



*Service Users in Research*  
Mental Health Research Network



**National Institute for  
Health Research**

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## **Service Users in Research Bulletin**

### **Issue Eighteen: October 2011**

This is the eighteenth edition of the bulletin that we send out to members via post or email. In these bulletins we provide news about mental health research and advertise user involvement opportunities and events in the NIHR Mental Health Research Network (MHRN). We also advertise opportunities for people to get involved in mental health research with other organisations.

**If anyone has anything that they would like to be in the bulletin or if you would like to join Service Users in Research then please let us know. You can email us at: [mhrnppi@kcl.ac.uk](mailto:mhrnppi@kcl.ac.uk).**

**To join Service Users in Research please fill out the membership form which is sent out alongside this email. You can also join online at:**

**<http://www.mhrn.info/pages/join-service-users-in-research-online.html>**

**These bulletins are additionally placed online at [www.mhrn.info](http://www.mhrn.info)**

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***Please note that for events organised by MHRN hubs or local NHS trusts, travel expenses are usually only able to be offered to people living in the area covered by that hub or NHS trust. Please always check beforehand.***

## **SUNLOWS Seminars 2011**

The service-user consultants attached to the North London Hub of the Mental Health Research Network are organising a series of seminars showcasing some of the most interesting and up-to-date mental health research. The seminars aim to inform service-users and carers in North London, West London, North East London, Central and East London, Essex, Hertfordshire, Berkshire, and Oxfordshire (all regions covered by the Hub) about the latest research being undertaken in mental health. We will provide both professional and service-user perspectives on the following topics:

**Friday 28<sup>th</sup> October 2011- 2pm to 4.30pm**

### **An investigation of the impact of introducing Individual Placement and Support in a mental health catchment area**

Speakers: Bryn Lloyd-Evans (UCL), the former study lead researcher (Camden and Islington NHS Foundation Trust), along with David Hindle (service user researcher). Employment rates of people with severe mental health issues are very low and have fallen over the past few decades. Individual Placement and Support (IPS) helps people find and keep jobs. Studies in the USA have shown that IPS is successful in increasing employment, but UK studies suggest possible difficulties in finding people willing to use the scheme. This seminar will discuss the ongoing WISE study, which aims to find out how much difference IPS makes when introduced into an area (Camden), and how to maximise its success. In addition, the seminar will examine the role of service user researchers in the study.

All seminars will be held at the offices of the MHRN North London Hub, Imperial College, The Claybrook Centre, St Dunstan's Road, London W6 8RP. Please email or call Rosie Evans at: [r.evans@imperial.ac.uk](mailto:r.evans@imperial.ac.uk) or 02073861145 to register. Seminars will take about 2 hours with at least 1 hour for discussion. Tea, coffee, and biscuits will be served at 2pm and, for those with excess energy, we will continue the debate and networking afterwards in a local pub or cafe. Further details regarding future seminars will be available soon. The SUNLOWS website ([www.sunlows.org.uk](http://www.sunlows.org.uk)) contains information about mental health research being carried out in the North London area and is maintained by people with experience of mental health problems who work with the hub.



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## **Would you like to get involved with INVOLVE?**

## **We are looking for new members**

INVOLVE has a key national role supporting public involvement in NHS, public health and social care research. We are looking for people with an understanding and experience of public involvement in research to join our Working Groups. INVOLVE has around 30 members with a range of skills and backgrounds.

INVOLVE is funded by and is part of the National Institute for Health Research (NIHR).

# **INVOLVE**

Supporting public involvement  
in NHS, public health and  
social care research

## Who are we looking for?

- **Members of the public**, including patients and potential patients, carers, people who use health and social care services, disabled people.
- People from **voluntary sector organisations** which represent people who use health and social services.
- People from **NHS, local authority and research organisations** with commitment and ability to promote public involvement in NHS, public health and social care research.

We value diversity and welcome applications from all sections of the community.

## What is involved?

- Participation in four meetings a year, mainly in London.
- Opportunities for undertaking other activities for INVOLVE as agreed.

Your expenses for INVOLVE activities will be covered. If you are appointed as a public member and are not employed full-time in the public sector, you may also claim a committee fee.

## How can I find out more?

Look at our website [www.invo.org.uk/Membership.asp](http://www.invo.org.uk/Membership.asp)

This has more information and Frequently Asked Questions which we will update during the application period.

### Get a Membership Information and Application Pack

You can download a pack from our website or contact us to have one sent to you:

Tel: 02380 651088 (Text phone: 02380 626239)

Email: [membership@invo.org.uk](mailto:membership@invo.org.uk)

### Attend a Membership Information Meeting

<b>Tuesday 4 October 2011</b>	<b>Bristol</b>
<b>Thursday 13 October 2011</b>	<b>Manchester</b>
<b>Monday 17 October 2011</b>	<b>London</b>

The meetings are an opportunity to meet some current Working Group members, find out more about being a member and get advice on how to apply. Places are limited - **you must book in advance**.

It is not essential to attend one of these meetings to apply for membership. Information provided will also be available on our website.

For more information about the Membership Information Meetings and to apply for a place, please contact Professional Briefings on [www.profbriefings.co.uk/involvemim](http://www.profbriefings.co.uk/involvemim) or call 01920 487 672.

The closing date for all applications is **12 noon on Monday 31 October 2011**

If you would like any of this information in a different format please contact us.

[www.invo.org.uk](http://www.invo.org.uk)

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[www.mhrn.info](http://www.mhrn.info)  
[www.sunlows.org.uk](http://www.sunlows.org.uk)



**NHS**

**National Institute for  
Health Research**

## INVOLVEMENT MERGER

### NORTH MEETS SOUTH

The North London and the South London & South East Hubs of the NIHR Mental Health Research Network (MHRN) are excited to announce that their Patient and Public Involvement (PPI) activity is merging.

By combining the expertise and experience of both Hubs there will be more opportunities for service users and carers to get involved with research and to meet other members.

Both Hubs will be aiming to:

- organise away days
- host SUnLOWS Seminars
- seek involvement with the FAST-R service
- provide opportunities to sit on advisory panels and attend management committee meetings
- provide opportunities to get involved with research projects.

This merge will come into effect immediately but please bear with us during this process. If you have any questions with regards to this, please do not hesitate to contact Stu or Jemma at either hub (details above).

The Mental Health Research Network is part of the National Institute for Health Research and supports studies in England.



*Mental Health  
Research Network*

# Book Review



## Alternatives Beyond Psychiatry

Edited by Peter Stastny & Peter Lehmann

Published by Peter Lehmann Publishing (RRP £17.42)

ISBN: 0954542819

*What helps me if I go mad? How can I find trustworthy help for a relative or a friend in need? How can I protect myself from coercive treatment? Where can I talk to like-minded people about my own experiences with psychiatry and about my life? What should I do if I can no longer bear to work in the mental health field? What are the alternatives to psychiatry? How can I get involved in creating alternatives? Assuming psychiatry would be abolished, what do you propose instead?*

These are the questions addressed in this eclectic collection of articles which features contributions from over 60 authors, from across five continents. Contributors include service users, carers, psychiatrists, therapists, academics and lawyers, all of whom share their views and experiences of psychiatry and reflect upon the issue of how viable, successful alternatives models of mental health care and support can be provided.

The articles have been compiled by German compatriots; Peter Lehmann and Peter Stastny, both active campaigners for alternative mental health services. Lehman is a survivor and mental health activist. Stastny is an Associate Professor of Psychiatry at the Albert Einstein College of Medicine in New York and also one of the founders of INTAR – the International Network Toward Alternatives and Recovery.

Whilst the book is a considerable 430 pages long, this shouldn't put off potential readers. It is usefully organised under relevant section headings and individual articles are short and accessible. Sections include:

- Why Psychiatry Hurts More Than It Helps
- Actual Alternatives
- Organised Self-Help
- Models of Professional Support
- General and Specific Beneficiaries of Alternative Approaches
- Realizing Alternatives & Humane Treatment
- Why We Need Alternatives to Psychiatry

The contributors, span a range of backgrounds, ages, cultures and perspectives but are united by their sense of alienation in relation to mainstream psychiatry and by their shared conviction that mental health care needs to move beyond the limited psychiatric models on offer to provide a far broader choice of support options which uphold peoples' right to determine what will help and hinder them in their journey towards wellness.

The title of the book led me to expect an angry denunciation of psychiatry and indeed much of what is written emanates from a position of; at the very least, extreme dissatisfaction with the western psychiatric system and the limiting and often oppressive nature of the bio-medical paradigm. What emerged, as I began to read however, was a collection of largely positive and uplifting perspectives; of authors keen to share their personal stories of having discovered innovative and creative alternative approaches which work well for them.

I found all of the articles in this collection fascinating reading and experienced a whole gamut of emotions on the journey through them. A number stood out for me in particular though: I was greatly moved by 90 year old, Dorothea Buck-Zerchin's brave and harrowing account of the inhumane treatments she endured and witnessed in German psychiatric institutions from the age of 19. Her story of enforced sterilisation, ice water treatments, restraint and sedation truly brought home to me why the 'survivor' movement has been so named. Given her experiences it is a damning indictment of the current psychiatric system that Buck feels that years of "progress" have still not overcome many of the most inhumane elements of care and dehumanising attitudes in psychiatry.

Rousing reading also, was Kate Millett's provocatively titled 'The Myth of Mental Illness'. In this powerful rhetorical piece Millett examines from a legal perspective, the extraordinary powers of the state over the individual with respect to mental health, seeking to understand how Western society has arrived at a point where it is accepted that Psychiatry can and should act an agent of social control.

In later sections I was impressed by various accounts of user-led projects which have established successful alternative models. These include a number of accounts of Soteria and Soteria-inspired communities whose members support each other through episodes of altered consciousness, crisis houses such as Hotel Magnus Stenbock in Sweden and the Berlin Runaway House, which provide a place of sanctuary to those in mental distress. Also, user groups who have taken a holistic and de-pathologising approach to mental health experiences, replacing negative medical terminology and approaches with more positive language and perspectives which more accurately reflect peoples lived experience. In this regard I was inspired by Maryse Mitchell-Brody's account of 'The Icarus Project' in the US, whose members have created a new culture and language around bipolar disorder, describing it as a "dangerous gift" which imbues them with many positive abilities and attributes including, creativity, empathy, energy and sensitivity. Mitchell-Brody compellingly describes how this approach has enabled members of the project to become more accepting of themselves and able to use their past experiences and insights in positive ways to help others who struggle with extreme mood states. Also, noteworthy in this context is Rufus May's description of his involvement in establishing 'unusual belief groups' and 'Evolving Minds Public Meetings' in the UK with people who hear voices or have beliefs the psychiatric profession would define as 'delusional'. Framing the account in relation to his personal experience of being a 'mental health patient' who went on to discover meaning in his past belief that he was a Spy, May describes how these groups and events encourage people to explore their experiences in a myriad of different ways, using the meaning they find in them to learn to live with their voices and beliefs rather than seeking to suppress them.

'Alternatives Beyond Psychiatry' could be categorised under many headings; self-help guide, personal memoir, historical critique, intellectual treatise and political manifesto to name but a few, with articles often embodying a combination of these forms. Above all, for me, this wonderful book is a celebration of what has and what can continue to be achieved by those associated with the service user/survivor movement; people who

have taken their negative, often tragic, experiences of the psychiatric system, of extreme mental states and mental suffering and used them as a force for good, a springboard to find and create alternative approaches, which have enabled them and others to understand and live well with 'madness'. In the tradition of the very best work which has taken place within the survivor/service user activist movement, these authors collectively seek to reclaim 'madness', redefining it as that which lies within the universal spectrum of human experience and that, which if approached with humanity and understanding can both strengthen and inspire.

Kirsty Stevenson-Turner    Service User Researcher

## Would you like to review a book for us?

If you would like to review a book for us then please let us know. The book needs to be on a mental health topic (ideally vaguely related to research, mental health services etc). If you do have any ideas of a book that you would like to review for the Bulletin then please let us know. If you write a review for us, we will buy the book for you, and we will give you a £25 Amazon voucher as a token of our appreciation. Please email [mhrnppi@kcl.ac.uk](mailto:mhrnppi@kcl.ac.uk) if you have any suggestions.

## New Scientist article on personality disorders



A really good article on personality disorders appeared in the August 27<sup>th</sup> edition of the New Scientist. You can read the article in full by clicking [here](#). Fenella Lemonsky, who works with the MHRN's North London hub is quoted quite extensively in the article.

## Mental Health Research in the News

### Schizophrenia and epilepsy have 'strong link'

'People with schizophrenia are six times more likely to develop epilepsy, says a study which finds a strong relationship between the two diseases'

See: <http://www.bbc.co.uk/news/health-14948264>

## Brain 'rejects negative thoughts'

'One reason optimists retain a positive outlook even in the face of evidence to the contrary has been discovered, say researchers'

See: <http://www.bbc.co.uk/news/health-15214080>

The BBC picked up on this study from a research team from University College London. The original research paper entitled 'How unrealistic optimism is maintained in the face of reality' has been published online in the journal [Nature Neuroscience](#).

If you do have access to the journal then you can access the paper by clicking [here](#). I'm not going to say too much about the research itself as the Wellcome Trust have produced a rather good press release about the findings together with a short film. The press release is reproduced below:

### Brain imaging reveals why we remain optimistic in the face of reality

*(This press release has been reproduced with kind permission from the Wellcome Trust)*



The Wellcome Trust have produced a short film about the research which can be viewed by clicking [here](#)

For some people, the glass is always half-full. Even when a football fan's team has lost ten matches in a row, he might still be convinced his team can reverse its run of bad luck. So why, in the face of clear evidence to the contrary, do some people remain so optimistic about the future?

In a study published today in 'Nature Neuroscience', researchers at the Wellcome Trust Centre for Neuroimaging at UCL (University College London) show that people who are very optimistic about the outcome of events tend to learn only from information that reinforces their

rose-tinted view of the world. This is related to 'faulty' function of their frontal lobes.

People's predictions of the future are often unrealistically optimistic. A problem that has puzzled scientists for decades is why human optimism is so pervasive, when reality continually confronts us with information that challenges these biased beliefs.

"Seeing the glass as half-full rather than half-empty can be a positive thing - it can lower stress and anxiety and be good for our health and well-being," explains Dr Tali Sharot. "But it can also mean that we are less likely to take precautionary action, such as practising safe sex or saving for retirement. So why don't we learn from cautionary information?"

In this new study, Dr Sharot and Professor Ray Dolan from the Wellcome Trust Centre for Neuroimaging, together with Christoph Korn from the Berlin School of Mind and Brain, have shown that our failure to alter optimistic predictions when presented with conflicting information is due to errors in how we process the information in our brains.

Nineteen volunteers were presented with a series of negative life events, such as car theft or Parkinson's disease, while lying in a functional magnetic resonance imaging (fMRI) scanner, which measures activity in the brain. They were asked to estimate the probability that this event would happen to them in the future. After a short pause, the volunteers were told the average probability of this event occurring. In total, the participants saw 80 such events.

After the scanning sessions, the participants were asked once again to estimate the probability of each event occurring to them. They were also asked to fill in a questionnaire measuring their level of optimism.

The researchers found that people did, in fact, update their estimates based on the information given, but only if the information was better than expected. For example, if they had predicted that their likelihood of suffering from cancer was 40 per cent, but the average likelihood was 30 per cent, they might adjust their estimate to 32 per cent. If the information was worse than expected - for example, if they had estimated 10 per cent - then they tended to adjust their estimate much less, as if ignoring the data.

The results of the brain scans suggested why this might be the case. All participants showed increased activity in the frontal lobes of the brain when the information given was better than expected; this activity actively processed the information to recalculate an estimate. However, when the information was worse than estimated, the more optimistic a participant was (according to the personality questionnaire), the less efficiently activity in these frontal regions coded for it, suggesting they were disregarding the evidence presented to them.

Dr Sharot adds: "Our study suggests that we pick and choose the information that we listen to. The more optimistic we are, the less likely we are to be influenced by negative information about the future. This can have benefits for our mental health, but there are obvious downsides. Many experts believe the financial crisis in 2008 was precipitated by analysts overestimating the performance of their assets even in the face of clear evidence to the contrary."

Commenting on the study, Dr John Williams, Head of Neuroscience and Mental Health at the Wellcome Trust, said: "Being optimistic must clearly have some benefits, but is it always helpful and why do some people have a less rosy outlook on life? Understanding how some people always manage to remain optimistic could provide useful insights into what happens when our brains do not function properly."

The research was funded by the Wellcome Trust, the British Academy and the German Academic Exchange Service.

## Some more events ...

It's the start of the academic year for most universities and colleges throughout the country. That means that there are a lot of talks and events happening. These events are not all mental health related. I've listed some of these below. If anyone knows of any events outside of London that might be of interest then please do let us know.

## The London Science Festival



Free events are happening across London from October 17-26<sup>th</sup>. Have a look at the website for further details:

<http://www.londonsciencefestival.com/2011/>

Despite the image on the website to the left there are actually talks on wide variety of subjects.

### **When will we understand Autism Spectrum Disorders?**

This is the Royal Society's Rosalind Franklin prize lecture which will be held on October 26<sup>th</sup> 2011 at 6.30pm at the Royal Society in London. Click [here](#).