

Spring 2009

# The Advocate



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

## UKAN UPDATE



This winter we said goodbye to Irene Harris (pictured), who resigned as UKAN Company Secretary through continuing ill health after many years of dedicated service to the organisation. Irene was a great person to work with – she was always ready to

volunteer, even for the sticky jobs no-one else wanted! She was quiet and didn't take up a lot of time and space at meetings, but she thought a lot, and this was apparent whenever she did voice her thoughts. She had that great attribute called common sense. She will be greatly missed, and leaves an Irene shaped hole at the heart of our trustee board. We wish her health and joy.

Despite the loss of our office base and our workers, the trustees and volunteers have continued to do the dozens of little jobs that keep an organisation functioning, and link up through e-mail and the website with groups and individuals around the country, answering queries about advocacy and training. Thanks are due in particular to Justine Morrison, who despite no longer being a paid UKAN worker, continues to make sure our bills are paid, that our accounts are in order, and that various official bodies like the Charity Commission and Companies House are happy with us. Otherwise we've had representation on the Advocacy Consortium UK group, (developing a generic advocacy network across the UK), and at the AWARD working group for a national advocacy qualification. We were represented at the NSUN 'Experience and Innovation' conference, and at various other mainstream events. We sent in a statement supporting increased resources for advocacy prior to the first reading of the Disabled Persons (Independent Living) Bill in May 2008, and ran a workshop at a national event for Patient and Public Involvement Forums (before they were reformed into LINKs). Currently we are undertaking a major review of one of our member groups.

But in terms of the ferment of activity of previous years, this has been a greatly reduced role for UKAN. The trustees have faced severe soul searching as to what the organisation is for, and how to adapt to changing times. Although our recent AGM was quite lively, and featured a great talk by Peter Campbell, we were not quorate in terms of our member groups, and because of this we have decided to undertake a period of consultation with our 200+ members about the role, purpose and structure of UKAN. There is no doubt that a strong national mental health service user voice is as necessary as ever. Detention under the Mental Health Act is increasing according to the Healthcare Commission. Involvement and advocacy are increasingly controlled and hidebound within the system. Consultation when it does happen is too often about matters that have already been decided. Millions are spent combating stigma and discrimination at one end of the system, while the other end produces it by labelling and mistreating us. "Social inclusion" is too often a fine concept used to legitimise cuts to the services we value most.

The job UKAN was set up to do is not finished, nor has its unique role been taken over by other organisations, but we do need to adapt and evolve to the changing times to be 'fit for purpose'. Although we had misgivings about the independence and democracy of the new National Survivor and User Network when it was set up, time has moved on, and NSUN is now a key element in our movement. UKAN needs to have meaningful communication with NSUN, so that the two groups are genuinely mutually supportive. Most importantly we need to work out policies that resonate with our own member groups, so that UKAN again becomes a vibrant centre.

With this in mind we intend to embark on an ongoing period of consultation with the member groups who set UKAN up. UKAN is not separate from these groups. It is their collective voice, and we need to get back to our grass roots

beginnings and find out how best to serve those groups now.

The last page of this newsletter is a survey, which we'd like your group to discuss and return to us, to let us know what you think UKAN should be doing now, and what our purpose is in the changing world of 'mental health'.

UKAN was willed into existence by the needs of people on the receiving end of mental health services. It survives in a hostile environment through the continuing will of those people and the groups we have created in our communities, so please help us to make it thrive.

Lastly, some acknowledgements are due. I would like to thank Tony Heyes and the O'Hara Charitable Trust for their very generous donation of £500 to enable the printing and distribution of this edition of *The Advocate*. Thanks also to Justine for her time and effort in soliciting and editing articles and putting the whole thing together.

**Terry Simpson**  
**February 2009**

### CHANGE OF ADDRESS

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#### **Editorial Policy**

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## Meet the UKAN Management Committee

**Alisdair Cameron** has variously been an academic historian, a lawyer and a user of mental health services, in between stretches of generalised faffing about. His day job is as team leader at Launchpad, the mental health service user involvement project for Newcastle upon Tyne, and he is also co-chair of the Northumberland, Tyne and Wear Service User and Carer network. He is a director of NAGAS (Newcastle and Gateshead Arts Studio), vice-chair of MHNE and board member of NSUN (National Survivor and User Network). In spare moments he shuffles all of the letters from the aforementioned acronyms and sees what they can spell out.

**Graham Estop** I see UKAN as an important national service-user organisation, with its roots in the user movement and organisations like Survivors Speak Out, Nottingham Advocacy Group, Voices (now Perceptions) Forum and Mindlink. I worked as the coordinator of Perceptions Forum for 5 years, and am now coordinator at the Involve service-user project based at Doncaster Mind. We are members of UKAN and see it as an umbrella group which can link and hopefully support local service-user involvement and advocacy groups.

**Robert Hailes - Treasurer** A bipolar sufferer now recovered well and involved with a few organisations specialising in mental health care. A former director and treasurer of Loud and Clear Mental Health Advocacy in North West London but then moved on to be involved in UKAN a few years ago and am currently their treasurer. Recently joined The Bipolar MDF Organisation but have attended their local monthly meeting for over nine years. Currently representing UKAN at meetings of The AWARD Working Group planning the introduction of qualification for advocates and also meetings of Advocacy Consortium UK a national network for advocacy.

**Carol Jenkin** I have spent over 28 years, over half my life, in mental health and as an advocate. I am a Black user sufferer, activist, speaker, consultant and writer for the past 16 years plus. I developed a support network and befriending scheme called BUDDIES, now based in Manchester. I'm currently working as a Community Development worker in Manchester as a User Participation and Community Engagement Advisor. I have worked in the past with UKAN as a specialist advisor on the involvement inclusion of Black individuals and projects. My aim is to provide a positive role model to a system which portrays mental health as a negative, impossible and stigmatised place to be. Please keep supporting UKAN. Get involved in the drive to move us on as an organisation that will support and influence service provision and user involvement.

**Peter Munn - Vice-chair** is currently a deputy representative for Europe and Russia for the World Network of Users and Survivors of Psychiatry (WNUSP). Other roles include Wales Coordinator for Mental Health Media's Open Up project ; panel member of Mindlink Cymru; and member of the Wales Alliance for Mental Health (WAMH). Peter is a founder member of Cymar (the Welsh Association of Mental Health Patients' Councils and Advocacy Schemes).

**Terry Simpson - Chair** was Co-ordinator of the UK Advocacy Network (UKAN), from 1993 – 2002, and is currently Chair of the Board of trustees. His poem 'Rubbish' won the 2001 Martha Robinson Poetry Competition. He has written 2 plays, which have been filmed for use on Open University courses. He has been involved in editing several collections of writing by mental health survivors, including *And The World Really Had Changed*, (a poetry anthology), *Doorways In The Night*, (survivor accounts of mental health recovery), and *The Mind Machine*, (a collection of short stories). He has now

completely recovered from a diagnosis of 'delusions', and is currently living on a zebra farm in West Yorkshire, and hoping to record an album with Tom Waits later this year.

**Andrew Wetherell** has worked in the UK Mental Health Service User Movement since early 1994 and his work has included developing self-help support initiatives and managing advocacy services. He was Chairperson of the UK Advocacy Network (1997 - 1998) and a member of the Government's Independent Reference Group. During 1998 and 1999, Andrew worked for the NHS Executive and was responsible for service user participation at Ashworth, Broadmoor and Rampton High Security Hospitals. Until March, 2000, he worked with the Hamlet Trust developing service user initiatives in Central and Eastern Europe. He now runs a freelance mental health training and development consultancy with his wife, Roberta. Andrew was also an associate trainer with The Sainsbury Centre for Mental Health from 1997 to 2006.

## Sad goodbye to Mike Paxton

We were deeply sorry to hear about the recent death of Mike 'Max' Paxton, at his home in November. Mike was in frequent contact with us by letter, 'phone and text, and his views were often very sharp and amusing - like noticing the military language we use in mental health - 'task forces', 'strategic' plans & 'commissions'. Mike was a member of Slough Mental Health User Group, who kept us entertained with their funny, informative and irreverent newsletter until the group folded last year, when they generously donated the remaining cash in their account to UKAN. Mike was from the old school of the survivor movement, hating jargon, challenging the darker side of concepts like recovery and social inclusion, and always looking for the truth beneath the rhetoric. He will be missed.

**Terry Simpson**

## 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 \_\_\_\_\_  
(Suggestion £20)

I would like to make a regular contribution by standing order  
YES / NO  
(We will contact you about this)

Postal address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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Please make cheques payable to UKAN and send with completed form to: **UKAN, c/o 8 Beulah View, Leeds LS6 2LA**

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## Peter Linnett: Obituary

Peter Linnett died on 1 September 2007 in Melbourne, Australia, of a brain tumour. I remember first reading his article *Which Way to Utopia? Thoughts on User Involvement*, in an issue of MindLink (later published in OpenMind 98 in 1999). In it, Peter used his experience of being employed as a worker to promote user involvement in a large national mental health voluntary sector organisation (and finding it far more difficult and problematic than he expected), to think about the real implications about user involvement. He suggested that user involvement was a revolutionary, utopian idea, with profound implications for the way mental health services are run, and for how service users and mental health workers might interact with one another. This piece so impressed me that I wrote to him, and we began a correspondence that turned into a friendship over the years.

Peter wrote a number of other important essays, published in Asylum magazine and elsewhere, such as *The Creativity of Survival: the true connections between creativity and mental distress*, and *The Myth of Mental Health*. He put his essays together for a book, but unfortunately was unable to find a publisher during his lifetime. In 2006 he gave a lecture for the Centre for Citizenship and Community Mental Health at the University of Bradford, with the title *Beyond Mental Health or Illness: The Deeper Meanings of Crisis and Distress*.

Peter was one of the most profound thinkers about mental health services to come from a user/survivor background. His work's importance lay in his ability to explore/unpick the many unexamined assumptions in the field.

Towards the end of his life, he renewed his early interest in Buddhism, and published several articles about this. An Australian by birth, he had lived for many years in the UK. His death at a relatively young age (he was in his early 50s) is an enormous loss to the user/survivor movement, and to the entire mental health field.

**Peter Relton**

## Which way to Utopia?

*Thoughts on 'user involvement'*  
by Peter Linnett

'A map of the world that does not include Utopia is not worth even glancing at.' Oscar Wilde

Recently I completed two years as the first user-involvement development worker employed by a large English mental health charity. It was the hardest, most gruelling job I have ever done.

The purpose of user involvement is to change the balance of power in an organization to take some away from professionals and to give more to clients (I prefer this term to 'service user').

Underlying user involvement is the idea that clients are the experts on their own needs. Involving them in policy-making, training, recruitment and so on, ideally ensures that their needs and concerns become central to the organization's service delivery.

User involvement now has 'politically correct' status in mental health. In any organization, unstated organizational purposes usually underlie stated ones. In the case of mental health user involvement, these may include the desire to impress organizations that purchase mental health services, and to appear to be doing the right thing. These purposes are not necessarily incompatible with the stated ones. But if action does not match the stated commitment, staff and clients may develop doubts about the real purpose.

### **Roles and power**

Being a professional is a socially acceptable and sustainable role. Being a 'user of mental health services' is not - except in the mental health world. In that world, clients may have unofficial kinds of power - such as the power to protest to purchasers of services, funding bodies and the media about the quality of service they receive. They do not have official kinds of power, unless these are granted by the organization. Such

granted power may include membership of management committees and other policy-making groups. But if official power is granted to clients, it can also be taken away. At worst this power may be an illusion, acting to damp down demands with which an organization feels uncomfortable. It may confine people even more firmly in the role/category of 'service user'. This is exemplified by the often-used expression 'the user perspective'.

If clients do gain genuine official power, they are no longer solely clients or 'service users'. But they are still regarded as such by the organization concerned - they may even regard themselves as such. Boundaries between roles become blurred, usually without those involved realizing or accepting the implications. In these circumstances, the balance of power has shifted. A fundamental change has taken place, which should lead to changes throughout the organization. These cannot happen unless 'clients' cease to be seen solely in that role.

It is hard to achieve this, because there is little or no fluidity of roles in mental health. We all embody multiple roles: our roles are fluid, so is life. Rigid role distinctions make user involvement impossible to achieve. They cut off the possibility of a creative approach to running services and to living our lives. Consider the acute crisis of identity suffered by some mental health workers who have also experienced mental distress. Staff's role is to deliver a service - not to be 'mentally ill'. Clients' role is to be 'mentally ill' - to receive a service, not help deliver it.

When these roles become blurred, confusion and anxiety result. It is understandable that people end up preferring the security of traditional roles. Even if they genuinely want change, there are tremendous pressures to maintain things as they are. The paradox of 'user involvement' is that achieving it means people being released from the exclusive roles of 'client/service user' or 'employee/ service provider'.

Genuine user involvement leads to fundamental

change. This is rare because managements usually haven't the stomach for it. It means staff giving up some of their power and status. For clients, it means taking on responsibility and being accountable for any work they do. Organisations have to take a long hard look at how they work and ask whether their methods are compatible with the work's aims.

An example. Disparities of income and employment status play a large part in creating distance between staff and clients. However well-meaning, a senior manager earning £40,000 a year will have trouble understanding the life of a client living alone in a bedsit on £50 a week. There is a tremendous amount of money available to run organizations and employ staff - could more of this money be given directly to the people these organizations exist to help? Impossible, you say? Not practical? If organizations think this kind of change is impossible, they should not even try to implement user involvement. If they are going to do it, they must address implications such as this. For user involvement has major personal, organizational, social and political implications. It's hardly surprising that individuals and organizations are reluctant to address these implications. Even if they want to address them, the social/legal/political structures that would make action possible barely exist.

### **The idea of a 'mental health service'**

In his book *Asylums*, Erving Goffman discusses the classic distinction between the server and the served. 'The server' provides a service (a shopkeeper, solicitor, mechanic and so on). 'The served' person receives or makes use of the service. Provided both sides observe mutually-agreed rules, their transaction should be straightforward. When the 'transaction' involves more intimate matters - such as in a doctor-patient relationship - problems tend to arise in adhering strictly to this model. In mental health work, a client's experiences and the means used to deal with them create fundamental personal changes. A worker and a client may both spend a great deal of time in the same environment. The worker often finds that this work stirs deep and sometimes disturbing emotions. It is highly

demanding and challenging, in ways that require a response as a person, not as a detached professional.

Is the mental health worker ('the server') simply delivering a service to 'the served' (the client)? Essential to this model is the element of impersonality in the relationship - exemplified in the 'serviced' person paying for the service. The two sides should not let the relationship become personal; if they do, a straightforward transaction becomes less likely. But to be truly humane, relationships between 'workers' and 'clients' must have a personal element - 'workers' must truly 'attend to' 'clients'. (The word 'therapeutic' derives from the Greek *therapeuo* - wait on, attend.) If this happens, people are no longer merely elements of an impersonal 'service'. Sometimes relationships are not humane, and they then act as a powerful reminder of what should be happening. By imposing an inappropriate model on mental health work, western societies have compromised the true aims of that work.

What does this have to do with user involvement? Everything. Once we accept that mental health work must have a personal element, we open the way to seeing people as individuals - not as 'clients', not as 'employees' or 'service providers'. This is not just a matter of words or of sentiment. Once we accept that no one is ever just a 'client', just an 'employee', we open up the revolutionary path of user involvement. For it is revolutionary: its implications go beyond mental health to the wider society. In its strategy to tackle so-called 'social exclusion', the UK Government would be well advised to heed the lessons of user-involvement activity. (Tackling 'social exclusion' currently appears to mean committees and expensive conferences for people who are very much a part of society.) The questioning of roles that occurs in user involvement has the potential to transform not only mental health work but society itself.

### **A utopian idea?**

I said user involvement is revolutionary. It is

more than that; it is a Utopian idea. Sir Thomas More's book *Utopia* (1516) described 'an imaginary place with a perfect social and political system'. The word Utopia is often used to describe 'an ideally perfect place or state of things' (OED).

Utopia is a Latin word. It means 'nowhere'.

That the idea of user involvement exists at all is a tribute to many survivor activists (though most go beyond it to the idea of user-controlled services). If we bear in mind the history of psychiatry, it is a miracle that any attempts at user involvement have been made at all.

User involvement is a Utopian idea - not because it is so hard to practice, but because as soon as it is done genuinely, it becomes something else. In this sense, there cannot be such a thing as 'user involvement'. The organization/people concerned move beyond fixed roles, and permanently change the balance of power. They are then in uncharted waters, ones we have no name for at present. They are 'nowhere'. If attempts at user involvement fail, it is often through fear, such as an explorer might feel in an unmapped landscape. But usually organizations do not get this far. Either they do not realize the implications; or they are aware of the implications and evade them; or wider pressures beyond the organization inhibit or prevent progress.

You may think I have been unduly critical of sincere attempts at user involvement. Having attempted it myself, I am critical because it is too important to be done unthinkingly. Doing user involvement means becoming revolutionary. Unwilling or unaware revolutionaries are not going to change anything for the better. They may even make things worse.

Should the mental health map contain Utopia?

**Peter Linnett**

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## **“Advocacy - that’s counselling, isn’t it?”**

*In memory of, and tribute to, the life and work of Pete’ Shaughnessy,  
whom we sadly lost on 15th December, 2002*

*Pete’ Shaughnessy ~ Loyal, forthright, charismatic, kind, sensitive, resourceful and dynamic, to list just a few of his qualities. He was a man who made a massive positive impact through the UK. Mental Health Service User Movement and his presence is greatly missed by many*

*We love & miss you Pete’ ~ Roberta & Andrew*

“Absolutely not” is of course the answer!  
However, the above statement was made in relatively recent times to a close and dear colleague of mine, the late Professor David Brandon, and it was made by someone who really should have had a better understanding of advocacy and its role within modern mental health services.

David enlightened the individual in his own unique style by gently pointing out that the biggest clue to advocacy and counselling actually being totally different from one another was the fact that they were *spelt differently!* He got his point across well on the day, but this example highlights that whilst mental health advocacy has been visible within our services since the mid-eighties, there is still a long way to go in establishing this vital service as part and parcel of mainstream mental health provision. Indeed, advocacy availability is still quite patchy across the country and can often be seen struggling for recognition, understanding and appropriate resources at various places within the UK.

With a statutory right to Independent Mental Health Advocacy being enshrined within new legislation for individuals who are subject to the Mental Health Act 2007 (Amended 1983 Act), there are many questions being asked and these include the following:

- What does an effective advocacy service look like?
- How should independent advocacy be commissioned?
- What qualities make a good professional advocate?

- Are there certain patients and areas of care that require priority attention?

and,

- What about “Patient Advice & Liaison Services” (PALS) and “Independent Complaints Advocacy Services” (ICAS)?

Obviously, the above few questions do not represent a comprehensive list of “white-hot” issues around the UK, but I consider them to be amongst some of the more important topics in this particular context, and as such, I will try to cover them to some degree within this short article as well as highlighting areas of good practice.

It is interesting to note that, contrary to popular belief, advocacy is not a new concept. In point of fact it dates back nearly 400 years to 1620(1) and next to mutual self-help support, I consider it to be the single most important service user defined and developed initiative within the world of mental health. The value of such independent support and provision of balanced information is immeasurable but absolutely vital and must, therefore, be properly recognised, supported and commissioned for the benefit of all stakeholders.

Since the pioneering work of the UK Advocacy Network in partnership with the Department of Health(2) back in the early 1990’s, the understanding and expectations of advocacy have moved on a long way, culminating in the current recommendations in relation to Independent Mental Health Advocacy. These recommendations are to be broadly welcomed,

particularly the statutory right to this service for those who are subject to the Act. However, whilst well-intentioned, the suggestion that patients who become subject to compulsion should be seen within three days would appear to be unrealistic when considering likely current capacity within the advocacy provider market.

An area of serious concern in relation to these new proposals has to be in relation to a statutory right to advocacy for individuals who are "sectioned". Whilst this entitlement is, of course, a good thing, we must remember the many other people who may not be subject to the Act but who are highly vulnerable, disempowered and excluded, thereby having high needs for advocacy input. The new legislation could create an unpleasant smoke-screen which obscures the latter group of people and denies them access to this vital service. Indeed, it could actually create a most unwelcome two-tier system in this context.

Of equal concern is the possibility of advocates having to become part of the world of academia and achieve "accreditation" / a professional advocacy qualification in order to "practice" advocacy. To my mind this would be a disaster and, indeed, un-workable in practice. Far more preferable would be "accreditation" via robust service commissioning where ongoing performance management and quality monitoring processes could ensure "accredited services" ~ not individual advocates. The value of an advocate who has a lived experience of mental health problems cannot be accurately quantified but can have unique importance and impact for current service users in receipt of advocacy support from such individuals.

### **What does an effective advocacy service look like?**

Broadly speaking, an effective advocacy service will usually display certain key characteristics and these commonly include adequate funding, proactive as well as reactive approaches, plus properly trained, supported and supervised staff. In addition to being well co-ordinated, responsible and professional, good advocacy service providers will have effective policies and

procedures in place including a suitable "engagement protocol".

Whilst on the issue of policies, so far as the all-important "confidentiality" issue is concerned, a pragmatic approach is needed where service users are informed upon first contact with the advocate that if significant issues arise where there is risk either to the client and /or others, then confidentiality will be breached.

Finally, it is crucial for advocacy services to maintain a "healthy diplomatic tension" between themselves and service providers which allows an appropriate functional working relationship at all times.

### **How should independent advocacy be commissioned?**

The Durham University review(3) of advocacy service delivery at Ashworth High Security Hospital provides a wealth of invaluable data in respect of commissioning considerations for advocacy services and I would endorse the fact that these arrangements must always be independent of service provision. Given this fact, it seems to me quite appropriate for skilled service commissioners to carry out this process and then closely monitor quality and performance of the services they commission.

One team of service commissioners I am aware of adopted commendable practices as part of their supportive commissioning approach and these included the refreshing method of allocating a separate costing under the "advocacy" heading for each of the patients they are responsible for. In this way, equitable, meaningful and appropriate funding was made available to the advocacy service provider and is, in my view, eminently better than just providing a blanket sum for "x" number of patients, regardless of individual needs.

The above team also expected each of the service users they are responsible for to be seen at least once every six months by an advocate, and one of these meetings was to be before the Care Programme Approach (C.P.A.) meeting. In

addition, this particular team considered independent external review of the services they commission to be crucial and duly expected their advocacy service providers to undergo such a process (funded by the commissioners) before the end of each contract.

### **What qualities make a good professional advocate?**

From my experience in the advocacy field, I consider the following to be the main qualities in this connection(4):

- The ability to be clear-thinking and focussed on the service user's agenda
- A non-judgemental approach towards patients
- A knowledge of mental health legislation
- Good listening and communication skills
- Patience
- The ability to keep one's own agenda firmly to one side
- A good support network for off-loading and use as a sounding-board

Additionally, there is the issue of empathy which past or present service users can bring to the equation. Whilst this can be invaluable it is not, of course, a pre-requisite for the role of an advocate. However, at the same time it must be emphasised that mental health service user-led organisations are often highly competent in providing professional advocacy services throughout the UK.

### **Are there certain patients and areas of care that require priority attention?**

As already intimated above, the focus of all advocacy service providers must essentially be on the most vulnerable, excluded and disempowered service users and this, of course, necessitates a proactive as well as reactive approach. Effective service commissioning should adopt this approach where active in-reach onto wards is a key part of the process so even those in seclusion can access an advocate when required.

Due to the liberal "aerosol" use of the word

"advocacy", the true meaning of this process is sometimes lost. For this reason, all interested parties need to arrive at a shared understanding in this respect, and the following definition could well be helpful: enabling people's growth towards self-advocacy

Therefore, it is important for advocates to focus on meeting with vulnerable and disempowered service users well ahead of their CPA review and other important events such as tribunals in order to provide support and assistance in preparing & submitting pre-meeting reports *from the patient themselves*. (Good advocacy should be about informing and helping service users to take on more responsibility and do more for themselves with appropriate levels of support).

### **What about "PALS"(5) and "ICAS"(6)?**

Clearly, these two processes are not independent advocacy in any way, shape or form, and like Advocacy, neither are they mechanisms for service user participation. However, "PALS" and "ICAS" need to work in conjunction with one another as well as with independent advocacy services as and when appropriate. This will require a mutual knowledge and respect of each other's remits and the role of individual advocates will, of course, need to include informing service users about the role and function of "PALS" and "ICAS" when relevant.

### **Other considerations**

As well as *empowerment* of individual service users, there are two other key specific gains which flow from an effective advocacy service and these are summarised as follows:

- 1) By having an effective advocacy service in place, early resolution of various issues can often be achieved. Whilst advocacy is not specifically about complaints, a well delivered service can result in a reduced number of formal complaints being submitted.
- 2) Ward staff broadly welcome good advocacy with open arms. In particular, it can relieve them of advocacy-type duties which they have always carried out. This is in recognition

of the fact that staff do, of course, advocate for patients. However, if they were to do so in the *fullest* sense of the word, they would inevitably encounter an intolerable conflict of interest and this is an unreasonable expectation for any staff member to be subject to.

Independent Mental Health Advocacy provision should be an integral part of today's mental healthcare. The process brings an invaluable service to both patients and practitioners and must be adequately supported if we are to see it flourish in the 21<sup>st</sup> Century ~ let's hope it does!

### **A final thought**

Cultural change is, without doubt, a slow process. However, I look forward optimistically to the time when rather than, "*Advocacy, that's counselling isn't it?*" we can expect responses like, "*Advocacy, exactly which type do you mean?*"

**Andrew Wetherell**

### **ARW Mental Health Training & Consultancy**

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## **Mental Health Act 2007**

The Mental Health Act 2007 is not a brand new Act. It amends the Mental Health Act 1983. The main changes to the 1983 Act made by the 2007 Act are as follows:

### **Definition of Mental Disorder**

A single definition of 'mental disorder' now applies throughout the Act. The former categories of 'mental disorder' have been abolished. These amendments complement the changes to the criteria for detention.

### **Criteria for Detention**

A new 'appropriate medical treatment' test will be introduced and apply to all the longer-term powers of detention. It will not be possible for people to be compulsorily detained or for their detention to be continued unless appropriate medical treatment is available. The so-called 'treatability test' will also be abolished.

### **Professional Roles**

There will be a broadening of the group of professionals who can take on the functions currently performed by the Approved Social Worker and Responsible Medical Officer.

### **Nearest Relative**

Patients will have the right to make an application to the County Court to displace their Nearest Relative where there are reasonable grounds for doing so. The provisions for determining the Nearest Relative will be amended to include civil partners as the equivalent of a wife or husband.

### **Supervised Community Treatment**

The power to use SCT will be introduced for patients following a period of detention in hospital, to ensure they continue with the medical treatment that they have been assessed as needing. This is the most contentious of the amendments to the Act and one could argue that it is the primary consideration underlying the review of mental health legislation.

**Mental Health Review Tribunal (MHRT):** changes will be made to reduce the time before a case has to be referred to the MHRT by hospital managers. The Act will introduce a single Tribunal for England. The Tribunal in Wales will remain.

### **Age Appropriate Services**

Hospital managers will be required to ensure that patients aged under 18 admitted to hospital for 'mental disorder' are accommodated in a suitable environment.

### **Advocacy**

A national authority will make arrangements for advocacy to be provided by Independent Mental Health Advocates. The form of advocacy envisaged bears little relationship to the UKAN model of user controlled mental health advocacy, although one could argue that without UKAN's pioneering work in the field, no arrangements for advocacy would have been made in the legislation. UKAN was the first organisation to define good practice in mental health advocacy, to develop comprehensive mental health advocacy training materials and to publish national mental health advocacy standards. The principles espoused by the Government sponsored initiatives that now take the lead on mental health advocacy bear a remarkable similarity in most respects to the work produced by UKAN in the past 14 years (although it is hard to find UKAN credited anywhere in the work of these organisations and initiatives).

### **Electro-convulsive Therapy**

Safeguards will be introduced regarding the use of this controversial treatment. Advance decisions will be able to indicate a person's unwillingness to receive the treatment but the principle will remain that ECT can still be used 'in emergencies', supposedly when necessary to save a person's life or prevent serious deterioration in their condition. It will be interesting to see if these new safeguards result in a reduction in the number of ECT courses administered in England and Wales, or whether the treatment will continue to be used as liberally as it has been in recent years.

The majority of the new measures contained in the 2007 Act were introduced in November 2008 but the provisions relating to advocacy will not come into force until April 2009 at the earliest.

On the face of it, the introduction of a right to advocacy for people detained under the Mental Health Act seems to be cause for celebration but the limited nature of the IMHAs' role should be viewed with caution and the requirement that statutory agencies provide a particular form of advocacy service might result in a reduction in the resources available to advocacy services operating outside of this limited sphere.

Terry Simpson has argued that the reason for introducing the Amending Act was to introduce compulsory treatment in the community and that all of the other measures can be considered as sweeteners enabling this to happen with a minimum of fuss. Several of the other new provisions seem to favour the cause of safeguarding or promoting service user rights but these are surely outweighed by the introduction of community treatment orders (in the guise of Supervised Community Treatment), which will extend the remit of compulsory medical treatment outside of hospitals and other medical institutions and into people's day-to-day lives.

**Patrick Wood**

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## Career Opportunities in Compulsory Treatment?



***Graham Estop asks how well the Mental Health Alliance did in representing service user concerns to the government on the amendment of the Mental Health Act which took effect last November***

I think this was Terry Simpson's quip about the breakaway group from the Mental Health Alliance. They called themselves the Mental Health Coalition and emphasised their professional interests, but broke the unity of the Alliance which had held till just before the amended Mental Health Act 2007 was passed – an Act which ushered in the brave new world of compulsory psychiatric powers in the community. The Coalition included clinical psychologists, nurses and occupational therapists. They wanted to be more like psychiatrists it seemed – rather than different.

Tony Zigmond of the Royal College of Psychiatrists had claimed, in a letter to *The Guardian*, that in European Case Law only doctors have the legal qualifications to recommend the detention of someone under the Mental Health Act. However, the BPS (British Psychological Society) spokesman followed up with a letter on 4 May 2007 which made clear his wish that psychologists and others be allowed to section people too.

He wrote: "People with mental health problems do not want merely to be diagnosed with purported illnesses and prescribed medication. They want ... a team from a range of backgrounds – nurses, psychologists, social workers and occupational therapists, in addition to doctors". In the same edition of *The Guardian*,

Health Minister, Rosie Winterton clearly backed this position, writing: "I'm at a loss to understand why the MHA and RCP insist on standing in the way of this improvement".

What brought things to a head though, was perhaps the House of Lords then passing (temporarily) an amendment that a qualified doctor must be involved in any decisions to renew detention or impose a community treatment order (as reported, for example, in *MH Today*, April 2007).

We are all for multidisciplinary mental health, but I'm uneasy that the BPS, in particular, appeared to seek to win professional advancement by enthusiastically backing from the outset the government's wish to extend compulsion into the community. I'm critical because I believe they lobbied for this too independently of the Alliance. And I would be interested to hear the degree to which the BPS drew up its positions and policies in consultation with its own service-user committee.

The Alliance could only be effective if organisations, whatever they thought individually, maintained a joint front publicly. Organisations like Mind and the RCP channelled their views very explicitly through the Alliance. The breakaway professional groups abandoned this principle.

Given the MH Coalition finally got its way, it's not surprising that they welcomed the newly amended Mental Health Act in fulsome terms. "It should be welcomed by professionals and service-users alike," they said. But the Chair of the Alliance reflected the broader view – and one closer to that of service-users/survivors – that it was "overall a disappointment – at best a mild improvement". (These quotes as published in Mental Health Today, September 2007)

The Alliance was particularly disappointed with the broad definition of 'mental disorder' and loose conditions for imposition of Community Treatment Orders (CTOs). Rowena Daw deplored the lack of any recognition of civil rights issues, and observed that services had run down in the 20 years since the introduction of CTOs in Australia.

This kind of outcome, though, was predictable from the outset. The government was always committed to introducing CTOs (or "Supervised Community Treatment"), and the Alliance approach of polite dialogue was never going to shift this much, however cogent the arguments, research and analysis. The Alliance never really established a campaigning profile in the media, calling off its planned mass demonstration in London in 2002. This was due to the Ian Huntley murders being in the news, but the decision reflected an underlying hesitancy.

**'Nominated Person' or 'Nearest Relative'**  
Apart from the centrality of the CTO issue, the government's original proposal to reassign the rights of the 'Nearest Relative' to a 'Nominated Person' (nominated by the patient or service-user) was popular with survivors. I would like to hear an account of why the final Act made a U-turn and reinstated the position of the Nearest Relative. This is defined according to a pre-defined rank order, such that, for example the older parent arbitrarily takes precedence over the younger, and parents take precedence over siblings, etc. The government rejected the Alliance compromise amendment which would have allowed the service-user to make a choice (e.g. through an advance statement) between

relatives. Again, this U-turn may have come about through people lobbying outside of the Alliance.

### **Advocacy**

The third main area of concern to service-users – advocacy – had a more positive outcome. All detained or sectioned patients – including ones on supervised community treatment - are to have the right to advocacy. The Government had originally drafted this into the legislation, then dropped it, then put it back in at the last moment. According to Mental Health Today, this was the result of "last minute trading between the Department of Health and House of Lords".

How the 2007 amended Act turned out, then, seems to have been more like a lottery than through the Government entering into a constructive dialogue with stakeholders! Chris Walker of NCVO (National Council for Voluntary Organisations) suggests in *Society Guardian* (10 October) that the government seeks to co-opt and mute the voluntary sector through the many consultation and engagement processes; and that the sector in turn threatens to substitute for, rather than supplement, the participation of beneficiaries (i.e. service-users, etc).

Remember, though, that service-users and survivors still managed to go ahead with a march through London just 2 weeks after the Alliance had decided to cancel theirs! Congratulations to people like Cully Downer for organising this! One of the downsides of the Alliance is that it had generally made it harder for service-users to make their feelings known. The structure of the Alliance meant that it was led by senior members of the charities and professions where service-users are not well represented. The national charities and professions need to maintain a relationship with the government, while service-users and survivors would have had nothing to lose through more aggressive campaigning. Stronger starting positions could have been established than the Alliance could muster.

*I should acknowledge that I was one of the reps on the Alliance from Perceptions Forum.*

## Shocking: An interview with Una Parker

***At a UKAN annual general meeting in the late 1990s our group members decided that UKAN should campaign that Electro Convulsive Therapy (ECT) be stopped until such a time as it was proved to be safe and effective. This has remained network policy to the present day, and with recent changes to the Mental Health Act, which included some changes in the regulations relating to ECT, we thought it was time to catch up with Una Parker, a long term campaigner against the use of ECT, and contact person for UKAN member group ECT Anonymous.***

***Una, what did you want to see in the revised Mental Health Act?***

Ultimately I would like to see ECT stopped altogether. ECT Anonymous has campaigned to see ECT taken out of the main part of the Mental Health Act and placed in the section that deals with 'dangerous treatments', such as psychosurgery. This would mean there was a lot more restriction on its use, for instance, that it could only be given with the full permission of the person involved, not forcibly as is the case now.

***So people are still forced to have shock in UK psychiatric establishments?***

They certainly are. It's surprising how many members of the public think shock stopped happening long ago, and don't believe people can be forced to have it, but it still happens. It's more common for people to be persuaded to have it without being told of the dangers, and because they are in a vulnerable state, they agree, and only find out about the real damage it can do when it's too late.

***Do you know the extent of people who are forced to have ECT in the UK?***

According to the 1999 Statistical Bulletin 59% of detained people who had ECT did not consent to treatment – 709 people. But what studies have been done to find the psychological effects of ECT on those people? From research study into the effects of torture that I heard at the



**Una Parker, ECT Anonymous**

1997 World Congress on Mental Health I had the impression that forced ECT treatment would be very likely to be experienced in a similar way as torture. People who are considered to lack capacity should not be treated with ECT unless they have stated consent in an advance directive.

***And apart from detained patients many more people are put under pressure to have ECT?***

People still ring me up because they've had ECT



recently, and often feel they have been tricked, without being told the full consequences. They are persuaded on the grounds that it will help, then feel betrayed when it doesn't, and they are left with all kinds of unwanted after effects.

***Do you think the use of ECT is falling?***

It seems to be falling in some places, whereas in others its use goes on, and sometimes increases. It's hard to say because statistics are hard to come by. We know that there were about 10,000 treatments in the UK in 1999. The Department of Health at that time said they would continue to provide statistics, but as far as I know this has not happened. It would be useful to have an annual check, particularly on forced treatment, although people who are pressurised to have ECT wouldn't be picked up by those figures (1).

***Do you think there were any gains in the recent change to the Mental Health Act?***

Stopping its use on people younger than 18 is to be welcomed, and also giving more weight to advance directives, although as so often in mental health, ultimately the doctor has the power to override the person's own opinion if he thinks the person lacks capacity.

***Earlier you mentioned research. I know that another recent study found that ECT causes brain damage, particularly memory loss (2). Are you aware of other research going on?***

There's not enough, but I'm pleased to hear that a researcher at Bristol University is looking into the experiences of gaps in autobiographical memory (your memories of your own life) for people who have had ECT in the last 15 years. But really there is already enough evidence, it's just that it is not being taken notice of.

***I suppose the argument continues to be that it helps some people. Why do you think this is not valid?***

Three separate studies in the 1990s by Mind, ECT Anonymous and UKAN all found that

roughly a third of people felt ECT had been helpful, a third found it had made little difference (i.e. it was ineffective), and a third felt its use had been harmful. Given the well-documented damage this treatment causes I can't believe those ratios would be tolerated in any other form of medicine.

***Yes, two consultants in the 1990s doing operations on children in Bristol were struck off for poor results, even though many parents supported them and said their own child had been helped. Quite rightly the fact that some people were helped was not taken as evidence that all was well, yet somehow in mental health we seem to accept that argument. Do you think the fact that such large amounts of damage are acceptable in mental health is a sign of lower standards, and of the stigma and discrimination towards distressed people?***

I think it must be that, because professionals don't listen to what people say to them about the various problems they've been having about memory. People should get help with memory problems. People who have been involved in the mental health system are not believed over physical health problems (3, so obviously anything we say about our mental health is even more likely to be dismissed

***So what can people do?***

You can let your MP know you are not happy about the ongoing use of ECT, particularly against people's will, and in cases where people are persuaded to have it when vulnerable. You can get informed and ask for the facts and figures. There really are better ways of helping distressed people, and it's time we stopped this treatment once and for all.

1. According to the *Electro Convulsive Therapy: Survey covering the period January 2002 to March 2002, England*, there has been a steady decline in usage since 1991. In the three months surveyed, 12,800 administrations were given to 2,272 people. These figures showed a 22% overall fall

in administrations compared with a similar period surveyed and reported in 1999. This situation is contrasted with the approximately 140,000 recorded ECT administrations in 1985.

The 2002 Survey was only the second attempt at ECT data collation and analysis from all English NHS trusts providing mental health services, and English private hospitals registered to detain people under the Mental Health Act 1983. The NHS aggregate data return method was discontinued in 1991, and replaced by Hospital Episode Statistics (HES) where much finer detailed data was proposed to be collated for analysis. However, ECT Survey data in comparison to HES data from the last quarter of 2001-2002 shows "clear evidence of the inadequate recording of ECT data on the HES system.....HES still appears to significantly underestimate activity". [www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalhealthcare/DH\\_4000216](http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalhealthcare/DH_4000216)

2. The elderly, women and people with lower IQs are the most vulnerable to brain damage, particularly memory loss, according to a large-scale study on the long-term effects of electroconvulsive therapy (ECT). In the New York study, published in the *Neuropsychopharmacology international journal*, (January 2007), researchers followed 347 patients for six months.

The research team, led by Harold Sackeim, who had previously supported the view that ECT is harmless, said the study provided the evidence that "adverse cognitive effects can persist for an extended period and that they characterise routine treatment with ECT". The "more severe and persisting" memory problems were found in those given ECT to both sides of the brain, leading the team to conclude there was "little justification" for such treatment.

3. See for instance 'Equal Treatment – Closing The Gap', published by the Disability Rights Commission in 2005.

## Resources

You can get a copy of the booklet *The Things You Need To Know Before Having Shock Treatment*, from UKAN for £2, which includes the cost of post and packaging.

The Electroshock Quotationary is an extraordinary collection of comments and quotes about shock drawn together by the campaigner Leonard Frank and friends at: [www.endofshock.com/I02C\\_ECT.PDF](http://www.endofshock.com/I02C_ECT.PDF)

See also,

[www.ect.org](http://www.ect.org)  
[www.mindfreedom.org](http://www.mindfreedom.org)

Alison Cobb from Mind helped us to clarify the implications of the changes to the 1983 Mental Health Act with regard to ECT. According to Alison the short version of the intended changes is:

- you can't be given ECT if you have capacity to consent and you refuse it except in certain urgent treatment situations.
- if you lack capacity then there must be a SOAD (second opinion appointed doctor) to authorise treatment, but they cannot do so if you have a valid advance decision refusing it (urgent treatment exceptions apply here too).
- if you are under 18 you get a second opinion whether or not you are detained even if you consent.

As the draft code for England says, "a certificate under section 58A can never authorise treatment of a patient who could consent, but has not done so."

In a bit more detail:

The new section 58A covers ECT and it applies to people aged 18 and over who are detained, and people aged under 18 whether they are detained or not. For people with capacity, ECT can only be given with consent. This consent must be certified by the approved clinician in charge of the treatment, or a SOAD (for under 18s it must be a SOAD). The only exception is in

certain urgent treatment situations. There are two sets of criteria of urgency that can allow ECT without consent or a second opinion, i.e. that treatment is:

- (a) immediately necessary to save the patient's life;
- or it is
- (b) a treatment which is not irreversible and is immediately necessary to prevent a serious deterioration of the patient's condition. The other two criteria for urgent treatment do not apply to ECT.

If a person lacks capacity they have a SOAD second opinion as now. But the SOAD cannot authorise treatment if:

- there is a valid and applicable advance decision made by the patient (under the Mental Capacity Act) refusing the treatment in question;
- a suitably authorised attorney or deputy objects to the treatment on the patient's behalf; or
- it would conflict with a decision of the Court of Protection which prevents the treatment being given.

Under 18s cannot be given ECT without a SOAD certificate, either saying that they have capacity and have consented and the treatment is appropriate, or that they lack capacity and the treatment is appropriate. If they are an informal patient and do not have capacity, there must still be normal lawful authority to give it, e.g. a court order or provisions of the Mental Capacity Act (if they are 16 or 17).

The draft reference guide to the Mental Health Act – i.e. the Dept of Health's explanatory guide that sits alongside the code of practice, covers this on pages 166-169 - it is the last download listed at: [www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_079842](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_079842)

**Terry Simpson**

## **Buddies Training Sessions**

In the near future, we'll be seeing the professionalizing of advocacy services to fit in with the new Mental Health Act. Advocacy was pushed for and promoted by service users as a model for people suffering mental health. There is a fear that because of these moves to professionalize it, the service user in desperate need of these services will be put off and not want to use this type of static service.

I believe that service users need to start looking at some alternative ways of supporting each other through particular times of distress and needing support. So I am providing training in:

- **Supporting and Advocacy Skills**

For service users, survivors, carers and communities, there needs to be a move by all to gain some form of understanding about mental health and the issues surrounding mental health so I am providing a session where individuals can explore mental health and gain understanding from a mental health sufferer/survivor perspective:

- **Understanding Mental Health**

If you are interested in attending either session, or in running a particular session yourself, please contact:

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## A Conversation With Thomas Szasz

The Centre For Excellence in Interdisciplinary Mental Health is a piece of survivor friendly territory right at the heart of Birmingham University. It seems unlikely at first that money would be found for a plush suite of offices dedicated to the cause of taking radical messages about mental health to the rest of the university and beyond, but that's what seems to have happened. Mostly staffed by service users/survivors, the Centre runs a series of events featuring people who have made a worldwide contribution to ideas about mental health, and on 19 September 2007 Thomas Szasz was the first speaker in that series.

All I knew about Thomas Szasz beforehand was that he'd written a book called 'The Myth of Mental Illness', (which I thought was a great title), and that back in the 1960s and 70s he was second only to R.D.Laing as the great anti-psychiatrist. I was expecting an ancient wizened man who we would have to revere and listen to politely, but the reality was somewhat different. Although 87 years old at the time Thomas Szasz was a sprightly, bright-eyed man, and his sharpness and memory seemed completely undiminished.

He talked for about twenty minutes, then the 25 people in a circle around him were invited to make comments and ask questions. His basic tenet seems to be that life is a series of challenges, a blessing but a burden too, and that people go 'mad' because life has become too unpleasant. Calling this process an illness is part of a system of social control, and according to Szasz 'medicine has become an arm of the state'. He commented that 'illness' is a concept that only dates back as far as the 1850s. Before that medicine was based on millennia old ideas about 'humours' which the new science could find no evidence for. 'Illness' is measurable, and belongs to the realm of chemistry and physics, whereas 'madness' according to Szasz is more like art or language, which are not scientifically objective, but only have meaning within a certain social



**Thomas Szasz**

context. So he believes that hallucinations or hearing voices might be a way of communicating with ourselves when no-one else seems to be listening. Delusions might be simply beliefs that are unusual to other people, and possibly attract attention when they have an element of threat. But in any case all these 'symptoms' are understandable in terms of our lives and social relationships and calling them 'illness' is just a means of keeping us under control.

In support of this view Szasz argues that physical diseases don't come in and out of fashion, whereas psychiatric diagnoses seem to do exactly that. He wrote extensively in his 1970 book 'The Manufacture of Madness' about what was then considered the 'illness' of homosexuality. Now society has changed and this has been quietly dropped as a diagnosis. Similarly 'hysteria' was eliminated in 1980. The point is we didn't find a cure, our ideas about these things simply changed.

Szasz doesn't think we should just abandon people who are suffering. Rather we need to treat each person as an individual, and think

about them in the entire social context of their life. He believes that we do need helpers, just that organised medical practitioners are no more qualified for this role than anyone else. He suggested a role for therapy if it helps increase self-determination.

An approved social worker defended her role of sectioning people for their own protection, but Szasz rejected this, saying 'it's not your business to interfere.' He went on to make a fascinating point about using mental health law to stop people doing violence. 'Where does it stop? Should you stop people killing each other in Iraq?'

He was asked a searching question about his links to Scientology, and the organisation the Citizens Commission for Human Rights (CCHR), which he set up and is funded through Scientology. He answered that the CCHR is the only organisation that has money and can help people get out of the prisons called mental hospitals, and justified the link with Scientology on that basis. He denied that Scientology was coercive.

Szasz is not actually anti-psychiatry as such, just against coercive psychiatry. He said he has no objection to 'psychiatric acts between consenting adults', and believes in freedom and responsibility. From this and other statements it became clear that Szasz is a big supporter of capitalism, and the free market. When it was pointed out that current capitalism had led to the development of the big multi-national drug corporations which were skewing the debate about mental health so much, he was very much against corporations, and, for instance the widespread drugging of children, which is the result of their aggressive marketing. He seemed to see the corporations as part of the problem as much as the coercive power of the state, and to be in favour of a much purer vision of a society of empowered individuals. Interestingly, when asked about children, he said he had no objection to children being coerced. 'It's their job to be coerced', but only up to the age of 18, when they become responsible

citizens. This puzzled me a bit, since once you allow that it's ok to coerce one section of the population, doesn't that open the floodgates?

I don't remember sitting for two hours and being so completely absorbed at a mental health event for years. I came away feeling really stimulated and that I'd met one of the most interesting and forthright thinkers in the field.

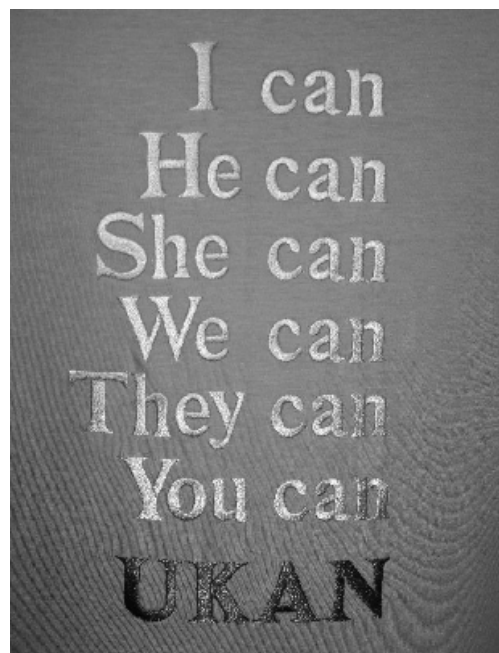
*You can see a film of the event on the Centre of Excellence website by following the link at:*

**[www.ceimh.bham.ac.uk/tv/szaszpreview.shtml](http://www.ceimh.bham.ac.uk/tv/szaszpreview.shtml)**

*In fact the whole site is worth a good look around, and, for instance, you can see one of the subsequent talks 'A Conversation with Richard Warner', six films of the session on 'Recovery from Schizophrenia Throughout the Twentieth Century' by following the link:*

**<http://www.ceimh.bham.ac.uk/tv/WarnerPartOne.shtml>**

## **Terry Simpson**



## User involvement and mental health services

Despite government policy and agendas that services should involve the people that use them, the involvement of the mental health service user, their families and their communities doesn't seem to be fully happening. In fact, the opposite actually seems to be happening. It is the professionals who seem to dominate and generate strategies and action in the mental health field whilst service user, and carer, involvement is limited. Also, in my experience, individuals are often chosen for their particular stance on things (i.e. safe, don't rock the boat type stance). However, I have often seen positive outcomes when service users or carers challenge things.

What seems to be happening today is the closure and non-support of self-help groups and also the withdrawal of people who have been prominent and involved in the user movement in the past. In this time of so-called involvement there seems to be a kind of apathy within the service user movement. This should be a worrying factor for all of us as it creates a re-occurring negative image within the mental health field.

The professionals and the government should be worried that they are determining the agenda for the people who need and use services. The professionals' stance seems to be one of keeping their jobs, positions and work practices. This isn't helpful as it leads to whole groups of different people feeling devalued, disempowered and using services that don't meet or demonstrate understanding of their needs or wants.

Families and carers are frustrated that the services their family members are using are not helping. There is also a repetitive and underlying negative message being sent to all who need or require mental health services now or in the future - that as service users we are not coherent enough to have any opinions, and that, if we do have opinions, that our voices, views

and opinions are not welcomed, wanted or valued. It is not surprising then that people who have mental health problems fear to say so, or seek help.

The mental health system and those involved in it need to take a step back and look at what messages are being sent to those at the grassroots level. They also need to look at the consequences of such messages, for example, the intense impact on Black and ethnic minority service users, their families and communities that can lead to exclusion.

I am afraid that there could come a time when everything is so professionalized that those needing mental health services will feel so alienated from them that they will not use them nor seek them out in their hour of need. I am concerned that taxpayers' money is being wrongly used and wasted on services that are of no use to anyone, except those working within them.

The questions to be asked are: Does the mental health system care about this lack of take-up? Or does it keep doing what it is doing regardless of these consequences? Carrying on regardless will continue to impact badly on the mental health sufferer, with consequences often being felt by Black and ethnic minority service users and their communities. And blame for negative incidents, which are bound to happen sometimes, is wrongly allocated and creates a revolving door of blame, which ends in one place - back on the mental health sufferer and not the professionals, who always have a succession of reasons for the event happening.

Policies have to be implemented, monitored and action taken if they are not. Until this positive action is taken, things will carry on regardless of negative impact and cost to all concerned.

**Carol Jenkin**

## Artists at MIND



**Sarah Cocker**

The Mind in Bradford art group has been on the go since April 2001 and is going from strength to strength. Groups are held on Tuesday and Thursday evenings from 6.30 p.m. to 8.30 p.m. and have been attended by at least a hundred people over the years. Members drop in and out as they please, some attend every week, while others attend every now and then. Being a very active group, materials used vary from traditional drawing and painting mediums to collage, spray paint, oil pastels and sculpture.



**From left to right: Michael, Keith and Issy**

But how did it all start? Mind in Bradford began in 1986 and was a user-led local group. Sue Wilde (then Sue Dodsworth), acting Chair Person from 1997 to 2003 and a user of mental health services for 15 years, attended some art sessions facilitated by Stuart Wilde at Anomie, an art group made up of outsiders, insiders and artists all linked with mental health which ran during the 1990s. Based on this experience, Sue asked Stuart if he would be interested in facilitating an initial 10 art sessions at Mind. He accepted the offer and, due to its success, is still here. Stuart has paranoid schizophrenia and has been a regular user at Mind since 1989. He views his facilitating the art group as putting something back into Mind. Stuart has a background in art – he has a Fine Art degree, completed a community arts training program and has facilitated other art groups. (Has anybody made a connection between Sue and Stuart's surnames? Yes, they met through the art group and got it together in 2001 and married in 2007 – congratulations to them both!).



**From left to right: Keith, Clive, Sue and Stuart**

In the beginning groups were held in the kitchen / dining area, which proved to be a challenge. A room was made available in 2003, which is still the art room today. The group is run on a shoestring and, as Stuart puts it, 'It has been a labour of love, but I've learnt a lot and love it! The art group has helped people move on in their lives, not just through art, but in being part of a group, having companionship, and in confidence building.'

There is a permanent display of artwork on show in the centre, which is regularly updated. Spin-offs from the group include exhibitions of group members' art work at Care Foundation conferences, an exhibition at the Recovery and Discovery conference at Bradford University in 2003 and two big shows at St Mary's in Bradford – a drop in for the homeless.

Members find the art group invaluable. A key function of the art group for Mind is that it allows 'self help' in a safe, non-judgmental setting where people are free to express their feelings, experiences and thoughts. Terry says the art group 'takes us out of from what we are suffering from, focusing on something useful, something different, something therapeutic'. For Keith 'It takes me out of everyday stresses and strains. You meet people from all walks of life with similar health problems. It's a different environment, getting me out of my flat.' Graham commented 'It's an opportunity to empty your mind of your troubles.'



**Sue and Stuart Wilde**

So how did I become involved? I contacted Mind in the hope of helping out with the art group in some way as I was thinking of changing career, from Design Manager to becoming an Art Therapist, and wanted some experience with art in the mental health sector. I attended the art group for five weeks, then, as luck would have it, Stuart took a three-month break to get married to Sue and take a long earned rest. I was asked to facilitate the group in Stuart's absence, and on his return was asked to facilitate an additional group on Thursdays, which started in January 08. My background is in art and design - I have a degree in Product Design and have recently completed the Art Therapy Foundation Course at Sheffield University. My experience at Mind helped me to make the decision to apply for the MA in Art Psychotherapy at Sheffield University,



**Graham Binns**

which I have subsequently been accepted on to. I attribute my success to my experience at Mind.

Where from here? I organised a trip to visit the Gustav Klimt exhibition at Tate Liverpool which proved a big hit with all who attended. It was a great day out, giving us all inspiration for our future artwork, with many suggesting ideas for other art-based days out as a result. Stuart and I have plenty of ideas for the future, so who knows what will happen next - watch this space!



**Left to right: Andrew, Graham, Howard, Simon and Issy outside TATE Liverpool**

**Sarah Cocker  
Mind in Bradford**



## Greater Goings On ...(than you could ever guess)



A joint project by UKAN, Asylum Associates and Sheffield Hallam University (SHU), *Greater Goings on... (than you could ever guess)* is a collection of poems by people with experience of mental distress. It includes an essay by Peter Campbell on the value of service

user poetry in health care training as well as a specially commissioned poem from Ian MacMillan and beautiful colour illustrations by Barbara Kirk.

The unique publication is the brainchild of Neil Carver, a SHU lecturer in Mental Health Nursing. Neil and his colleague Mental Health Nursing lecturer Nicola Clibbens, and UKAN'S Terry Simpson and Justine Morrison were the book's editors. Most of the poems featured were chosen from entries to the national *Poems for Learning* competition. A launch event in December 2007 featured Ian MacMillan and Terry Simpson and was attended by poets, service users, students and professionals.

Neil and Nicola told UKAN what has been going on since the book launch: "The main thing that has been happening is that poems are being integrated into particular teaching sessions where they are most relevant. So far it's been a great success! Because the poems are so personal the students seem to really feel an



Left to right: Terry, Ian, Neil, Nicola & Justine

emotional connection with the writer and this motivates them to debate and explore the issues in the poems in much greater depth. For instance first year students have been debating just how people go about getting help. As professionals we can use impersonal technical terms such as 'referrals' or 'pathways to care' but the poem used gives a real insight into the actual experience of being 'a referral'.



Glyn Butcher reads at the launch

The book is also now on the mental health nursing reading lists and other health related courses in the University are utilising the poems. Looking to the future there are many possibilities. There is a wealth of creativity out there and it would be great if we were able to hold future competitions that could involve, say, prose or photography as well as poetry".

### A Review of *Greater Goings On...* By Lynda Steele

This collection of intimate poems skilfully describes mental distress, often at its worst, and how it is managed on a day to day level.

In "Unwell Again", by Martin Treacher, the line "Capacity to interact seems lost and gone for good" sums up the paradoxical element which so many of the other poets include, which is that during periods of extreme mental distress, the feelings of loneliness and isolation seem too much to bear, but "letting someone in" has no meaning.

Another theme echoed in the poems is the experience of lack of understanding from other people, family and friends included, who are apparently "normal". I hate this word but it is relevant here as it is part of the problem;

labelling people in negative terms. In "What is Understanding" by Jan MacAskill it appears that she has been given a label which she is afraid of owning. Now, "I'm one of them too," and she associates "them" with,

"...schizophrenics running  
Round with knives.  
Dangerous. Not living normal lives. "

It seems that now, she will have to reevaluate her position. Is she one of "them" or one of "us". Perhaps, like a lot of service users with labels, she may attempt to keep it a secret to avoid the stigma and lack of acceptance in general.

Along with isolation and lack of empathy, there is also a thread of fear running through a number of the poems. David Kemp, in his poem, says,

"WE NEED YOUR SUPPORT, YOUR HELP,  
AND YOUR AID.  
WE NEED TO BE SHELTERED WHEN WE GET  
AFRAID."

His poem, written completely in capital letters, conveys very starkly the mix of painful feelings I mentioned earlier. In his very honest and detailed account of his own experience, he begins with a narrative covering the raw facts about the effect his illness has on his life. The nightmarish scenario of losing a sense of oneself is highlighted in the line, "Now your life's not your own, you have no control". This sensation is very difficult to understand for someone who has not felt it. Many of the feelings described by David and the other poets are experiential. They are outside of our language but these poets have made a brave and genuine attempt at using the form of words to capture the unimaginable...Greater Goings on...

If you would like a copy of **Greater Goings On...** please send a cheque for £6 made payable to Asylum Associates to:

**Asylum Associates  
The Limbrick Centre  
Limbrick Road  
Sheffield, S6 2PE**

## **Hearing Voices: the personal stories of voice hearers**

Intervoice and Ben Gray are putting together a book on the experiences and stories of hearing voices.

The emphasis is about all sorts of voices and voice hearers and all sorts of points of view and personal journeys.

What did the voices say? How did they make you feel? What was the reaction of family, friends and mental health professionals?

If we are going to change and improve voice hearers' lives, then your stories are the first place to start.

If you would like to contribute to this book, then please send your story to the email below.

You should try to write between 1- 10 pages on your experiences (300- 3000 words).

All profits will be donated to the funding of Intervoice.

**Email: [voices2009@hotmail.co.uk](mailto:voices2009@hotmail.co.uk)**

### ***Dark Angels: a novel***

I thought UKAN might be interested to know that I have written a short novel *Dark Angels* about a mental health nurse who is victimised for 'blowing the whistle' on patient abuse at the hospital where she works.

It is published in both e-book and paperback and is available from:

**Website: [chipmunkpublishing.com](http://chipmunkpublishing.com)**

**Email: [info@chipmunkpublishing.com](mailto:info@chipmunkpublishing.com)**

**Robert Dando**

## FIGHTING PIGEONS

For Frank Bangay

One can't always track the music within  
But you know it's there.

Wings beating, wings beating,  
Away from the gunfire around the asylums,  
The schizophrenia arguments, the great psychopharmacy  
debate.

A need to convey more pressing messages.

Down to the streets of Hackney –  
Mare Street, Mayola Road.  
Flowers in window pots, grain on the pavement.  
Poems on a postcard, on posters,

Hand-written pages dropping through your letter box  
In a brown envelope  
To hit the right spot during a day of despair.

Wings beating, wings beating.  
Falcons becalmed against the skyline.

Away from the gunfire around the asylums.

Fighting pigeons,  
Leaving asylum.

Fighting for peace.

**c. peter campbell**

In the early 1980s, before I first met Frank  
Bangay, he was a member of a group of musicians  
called The Fighting Pigeons – I have always  
thought it was a wonderful name for a group.

**Suzan Arisoy's** *Bi-Polar Recovery:*  
*twenty years of manic depression*  
*and medication in poetry and prose*  
is available as an e-book from:

**chipmunkpublishing.com**

## Consultation

We'll have a great big meeting  
and pull everybody in  
we'll let them air their grievances  
and bare their teeth at sin  
we'll make a point of gratitude  
a policy of choice  
to show them that we really care  
and that they have a voice  
and when the meeting's over  
and they've all had their say  
we'll gather the opinions up  
and throw them all away

**Terry Simpson**

## The Bi-Polar Express

Less ladders, more snakes  
More bumps more breaks  
Hard times hard knocks  
Sharp rocks, big shocks

More colours; loud, bright  
Grand vision – insight  
Mind expanding; wide, deep  
More day, less sleep

Tall orders, short shrift  
Wasting money: spendthrift  
Seeing links; knowing things  
Flying high, open wings

Crash landing, hit the ground  
Found a penny – lost a pound  
Watch the colours; see them fade  
As it rains on my parade

**Suzan Arisoy**

## Listening to the Silences: In a world of hearing voices by Roy Vincent

In the autumn of 1979, I began to hear voices and experience other phenomena, and have done so ever since. Thus in over 27 years, I have never been free from intrusions that enter blatantly or subliminally into my mind and mental faculties, and forcefully or subtly into my body and senses.

I use the word 'intrusion' deliberately, for that is what they are – not the product of an aberrant mind nor of a diseased brain; not hallucinations nor yet delusions. Because of what I was doing at the outset in 1979, I have no doubt, not the slightest shadow, that what I experience is of spiritual origin. Use of the word 'spiritual' to some immediately suggests 'religion', 'spiritualism', 'theology' and the like – words that to many are off-putting, and likely to prevent them from even opening my book. Forget such preconceptions. I am an engineer and my approach and language are those of an engineer – as precise and realistic as I can be within a realm of experience that is most imprecise and unrealistic.

From the beginning I have kept notes, which from 1998 began to turn into coherent writing as I became computer literate. In my parallel reading from the field of mental health, I found what are called 'The First Rank Symptoms' of schizophrenia, and I realised that I had experienced them all, and recorded and written of them, albeit in my own words. Yet – and this is the most important point that I am desperately trying to make – I have never been ill from this cause, and neither have I, nor would I seek help or intervention from the world of psychiatry or that of religion. On the contrary, I write to inform those in both such worlds who endeavour to help the mentally ill and disturbed.

As fast as I wrote, my words were read avidly by friends who work in the field of psychiatry. As they read, they wanted to know about 'before' – i.e. about my life before the onset of the intrusions. I realised that I should indeed write



**Roy Vincent**

about 'before', in order to separate it from the events of 1979 and what has followed, for apart from the fact that both sequences happened to me, they are totally unconnected.

What happened 'before' is a story in itself, and it forms the first part of my book. In 1961, I had a successful career in the nuclear industry – a career of which I was robbed through the consequences of a medical misdiagnosis, and inappropriate and unnecessary medication. What is now known to have been a Cryptosporidia infection was treated as if 'nervous', and I began a life with Librium. After two years continuous use, an addict, dependent, and showing many of the side-effects of the drug, I began a 'psychiatric' year that opened with two episodes of cold turkey, then hospitalisation for a total of twenty weeks, 23 E.C.T.s, 'experiments' with a variety of drugs such as Tryptizol, Melleril, Valium, Pertofran and assorted benzodiazepines and barbiturates, plus insulin shock 'therapy' – and that ended with a farcical second opinion from someone who went on to become a doyen in the world of psychiatry.

I retired early with my career and home

wrecked, and in total, in real terms, I have lost over a half million pounds. But hard though it may be to believe, effectively I began a new life. It is a life that has been and is both fascinating and rewarding – even though after four years it included the events that then led to the spiritual intrusions. For, as I found out, not only are there the malevolent – the ones that plague the ‘schizophrenic’ - but there are also the benevolent.

The whole story is there in the book – of how under the tuition of renowned healer, the late Bruce Macmanaway, I found that I also had a talent to heal. It is a talent that I have used hopefully to good effect, and which has brought me many rewards in encounters with wonderful people.

My ‘engineering’ approach has led to a study of our interaction with the electrical environment, and an understanding of aspects of electricity and health. Becoming aware of the electrical nature of acupuncture, I expanded my knowledge and experience in this field also.

I identified over thirty different ploys that are used by intruding ‘entities’, and describe these in detail. I also realised that channels into the minds of the vulnerable can be opened via such activities as hypnotism and hypnotherapy, past life regression, Reiki, channelling and various forms of ‘divination’. There are cautions, too, for those involved in spirit release, and many of the esoteric practices that involve ‘opening the mind’, and references also to the possibility of such ‘recreational’ drugs as cannabis and mescaline having the same effect – the effect sought by the shaman figure and such. I speculate too on possible links with manic depression.

Among my heroes are such diverse individuals as Galileo, Paracelsus and Nikola Tesla, and I quote and draw conclusions from them as I do from the writing and communications of a wide variety of psychiatrists, psychologists and others in the field of mental health, such as Irving Gottesman, Julian Jaynes, Martin Roth, Kenneth McAll, A.W.Drummond, Wilson Van Dusen, Richard

Mackarness - to name a few. I have also drawn from that well-known hearer of voices and seer of visions, Teresa of Avila.

I am making my book freely available, for it is important that it is read. The only price that I ask is that you should use it or put it to use for others who are struggling within the morass that their mind has become, and that you should tell others of its Web address. I am now over 80, and still have many other things to achieve, so I cannot undertake to respond to any or all communications, but will try. In the meantime I can join poet W. B. Yeats, and speculate –

### **Where My Books Go**

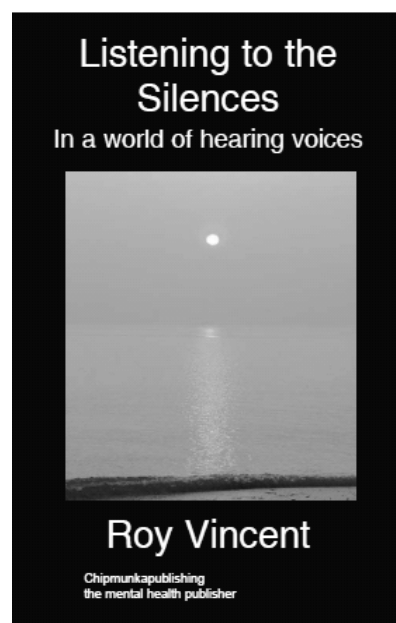
All the words that I utter,  
And all the words that I write,  
Must spread out their wings untiring,  
And never rest in their flight,  
Till they come to where your sad, sad heart is...

***Listening to the Silences: In a world of hearing voices*** (ISBN 9781847477590) is available for free in ebook form at:

**[www.royvincent.net](http://www.royvincent.net)**

It is also available as a paperback from:

**Website: [chipmunkpublishing.com](http://chipmunkpublishing.com)**



## **Pongo's Discharge Summary: a short story**

If you've ever been a psychiatric inpatient you will have had a discharge summary. A discharge summary is a report written by hospital staff which is sent to your GP and becomes part of your medical notes. It's worth getting hold of a copy of yours if you have one - it can be quite an eye-opener.

This piece originated in a project set by a creative writing tutor. She found a story on the internet about humans spending time in an ape enclosure at an Australian zoo. A psychologist was incarcerated with them and the experiment was supposed to lead to improved conditions for apes at the zoo. We were to write a story about this situation. Now, I don't know much about zoos - except I wouldn't want to be in one - so I imagined an alternative experimental scenario...

*On admission, Pongo was agitated and confused, showing highly disturbed behaviour. He bounded around the day room and swung from the curtains. He refused to engage with staff and shrieked at them from the top of the bookcase. He appeared to staff to be responding to auditory and visual hallucinations.*

*The team considered that Sectioning and medication were the way forward. Pongo was commenced on Haloperidol (20mg) and Diazepam (10mg), which initially had to be administered by the Control and Restraint team. After a few days Pongo settled well and his behaviour showed a marked improvement. He queued up for his medication at medication time, and was fully compliant. He spent the 8 hours per day he was awake slumped on the sofa watching Channel Five with the other patients.*

*Pongo was observed to have dietary issues and often flung instant mashed potato around the dining area. However, he liked the syrup sponge pudding with custard and frequently had seconds. On Friday afternoon, when fresh fruit is made available to the patients, Pongo became disruptive. All the fresh fruit was subsequently discovered hoarded in Pongo's room. As a result he lost garden privileges. Our Consultant diagnosed an acute schizophreniform disorder with psychotic features. There is also pencilled-in an alternative diagnosis - chimpanzee? -*

*but this condition does not appear in any of the psychiatric textbooks.*

*Pongo's behaviour on the ward was generally appropriate, except on one occasion when he helped himself to the night shift's Chinese takeaway. The Control and Restraint team were called and rapid tranquillization took place. That'll teach him.*

*During Pongo's stay a Mental Health Act Commissioner visited the Unit. She was impressed by the facilities, spoke privately with several of the patients and noted their concerns. One of the more deluded patients apparently complained that there was a monkey on the ward. The Mental Health Act Commissioner recommended in her report that the ward obtain a new TV aerial so that the patients could watch channels other than Five, and mentioned that she enjoyed her visit, especially the excellent lunch she had with the Ward Manager.*

*Pongo was discharged, prematurely in the opinion of many of the staff, when an RSPCA Inspector made an unexpected visit and closed the Unit with immediate effect. A prosecution for cruelty is pending. Our defence will be that a doctor ordered it as treatment and therefore no cruelty was intended, or indeed took place.\* Doctors are nice people and always have the best interests of their patients at heart. Patients may complain, but their perceptions and experiences are not as valid as those of the doctors because, well - they're mad. Who says they're mad? The doctors do. And the doctors are always right.*

*Prognosis - good, provided Pongo continues to take his medication. We will be sending the Home Treatment Team round to make sure that he does.*

**Florence Nytol**  
**Staff Nurse**  
**JC**

*\* I heard at a mental health conference once about an anonymous patient ( I think from Germany) who took a case to the European Court of Human Rights. This person was strapped to a bed and force fed. The court decided that this does not constitute cruel, degrading or inhumane treatment for - as I understand it - much the same reasons as detailed above.*

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# UK Advocacy Network

## Member Groups Questionnaire

### *Future direction / Priority areas for UKAN*

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**Where “1” is equal to “Definitely No”, “3” is equal to “No opinion”, and “5” is equal to “Definitely Yes”, please signify your opinion by circling one of the five numbers for each of the following questions:**

1) Do you feel UKAN should continue to deliver mental health advocacy training and development?

1                      2                      3                      4                      5

2) Do you support the concept of a National Advocacy Qualification?

1                      2                      3                      4                      5

3) Should UKAN look into developing accredited training materials and courses in relation to the National Advocacy Qualification?

1                      2                      3                      4                      5

4) Should UKAN have a campaigning and representational function in respect of national issues which affect mental health service users?

1                      2                      3                      4                      5

5) Do you think UKAN should become involved in helping to develop effective service user participation processes across the U.K.?

1                      2                      3                      4                      5

6) Should UKAN offer reviews of advocacy service provision to projects around the U.K.?

1                      2                      3                      4                      5

7) Do you think UKAN should offer guidance / assistance in relation to helping to develop and maintain Effective Independent Mental Health Advocacy within U.K. Prisons?

1                      2                      3                      4                      5



8) Should UKAN expand its current remit to becoming a national centre for good practice dissemination on independent mental health advocacy and service user participation?

1                      2                      3                      4                      5

9) Do you think UKAN should develop specific training materials in relation to assisting service users to become their own advocate?

1                      2                      3                      4                      5

10) Should UKAN carry out National Surveys on key issues such as ECT, the National Advocacy Qualification, funding for independent advocacy, medication, etc.?

1                      2                      3                      4                      5

11) Should UKAN continue with publishing *The Advocate*?

1                      2                      3                      4                      5

12) If you think *The Advocate* should continue, how often should it be published (subject to adequate funding being available)?

Annually                      Quarterly                      Monthly

Please feel free to add any other comments below (Please use additional sheets if you need more room)

.....  
.....  
.....  
.....

Name / group name: .....

Did you complete this form as an individual or on behalf of your group? .....

**Thank you for taking the time to complete and return this questionnaire by  
Thursday 9th April 2009**

**Please return completed form to:  
UKAN  
C/o 8 Beulah View  
LEEDS**

