

# Whose Recovery is it Anyway?

Social Perspectives Network, in partnership with the Delivering Race Equality Programme, Social Care Institute for Excellence, and the Sexual Orientation and Gender Identity Advisory Group

## Paper 11



Social Perspectives Network is a unique coalition of service users/survivors, carers, policy makers, academics, students, and practitioners interested in how social factors both contribute to people becoming distressed, and play a crucial part in promoting people's recovery.

"Whose Recovery is it Anyway" is a paper from one of our study days aiming to share work and information looking at mental health from a social perspective.

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Social Perspectives Network

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## Introduction – Recovery, the new buzz word?

Recovery is a concept that is gaining prominence in the discourse on mental (ill) health, but it is contested and there is no consensus about its use or usefulness as a framework for mental health services. The concept continues to attract debate, but the voices of people from marginalised groups and communities such as Black and minority ethnic (BME) groups; lesbian, gay bisexual, and transgendered (LGBT) communities; refugees and asylum seekers are often absent from this debate. The Social Perspectives Network (SPN) with the aid of a very active steering group and with funding from the Delivering Race Equality Programme (DRE), the Social Care Institute for Excellence (SCIE), the Sexual Orientation and Gender Identity Advisory Group (SOGIAG) and the Care Services Improvement Partnership (CSIP) organised a study day to bring together individuals from these groups to debate, consider and reflect on the issues faced by marginalised groups in relation to recovery and diversity.

SPN brought together a diverse range of speakers to address the topic of recovery from their own perspectives. A central theme that ran through most of the presentations was the concern that the recovery agenda is now being colonised by mental health services and inevitably being re-articulated. This re-articulation means that services seem to adopt a rehabilitation model that sometimes gets narrowly interpreted to equate recovery with getting into employment. We know that many people who have experienced mental health problems would like to be in employment, but we also know that the world of work is not structured in such a way that it accommodates peoples' emotional distress. There were also concerns raised very articulately by Premila Trivedi (one of the Keynote speakers) who wondered whether adopting a recovery framework is just another way for mental health services to reduce services such as day centres. I am not suggesting that mental health workers/professionals cannot work from a recovery perspective and will end this introduction with some recommendations for practice.

Another theme that emerged during the study day was whether recovery is a relevant concept given the very different conceptions of mental health that exist within and across marginalised groups. Can we apply this framework to *all* communities and groups? Does it use concepts and language which are not relevant to and exclude those not in the mainstream? I would suggest that in the absence of consensus about terminology, we actually talk about 'models of recovery' that would enable us to embrace the diverse perspectives on the concept, but yet allowing an individualised approach to applying it in practice. Utilising the term 'models of recovery' should enable us to reach out to those groups who are marginalised within the discourse.

The study day also addressed what recovery approaches should include and there was an agreement that it should encompass a range of factors that are social, practical, emotional, cultural and spiritual. Another group that is missing from the debate is families and carers. In a very moving question and answer session a carer defined recovery from her perspective. She proposed

that it should be about enabling people to regain independence, assisting them to make relationships and to see recovery as a process that is not time limited, but aimed at improving quality of life over time.

So what are the implications for mental health practice and services? I suggest the following:

Firstly, they should acknowledge that emotional distress has deep-seated social roots and a narrow medical model approach is inadequate to facilitate a full understanding of a person's situation. I believe that this should be at the heart of the philosophy of recovery. In this way we can achieve an understanding of the processes of marginalisation, exclusion and discrimination that people experience.

Secondly, coming into contact with mental health services can be a most dis-empowering experience and often times this gets reinforced by the practices within mental health services. From a recovery perspective, I would expect that professionals actually engage in an analysis of the power of mental health institutions and the negative impact it can have on people's lives. I would urge an examination of the ways in which the actions of professionals are dis-empowering.

Thirdly, a recovery framework should emphasise that it is an individual journey of hope, regaining control over life circumstances and building personal strengths. Recovery should therefore be self-defined and the individual should be enabled to lead this process. What this means is that mental health professionals should be prepared to relinquish power and control and work in meaningful hope- inspiring relationships with people who use their services. We should also acknowledge that this journey is deeply influenced by the damaging effects of stigma and discrimination that affect all people who use mental health services regardless of their background. Moreover, people from minority and marginalised groups such as women, as well as asylum seekers and BME and LGBT people experience additional discrimination in the forms of racism, sexism or homophobia. It is imperative that these social factors are taken into account within the recovery framework.

I believe this study day has set the tone for a more inclusive debate on recovery. I would reiterate Rufus May's (one of the Key Note Speakers) call for us all to work together to create healing communities where people can come together as equals, have spaces where their voices can be heard and a range of approaches tested.

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## **Chairs Address**

**Melba Wilson, Director, Delivering Race Equality Programme and London Development Centre, CSIP**

Good morning everyone and welcome to this SPN study day on diversity and recovery 'whose recovery is it anyway?' I'm Melba Wilson. I'm directing the DRE programme nationally which means that as well as the London remit which I already had, DRE is writ large in terms of my attention and energies in supporting its implementation. I'm really pleased to be here – I'm a learner here as much as anyone else if not more so, so I was really pleased when Vicky asked me to chair this.

The subject is recovery and as the title suggests looking at whose recovery is it anyway? This suggests that recovery as with other aspects of mental health and wellness, wellbeing, requires an understanding and approaches which recognise and celebrate diversity, which acknowledge difference, and which promote learning and change. That's one of the things I like about these SPN study days. They really are about rolling your sleeves up and trying to getting underneath the subject so that we move the discussion forward.

The day is an opportunity to hear from discuss with people whose voices are seldom heard, about their views and experiences of recovery. And those views are I think as myriad as the people in this audience. The title recognises those struggles for power, for ownership, and for rights to come out or to be carved out, to find a place in care and provision for recovery approaches.

As many of you will also know, the language of recovery is contested – for some 'recovery' implies an illness or getting back to a norm or the way things used to be; others, such as the Royal College of Psychiatrists, the Social Care Institute for Excellence and CSIP in the paper 'A Common Purpose' view it as learning to live a meaningful life in the presence of ongoing symptoms or difficulties, and in a way it's encouraging that this definition has wide acceptance, including importantly in principle acceptance by mental health provider Trusts.

Recovery in a mental health context offers a huge potential for hope, and believing in the possibility of a positive future for people whose lives have sometimes been sidelined by services and those there to support them. It also however carries risks of failure, and risk of differences in interpretation, therefore whose recovery is it?

Today provides a platform to explore these issues and we do have a rich diversity of speakers and workshops who will be contributing to this evolving recovery agenda. The seminar also importantly brings together a strong partnership, including SPN and the Sexual Orientation and Gender Identity Advisory Group at the Department of Health (SOGIAG). In fact I remember when I was chair of a PCT two years ago and also chair of our diversity committee, we were asked to put people forward for this new group so I'm

really pleased to see that it's going from strength to strength. Also in this partnership are the Social Care Institute for Excellence, and something that is very dear to my heart, the Delivering Race Equality Programme.

The outcome of today will be written up so it will go out much more broadly than the people who are here today. We hope that it will serve as an invaluable tool in raising awareness of the richness and complexity of people's whole lives.

## **Keynote Presentation – Peter Lehmann, International Survivor Activist**

Good morning.

I feel very honoured to be invited here and be the first speaker. I come from Germany and I have to apologise a little for my English. It just improves a little each year, but on getting older I start to forget a lot of things all the time. This year I did not forget to take the plane but I forget all my cards with my address but in case you want to contact me I am here today. On the leaflets which are distributed there is my address, and my book is there on the table with my address also.

The European Network of User and Survivors of Psychiatry was founded in 1991. The working language of the network is English and it's always a pity to hear that people in England have not heard of the network because of problems with communication. Sometimes people who are elected to represent the network are not always those who bring the information back to their organisation. The UK Network is meant to be a European voice on European level decisions, for example the European Union or the European level of the World Health Organisation (WHO) level and so on - and it is very important that users and survivors of psychiatry are organised on a European level. We exchange some information. The basis of the network is to reduce any unilateral approach to emotional distress type disorders and to promote self determination for user/survivor controlled alternatives to psychiatry.

One of our problems is language. We have about 30-35 different languages in Europe and it is very hard so we have to learn plain English for example. When we have big meetings, people from England have problems to be understood because they speak too quickly for us, using complicated language and so we use simple language. This is very helpful, but for you it would be very easy to contact the representatives in the network, for example there is Mary Neville from England and board members from the UK, Netherlands and Ireland. You can contact them if you want and the website address for the Board is at the bottom of the leaflet.

One activity this year was the contribution to the World Psychiatric Association Congress whose theme was coercive treatment in psychiatry. It was agreed with WPA that on behalf of the user/survivor organisations that I would join the organisation committee. Key lectures were presented to the congress by Judith Chamberlain and Dorothy Arbuk- a German survivor with about 70 years of personal experience and witness of German fascism. You can see now that all the lectures are taped on video and dvd and we have brought to the internet all these pages that you can see and which are important for you as a user/survivor perspectives. We also had the declaration against coercive psychiatric treatment which a lot of organisations agreed and which was distributed there.

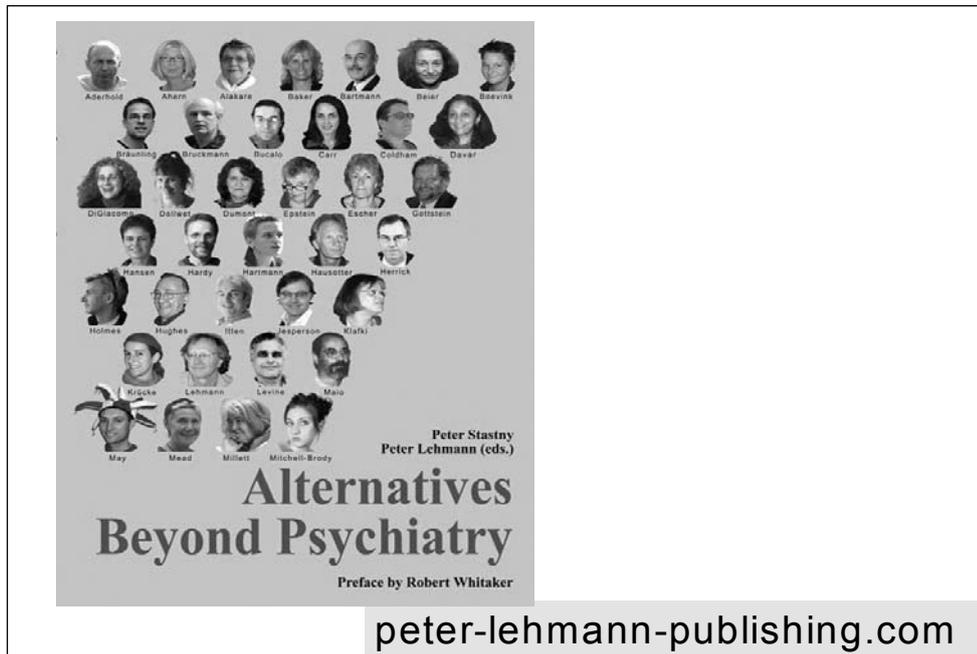
This action project against harassment and discrimination links with another activity on a European level within the framework of the community action programme. This seeks to combat discrimination together with MIND from England, mental health Europe and a lot of user survivor organisations. This made proposals to combat harassment which were presented to the European Union and you can read about it at the web address shown on the leaflet.

Another activity of the European network was participation at this conference on the future of mental health promotion and mental health care. Three main topics were accepted by WHO and the European commission to create a common strategy - developing innovative and comprehensive new policies in consultation with users, development of non stigmatising and self help approaches, and development of mental health legislation based on human rights. Of course, it doesn't mean anything until other organisations in different countries start to create pressure and refer to this paper. I mention it here, because sometimes the national organisations don't spread information about new successes on the European level.

Alternatives beyond psychiatry is the book which tackles all the topics which people are experts in this field address all the time. Over 30 years these are the questions that are regularly asked. The telephone rings: where can I help? How can I get medical help? How can I get help for a relative or friend in need? How can I protect myself from invasive treatment? What are the alternatives to psychiatry? How can I get involved in raising alternatives? Assuming psychiatry will be abolished, what can I do instead? I don't want to spend too much time on the book. There are some on the table and you can have a look and there are leaflets in your folder. I have been invited here to promote it. If there are any media people who write reviews for a small papers or magazines, you are kindly invited to review and you can have a review copy and this book.

One topic of the book is about Recovery. There is no German term for recovery. There is a huge tension in this term. You can understand it as recovering from a mental illness, reduction of symptoms or a cure with psychotic drugs, or as a statement of regaining freedom after leaving the psychiatric system. There are now in Germany books from psychiatrists speaking about recovery, supported by pharmaceutical companies. They are supported by people speaking about recovery through administration of psychotic drugs. So this important topic has been spoilt by big pharmaceutical companies. You can have a wonderful life again and so it is a big change and a big topic spoiled destroyed by big pharma. But you are starting the discussion here.

Thank you very much for your time.



## Journey through Mental Health Services and Recovery

Notes: Alleyn Wilson

This presentation took the innovative form of an interview between Guilaine Kinouani, team leader at the Fanon and Southside Partnership Project, and A, an African service user and community researcher with Fanon Project.

Firstly Guilaine asked A to tell us about some of his background experiences as a black service user in the mental health system. He told us that he had been admitted to hospital in January 2007 and was there for three months. It took him the first month to realise that he had a problem although he was unsure at first what this was. He was offered medication and although he initially refused this he came to accept that he was depressed. He also left university at this point. He had always been interested in spirituality but now sees this from a different perspective and is trying to put into practice a positive approach within his spirituality. During this period the most important help for him was a particular friend who maintained daily contact and did not “give him up”. This interest really helped him through this time and also helped him to expand and increase his social network giving him greater confidence and awareness. With Guilaine he has worked on different projects and is currently a trainer in mental health services, for instance undertaking role play with students. The main project he is now involved in is the Fanon Project.

Following this introduction, Guilaine then asked A three specific questions:

Guilaine acknowledged his experience of friendship in his journey from hospital to recovery and asked him **what had assisted him in the mental health system on his path to recovery?**

A stated that his beliefs and perceptions had taken him to “dangerous places” and that the out patient LEO (early intervention) service had been brilliant. It offered careers advice, counselling, and other services but the fact that it was spiritually based had been the biggest help. This meant that he found he could relate to the service candidly and that it was totally non-judgemental. All feedback was a two- way communication and he did not feel that services were delivered “to “him or that he was merely a patient with problems. This aspect, he thought, was vital to recovery. Underlying his recovery, and how it evolved, was his view of himself having been unwell as he thought he would be permanently damaged and unable to think – his mind was sometimes a blank and he was unable to engage, converse, or even to work out how to dress or get breakfast in a logical order. He thought his depression would never go away and that his memory was “shot”. However it all gradually came back and is now accelerating fast. He saw this as mainly being as result of the support of his friend who stuck with him, helped him to engage with the world and maintained his friendship and faith. He now believes that nothing, including one’s problems, is permanent and as things can change then there is always potential for improvement.

Guilaine then asked A **did he use his faith to make sense of his recovery?**

A said that what was seen as mental illness is an extreme end of a continuum which we are all on, and that all of us do have emotional problems. He said that he saw “madness” as an extreme attachment to something, or feelings and beliefs about what is going on. Sometimes what is experienced may not be happening. His personal perspective was a deep insight into reality and he had experienced what many others would not have done. As part of his recovery he had talked to a Buddhist teacher who had advised him to meditate and take his experiences whilst “ill” as his own personal insights. This had helped him on the recovery journey and was also part of his life now.

Finally Guilaine asked A **what could be done to make services more recovery oriented?**

He replied that whilst he was in hospital it was activities on the ward that made the most difference. Activities kept his mind engaged and the alternative would have been to do nothing and sit staring at the wall which was unhelpful and could lead to inappropriate “head trips”. The activity that he found especially helpful was an exercise class run by a Rastafarian to reggae music that energised people and left them hyped up in a good way. He also found art therapy helped him to find insights by putting some of his thoughts and experiences on paper so that he could analyse them. He found the yoga helpful as well. When he was an outpatient, psychology had been available. He found it helpful that this was not forced upon him. A had been able to use available group therapy to guide his meditation so that he could look at

different types of pain and this helped to guide him through experiences that were not based on false hopes.

As creativity had been important to him before he was ill, he was pleased to find that he is now happier with his creative thinking and work. He finished this honest and inspirational interview by reading one of his poems to the audience.

## **Experience of recovery as interpreted by mental health services: Premila Trivedi**

Notes: Joanna Hicks, UCLAN

Premila opened her presentation by sharing her own experience of using mental health services. She described herself as being a service user and trainer, with experience of recovering following use of mental health services. She continues to use services in times of 'desperation.'

A powerful and thought provoking set of observations were presented. Premila raised a number of concerns regarding the interpretation of 'recovery' by some mental health service providers and posed some important questions. She illustrated her points with four examples of individual service users and their experiences, and these are listed towards the end of this report.

Premila voiced concerns about services appropriating recovery and seeing themselves as the "experts" - there is an observation that recovery is different for each individual, and there may be discrepancy between what the service provider and service user perceive as 'recovered'.

It was noted that recovery is a current 'buzz word' and a major focus on recovery training. But Premila questioned whether the adoption of the recovery ethos by services goes far beyond training and asked 'Are services really prepared to take on a different way of working?'

The notion of recovery was explored and there was recognition that even though service users may be sufficiently recovered to be capable of leading normal lives, they may sometimes need support. Thus are they 'recovered' ...or not?

Premila noted that the concepts of self advocacy and empowerment have been around for ages in terms of the social model of mental health, but have not always been seen as part of 'recovery'.

The issues of oppression on mental health were explored, in particular the way in which racism, sexism and other oppressive factors can affect recovery. The question was asked whether recovery models consider these factors. The point was made that there needs to be more space for more narrative and stories to be heard from people from disadvantaged groups.

The following questions were posed:

- Does the system really value journeys as defined by users, or are they trying to create their own version to suit their needs?
- Are people being forced into recovery by services and is the recovery model being used to justify cuts in services
- Is recovery just the current flavour?
- Where do pharmaceutical companies stand regarding the notion of recovery? What are their interests?
- Is the mental health system interpreting recovery in a way that keeps power in the system?

**Example 1**

Drastic cuts are being made in day services where a recovery perspective is adopted. Little attempt is made to help people work through the process and bridge the gap between old and new approaches. This leaves many isolated, confused and vulnerable.

**Example 2**

A 61 year old Indian service user living in a group home has established a meaningful relationship for the first time and is enjoying using local leisure facilities. The next step on the recovery model used by the service provider is to move him towards culturally inappropriate independent living. However, at present the service user is in a stable and positive position, thus there are concerns about disturbing and disrupting this with a push towards the next step within the recovery model – is this really in the best interests of the service user?

**Example 3**

Lack of support given to service user and a perceived 'rose tinted' view of their recovery, even when they are crying out for help.

**Example 4**

A black service user, who has worked to identify internalised racism as a major contributory factor to her mental health problems is left feeling abandoned after being told her issues are too complex and no other treatments available.

## Poem by Rob Gee

The poem below is based on a list devised by the Homeward Project, Toronto (1992) which I found on the East Dorset Community Recovery Service website. The CRS is a Mental Health Service, actively promoting Mental Health Recovery and Social Inclusion. Their site is constructed and run by service users, for service users: It is intended as a primary resource for everyone with an interest in mental health recovery.

### **TWELVE POINTS OF WELLNESS AND BEING HAPPY OR HELPFUL HANDY HINTS FOR A GOOD RECOVERY**

#### **ONE!**

Live somewhere you like that's not too shabby  
In certain parts of Preston this isn't very easy (talk about UK crap towns)

#### **TWO!**

Do something you believe in that's meaningful to you

#### **THREE!**

Find someone to laugh with and pour your heart out to

#### **FOUR!**

Accept yourself. And like yourself. 'Cause you're alright. It's true!

#### **FIVE!**

Make the effort to have some fun, even if it means being stu-  
Pid

#### **SIX!**

Recognise your choices. Look at them and realise  
That you and you alone have the power to live your life  
Unless you're on a section, and then the shrink decides

#### **SEVEN!**

There are few things finer than knowing that you can do  
Most of the things you want to  
And if you can make that happen in your head  
Well then I envy you  
'Cause I'll never fuck a Nolan  
And it leaves me feeling blue

#### **EIGHT!**

Treat yourself and take a risk  
As long as it's worth the benefits  
Ships are safer in the harbour  
But that's not what they're designed for  
And do it shamelessly with heart in your song  
'Cause at the end of the day – what can possibly go wrong?

**NINE!**

There are lots of things that you can't change  
And if you dwell on them you'll go deranged  
So focus on the other stuff  
Cause there's lots of them and that's enough

**TEN!**

Is having space of your own where you can shelter  
From life's hurly burly helter skelter

**ELEVEN!**

Don't be afraid to ask for help  
While doing what you can to help yourself  
And when the boot's on the other foot  
We can all reap the benefits of number ...

**TWELVE!**

Offer help to others when they're in crisis  
Which doesn't mean solving all their problems and cares  
Often it just means being there

So the next time you end up on your uppers  
And life kicks the living daylights out of your happy ever afters  
I hope these twelve steps help you recover and get through  
And don't forget, not mentioned yet: Number ...

**THIRTEEN!**

Do a Wrong Dance or two

## Inter-cultural perspectives - Maori Mental Health Services Workshop

Facilitator: Tanya Kennard-Campbell

Notes: Peter Ferns

She introduced us to mental health services in New Zealand and explained that there are parallel services for Maori people. This had come about as a result of the principles enshrined in the Treaty of Waitangi (1840) with the British Crown which promised to preserve and respect Maori culture in all aspects of governance in New Zealand and more recently in public services. The Treaty was negotiated due to the very effective resistance to colonialism mounted by Maori people who remained an undefeated indigenous people. Much of Maori mental health services are based on the guiding principles in this Treaty and Maori ideas and concepts about mental health exist alongside Western ones quite happily in modern mental health services in New Zealand, including the use of Maori healers and spiritual advisers.

Tanya introduced a commonly used model of Maori mental health based on 'four cornerstones' which represent the four walls of a Maori home. They are *Wairua* or spiritual health; *Tinana* or physical health; *Whanau* or family well-being and *Hinengaro* or psychic health to do with one's thoughts, feelings and resulting behaviours. These four cornerstones present a holistic approach to looking to Maori mental health rather than a more rigid medical approach of diagnosis of symptoms and treatment with a narrow range of therapeutic interventions, often based on concepts of individual pathology. The Maori model demands a much greater understanding of cultural identity and social context, the involvement of family or *Whanau* in any intervention as well as wider recognition of community and spiritual meaning of distress for Maori people.

The spiritual dimension of mental distress in Maori culture is often the most important aspect and must be a focal element of any intervention with the person and *Whanau*. It was emphasised that Maori individuals never 'sit alone'; the truth is that they have been touched by family and their 'ancestors'. They can only understand their situation fully through consideration of this truth and they can gain valuable wisdom through this deeper understanding.

We then viewed a video on Maori mental health called '*Te Waka Oranga Hinengaro*'. The video showed a variety of Maori mental health workers talking about their experiences of their work and their motivation for undertaking the work. What was striking about this video was the degree to which the Maori

workers brought their cultural knowledge and identity into their everyday practice in mental health – a task that would be difficult in the UK at present. The resulting culturally appropriate services took a much more family-oriented approach to their work and backed this up with person-centred assessment and planning to meet needs.

The therapeutic assistance offered was also much wider, more flexible and aimed at social inclusion than is the case in the UK for BME service users. There appeared to be a genuine respect for the knowledge and expertise of families in working in partnership with services to assist the individual in distress. The issues of racism and having one's culture devalued was a prominent feature in work with Maori people experiencing distress. A lot of one-to-one work involved building trust and then reinforcing cultural identity and empowerment of the person and their family. The use of culturally appropriate activities and involvement in expression of emotions was a high priority and experiences through artwork and crafts such as wood-carving were an important element of the recovery work being done. There was a lot of emphasis of working with young people which, in light of UK's experience of trying to reach Black young men, was very interesting and heartening. At one point a powerful statement about a different approach to 'professionalism' was made by a psychiatrist who stated "I am not an expert – I'm an apprentice. I'm learning from my (service users)..."

The importance of good teamwork and support for culturally appropriate practice in the workplace was highlighted as being crucial for Maori mental health workers as well as White workers who had joined Maori services. The culture of services was seen as directly linked to the quality of the experiences of service users, particularly when it comes to new workers being inducted into the service through a proper welcome and being offered coaching by their colleagues. The message very much was healthy workers lead to healthy clients! This is a very important message to mental health workers in this country. Finally, the video made the point that Maori mental health is about taking the 'best of both worlds' by taking Western concepts and ideas about mental health and combining them in a culturally sensitive way with Maori beliefs and culture. It is then quite possible to see mental distress as a form of spiritual, social or family distress as well.

There followed a lively discussion with a lot of questions about Maori culture and customs. For example, when a Maori person becomes uncommunicative it may represent a culturally appropriate response to a hostile world and can only really be 'broken through' by another Maori person who understands this experience. Parallels were also drawn with Australian Aboriginal people who experienced more of an attack on their fundamental cultural beliefs and ways

of living resulting in greater social problems of drug and alcohol abuse and family disintegration, with such phenomena as the 'Stolen Generation'. There was further discussion about the Maori approach to dealing with individual distress through a community based approach centred on the *Marai* or 'meeting house' where whole communities can come and support individuals to get through a spiritual or psychological crisis. The discussion then centred on how judgements were made about culturally appropriate spiritual distress and something else that may be described as 'clinical' symptoms of mental health problems. *Mate Maori* suggests a listening approach followed by 'cultural treatments' rather than just medical ones for distressed Maori people.

The workshop ended rather hurriedly as we had been so engaged in the discussion that we had over-run into our lunch break – a true measure of success! Thank you Tanya.

## **Women and Mental Health Workshop: Staying Well**

Facilitator: Jolie Goodman

Notes: Vicky Nicholls

Jolie Goodman introduced herself and the aim of the workshop. The aim was to share a safe space, where participants could share thoughts and experiences on what helps us to stay well and what those around us including mental health services could do to help with this. Jolie acknowledged the diversity of the women in the group, including women of different ethnicities, ages, mental health experiences and professional and personal identities. Jolie facilitates a service user only women's forum in Southwark.

Areas of interest and concern included: linking primary and secondary care for women with postnatal depression; funding for specialist services; race - what do black people think about recovery? (there is a group looking at the views of African and Asian people); and the possibility of personal recovery ('if I died and came back I would be well, I'd be calm, I wouldn't be taking medication, I'd be normal').

Some people were particularly involved with service user perspectives and social enterprises as part of their journeys; others with support groups for lesbians and gay men. One person worked in a Trust where retraining in a recovery perspective was happening but she wanted to see work on more ongoing ways of being.

The main discussions centred around the place of the menstrual cycle in women's lives and the significance of the menopause; workplace discrimination; and issues around mental health services.

### **Menstrual cycle**

During the discussion about pre-menstrual tension, one experience voiced was of really bad depression every month, with PMT heightening emotions for two weeks before menstruation. This person said she felt unsafe at these times and in danger of taking OD/ taking anyone on. "All our blood is red", a book about the menstrual cycle was brought to participants' attention. This contains the idea that when a woman is in period she speaks the truth, that all the things we are conditioned not to say come out. One participant commented that as a child-bearer and parent this is linked to bringing children up which she 'couldn't do without rum and sisters'.

Some women found that the 'rational brain goes on holiday for a week' before menstruation, while others struggled with water retention particularly when on medication. The need for plenty of sleep at times of menstruation was discussed. One person described how she had learned that her period was linked to not feeling able to go out and needing to eat well, sleep, and look after herself; while another highlighted her need to take 2-3 days off, 'that's my way of coping'.

The discussion touched on feelings around menopause, which one participant found daunting. Another spoke of living with uncertainty, while another described the discomfort of hot flushes, needing to take off clothes and feeling desperate to find a fan!

### **Mental health in the workplace**

The discussion moved on to mental health experiences in the workplace. One participant had experienced workplace discrimination on the basis of her depression. She had worked in mental health services for 25 years, when she experienced a reactive depression. She knew she needed to get back to work but found a terrible attitude – people didn't want to talk about her mental health experience. Some raised the matter of whether this might be because she could now see the sides of both service users and staff and this frightened staff. She had been blocked from attending training. The reason given was that of stats and workloads. She felt that there was a subtext of 'we've had to cover her work for too long'.

Another woman worked in a therapeutic community for young people with behavioural and emotional problems. She described how when she was poorly and off work for six months they didn't want her to go back. Others present voiced their support for her decision in going back anyway.

### **Women and mental health services**

In principal there are women-only wards across the country. Jolie talked about the women-only wards in Southwark and in Kent, for which there had been much campaigning. In one participant's local area 'we did have separate wards, but these are now putting back to being a mixed ward.' This was due to the pressure on Trusts to provide separate beds for under-18s - the beds previously for women only were being used in this way now.

A crisis accommodation service that is being developed in this locality as an alternative, which would offer a room in a mixed place, would not be appropriate for this person who felt she wouldn't survive in such a place because the bedrooms are mixed. As with many women she found that mixed wards can exacerbate distress. Wards were 'not nice places for anyone, not safe'. One woman knew what she wanted – she asked to come in for half an hour only, to talk to a crisis team, but this had been rejected.

Home treatment teams are now available in most places. However such a service isn't appropriate for everyone. One woman, for example, said that her home situation was 'no good, I couldn't get back in the house where my mother lives' (and couldn't be treated at home). Another woman described having been admitted through A&E when a home treatment team hadn't worked, but because no place was available she was sent back to the home treatment team which was known not to be working for her.

One woman spoke about a therapeutic community for people diagnosed with personality disorder, which was very socially containing. Whilst there people have their section lifted and it offers a real alternative. Treatment comes from

people's peers, and it can be so much better hearing from someone who's been through it. However, there can be problems of scapegoating and bullying.

A drug and alcohol team with a place run by nuns was discussed. While the experience of discussing drugs with nuns was strange it was found to be really calming.

The basic experience of absence and abandonment was raised. Some felt it is all about relationship. One view expressed which found a lot of support was that while paid workers carve the cake it will never be a flexible service. The issue of Trusts having no pride in existing services was also raised.

Ending on a more positive note, Jolie talked about the successful Southwark campaign for female only wards – a woman had come in as Director of Services, who saw this as a moral responsibility. Although there was a huge mountain of resistance they succeeded. She felt that having women in positions of power can make a big difference, so can remembering the little pleasures in life, such as complementary therapies. One woman ended by saying how much she enjoyed being part of an online community, which meant she had friends online from USA at 3am.

Jolie rounded up by thanking everyone for being part of such a special group and reminded participants to take care of themselves – the main message to come from the group.

## **LGBT (lesbian, gay bisexual and transgender people and families) Issues in Recovery**

Facilitator: Howard Delmonte from PACE

Notes: Jeanette Copperman

PACE was set up 20 years ago to provide counselling services to the LGBT communities. PACE provides a range of services including drug and alcohol services, help with employment and counselling. Howard had been asked 7 years ago to set up a family and couples service which had received Home Office funding. The service provides a space to think about family, mental health and sexual orientation together and provides free family therapy for any members of a family. They always ask people who do you consider to be your family? They do not make assumptions or set up expectations. The people themselves decide who to bring along – friends, biological family.

5 volunteer family therapists run the couples service which is free. There is a LGBT parenting group for biological and adopted children, same sex couples, co parents, and support groups for people thinking about parenting

Before working in this service he had worked for 22 years in mental health services and trained as a music therapist.

Howard gave out 2 handouts which summarised the main action points for services and information about LGBT people's previous experiences of counselling and therapy.

### **Main Issues in Recovery**

Family – it is important to think about the messages that come from family. Howard recommended Robin Skinner and John Cleese's 'Families and How to Survive Them. 'You don't completely recover from family!'

Messages come from our families of birth about being LGBT, from the media and culture, and from our current family. We are shaped by a family's culture and their implicit and explicit messages

Choice and control are important in what recovery means to people

Amongst other studies Diagnosis Homophobic published by PACE researched the messages that mental health services give to LGBT people and found that pathologising LGBT people was still part of the mental health landscape. Fear is a huge component of mental health difficulties around LGBT issues

Research suggests that 1 in 4 LGBT young people from the age of 13 has experienced mental distress. One in 5 thought about or attempted suicide

Major providers of family services were asked about their understanding of and services for LGBT people but the results were alarmingly limited.

PACE carries out training with practitioners from organisations such as Relate, Samaritans and others. In general we are moving in a positive direction in terms of LGBT people but there are some difficult issues.

Doctors rarely think about sexuality and it is frequently not mentioned whilst it might be a component of mental distress

There are issues for people who have to live for decades thinking about it all the time – how much do I say. Learning to hide and stigma have an impact on mental health very rarely considered.

### **Workshop Participants**

People in the workshop were asked to say what motivated them to come to this workshop

People attending the workshop came from a variety of work backgrounds including team leaders in mainstream mental health services, Rethink workers, survivors, forensic mental health, researchers, social workers and social work lecturers.

They were interested in building LGBT issues into mental health research, people who experienced social exclusion/survivors, linking with orthodox Jewish community amongst which sexuality was a taboo, and social work supervision on complex case work

### **Discussion**

The history of mental health services in relation to LGBT people persists with a history of aversion therapies and hormone therapies. This reinforces the impact of shame and stigma on LGBT mental health

PACE gets one or two referrals a week for refugees who have received death threats in their countries of origin.

Gay and dyke are terms of abuse in the school playground. PACE provide training for teachers and youth workers.

### **Ways forward**

Practitioners should use open questioning more. If they are dealing with relationships ask what the particular relationship looks like and ask about next of kin in an open way.

Therapists need to look at their own attitudes and fears.

## **Suggested action points from PACE**

- Give all service users information with equal opportunity statements which include sexual identity.
- Include this information in all initial correspondence.
- Display information which indicates that your service is aiming to improve access for lesbian, gay and bisexual service users in waiting rooms and consultation areas.
- Find positive images of lesbians and gay men which reflect the diversity within lesbian, gay and bisexual communities i.e. not all lesbians, gay men and bisexual people are able-bodied and white.
- Display such positive and diverse images in your waiting rooms and consultation areas.
- Provide leaflets which give information about local and national support groups and information for lesbian, gay and bisexual service users in your waiting rooms.
- Designate a member of staff to make sure that resources and positive images are kept up to date and replenished.
- Design assessment/intake/admission forms or protocols which do not embed heterosexist (assumptions that people are heterosexual) e.g. ensure the possibility of a same-sex partner/relationship as an option when completing a form which might otherwise have only asked about "marital status".
- Monitor and audit the use of your service by lesbians, gay men and bisexual people. Be sensitive to the need for such information to be kept confidential.
- Keep lesbian, gay and bisexual equality issues on your agenda through regular supervision, team meetings and training events.

## **Reference**

Lesbian, gay and bisexual identity work in mental health:  
An evidence based guide for people who work with families

Available from PACE at, 34 HARTHAM ROAD, LONDON, N7 9JL  
020 7700 1323

## **AWAAZ**

Facilitator: Angela Kandola

Notes: Terry Bamford

Awaaz is a community-based organisation serving the Asian community in Nottingham. Angela Kandola leads the organisation and described how it had grown from her own short term project appointment eleven years ago to a flourishing resource centre which now employs 5 staff.

Nottingham has a substantial Asian community and serves those speaking the three main Asian languages-Punjabi, Urdu and Hindi; it also provides a service to other minority groups from the south Asian continent. Its aim is to provide one to one support, group therapy and advocacy service for the Asian community on all mental health issues. It has an open referral system and now generates the majority of its referrals directly from the community rather than through professionals.

The service still has to justify the need for a separate Asian mental health organisation. It argues that it is needed because of:

- The lack of awareness of mental health issues in the Asian community by the community itself and by statutory services
- The stigma attached to mental ill health is particularly powerful in the Asian community
- Language and communication barriers
- Lack of suitably qualified staff and culturally relevant services
- The continuing belief in the local community that Asians 'look after their own'
- A culturally specific service to address the cultural, religious aspects in their lives.

Awaaz offers a range of services both in primary care and secondary care - counselling, assessments in conjunction with statutory assessments, group therapy, advocacy, individual support, information and advice on mental health issues and a drop in service. AWAAZ carries out its own assessments on each individual and implements an agreed care plan with the individual, which is reviewed on a regular basis. While the service has a central Resource Unit base it operates on an outreach basis and sees individuals in GP premises, community centres or where is most appropriate for the individual.

From its experience AWAAZ believes that it has changed the culture of concealment in the Asian community by raising awareness of the issues and by engagement with the local community. Many who have come to the service for mental health support in a culturally sensitive manner and receive support then in turn refer others in need. The service has been recognised through individuals who have used the service then spread the word in the community i.e. word of mouth.

The overall work of the project is supported by a Management Committee which includes user and carer representation.

**Discussion:**

Q: What types of community engagement do you have?

A: We believe in respecting the local community. That means dressing appropriately. It means respecting older people as well as communicating in the relevant language and being sensitive to religious beliefs. You work with local community groups.

Q: What is the nature of the assessment provided by AWAAZ?

A: There are up to 3 one to one sessions with a worker following which a care plan is prepared on the basis of the needs identified. This identifies what can be provided by AWAAZ, what is available from other agencies, and goals for the individual. We explain the limits of confidentiality on the first visit and are honest about what can and can't be done.

Q: The Delivering Race Equality programme aims to 'mainstream' sensitive services. Is there a risk in fragmented services for fragmented communities?

A: There aren't any Community Development Workers so we do not know as yet if there will be a risk in fragmented services. Some are now on the way so the issue will be how best to mesh together statutory services, the voluntary sector and the CDWs. There is always a need for culturally sensitive specific services and the evidence is there that individuals do not engage consistently with mainstream services hence a lot of individuals miss their appointments with statutory services. There are also not enough specialist resources in the statutory services to deliver specialist services.

Q: Why and how do you work with 16 and 17 year olds?

A: We were set up with a remit of 16-65 as our target age group. In practice we don't get many referrals from young people but sometimes from their parents who seek advice. We work in partnership with the CAMHS services and provide advice guidance and support with assessments. We have just taken a referral for a 16 year old and there are a lot of cultural issues and isolation for this individual who feels more comfortable engaging with Awaaz than mainstream services. The level of support provided to 16 -17 year olds is exactly the same as to any other individual accessing our services.

Q: Are there enough interpreters?

A: No -at least not enough skilled interpreters in this area. They need to be trained in mental health and to be able to understand the context. Mental health is a very important area and decisions are made by the psychiatrist in the initial assessment. It is important that the interpretation is accurate as it can affect an individual's assessment/medication.

Q: Why is stigma greater in the Asian Community?

A: First it can affect marriage prospects if individuals are seen as 'mad'. Second there is a cultural association of mental ill health and black magic. The answer is education of families and the community. The stigma is so great, if an individual has a mental health problem, the whole family can be

labelled “mad” and isolated from the community. Awaaz works to raise awareness and educate individuals in the community on mental health hence try to break down the barrier and stigma. A lot of service users or their families are not aware of the medication they are given and the side effects, this is one particular area we focus on.

Q: What is your own experience and background?

A: I have worked in education then followed onto working with Asian/African Caribbean women fleeing from domestic violence who also had mental health issues. I have been working at Awaaz for the past eleven years dealing specifically with the Asian community with mental health difficulties both in primary and secondary care.

Q: Do you have too much demand for your services?

A: Yes- we now have a waiting list of up to 3 months for most services but still accept crisis referrals. Each year, the number of referrals increase hence we have a waiting list up to 3 months. Each referral is assessed and if there is a referral which is in need of immediate support i.e. crisis, we will deal with the referral straight away.

Q: Where does your funding come from?

A: Our funding comes from Adult Services Housing and Health and Nottingham City PCT.

Q: What are the key elements in your success?

A: We deliver a culturally appropriate sensitive service which the community we serve feel comfortable to access. We treat every service user/carer with respect. We give them a sense of being treated as human beings with a sense of dignity. Once individuals accessing our service have built a trusting relationship with the organisation, we then encourage them to access mainstream services. Hence Awaaz is a stepping stone for the Asian community with any form of mental health problems prior to engaging with other services and feeling comfortable in doing this.

## Carers and Mental Health

"Ann" Interviewed by Guilaine Kinouani  
Notes: Randall Chan

Q: Tell us about the background of how you became a carer.

A: I fell into caring for my 34 daughter "by accident". She completed a second degree and was reasonably employed, but was sectioned two years ago after suffering from depression for ten years. Every time she began to get better, she then tripped over into a manic phase, which was not noticed by the services.

I became labelled as a "carer" because of being her mother. I am uncomfortable with this term. I feel it has been destructive to my relationship with my daughter.

There is an inherent conflict because services and drug companies who only think in the short term, whereas as a mother, I think long term. The services would assume that my daughter was "better" but as a mother I know she is not functioning at her best.

Q: What are the expectations the services have of your daughter?

A: They expect the carer to be compliant.  
The services expect to inform me as the carer, but my daughter doesn't want me to be informed, as it undermines her independence, and she reacts to me like an adolescent.

I think there the two important factors are  
Making relationships  
Getting a job, something that she wants to do and gets her out and about

However, the process of getting a job is overly stressful for her. Once while she was being interviewed for a job she became unwell and ran out of the interview. Then later she had to explain why. What would help her is to be offered a job with gradual progress to take into account the effect of the medications.

Q: Do you think that "positive discrimination" would have been helpful in her case?

A: I haven't thought about that, but I do think that we need legislation that will protect people from the stigma of reporting past mental health problems. Her work didn't allow time for the doctor appointments, and appointments were not available out of hours, resulting in her leaving the job and then becoming very unwell.

Q: How have services helped?

A: The carers' group has been very helpful. I got support from others in a safe place when my daughter didn't want to have information disclosed to me.

I was able to be part of the decision making and planning in conjunction with the psychiatrist. This was better when she was very ill; less so when she was getting better.

Q: How do you deal with your own insecurities?

A: I have a supportive husband. A few friends know, so my daughter herself feels okay talking to them.

Q: Do you find that disclosure and stigma are issues for sufferers AND carers?

A: It is not easy to challenge the problem of stigma. I would be more politically active would it not be for my daughter's discomfort with disclosure. I also deal with the stigma of being a schizo-genic mother.

I do find some comfort in the bio-medical model, as it does appear to be a brain chemical issue that causes the problem. Drugs seem to help bring her out of delusions. However, I do know of literature that shows people getting better without drugs.

The inpatient services are helpful, but some parts of it were very unhelpful. The environment can be very untherapeutic due to crowding.

Q: What do you think the ideal situation for best helping those with psychosis?

A: More activities would help. Attending a residential hostel for women with depression allowed her to talk with others and make friends. But that hostel has been closed down due to cost cutting.

Q: What do you think of "recovery"?

A: I wasn't familiar with the concept until today, even though I'm a psychologist!

My definition of recovery is about quality of life:

- regaining independence
- able to live independently
- able to enjoy life and make relationships
- ideally hold a job that she wants to do

However, services see "recovery" in terms of a set time frame, with no reference to quality of life.

Q: How can mental health services better support you as a carer?

A: By offering continuity of staff (but this can't be offered). For example, my daughter's key worker has changed many times. I end up being the one doing the health services' job because she lives with us.

Q: Do you feel recognised?

A: No. Especially in national policy women are expected to provide informal care. I am taken for granted because as a woman I just do it.

I don't know how conferences such as this one can impact services, especially where the medical model is so prevalent. The same things are said year after year, but nothing changes.

Q: If there were no constraints on resources, what would you like done?

A: Have a professional support person so that the family is not solely responsible.

General discussion: Carers are being drawn in more recently. Before, carers were not acknowledged, and it felt as if we had to go to battle. Obtaining supported housing has finally allowed the carer to have a more normal life.

Comments: Provide "solution focussed" training for carers.

Mental Health systems do not seem compatible for including carers.

Confidentiality always comes up as an issue, but there is no confidentiality for carers!

Question to all: How are you collaborating with carers?

Answers:

-we now ask carers how they are

-we know the family through visiting them

-we are more accessible and allow carers to contact us

# Recovering Healing Communities

## Rufus May

Recovery is a word that has been used recently in mental health contexts. I like the flexibility of the recovery concept: We can talk about recovery from many things; we do not need to assume that to talk of recovery we have to imply that we are recovering from a 'mental disorder'. For example: We can consider how we recover from spiritual crisis, from alienation, from a toxic society, from emotional trauma, from a psychiatric system, from mental distress, or from demoralisation. In this talk I will look at how we recover groups of people and relationships that support the healing process.

### **The limitations of organisational approaches to recovery**

There are many different ways to recover some people use psychiatric medication and find it helpful, some people prefer to avoid the use of psychiatric drugs or minimize their use. The Recovery report (A Common Purpose: recovery in future mental health services) by CSIP, RCP and SCIE brought out earlier this year, in part provoked this conference. Therefore I will briefly comment on it.

The report does do some good by acknowledging the role of hope and strength as a focus in service provision. However it does not acknowledge the fact that many people have found that an important part of their recovery was to reduce their use of psychiatric drugs or avoid using them in the first place. This is important, as reducing medication is something that prescribers are generally bad at doing. Instead the report repeatedly defends established treatments and in the report's only quote that outlines someone's personal experience, recovery writer Pat Deegan says how she continues to find medication useful.

What the report avoids is the central need to put the service user's views about how they wish to approach their recovery at the heart of service provision. It also avoids neatly the finding in the recovery literature that many people find meaning in their actual experiences of distress and confusion. The report weakens this to a vaguer statement about how 'finding meaning in personal experience can be important'. If people are able to find meaning in experiences such as hearing voices, feelings of despair or mania this significantly challenges traditional treatment approaches which seek to suppress experiences rather than work with them meaningfully. It is therefore important for this aspect of recovery accounts to be overlooked by the establishment otherwise we would need to acknowledge the role psychiatric systems have had in denying the important social roots of people's distress. The report emphasizes the people who use mental health service's ongoing disability and implies their ongoing dependence on mental health services. This kind of recovery may keep the status quo unperturbed but does not give us a very adventurous vision of future mental health service provision.

The 'A Common Purpose' recovery report appears to be a dilution of the values of recovery literature: A rear guard action to assimilate and weaken the implications of recovery accounts and research. We can expect mental health establishment organizations to do this.

## **Recovering Healing Communities**

For me recovery is a concept with strengths and limitations like any other. For this discussion I am interested in thinking about applying recovery to communities. How can we recover healing communities? Communities that listen, that enable, that offer space for growth and change in a flexible way; Communities that allow people to speak their truths, that create atmospheres of trust and allow people to choose ways forward in their lives, that enable conflicts to be peacefully resolved. If we are to recover healing communities the implications for how we do things in mental health are radical. It will not come from top-down policy directives but from grass roots pressure that the media will no longer be able to ignore. We have to say loudly that our experiences of distress and confusion are meaningful, that they relate to social injustices and cultural contexts, that our so-called symptoms are messengers that should not be shot down with mind numbing medication but listened to and made sense of.

Healing communities are about people coming together as equals, spaces where people can be listened to and a range of approaches tried out. We have to be open-minded: To use technical language we have to take a social constructionist view to look at how language and the way we describe ourselves can limit our freedom. The solution is thus to create spaces that embrace different ways of seeing the world. If we have had much contact with mental health services our worlds may have been colonised by psychiatric concepts. The concept of recovery can be usefully juxtaposed against pessimistic stories people are so often told - that they have a lifelong biologically caused condition and there is nothing they can do about it apart from taking their pills. As well as this I have found it useful to enable people to deconstruct established terms like diagnostic language and the clinical language that is so often about what is lacking and does not look at the different possible meanings of people's experiences. Once we have deconstructed the medical model of distress, then we can reconstruct our stories using language that pays attention to our lived experience and links us to being able to take positive actions (for ourselves and others).

Healing communities are about ones where we can listen to our deeper values and wisdom find ways to care and support each other. They may be spaces where lots of talking or creative expression takes place, they may be spaces of meditative and peaceful silence. Through these spaces we can find new ways to live harmoniously, balancing our own needs to be creative with the wider needs of the communities we live within.

## **What are the obstacles to the creation of healing communities?**

Broadly speaking there are the values of capitalism such as consumerism and individualism that appear to challenge our sense of community and well-being. The media psychologist Oliver James has outlined this well in his recent book *Affluenza*. James shows how Britain has twice the levels of psychiatric distress compared to many European countries and links this to our levels of economic inequality and competitiveness.

Then there are particular forces that relate to mental health service provision that may in fact undermine the development of healing communities. Firstly, the pharmaceutical industry's promotion of disease models and the assumption that drug treatment is both necessary and desirable for almost all forms of distress. The promotional material of the pharmaceutical industry is rife in mental health services and governmental organisations like NIMHE have also continued to collude with drug company funding and partnerships. Secondly the pressure on mental health professionals to create a sense of safety by treating people in crisis coercively with a 'we know what's best for you' attitude. Thirdly the self-interest of professionals means there is a tendency to colonise expertise rather than share it with the wider communities surrounding someone in distress. And finally the tendency of the media to pander to the afore-mentioned values via pundits like SANE's Marjorie Wallace and mental health stories that focus on dangerousness. All these processes act to isolate the individual in distress from supportive others and pacify their ability to become an active agent in their life. So how do we counter all that?

## **How do we create healing communities?**

We need to work both underground and over-ground to build healing communities; to create places that are understanding, optimistic and supportive. These communities will need to be strong enough to resist the wider values of society that appear to be quite toxic to emotional well-being. I see it as important to work both inside and outside of mental health organisations. Initially people need places of safety to express their experiences and to hear from others about how they have dealt with and navigated similar experiences. At times these will need to be safely away from the prying eyes of risk assessments and therefore have an 'underground' quality. Self help groups seem an excellent resource that complement one to one supportive relationships. I am involved in setting up groups within hospital and community settings. I also divide my time between paid work initiatives, which provides me with some economic stability, and voluntary initiatives where I have more freedom to be creative.

If once we are on safe ground, we speak up about our recovery stories and different ways of living with difficult emotions and experiences; we can establish our journeys through pain and confusion as legitimate, worthy of being respectfully listened to and learned from. We have to find ways of

doing this both in independent media such as independent films, publications and web sites and as we get stronger the forums of newspapers, radio and television are worth tackling. Homosexuality was de-medicalised in the 1970's not because of an evidence base but because of a popular movement, which started underground and gradually became more and more visible in wider society. Nevertheless, academic workers will be a valuable part of this consciousness raising process, which will involve challenging received wisdom about 'mental illness' and treatment.

There is great wisdom in the origins of the hearing voices movement, which initially studied both voice hearers who had never used psychiatric services as well as voice hearers who had use psychiatric services. Following on from the broad range of knowledge gained from this approach, we have sought to make links with and gain a dialogue with people who have opted out of conventional mental health services and found their own ways to live with and transcend distressing experiences. It can be very empowering to hear about how someone has managed their distress outside of the usual systems of mental health care.

In West Yorkshire we have attempted to plant the seeds for supporting the growth of healing communities by running regular Evolving Minds public meetings which are open to everybody ([www.evolving-minds.co.uk](http://www.evolving-minds.co.uk)). Evolving Minds meetings happen in the evening and look at different ways to approach mental health problems. We highlight the value of personal experience and diversity of approaches. We also always warm up our meetings with some storytelling, poetry or music. Examples of subjects recently covered at the meetings are sacred chanting, conflict resolution, ways to develop a positive attitude, five rhythms dancing, shamanic healing practices, using narrative therapy techniques, grounding techniques, mindfulness and how to live in a sick society. Running these meetings we have found it useful to link with different faith communities such as Buddhists, Pagans, Quakers, Christian and Islamic groups. We also now have good links with green and peace promoting organisations. These are not therapy meetings; up to 30 people can attend - they are more public education spaces where we learn from each other in various formats.

The increased knowledge about holistic approaches to dealing with emotional health problems means that we can introduce people using mental health services to a broader range of strategies and ideas. For example the current members of our hearing voices group in Bradford use coping strategies that include the following: Yoga, shadow boxing, diary writing, drama work, prayer, relaxation strategies, physical exercise, generating compassion for aggressive voices, talking with voices, using non violent communication techniques, visualisation techniques, walking in nature and art work. Quite a few group members have chosen to use such strategies as a way to successfully reduce their use of psychiatric medication. We have been able to introduce some alternative approaches into the local psychiatric hospital such as recovery self-help groups, tai chi, 5 rhythms dance and drama classes. I see these initiatives as ways of *bringing the community into the hospital*.

The Evolving Minds meetings have had a number of side effects! They have generated a campaigning group who have initiated three Great Escape Bed Pushes to highlight the need for more alternatives to coercive psychiatric practice (see [www.bedpush.com](http://www.bedpush.com) ). One of the latest spin off projects from Evolving Minds is a Coming off Psychiatric Medication Support group that meets weekly since June this year. We have also established a web site: [www.comingoff.com](http://www.comingoff.com) . This aims to provide information about how to reduce medication and alternative ways to deal with difficult emotions and thoughts that may re-emerge or emerge as part of the withdrawal process. This project has a number of volunteers whose skills include reflexology, tai chi and qi gung, counselling, community theatre and pharmacy knowledge.

## **Conclusion**

The process of recovering healing communities is about creating communities of hope, of acceptance, of opportunity, of open-mindedness, of creativity, of understanding, of restorative justice, and of love.

## **LGBT workshop on Recovery**

Facilitator: Jo Beecham, PACE

Notes: Raza Griffiths, SPN

One of the issues highlighted during this workshop was many peoples underestimation of the continuing issues faced by LGBT people despite recent positive changes in attitude and legislation such as civil partnerships.

Whilst many people were coming out at ever younger ages these days in a more LGBT-affirmative environment, this was not always the case and participants highlighted negative reactions due to culture, religion and social attitudes.

There were a lack of support systems for LGBT people and a lack of government commitment to LGBT health through funding LGBT support groups.

Coming out could often be a traumatic time, with fears of rejection by friends, family and work colleagues at their height. But the coming out process could also result in greater clarity by helping determine who your real friends were.

Incidence of mental distress including diagnosis of schizophrenia, as well as relationship breakdowns, often coincided with coming out in the late teens, making this a difficult time. Service provision for these vulnerable people, as with provision for LGBT people of all ages, was poor. However, there was now an LGBT component in schools in the context of sex and relationships education. This was a legitimate thing to do particularly given the Goods and Services Act which bound schools to give diverse perspectives on families.

Older LGBT people were especially neglected. They had often had to live in the closet for much of their life and one person spoke of a friend who had been a senior Officer in the American Armed Forces who came out when he was 60 after he left the Services. Considerable social pressure was placed on him at social functions where the expectation was that he should be married or have a female partner to bring with him. Older LGBT people sometimes felt they had to go back into the closet on entering institutionalised settings such as nursing homes.

There was a fear of interacting with services due to the assumptions they might make around what was normal, such as the assumption that older people – whether gay or straight - did not have a sex life. Or the assumptions inherent in the use of terms such as 'husband' and 'wife'. The term 'partner' was more suitable when referring to LGBT people in relationships. Professionals sometimes felt anxious about not knowing the correct terms to use. Some of these issues needed to be dealt with by better staff training which needed to include an LGBT component rather than being completely generic. There was however the issue of preaching to the converted and the difficulties of reaching practitioners who had homophobic attitudes. The recent role of psychiatry in particular in persecution of LGBT people through 'treatments' such as aversion therapy could not be ignored.

One of the debates in the workshop was whether the emphasis should be on creating generic services which were non discriminatory, or more LGBT specific services. The second option would entail the need for a myriad of specific services to cater for every single group in society. Social work approached the issue of catering for diversity in a different way. Social work was about catering to the needs of the individual client and was based on core values which were based on social perspectives which were anti discriminatory. There was little such training for doctors or nurses, though some did undertake THORN courses. Adult services had a basically medical perspective which did not focus on the environment or friends and family, which, especially in the case of LGBT people, could often contribute to their problems. There needed to be more counselling services for children.

Services across the country varied enormously especially CAMHS teams, which could sometimes be brilliant. But it was a question of money. Better funding would lead to better services. One person also pointed out WRAP approaches to mental health recovery used some of the ideas in the 12 Steps taken from Alcoholics Anonymous.

A major recent development which would help provide better LGBT services was the inclusion of questions within the national inpatient survey of sexual orientation. One of the reasons that had previously been given to not have it included was that people would not understand how to fill in this question. This was an indictment of services, which had a duty to communicate with patients properly.

# Workshop on Recovery Research

Facilitators: Jerry Tew, Jan Wallcraft

Notes: Jayasree Kalathil

The purpose of the workshop was to develop an agenda for research into recovery. Recovery is a contested concept, whose theoretical basis requires further development. The existing research base is not substantial enough to include the various ways in which different groups and individuals understand recovery.

## Some issues for recovery research – Jerry Tew

Recovery was a concept that was developed primarily by service users and survivors based on their experiences. In recent times it has been appropriated by mental health professionals and re-articulated in the form of models that many people feel disempowers service users. The question of professional power in deciding and drafting recovery models is important.

While recovery, for service users, has meant reclaiming their journeys, the professional articulation tends to be closer to the traditional understanding of “rehabilitation,” where the professional always knows best. Many services that claim to work on a recovery model deliver services that are based on the traditional rehabilitation models. It is also becoming clearer that these recovery models do not allow for a diverse range of experiences, identities and understandings of mental distress or well being.

There are several areas in which recovery research need to develop. Three main areas are:

1. Outcomes: The government’s interest in the recovery agenda has increased the pressure to measure and evaluate recovery outcomes. But what are the outcomes that need measuring? Are there outcomes that mark recovery that are common to diverse cultures, identities and individuals? Or are recovery journeys so individual and different that measuring common outcomes become pointless?
2. Processes: There needs to be narrative research that explores the processes of recovery. What are recovery journeys like? What are the elements, incidents etc (e.g., a nurturing friend, an epiphanic moment) that enables the journey? What do non-mainstream, diverse perspectives on recovery look like?
3. Services: Many services now claim that they work on a recovery model. How do we tell whether a service is promoting or prohibiting recovery?
4. Recovery research also needs to establish that recovery is not something that is done *to* people but *alongside* people. Recovery cannot become “manualised intervention,” where people are subjected to models that have no connection to their lived experiences. Research also needs to look at how organisational change can be brought about in working towards recovery.

## **Some findings from the SPN study on recovery and diversity – Jan Wallcraft**

As part of a recovery project, SPN organised two focus groups to gather perspectives from Black and Minority Ethnic groups, one of which was specifically for women from BME communities. Some of the main points that came up in these focus groups were:

- Recovery is moving towards a new place; not getting back to where you were.
- Recovery is a journey and not an end point.
- It is taking back control of one's life.
- Recovery is about developing a sense of worth.
- Current recovery models rely on medical models of cure.
- Recovery involves developing solidarity with other BME people; participating in discussions.
- Employment, diet, sleep, holidays, friends are all important in recovery.
- What does not help in the journey to recovery is medication.

The workshop attendees then split into small groups to discuss what they thought was important to be researched.

### **Research questions raised in Group 1**

1. Is there a difference between people who use medication and those who don't in terms of their recovery? For example, do people who are not using medication have stronger social support (e.g. home support as opposed to hospital admission – which is more successful for recovery – do we know)? Do those not using medication have an improved quality of life because of not getting side effects which themselves could prevent recovery? What effect on recovery does withdrawal from medication have?

2. What do service users themselves *feel* about recovery? Especially those who have been in the system for a long time and now may be told this is how things are and will be.

3. How can there be research which is objective and relates to objective measurables when recovery is so subjective and personal?

4. Service users, especially those hospitalised, are said to learn illness behaviour by copying other patients. Could it be possible then to find out what makes for recovery and then import champions into parts of the mental health system to demonstrate this?

### **Research questions raised in Group 2**

1. How is recovery being realised within different services? Does it often only mean cuts in resources?

2. Can there be a comparison of outcomes of rehabilitation and recovery?

3. Are there common issues in people's journeys of recovery? What helps and what hinders? What are some of the coping strategies that have worked for service users and carers?

4. What is particular to people from different groups, with different identities, cultures and types of distress experiences?

### **Research questions raised in Group 3**

1. We need to understand the concept of recovery better. Who decides that someone has recovered?

2. Everyone has something to recover from. What are the elements of these journeys?

3. What is the role of the family in recovery?

4. How can recovery be measured? What are we measuring?

### **Group Feedback and Discussion – Jerry Tew**

#### ***What is it important to research in relation to recovery?***

- Relationship between positive recovery outcomes for service users and their experience of the degree of choice they were offered by services
- What bits of people's recovery should mental health services get involved in?
- Effective strategies for staff training and changing organisational culture – including role of service users in delivery of training and consultancy
- Defining what constitutes recovery – balance between generalisable elements (e.g. empowerment), culturally specific elements (e.g. reclaiming particular social roles) and uniqueness of people's aspirations and journeys

#### ***Common research issues in relation to everyone's recovery***

- Medication – how does it help or hinder people's journeys?
- Influence on outcomes of dominant orientation of professional culture
- Effective support for people who choose not to use medication
- Impact of compulsion / use of advanced directives
- Choice vs. paternalism – attitudes of practitioners / organisational cultures

- Use of Care Programme Approach in ways that enable service users to take charge of their recovery plans
- Power, oppression and empowerment in relationships with workers, families, communities, public at large...

***Potential differences in recovery experience***

- How medication / illness model is viewed within one's cultural context; beliefs around efficacy and appropriateness of medication
- Experience of choice for different minority ethnic and other social groups
- Meanings given to mental distress depending on cultural context, gender, sexual orientation, etc
- What recovery 'tools' work for different folk – moving beyond a 'one size fits all' mental health service

# **African Caribbean perspectives on Recovery**

SPN workshop facilitated by:

Guilaine Kinouani

A

Lloyd Lindsay

The workshop started by setting the scene for the black experience of using and accessing mental health services.

The following facts were presented:

Higher prevalence rates of severe and enduring mental illness have been found in some ethnic groups with African Caribbean men up to seven times more likely to be diagnosed as schizophrenic.

Many studies have documented ethnic differences at the point of access, with Afro-Caribbean and African men more frequently accessing care through adverse and coercive pathways and with higher police involvement.

Some evidence suggests that they are also disproportionately transferred to psychiatric units under a Mental Health Act order whilst in prison and disproportionately come into contact with the criminal justice system when in the community. Yet self report studies and systematic reviews show no significant differences in offending rates between ethnic groups.

Moreover, inequities have also been noted in the granting of bail on the basis of psychiatric reports. Indeed, black males are 3 times less likely to be granted bail even in the presence of more favourable indices of criminality and more stable housing conditions.

Unsurprisingly, Black and Minority Ethnic groups are less satisfied with services and therefore less likely to engage as they find them less appropriate for their needs.

Black people are also less likely to agree with their diagnoses and more likely to get into conflicts with clinicians and care teams.

The workshop then went on to discuss and explore possible causes for such findings and experiences.

Cultural factors were cited as possible reasons for the current situation including;

- Ethnic difference in help seeking behaviours and delayed treatment
- Cultural discrepancies between practitioner's diagnosis and patients' cultural readings

- The inappropriateness of imposing a narrow diagnostic framework on people who have different frames of references and worldviews was also mentioned.

Socio-demographic and environmental factors were also discussed with particular reference to:

- Social exclusion inequities
- Exposure to racism.

The latter point was hotly debated. Many wondered the place racism (at individual and institutional levels within both the criminal and mental health system) played in the current inequities. Though most agreed that causal relationships were hard to establish, the consensus that there was a need for tackling service users 'perceptions, attributions and expectations of racist treatments' and care teams 'expectations and perceptions of aggression in Black mental health service users'.

### **The Recovery Project**

The Southside Fanon UCLAN Recovery Project was presented. This enabled the discussed experiences and findings to be envisaged within a "Recovery" framework. The impact of the above mentioned adverse experiences on African Caribbean recovery conceptualisations of recovery was also discussed.

The Fanon UCLAN project feeds into the Delivering Race Equality programme which is a national action plan aimed to reducing mental health inequalities.

The main research questions of the project were presented. In essence the project aims to answer the following questions:  
How could African and African-Caribbean perspectives on recovery improve current mental health provisions within Lambeth?

Or specifically:

- How do black service users define *recovery* and what would pathways to recovery look like from their accounts?
- What factors facilitate recovery and what are the barriers to achieve recovery from a black mental health service user' perspective?

The project uses a mixed methodology including questionnaires, interviews, discussions and focus groups and has user involvement at the core of its ethos and process. Service users were trained to be researchers and are supported by Southside Fanon and UCLAN.

The main themes for the project were discussed:

It was acknowledged that as the project was still ongoing, it was difficult to make conclusions at this stage.

Second, although the project had uncovered a variety of themes which may be considered universal a number of culturally specific issues were discussed including:

- Cultural identity issues and the need for a sense of historical and cultural belonging
- Dealing with past wounds to do with experiences of racism and internalised racism
- Helping black people come to terms of traumatic experiences of service access
- The importance of fostering cultural pride
- The importance of exposing positive black role models .Specifically, people who have used mental health services and have “recovered”
- Language was also discussed particularly, whether Recovery was an appropriate word and/or concept to use. Many black service users did not feel they suffered from a mental illness but read their experiences spiritually. So far, the research had indicated that the concept of Recovery could be helpful even to those with different cultural interpretations However, cautions were raised with regards to the embedment of the term in language which may not be neutral. In this sense talking about recovery within mental health services rather than recovering from mental health difficulties was more appropriate in order to limit Eurocentric and/or biological assumptions.

Lloyd and A then focused on their personal experiences of recovery and touched upon cultural heritage and identity issues. They stressed that they did not think of themselves as victims but survivors.

A stressed the importance of true friendship and unconditional support. The workshop ended with Lloyd reading one of his poems on Recovery.

# **Forced Migration and Mental Health and Recovery Face 2 Face Workshop**

Facilitator: David Palmer

Notes: Peter Ferns

David opened the workshop by explaining the complex and multi-faceted nature of migration and mental health due to the factors surrounding forced migration such as the experiences of loss, separation from family/friends, exile, war, torture, trauma and imprisonment. The issue of recovery can be contentious in this field as there is a current debate about whether people who experience forced migration can actually ever 'recover' unless they successfully return to their home country.

Recovery in migrants with mental distress would have to encompass a cluster of factors which are practical, social, emotional and cultural. The immigration process itself can be very stressful and along with separation and loss, it can lead to great pressures for people in their everyday lives. David quoted studies that have linked suicides to Home Office decisions and procedures in immigration cases. The existence of wider social factors impacting upon new migrants' mental health means that a more holistic approach to looking at people's needs is required. There must be consideration of the experience of encountering different cultural traditions in a new country along with destitution, detention and denial of access to basic health care in many instances. Issues such as 'trauma' and 'torture' cannot be treated in isolation but must be considered within this wider social context.

Every culture has its own knowledge of human psychology and has stigma attached to mental health problems and such stigma has to be tackled both within and outside of different ethnic communities. In Face 2 Face, recovery takes the form of one-to-one work focused around self-help, developing one's own activities and interests, first language advocacy and mentoring. The model of mentoring employed by the Project is a broad and flexible one which incorporates befriending, general support and language help. The mentors are usually doctors who are themselves newly-arrived migrants and many share similar experiences to those they are working with. The doctors involved often have to wait a period of time to re-train or have their qualifications ratified before they can practice here and this can take some years. So the project provides a useful opportunity for doctors to be undertaking something that is educational and developmental for them on a personal level as well as helping other forced migrants. They often feel challenged by the holistic approach adopted by the Project which may go against their traditional professional medical training.

Referrals to the Project come mainly from the Community Mental Health Team and the Refugee Support Service with the main criterion being that the person must be motivated to join the scheme and 'want to do it'. There is an ongoing evaluation study taking a 'longitudinal' approach, looking at the 'beginning', 'middle' and 'end' experiences of service users. Methods of data collection include the use of questionnaires, one-to-one interviews and focus

groups The outcomes identified so far have been increases in self-confidence, self-respect and self-worth. In fact there have been some remarkable gains for 'mentees' from the scheme highlighting the importance of cultural understanding and first language approaches. One clear finding so far is that further work needs to be undertaken in reducing stigma in the refugees' own communities.

We then viewed a short video about the Project containing statements from the service users of the scheme as well as the doctors providing mentorship to the service users. There was a heart-rending account from one woman 'mentee' who described how she witnessed the killing of her sister by a policeman in her country and the subsequent distress she experienced. She felt that she was not understood and looked down upon until she joined the Project and gained her self-confidence back. There were also several doctors who described the profound impact their work as mentors had had on them and the learning they had gained from operating in more ways than purely medical roles. The importance of cultural understanding, working in first language and above all listening actively to people was highlighted.

Following the video there was a lively and wide-ranging discussion about the implications of the Project for work with forced migrants, refugees and asylum seekers; the mutual benefits for mentors and 'mentees' and the under-usage of the skills and capabilities of this group of migrants in the UK. David emphasised the importance of training for the project volunteers around a social model approach to mental health to counteract other forms of professional and medical training mentors may have received previously. The issue of mentors being doctors was raised and it was agreed that the same approach could be used for any group of migrants who wished to volunteer in providing support to their peers who may be experiencing mental distress. Several of the doctors who have been through the scheme had expressed a new interest in working in the mental health field as well, which was another beneficial spin-off for the project. The issue of how effective such doctors could be in the mental health field and how they could be assisted in spreading their expertise in culturally appropriate practices was discussed. In the current climate of attitudes to migrants and doctors from abroad it was agreed that there would be many barriers to overcome.

The project is funded for a further six months and has attracted much praise and attention, even on an international basis with queries from America and Australia. It is hoped that the video being produced will attract further funding for the project. There is more work to be done in challenging stigma in the various migrant communities and to question some of the simplistic diagnoses being given to migrants in mental distress such as 'Post Traumatic Stress Disorder'. Examples of how stigma operates were given such as in the work of interpreters who may be prejudiced against migrants who are seen as 'mentally ill' or 'mad'. Other wider social and cultural factors must be tackled such as shock, stress, isolation, poverty, lack of support, and misinterpretation and misdiagnosis of culturally appropriate forms of expression of emotions. The overall message was that there needs to be more positive engagement of migrant communities to foster self-help and tap into the enormous potential

and skills in those communities. This would not only be empowering for the communities concerned but would also be economically more efficient.

## **The Hikmat Project “Like Suffer in a Dark Fridge”**

Facilitator: Fiona Hutton

Notes: Jean Healy

The Hikmat BME Centre is aimed at members of black and ethnic minority communities in Exeter and surrounding areas and was started two years ago in response to research undertaken by the founders for Devon County Council and Age Concern entitled “Removing the Barriers: meeting the needs of minority ethnic elders in Exeter”. The research looked at health and social care needs of local older people from minority ethnic groups. The Hikmat Centre has recently run, in partnership with the University of Central Lancashire (UCLAN), a mental health mapping exercise, and has been identifying and training researchers from among the minority communities. The project was co-ordinated by Fiona Hutton, and the workshop title “Like suffer in a dark fridge” was the response of a participant to the question “Do you want to say anything else about what it is like having a mental health problem and coming to live in Exeter?” The weather is a nasty shock for many people coming from the southern hemisphere, and other regions, and has significant impact.

The project looked at experiences that people had during mental illness, where they went for help and their experience of using statutory services. Fiona said that Exeter was perceived to be a quiet, middle class area with an embedded BME community, with a parallel to Cambridge. The results of their research surprised everyone.

The workshop started with a task. Based on the book “The Kite Runner” we had to imagine ourselves in a pitch black hole in an oil tanker, with several other people, escaping over the border into Pakistan. The main character in the book describes the fear, and the only thing that he could see was a tiny light from his father’s watch. We were asked to draw – no words allowed – this scenario. We then took someone else’s drawing and gave our own interpretation to the group. Fiona asked how we found the task and most people found it very hard to interpret someone else’s feelings - and to hear their own drawing being interpreted wrongly.

Fiona said that it was very hard listening to stories and interpreting other people’s problems, especially if they found it even harder than usual to articulate these because of language problems. It is very easy to misinterpret people’s stories, and put our own slant on the tale.

Communication was difficult even in embedded communities, some of whom had been in England for 40 years, but did not have much grasp of the English language, particularly written English. Poor communication was cited as being the biggest barrier to take-up of services. It totally undermined confidence. Many people did not write in even their first language. For example, although most people living in China speak Cantonese, not many people actually write it. Fiona said it was a waste of time producing leaflets,

and that the money could be better spent on information events that include entertainment or refreshment as an incentive or reward. Such events can really help capacity building, as well as imparting the information, or consulting a stakeholder group, much more effectively.

### **Statistics**

The statistics from Exeter were alarming.

27.3% of whites people in Exeter lived in houses either overcrowded or without central heating, but 36.8% of non whites did.

Out of 76% of people surveyed living in the UK for more than 5 years, only 40% considered themselves fluent in English, and only 28% were comfortable with written English.

### *Perceived Causes of Mental Ill Health*

Men put sexual assault as top of their list

Women put sexual assault as 5<sup>th</sup> in their list – reasons could be honour based

Women rated social isolation as 2<sup>nd</sup> whilst men rated social isolation 5<sup>th</sup>.

One third of those surveyed had been separated from their families.

Just less than one quarter had experienced war

Two thirds experienced discrimination and 36% racial abuse

### *GP Services*

Whilst 93% of people were registered with a GP in Devon, 65% of people who had contacted their GP in relation to mental health issues were satisfied with the service, but only 25% actually consulted their GP

### *Communication*

38% described communication with their GP as difficult because of language difficulties – felt that GPs acted as if they understood, but didn't really  
85% were not offered an interpreter and only 2 were offered a leaflet in their own language.

The Hikmat Centre has produced a monitoring form (below) which sets down a number of ways that the lives of service users can be improved. Many of these sought after outcomes are oriented to mental well-being. By recording the numbers of participants of a given activity or resource, estimates can be made as to the effectiveness of interventions. This can include walking – increasing confidence and orientation, and decreasing social isolation. As a result of this list, much valued evidence has been built up in 6 months, evidence which is quantitative and transferable.

### *Senior Council*

Hikmat are taking advantage of a pilot government project whereby everyone aged 50 plus has been invited to join a Senior Council, to act as a 'critical friend' to the statutory agencies. The programme they are devising has engaged almost all their service users and given confidence through

workshops where their team of translators gets people's voices heard and recorded.

Thousands in the community meet up and their decisions are fed into city councils, county councils and the NHS. Devon County Council received almost a million pounds to start this project.

These people are encouraged to talk, to practice using and understanding the language – the emphasis is on fun, and rather than using money to print leaflets, groups are taking on outings. As they get more practised in the language, more and more sit on different panels and get a voice. Through the Hikmat project 38 people will talk to the Senior Executive at Exeter and Devon Councils – this has taken 6 months only for them to reach this degree of communication. This has a great personal effect and aids in their everyday lives.

Fiona said there was much funding in place for user-led projects – they started with £200 and 20 people, and this year have a bid in for £100,000 funding for a project to run in North Devon next year.

### **Lessons learnt**

To take professionals out of picture and relinquish control and power.

Once you have a venue and things in place – override obstacles to prevent people coming. We should value the amateur. One suggestion was to reward people for their time, for example with high street vouchers which are available at the Post Office or on line, or by making sure there is a good entertainments section in the event budget which could contribute to a trip out at another time. Nottingham PCT and Rethink were identified as organisations with good policy regarding this.

**Hikmat Performance Management Framework**

Year:

Month:

OUTCOMES	ACTIVITY ENGAGED IN, INFORMATION GIVEN, OR FINANCIAL INVESTMENT MADE	NUMBERS ATTENDING
Decreased social isolation		
Decreased depression		
Decreased apathy		
Increased social skills		
Increased assertiveness		

OUTCOMES	ACTIVITY ENGAGED IN, INFORMATION GIVEN, OR FINANCIAL INVESTMENT MADE	NUMBERS ATTENDING
Increased creativity		
Increased self confidence		
Increased orientation		
Increased awareness of statutory sector services		
Increased awareness of voluntary sector services		

OUTCOMES	ACTIVITY ENGAGED IN, INFORMATION GIVEN, OR FINANCIAL INVESTMENT MADE	NUMBERS ATTENDING
Increased engagement with statutory services		
Improvements in foot-care		
Improvements in nutrition		
Improvements in blood pressure		
Improvements in mobility		
Improvements in diabetes		

## Panel discussion

Notes: Terry Bamford

Frank Keating chaired the panel discussion. He set a time limit of 2 minutes for initial contributions from the panel before opening up the discussion. He noted the various meanings in which the word recovery had been used in the course of the day- as healing, as a personal journey, as freedom from symptoms- and posed the question 'Is Recovery the right word?'

Jan Wallcraft said that while it was a problematic word as recovery was personal and took many different forms, there was no adequate word to replace it. What are we recovering from? She suggested that the transition from isolation, loneliness, loss of power, loss of self-esteem and loneliness to faith, self-esteem, health, life, wholeness was so important that no other word could go in between.

Professor Dinesh Bhugra said that he had serious doubts at first about recovery as a concept but had come round to its use for 3 reasons. First it gave a holistic picture of the individual's journey back to self-esteem. It was different from rehabilitation because it captured the elements of mind, body and spirit as well as social functioning. It was personal and unique recognising the emotions of the individual. Second, it described a return to functioning after a clinical episode. Third, it was different from a fractured leg or a burst appendix as it was seen from an individual's perspective, not as a clinical diagnosis.

Premila Trivedi reiterated her concerns expressed in the morning session. She welcomed recovery as long as it was seen as personal and individual. There was a danger that the widespread adoption of the concept within mental health trusts could lead to a one size fits all approach with work seen as the crucial element in recovery. Recovery had to be about rights and relationships. It was not and should not be seen as a big new idea. It was rather the expression of the social model of mental health.

Professor Phil Thomas said that in a medical sense recovery was the restoration of health. He emphasised the importance of regaining what had once been yours. The word recovery had come from the survivor movement and a survivor, Ron Coleman, had first used the word to capture his own way of understanding. There was however a danger of creeping colonisation. Engagement with the concepts of recovery by mental health professionals was a good thing but a takeover with the dialogue controlled by professionals would be wrong. The meaning of the word had to be negotiated for each individual.

In the wide ranging discussion which followed it was suggested that recovery needed to be seen not only as recovery from a mental health episode but also from the consequences of such an episode- loss of income, possible loss of property, sometimes loss of liberty. People were excluded from society. The individualisation of recovery expressed by the panel did not focus enough on the need for society to change as well.

Peter Lehmann challenged the word recovery. People were different and their responses didn't fall neatly into a category which one word could embrace.

A who had spoken in the morning expressed recovery in a different way. He viewed it in terms of disentanglement and reengagement with the world but viewing it from a different perspective. There was a danger in seeing it only as return to work. It was about regaining purpose and meaning.

Dinesh said that spirituality and community were important parts of the context in which recovery could take place. Recovery was a set of building blocks which were different for different people. Medication, rehabilitation, employment could be building blocks for some people but not for others. As clinicians trained in diagnosis, he and his colleagues needed to find new ways of relating to patients.

This statement led to a challenge from one participant about the arrogance of clinicians purporting to define an illness like schizophrenia. Many people recovered without mental health services at all. There was a danger in pathologising individuals. The problem may be elsewhere in society.

A questioner asked whether the system was capable of dealing with people whose life experience and social expectations were wholly different from our own social constructs.

Premila saw community development and community engagement as vital parts of the process. Professionals had to be more humble and recognise that recovery is from one's life experiences and involves looking at oneself including aspects which were unpleasant like internalised racism.

A questioner from a mental health trust warned that measuring staff against their ability to promote recovery had its dangers in a system which had not previously been geared to recovery.

Dinesh reiterated that recovery was a unique individual process. Culture shaped individualism. What we were about was regaining a satisfactory life which made individuals feel that they were contributing to the social good.

## **Closing summary**

Yvonne Christie thanked SPN for an excellent and invigorating day. She pulled out some key themes- the concept of social recovery, the sense of regaining something which had been lost, the danger of labels and the importance of recognising that individualisation was conceptualised differently in different cultures.

We can change things, she told the audience, but we need to change attitudes and not just words. The adoption of the recovery approach was both challenge and opportunity. Our task was to use the opportunity to reshape services.

## Speakers and Workshop Leaders

**Angela Kandola** has over 11 years of experience of working in the field of Asian Mental Health. As manager of AWAAZ she has been key in developing the organisation into an example of good practice in providing a dedicated professional service to the Asian community of Nottingham. Angela has led on innovative initiatives that have highlighted unmet needs and constructively challenged wider services to develop positive appropriate services. Combined with her mental health experience Angela has worked in the education, independent and private sectors in various roles. Prior to working in mental health, Angela worked in domestic violence with Asian and African Caribbean women whom were fleeing from violent partners, providing them with a safe haven, housing, independence, empowerment and a return back to the community in a safe environment.

**David Palmer** is Deputy Director of the Migrant and Refugee Communities Forum. David's professional and academic career has been in the field of health and social care and he has worked extensively with forced migrants on the institutional and personal issues impacting on individuals and communities. His writing on the health of forced migrants includes a guide for health workers and a number of articles and research papers on the issues of forced migration and mental health.

**Frank Keating** is a Senior Lecturer in the Health and Social Care Department at Royal Holloway University of London where he is Programme Director for the MSc in Social work. Frank contributes to mental health teaching on the social work programmes. He was lead author for the ground breaking report: Breaking the Circles of Fear. He has recently published a health briefing on African and Caribbean men and mental health.

**Guilaine Kinouani** is Community Development worker for Southside Fanon, an Honorary Researcher for South London and the Maudsley NHS Foundation Trust and a Carers group facilitator for the LEO (Early Onset in Psychosis) services in Lambeth. Her main role involves researching the needs of the local Black and minority ethnic population. She is currently leading the Southside Fanon /UCLAN recovery project.

Her background is varied and includes mental health, sociology and psychology. She is currently completing a PhD in Cross-cultural psychology which is enabling her to pursue her interests for cultural issues in mental health.

Guilaine is committed to the Delivering Race Equality in Mental health programme.

**Howard Delmonte** is the Co-ordinator and founder of the Family Support Service at PACE. The FSS provides services to families with children who are gay, lesbian, bisexual or questioning their sexuality. Howard is a qualified systemic couple therapist, arts therapist and group counsellor and at PACE he

has over the past 7 years run various week-end workshops, seminars, trainings and written several articles for journals and periodicals.

**Jerry Tew** is Senior Lecturer in Social Work at the University of Birmingham and co-chair of the SPN Research Group. His research interests and publications have been in relation to social perspectives on mental health, service user involvement and recovery. He is Social Care Lead for the Heart of England Hub of the Mental Health Research Network and has been a member of the MHRN Rehabilitation and Recovery Research Group.

**Jo Beecham** is the Family Support Liaison at PACE, London's leading charity promoting the mental health and emotional wellbeing of the lesbian, gay, bisexual and transgender (LGBT) community. Jo also has a private psychotherapy practice where she does face-to-face work with individuals and couples and online therapy with individuals. She recently returned from New York where she lived for eight years, working at New York University researching the impact of victimization on the lives of LGBT youth. In New York, she saw individuals and couples for psychotherapy and ran groups at the medical clinic, Callen-Lorde and the mental health centre, Rainbow Heights both of which cater specifically to the lgbt community. Jo was actively involved in the aftermath of 9/11, facilitating debriefing sessions with New York City Fire-fighters and Police Officers and later making presentations on the impact of stress and Post Traumatic Stress at different police precincts throughout NYC.

**Jolie Goodman** is an artist and survivor of the psychiatric system; she has an MA in Fine Art from Chelsea College of Art & Design. She has 30 portraits on permanent display in the Boardroom of the Maudsley Hospital in South London. These portraits entitled, '*A Portrayal of the Psychiatric System*', include the chief executive, staff and service users, interrogate and subvert power and accountability within the psychiatric system. She also painted *Madly Famous*, six portraits of celebrity psychiatric users displayed at the mental health charity National Mind's Headquarters in Stratford, London

She is exhibiting four portraits at City Hall: Walter Wolfgang, Labour Party National Executive, Camila Batmanghelidjh founder of Kid's Company, Helen John Greenham Common activist and Brian Haw peace activist in a show called *Rebels & Troublemakers*.

Her experiences of an acute mixed sex ward, in Southwark, led to her co-founding the Campaign for Women Only Psychiatric Wards in 1998. Wards in Southwark were segregated in February 2004. She has been involved in staff training for the past seven years, including training in women's experiences of the mental health system at the Tizard Centre, Royal Holloway & Bedford College, University of Brighton, National Mind and South London and Maudsley Trust. For the past year she has worked as a trainer for Inequality Agenda.

Currently she divides her time between painting, freelance Mental Health Consultancy, working as Southwark Mind's Women's Development Worker and her two children.

**Lloyd Lindsey** is an artist who has interest in drama development .He is currently working as a Community Research Co-ordinator for the Southside Fanon /UCLAN Recovery research project. Lloyd went on a journey to the Gambia on a mission of self-discovery and is devoted to using his learning to empower service users in their quest for identity and recovery.

**Peter Lehmann.** Born in Calw (Black Forest, Germany) in 1950. Education as social-pedagogist. Living in Berlin. Author and editor since 1986, then foundation of Peter Lehmann Publishing and Mail-Order Bookstore. 1989 co-founder of the Association for Protection against Psychiatric Violence (running the Runaway-house Berlin). From 1997 to 1999, Chair of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP), since 2003, board member for the North East European region. 2002, co-founder of *Für alle Fälle* (In Any Case) and board member in this organisation. Member of Mind Freedom International and, since 2002, its designated representative to the United Nations. Since 2004, member of INTAR (International Network toward Alternatives and Recovery). Publications include, *Coming off Psychiatric Drugs: Successful Withdrawal from Neuroleptics, Antidepressants, Lithium, Carbamazepine and Tranquilizers*, edited 2004 / *Psychopharmaka absetzen: Erfolgreiches Absetzen von Neuroleptika, Antidepressiva, Lithium, Carbamazepin und Tranquilizern*, edited 1998, 3., revised edition in preparation for December 2007 / *Liberarsi dagli psicofarmaci: Riuscire con pieno successo a liberarsi da neurolettici, antidepressivi, stabilizzanti dell'umore, Ritalin e tranquillanti*, in preparation for January 2008 / Βγαίνοντας από τα ψυχοφάρμακα: Εμπειρίες επιτυχημένης διακοπής νευροληπτικών, αντικαταθλιπτικών, λιθίου, καρβαμαζεπίνης και αγχολυτικών, in preparation for March 2008. *Alternatives beyond Psychiatry* and *Statt Psychiatrie 2*, both edited in 2007 together with Peter Stastny. More at [www.peter-lehmann.de/inter](http://www.peter-lehmann.de/inter)

**Philip Thomas** is Professor of Philosophy, Diversity and Mental Health in the Institute for Philosophy, Diversity and Mental Health at the Centre for Ethnicity and Health in the University of Central Lancashire. He is also chair of *Sharing Voices Bradford*, a community development project working with Bradford's diverse ethnic communities. After working as a full-time consultant psychiatrist in the NHS for over twenty years, he left clinical practice in 2004 to focus on community development, writing and academic work. His academic interests include philosophy (post-structuralism and critical theory), and their application to psychiatry, especially social and cultural psychiatry, psychology and medicine. He is also interested in narrative and the moral and ethical problems of representation in medicine and literature. He is particularly interested in the practical value of narrative in 'recovery' from psychosis. He has developed alliances with survivors of psychiatry, service users and community groups, locally, nationally and internationally, and is well known for the column he wrote with his colleague Pat Bracken in *Open Mind* magazine, called *Postpsychiatry*. He is a founder member and co-chair of the Critical

Psychiatry Network in Britain. He has published well over 100 scholarly papers. Free Association Books published his first book, *Dialectics of Schizophrenia*, in 1997. His second book *Voices of Reason, Voices of Insanity* written with Ivan Leudar and published by Brunner-Routledge in April 2000, examined the different meanings attached to the experience of hearing voices over 2,500 years of Western culture. Oxford University Press published his third book, *Postpsychiatry*, co-authored with Pat Bracken, in 2005.

**Premila Trivedi** is many things, including an Asian long-term user of MH services. For many years she was a 'good' patient but over the last ten years has found herself on a journey of discovery/recovery, become much more challenging to services and is learning to do life better. Because of her personal experiences, Premila has a particular interest in how issues of 'race' and culture are addressed (or not) within MH services and has written several book chapters and articles on this. She currently works as a freelance service user trainer and part-time as a trainer in the Education & Training Dept of a large MH Trust.

**Raza Griffiths** is a survivor who uses his experiences within the mental health system to inform his work as SPN Joint Network Co-ordinator.

Raza's multiple mental health interests are reflected in the key role he has played in organising recent SPN study days on mental health and employment, spirituality, the White Paper Our Health Our Care Our Say and finally, recovery and diversity. He actively campaigned around the Mental Health Bill (now Act) and has now shifted his attention to the Act's Code of Practice.

He is passionate about survivor representation and also diversity issues and is an experienced trainer who has delivered mental health and diversity training to the NHS, local authorities and Kent Police.

Outside SPN, Raza is the South East regional Co-coordinator for Open Up and is also an Expert Adviser for SHIFT. This continues his active involvement in stigma busting around mental health, which started when he was Training Officer at Media Bureau, a national survivor led project which delivered media skills training and support to over 300 survivors who got their voice heard in the national and regional media to challenge stigma and discrimination around mental health issues.

When not juggling his three jobs, Raza enjoys cycling, swimming, meditation, eating and cooking and travelling in unusual locations.

### **Rob Gee**

Performance poet, comic and reformed psychiatric nurse, Rob has clocked up over 1500 shows across venues and festivals in Australia, North America and Europe. He has worked with many people who use the mental health services and continues to work closely with mental health organisations.

**Rufus May** works as a psychologist in Bradford Adult Mental Health. He has an interest in holistic approaches to mental health problems. He is one of the facilitators of a hearing voices group and several self help groups in Bradford.

He is one of the organisers of Evolving Minds a monthly public meeting that explores different approaches to mental health. Rufus is open about his own experiences of psychiatric detention and treatment when he was eighteen years old. He is interested in education and media initiatives that will make society more compassionate and open-minded in its approach to people's distress and confusion. Rufus has some articles available at Bradford's Centre for Citizenship and Community Mental Health website.  
<http://www.brad.ac.uk/acad/health/research/cccmh/articles.php>

**Tanya Kennard-Campbell** is an experienced registered mental health nurse, Recovery and principle based trainer.

Tanya runs her own consultancy business (Freemind consultancy) delivering training and consultancy to individuals, communities and organisations, her substantive contract is as programme manager for CSIP Eastern's Whole Life programme.

Tanya has spent 15 years working in Aotearoa (New Zealand) and particularly enjoyed working from the different cultural frameworks of the peoples of this country. These perspectives challenge mainstream meanings in Mental illness and offers new ways and meanings in people's distress.

**Vicky Nicholls** is one of two joint coordinators at SPN. She also works as a freelance trainer and researcher in health and social care, specializing in spirituality and mental health. Prior to this she coordinated Strategies for Living II, a user-led research project, at the Mental Health Foundation, and a national Project on spirituality and mental health in partnership with NIMHE and Professor Peter Gilbert. As a new mum she experienced postnatal depression and is now the mother of a lively and thriving three year old with a particular interest in research and practice on issues around transition, parenthood and family wellbeing.

**Yvonne Christie** lives in South East London and has been an advocate for improved changes in mental health services for 2 decades now. Yvonne has spent many years looking at addressing inequalities in a range of services with changes in mental health being a key development area. A case in point is working on 'Breaking the Circles of Fear' (SCMH) and Black Spaces (Mental Health Foundation). Yvonne works as an independent consultant and is currently looking at Recovery in relation to Black and Asian people in collaboration with Catch-Afiya and other independent consultants.

## Our Partners

**The Social Care Institute for Excellence (SCIE)** was established by Government in 2001 to improve social care services for adults and children in the United Kingdom. It achieves this by identifying good practice and helping to embed it in everyday social care provision.

SCIE works to disseminate knowledge-based good practice guidance; involve service users, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care; enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.

With Care Services Improvement Partnership and the Royal College of Psychiatrists, SCIE produced 'A Common Purpose', a joint position statement on recovery.

**Delivering Race Equality in Mental Health Care (DRE)** is a comprehensive action plan for eliminating discrimination and achieving equality in mental health care for all people of Black and minority ethnic (BME) status. It is based on three building blocks:

- More appropriate and responsive services - achieved through action to improve mental health care for black and minority ethnic patients, developing a more culturally capable workforce, and finding new pathways to care and recovery.
- Community engagement - achieved by engaging communities in planning services, and supported by 500 new community development workers and the expertise of independent sector BME service providers.
- Better information - from improved monitoring of ethnicity, better dissemination of information and good practice, and by improving knowledge about effective services. This includes the new regular census of mental health patients covering their ethnicity, faith, legal status and more.

**Sexual Orientation and Gender Identity Advisory Group - SOGIAG** is developing a new strategy for the Department of Health to promote equality and eliminate discrimination for Lesbian, Gay, Bisexual and Transgender (LGBT) people in health & social care (as both service users and employees).

It places at the centre of its work LGBT people who use and deliver health and social care services, in order to ensure opportunities for their experiences to inform service development and improvement.

Its work is underpinned by,

- a commitment to equality, human rights and social justice;
- a respect for diversity;
- and a commitment to challenge discrimination and exclusion within the organisations and communities on whose behalf we are working.

### **Workstreams**

There are four key workstreams: Better employment, Inclusive services, Transgender and Reducing health inequalities.

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