a year ago, is funded and organised by Mencap and chaired by Lord Rix. Its core membership includes people with a range of disabilities and

their representative bodies (interestingly, Dr Ladyman chaired the APPG on Autism until recently). I have been to four parliament/public interface meetings on learning disability/mental health issues over the past year and on each occasion, as on this one, certain themes can be identified, perhaps predictably:

- Much of what is promised by Ministers concerns matters that will not cost the government substantial amounts of money. For example, there is often much talk of the need to change public attitudes and language concerning mental health/disability/minority groups. On the one hand it is heartening to see that these matters are being given high-level attention but on the other, it also sets one thinking – if these things *could* be changed without major funding, then why isn't it happening? The answer, of course, is that attitudes are far harder to change than policies or investment priorities.

- One of the most frequently quoted concerns on the part of people with learning disabilities themselves, is that the registration mechanisms for people with learning disability employ standards that are too demanding to be met. In other words, they are concerned that they are losing their label. Why do they wish to be labelled as a person with learning disability? Surely they'd want to lose that, one might think? It's really about funding and access to specialist support but I find it very interesting to see this dynamic being expressed in these contexts.
- There is increasing recognition that people with the most difficult problems are being poorly served. This was one of Dr Ladyman's main themes at the meeting of the APPGLD.

One of Dr Ladyman's insights was that one success of 'Valuing People' – and indeed of the parallel documents 'Fulfilling the Promises' and 'The Same as You' – has been to improve the situation of people with mild and moderate problems. This is a great step forward, and it makes sense. For, throughout the document, there is an assumption that it is aimed at people who have the capacity to reflect upon their situation, and to make choices for themselves. In other words, in this respect it was aimed at people who do not have severe learning disabilities. As a result it is only natural that 'Valuing People' has improved the situation of people with a mild degree of learning disability. But what of those who have more severe disabilities or severely disturbed behaviour – such as aggression or offending problems? Here, Dr Ladyman said that the increased inclusion of people with mild learning disabilities as a result of 'Valuing People' has also **"highlighted the problems of people with severe and complex disabilities"**.

Might we be entering a new, post-'Valuing People' era, of more attention being given to the challenges of people with more severe problems – especially those with difficult psychiatric problems? Will it happen? Let us take every opportunity to ensure it does. ■

Useful links

www.valuingpeople.gov.uk
www.scotland.gov.uk/ldsr/docs/tsay-00.asp
www.wales.gov.uk/subisocialpolicy/content/learning/ldagreport/contents-e.htm

Learning disability and structural violence

Jack Piachaud

Jenny was six when her inadequate single mother, dominated by a cantankerous grandmother, placed her in a huge institution, in a ward with 35 other children. Through the next 16 years she became a timid, angry soul who would appreciate a kind word and touch but could not contain the anger brought on by such closeness. For the staff, she was a devil who repaid kindness with a bite. Self-injury became one way to resolve the complex internal feelings and sometimes gain attention. Hers was severe challenging behaviour.

She escaped, like most of her generation, from a social structure that kept people with learning disability deprived of many human rights and in poverty compared to the rest. She now lives in an ordinary house with four others and sufficient staff for her emotional capacities. She is no longer a devil.

Social structures emerge through many complex interactions from the most benign to the most malign forces. Where these structures cause neglect of human rights, extreme poverty and the fear of violence, as in these old institutions, this may be described as structural violence.

Such structural violence determines the shape of the bleaker parts of our globe – refugee camps, the highly indebted countries and failing states; all places where health and human rights are neglected. The UK Physicians for Human Rights group has proposed that the health of people with learning disabilities, because they are such a neglected group, should be an indicator of the UN-enshrined Right to Health.

Militarism, perhaps, represents the most extreme form of structural violence. The ancient city-state of Sparta prided itself on its military prowess and is reputed to have left its babies to the elements so that only the strongest would survive. This "survival of the fittest" found resurgence in the eugenics movement and in the rise of fascism. I recall meeting Hans on a PASS workshop in the early 1980s; he was Jewish, born in Germany in 1928. He told me, with the vividness of seared in memories, how as a child he could not go out of the house lest he be taken away and killed.

What happens to people with learning disability in war?

There are media reports from wars in Bosnia and the Congo of patients left locked up in institutions, dying from starvation as staff fled in fear of their lives. In a children's home in Northern Serbia the death rate quadrupled between 1993 and 1995, the years of war and sanctions. In Iraq, in April 2003, the looting of the only institution in Baghdad left six hundred mentally disordered people wandering the streets without care, with fewer than half eventually returning.

Yet, as in all situations, there are stories of bravery and dignity. At the Medical Foundation for the Care of Victims of Torture I have seen three unaccompanied teenagers to consider the possibility of developmental disorders. Maria, aged 17 years, was sent by her family, I am sure at great cost, to the UK from Eritrea; an act of mercy for a vulnerable child. Even at the height of the Yugoslav wars, a service for children with autism flourished in Belgrade. With two staff to a class of five it was special. Ten miles away, three hundred residents in a large institution remained cared for but in poverty. Two hundred miles away in an even more poverty-stricken institution, a small, bare, rank, dark room was home for a dozen children with severe learning disability. War brings huge inequalities, and neglect is more common than heroism.

Robert Edgerton, the social anthropologist who described many cultural aspects of learning disabilities, concluded that all ranges of opinion and actuality were possible in society. In those societies that neglected their disabled there would be some who protected and vice versa; none of this was directly related to wealth.

What of the camps in the Sudan now? Is the severely disabled child protected? The famine will create developmental problems for many children. If your family were starving, whom would you feed? Let us pray we are never put to the test.

And what of the poor areas of the world, neither in famine nor in war? Last October, an article condemning the care of children with learning disability in Russia appeared in the *Lancet* about the same time as I visited Ekaterinburg to start some work with a children's institution. Indeed the situation was sad, like our own institutions several decades ago, but whom do we condemn? The Western economic forces for allowing the economic collapse in 1998 and the emergence of the wickedly rich oligarchs to spend millions on their football teams? The staff who struggle with limited pay and resources, the parents who for decades were told that institutional care was the right way? Joseph Stalin or the Czar?

In Zimbabwe, at a time before Robert Mugabe started to destroy his people in the lost cause of righting historical wrongs, I was fortunate enough to meet some wonderful people running the Children's Rehab Unit in Harare. Most exciting was a three-day workshop for mothers and children. The children had been seen through the community-based rehabilitation programmes and invitations had gone to those with behavioural problems. Tendai was five and ran around all day, refusing to be held except when we all gathered to sing. He was loved by his mother and tolerated by his village. He will learn, she said, maybe a few words, maybe to help clear the land and not get into trouble. Above all, she wanted to know why Tendai was as he was.

As we move to a greater global understanding we should recall that the great majority of people with learning disability are cared for by their families, with no access to services. Before we condemn we should consider how to help. Perhaps striving to make the world a more just place, with the wealth better distributed, is the most important thing we can do. If in doubt, go and look for yourselves. ■



A children's home in Serbia (1996)

Advocating on behalf of parents with learning disabilities in care proceedings – a legal perspective

Lucy Verity, Hornby & Levy, Solicitors

If a local authority social services department decides that a child is at risk of harm from his or her parent(s) it may issue care proceedings and ask the court for permission to remove that child from its family, possibly permanently. As a solicitor acting in care proceedings (representing both children and parents), I am often involved in cases with parents who have learning disabilities. The risks of harm to the child are usually perceived to be neglect, physical or emotional abuse, arising from the parent's chaotic lifestyle, difficulty in coping, poor self-esteem, poor life-skills and limited intellectual functioning.

From a practical point of view, the medical profession has a huge role to play in such proceedings by providing expert evidence to assist the court in coming to a decision about whether to remove a child (often a newborn baby). Expert opinion should always be sought as to the parent's:

- family experiences and psychosocial history
- life-skills
- capacity to learn new skills
- support and resources available.

As far as I am aware, there is no firm evidence to equate parenting ability with intelligence. However, social services and perhaps the court, will often have a presumption of incompetence (maybe unconsciously) when faced with a parent with learning disabilities. The parent's solicitor should, with the assistance of medical experts, highlight the positives.

If a parent is going to undergo a family assessment, the medical expert can explain the ways in which parenting skills can most effectively be taught. Further, that information is absolutely vital to the solicitor acting for the parent, who

needs to know the best way in which complex evidence (often contained in pages upon pages of documents) can be explained to a client who is under a lot of stress.

Social services have a legal duty to try to keep a child with its parents and it is therefore always essential to consider what resources could be put into a family to help keep it together. Resources can vary from intensive support from learning disability social workers and family aides, to a washing machine or a travel card. A medical expert should always be instructed to advise the court what support could assist the parent and will often have better insider knowledge than the solicitor as to what local resources exist, such as Mencap, support groups etc.

The final decision will be made on the basis of the "*paramountcy principle*" i.e. that the welfare of the child is the paramount consideration. All the professionals involved in care proceedings are faced with competing rights – the rights of the child to have its welfare served, and the rights of the parent(s) to be given the opportunity to bring up the child. This competition of rights was thrown into sharper focus after the Human Rights Act 1998, which provides for a right to "family life" at article 8. Solicitors advocating for parents should argue both for the parent's right to a family life, and also for the child's right to be brought up within its own natural family. The courts should not engage in social engineering; the standard of parenting required is "good enough".

It is beyond the scope of this short article to enquire whether in fact the implementation of the Human Rights Act has led to more children being brought up by learning disabled parents but the new law is certainly there to be used by all those advocating for this client group.

I would like to finish with a request (or plea) to medical experts. You are there to give expert opinions, and solicitors such as myself will often rely on you to provide us with information. Please tell us: if our letters of instruction are unhelpful; if we ask for information which is irrelevant or too limited (often all the social worker will want to know is the parent's IQ); if after interviewing our client you believe that he or she has absolutely no idea of what is going on because we haven't advised them properly; if you know of a very good local resource which might help our client. ■

Useful links

See Council Report CR105: *Patients as Parents*
www.rcpsych.ac.uk/publications/cr/cr105.htm

Review of mental health legislation in Northern Ireland

Maria McGinnity, Member of the Legal Issues Working Group of RMHLD (NI)

It may come as a surprise to hear that Northern Ireland, with a population of just over one and a half million, has its own mental health legislation, distinct from other UK and from Irish legislation. In many ways this has served well in the past, providing a lead for developments in mental health and learning disability services and practice. When the Chair of Mental Health was established in 1948 it was one of the first in the UK and the "Special Care" service for people with learning disability was a model of community-based service at the same time. The timing of later revisions in 1961 and 1986 followed the major developments in mental health law in the rest of the UK, including the use of the least restrictive option. Patient protection was strengthened with the introduction of a Mental Health Review Tribunal in 1961 and the Mental Health Commission in 1986. The Mental Health (NI) Order 1986 remains, however, distinctly different.

Present legislation

Northern Ireland was one of the first jurisdictions to give a definition of mental illness in the legislation i.e. "a state of mind which affects a person's thinking, perceiving, emotion or judgement to the extent that he requires care or medical treatment in his own interests or in the interest of other persons". The definition of mental disorder specifically excludes treatment under the order "by reason only of personality disorder" (among other conditions). Psychiatrists have mostly been happy with this but there was a public outcry after a murder was committed in the 1990s by a man who could not be detained. The criteria for detention in hospital for assessment and treatment are also very narrow, based on "substantial likelihood of serious physical harm to self or others" with no grounds for the health and welfare of the patient or psychological harm. This leaves some deteriorating patients untreated.

There are positives and negatives, too, for learning disability (the term mental handicap is used in the Order). The guardianship provision has allowed many people with learning disability to be protected from abuse, as the grounds are severe mental handicap, rather than severe mental impairment as in England and Wales. Recently, however, a major problem has arisen in the operation of the present Mental Health Order since the interpretation

of the definition of severe mental handicap and Impairment by Mental Health Review Tribunals has been challenged for those with an IQ over 55. There is no category of mental impairment owing to this being dropped at the committee stage in parliament, leaving a gap in the provisions that was filled, until 2002, by a more liberal interpretation of "severe" supported by the Code of Practice. This has led to inconsistencies in interpretation and some offender patients being discharged.

The review of mental health and learning disability (Northern Ireland)

The process

The review of legislation is part of a major review of strategy and services for people with mental illness and for those with learning disability and is much broader than mental health legislation. The Legal Issues Working Group is charged specifically with review of the Mental Health (NI) Order 1986. The remit of the review is to be open and inclusive and to involve user and carer representation. The Royal College of Psychiatrists was asked to put forward submissions at the outset and since we had anticipated this we already had a working group, which submitted a collection of papers. The College was also asked for nominations and both psychiatry and the psychiatry of learning disability are now represented on all of the Legal Issues Working Group sub-committees. As there are only 10 consultants in learning disability in the province this is quite a burden of involvement. The working group on learning disability strategy and services, which also has some psychiatry representation, is expected to produce a report for consultation in the early autumn.

Approach and issues

The Legal Issues Working Group is in progress with an intention to learn from international and particularly the English and Scottish experiences and to find our own solution.

Compliance with human rights legislation is now a requirement, which the present Order fails to meet. There are also wide-ranging implications from the introduction of other legislation, particularly that concerning incapacity/capacity. As a sound basis for legislation, Scotland incorporated principles in the face of both their Incapacity Act and their new Mental Health Act and this is likely to be considered.

Of particular interest to us in learning disability there is likely to be a strong lobby in favour of removing learning disability from the umbrella of mental health legislation altogether. Watch this space! ■

Report from the Faculty of Learning Disability Psychiatry, Irish College of Psychiatrists

Verena Keane, Secretary – Faculty of Learning Disability Psychiatry, Irish College of Psychiatrists

- Last year, the European Year of Disability, was a watershed for learning disability psychiatry in Ireland. The learning disability faculty has produced a policy document on a proposed model for a mental health service for people with learning disabilities in Ireland; this is due to be launched in July 2004, as an Occasional Paper of the Irish College of Psychiatrists. The faculty is extremely grateful to both the Department of Health and Children (Ireland) and the learning disability faculty for their financial assistance towards the production of this policy document.
- The chairperson of the learning disability faculty, Dr Mary Kelly, has been nominated to be a member of the Department of Health and Children's Expert Mental Health Review Group. This expert group will set out the mental health strategy for the next ten years or so. Congratulations Mary!
- The National Disability Authority (NDA) produced a report, 'Review of Access to Mental Health Services for People with Intellectual Disabilities'. The NDA was established by the National Disability Authority Act (1999), whose principal function is "to act as a central, national body which will assist the Minister in the co-ordination and development of policy relating to persons with disabilities". The NDA concluded "a comprehensive mental health service for people with intellectual disabilities must be provided, underpinned by legislation as a matter of urgency". Furthermore, the NDA recommended that the service must be integrated into the mainstream mental health service, clarified in an agreed national strategy "... and resourced in line with international best practice".
- The Mental Health Commission set up in 2002, following the Mental Health Act 2001, has a working committee on intellectual disability and mental health services. This committee has representation from the Irish College of Psychiatrists and has recently presented its first working paper to the Mental Health Commission.
- Lastly and by no means least, the Inspector of Mental Hospitals Report (2002) addresses for the first time mental health services for people with intellectual disabilities. The report advocates that stakeholders be

brought together in an attempt to work towards a more co-ordinated approach to rational service delivery. ■

Useful links

See Occasional Paper OP58: *Proposed Model for the Delivery of a Mental Health Service to People with Intellectual Disability*
www.rcpsych.ac.uk/publications/op/op58.htm

The annual SpR conference – more than just a meeting

Edward da Costa

The term conference is defined in the Oxford Dictionary as "a meeting: exchange of views". It does not boggle the mind to understand that a conference in any medical specialty can be used for achieving many objectives besides that of being a unique educational platform. Conferences for practitioners in medical specialties will be both relevant to that specialty and their role as a medical practitioner, maybe primarily research-oriented or focusing on clinical practice, or catering to medical practitioners in both these domains, as is often the case with conferences for members of a faculty in medicine. A well organised conference for faculty members should bring together a range of speakers from diverse backgrounds within the specialty and will not uncommonly include charismatic and enigmatic scientists who through research have pushed the boundaries of scientific knowledge ever further and are able to disseminate this knowledge with an obvious passion. Many of us can recall an interesting lecture or anecdote from a particular conference that may have taken place many years previously and yet still influences our clinical practice or our understanding of the merits of a research paper today. The majority of delegates attending conferences, however, are clinical practitioners who would like to have their quest for scientific knowledge tempered with the ageless charm of lectures relevant to their practice at a "grass roots" level. It is therefore imperative that a balance is achieved and the quest for scientific knowledge should not overwhelm but should merge comfortably with the objective of building a foundation of good clinical practice. Lectures from "ordinary" clinicians, often working with Herculean case-loads, can provide a goldmine of valuable information to both novices and old hands and this is also accomplished by workshops with interactive discussion between delegates on a range of topics. Conferences are a useful medium for continuing professional development; an essential ingredient of good clinical practice.

In the specialty of learning disability, and perhaps more generally in psychiatric specialties, a conference is often a forum for a meeting of kindred spirits who may have been widely dispersed geographically over the years. Reliving old memories and the development of camaraderie are often as unforgettable as the content of lectures. Inside knowledge and views are informally exchanged on the benefits and pitfalls of working in various areas; and for aspiring consultants, or those simply wanting a change of scenery, this is a useful forum to glean more information.

Traditionally, specialist registrars (SpRs) in the psychiatry of learning disability have organised conferences singly or in groups with the aim of achieving a range of objectives, including that of providing a unique educational platform and this has been reflected in the content and themes of conferences, which have been wide-ranging, reflecting the breadth of clinical experience and knowledge emerging in this field. The conferences have been organised on a residential basis over two days at major venues. They have been aimed at SpRs and consultants in learning disability and allied disciplines of psychiatry and have been well received by many delegates.

The themes for the conferences in the last two years were psychotherapy and autism; the forthcoming conference will focus on forensic psychiatric practice in learning disability (reflecting specialism in the catchment area of North London and Essex) and also has a half-day devoted to research presentations by The Penrose Society. It is essential that this tradition of an annual conference by SpRs is maintained and it is heartening for future organisers to know that the faculty have offered to provide the advice and support of the faculty finance officer and academic sub-group in dealing with some of the administrative and organisational issues, thereby placing much less of a burden on future organisers. However for those wishing to take the plunge on their own or in groups, the SpRs in the North-East Thames Rotation who are organising this year's conference can vouch that this undertaking offers a fulfilling and exciting experience of contending with organisational, financial and administrative issues on a much bigger scale than one is likely to encounter in the normal course of one's post, as well as aiming to maintain the rich tradition of well organised conferences over the years. ■

**THE ROYAL COLLEGE OF PSYCHIATRISTS
Faculty of the Psychiatry of Learning Disability
in association with THE PENROSE SOCIETY**

**Annual Residential Conference of Specialist Registrars
in Learning Disabilities**

FORENSIC ASPECTS OF THE PSYCHIATRY OF LEARNING DISABILITY

The Royal Chace Hotel, Enfield
on 25 and 26 November 2004

This conference is being organised by specialist registrars in learning disability in association with The Penrose Society. The conference will focus on various aspects of forensic psychiatric practice in the context of patients with learning disabilities and also devotes a half-day to research presentations by The Penrose Society. There will be an emphasis on topics relevant to clinical practice, including assessment, management, legislation and psychiatric court reports. The conference is aimed at specialist registrars and consultants in learning disability and forensic psychiatry and will also be relevant for professionals in other disciplines of psychiatry. For informal enquiries please contact Dr Edward da Costa on 07766 253770.

For registration details please contact:

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In conversation: Matthew Kelly

... after winning a BAFTA award for playing the role of a learning disabled man in 'Of Mice and Men' by John Steinbeck

Oladimeji Kareem (interviewer)

Introduction

'Of Mice and Men' is set in the farmland of the Salinas Valley, the birthplace of the author, John Steinbeck. Against the backdrop of America's Great Depression, George and Lennie were migrant farm workers who were determined to buy a small farm of their own after years of eking out a living as itinerant workers. The two friends soon discovered the flipside of their American dream and the friendship was tested to its limits.

Matthew Kelly and George Costigan portrayed Lennie and George respectively in Jonathan Church's successful stage production and Mr Kelly won a BAFTA award for his performance.

OK: You are a well known television presenter and I particularly use to enjoy your 'Stars in Their Eyes' shows; can you tell us a bit more about your background?

MK: I have been an actor for 37 years. I started in 1967 in 'Variety' and was in theatre for 10 years as an actor and stage manager. I then went into television and four years later became a presenter. I still go back to the theatre every year to do a play. I first played Lennie in 'Of Mice and Men' 17 years ago at the Sheffield Crucible. I played him again two years ago at the Birmingham Rep, after which we did nothing with that production for a year until it went out on tour for four months and later came to the West End.

OK: Can I ask what attracted you to stage acting?

MK: I have been sure I never wanted to do anything else from the age of six and I still don't.

OK: The character of Lennie that you play in 'Of Mice and Men' certainly has a learning disability. How did you feel when you initially considered playing that part?

MK: Well, I've done it before. I was in the West End in 1976-77 in a play called 'Something Peculiar'. I played a 19-year-old with learning disabilities and I was 26 or 27 at the time.

OK: So it wasn't difficult for you taking on the role of Lennie then?

MK: Lennie, I think, was quite specific in a way. But as an actor, particularly as somebody who has worked on Saturday night telly, you certainly get to meet people with learning disabilities. You get used to being with them and forming relationships with them and understanding them. I once got involved in "disability diving" and we went to Antigua with a group of kids with severe learning difficulties and autism. It was interesting taking them diving, though up until that time I had never spent any particular time with autistic people. I was frightened of them because, as you know, with autism you can't use any of your tricks, charms or wits because they are in a parallel universe; or that's how it looked to me.

OK: So, when you came out of that experience did anything change in your perception of people with learning disability, or other groups that you don't really know for that matter?

MK: Yes, I think so. There was a time when the whole disability question was raised and mainly discussed by people who have a disability. Getting off that plane with all those kids, I certainly realised that everybody, no matter what their opinion of the world is, whether they actually appear to be part of the world or not, actually has a value. For people with a disability it is a way of life, that's what they know and they should not be viewed as if there is something wrong with them. I think that "differently able group" should be a better description because in the end we all have different abilities and disabilities.

OK: Lennie was a big person, just like you, but had a mind of a child. He was described by other characters in the play as "just like a kid" or "like a big baby". Did you have to make any specific preparations or adjustments in order to play the role?

MK: I had to first of all decide his level of disability in order to play the role. I made the decision that he was autistic because of certain little giveaways in the script. Anything you want to know about a character is often in the script and can be enhanced by stage directions. For instance, one stage direction asked that Lennie does not move his arms when he walks. That to me appeared to be because he was a bit obsessive and I have observed that particularly in autistic people.

OK: Have you been involved in any other way with people with learning disability, because one would expect that in your acting role, finding some inner sense of disability might be an essential ingredient to playing the character successfully?

MK: Yes, I am a patron of an organisation called 'Disability Challengers' in Guildford and there are lots of autistic children there, so my experience is mostly observational, although I think that I can be quite obsessive and repetitive myself. I don't know what I drew from within me except to say that there were a lot of things happening to me at the time of the staging of the play that obviously helped the performance. This man, Lennie, is in trouble all the time, afraid most of the time, given instructions all the time because he cannot remember anything. He, however, knows when he is being naughty and he does have a sense of morality. His major problem is that he is big and does not really know his own strength –

OK: – which got him in to lots of serious trouble like killing the dog and killing Curley's wife.

MK: – yes of course!

OK: Did it ever come up in conversation, for instance with your director, Jonathan Church, whether the role of Lenny should actually have been acted by someone with a learning disability?

MK: Interestingly at the time we were on tour, there was a concurrent tour of 'Of Mice and Men' played by two guys with disabilities. I have met them both; they went out from Coventry and their group is called the 'Shysters'. Their Lennie was not as big as me but kind of more rounded; I didn't see their show but I gather they were fantastic. I think people with learning disability should play all parts in plays. There has to be integration on all fronts as far as drama is concerned, as that is the purpose of drama.

OK: People with learning disability are increasingly getting involved in the theatre and in drama. What would your advice be to them?

MK: Well, my advice to everybody is to get involved with drama because it is better than watching the telly; there is a fantastic amount to be learnt from improvisation. My advice would not be any different to people who have a disability than it would be to anybody else. I personally think that everybody should be given an equity card at birth, just in case they need it. Drama should be used in every school; it's not just about learning, it's about socialisation as well. It is important to have groups that can stage people with disability alongside those without. It will enable people to get to know each other better and develop a sense of respect for one another.

OK: Lennie was misunderstood, abused and denigrated by others. In playing the role, could you explain how this made you feel when you were being treated that way?

MK: As an actor, if you are playing somebody with problems, that character has his own audience. It makes him vulnerable and if I ever thought that they were laughing at Lennie because of his disability then I got very upset. There is not a lot one can do, though, because you would have to come out of character in order to deal with it. If you are playing somebody without a disability then you are in a stronger position.

OK: Did you find any particular scenes or parts in the play too emotional or too difficult to act?

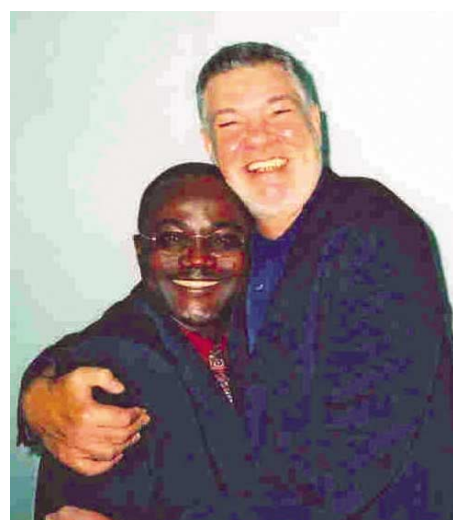
MK: No, I found it very easy because Lennie is a very emotional man and I suppose most men find it very difficult to express their emotions. But I am able to go to the theatre, dress up and express emotions that are not necessarily mine. You know I have cried a lot in the play and because he is a man in distress, you dissociate from yourself a bit and you become the character.

OK: What is your view generally on how people with learning disability are viewed and treated in this society?

MK: I think things will get progressively better as more people with disabilities become more visible in society. Some people think of just putting them in a day centre to keep them out of the way, without taking time to find out what their values are, so we have a long way to go. Another thing is that we live in a world that does things in a particular way and cannot tolerate laterality much. It therefore means that people with disabilities, even if talented, are seen as different. People need to start dealing with these issues and make allowances to accommodate all members of their communities.

OK: Thank you very much Matthew.

MK: Thank you. ■



*Oladimeji Kareem
and Matthew Kelly*

Letters

From Professor Sheila Hollins

Dear Colleague,

This is my second and final year as Vice President of the College. Many people have been encouraging me to stand for President in 2005. In considering this challenge I have decided to consult you – the members of the Learning Disability Faculty – and seek your advice. We are one of the smaller faculties. What do you think would be the advantage for our specialty of having a President in the Faculty? Do you think your colleagues in other specialties would recognise the value of having an learning disability specialist as President? How would you persuade your colleagues that the specialism of the candidate is less important than a combination of political experience and commitment to a vulnerable patient group? I am increasingly aware of the human rights issues, discrimination and social exclusion which confront our patients in all specialties and believe that while our clinical practice will always demand the best we can offer on an individual basis, there are wider societal and political challenges to mental health to which the College must also respond. Are there any key issues you would like to see being prioritised by the College? Is there anything you would like me to pick up in my final months as Vice President?

Best wishes,

Sheila Hollins

*Vice-President, Royal College of Psychiatrists
Professor of Psychiatry of Learning Disability and
Head of Department of Mental Health, St George's
Hospital Medical School, University of London*

From Dr Ekkehart Staufenberg

Dear Editor,

Learning Disability & Neuropsychiatry at the School of Medicine, Health Policy & Practice

Greg O'Brien's letter (Newsletter January 2004) aptly summarises some of the opportunities that are arising within the current reconfiguration, not only of the content, but also of the mode of delivery of undergraduate medical curricula. Following a pilot project based on problem-based learning at the University of Manchester, our enthusiasm as facilitators, seminar leads, tutors, as well as the feedback from "guinea pig" undergraduate students eventually translated to this having become the preferred mode of undergraduate curriculum development for medical schools in England and Wales.

The School of Medicine, Health Policy and Practice at the University of East Anglia opened its doors to the first undergraduate medical school in September 2002 after several years of planning, and on the third attempt over the last thirty years. We now have some 130 students per year intake, get nearly 800 applications per year, and have one of the highest proportions of mature students, often with previous science and some social science degrees, as well as the one of the highest proportions of individuals entering medical school with individuals coming through adult education 'A' Level completion following high-achieving other professional careers.

The innovative and, by the General Medical Council highly praised, curriculum is summarised in groupings of medical specialties. The two groupings most relevant to developmental neuropsychiatry and learning disability psychiatry are that of the 'Mind Unit Shadow Team', and the 'Senses Unit Shadow Team'. The former combines psychiatrists, psychologists, social workers, service users and leads from other professions allied to health in one curriculum development team, while the latter brings together neurology, ophthalmology, ENT, physiotherapy post-stroke rehabilitation, and acquired brain injury specialists. The neuropsychiatry of epilepsy, acquired brain injury and other key central nervous system (often chronic neurological) and neuro-behavioural disorders are represented through membership of a lead senior lecturer in neuropsychiatry linking both teams. The emphasis on the patient/user perspective with regard to resulting associated disabilities, the carer context, and psychosocial, health economic, ethical, legal and a whole range of other aspects of the curriculum are delivered as part of the undergraduate students participating in general practitioner-based surgery environments from Week 4 of their entry to the School of Health Policy and Practice. Exposure early on with regard to disabilities, both acquired

and, in particular, developmental and with associated learning disability, brings the students into contact in a national manner with issues focusing around the population we specifically care about and hold clinical and professional stewardship for in our services and academic environments.

The four weeks prior to attending the first primary care environments – supported by parallel tutorials, self-learning, group enquiry, problem-based learning and occasional lecture only – is spent by the undergraduate students in a module called ‘Being a Patient Being a Doctor’. The issues of the ethics of equality, access to services, inclusion based around research and practice evidence have recently been rated as one of the most important reasons why undergraduate medical school applicants come and subsequently rate the course as extremely satisfactory (regular or prospective audits are available from the UEA, Deanery Office, the School of Medicine Health Policy and Practice).

In particular the presence of users on the Undergraduate Curriculum Development Teams, access to the individuals and their carer/family, and the incorporation of an entire section on the learning disability population into various components of the undergraduate curriculum (not just the Mind and the Senses one) is being valued. It is possibly also one of the first undergraduate courses which has been able specifically to address issues on Asperger’s Syndrome and high functioning autism in both the Mind, and the Learning Disability separate sections across the curriculum, very much confirming what Professor Greg O’Brien says –

that the “involvement at the very hub of strategic and decision-making environment is difficult to find a substitute elsewhere”.

The curriculum teams and academic clinicians at the School of Medicine, Health Policy and Practice, University of East Anglia seem to be working in an environment catalysed by mutual enthusiasm for a curriculum development based on the focus on people with disabilities and the relevant OSCEs to go with it. A supporting pool of individuals with disability who have participated in an in-depth programme allows us also not to have to rely on actors too often, but have these individuals provide standardised assessment and training environments for the undergraduate students both during their clinical attachments, as well as for the examinations. The integration of primary care, secondary care and academic clinical curriculum development, therefore, appears to be working at this School of Medicine Health Policy and Practice and has been highly commended by the General Medical Council as exemplary.

Yours sincerely,

Dr Ekkehart F. A. Staufenberg

*Consultant Neuropsychiatrist and Hon. Neurologist
Norwich Epilepsy Clinic
Senior Lecturer (Hon.) in Development Neuropsychiatry and
Lead Consultant Forensic Neuropsychiatrist, Broadland Clinic
Forensic Service – East Anglia*

Green light for mental health

The Valuing People Support Team and the National Institute for Mental Health England have recently published Green Light (valuing.people.info@doh.gsi.gov.uk) to enable services to look at ways to improve mental health support to people with learning disabilities. In particular it looks at how Mental Health Local Implementation Teams (LITs) and Learning Disabilities Partnership Boards can work together to ensure that the recommendations of the NSF for Mental Health are implemented for those with learning disabilities.

Geraldine Holt

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. Please ensure that anyone pictured is aware that their photograph may be used in this newsletter; their written permission will be required.

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 web-pages.

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Conferences and meetings

Royal Society of Medicine

Forum on Intellectual Disability

23 September 2004

'Practical ideas about improving access to health services for people with intellectual disabilities'

2 December 2004

'Epilepsy & intellectual disability'

E-mail: learning.disability@rsm.ac.uk

Website: www.rsm.ac.uk/learning-disability

EAMHMR

Conference

6-8 October 2005

Sitges - Barcelona, Spain

NADD

21st Annual Conference

27-30 October 2004

Mental Health Aspects of Developmental Disorders

Vancouver, Canada

www.thenadd.org

UEA School of Medicine, Health Policy and Practice

Fourth Biennial Conference

17 September 2004

High Risk & Offending Conduct in Individuals with Learning or Developmental Disability who are Severely and Personality Disordered

E-mail: ekkehart.staufenberg@norwich-pct.nhs.uk

Faculty of the Psychiatry of Learning Disability, Royal College of Psychiatrists

30 September - 1 October 2004

Annual residential meeting

Radisson Hotel, Glasgow

20 April 2005

Spring Meeting

Regent's College, London

E-mail: pcornell@rcpsych.ac.uk

Website: www.rcpsych.ac.uk