Paving the way for mental health services that promote recovery

Working with health professionals and policy-makers around the world

Getting service users involved

Different cultural attitudes to caring responsibilities

Offering better care to people with a personality disorder

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Improving the life chances of children in Ethiopia
Professor Graham Thornicroft writes:

I would like to welcome you to this issue of *Towards Mental Health* which tells you about some of the research based in the Health Service and Population Research Department (HSPR) at the Institute of Psychiatry, King's College London.

Over the last year, we have been pleased to contribute to the work of the new specialist Biomedical Research Centre (BRC) for Mental Health at South London and Maudsley NHS Foundation Trust/Institute of Psychiatry, with different members of the Department involved in a number of the research themes that make up the BRC. We have also continued to develop international research projects, particularly in developing countries, in collaboration with local clinicians and researchers, many of which we have detailed inside, and have been involved in the launch of a major campaign for global mental health to highlight the stigmatisation of mental illness in many countries. Our UK-based projects continue to inform national mental health policy and currently include major research programmes on stigma and discrimination, primary care mental health, inpatient care and recovery.

Our Department continues to grow: we currently have 110 members of staff, including 15 professors, five readers, nine senior lecturers and 62 PhD students. We run two MSc courses, short courses for mental health workers, and a new summer school which offers short courses in research methods. A new e-learning short course on research methods for social workers has also recently been launched.

I hope you find the research described inside this publication of interest. All researchers are very happy to be contacted to discuss their work in more detail, and we hope those of you who work in mental health services feel inspired to join us in carrying out research to help develop policy for future high quality mental health services.

Graham Thornicroft is a Professor of Community Psychiatry and Head of the Health Service and Population Research Department.

Published by Health Service and Population Research at the Institute of Psychiatry, King’s College London
David Goldberg Centre
De Crespigny Park
Denmark Hill
London SE5 8AF
www.hspr.iop.kcl.ac.uk
Written and designed by Jane Smith and Sophie Gibson
Inside Out, 020 1855 0865
Printed by Calverts
January 2009

Mike Slade has a vision – to see mental health services in this country transformed. He has returned to London from a year abroad, inspired by the success of recovery-focused mental health services he visited in Australia, New Zealand, Canada and the USA that support people in their quest to live a fulfilling life, fostering their individual strengths and abilities rather than ‘treating’ them according to clinical textbooks. Already a pioneer in delivering training to help mental health professionals shift the way they work towards recovery, Mike has come back, he says, with a more rounded understanding of the task ahead, and even more convinced of the need to question ‘deeply embedded culturally-based beliefs’ that inadvertently promote dependency and impoverish people’s expectations.

‘The challenge is to move beyond the view that a good patient is a compliant one, who does what the professional says because the professional knows best.’

A stark contrast to the concept of recovery – where a person with mental illness defines his or her future goals, which may differ as much as individual people do. ‘One person may aspire to symptom reduction, another to have a love life, another to get a job. Someone else may want more friends, another person will want to stay out of hospital,’ said Mike, a Reader in Health Services Research who leads the Community Mental Health team in HSPR. ‘The role of the professional in recovery-focused services, he says, is to help people attain their aspirations, to listen to people’s wishes and act on them, even if they go against the grain of the existing culture – if someone wants to come off medication, for example.’

‘I was inspired by the centres I visited that don’t put all their energies into preventing relapse and controlling symptoms, but instead look at growth opportunities for each individual and see their desires and aims as part of the solution, not part of the problem,’ he said.

‘I learned that services can exist without mental health professionals running them. A recent multi-site randomised controlled trial of consumer-operated services in the USA showed that these services promoted empowerment more than traditional services. Some of the services I saw had peer triage workers – the first person you meet when you turn up is someone who also has experience of mental illness. ‘This changes expectations about the service and what it can offer.’

All the recovery-focused services concentrate on amplifying what people can do rather than what they can’t, and to that end often provide support in a context other than a traditional outpatient clinic, hospital ward or health authority-owned office. ‘In Boston, for example, I found services provided in an educational context. Instead of being assessed for their mental state when people arrive, they are registered as students with Boston University, and given access to all sorts of courses, from “how to set up a bank account” to anger management. This approach creates a climate in which both students and professionals work and interact differently – staff respond, for example, with an educational rather than a clinical response to any behavioural issues. Within a week or two of enrolment, most people who accessed the services were wandering around Boston feeling just like any other student, instead of feeling like someone set apart and different, someone in need of help.’

Environment is important to recovery too, he says, and is something traditional services rarely consider. ‘Many of the services were set in beautiful surroundings. In Toronto, I saw a working farm set up for people with experience of mental illness. There, they were woken up at 8am each day to feed the chickens – not because someone thought it was good for them to get up, but because they had something to offer to another creature. This is a totally different view of the world, where people with mental illness have something
to give and are not just passive recipients. This reciprocity is at the heart of recovery.’ After working as a psychologist for 15 years, he has seen at first hand how some mental health practices can hold people back. While the concept of recovery promotes wellness, self-help and self-determination, traditional services emphasise management and medication in line with professional expertise learned through training. ‘The system we operate tries to impose uniformity, it takes responsibility away from people under the guise of “risk management” and can lead to a conveyor belt mentality that works against individualised care,’ he said. ‘The existing mental health system doesn’t organise itself around the fact that people with mental health problems have individual identities.’

Now Mike has written a book arguing the case for recovery, which includes 26 examples of good practice from his experiences while travelling. Personal Recovery and Mental Illness, a guide for mental health professionals, will be published later in 2009 by Cambridge University Press and includes a scholarly expertise learned through training. ‘The book aims to convince about recovery, crystallise what it means, and catalyse towards concrete actions by specific example,’ he said. Recovery-focused services have been government policy in this country since 2001, but to date progress on a shift in culture has been slow. The climate is beginning to change, however, as the NHS National Institute for Health Research has just invested £2 million in a five-year programme that has the ‘audacious goal’ of developing a recovery focus in mental health services in England. Mike is leading the research, which he hopes will provide professionals – including those who may be cynical that ‘recovery’ is simply the latest fad – with the evidence they need to persuade them to change their way of working and, most importantly, their attitude.

The plan is to spend 18 months preparing for a trial that compares recovery-focused with traditional services in south London and Gloucester. The preparatory period will include a national survey of 60 specialist adult services and 600 service users to discover what elements, if any, of the recovery concept are already being put into practice in England. Another task will be to develop a recovery-focused intervention that can be used to change attitudes and develop the skills of professionals – training or clinical supervision, or giving staff the tools to support service users in their efforts to access employment, for example.

Mike has already coordinated and evaluated pilot training about recovery for mental health workers in South London and Maudsley NHS Foundation Trust (SLaM) and this has since been extended to other services in SLaM’s portfolio. (The RETRAIN project was named by Guy’s and St Thomas’ Charity as Best Example of Patient/Service User Involvement at a 2008 event to showcase projects the charity supports: RETRAIN was developed with the help of £206,500 worth of funding from Guy’s and St Thomas’, the largest NHS-related charity in the UK.) Now 20 of SLaM’s services will participate in a randomised controlled trial alongside 10 services in Gloucestershire. The success of the recovery-focused intervention will be gauged by comparing the experiences of service users after three years. ‘One of the real methodological challenges of this trial is working out the evaluation process, as each service user will have individual, different recovery goals and we therefore need to find a way of measuring them,’ said Mike.

Service users will be involved throughout the project, both as co-investigators, and as members of an international advisory board – including people he met while travelling. ‘Another priority for the preparatory period is to think how this involvement will work, so it is not just a tokenistic tick in the box on the grant form,’ he said.

But for Mike, the biggest challenge ahead is the longer-term one: to change the system – ‘and to change it with compassion for, and understanding of, people working within it, to gain the support of those people, rather than imposing change on them,’ he said. ‘As it stands, there is a group of people who work in the public sector who “help those who need help.” Recovery isn’t like that – it’s about two-way learning and two-way communication. Mental health workers need a broad range of skills – they need expertise in coaching as well as being prescriptive, with space for more authentic human to human relationships. If we can show through this trial that shifting attitudes and working practice makes a difference, if we can provide the evidence, then I think it will be easier in future to make the changes that need to happen. ‘Recovery-focused simply means a belief that normal human needs do apply. So that means, as health professionals, that we should be focusing on supporting these everyday goals. If people are given the right support and help, they can make decisions themselves about their own lives.’

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Personal Recovery and Mental Illness, a guide for mental health professionals, to be published in 2009 by Cambridge University Press, cambridge.org
Helping victims of trafficking reclaim their lives in Moldova

Moldova has the highest number of victims of human trafficking in eastern Europe, says the International Organization for Migration (IOM). Widespread poverty and lack of job opportunities there make young women easy prey for criminal organisations who lure them into virtual slavery with false promises of job offers abroad. Human traffickers reap huge amounts of money by exploiting their victims, forcing them to work illegally, often in the sex industry, for no payment. Victims of trafficking find themselves isolated in a strange country, with no-one to turn to for help – their experiences often include violence, rape and imprisonment.

The women who manage to escape and return to their home countries are depressed, suffer from post traumatic stress disorder, and have physical ill health and injuries, including gynaecological problems. Some also have drug addictions, which began during trafficking.

An IOM-managed centre in Chisinau, the capital of Moldova, is one of many run by the organisation around the world to help victims of trafficking reclaim their lives in their home countries. HSPR researchers are working with IOM staff there to carry out research that will help formulate services specifically designed to meet their mental health needs – not just when they first return, but as they continue to try to rebuild their lives.

So far, about 100 young women, who accessed the centre’s services on their initial return, have been interviewed by researchers about their experiences, both during trafficking and in the first six months of being back in Moldova, which sits between Romania and Ukraine.

The research is being carried out by Moldovan psychiatrist Nicolae Ostrovschi, who came to the Institute of Psychiatry to learn about methodology by undertaking a Psychiatric Research MSc before starting the project. His study and research have been funded by a Wellcome Trust Masters Training Fellowship, and he is being supervised jointly by Professor Mihai Hotineanu, a senior psychiatrist in Moldova, and Melanie Abas in HSPR’s Section of Epidemiology.

The women who have been interviewed are aged between 18 and 24 and were taken by the traffickers to Turkey, Russia, Israel, Ukraine, Kosovo, United Arab Emirates, Macedonia and Albania. Fifty-two per cent of them have one or more children: they nearly always left their children in Moldova and were separated from them throughout the trafficking experience.

During the interviews, the women are talking about their experiences – often including horrendous violations of human rights – and what it’s been like trying to start again in Moldova. In addition, the researchers are asking about their childhood and pre-trafficking life.

‘We need to understand what sort of mental health problems these women have as a result of their experiences during trafficking,’ said Melanie. ‘But we also need to know if their mental health problems are related to what happened before then to make them vulnerable to exploitation. They may have had earlier disrupted family lives or been exposed to violence, and this might affect the mental health treatment they need when they escape from the trafficking.

‘We also need to understand fully the difficulties they face in coming back – many women still feel unsafe because the trafficker might still be in operation, for example, and they may be getting threats from the traffickers to stop them talking to the police.’

The research team is assessing the women’s mental health six months after their return, and finding out what sort of support they now have from family and friends. ‘Many of the women feel isolated and ashamed. They’ve been deceived and exploited, and perhaps their family thought they were going off to another country to be an au pair or a nanny, to hold a respectable job. Their family may be ashamed of them because of what’s happened and may not want to know them again. Because traffickers have taken their passports, they often have to battle to get their identity back. Sometimes they have to fight to reclaim property, which may have been taken over in their absence. They may have problems getting a job and supporting themselves. All this contributes to the state of their mental health.’

‘The experiences the women share will help inform the development of services and treatments to meet their needs. At the moment, they are offered practical and psychological support from the IOM centre for a year, and a psychologist based there is very keen to make improved, ongoing treatment available.

IOM works in partnership with not just the Moldovan government, but governments across the world to combat trafficking, offering practical help to victims, and campaigning against the crime: it estimates 800,000 people a year are trafficked across international borders. IOM will use the results of this research to also develop and hone treatment in other centres.

Melanie Abas is a member of an IOM Expert Group that has developed Guidelines for health professionals working with trafficked persons. The IOM, in collaboration with the London School for Hygiene and Tropical Medicine, brought together experts on health and human trafficking from across the world to draw up the guidelines as part of the broader United Nations Global Initiative to Fight Human Trafficking.

International Organization for Migration, www.iom.int
Different cultural attitudes to caring responsibilities

South Asian and black Caribbean people looking after a relative or partner who has dementia are more likely to accept and embrace their role as carer than their British white counterparts. A study carried out by HSPR’s Mental Health and Ageing team found white British carers were more likely to feel their life had been put on hold, did not find their role as a carer to be rewarding, and were fearful about the possibility of caring responsibilities continuing indefinitely. South Asian and black Caribbean people who were interviewed, however, were more likely to feel their lives were still continuing, albeit differently, were more likely to prioritise the person they were caring for, and to reap rewards from the relationship. They were more likely to see the role of carer as ‘natural, expected and virtuous.’

The study involved in-depth interviews with 10 black Caribbean people, 10 South Asian people, and 12 white British people, all of whom are caring for a member of their family who has dementia – a parent, or spouse, for example. Most of the interviewees – recruited through community mental health teams for older people, services for carers and community services in four south London boroughs – were women, and their ages ranged from 33 to 87.

The research team found that South Asian and black Caribbean carers were more likely to have religious faith, and that those beliefs and values motivated them and helped them to cope. They were more likely to believe it was right to make sacrifices for their partners or parents, that it was part of the responsibility of marriage or the duty of a child. A high proportion of black Caribbean carers had worked as nurses and felt a natural inclination towards caregiving. “Seeing caring as natural, expected or virtuous helped to minimise the disruption felt by carers, and helped them to continue to derive rewards from the relationship,” said Professor Sube Banerjee who heads the Mental Health and Ageing team. “Caring was a natural development in their lives, and this view helped them adapt to the change in their roles.”

Most of the white British interviewees, however, felt the changes caused by dementia marked the end of the relationship with their relative or spouse. Their role as carer often caused conflict in their lives as they tried to continue with a career and a social life at the same time. Carers who felt like this – dubbed as having a ‘non-traditional caring ideology’ by the research team – were more eager to relinquish their caregiving responsibilities and more likely to feel their needs were not being met by health and social care services.

In the UK, around two-thirds of older people with dementia are supported by family members. “Caring for a person with dementia exerts huge psychological, physical and emotional demands on everyone,” said Sube. “Attitudes towards caregiving, and the way individual carers appraise and adjust to the role, can help us plan services to support them. “So, for example, many carers with traditional ideologies – those who accepted and welcomed their role – prioritised the care of the person with dementia over their own physical and mental health. Offering those carers services that would benefit their relative or spouse – like a place at a day centre that supports rather than substitutes for family members – is important, and professional staff must also reassure carers that it is natural and necessary to take time for themselves.

“Carers who hold non-traditional ideologies – those who derive little satisfaction from their role – should be offered as much practical support as possible to help them maintain other parts of their lives. There is scope for a change in government policy and the benefit system to support and promote the role of family carers, to acknowledge the value that families bring in terms of preventing expensive institutionalisation. Specific grants or targeted benefits could legitimise the caregiving role, as well as give direct help to people in this position.”

■ Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK (Vanessa Lawrence, Joanna Murray, Kritika Samsi and Sube Banerjee), British Journal of Psychiatry, September 2008.

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Rachel Jenkins spends about a third of each year away from her office in HSPR and her home in south London. As Director of the World Health Organisation Collaborating Centre for Research and Training in Mental Health (WHOCC) based at the Institute of Psychiatry, she is constantly on the move overseas, helping place mental health on government agendas and supporting professionals to improve services.

In the last four years she has worked in Russia, Kenya, Pakistan, Djibouti, Egypt, Georgia, Ethiopia, Tanzania mainland and Zanzibar, with governments, health professionals and non-governmental organisations (NGOs), developing locally appropriate policies, services and training to treat and support people with mental health problems and their families, and to promote good mental health and prevent illness.

‘When I start work with a new country, I am normally invited to go for a couple of weeks, talk to the government officials and all the key players to find out what there is, how things work now,’ she said. ‘You have to get to know different governments, their health systems, their social welfare, education and criminal justice systems, the NGOs and the politics of each country. Diplomatic skills are essential – often you are trying to get things done in a sustainable way that will survive local politics. I work as a team with local partners, and together we make recommendations, advise the government about what needs to be done to build capacity and to develop and implement policies that begin to meet people’s needs. It’s sometimes a challenge to ensure that mental health is considered and integrated into the generic strategies and policies that can affect it, rather than being seen as a stand-alone programme.

‘Training of the health workers who deliver services is always crucial – so once policies have been agreed, I often help train the trainers, so services, especially those based in primary care, can begin to reflect that policy. It’s important too to put in place a sustainable system that means the training will continue.’

So in Kenya, for example, after working with the government and NGOs to get policies on mental health agreed centrally, she has developed a week-long professional development course for thousands of primary health care workers which gives them the information and skills they need to detect and treat mental health problems.

The relationships with low and middle income countries are mostly long-term: work in Tanzania mainland, Zanzibar and Kenya, for example, started a decade ago, and Rachel first set foot in Russia at the turn of the century. Often, one of the stumbling blocks to progressing projects more quickly is lack of money. ‘There are, or have been, grants for some of the work – for example in Kenya, Tanzania and Russia. But often I am approached by different countries who request help but have no funding. As a result, I often start work in a country without financial support, and then apply for grants to be able to continue.’

To enable this unfunded work to happen, Rachel accepts a variety of commissions from the UK and other countries in the west to keep her overall budget in the black. ‘These pieces of work are always relevant to her interests and expertise – epidemiology, policy and primary

Working with health professionals and policy-makers around the world
Looking to the future in the UK

The Foresight Mental Capacity and Wellbeing Project’s final report, Making the most of ourselves in the 21st century, used evidence from more than 80 areas of science to map how mental capital and mental wellbeing evolve and are influenced from birth to death, and to identify how the UK government can act in the best interests of people’s mental resources – which in turn could reap economic and social returns.

The report lists factors that will either hinder or help our mental capital and wellbeing – longer life spans leading to increased numbers of people with dementia as well as a changing concept of older age and retirement, for example. Its recommendations include proposals to help realise mental potential at every stage in life, and for specific groups of people.

Rachel Jenkins was part of the Project’s Science Coordination Team and led work on ‘mental health and mental ill health’, making a wide range of innovative recommendations ‘to improve mental health promotion, prevention, treatment and rehabilitation services.’ In addition to a series of proposals designed to help tackle the negative implications of debt for mental health, Rachel particularly wanted to highlight the plight of looked-after children, recommending that more investment needs to be made to support them.

Governments should take account of implications for mental health when developing policies not just on health, but also on employment, housing and crime – all of which affect the likelihood of developing common mental disorders such as depression, she said.

The report also calls for improved access to treatments for mental health problems – extending treatment for depression to all those who are depressed, for example, and investing in better diagnoses and treatments for dementia. It recommends promoting positive mental health and wellbeing at all stages in life and lists a five point individual action plan for being mentally well – spend time with friends and neighbours; be active; be curious and appreciate small things; keep learning; and help other people.

“Small increases in levels of wellbeing can produce a large decrease in mental health problems across all ages,” says the report. The extensive two-year Project involved more than 400 experts from around the world and the report was sponsored by the UK Government’s Department for Innovation, Universities and Skills.

www.foresight.gov.uk

Rachel Jenkins was invited to join the Department of Health as Principal Medical Officer at the end of 2005. She was invited to join the Department of Health when working in the WHOCC and to include all aspects of mental health policy, and from 1990 to 1996, she led a team of mental health professionals working on UK policy and initiated links with WHO and other countries.

In 1997, she came to direct the WHOCC, on secondment from the Department (nowadays she is directly employed by the IoP as Professor of Epidemiology and International Mental Health Policy) and that’s when the overseas work started in earnest. The WHOCC is one of an international network of collaborating centres that carry out work in support of the United Nation’s agency for health.

The Institute of Psychiatry had been designated a WHOCC since 1993, and when I arrived, I was able to set up a comprehensive programme of activity in low and middle income countries to support WHO’s overall objectives, to close the gap between what is needed and what is currently available to reduce the burden of mental ill health around the world, and to promote mental health.

“The work can be quite gruelling, and most of the flights are long-haul, and so often I will cluster visits together if it makes sense logistically. Sometimes it feels a long time to be away and living out of a suitcase.

But I love the different countries, and the different cultures. And I have so much respect for the people who work in often very difficult environments. It’s a very inspiring experience and immensely satisfying to be able to do what I can to support them, and to be able to work with them to make a sustained difference.

Sometimes, you can feel a bit dispirited. In Djibouti, for example, it has been difficult to obtain resources for continued work, while in Georgia, progress has been delayed for political reasons. But when I look back over a 10-year period, things have always moved forward.”

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Bringing different disciplines together for health research

Computer experts, lawyers and psychiatrists are working together to explore the potential for designing a programme that would help health and social care professionals decide if the Mental Capacity Act applies to an individual. The project is exemplary of an interdisciplinary approach to research about health and health-related topics that is to be fostered across King’s College London by a new Health and Society Research Centre that will launch in 2009.

HSPR’s George Szmukler, a Professor of Psychiatry and Society, is collaborating on the computer programme idea with colleagues in the Law School and the Department of Computing Science in the School of Physical Sciences and Engineering at King’s. He is also one of the leading lights in the new Centre that will encourage researchers working in different fields to team up and bring new perspectives to important issues of health. ‘We aim to develop new ways of thinking about major health issues in relation to society, to come up with novel approaches and new ways of studying health-related problems that have strong social relevance,’ he said.

George, and Professor Brian Salter in the School of Social Science and Public Policy, will be Co-Directors of the Centre, which builds on the success of a Health and Society Research Network at King’s that has already led to collaborative work like the computer project. Another example is work being carried out by psychiatrists, lawyers, philosophers and social scientists who have come together through the Network to look at mental health law and issues of rationality and values in treatment decision-making.

‘Through seminars, brainstorming sessions and other opportunities for exchanging ideas, the Network has created a climate where people of different disciplines within King’s want to work together, want to cross boundaries,’ said George, who originally had the idea of setting up the Network when he was Dean of the Institute of Psychiatry, one of King’s nine Schools. ‘Interdisciplinary research is about taking different perspectives, about being flexible, about jointly looking at a problem and possibly coming up with a new kind of formulation. The interaction of disciplines may lead through novel formulations to novel solutions.’

The Centre will help groups of researchers from different disciplines to develop high quality, large-scale research programmes related to the theme of health and society that will have a national and international impact. ‘There are certain areas of health – like stem cell therapy and genetics – that present clear issues for society,’ said George. ‘The public accepts these potentially potent new technologies, but they also induce huge fears. People working in these areas are already aware of the social dimension. But there are many other fields where health and healthcare share concerns with sociology, law, philosophy, economics and history, for example, where the interests of researchers working in different disciplines can overlap.’

‘Through the Centre, researchers will be able to find colleagues in other disciplines interested in the same topic. A senior coordinator will organise a programme of conferences and workshops aimed at developing methodologies as well as bringing together different groups in King’s who could collaborate. The Centre will also establish links with potential funding organisations. George cites the King’s Centre for Military Health Research as a prime example of successful interdisciplinary working already in operation at King’s. Set up as a joint initiative between the Institute of Psychiatry and the Department of War Studies in the School of Social Science and Public Policy, the research programme there has looked at the health consequences of the 1991 Gulf War and the mental health of armed forces in Iraq, and the results have had substantial influence on government policy.’

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Health and Society Research Network,
www.kcl.ac.uk/research/groups/healthsoc/index.html

New website about learning disabilities

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www.learningdisabilityonline.com has been created and launched by Steve Hardy who works at The Estia Centre. The Centre has a remit of undertaking research and providing training to meet the needs of people with learning disabilities who have mental health problems: it is run by South London and Maudsley NHS Foundation Trust and is also part of HSPR.

Steve is the Training and Consultancy Manager there and decided to put together the personally-run website as a resource for professionals working in health and social services with people with learning disabilities to fill a gap in the market. ‘Most organisations only list their own activities, and I thought there was a need for a site where people could get an overview of all the training, networks, news, policy, resources, policy decisions, reports and events being organised and produced by a variety of groups and agencies in the UK,’ he said.

Supporting people with learning disabilities – the name of the site – also includes links to different organisations, including academic centres like The Estia Centre, organisations led by people with learning disabilities and relevant charities. And it gives a platform to the activities of the Tuesdy Group, a group of people with learning disabilities who meet every fortnight in Lewisham, south London, and are supported by staff from The Estia Centre, including Steve. The Group’s members give each other support and talk about how to stay well – and also discuss services designed for them. Representatives of the Group are available to talk at conferences about their experiences of mental health services, GPs and hospitals.

Within the first two months of launching, the site had already had more than 2,000 visits. ‘I’m regularly updating the site,’ said Steve, ‘and am planning in the future to develop it to include pages for people with learning disabilities and pages for carers. The idea is to present a comprehensive collection of information and resources around learning disabilities, all on one site.’

Steve already runs an electronic Mental Health in Learning Disabilities Network, a forum for anyone interested in the mental health needs of people with learning disabilities to share information, resources and good practice. Contact him to join the Network.

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Supporting people with learning disabilities,
www.learningdisabilityonline.com
The Estia Centre,
www.estiacentre.org
Maudsley International scheme helps build services in Sri Lanka

In Sri Lanka, more than two decades of civil war and the 2004 tsunami have taken their toll on people’s mental health. Now Maudsley International’s Volunteer Sri Lanka gives professionals working for South London and Maudsley NHS Foundation Trust (SLaM) the chance to help build and develop mental health services there to meet the needs of the five to 10 per cent of Sri Lankans who are estimated to have mental health problems.

The scheme is a partnership between the VSO (Voluntary Services Overseas) and SLaM and was brokered by Maudsley International, set up a year ago to share the clinical and research expertise and experience of staff at SLaM and the Institute of Psychiatry (IoP) with colleagues overseas, particularly those working in low and middle income countries. Maudsley International is based within HSPR and is directed by Nick Bouras, Professor Emeritus of Psychiatry, assisted by newly-appointed Project Manager Franco Henwood.

The volunteering scheme in Sri Lanka builds on the work of the UK-Sri Lanka Trauma Group, a charity originally launched in 1996 and comprising Sri Lankan and British mental health professionals, many of whom are based at the IoP and SLaM. Volunteers from the charity have set up Samutthâna, the King’s College London Resource Centre for Trauma, Displacement and Mental Health with the help of a grant from CAFOD (Catholic Agency for Overseas Development). Based in Colombo, the largest city in Sri Lanka, the Centre provides training and support to organisations and individuals who are helping people who have had traumatic experiences as a result of the tsunami or the conflict.

Volunteer Sri Lanka is keen to hear from occupational therapists, psychiatric nurses, psychiatric social workers, clinical psychologists and managers, particularly those with experience of community services run by SLaM. Volunteers will work alongside local health professionals, helping them to deliver high quality mental health services provided by VSO’s partner organisations there – both government and non-governmental agencies.

‘Volunteers are involved in training, coaching and mentoring, enabling partners to develop and strengthen services, and supporting them to implement a new mental health policy in Sri Lanka,’ said Ruth Grearson from VSO. ‘The focus is on supporting the development of more holistic and less medicalised services that promote recovery, and that service users can access in the community. The vision is that more people with mental health problems can take part in society and fulfil their potential,’ she said.

The VSO/SLaM volunteering scheme forms part of a European Community-funded project to improve community-based mental health services in seven provinces in Sri Lanka. Volunteers are asked to commit to working in Sri Lanka for between nine months and two years. VSO offers support to volunteers, giving them training, a volunteering allowance, return flights and accommodation. NHS employees get full pension credits during their absence under a government fund announced in 2008 to cover the pension costs of UK public servants volunteering overseas.

Volunteer Sri Lanka was launched at the end of 2008. ‘More than 50 people who were potentially interested came to a launch event,’ said Nick Bouras. ‘The way this partnership works is that if people apply to become a volunteer, they qualify to apply for a career break with SLaM. This joint venture is a very good example of Maudsley International’s raison d’être – to develop and coordinate partnerships between SLaM and/or the IoP and other organisations to deliver projects that will help meet the mental health needs of people around the world.’

VSO, www.vso.org.uk/srilanka

■ Another new project launched under the Maudsley International banner is a pilot online professional development scheme for UK-trained psychiatrists working in low and middle income countries. The pilot will evaluate the success of linking psychiatrists working in non-governmental organisations or the public sector in India and Africa with volunteer psychiatrists working for SLaM who have agreed to be individual clinical mentors. As well as getting support by email, participating psychiatrists in Africa and India will be able to access online forums and noticeboards.

■ A dozen psychiatrists from Japan learned more about SLaM’s early intervention services for people who have had a first episode of psychosis – and the research that helped to develop them – thanks to a Maudsley International-organised visit in November 2008. The psychiatrists visited clinical services and attended specially-organised lectures at the IoP. They also met with mental health tsar Louis Appleby at the UK Department of Health. The visit was organised with the National Institute of Mental Health in Tokyo.
Training local people to offer community-based support in India

Community-based services for people with schizophrenia in India are almost non-existent. ‘The usual care that is available is only medical management, followed by inpatient treatment,’ said Sujit John, who works at the Schizophrenia Research Foundation (SCARF), a non-governmental organisation based in Chennai. ‘A handful of psychiatric hospital-based teaching institutions have vocational training and rehab centres, but these are all located in urban areas, leaving the vast majority of rural India with no access to these services.’

SCARF runs a Centre in Chennai, where a team of psychiatrists, psychologists, social workers and rehabilitation staff offer people with schizophrenia a wide range of services, including an employment bureau and support for families. The organisation also runs outreach clinics in surrounding rural areas, but services provided at those clinics mostly focus on medication. ‘This is primarily due to shortage of resources in terms of manpower, finance and logistics,’ said Sujit.

Now SCARF and HSPR are two of the collaborators on a new project that will recruit high school or college graduates with no previous experience of mental health work and train them as community health workers, giving them the skills and knowledge they need to support people with schizophrenia and their families who live in their neighbourhood. ‘Some of our outreach clinics already employ community health workers,’ said Sujit, ‘and our prior experience of training high school graduates and using them to deliver mental health services has been rewarding. For this new project, we will be starting an outreach clinic in a rural area where SCARF has not previously initiated any community-based work, and six to eight community health workers will be recruited locally.’

The idea is that the community health workers trained as part of the Wellcome Trust-funded Randomised Controlled Trial of Community Care for People with Schizophrenia (COPSI) will not only work with individuals and their families in their homes: they will also liaise with other service users to stay well and avoid relapse by helping them and their families better understand the symptoms of schizophrenia – and to understand more about medication and treatment. They will also work with services users to improve their physical health and their quality of life.

Another team of community health workers will be recruited and trained for the project in Goa, through the Institute of Psychiatry and Human Behaviour, the specialist treatment and teaching hospital for the state.

The randomised controlled trial will start in Spring of 2009 and, after a year, will compare the symptoms and quality of life of a group of people who have received support from community health workers with a group of people and their families who continue to receive ‘treatment as usual’ – likely to be medication prescribed at an outpatient clinic.

And the research teams in India will carry out in-depth interviews with service users and their carers from both sites, to gather their views on the community-based care package. A sample of the community health workers will also be interviewed to find out what they think about their training, the work, and whether they believe they have made a difference.

USA students contribute to nursing research

Six student health professionals from Florida International University in Miami have spent time working with the team in Mental Health Nursing in HSPR over the last three years. They visited as part of a scheme that gives minority undergraduate and graduate students at Florida International the chance to study abroad and launch careers in research.

Under the Minority Health International Research Programme (MHIRT), students work for one semester on research projects either here in Mental Health Nursing, at the University La Sapienza in Rome, at the University of Witten/Herdecke in Germany or at the University of Colombia. MHIRT is funded by the National Centre on Minority Health and Health Disparities and The Fogarty International Centre of the National Institute of Health. The scheme aims to open research career doors to minority students and is part of a long-term strategy to encourage health graduates to pursue careers in biomedical, nursing and social science research, said Debbie Robson in Mental Health Nursing. The emphasis is on conducting research that will ultimately lead to reducing health disparities among minority populations in the USA, she said. ‘Students mentored by Mental Health Nursing staff under the scheme have made valuable contributions to several projects, including an evaluation of a specialist smoking cessation service for people with schizophrenia; a pilot study of medication adherence in people with mental illness in prisons; and a study about the mental health needs of people with multiple sclerosis.’

Minority Health International Research Programme, http://mhirt.fiu.edu
If the study proves that support from community health workers is effective, the approach could be replicated across India. ‘At the moment, we believe that a substantial number of patients with schizophrenia in India remain untreated,’ said Sujit. ‘The implications of the study for a resource-poor country like India are huge. The COPS I trial offers a unique opportunity to scale up mental health services by identifying the minimum requirements to deliver effective community-based care through community health workers to people with schizophrenia.’

‘If we can prove that this low-cost model of community care is clinically- and cost-effective in a low to middle income country, the study will have a significant impact on policy nationally and could impact on other low and middle income countries around the world,’ said Graham Thornicroft, head of HSPR and principal investigator for the trial.

Previous research around the globe has shown that community support for people with schizophrenia can not only improve symptoms and quality of life, it can also reduce stigma and discrimination. SCARF is also the Indian coordinating site for the anti-stigma programme of the World Psychiatric Association – and one of the few non-governmental organisations in the world to be named as a WHO Collaborating Centre for Mental Health Research and Training.

Other collaborators on COPS I include Vikram Patel from the London School of Hygiene and Tropical Medicine, a Professor of International Mental Health who is based in the non-governmental organisation Sangath in Goa and leads a number of studies there, and Mathew Vargese at India’s National Institute for Mental Health and Neurosciences.

Schizophrenia Research Foundation, www.scarfindia.org

Movement for Global Mental Health launch

The Movement for Global Mental Health was launched on World Mental Health Day 2008. HSPR’s Professors Martin Prince and Graham Thornicroft are two of the key players in the campaign for better treatments and services for mental illness across the world. The Movement has grown from The Lancet Series on Global Mental Health published in 2007 that highlighted the neglect and stigmatisation of mental illness in many countries and provided evidence for the need for investment in both services and research.

A new website – www.globalmentalhealth.org – outlines the Movement’s goals for better research, better packages of care that respect human rights and support for people delivering them. It also wants to monitor country responses to the call for action on mental health. The site includes harrowing images of people with mental health problems living in shocking conditions in institutions and communities to publicise their appalling plight and the urgent need for change.

To coincide with the launch of the Movement, The Lancet published an article by the Movement’s Advisory Group. Professor Martin Prince was among the authors of the paper, which also highlighted commitment by some governments since the publication of the Series on Global Mental Health.

‘The Movement is not an organisation,’ says the article. ‘It has no constitution, no office, no board of governors and no budget. Anybody and any organisation can join the Movement – all that is required is support for the specific goals of scaling up services for and protecting the human rights of people living with mental disorders.

‘Ultimately we hope that substantial progress in scaling up services for people with mental disorders will take its place alongside progress in HIV/AIDS treatment and maternal and child survival as one of the great public health successes of our times.’

The Movement is organising a Global Mental Health Summit on 2 September 2009 in Athens at the same time as the World Congress of the World Federation for Mental Health.

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Movement for Global Mental Health, www.globalmentalhealth.org

In many countries around the world, including India, people with schizophrenia are often restrained and deprived of decent facilities instead of getting the treatment and support they need.
Investing more in treatments will save money

Treating more people with depression and anxiety disorders so they are well enough to work could help bring down the cost of mental health care in England, says Paying the Price: The Cost of Mental Health Care in England to 2026. A team in HSPR’s Centre for the Economics of Mental Health (CEMH) were among the authors of the report, published in 2008, which predicts the bill for mental health services in England is set to soar from £22.5 billion in 2007 to £47 billion within two decades.

In addition to the bill for services, mental illness in England cost another £26.1 billion in 2007 – the estimated amount of earnings lost because of the thousands of people unable to work. The cost of lost earnings is projected to rise to £41 billion by 2026.

“We found that paying for more people to be treated would create net savings as reductions in lost employment costs would outweigh treatment costs,” said Martin Knapp, one of the authors of the report, a Professor of Health Economics and Director of the CEMH. “A third of adults with depression and a half of adults with anxiety disorders are not in touch with services, so there is significant potential to treat more people with those illnesses and make savings because of the boost to the workforce.”

The report also suggests other savings in the cost of mental health services could be made by expanding crisis and early intervention services for people with schizophrenia to reduce the number of expensive days spent in hospital – and by improving diagnosis and treatment of dementia. The main reason for more than doubling NHS and social care costs in 20 years is due to the predicted dramatic increase in the number of people with dementia: the authors therefore recommend making early detection of dementia a priority, and investment in cost-effective treatments.

The report contains chapters on eight different disorders: depression, anxiety disorders, schizophrenia, bipolar disorder, eating disorders, personality disorder, disorders affecting children and adolescents, and dementia. The authors say there is a paucity of high quality evidence on eight different disorders – which will go online later in 2009. The development and evaluation of both have been backed by the UK Skills for Care Innovation Fund. “By presenting these courses online, we hope to promote evidence-based practice among a larger number of social workers than is currently possible using traditional educational methods,” said Martin, who is also a qualified social worker.

New online course for social workers

Research methods and critical appraisal is a new e-learning short course launched for social workers in January 2009. It is based on a module of the MSc in Mental Health Social Work with Children and Adults, one of the two Masters programmes run by HSPR.

MSc Programme Leader Martin Webber has developed and piloted both this course and a second one – Research protocol writing for social workers – which will go online later in 2009. The development and evaluation of both have been backed by the UK Skills for Care Innovation Fund. “By offering these courses online, we hope to promote evidence-based practice among a larger number of social workers than is currently possible using traditional educational methods,” said Martin, who is also a qualified social worker.

“Social workers are increasingly encouraged to become research-minded and integrate research findings in their practice. But there is a paucity of high quality accessible training for them,” The 16-week stand-alone Research methods and critical appraisal course allows social workers to fit their study around work, home and life commitments. Through online lectures, moderated discussion forums, real-time online seminars and access to course tutors for email and telephone support, the course covers a range of methods used in research and sets out to help social workers develop confidence in understanding and applying research findings in their day-to-day work.

“The content of the course materials are well-explained and do not require assistance to understand them,” said one of the social workers who volunteered to join the pilot course, which Martin evaluated to make sure it was fit for purpose. “The pace of the presentations is excellent and one can also download each one.” Another volunteer student said: “I was able to rewind and repeat things as and when I wanted. I was also able to choose when and for how long I studied.”

Students who sign up for the short course need to set aside five to 10 hours for studying each week. The course provides 30 credits at Masters level and 30 credits at higher specialist or advanced level in the Post-Qualifying Framework for Social Work. Research methods and critical appraisal also includes two opportunities to meet fellow students and tutors ‘in the flesh’ – at the beginning and halfway through. “This allows people to put a name to a face when communicating online,” said Martin.

The course is designed for social workers, but would also appeal to someone working in health or social care who is interested in developing their research skills, he said. The MSc in Mental Health Social Work with Children and Adults runs as a two-year part-time programme. “Students will be able to progress to the full Masters degree when they complete the short course, if they wish,” Martin added.

Martin Webber is available at martin.webber@icp.kcl.ac.uk

Research methods and critical appraisal for social workers, www.icp.kcl.ac.uk/sites-hmca

MSc in Mental Health Social Work with Children and Adults, www.icp.kcl.ac.uk/courses
Can offering support to mental health service users who are victims of domestic violence help reduce the abuse they suffer? A pilot study seeks to find out if an experienced domestic violence advocate, offering advice and information about personal safety and based within community mental health teams, can make a difference.

Twenty per cent of women in England and Wales report physical assault by a current or former partner, as do one in seven men in the UK, though generally this is less serious than the violence experienced by women. ‘Mental health service users experience higher rates of domestic violence than this, and most of it is undetected,’ said Louise Howard in Community Mental Health in HSPR.

‘Domestic violence is associated with many mental health problems – depression, post traumatic stress disorder, anxiety, insomnia, alcohol and drug abuse, and suicide attempts. Service users who are exposed to domestic violence may experience more severe symptoms than those who do not experience it.’

What’s more, Louise says people with mental health problems who experience violence at home are unlikely to seek help from health professionals, and when they do, the response and support they are offered is often inadequate. ‘Mental health workers don’t often ask about domestic violence and service users are reluctant to talk about their experiences unless they are directly questioned,’ she said. ‘Lack of training and confidence may be among the reasons why health professionals rarely enquire, or if a service user discloses to them, are not sure what to do.’

Community mental health team-based advocacy is a new type of support for victims of domestic violence that is being developed by a research team led by Louise, with financial support from South London and Maudsley Charitable Trust. Its success will be evaluated in a three-year pilot project funded by the NHS National Institute for Health Research.

As part of the study, all mental health workers based within the participating community teams will be trained so they are better equipped to help both women and men who are abused by their current or former partners. Dr Roxane Agnew-Davies, a Senior Research Fellow at London South Bank University and Mental Health Advisor to the Department of Health (DoH), will train them in line with DoH guidelines about how healthcare professionals should ask about and respond to domestic violence, and about child protection issues. Some 75-80 service users who experience domestic violence and are in contact with community mental health teams will be recruited to the study. Some community teams will offer access to an advocate, whereas others will offer ‘treatment as usual’.

The advocates will be managed by a domestic violence and hate crime project run by Bede House, a community-based charity in south London. Bede House has dedicated caseworkers who offer practical and emotional support to victims of domestic violence to help make their lives safer.

A researcher will interview all participating service users three months after they join the study to see if the severity and frequency of the domestic violence they experience has decreased, and allow researchers to gauge if meeting regularly with an advocate has made a difference.

As well as South Bank University and Bede House, Louise, a Clinical Reader in Women’s Mental Health, is collaborating with the University of Bristol, South London and Maudsley NHS Foundation Trust, and HSPR colleagues in the Service User Research Enterprise and Centre for the Economics of Mental Health.

The results of the pilot will help the research team design a larger, multi-centre trial of advocacy for domestic violence.

‘Mental illness may be precipitated by abuse, but severe and chronic mental illness can also put women at risk of abuse – as a result of medication, the illness itself, living conditions or co-occurring substance misuse that can make them more vulnerable,’ said Louise. ‘Access to advocacy within community mental health teams is a new way of responding to people’s needs around domestic violence that could lead to improvement in care of people in contact with mental health services who are experiencing it. It is a timely study as many mental health trusts are currently writing policies on domestic violence, and the Royal College of Psychiatrists has published guidelines recommending partner violence is asked about as part of the clinical assessment of all patients.’

Louise Howard is involved in another study that will investigate the impact of domestic violence during pregnancy on child development. Using information from the Avon Longitudinal Study of Parents and Children (ALSPAC), Louise will look at records of women who reported domestic violence during pregnancy and those of their children – up to the age of 11 – to see if cognitive, emotional and behavioural development was adversely affected. The ALSPAC cohort includes records of more than 14,000 women living in Avon, UK, who delivered a baby between 1 April 1991 and 31 December 1992. Researchers have followed them and their children at regular intervals since then, looking at the children’s health and development.

‘Domestic violence in pregnancy is associated with maternal mental health problems and low birth weight as well as preterm pregnancy,’ said Louise. ‘However, its impact on child development has not been previously investigated.’

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Avon Longitudinal Study of Parents and Children, www.bristol.ac.uk/alspac
Bede House, www.bedehouse.org
Jair Mari first visited the Institute of Psychiatry (IoP) in 1981 to undertake his PhD. For the past year, he has been revisiting his Camberwell haunts during a sabbatical spent in HSPR, which has given him time to think about and plan both future research and how best to develop mental health services in Brazil, his homeland. He has also had the chance to work with colleagues in HSPR and around the world on the new Movement for Global Mental Health, launched via a website last October, on World Mental Health Day 2008.

A Professor of Psychiatry at the Federal University of Sao Paulo, Jair’s career in Brazil has been as much about politics as academic activities and clinical practice, and over the past two decades, he has been instrumental in transforming postgraduate training and the research ethos there. ‘When I first came to the IoP, I knew very little about research. I had qualified as a doctor, then a psychiatrist, and was working with patients. I got a scholarship from the Sao Paulo Research Fund to come to London, and went to the London School of Hygiene and Tropical Medicine where I learned about the design of studies, biostatistics and epidemiology, before coming to the IoP for the PhD. That was about psychiatry in general practice: we knew nothing about that in Brazil, so it was an important piece of work. I did the field work in Brazil and then wrote it up in London.’

His IoP experience and the subsequent impact of his research inspired him to take up the cudgel to campaign for more evidence-based practice in Brazil, with high quality teaching as a starting point. Returning to Sao Paulo after completing his PhD, he was a tenured professor within 10 years: by that time he had started developing – and ultimately revolutionising – postgraduate training in the Department of Psychiatry.

‘In the 1980s, there was very little research in Brazil. Even though quite a few Brazilians had gone abroad for postgraduate study, only a handful had gone back to apply what they had learned. None of the old professors wanted to do research or had studied research methodology. There was resistance to employing younger people, and the older teachers were civil servants and therefore couldn’t be fired. We had to convince people it was the right thing to train people properly in how to do research to inform the clinical work we were doing. I gathered together people who had had the same kind of exposure to research as I had had in London, people who knew about the importance of having methodology training and high standards in academia. Many of the students I started to train had some sort of contract so were then allowed to supervise other students. Slowly, I built up a team – I trained 18 people to PhD level, and now we have a team of 24 supervisors in our department, each one of them has four to five students, so we now have 80-90 people undertaking MScs and PhDs at any one time. As a result, we produce 60-70 international papers a year.’

So successful was his campaign to introduce rigorous standards in the Department of Psychiatry, he was invited to be head of all postgraduate education at the university, responsible for 44 programmes and 2,500 students. And he stood, and was elected by colleagues, as a representative advisor on the main committee for postgraduate
Ministry of Education (the rules dictate now given exposure to training in research new courses, gave grants, sent people abroad, nine years helped to ‘radically change in January 2008.

people across Brazil signed up at its launch 1996-99, then 2001-07 – and during those

He held this political role for three terms – place in the world league in terms of number

education, and as a result, on policy and

There was so much administration, on top

We closed old courses, re-organised, launched new courses, gave grants, sent people abroad, trained new people so teachers really knew what they were doing.

‘It had a huge impact on postgraduate education, and as a result, on policy and practice, not just in psychiatry, but across the board in medicine. Junior doctors are now given exposure to training in research methods, on how to select the best evidence to inform their practice. Brazil is now in 18th place in the world league in terms of number and impact of international publications in medicine. And we changed attitudes across academia.’ The popularity of an online research methodology course he helped to develop for health professionals is a testament to how highly research is now valued: 3,000 people across Brazil signed up at its launch in January 2008.

In 2007, he left the committee at the Ministry of Education (the rules dictate a maximum two consecutive terms). ‘It had been an intense and active period of my life. There was so much administration, on top of my teaching, research, writing and private practice,’ he said.

‘His sabbatical in HSPR – from January 2008 to January 2009 – has given him a chance to step back from the hustle and bustle of that active life and ‘think about things properly.’ ‘In Brazil, we have 5,000 psychiatrists now but we don’t have the people who can manage the organisation and infrastructure. There is a huge gap between what is done and what we could be doing. I’ve spent time seeing how things are organised here, both in services and in research, and will be taking many ideas back with me. For example, the IT system here is far superior, and we need to develop a better one in Brazil for recording information. And we have very few community-based services. They are currently building a centre in the community in the heart of Sao Paulo and when I return, we shall start training people there to undertake research, especially around early intervention for psychosis and outreach work.’

He is on the Executive Committee of the newly launched Movement for Global Mental Health and is taking on the task of strengthening dissemination of research results. During his busiest time in Sao Paulo, he was also editor of the Revista Brasileira de Psiquiatria and, together with a team of young investigators, transformed the publication, turning it into ‘the top Brazilian Journal, with international appeal,’ he says. From this experience, he is now helping editors of journals in developing countries improve their publications, and has financial support from the World Psychiatric Association to do so.

In London, he also started to analyse the results of a series of two major studies assessing the impact of violence on the mental health of people in living in Sao Paulo and Rio: he is head of the Millennium Institute for Violence and Mental Health, a programme of research supported by the Brazilian Research Council, the State of Sao Paulo Funding Agency and the Ministry of Education, and involving collaborators in HSPR – Professor Martin Prince and Dr Cleusa Ferri in the Section of Epidemiology. ‘Brazil nowadays is solving many of its problems, but one thing we are still ashamed of is violence, and this is very important research in the area,’ he says.

During his sabbatical, he also agreed to interview a handful of ‘influential people’ for the State of Sao Paulo Medical Council. His interview with the IoP’s Professor Avshalom Caspi about his work on antisocial behaviour, for example, was published in a magazine read by 100,000 doctors in the state of Sao Paulo.

He is brimming with plans for his return to Brazil and looking forward to new challenges in Sao Paulo. ‘I shall be campaigning for more money for mental health research in order to evaluate, and then improve, training and services. My department is expanding, with a new imaging lab and an experimental biology lab being installed and I know little about this so I have a lot to learn,’ he says. ‘And Professor Nick Bouras is helping to set up a formal agreement between my university and King’s College London, so in future students can spend one month here as part of their training in Brazil.’

He has thoroughly enjoyed being in London, he says: ‘The only thing I have really missed is seeing my daughters regularly. My 18-year-old has just finished her first year at medical school at the state university, and I am very proud of her.’ And he thinks the capital is a better place than when he first visited as a PhD student. ‘I used to have to go to Leicester Square to get an expresso – but now they sell them in the IoP café,’ he says.

■ Movement for Global Mental Health – page 11

New Camberwell Assessment of Need for Mothers

C AN-M: Camberwell Assessment of Need for Mothers was published by the Royal College of Psychiatrists in July 2008. The CAN-M has been developed by a team in HSPR led by Dr Louise Howard and is a tool for assessing the needs of pregnant women and mothers with severe mental illness. It is designed to be used by health professionals working in mental health, obstetric and primary care services. The book includes chapters on the needs of women with mental health problems during pregnancy and the postnatal period; the needs of severely mentally ill mothers with children; and the impact of maternal mental illness on the developing child. It also includes the rating scales, descriptions of how they were developed and their psychometric properties, administration details, a full training programme, guidance on scoring and blank assessment forms for photocopying.

■ CAN-M: Camberwell Assessment of Need for Mothers (Louise Howard, Katherine Hunt, Mike Slade, Veronica O’Keane, Trudi Seneviratne, Morven Leese, Graham Thornicroft and Malcom Wiseman), £75, available from www.rcpsych.ac.uk/publications.aspx
Informing the task of aid workers

How best should aid be organised to help the millions of people around the world living in a war zone or in the aftermath of earthquakes, floods and other natural disasters? Maya Semrau in HSPR is involved in a project that aims to develop an easy-to-use questionnaire that can assess people’s needs quickly and accurately to inform emergency relief and the task of aid workers.

The Humanitarian and Emergency Settings’ Perceived Needs Scale (HESPER) is based on the short version of the Camberwell Assessment of Need (CAN), originally developed by a team in HSPR to assess the needs of people with mental health problems. Different versions of CAN have since been produced to measure the needs of specific groups of people, and the tools are used around the world.

The HESPER project is a collaboration between HSPR and the World Health Organisation (WHO) in Geneva: the preparatory stages were carried out by Maya as part of her dissertation for the MSc in Mental Health Services Research, and she is continuing to work on the project for her PhD, with Medical Research Council support.

Senior researchers in HSPR, other schools in King’s College London and at WHO — in particular Dr Mark van Ommeren — have been involved in an advisory capacity, and Maya has worked with emergency experts in different countries – Sierra Leone, Colombia, The Netherlands and the USA, for example – to draw up the draft questionnaire. The next step will be to test it in the field for validity and reliability, again with the help of aid workers overseas.

‘WHO and other humanitarian agencies have recommended that a prioritisation of rapid needs assessments in emergency situations is vital in enabling efficient and effective emergency relief,” said Maya. ‘By the end of last year, more than 60 million people were reported to be displaced due to some large-scale humanitarian emergency.

‘HESPER is being designed to assess needs expressed by the people living in emergency situations themselves – not just psychological needs, but physical and social ones too. Someone may experience trauma or loss-induced psychological distress after a disaster, but they may at the same time suffer severely due to lack of security, and have needs related to water and sanitation – when toilet facilities are available but in such a state that they undermine people’s perception of their dignity, for example.’

The new assessment tool will be field-tested in low and middle income countries, as this is where most large-scale disasters occur, but it could be relevant in future across the globe, said Maya. Aid workers will be able to use HESPER to collect information from a representative sample of people, then aggregate the data to inform their relief plan.

Ultimately, when the 15-minute questionnaire has been perfected in the field, it will be translated into many languages so it can be used in any country.

In future, HESPER could also be modified for separate disaster-affected population groups, for instance adolescents or younger children,” said Maya.

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Launch of HSPR Summer School

The first ever HSPR Summer School was held in 2008 – and the two short courses offering ‘tasters’ of economic evaluation and qualitative research methods were both sold out. The Summer School took place at King’s College London’s Waterloo campus and followed the fourth International Mental Health (IMH) Conference organised by the Institute of Psychiatry.

The two-day course in Economic Evaluation in Mental Health was led by Professor Martin Knapp and his team from the Centre for the Economics of Mental Health, while the three-day Introduction to Qualitative Research Methods was led by HSPR’s Joanna Murray and Craig Morgan, both experts in this methodology.

The HSPR Summer School will be staged again in September 2009: details will be posted on the events page at www.iop.kcl.ac.uk nearer the time.

Good employment practice for women

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SPR is applying for an Athena Swan Silver Award. The awards are made by the Athena Swan Charter for Women in Science and recognise good practice on recruiting and promoting women working in science, engineering and technology (SET) in higher education and research. Any university or research institution that is committed to the advancement of the careers of women in SET can apply for membership.

Universities must achieve a Bronze Award before individual departments can apply for recognition in their own right: King’s College London has been given a Bronze Award for measures introduced to support the careers of women academics, including a mentoring scheme.

Athena Swan Charter, www.athenawsan.org.uk
**A new resource for researchers**

A new facility for searching and analysing the South London and Maudsley NHS Foundation Trust (SLaM) clinical records database has been set up as a resource for researchers investigating a wide variety of mental health problems. SLaM is the provider of the most extensive portfolio of mental health services in the UK, running both services for people living in south east London and specialist services for people referred from across the country, and has kept clinical records electronically for the past decade. A new computer system allows that large dataset to be used for research purposes.

The development of CRIS – Case Register Interactive Search – has been led by Rob Stewart in HSPR’s Section of Epidemiology. The database contains records of everyone who has been in contact with SLaM’s specialist and general mental health services over the past 10 years: initially, some 130,000 existing records have been uploaded, and CRIS has been designed to update itself every 24 hours by linking with the existing system that keeps case records electronically.

All the information has been – and will continue to be – made anonymous to protect patient privacy and the database will be held within the SLaM “firewall”, said Rob.

‘Ethical approval has been obtained for secondary analyses and the project has been approved by the Trust Caldicott Guardian and Executive Committee.’ CRIS will be a resource for researchers across the Institute of Psychiatry (IoP) and SLaM, and its development has been supported by capital money awarded to the Biomedical Research Centre for Mental Health, run jointly by the IoP and SLaM and funded by the NHS National Institute for Health Research. The project has been a joint venture between the IoP and SLaM, involving the mental health trust’s Information Department and the expertise of management and technology consultants BearingPoint, responsible for developing the system.

HSPR’s Service User Research Enterprise (SURE) has also been involved to lead on security and to make sure service user groups are confident about the purpose of CRIS, anonymity and appropriate use of the information.

Grants awarded by SLaM’s Trustees and Guy’s and St Thomas’ Trustees will support the creation of a computer suite and base for CRIS, and will increase the team of staff who are administering and working on the system. All users will need to have a SLaM contract (honorary or substantive) and will need to register both themselves and their projects. ‘This is a huge resource for researchers and we want the new programme to generate as much research as possible,’ said Rob.

**Claire Henderson returns to HSPR**

Meet Claire Henderson: she returned to HSPR in 2008 after five years of working in mental health services and mental health research in New York. For in 2003, when her four-year MRC Training Fellowship in HSPR was complete, she, her husband and her one-year-old child packed their bags and headed west.

“One of the reasons I wanted to go to America was because I was keen to get a job just in research,” she said. ‘In the UK, there are no research-only jobs. You need to combine research with clinical work and women with children often end up as clinicians as a result.’

It took a while to find the research post in the USA: she worked first for the Bronx Psychiatric Center; funded by New York State, at a day centre offering long-term care to people with mental health problems, and at the same time studied at Columbia University on a Public Psychiatry Fellowship, learning about a huge variety of different agencies in the public sector there that provide care to people with mental health problems.

She then moved to a consultant-level clinical post in a newly-created assertive community treatment team based at the Bronx Psychiatric Center, before finding the research-only job she had been looking for – with the federal government, based in a Department of Veteran Affairs (VA) hospital in the Bronx. The job was about health services research and programme evaluation in a group based within the hospital and with links to Mount Sinai School of Medicine.

‘The VA was beginning to embrace the concept of recovery, and at the same time, there was new funding for mental health because of newly returning veterans from the conflicts in Iraq and Afghanistan. The biggest group supported by the VA are still Vietnam veterans, but as well as services for this ageing population, there is now a need for services for this younger group, many of whom don’t want to recognise they may have post traumatic stress disorder, for example.’

Her research centred around the evaluation of initiatives to introduce recovery-focused services – training for staff and veterans, and supported employment, for example.

While she was in New York, her second child was born – and one of the reasons she and her family decided to return home was to be closer to extended family members as her children grow older.

Now she is back in the Community Mental Health team, working on a number of projects around Joint Crisis Plans for people with severe mental illness (her PhD was a project evaluating their success that led to the major CRIMSON trial of Joint Crisis Plans currently being undertaken in Community Mental Health) and on stigma. ‘I’m spending most of my time on the evaluation of Time to Change, the charity-led campaign that is challenging stigma and discrimination in England,’ she said.

‘It’s very good to be back, working with other people who are interested in health services research – though we were sad not to be in New York on the night of the presidential elections’

Time to Change – page 22.
Volunteering boosts self-esteem and wellbeing and helps recovery

Volunteering can contribute significantly to the recovery of people who have been mentally unwell, making a real, positive difference to their lives. As Capital Volunteering – a major London-based project that offered a myriad of volunteering opportunities to people with mental health problems – drew to an end last autumn, an HSPR evaluation showed that it had enabled people to make friends and develop a social life, often for the first time in years.

Capital Volunteering was launched in 2005 by Community Service Volunteers and the London Development Centre for Mental Health, with £7.3 million worth of funding from the Treasury’s Invest to Save budget. The idea was that volunteering would help people learn new skills, gain employment, make a difference to their wellbeing, and reduce their reliance on government-funded mental health services.

And the evaluation proved that the scheme’s value in terms of social capital was enormous, said Joanna Murray from HSPR, who led the research and sat on the Capital Volunteering Partnership Board. ‘Volunteering didn’t stop people being mentally ill, or get them a full-time job,’ she said. ‘But our evaluation showed that people who took part in Capital Volunteering gained self-confidence and met new people. Volunteering gave structure to their lives, something to get out of bed for. People learned new skills and enjoyed helping others. Most importantly, they made friends, started going out, even went on holiday together.

‘Being part of a social network makes people feel valued. They have access to emotional support and practical help if they need it, and this access may help people recover from illness and stay well. What’s more, being able to help others – as a volunteer or a friend – helps boost self-esteem and wellbeing,’ she said.

Capital Volunteering supported about 100 projects in 11 London boroughs sited within four mental health trusts – Camden and Islington NHS Foundation Trust, North East London NHS Foundation Trust, Central and North West London Mental Health NHS Trust and South London and Maudsley NHS Foundation Trust. The emphasis was on local needs: each borough set up its own steering group in its own way to spend its share of the money on projects which best suited local people. Each of the projects was managed locally and separately, and as well as evaluating the experiences of the volunteers, the HSPR team has interviewed a sample of 30 project leaders so future volunteering schemes can learn which models are most successful.

The HSPR researchers first interviewed 150 people when they signed up as a volunteer to one of 51 different projects across the

I’ve made friends. Even now when the groups are not on, we meet and go to karaoke, and we all went abroad, and I never thought I would do that.’

‘I think I enjoyed the fact that I had to get up in the morning and have my shower and do my hair and think about what to wear and take out those nice things which I never used to wear.’

‘It has helped me to come back from myself. It has helped me to build back my life. When I focus on doing something for someone else, I get stronger.’

‘I now sort of like myself. There are times in the past when I have not been too happy with me. I now feel as if I wouldn’t mind me as a friend. It’s a nice feeling that you are needed.’

‘When I got sick, I lost everything. I lost confidence and my memory. I used to forget things. I used to be like a robot. Now coming here, I’m talking to people. I am taking charge. They are giving me responsibility to cook, shop. I feel good.

These quotes are taken from interviews with volunteers, carried out by the research team evaluating the success of Capital Volunteering.
participating boroughs between July 2005 and January 2007. Those agreeing to take part in the evaluation ranged in age from 20 to 81, though the majority were aged between 30 and 59. Their experience of mental illness included bipolar disorder, depression, schizophrenia, personality disorder, autism and Asperger’s syndrome, eating disorders and post traumatic stress disorder.

The final report describes the experiences of 95 members of that cohort who were followed up after a year. Of those 95, 45 per cent were still involved with Capital Volunteering: a further 19 per cent had still been involved when they were interviewed after six months but had since left.

The majority of the 95 people interviewed continued to be out of work; more than 90 per cent were on benefits at both the first interview and 12 months on.

But 85 per cent said they had benefited from joining a Capital Volunteering project by meeting people and making friends. Other reported gains included increased self-confidence and learning new skills. Ninety per cent of those who continued to be involved past six months said they felt they were supporting other people and therefore making a contribution.

More than 5,500 people with mental health problems were involved in Capital Volunteering during its lifetime, said Director Claire Helman.

Many of the projects launched under the umbrella of the scheme will continue in future, she said, either independently with new funding or by being ‘mainstreamed’ into existing organisations’ activities.

And a Capital Volunteering Legacy Fund – set up ‘through a combination of efficiency gains and additional funding’ – will help continue to provide support for people with mental health problems to become more socially included through volunteering, and specifically support schemes that are led by people with experience of mental illness.

The ‘principles, approach and achievements’ of Capital Volunteering will be promoted in future by feeding into national and regional policy consultations, conferences, and government draft guidelines, she said.

The type of volunteering the evaluation team felt had the most impact was placement, said Joanna, where people were given a position with a community or voluntary organisation and offered support from the Capital Volunteering project. Other types of projects launched under the Capital Volunteering banner included befriending and mentoring schemes – in which volunteers either gave or received support; training courses; and social support groups, including gardening and art projects.

HSPR researchers Abigail Easter and Sophie Bellringer also carried out long, in-depth interviews with 18 people who had joined a Capital Volunteering project to gain a wider perspective on their experience. All of them said before they had started volunteering, they had been either depressed, isolated or lonely, had felt discontented and that there was no purpose to their lives. Twelve of them said their lives had lacked activity, and that they felt they were just wasting time.

‘These 18 individuals all rated new friendships as the top gain from their volunteering experience, and talked about feeling more confident, more motivated and having higher self-esteem and self-worth. ’There is no doubt that Capital Volunteering shows that giving people with mental health problems the chance to volunteer can help them on the road to their personal recovery,’ said Joanna.

Suzanne Smith volunteers at a British Heart Foundation Shop. She had experienced depression for a decade before getting involved with Capital Volunteering.

‘I used to be really happy-go-lucky but the depression ruined that and I lost friends. Since I’ve been volunteering at the shop, I’m much more confident and bubbly. Now I’ve made two really close friends and often go out with them. It’s definitely helped with my recovery.’
Improving the life chances of children in Ethiopia

Around 1,000 women in Ethiopia are helping researchers find out if a mother’s state of mind has an effect on their child’s health, development, and likelihood of survival. They have been giving information regularly over the past three years to a team of 10 data collectors, (pictured right), employed by Charlotte Hanlon and Girmay Medhin; both are undertaking PhD projects, supervised by colleagues in HSPR’s Section of Epidemiology, and at the Department of Psychiatry and Community Health in the Faculty of Medicine at the University of Addis Ababa.

In rural Ethiopia, around one in 10 children dies before he or she reaches their first birthday, and half of children under the age of five are chronically undernourished. The information collected in this study will allow the research team to identify if having a mother with a mental health problem such as depression makes a difference to the life chances of a baby – do mothers with mental health problems stop breast feeding early?, for example, or are they less likely to seek medical help?, or vaccinate their child?

One thousand and sixty-five mothers-to-be were first interviewed about their physical and mental health, and their household and family circumstances, during the third trimester of their pregnancy. The majority have given information since then at regular intervals, and a smaller sample of the children have had development checks. The Wellcome Trust-funded study is tracking the mother and child pairs until Autumn 2009, when the children will be three-and-a-half years old.

The participating mothers live in mostly rural areas, both highland and lowland,” said Charlotte, “and our interviewers might have to walk for two hours to get to them, and two hours back again. They visit the same women each time we do a follow-up and have built up a rapport with them. The data collectors, who all live in Butajira, have all stuck with the project since it began, and have become very loyal to it.’

Charlotte’s PhD is looking at risk factors that play a part in the development of postnatal depression. Girmay’s project focuses on the first year of life of the children, looking to see if their growth, development and mortality are affected if their mothers have a common mental illness, such as depression. Further analyses will continue to be undertaken on information collected from the cohort as the children have grown older.

Both Charlotte and Girmay are applying for financial support to be able to continue to follow the pairs until the children are eight-years-old, allowing the research team to start measuring educational performance and potentially link differences to maternal mental health.

In the meantime, the cohort of women is to be followed up by researchers in a completely separate Asthma UK-funded study researching if there is a link between the development of asthma and allergies and exposure to parasites. ‘They will be using our cohort until the children are five, and the same team of data collectors,’ said Charlotte.

Links between the Institute of Psychiatry (IoP) and Addis Ababa University have been strengthened by a research ‘exchange’ set up with the help of funding from the IoP-based charity the Psychiatry Research Trust, HSPR and a sister department at the IoP, the Division of Psychological Medicine and Psychiatry.

Visits from IoP staff to Ethiopia and vice versa have helped build research capacity in Addis Ababa and launch collaborative work. In addition, financial support from the UK government’s Department for International Development and the British Council is funding visits to train psychiatrists and mental health workers based at Addis Ababa. The University of Toronto is also involved in this teaching programme.

Charlotte Hanlon

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Getting service users involved – despite the off-putting terminology

What does biomedical research mean? Do people with mental health problems who sign up to take part in this sort of research really know what it’s all about? Why do some people refuse to participate? Are words like “biomarker” and other parlance current in science baffling and off-putting to service users?

These are some of the questions Senior Research Fellow Dr Felicity Callard is trying to answer in a series of projects that aim to boost the participation of service users in the work of the Biomedical Research Centre (BRC) for Mental Health, based at the Institute of Psychiatry (IoP) and South London and Maudsley NHS Foundation Trust. Felicity is part of the Service User Research Enterprise (SURE) team in HSPR: Co-Director of SURE Professor Til Wykes and Head of HSPR Professor Graham Thornicroft are together leading a programme of research funded by the BRC about ‘stakeholder participation’. In addition to Felicity’s research focusing on service users, other teams are looking at getting carers involved, and studying issues of gender, culture and ethnicity to make sure all sorts of people are represented and feel able to have their say in BRC projects.

The BRC was set up in 2007 with five years’ worth of funding and was one of 11 to be created by the NHS National Institute for Health Research, all of which are located within NHS and university partnerships. Directed by Professor Simon Lovestone, the BRC is charged with ‘translational research’ – finding ways to help patients benefit more quickly from scientific breakthroughs.

There are six themes of research – substance use disorders (addictions); antisocial and aggressive behaviour; mental disorders starting in childhood; common mental illness, including depression; dementia; and psychosis – and the stakeholder participation programme aims to get service users, carers and healthy volunteers involved in each of them, regardless of their age, gender or ethnic background.

One of Felicity’s tasks is to set up an advisory committee of service users to ‘influence and engage with the activities of the BRC’. ‘We are hoping to get 18 people together to discuss what is going on, hear presentations and give advice about the research projects. We want service users on the committee who would potentially benefit from the research being undertaken in all of the six themes, so we can create small advisory panels for each of them. We need to think how best to do that, particularly for the mental disorders starting in childhood and dementia themes, given the extra support that people may need.’

The task is also difficult, she says, because of the language used in this new arena of research. Even the title ‘Biomedical Research Centre’ could deter people from getting involved in not only individual research projects, but also on the advisory committee. ‘Policy-makers should reflect on some of the difficulties that the language and terminology puts in the way of involvement,’ she said. ‘Government and funding bodies say service users and carers should be involved, but not much consideration is given to how difficult that can be when using terminology that can be off-putting.’

The wider challenge ahead then, she says, is to come up with a plan for public engagement, to encourage people to become involved as participants, not as ‘research subjects’, and to make sure they can contribute to the direction of the research funded by the Centre. That plan will be informed by various projects being carried out in collaboration with tranches of research funded under one of the six specific themes.

So, for example, Felicity is collaborating with Dr Kathryn Greenwood, a clinical and research psychologist in the IoP’s Department of Psychology, on a psychosis theme-funded project which aims to find out if genetic profiles make it possible to predict if cognitive remedial therapy would be of benefit to people with a diagnosis of schizophrenia. Felicity is running a linked but independent study, also funded by the BRC, convening focus groups of service users who have agreed to take part in this research and donate samples of their DNA – and also meeting with people who refused to participate. She wants to discover why they agreed or refused, and what they think about genetic research and genetic profiles.

And Felicity is similarly interviewing some of the participants in a research project being carried out under the umbrella of the substance use disorders theme, looking for biomarkers that may predict relapse in people who have previously been dependent on alcohol. They have agreed to give samples of their DNA and have a brain scan. ‘I will be exploring how they have interpreted the information they have been given about the purpose of the research, if they know what the researchers hope to learn as a result of the analysis of DNA and brain scans, and how they feel about the search for ‘markers’ that predict susceptibility to relapse,’ she said. ‘The biomarker research being carried out within the BRC involves complex models of causality, gene-environment interactions, susceptibility and responses to treatment.

Many people don’t know what biomarkers are, or indeed what biomedical means. Another difficult term is translational research – it’s very difficult to be confident that people we are asking to get involved and support the research know what that is. The research that the stakeholder participation theme is doing will ensure that any concerns and challenges that translational biomedical research might pose to service users and carers are taken into account.’

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If you have experience of mental ill health and are interested in joining the Service User Advisory Group of the Biomedical Research Centre for Mental Health, contact Katrina Young, Administrator in SURE, katrina.young@iop.kcl.ac.uk 020 7848 5104

The BRC is launching a new website in January 2009: http://brc.iop.kcl.ac.uk
A national across-England social marketing campaign is being launched in January 2009 by Time to Change, which seeks to combat stigma and discrimination against people with mental illness. Time to Change is the ‘brand’ of the campaign originally launched with the working title of Moving People and led by three mental health charities – MIND, Rethink and Mental Health Media. HSRP is to evaluate the success of the four-year anti-stigma campaign, which has £28 million worth of support from the Big Lottery Fund and Comic Relief.

The marketing campaign was piloted in Cambridge at the end of 2008 and will go national with adverts that are designed to break down myths surrounding mental health problems – and give people the facts.

In addition, there will be posters, leaflets and a toolkit available so local organisations can get involved and make sure the campaign has a high profile in their area. The key messages in the campaign are that mental illness is more common than most think, and that stigma and discrimination stops nine out of 10 people with mental health problems from getting treatment. More than 200 people with mental health problems to help break down stigma. More than 200

What do service users think about being ‘diagnosed’?

How do people feel when they are given a diagnosis of a mental health disorder? What effect can a “label” – given as a result of fitting a certain number of criteria laid down by a classification system – have on an individual?

The American Psychiatric Association (APA) is currently in the throes of an extensive updating of the Diagnostic and Statistical Manual of Mental Disorder (DSM), first published in 1952, with four revisions since. At the same time, the World Health Organisation is working on an updated version of its classification system, the International Classification of Diseases (ICD), which includes a special section on psychiatric illnesses and is currently in its 10th version. The revision of ICD-10 is due to be complete by 2015. Dr Diana Rose, Co-Director of the Service User Research Enterprise in HSRP thinks health professionals should take into account what a diagnosis given under either system can mean to a service user: “At the moment, the process of making a diagnosis under the classification systems is quite a negative one,” she says.

“It’s all about symptoms and negative functioning. The “logic” of making a diagnosis according to a classification system should include statements such as “x diagnosis does not preclude y behaviour” where y is a positive attribute. Sometimes people are relieved to get a diagnosis, but others fear the “label” they have been given will now define them, that they will be treated according to that label, and that they will never be able to get rid of it. I don’t think a diagnosis should take the form of a “master status”, which then essentially defines people. And for some service users, receiving a diagnosis often means they then get treatment they don’t want.”

Diana says more user-led research should be carried out about the experience of receiving a diagnosis to inform the updating processes of both classification systems. She has been invited to speak about service users’ perspectives on diagnosis at the 2009 APA Annual Meeting in San Francisco in May. “Giving a diagnosis should
Offering better care to people with personality disorder

A n estimated four per cent of the British population has a personality disorder, but there are few specialist services meeting their needs and little research has been undertaken to test treatments. Now, more than 100 people who have a diagnosis of borderline personality disorder are to be recruited to help test the success of Joint Crisis Plans – written plans, drawn up in collaboration with a mental health professional, stating a service user’s treatment preferences if they have self-harmed and are seeking help in a crisis. “The risk of self-harm is particularly high for people with borderline personality disorder and about 10 per cent of this population commit suicide,” said Dr Paul Moran, who is leading the new Medical Research Council-funded trial that seeks not only to ensure better care for people with a personality disorder, but also better relationships with mental health workers.

Many people with a personality disorder report that it is difficult to access help, particularly in a crisis. This problem was highlighted in Personality Disorder: no longer a diagnosis of exclusion, a major policy document published in 2003 by the National Institute for Mental Health in England. Paul was involved in drawing up this document and, since its publication, has led and collaborated on the evaluation of pilot specialist services for people with personality disorder both in forensic settings and in the community. He is currently a member of the NICE (National Institute for Health and Clinical Excellence) group developing guidelines for treatment and management of borderline personality disorder, due out in January 2009. The new two-year randomised controlled trial will test whether Joint Crisis Plans will help to reduce the number of incidents of self-harm, and whether the process of drawing up a plan itself will improve the relationship between the service user and his or her mental health worker. The idea is that the plans will improve the information available to staff in a crisis, and will also empower service users who have been involved in drawing up the plan,” said Paul. “We will involve service users in the design of the Joint Crisis Plans, working with them to draw up the items that should be included, and we will consult with service users and staff about the best way to recruit people to the trial.” A key aspect of drawing up a Joint Crisis Plan will be a facilitated meeting between the individual and relevant mental health professional, and both service users and staff will help determine the best way to set up these meetings. Borderline UK, a user-led organisation offering advice and support to people with a personality disorder, is also involved in the study.

Researchers will recruit participants through community mental health teams that are part of South London and Maudsley NHS Foundation Trust. Half of the 120 participants will draw up a Joint Crisis Plan with their mental health professional and researchers will compare how they fare over a six month period with the other half, who will be given “treatment as usual” from their community mental health team. As well as reducing the frequency of crises involving self-harm, or the threat of self-harm, and improving relationships with health professionals, Paul and his colleagues think the plans will result in service users being more satisfied with the care they are offered – and this may lead to an overall saving in the cost of care. “This study will have important consequences for service users, health professionals and researchers,” said Paul. “Not only will it contribute to knowledge about the treatment of a common and costly mental disorder, but we anticipate that, if shown to be effective, Joint Crisis Plans will promote a culture change in the relationship between clinicians and service users with a personality disorder.”

Joint Crisis Plans have already been shown to reduce coercive treatment under the Mental Health Act of people who have serious mental illness in a pilot study carried out by another HSPR research team.

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Borderline UK, www.borderlinelnk.co.uk

National Personality Disorder Programme, www.personalitydisorder.org.uk

not wipe out someone’s humanity, it should not be a negative thing,” she says. “But so often it is, because of the stigma attached to mental health problems.”

One of the recommendations she will be making is to include a chapter about stigma and the possible impact of being given a diagnosis in DSM-V, due for publication in 2012. ‘Clinicians must understand the influence of stigma when giving a diagnosis,’ she says.

The development of DSM-V is being led by a task force and 13 work groups; each group will review scientific advances in specific fields and evidence from recent research. These work groups are made up of researchers and clinicians, and include HSPR Professor Emeritus Sir David Goldberg (Mood Disorders) and researchers from sister departments at the Institute of Psychiatry: Professor Terrie Moffitt (ADHD and Disruptive Behaviour Disorders) and Professor Eric Taylor (Disorders in Childhood and Adolescence). The revision process started a few years ago, with a series of conferences to discuss up-to-date evidence that should be taken into account, for use by both the APA and WHO teams leading their respective reviews. Diana and Professor Graham Thornicroft, Head of HSPR, presented recommendations about taking service users’ perspectives and stigma into account at one such conference in Geneva.

‘Many service users receive more than one diagnosis throughout their psychiatric “career”,’ said Diana. “Sometimes they receive more than one at the same time. The average time to diagnosis for bipolar disorder, for example, is 10 years. Prior to that, many diagnoses can be given. The usefulness of these diagnoses will depend on whether they match an individual’s subjective experience.’

Diana also recommends that knowledge included in the classification system should not be esoteric: printed and web-based material should be available to let service users know what doctors know, she says.
Why Nisha volunteered in HSPR...

For the past two years, Nisha Mehta has been volunteering as a researcher in HSPR – at the same time as studying to be a doctor. Nisha is in her final year at King’s College London’s Medical School; last summer she was studying for her end-of-fourth-year medicine exams while preparing her first research paper and prize-winning poster summarising the work she started after meeting HSPR Head Graham Thornicroft in 2006.

The poster about Public attitudes towards people with mental illness in England and Scotland, 1994–2003 was given joint first prize at the 2008 ENMESH (European Network for Mental Health Service Evaluation) conference in Krakow, Poland. And the results of the research, with Nisha as first author, are due to be published in the British Journal of Psychiatry in 2009. The other authors are Aliya Kassam ‘who showed me the ropes and was a great mentor in helping with literature searching, showing me how to write a paper, statistics interpretation and references,’ statisticians Morven Leese and Georgia Butler, and Graham Thornicroft.

Nisha first met the team in HSPR when she transferred to King’s from Edinburgh during the third year of her medical training.

Medicine is her second degree: she studied Modern History at Oxford, then worked for a year at the Home Office and in Her Majesty’s Prison Service after graduating and being accepted on the Civil Service fast stream. She had also been offered a place at Edinburgh Medical School, which she had deferred and then took up after deciding the Civil Service wasn’t to be her chosen career path.

‘Unfortunately, it was a tragedy that led to my interest in mental health at Oxford,’ she said. ‘When I first went to College at 18, a couple of friends became seriously mentally ill and it was very hard for them. Sadly, a small number of people didn’t understand what was happening and would talk about them behind their backs, say dreadful things. My friends were both really unwell, and one of them committed suicide. I had never experienced mental illness before at close quarters. This was one of the reasons I applied to do medicine, and the experience made me feel very strongly about discrimination and the stigma of mental illness.

‘After a year in the civil service, I still felt that I wanted to be a doctor, and was still very interested in mental health. When I transferred to London, I picked King’s because I knew about the Institute of Psychiatry (IoP), and I was very interested in doing research in psychiatry in the future.

‘When I arrived, I contacted the Dean of the IoP, explained about my civil service experience in prisons and asked if there was any voluntary research I could do in that field. He put me in touch with Graham Thornicroft (who also does research in prisons) but after meeting him, it transpired we both had a real passion for fighting stigma against people with mental illness.

Nisha was asked if she would be interested in working on an in-depth analysis of the UK Department of Health (DoH) Attitudes to Mental Illness surveys over a 10-year period, looking for trends and differences between England and Scotland.

‘The DoH has previously collected a large annual or tri-annual data set about public attitudes to mental health,’ she said. ‘They do a less in-depth analysis of it, and hadn’t looked at longitudinal trends. It’s a really rich dataset, so I agreed to work on it on a voluntary basis. It was pretty tough at times! The first thing we did was to transform thousands of questionnaire results into a database, as all the information was available only in text format.’

Working with the team in HSPR, Nisha started to analyse the data. ‘We found a big difference between England and Scotland in 2000-2003 in terms of attitudes. In England, attitudes had deteriorated, there were more discriminatory statements towards people with mental health problems, while in Scotland, things were better,’ she said. ‘It turned out that the trends we observed coincided with the launch of a national anti-stigma campaign in Scotland, See Me.’

Nisha submitted an abstract of the project to the ENMESH international conference, held every two years for researchers in the field of mental health service research and evaluation. Graham Thornicroft was speaking there about evidence-based community programmes and Nisha went with him and the rest of the team.

‘I had not created a poster before,’ she said, ‘I made it after reading an article about how to create a great poster – and then it was announced at the conference dinner that I had won the poster prize! I was speechless and in shock!’

The poster, the paper, and the whole volunteering experience, have all helped with her successful application to the Academic Foundation Programme at King’s College, which she will begin next year when she graduates from Medical School. This is the first step on a route that will allow her to combine clinical and academic training at the same time. Her first two years as a junior doctor will include a four-month academic rotation and will be based at King’s College Hospital, a stone’s throw from the IoP and the HSPR Department.

‘This means I will be able to continue my voluntary work with HSPR,’ she said. ‘I love medicine, but the work in HSPR has crystallised my interest in research, and made me feel even more dedicated to the need to fight discrimination.

‘The medical course is long and exhausting – doing this research and working in HSPR has kept me going, I have felt valued by so many people who are passionate about the same things I feel passionate about. There are so many wonderful mentors here, who have been unfailingly supportive of me, and are still helping me get through the very steep learning curve that is the world of research.’

Nisha is presenting another poster about the research she has been involved in at the Fourth International Stigma Conference in January 2009, organised by HSPR and the World Psychiatric Association Scientific Section on Stigma and Mental Illness. The London conference brings together research leaders working to reduce stigma and discrimination around the world.

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