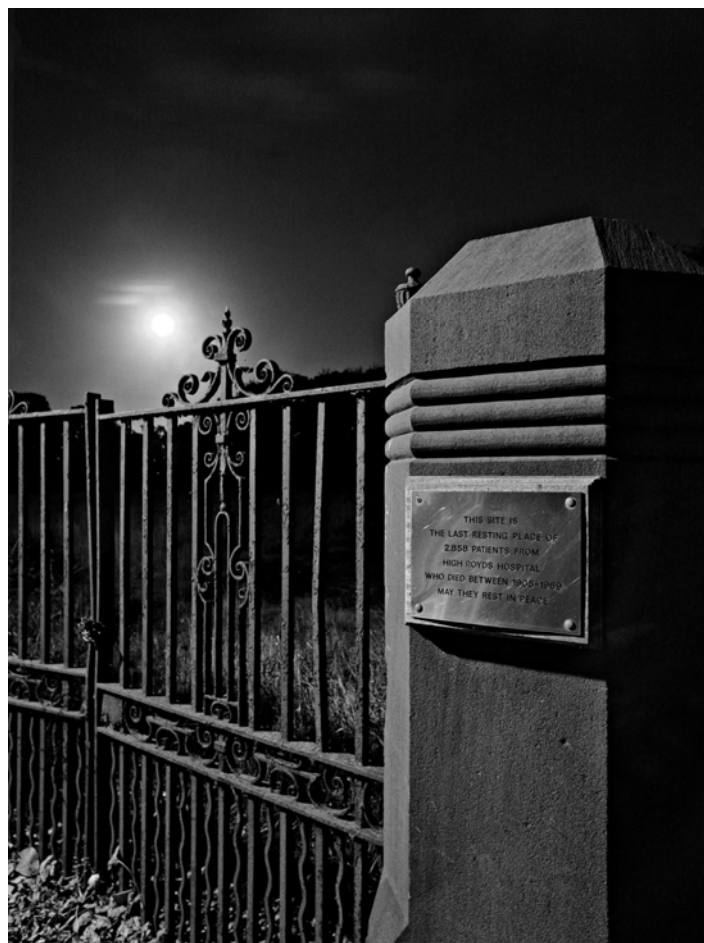


Winter 2009

The Advocate



Magazine of the UK Advocacy Network
The independent national user-led mental health organisation

News from the trustees

Following a successful AGM on 1st September, Terry Simpson, Peter Munn, Graham Estop, Carol Jenkin, Robert Hailes, Alisdair Cameron, and Andrew Wetherell were returned as trustees for the network. Justine Morrison continues to work as a volunteer.

At our first trustee meeting on 22nd October, Graham agreed to become our new company secretary and Robert agreed to continue as treasurer for another year after which he would like to stand down - so if you know any good treasurers, please do get in touch. Terry Simpson and Peter Munn continue as chair and vice-chair respectively.

Our next face-to-face meeting, to be held in Sheffield, will be a team building and future planning exercise. This could be an open meeting if people would like to meet the new management committee or make a contribution to our planning. Unfortunately, our current resources will not extend to paying expenses for this.

One of the ideas for future development is to explore the possibilities of working in the social enterprise arena, perhaps developing a social firm that may help support UKAN financially.

We are working with the National Survivor User Network (NSUN) and the Service User Survivor Trainers Network (SUSTN) on their user training work towards building capacity in the user movement. We hope to be able to promote a programme of user training initiatives in the next edition of The Advocate.

We are also investigating the possibility of some work around Independent Mental Health Advocacy with Nottingham University.

A team of people from the Welsh Assembly is further consulting on the Welsh Measure which will be put forward and, if successful, will be in place by the end of the financial year 2010. We attended a meeting in Aberystwyth following the

Cymar/UKAN submission of evidence to the Legal Competence Order some time ago. The most important change as far as advocacy is concerned is that they are proposing advocacy for all psychiatric hospital patients and not just those on detention. Further measures can be introduced after this first attempt and there is a commitment to move towards 'advocacy for all' as and when it is affordable, which unfortunately reflects the current financial climate.

An important Advocacy Wales conference and AGM entitled "Energising the Advocacy Movement in Wales" was held on November 12th. I plan to report on this in the next issue of The Advocate.

We are also actively involved in representation at the Advocacy Consortium UK and the Mental Health Alliance.

As you can see from my article on international networking (pages 12 & 13), we have been continuing our involvement with the World Network of Users and Survivors of Psychiatry (WNUSP), fulfilling our role as a board member at meetings and through communication.

Peter Munn

Thank you to all UKAN members, friends and allies

We'd particularly like to thank Hywel Davies who very generously donated £500 towards the printing and distribution of this edition of The Advocate. Thanks are due also to Brian Bertie, former volunteer worker and long time supporter of UKAN, for his recent donation. As always, many thanks to everyone who has contributed articles and photographs for The Advocate.

If you, or your group, would like to submit an article for the next edition, please contact us at: **UKAN, 8 Beulah View, Leeds, LS6 2LA** or **office@u-kan.co.uk**

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Cover photograph: by Mark Davies

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The Advocate seeks to publish a wide range of information and opinions. These are solely the authors' responsibility and in no way represent the views of UKAN as an organisation.

Friends of UKAN

The UK Advocacy Network (UKAN) is a network of groups that exists to promote and campaign for independent user led advocacy for all mental health service users and meaningful involvement of users in all aspects of mental health service planning and delivery. Since 1993 we have promoted good practice and the development of advocacy standards through our magazine *The Advocate*, our website and web forum, and a series of publications.

UKAN also aims to be a national voice promoting the human rights of all mental health service users and has played a major role in developing the 'user movement' in the UK during this time, supporting all initiatives which promote the views of survivors/service users.

Although essentially a network for groups, we would like to invite individuals who agree with our aims to support us by making a donation, or taking out a monthly standing order, thereby becoming a Friend of UKAN.

What will being a Friend of UKAN entitle me to?

If you do not already receive it, we will send you a copy of *The Advocate*. We will also include you in any consultations or debates about the organisation, advocacy, or wider mental health issues and in any campaigns we may from time to time be involved in.

I would like to be a Friend of UKAN

Name _____

I enclose a one-off payment of _____
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YES / NO
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Postal address _____

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UKAN's Annual General Meeting

by Terry Simpson



Peter Munn and Terry Simpson (AGM photographs by Graham Estop)

UKAN's Annual General Meeting was held on September 1st at The Circle in Sheffield. Prior to the meeting around twenty people saw a DVD of Louise Pembroke's extraordinary ballet, 'Dedication To The Seven', about the experience of living with what is labelled as 'psychosis', specifically hearing voices and seeing visions. Tom Halloran from Leeds Survivor Poets then gave a reading.

The current Chair, Terry Simpson reported on another difficult financial year, where our income (a total of £4,549) has mainly been from sales of literature, group subscriptions, donations, and from an evaluation we have done for one of our member groups. We continue to be represented on various bodies, including the Advocacy Consortium UK, and at meetings with the Equality and Human Rights Commission, (including with the Equality Minister, Jonathan Shaw. The EHRC are piloting an evaluation of advocacy re personalisation). Our relationship

with the National Survivor and User Network improved with some dialogue, and UKAN became a member of that network.

An issue of *The Advocate*, edited by Justine Morrison and funded by the O'Hara Charitable Trust, came out in the Spring of 2009, and was well received. We continue to get lots of requests for training. The debate about Independent Mental Health Advocacy, and UKAN's position towards the ongoing changes continued. Consultation with our members revealed that feelings were mixed, and the trustees have at the moment opted for continuing to provide our own brand of training, based on the pack we have developed.

Our consultation with our members was inconclusive, with only 10 respondents. Possibly the fact that it was a postal one (attached to *The Advocate*), and we didn't offer to pay postage was a factor in this. Of the responses there was



Sarah Yiannoullou, NSUN



Kate Hull Rodgers, Laughter Network

general support for UKAN to continue to provide advocacy training and development, and for the National Advocacy Qualification; for UKAN to have a campaigning and representational role, and to do national surveys on key issues and continue to publish *The Advocate*.

There are still around 200 member organisations in the UK Advocacy Network.

An audience member commented that the identity of UKAN was now less clear. Terry acknowledged there might be a need for “re-branding”, and that UKAN was not just about advocacy, but also about service user involvement and all user groups. Martin Coyle from Action for Advocacy told the meeting that he also attended meetings of the Advocacy Consortium (ACUK), and said he was interested in strengthening the advocacy sector as a whole.

There were then three presentations from national, continental and world organisations of users/survivors of psychiatry. Sarah Yiannoullou who recently began work as the Manager of the National Survivor and User Network (NSUN) talked about her work, and plans for that network (see pages 6 & 7 for a report by Sarah on what NSUN aims have been achieved so far).

Peter Munn presented a report on the World Network of Users and Survivors of Psychiatry (WNUSP), illustrated with some brilliant photos from their March conference in Kampala which he had attended.

Anne-Laure Donskoy gave a report on the European Network of Users and Survivors of Psychiatry (ENUSP). Anne-Laure is a freelance user researcher who had been invited to join ENUSP as an individual. ENUSP is now a virtual organisation using teleconferences. Anne-Laure argued that a Disability Conference in Brussels scheduled for December ignored mental health issues. There had also been a conference in Budapest on depression, sponsored by Lundbeck.

The AGM came to a riotous close with a Humour Workshop by Kate Hull Rodgers. Kate is a key member of the national Laughter Network www.laughternetwork.co.uk as well as being a mental health survivor. A Canadian who married a Yorkshireman, she talked on the theme of laughter being the best medicine, which went down a storm. She also talked openly and movingly about her experience as a service-user, and concluded “having a nervous breakdown has been my best career move!”

National Survivor User Network - where are we now?

by Sarah Yiannoullou, NSUN Manager

Having now been in the role of NSUN manager for 8 months, I can reflect on my time so far and look at how we are progressing the original aims of the network. It's been both exciting and overwhelming in just how ambitious the mission is.

The mission, 'to create a network, which will engage and support the wide diversity of mental health service users and survivors across England in order to strengthen the user voice,' is no mean feat – of course it is do-able - but to do it well and with the support of those that the network is there to serve is a tricky (complex) business!

As a networking organisation, it is paramount that the membership of NSUN increases significantly and we are able to manage the demands of a growing network. Continual and clear communication is essential and the redesign of the website will consider all of the identified needs and options to create an accessible, interactive and responsive site.

Over the last few months, I have come to realise that there are different expectations and views of the network so it is vital that we keep focused in order to ensure fidelity to the original aims.

So how are we achieving the aims of the organisation?

1. Facilitate active links between service user groups and individuals

We have two distinct networking functions, strengthening existing networks and capturing and including the smaller groups from diverse and marginalised communities who rarely have a voice within the traditional representative structures and committees. It is essential that NSUN has the infrastructure to support this.

Since March 2009, membership has risen by

38% and we want to strengthen engagement with existing members and continue to attract new members.

The first publication of NETWORK provided an update of the work of NSUN but also featured the work of members and some of the challenges faced by service user groups in the commissioning and tendering process.

Monthly e-newsletters and weekly bulletins are produced to ensure there is a regular distribution of information to network members. Of course, we recognise that we need to make efforts to engage with those who are not linked up via the Internet and have attended conferences, meetings and events to hear and share information from people across the country.

Following the launch of 'Dancing To Our Own Tunes: Reassessing BME service user involvement', Catch-a-fiya is leading the work that is taking forward the recommendations. A steering group has been established 'To Our Own Tunes' and will be meeting every 2 months over the next year.

Another initiative this year has been the Service Users Workers Peer Development/Support Forum. At the request of members, NSUN did further research into the value of a forum for people who have lived experience working in service user involvement roles. The first meeting was held on 29th September 2009 and was attended by eleven people from around the country. There was strong agreement that the group should continue on a two monthly basis.

2. Build capacity for service user groups

Our main capacity building activities are sign posting and providing information, organising workshops and developing the regional networks.

The logo for NSUN is displayed in a large, lowercase, sans-serif font. To the right of the text, there is a series of white silhouettes of people of various ages and sizes, connected by thin lines, suggesting a network or community.

North East

NSUN has finalised the contract with Mental Health North East, which is a network of service user groups. The work will be focused on the development of the network in terms of numbers and to provide support and capacity building to service user groups. The arrangement received full endorsement at the regional user and carer conference on 1st April this year at the Centre for Life in Newcastle.

South East

After a tendering process, the Canterbury and District Mental Health Forum won the contract to develop the service user regional network across the South East. As with the North East, the work promotes the aims and objectives of the network. The contract was signed earlier this year on 1st June.

West Midlands and London

We are starting discussions with local groups and networks in both regions and hope these regional networks are established in the New Year.

With 4 regional networks, we are almost half way to covering the 9 regions across the country.

3. Broker and facilitate access to service users for purposes of influencing and informing policy-makers and planners

As a central resource, NSUN will be visible to those who are looking to involve people in influencing policy at a strategic level. Our work with the National Mental Health Development Unit (NMH DU) is a good example of where we are working with others to facilitate and influence good practice based on the experience of those who have been keen to work at this level for many years.

The consortium, led by the NSUN, includes the Afiya Trust, Attend, Equalities National Council, Together, Mental Health Foundation and the Social Perspectives Network. An early action is to undertake a baseline assessment of the strengths, gaps and development potential for user and carer involvement across each of NMH DU's programme areas.

NSUN is not representative, but a mechanism for information and opportunities to be disseminated to those who are in the position or have the expertise and mandate to be involved in consultations, projects and boards. We are not 'doing' the involvement but assessing then recommending how involvement can best be achieved, reflecting on previous work such as the Making A Real Difference products.

4. Develop a training programme in confidence building, committee, interview and staff training skills

We will be conducting a training consultation with partners to establish what is needed to strengthen activity of individuals, groups and networks. We are working with existing networks offering support and coordination and will progress this work in the New Year.

We are about to become a fully independent organisation before the end of the year. Therefore, we must realise the above aims and wish ourselves well.

For copies of the publications mentioned in this article, or to sign up as an NSUN member, please contact:

Telephone: 0845 602 0779
Email: info@nsun.org.uk
www.nsun.org.uk

Putting survivors and our organisations and movement first

by Peter Beresford, Chair of Shaping Our Lives

Yesterday I heard that a survivor friend of mine with a hearing impairment had been sectioned. Despite commitments to ensure communication access, staff expected friends he wanted to speak to, to pass messages through them rather than provide the text phone service he needs and should have a right to. This very basic, routine breach of any meaningful interpretation of the Disability Equality Duty and the Disability Discrimination Act stands in sharp contrast to the kind of rhetoric we are increasingly hearing about 'modern' mental health from its leads and policymakers.

At a recent large national seminar I heard such policy leads setting out the benefits being offered by New Horizons, the latest strategy for 'mental health and wellbeing'. We were taken on a whirlwind journey highlighting the way that this strategy will tackle stigma and discrimination, what the National Service Framework achieved to improve mental health services and the lives of those with 'poor mental health', as well as the new focus on broader 'mental wellbeing' and the work of the Future Vision Coalition.

All this needs to be put in the context of yet more evidence, this time from the Care Quality Commission, of the poor quality and lack of safety in mental health wards, the continuing institutionalised inequalities facing black and minority ethnic mental health service users and the ongoing overreliance of the psychiatric system on drug therapy and medicalised responses to the broader social difficulties that face many mental health service users. As we enter serious recession, with fewer jobs and more social insecurity, not only are disproportionate numbers of mental health service users living on low incomes, held in a poverty trap and excluded from meaningful employment and other activities, but yet again they are being attacked for relying on disability and incapacity benefits and further efforts are



Peter Beresford

being made to deny them access to these. Put in this kind of context we might wonder what real value there is in lining up celebs like Stephen Fry and Alistair Campbell (do we really want to be associated with someone who helped take us into an unnecessary war in Iraq and acted as Blair's pit bull?) to encourage 'public education' and 'anti-stigma' action. To be truthful, a better target might be the politicians and media, which continue to harass and negatively stereotype mental health service users/survivors routinely.

So what point am I making? I suppose it is a simple one. These are really difficult times. We are now in a time of serious economic difficulty, where people at the bottom of the economic pile, as many mental health service users/survivors are, are likely to face the biggest difficulties. Also, there is a real likelihood that

we may have a Conservative government after the general election next year and from what we are already hearing from the opposition, about benefits reform and public spending cuts, and from what we know from the past, this can hardly be reassuring for those of us who want to see much improved support for mental health service users and a less 'maddening and distressing' society all round.

One lesson I have learnt over the years since I first used mental health services has been that if there is any hope, it lies with us and our own organisations. It is other mental health service users/survivors who've most helped me feel better about myself and given me confidence. It is our organisations which have I feel played the key part in helping to improve policies, attitudes and practices. But we know we have a very long way to go. So for me the main thing is how can we as mental health service users/survivors grow stronger? How can our local and national organisations and our movement grow in strength, solidarity, diversity and effectiveness?

I think the key first step is to recognise the crucial importance of asking this question. I don't think the gains we have got from much 'user involvement' have so far really justified the energy we have put into it. A lot of effort and pain, for very limited gain, is my view. What I think we need to be able to do more of is campaigning and showing that we can apply pressure. Too much of user involvement is hearing nice words, that often don't mean much in terms of actual change. In policy and politics, it's the influence you can exert, the power you can gain that make the difference.

I think there are some key next steps for us:

- Our first focus for what we do, and where we do it, should be in our own user/ survivor controlled organisations – at national and local levels;
- These need to prioritise getting money, security and visibility for themselves rather than for traditional mental health charities, which are constrained in all sorts of ways

from securing our rights (as partners with government, as service providers and so on);

- We should keep up the efforts and try and increase them to set up our own user controlled services, social firms, cooperatives etc.;
- We should build stronger alliances with other service user movements for the strength and solidarity this will achieve, without surrendering our uniqueness and independence;
- We should build alliances with supportive practitioners and trade unions;
- We should develop and strengthen our own voices, through our own newsletters, media, websites, writings, arts and so on;
- We should work hard to be more inclusive and address diversity as best we can, giving greater priority to outreach and engagement - to include all those groups of service users/survivors who are especially marginalised and disempowered; and,
- Finally, we should reaffirm and raise high our principles and values. These are principles of self-advocacy – to speak and act for ourselves - of our equal worth as human beings and our equal human and civil rights.

These are just my thoughts from my experience. I know others will have other ideas. I hope other survivors will add to this, change things they don't like and include what they think is important. One thing I think we are all agreed about, is that we want to see a better society and a better world which values all people and treats them all with respect and equality, including those of us with experience of madness, distress and mental health services.

Peter Beresford is Chair of Shaping Our Lives, the national service user organisation and network, and Director of the Centre for Citizen Participation at Brunel University. He is a long term user of mental health services.

www.shapingourlives.org.uk

The impact of suicide on others – the need to develop a comprehensive suicide bereavement/prevention policy

by Mike Bush, Mental Health Lecturer

In Britain, there is a suicide every 90 minutes and research suggests that it could be three times higher than this, as coroners often return verdicts of misadventure or open verdicts. For every suicide 6 to 8 people are intimately affected, with many more having resultant bereavement problems. To lose someone you love through suicide is indescribably awful. It has been referred to as a personal holocaust. People torture themselves with a million questions of 'Why?' There is a whole kaleidoscope of emotions and feelings stirring around in a pit of despair. The sense of rejection can be crushing too. How can he have loved me to do what he did? Then there is the searing guilt - if only I'd done this or that - the replaying in the mind of countless permutations of possible scenarios of what may have been.

Over 30 years ago, I was bereaved through my father's suicide. At that time there was no support available to my sister and me, other than what we could offer each other. It was incredibly hard. My sister became depressed and I went with her to see a psychiatrist who just told her to take tablets. There was no referral to a counsellor to whom she could ventilate her feelings. I was only 19 at the time and knew nothing about mental health problems and distress. However, common sense and intuition told me she needed someone to talk to but this was not on offer. The tablets had all sorts of nasty side effects and my sister gave up taking them. As a consequence, she became more depressed and suffered with depression for many more years. It is a fact that people bereaved through suicide are more likely to have mental health problems and be at increased risk of suicide themselves.

In general terms, men have a lot more difficulty than women discussing their emotional issues and problems. Male macho culture, and the concept that 'big boys don't cry' is still very much around and accounts for the fact that



Mike Bush

many more men than women take their own lives. There is also a strong need to develop culturally sensitive suicide bereavement/prevention services to people from ethnic minorities and asylum seekers and refugees. Another important need is to develop a suicide bereavement service for children and young people. This by its very nature will demand a skilful, sensitive and specialised response. Another area of concern is a mental health worker who loses service users through suicide. These workers need help and support in the distress that they are experiencing and often with the guilt around their perceived professional failure towards the person they have lost.

We need to build a coalition of interested organisations to develop a national suicide bereavement response. This also needs to be incorporated into the National Suicide Prevention Strategy similar to that developed in Australia. Presently, in Britain we have a number of voluntary groups trying to provide a good service. However, they are limited by inadequate funding. This leads to a postcode lottery with some provision in some places and little or nothing elsewhere. Suicide bereavement and prevention are opposite sides to the same coin; if we do not provide good support to

those bereaved through suicide we will have further suicides. There is a lot of good evidence that properly run suicide bereavement support groups save lives and help to reduce mental and emotional distress. I was involved in running the Leeds organisation of Survivors of Suicide for 15 years and I know that during that time the group really helped many people bereaved through suicide and I am sure it played an important role in preventing further suicides.

The Samaritans have people bereaved through suicide as one of their priority groups. I gave a keynote speech at the National Samaritans Conference in September, 2009 on the 'Impact of Suicide on Others' and highlighted the need for a national response. This is clearly necessary as, every day, people are being bereaved through suicide. They are an overlooked, badly neglected group of people, whose acute needs and problems are very considerable and warrant a compassionate, well-organised and systematic response. If we live in a civilised society, is this too much to ask? Common humanity demands that we take effective action but, in addition, a fully funded national suicide bereavement strategy would prove to be very cost-effective because of its effect in relieving mental distress and helping to reduce further suicides. We desperately need a national, well-funded, organised, compassionate response to people bereaved through suicide throughout the country as soon as possible. I am delighted to say that the Samaritans are very supportive of the need for this and a meeting of interested organisations is being planned to explore this further early in the New Year.

To see Mike's speech at the Samaritans conference, go to:

<http://www.pollenstudio.co.uk/samaritans/>

If you are interested in this campaign and would like to be kept informed of its progress, please contact us at: **UKAN, 8 Beulah View, Leeds LS6 2LA** or office@u-kan.co.uk and we will forward your name and contact details to Mike.

“Can You Accept the Truth?”



MAAT Probe Group, based in Sheffield, came together 18 months ago to support and represent African Caribbean service users; to

understand their experiences as service users; and to seek to expose and address the disparities that African Caribbean service users experience in their daily lives.

In October, MAAT Probe Group produced the report “Can You Accept the Truth?” about the findings of their monitoring exercise looking at the experience of African Caribbean mental health service users.

The participants were 63 African Caribbean mental health service users from 5 different trusts spanning 3 national regions. To see the findings, go to: www.maat.face-2-face.org.uk/

As a result, the group has developed a series of recommendations for mental health services. These include:

- An alternative to Control and Restraint (C&R) used in difficult situations on the ward (e.g. RESPECT, SCIP or Studio III training);
- Less dependence on medication and greater use of OT and talking therapies;
- More ethnic staff; and
- More training of staff by service users.

The recommendations conclude: “We would like to know why more respect and better treatment is afforded to African Caribbean service users in the community - in direct contrast with their experience of inpatient care.”

MAAT Probe Group is determined to build on the network of African Caribbean service users they have developed over the past 18 months and to campaign for an alternative to the use of C&R as the main means of crisis intervention in mental health services.

International Networking

by Peter Munn



Peter Munn and delegates from Denmark and Lithuania,
Vejle 2004

We are not alone. Did you know that there is a European Network of Users and Survivors of Psychiatry? And did you know that it is chaired by Mindlink's very own Mary Nettle?

This network is responsible for establishing the World Network of Users and Survivors of Psychiatry.

The World Network of Users and Survivors of Psychiatry (WNUSP) held its inaugural conference in Vancouver in 2001. The resulting statutes state that there shall be no less than one, and no more than three, board members from each of the following regions:

- Africa and the Middle East
- Americas
- Europe and the Russian Federation
- Asia and the Pacific

So I could not have been more wrong when I sat in my hospital bed feeling that I was alone. Now we are linked with users and survivors from around the world.

In July 2004, as chair of UKAN, I was fortunate enough to go to the second WNUSP General Assembly, which was held in Vejle, Denmark. There, I was elected as a deputy rep to WNUSP for Europe and Russia and Mary Nettle was elected chair of ENUSP. Representatives from 50 different countries agreed to hold the next General Assembly and conference in Africa if possible.

In March this year, Mental Health Uganda (MHU) hosted this gathering in Kampala. I managed to scrape together the £500 for the fare and went to the conference. The main theme was the Convention of Rights for Persons with Disabilities (CRPD). The convention, which was ratified in this country on 8th June 2009, is a powerful tool for human rights and has been the main body of work done by the network since Denmark.

I facilitated a presentation and discussion on international training and the work of the Service User Survivor Trainer Network (SUSTN) to people from 35 different countries. I also participated in a workshop that was helping MHU to comment on proposals for a new mental health act for Uganda written by two psychiatrists. It was good to bring to bear on the



Mary Nettle, Chair WNUSP

process my experience from the UK 2007 Mental Health Act consultation and the Mental Health Alliance activity.

At the General Assembly, we had elections for the WNUSP board and I was returned as the deputy rep as before. The two elected reps were Gabor Gombos from Hungary, whom I voted for because of his knowledge and experience, and Joljn Santegoeds from the Netherlands. There had to be a gender balance so I accepted the deputy post again.

For me, the overriding fact about the World Network is that it is about protecting the human rights and dignity of those who experience mental distress. If we could get this right for people around the world who are marginalised in this way we will have it right for all.

It is hoped that the next General Assembly will be in Argentina. I have already started a fund that might help support more people to go from the UK. If you care to donate to the cause, the International User Involvement and Arts fund, then please contact me at:

Email: pierrelemunn@googlemail.com



Joljn Santegoeds, European WNUSP Rep

For more information about the organisations mentioned in this article, visit their websites at:

- www.enusp.org
- www.wnusp.net
- www.mentalhealthuganda.org
- www.sustn.net



Some of the delegates in Kampala, March 2009. (For more pictures taken by Kampala delegates, you can view the web album at: <http://picasaweb.google.co.uk/pierrelemunn/WorldNetworkOfUsersAndSurvivorsOfPsychiatryWNUSP?authkey=GvIsRgCPCXlrKjvOfRvwE#>)

The Greek Experience *by Peter Bullimore, Tori Reeve, Kate Crawford & Linda Whiting, Asylum Associates*



Tori Reeve, Kate Crawford and Marianna Keffalinou and Peter Bullimore

It was at a conference in Manchester in September 2008 that we first met Marianna Keffalinou. She had come over from Athens to meet Peter Bullimore to see if there was any way he could help her brother who is a voice hearer. She told us about the barbaric conditions of the Greek mental health service whereby patients would be tied to the beds. On one occasion, two patients died after a fire in the hospital as they were unable to escape. Her brother had been sectioned and was being treated like a criminal. This had upset and angered Marianna so much that she came to England to seek help.

We first went over to Athens at the beginning of April and spent five days there. On the first night, we attended a public meeting that Marianna had arranged to raise awareness around hearing voices where Peter and Kate told their stories in order to create hope and inspiration for the group members. Four psychiatrists and thirty-six other people attended the presentation. On the second day, we visited a hostel for sufferers of mental illness where they spoke to us of their

experiences of the Greek mental health services. Later that evening, we went to a psychiatric hospital and met some of the patients. They spoke to us about their problems and what the hospital was like, and again we endeavoured to create some hope for them to one day be able to recover. Towards the end of the hospital visit, the patients were demanding a hearing voices group. They enjoyed our visit and asked us to come back the next time we were in Athens. The day after, we joined an anti-stigma group where we exchanged information about how England and Greece deal with the stigma of mental illness. Kate and Peter talked about recovery and we answered questions the group members posed about British psychiatric care. After the meeting, we then went for drinks at the Hilton with some of the group members. They too thanked us for coming and asked us to visit them again.

Six weeks later, we took a second trip to Athens and spent a further five days there. We joined a debate about mental illness in which

various different people spoke, some sufferers, some carers and some professionals. Afterwards, we took part in a demonstration. The police closed the main road and a football match followed, then a march ensued. Patients we had met in the hospital on our previous trip joined us, and afterwards we all went for a meal. The following day, we met with the members of the anti-stigma group again and Peter and I spoke about our experiences.

On the final day, we did a full day's workshop on hearing voices. Kate and Peter told their stories and we did the hearing voices exercise to an audience of professionals. Peter ran a session on working with voices, in which the director of the hospital took a great interest. The room was quite small but was full of people willing to learn. In fact, there were many other people who wanted to attend but there wasn't enough room, hence the reason we are returning in 2010. At the end of the training, the director approached Peter and told him he had destroyed so many lives with Haloperidol and he wanted to make amends. He said he was retiring in two years and wanted to leave a legacy and he has asked Peter and Asylum Associates to help him. We start to build that legacy in January when we will be teaching all his staff and setting up groups on all the wards.

During our time in Athens, we raised a lot of awareness about mental health, specifically voice hearing and paranoia. We feel that we helped both clients and professionals to see that although these experiences can be serious and very debilitating at times, they can be managed, and sufferers can go on to lead fulfilling lives, or at least learn to cope with their experiences. The Greek people were very grateful for us coming

They have shown great initiative for change. As is the case in most countries, the wheels in mental health grind very slowly but the wheels in Greece have been rusted for years. With the collaborative work of a forward thinking director and Asylum Associates the wheels are turning again.

MindFreedom International

MindFreedom International is an independent nonprofit organisation that unites 100 grassroots groups, including UKAN, and thousands of members to peacefully take action for human rights in the mental health system.

While MindFreedom International is open to the public, a majority of its members identify themselves as 'psychiatric survivors,' that is, individuals who have personally experienced human rights violations in the mental health system. All who support human rights are welcome to join. MindFreedom International members and leaders include mental health professionals, advocates, lawyers and family members.

David Oaks, director of MindFreedom International, and a regular contributor to *The Advocate*, is named alongside the Dalai Lama as one of the "50 Visionaries Who Are Changing Your World" in the November/December 2009 issue of *Utne*, an American bimonthly magazine that provides "alternative coverage of politics, culture, and new ideas."

MindFreedom International is currently sponsoring the 'Say NO to Electroshock' petition calling for ECT to be abolished. If you agree with the statement that: "Electroshock is brain damage and causes more harm than good therefore it should be abolished" and would like to sign the petition, go to:
<http://www.thepetitionsite.com/1/say-no-to-electroshock>

To find out more about MindFreedom International, visit their website at www.MindFreedom.org where you can learn about about their campaigns, sponsor groups, board, and more. In the section "ABOUT US" you'll find information about MindFreedom's mission, goals, staff, and contact information. And in the "NEWS" section, you'll find some news specifically about MindFreedom International alongside general news.

The Normality of Madness

by John McCarthy, Mad Pride Ireland

When I first started to use the word 'madness' or being 'mad' in reference to myself, a number of years ago, I generally received laughter, love, and opposition in equal proportions. But I persisted and that persistence has paid off. More and more people are beginning to feel comfortable in and around the use of madness as an alternative phrase to mental illness. So let's have a little thought about this word madness. That's simply what it is, a word.

It is a word that has been stolen from us. We, who live with the normality of madness as a reality in our everyday lives. Stolen and perverted into something to be afraid of. You see, the mad community is the most peaceful, loving, and caring section of the total community. We are the people who give you music, art, poetry, playwrights, actors, musicians... and yet despite these gifts you choose to persecute us.

There is no doubt that we who are mad are different. It is how you treat that difference that is the issue. Ignorance, prejudice and stigma attach to us like limpets. In my opinion, the only people who can shake off those limpets are we, the mad community, ourselves.

I meet so many young people who descend into madness. Descend into a deep place of darkness, in part, because we have a system across the globe that promotes fear. Indeed, it uses fear to maintain the power that gives the control that the present system so passionately needs in order to maintain its position. Ignorance and stigma have prevented us all from being able to stand up and acknowledge our simple, confused emotions at an early stage, prior to it becoming an emergency. How wonderful would it be if our young people could go home and state: "I am crying a lot lately. I am getting angry and I don't know why. I think I may be getting depressed." As simply as they can say: "I have a runny nose. Do you think I am getting a cold?" before it becomes pneumonia.

Embrace us for our difference rather than reject us. Your lives and ours would improve so dramatically.

As has been the case with all human rights campaigns, if we in the mad community are ever to gain a place of equality and dignity within the general community, we have to lead this call for our human rights ourselves. We must request all of those well-minded, articulate people who so passionately wish to speak on our behalf, to allow us to do it for ourselves. As one of these kind academics said to me once: "Please let me be your voice." I replied (and I know the person was a little taken aback) by saying: "Please be my ear as I have my own voice."

Can you imagine the gay movement succeeding if a straight person had led it? Can you imagine the black movement succeeding if a white person had led it? Can you imagine the feminist movement succeeding if a man had led it? So it is with the mad movement in this area of abuse of our human rights. If we are to become equals in this society, then we of the mad community have to stand up and say I am mad and I am proud.

May I take this opportunity to thank all 5,000 of you who embraced and celebrated with us at Mad Pride Ireland's first event in Fitzgerald Park, Cork on 8th June this year and the 10,000 of you who attended on the 7th June. In 2009, we spread to Portlaoise where, despite the rain, 2,500 people turned out. Next year, we will have 4 events, including one in Killarney in response to a request by our NHS to host Mad Pride Ireland Family Fun Day at a world conference of mental health bodies, as a best example of the fight against stigma.

Thank you, all of you who had the courage to stand with us. Together we can change, by embracing and celebrating difference.

www.madprideireland.ie

Former patients to be honoured

by Terry Simpson



Chapel entrance (Photograph by Mark Davies)

On the gatepost of a field in Menston, West Yorkshire, there used to be a plaque (see cover photograph), which stated that 'this site is the last resting place of 2,858 patients from High Royds Hospital who died between 1905 – 1969. May they rest in peace.' There are no gravestones, no flowers, no names, just an expanse of grass, with a little dilapidated chapel building.

For many years, this served as a bleak reminder of a system where individual identity was worth less than a psychiatric label. But for the last few years, a group has been campaigning to have a proper monument for the people who died at High Royds, (or West Yorkshire Pauper Lunatic Asylum, to give it its original name). This group, describing itself as 'a combination of local and mental health interests', has created a charitable company to take responsibility for the derelict

chapel and land, with the objective of restoring some dignity to the resting place of the former patients, who are buried in unmarked paupers graves. The present developers of the High Royds site, the Gladedale Group, who are turning the old hospital buildings into flats, have donated the land and chapel to the Friends of High Royds Memorial Garden, and plans are going ahead to restore the chapel building and make a permanent display there, as well as create the memorial garden.

Interest in the campaign was helped by a display of photos produced by local photographer Mark Davies, which you can see at:

www.highroydshospital.co.uk

(Mark has also done work on other local institutions, see:

www.meanwoodpark.co.uk and

www.stanleyroydhospital.co.uk)

Also recently, Jean Davison, who was a patient at the hospital in the 1960s and 70s, has published a very readable book about her treatment at High Royds entitled 'The Dark Threads' (see page 18 for a review).

You can view a video about the group's plans by entering 'High Royds - The Asylum Cemetery' into the You Tube search engine, or going direct to:

www.youtube.com/watch?v=_DGPZnCmKWo

The group is raising funds by offering 'shares' to supporters, and selling copies of a High Royds nurses badge for £5. Find out more by writing to:

John W. Steel OBE
1 Holme Park
Burley-in-Wharfedale
Ilkley LS29 7QT

John, along with other key members of the Friends of High Royds Memorial Garden, Ron Sweeney and Derek Hutchinson, is a long-standing activist in one of UKAN's member groups, Leeds Involvement Project.

A review of Jean Davison's 'The Dark Threads' (Accent Press) - a psychiatric survivor's story by Tim Coupland

If you are feeling jaded with the modern 'mental health' system, with its jargon, constant changes and underlying shortages, you could do worse than reassure yourself that some things at least have improved, by reading Jean Davison's story of being a mental patient in the 1960s and 70s. Although I found this on the 'Misery Memoir' section of the bookshop, it actually is much more than that, and is one of the best accounts I've ever read of what it was like to be on the receiving end of hospital treatment in those days.

The startling difference between then and now is how easy it was in those days to be sucked into the system. The young girl in the story had an admittedly dysfunctional family, but otherwise seems to have no more angst than the average teenager. No matter, after asking her GP for help, she is quickly drawn into the world of drugs, ECT and inpatient life and soon becomes institutionalised, only escaping several years later through a massive effort of will and determination.

The thing that makes this memoir stand out is that it is so well written. It never gets bogged down in the dire things that happen along the way, though there are some very detailed descriptions of, for instance, attending the ECT clinic. The main story is interspersed with flashbacks to the time before hospital, and excerpts from the case notes of various doctors. These changes of point of view give us a fuller picture and mean that although this is a dark story, you feel compelled to keep turning the pages.

The way the process of psychiatric labelling can systematically destroy self-belief is graphically described when she returns to the hospital:

The worst thing about being constantly taught that you're 'sick', 'inadequate' or have a 'weaker personality' is that you might eventually come to believe it. And the worst thing about coming to believe it is that this will help it become true.

The closed world of the old psychiatric ward, with its characters, injustices and general hopelessness is brilliantly captured. Anyone who has experienced this will instantly recognise this as an authentic picture. But the quality of the description and the dark humour that underlies the story prevent it from getting miserable:

There were no pale Ophelias among whiskery-faced women who dribbled and grimaced and spat. Trying to find romantic literary depictions of madness here would be as futile as trying to ride a rainbow or dance on clouds while the sky spewed out black, bitter rain over all that moved.

When she eventually gets out of hospital, and is trying to get her life back on track, the legacy of being an in-patient is strong:

I brushed some pink blusher onto my chalk-white cheeks, blended it carefully with my fingers as it said in the magazines to try to achieve a natural healthy look, and forced a smile onto my lips. They're not going to look closely at me, I thought. Perhaps I looked at least passable from a distance. I stood back, and stared in dismay at the mental patient in the mirror.

This book works on many different levels, and the themes of class and power are never far from the surface. The main character is from a poor, working class background, and questions whether a middle-class person would have received the same treatment. The power differentials between staff and patients are apparent when she joins The Felix Club for ex-patients:

A tall, thin man in jeans and trainers took Helen and me aside on our arrival. 'My name's Ernest Wormald and I'm a social worker. First let me tell you it's important to understand there's no difference between workers and members. No one is in charge.' Having said this, he took us back into the main room where he proceeded to take charge.

This is essentially a hopeful book, a book about survival, and a mind that stayed awake, kept thinking, and eventually found a way out of the maze.

In memory of Linda Hart

by Terry Simpson

Linda Hart, the artist, prize winning author, and survivor activist, died in August from an infection while recovering from a brain haemorrhage. Linda, who was 61, had a fairly recent connection with UKAN, having been one of the winners of the poetry competition we organised jointly with Sheffield Hallam University and Asylum magazine in 2005.

Linda was a prolific poet, and had come to national fame when her book 'Phone at Nine Just To Say You're Alive' was the Mind Book of the Year in 1996. Linda's account is a down-to-earth journal of a day-to-day struggle with ill health and the mental health system. Like Linda herself, it's frank, painful, but ultimately a very warm and human book about surviving.

Perhaps Linda will be most remembered for her extraordinary artwork. Linda created 3-D installations that describe the multi-layered and often tortured world of extreme states of mind. Monsters, animals, insects and people inhabit strange complex dream-like landscapes where every image has a meaning, and the mental health system looms large. Postcards of these works are available (through Mind publications), but they don't do justice to the immense power of the original works. 'Barbie's Bad Hair Day', for instance, stands about four foot high and leaps out about a foot from its frame. The teeth are an actual sheep's jaw bone, and when you look closely, you see that the eye-lashes are really worms. Everything about this image is disturbing, particularly when related to the blandness of a Barbie doll. It's as if we are looking beneath the surface of the modern world to its dark underside.

Linda was increasingly disabled, and could seem argumentative and bitter. She was very angry about oppression in all its forms, but when you got to know her she was also very kind, extremely generous, very smart and highly knowledgeable about film, literature and life in general. In the Society Guardian of January 2002,



she was invited to list her favourite literature, and among other things she chose the 'psychiatrist's bible', the Diagnostic and Statistical Manual (DSM), which she described as 'the greatest work of fiction.' She had a twinkle in her Irish eyes that meant humour was never far away under the surface, however bad her pain might be. The last words are hers, in a poem typical for its dark humour from the collection 'In The Asylum'.

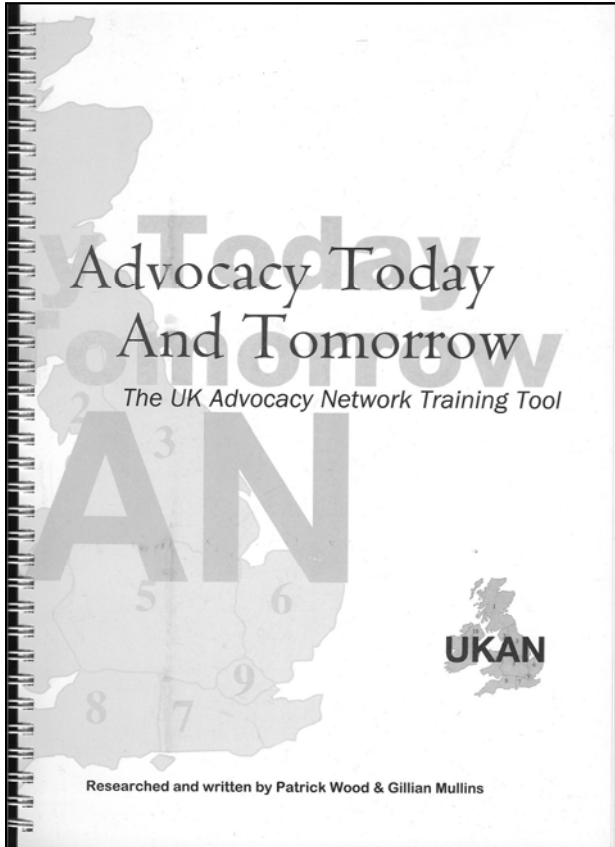
A Relapse

They could tell he was having a
Relapse,
When his pacing
Went in ever decreasing circles
'til his own shadow
Caught up with him
And trampled him to
Death.

It's comforting I think, at such times,
To have the Experts and the Qualified
On hand,
To recognise
That a person has
Died.

Linda Hart (4.12.03)

Advocacy Today and Tomorrow: The UK Advocacy Network Training Tool



Written by Patrick Wood and Gillian Mullins

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