**Centre of Excellence in
Interdisciplinary Mental Health (CEIMH)
The University of Birmingham**

# Two Decades of Change

## CELEBRATING USER INVOLVEMENT

**2 November 2006**



**Marion Clark and Tony Glynn**

# Acknowledgements

To the speakers who provided food for thought and discussion, reflections on past experience, inspiring stories and some ideas on the direction of user involvement.

To the musicians, drummers and poets.

To the CEIMH staff for organising and providing financial support, the caterers for wonderful food, and to Angus who stepped in to get us the all important PA system!

Suresearch members and especially Jean and Elle who helped make the day a success.

To the participants, for engaging wholeheartedly in this successful day.

Musicians:

| | |
|---|---|
| Screw Loose : | Warren Pascall (bass) |
| (Cannock MIND band) | Neil Simpson (drums) |
| | Chris Peters (electric guitar) |
| | Colin Pritchard (lead guitar) |
| | David Howes (rhythm guitar) |
| | |
| African Drums: | Lloyd Tatham |
| | Helena Madden |
| | |
| Singers: | Peter Grinnell |
| | Barbara Norden |
| | Carl Thomas |

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# Introduction

# Introduction

*"When people not used to speaking out are heard by people not used to listening, real changes can be made"*
*(John O'Brien, 1992).*

## Why this event?

In 2006 Colin Gell, a mental health service-user activist of many years approached the Centre of Excellence in Interdisciplinary Mental Health (CEIMH) with the idea of hosting an event that would celebrate 20 years of service-user involvement. He knew that national MIND would be holding such an event but recognised that for a lot of service-users it was not always possible to travel across country. On November 2nd 2006 Suresearch (a network of service-users, carers and academic allies) and CEIMH staff who have themselves been on the receiving end of mental health services, organised an event where service-users and their supporters could come from across the West Midlands area and exchange their experiences, history and hopes for the future.

The aim of the day was to provide participants with a variety of opportunities for reflection on the history of user involvement, discussion and information exchange, as well as an opportunity to celebrate what has been achieved over the past two decades and identify what needs to be done in the future.

The event brought together more than 60 people with lived experience of mental health services from the West Midlands area. People with many years' experience of user involvement in all areas, e.g. challenging traditional concepts of mental distress and mental health, working to change services, delivering training, and research were involved.

A warm and welcoming atmosphere was seen as an essential for helping everyone to feel involved in elaborating and building the user knowledge base. The atmosphere created was greatly enhanced by the musicians and singers who took part, the quality of the venue, the wonderful food and the welcome and assistance from the CEIMH team.

From the start those involved agreed that the day was not going to be 'just another conference'. It would be a day of celebration, reflection, good food and music where people could participate as little or as much as they wanted. Every opportunity was given to people to enable them to have their say. These included: discussion groups, video-box, a question and answer session with a group of influential service-users who addressed people's concerns for the future and a 'time-line' which would capture people's journeys through the mental health system over the past 20 years.

The day began with refreshments and Carl Thomas welcoming people with his music. Colin Gell launched the event with some 'eye-opening' details about how and when mental health service-user involvement started and what had been achieved as a result.



Carl Thomas

He informed us that John Perceval (a relative of a British Prime Minister) started the first user group in England in 1845. It was called 'The Alleged Lunatics Friends Society' and lasted for ten years. (For full text of Colin's speech, see pages 32-34). He was also clear that the day was about celebrating ourselves and the difference we had made together by becoming involved as service users.

Peter Campbell, another veteran activist, followed with a compelling keynote speech in which he reflected on his involvement since 1985 and what it meant to him. Starting with his early days of using services when he was in and out of hospital and feeling isolated, alienated and without a voice, Peter recalled what a difference advocacy made to him when he was in ward rounds. He also highlighted how positive it was for him to meet other service users and how he learnt a lot about hearing voices and self-harm as well as his own distress (for full text of Peter's speech, see page 36-48).

After a break with refreshments and music, people moved into discussion groups. Each group considered three questions:

- What is user involvement and what has it meant to you?
- What were your experiences of user involvement?
- What are your hopes for the future?

All of the groups generated positive views about user involvement. Many people described their experience of involvement as 'keeping them sane' and 'giving them a sense of direction'. Many hopes were shared for the future. (see page 5-7 for full details of what was shared in the groups).

By lunchtime the whole Centre was buzzing with people deep in discussion, enjoying a wonderful meal and the live music provided by David Howes and 'Screw loose'. There were also opportunities for people who wanted to share their views and experiences through the video box and time line.



'Screwloose' in action

The afternoon session opened with inspiring stories of journeys through mental health services and recovery, with opportunities for participants to tell their stories (see pages 9-18). After this there was a question and answer session chaired by Mary Nettle, (service user consultant) with panel members Barbara Crosland (User Involvement lead from NIMHE/CSIP) Mark Hillier, (lead from Patient and Public Involvement/Social Inclusion) and Terry Simpson (United Kingdom Advocacy Network-UKAN). Panel members responded to participants' questions on a range of issues (see page 23-26 for a summary).

People then moved on for tea, more music and poetry. Before they went home participants were asked to fill in evaluation forms about what they thought of the day (see page 28-30 for details).

# Group discussions

## Group discussions

This part of the day was about hearing from service users about what they thought about what user involvement means, their experiences, good and bad of involvement and their hopes for the future.  (Quotes from participants are in italics).

### What does user involvement mean to you?

Most people made it plain that what they valued was being listened to as equals; being asked about treatment and services.  But they were also concerned that the changes made as a result of what they said should be real, not tokenistic. People acknowledged that service users are now welcome in places where they were not in the past and that meant that barriers were being broken down.

> *"I want to be part of the solution, involved to make a difference".*

Views about meeting and working alongside other service users centred around the therapeutic and empowering nature of involvement:

> *"It's being part of something and in a safe, non-judgemental environment, not feeling alone".*

- Feeling connected, sharing experiences, gaining knowledge, doing things never done before.
- Having a network of people who understand to call on for support.
- Having a voice and the confidence to negotiate your own care plan.

> *"It's feeling encouraged and gaining self-worth, confidence and self esteem".*

Experiences of being part of user involvement initiatives also revealed practical difficulties such as:

- Payment for involvement and funding for groups can be variable.
- Funding for projects can disappear.
- The problems of being the one service user representative on a committee or board.

Experience of user involvement also highlighted that it was necessary to:

- Learn from work done by people with learning difficulties.
- Give publicity to positive experiences.
- Generate political activity, such as lobbying Parliament.
- Develop work on cultural awareness and ensure all perspectives are included.

## Hopes for the future

Participants shared a very comprehensive set of views about what was required for better mental health services and equal rights for service users. These were:

**Education, training and employment for service users**

- Access to education and training to develop and sustain wider involvement.
- Greater opportunities generally to build skills and confidence.
- Re-employment of service users who have had to have time out.
- Mental health organisations to be involved in the education of employers so that attitudes to employing service users change.
- More support for service user workers.

**Treatment and services for service users**

- Access to alternatives to "normal" medication.
- More counselling to be made available.
- Holistic approaches to be available.
- Treatment should be a matter for negotiation; self management should be an option.

- Independent user-led treatment where people feel safe.
- We need to know whether services have actually improved in the way service users have suggested.
- We need more evaluation of services such as Home Treatment, and more ward visits to check on standards of care.

**Staff training**

- We need health workers to work alongside service users, flexibly and across boundaries.
- Staff need exposure to user involvement at an early stage in their training.
- There should be an 'expert by experience' in every mental health team to help change views and culture.

**A stronger voice**

- We need a strong national voice.
- We need a national  network of user groups, to increase capacity.
- We need more lobbying of Parliament.
- We need to build national and international links with service users.

**Equality**

- Inclusion must mean what service users say they need.
- Every service user should have user involvement explained to them.
- Services which are respectful and compassionate should be maintained.
- Genuine advocacy should be available to all.
- All people should be valued.
- We need to find ways to reduce stigma.
- Young people need their own organisations to reflect their needs.
- A Centre like CEIMH should be permanent.

# Stories

*The afternoon session opened with inspirational stories of journeys through mental health services and recovery.*

## Jean's story

Jean gave a very moving account of how being in a psychiatric hospital really changed her life. After an emergency admission into the Queen Elizabeth Psychiatric Hospital (QEPH), Birmingham which Jean found very traumatic she was put on a lot of medication as well as being told that she had to have ECT.  On discharge, Jean recalled going home to an empty home with only her dog for company.  She told us that after weeks of being housebound she was referred to a day-centre where staff could spend more time with her and encourage her to get involved in different groups.  She felt safe at the day-centre and describes the atmosphere as:

> *"One of peace, where service-users and facilitators were interested in me and other service-users – I could be myself and not afraid".*



In 2001 Jean was persuaded to attend a conference on 'Women's Voices / Women's Choices' in Digbeth, Birmingham where, as her confidence grew, she was asked to do a three minute 'soap-box' talk which she did to about 80 delegates.  This in turn led to her becoming involved with Suresearch where she is now a very active member and enjoys every minute of it "as I feel that I'm being thought well of".  Suresearch gave Jean a purpose in life, a reason to get out of bed and educated her in research skills

which she uses to brilliant effect.  Above all, Jean told us, what changed her life were the good, solid friends she has made in the user movement.

Jean is now involved in teaching social work students and feels that the slow uphill struggle that started after her discharge from the QEPH was eased by supportive workers at the Hawkesley Day Centre, doctors, medication and the many friends she has met through Suresearch.

# John's story

John, as always, gave a highly entertaining account of his life since accessing care through 'direct payments'. John explained to us that direct payments was a way of buying your own care, making your own decisions and helping people become independent. This has been a very positive experience for him although at times he needed help with managing his own finances.



After looking at his care plan John noticed that there was nothing on it to help him with his stroke/brain injury. He challenged this and got help with putting 'direct payments' into place. He found it helpful having carers come into his home to assist with washing and dressing but when it came to his psychological needs in relation to his personal care, John found that there still seemed to be barriers that needed to be overcome. It took John two years to get a named social worker; usually he was being dealt with by whichever duty social worker was on call. He told his social worker that he needed some respite care and was fixed up at a respite home in Southampton. John said that Southampton was a great place to go because he really needed a break away from Birmingham. It had been two or three years since John had had a holiday and he needed this break for his mental well-being. He was also able to have a carer with him to support his needs.

John was very philosophical about what 'direct payments' has done for him saying

> *"It is about enabling me to make my own choices, moving toward independence. I may have mental health problems, I may have physical problems, but I know what my needs are. It is about me planning out my own life, it is about what I want to do, not what I am being told to do"*

John sees independence as something we all need.  It isn't about disability, it's about choice, where we make our own choices and we are in control of our own finances.  He wants respite breaks when he needs it, not when they say.  He remembered a time when mental health service's idea of respite was to send him back into hospital; things are different if you are in control.  John advised us to 'go for it' and recommended  having respite care away from home, away from Birmingham with grey walls and grey sky, Cornwall would do.

A taste of John's sense of humour came through strong and clear when his mobile phone rang while he was talking.  After searching and finding his mobile, he continued talking when another of his phones rang.  John explained this by informing us *"I've been diagnosed with schizophrenia so I need one phone for me and one for my unreality"*.  Only John could get away with that.

# Denise's story

Denise's story was about her experience 25 years ago of Post-Natal Depression (PND), an illness she thought was not as well understood then as it is today; however, there is still a long way to go. She found the response to her condition to be very negative, and she was not encouraged to think she should get well. It is only in the last few years that she has begun to get better.

The turning point for her was when she wrote a poem and sent it in to be published, never thinking that it would. The effect of this rewarding experience was a great change in her feeling of self worth and she ended up writing enough poems to fill a whole book. ["Write it Down – (From the Poet Who Didn't Know It)"]. So far she has raised £1000 which will be donated to funding  more research into Post Natal Depression.

Denise is now involved in two service user groups – the Service User Reference Group (SURG) and Suresearch. She has a full diary and has no time to be depressed. It is well known that involvement in the arts and writing is good for bouts of depression. She feels very much that she has found herself and has a real sense of achievement, eloquently illustrated by one of her poems:


### Quality of Life

Where is the quality
Give me my sanity
I've done no wrong
I just want to be mentally strong
Everything I seem to do
Just turns out like I haven't got a clue
Please free me of the pain
Oh Lord it's such a strain
Physically everything looks all right

But inside I'm not so bright
Rid me of this state of mind
The world is so cruel why can't it be more kind
I wish others could understand
That when I don't feel so grand
I'm not too good on communication
Never mind the welfare of the nation
Everyone has their needs
Just like farmers sowing their seeds
I'd love to reap the harvest of good health
Then I'd say I had a lot of wealth
Hear my prayer Almighty God above
Bless me with your tender care and love
When you appear on this earth again oh Lord
No one will have time to be looking bored
Those of us who know you will rejoice
Those who don't have to make a choice
The heavenly Father is so near
Too late to shed a tear.

# Tony's story

Tony admitted that he found it difficult standing in front of a roomful of people, but that it was important to describe what user involvement had done for him and most importantly, what other service users had done for him. *"My life got better, the more of you I've met"*, he said.



Looking at his use of services over 20 years, for about 15 of those he was in the dark – accepting, vegetating, taking medication to make it all better. But what made things better for him was basic information – as basic as that. Around 1994 his Community Psychiatric Nurse (CPN) had pointed him towards the local MIND, which was when he started to collect information on his disorder, medication and on his rights. At the time all this seemed "self centred" but by 1998/9 he had the opportunity to do research work here at the University. This research was completely different to before, when he had been the subject. He had to interview people about their experiences of sectioning under the 1983 Mental Health Act. He was shocked at what he heard about service users being sectioned and other experiences.

The people he met then are still good friends. Those service users



taught him so much, he had gained more information through his contact with service users and they are the ones who keep him sane. The dream he had was of getting those kinds of people under one roof to meet together and talk. Look at today – this is it – and music as well!

Tony said he had never been to such an event before and thought it was absolutely fantastic. *"Today is a celebration of our existence*

*and it's well deserved"*. We recognise we are still here to influence the way in which mental health workers understand and work with us. Today celebrates how far we've travelled, and his thanks went to service users for that.

# Stewart's story

Stewart explained how he saw himself as a person with issues, coping with situations in his life rather than having a label as a mental health service user, or as having an illness. As a young teenager, he had been given a diagnosis of "schizophrenia", which he thought was helpful for his family, but not for him in that his life and expectations went down the drain – he was not expected to have work, relationships, a family. No wonder he got depressed.

He went on to describe two turning points in his life: the first was when he was in hospital, and one person on the team caring for him thought he could do more. The second was meeting another service user who was working and had a relationship. He decided he could do this as well.

About six years ago, Stewart was told he would not cope with work; now he is self-employed and does training. He became part of "Moving On", a group of users and professionals co-training on mental health. This was a very important experience for him, since he became a person with expertise and was also training other users and carers about recovery, and helped him develop his sense of worth and purpose in life.

Stewart stressed the importance of speaking out and mentioned the proposed demonstration in London against the Mental Health Bill – "*we should be there, voice our concerns and speak for those who can't*".

# Mary's story

Mary began by paying tribute to Peter Campbell, who she described as being very influential in her life. She pointed out that nobody had mentioned leadership; '*whilst this word does not always have good connotations in user/survivor circles, we need people to show us the way'*.

Mary had entered the mental health system in 1977. As many service users say, she knew nothing. There was no discussion about medication or someone's problems – treatment was totally drug oriented. But one day her CPN gave her a leaflet about a conference – the famous one at Edale – and just the one word "survivor" caused a light bulb to go on in her head. She felt the description was just right and felt herself to be a survivor of life. The way the leaflet was written was brilliant – friendly but efficient. She went to the conference with a group of people and found it was a most amazing experience. A great array of ideas was expressed, and there was Peter Campbell, holding it all together. We need people who can do that. That kind of leadership made the experience a good one and made people feel they could express diverse opinions. That's what we need within the user movement; we've got to be able to embrace diversity in all senses.

# Panel
# questions and answers

# Panel – questions and answers

## Questions from participants

These are the questions participants generated during the group discussions to be put to the Panel during the afternoon session.

### Services

- What do you see happening to people when services are closed?
- What changes have happened at the 'sharp end'?
- Why haven't Diversity Directorate celebrated Black History Month? Could you enquire?
- Does service user involvement actually change anything? Can you give three examples from your local service (large or small)?

### User involvement

- Partnership – how do we avoid being coopted onto an agenda set by professionals who are not listening to what users say?
- There are more and more user workers (including representatives on committees). How can they be better trained and supported? Can CEIMH help with this?
- What do the panel see as the dangers of becoming a "professional service user"? (Losing sight of where they came from.)
- Can anyone shed light on service user involvement in CAMHS (Children & Adolescent Mental Health Services)?
- Can user involvement end up as collusion and being something that is hard to challenge?

**General**

- How can mental health service users build a better national voice?
- Where do the panel think we are heading?
- Who's driving the changes needed?

# Summary of panel discussion

The members of the panel were Barbara Crosland, (User Involvement and Social Inclusion Lead from CSIP/NIMHE), Mark Hillier, (Patient and Public Involvement, Birmingham & Solihull Mental Health Trust), Terry Simpson, user involvement worker and survivor from United Kingdom Advocacy Network (UKAN), all of whom have many years' experience of working for user involvement. Mary Nettle, (User Consultant) chaired the session.

Three questions were picked at random from the list generated through the group discussions earlier in the day. There was only time for a couple of questions to be discussed thoroughly. We could have spent many hours addressing the issues raised by participants, and plan to include them in future events.

## How can mental health service users build a better national voice?

**Terry Simpson** said that he had worked for eight years with UKAN in Sheffield. UKAN is an independent organisation led by users and survivors. This network of about 220 groups has lost most of its funding, but a new national network is being set up. Service users need a central organisation for groups to feed into. The key players in user involvement are still the big voluntary organisations. UKAN is an independent organisation led by users and survivors.

Terry pointed out that it is hard to run a national network. He estimated  that there is a very broad network of about 50,000 people. Some people don't want a central voice, they want a voice for themselves. So what is the way forward? His view was that things have not changed over 20 years; medical people are still defining our condition – despite the work of the Hearing Voices and Self Harm networks, conditions/states are still labelled "schizophrenia", "psychosis" and so on. We are the best people to define our conditions, and this is what needs to be developed.

**Barbara Crosland's** view was that the key is networking together. It is not about taking one position and claiming to represent service users. There are different voices – black and minority ethnic communities, older people, young people and so on. With a national network, there would be a worry about the big voluntary organisations exerting their influence. There are not enough service users actively involved and people need to get their heads together to discuss how to change this.

**Mark Hillier** thought that often people got together in a crisis and posed two questions. Firstly, what would a national structure do and work for? For example, the Mental Health Bill, where people are reacting against compulsory treatment.  Secondly, what would we want a national body to do?

**Barbara** wondered how much voice local bodies would have in a national body. We need to get into discussions, so that we have influence before things are decided for us. Looking at the question of how do we do this, she pointed out that CSIP/NIMHE has a national user forum. She would be happy to link up with people who want to be involved in that.

**Terry**'s view was that we need to try to predict what will change, but the key thing is to develop our own strategies: what do we want independent of what other people want for us, e.g. one key issue is forced treatment. The element of coercion is very frightening. What do we know about this issue? Has coercion gone down in the past ten years? Has research been done on this and on ECT?

# Partnership – how do we avoid being co-opted onto an agenda set by professionals who are not listening to what service users say?

A participant pointed out that care is needed over using the notion of partnership all the time. Things came about through conflict that led to change. How can we manage to retain a radical edge but still work in partnership? How do we avoid being part of a tick-box exercise to support decisions already made, e.g. on the closure of day centres?

**Mark's** view was that you stay radical by having more than one partner, by keeping your foot in different camps and keeping ahead of the argument. We need to look at health services and other things that keep us healthy. We need to remember that there is not one view or set of views.

On the issue of consultation, he pointed out that sometimes things have to be changed anyway but it is essential to make sure users/survivors are listened to. Consultation should go along with information and awareness raising. Users need to have full information to ensure that changes are for the better. We need to encourage people to meet and discuss the various experiences they have gone through.

**Barbara** said that in addressing the dilemmas around being a paid user involvement worker and staying true to your values without being coopted by the system, it was good to keep yourself grounded. You need to go back to the grass roots regularly. She liked to spend a morning at a day service centre or with a user group, to keep herself in touch.

On the question of consultation, she pointed out that Mental Health Trusts have their agendas dictated from above, by the Department of Health, therefore it was good to lobby MPs. The key thing was to engage with people who have integrity.

**Terry** stressed the necessity to have independent organisations, which should be funded. It is possible to fund without trying to influence.

# What changes have been made at the sharp end?

**Barbara** said that on looking back at her experience ten years ago, mental health services now seem better. A concrete example was that at one time staff and service users at the local psychiatric hospital had separate dining rooms; these have now been combined and the extra space used for a recreation area. Also, it is great that the old asylums were closed and the focus is on what goes right for a lot of people every day.

**Terry** gave a dissenting view, saying that there is some truth in the view that there is a different climate, but that the ideas we still use to think about "mental distress" and "mental health" are still pretty much the same as 20 years ago. These ideas are a century old – people are still using terms like "schizophrenia" and "personality disorder", which don't mean anything really. We need a new way of looking at mental health and it has to be us who do that – *we* make the future. If not, things will still essentially be the same.

Finishing off the panel session of the programme, **Mary Nettle** pointed out that as mental health service users, we are constantly addressing questions of human rights and disability.

# How the event was received

## How the event was received

**Evaluation by the participants**
It can be truthfully said that the views of those who came to the day ranged from the highly appreciative to the ecstatic!  People who attended really enjoyed both the form and the content of the day, finding it informative, innovative, creative and enjoyable, and there were many requests for a similar event to be held again.

Participants gave feedback in three ways:
- Evaluation forms
- Comments in the 'Big Book' (accessible to all visitors to CEIMH)
- Emails

The forms show how much the participants appreciated and enjoyed the event.

*'The day was tops'*

*'Excellent day – makes a real change'*

*'Great'*

*'Brilliant day, well done – stories very moving'*

*'Very eventful and informative'*

*'Thoroughly enjoyable day'*

*'Very impressive, inspirational stories'*

'*Whoever thought of it and funded it should be congratulated for their vision*'

'*The food was "wicked"*'

'*Stories moving and encouraging*'

'*Very good day – innovative and creative – it inspired me*'

'*Very smooth operation – an enjoyable experience*'

'*Great to see how far the UK has come – would be interesting in coming to see more*' (Denmark)

'*Many thanks to Colin for thinking of it and Centre for making it real*'

# Extracts from the Visitors' Book

*'Brilliant facilities ……. Well deserved recognition of success of Suresearch'*

*'Thank you for asking me to come and making me feel able to do my own thing. Here's to many more opportunities'*

*'Nice place and a brilliant day'*

*'Really enjoyed today. Hope to be back doing other nice things soon'*

*'What a spread – truly a centre of excellence; BECAUSE WE'RE WORTH IT'*

*'Great venue, great day – really enjoyed the diversity of views. Encouraging to know there are so many people with such enthusiasm and drive'*

## Emails

These comments indicated that this event <u>was</u> experienced as different from the 'usual conferences' that service-users are asked to attend.  Having musicians and singers perform on the day made a massive contribution to the harmonious atmosphere throughout the day.

# Colin Gell
# opening address

# Colin Gell opening address

A guy called Hans who was a leading light in the user movement in Holland in the 1980s, said *"What we did is start a movement that can't and won't be stopped, the only way for it is to grow"*, and I think if you think back across the last 20 years, what Hans said was spot on.  The folks in Holland were an inspiration in the early days, they started patients' counselling and user groups back in the 1980s so they are celebrating 30 years of involvement. I think we have a lot to thank Dutch service users for.

It's great to see you all here today. Two decades, 20 years of involvement. If I think back to 1986, there didn't seem much of a chance of us being around



in 20 years time. I remember we had a conference in Nottingham in 1986 –here's a battered old programme I have kept. At it we talked for two days  about patients taking power.  I remember one of the doctors in Nottingham picking up this programme and ripping it up and saying "Patients taking power, rubbish, that will never happen."  Well maybe he was right, we haven't got power in the strictest sense, but  we certainly have a lot of influence and people who have been around for a while have seen that influence growing in many ways.

Looking at this Centre today and what is happening here is a sign of that.  So I think 20 years is a fair achievement, and that's not down to one or two folks, it's down to what hundreds and thousands of people like yourselves have achieved  and I think it's time we said 'well done' to each other and have a round of applause.  (Clapping).  Well done, you've all contributed; it's not one or two folk, you've all done your bit.

So, 1986 was generally seen as the year when a lot of things started to happen. If you look at the list you have in your folders, you will see there was a conference in Nottingham. Survivors Speak Out started to happen; MIND Link started. A programme called 'We're not mad, we're angry', was very influential at that time. It was probably the first time service users had been on television talking about their experiences. Certainly for me it was a real change in my career and also in my personal life, so I've got a lot to thank 1986 for.

But that wasn't the start of it, things were happening before then. Does anybody know when the first user group was formed? It was in 1845. A wonderful guy called John Percival, he was a relative of the Prime Minister of the time, I think, was committed to an asylum. He was a little bit unhappy about the way he had been treated, so he set up the Alleged Lunatics Friends Society and that group was around for about 10 years, and was quite effective in making changes within certain institutions. So nothing is new in this world! So good old John Percival, we've got a lot to thank him for. We think we're brave in the last few years, but to do what he did 150 years ago must have been tremendously brave. In 1922 patients and staff went on strike in Saxondale Hospital. Both patients and staff were unhappy with what was happening so they actually went on strike and it was reported in all the national newspapers.

Today it is not about looking back, today is about looking forward in some ways and looking at what we have all been involved in. As I said earlier, you've all done your bit, you've all contributed, you've all made a difference, so today is about you talking to each other and telling each other what you've been doing. And we've got a number of ways in which you can do that.

After Peter has spoken to us we've got discussion groups - a chance for folks to talk about what they've been doing, what's been good about that, what's been difficult maybe, and to learn from each other about how to take involvement forward. We've got the video box. I'm not quite sure what a video box is, but If you want to sit in front of one of these cameras to talk about your experiences, that's a possibility. We've got the Time Line. In the social space, there are some flip charts, they've all got different years on. What we'd like you to do is spend a bit of time, write on a poster or on a board what you were doing in that particular year, what was important for you. The other way you can have a say is,

this afternoon we've got some folks telling us their stories, how they got involved, what it meant, and there will also be a chance for folks to get involved in the 'open mind session', as we call it, so you can talk about your experiences.  We've also got a panel at the end, of some very important folks, like Mary Nettle, Mark Hillier, Terry Simpson and Barbara Crosland.  That's a chance for you to think about what the questions you'd like to ask panel members, what you're not so sure about, what's been bugging you, if you like, and they will answer your questions.

That's about it from me.  I always like to finish with a quotation and this is one from a guy called John O'Brien.  He actually described himself as a reformed mental health worker, whatever that means. John once said:

> *"When people who are not used to speaking out are heard by people who are not used to listening, then real changes can be made"..*

and that's what we're all about I think. We move on now to introduce our main speaker, someone I've known for 20 years as a friend and a colleague, and someone who has had a major impact on the user movement.  Peter Campbell's been around for over 20 years now, in London, nationally and in most parts of the country. So it's my great great pleasure to introduce my very good friend, Peter Campbell.
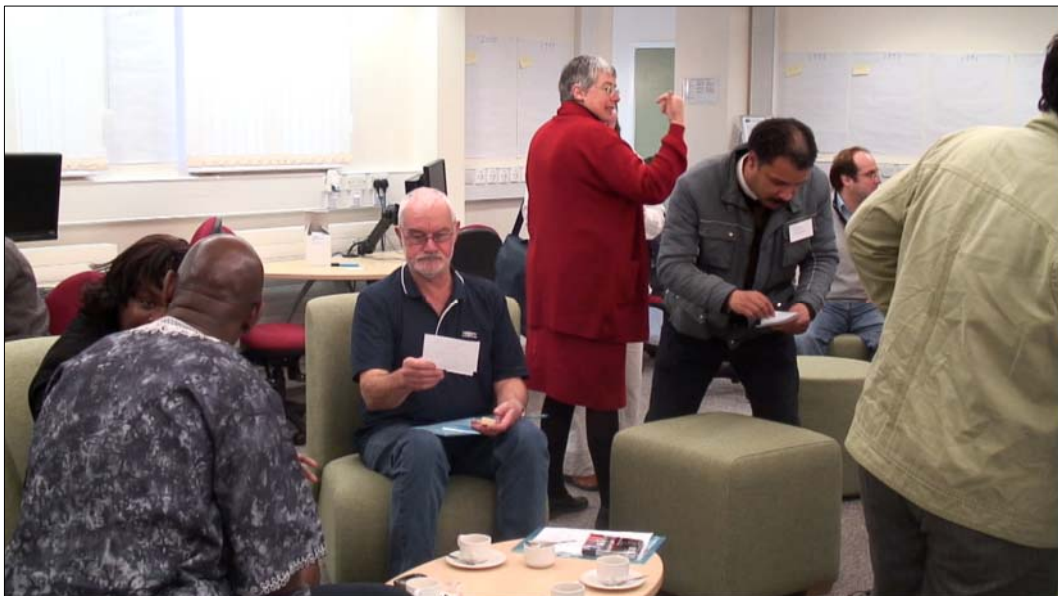
# Peter Campbell's opening address

## Peter Campbell's opening address

I'm really delighted to be here today and would like to thank Colin Gell and the other organisers for inviting me. I've been moving flat for the last couple of weeks and I've been totally focused on moving. I've been trying to move for the last three years and I've finally made it, so this is my first excursion back into the outside world again. It's nice to get out of my flat, it's nice to get out of London, it's nice to come up to Birmingham. It's also good to contribute to an event that is celebrating service user action, service user involvement, whatever you want to call it. It used to be called self advocacy in the 1980s, we used to talk about self advocacy but that seems to be a phrase of the past. Anyway, it's good to be able to talk about and celebrate service user action, because I think there are things worth celebrating, and I think it's useful to be aware of and look at our history and that informs us about how maybe we can do things better in the future.



So I'm going to talk about things that have happened over the last 20 years that I think are interesting and important. I'm not going to try to provide a balanced history. What I am talking about are my personal impressions. There's been a huge amount that has gone on in the last 20 years, so there are lot of organisations, a lot of developments, a lot of initiatives, which I won't be mentioning. That's not to say they weren't important or even more important than things that I do mention, so basically this is my impression of some things that are worth knowing about that happened in the last 20 years, and I'm going to focus on things that I know most about. The period 1985 to 1995 was when I was

most involved at a national level, so I will focus quite a bit on that decade.

I want to say a little bit about what my own involvement has been so you get an idea of what my perspective is. I got involved in things in the 1980s really, the early 1980s. I'd moved to a new part of London, I'd been unemployed or under-employed for a number of years, and I decided to give up trying to have a conventional career and decided that I would try to change things in the mental health field, and I thought the only way of doing that was to get involved in MIND. I wasn't aware at that point of any service user organisations, I was only aware of MIND. So I got involved in MIND in Camden, which is a local MIND organisation, as a volunteer. Through Mind in Camden I got involved in setting up a local service user group which was called Camden Mental Health Consortium, which was one of the first local action groups in London and still exists. It's been going since 1986, so it's a long running group. At the same time as I was involved in Camden Mental Health Consortium, I made contact with two other groups which were more radical, more campaigning groups, one of which was called The Campaign Against Psychiatric Oppression (CAPO) and the other one was called British Network for Alternatives to Psychiatry.

CAPO was a service user/survivor only group, quite a small radical, separatist network group. British Network for Alternatives to Psychiatry was a network too. It was largely London based and it was made up of mental health workers and service users. It was through my involvement with MIND in Camden that I got invited to get a bit involved with National MIND and I went to the 1985 MIND Annual Conference, in Kensington. There was a meeting of service users immediately afterwards and from that meeting Survivors Speak Out was founded and I was involved as an officer in Survivors Speak Out from 1986 to 1996, so that was my main national involvement during that period. Then in 1991 I was involved in setting up Survivors Poetry, with three other survivor poets and for two or three years I was very involved with that, and I am still involved with Survivors Poetry, but not to such a great degree. From the early 1990s I became a freelance trainer, earning my living by doing teaching work mainly, and so that's been being involved in the education field, which has been my main area of activity for the past 15 years or so.

So that's my own personal story of being involved.  It seems to me that it's important to celebrate service user/survivor action, and that seems to me to be a key feature of what we should be doing today. And I wanted to start off by saying what it has meant to me personally, not so much what it's done to change the world, if it has done anything, but what it's actually done in terms of having an influence on my life, and it certainly changed my life totally for the better.

In the early 1980s and before the 1980s, basically I was adrift.  I'd gone into mental health services for the first time in 1967 and for the next 15 years I was  going in and out of hospital, adrift, beneath the surface as much as on top of the surface, isolated, alienated from myself, from other people, carrying a whole lot of negative baggage around with me about who I was, what my problems were, that I was suffering from a mental illness all these kind of things.  Silenced. I had no voice at all.   Meeting other survivors who wanted to change things, who felt the same thing about their life, and who wanted to change things, totally transformed my life.  It changed the way I thought about my own experiences and the experiences of other people.  I realised that other people felt the same way as I did about how mental health services had treated them.  Other people had the same kind of interior experiences as I did, paranoia, psychotic episodes and whatever, and that made a great deal of difference to me.  I have also learned a lot about other difficulties that I don't have.  For example, hearing voices, self harm, areas that I was frightened about or had been repelled by, and through meeting survivors with those experiences I have learned a tremendous amount about whole areas of mental distress which I never knew about before.

Meeting other survivors has helped me cope better with my own distress.  I've had tremendous good fortune in having a number of close survivor friends who have helped me through a series of distressing episodes.  One of the most memorable things that's happened to me is actually having a survivor who is a friend of mine, be my advocate.  I'll never forget when I first had an advocate accompanying me into a ward round, and having a survivor acting as my advocate there made a tremendous difference.  Having people who would simply accept, 'OK, here you are, occasionally you do lose it, you lose control, you become very strange, you do things you wouldn't normally do, but that's OK, we all have phases like that'. Being accepted with the difficulties I

have by other survivors has made a tremendous difference to my life.

My own self esteem was transformed. In a way I have been liberated. I was able to take all those negative experiences in my life that I had to hide, I couldn't talk to anybody about, that I was ashamed of, and share them with other people. I was able to think about them, analyse them and use them in a constructive way. People listened to me and us collectively, and actually learnt from us and respected and valued our views. That has made an enormous change to the way I think about myself, to my whole life in general and to my feeling that I had a worthwhile life. I've done a lot of interesting things. I've been able to travel around the country, meeting other service users, talk at conferences, teach here and there. I've been able to develop teaching skills. I've been able to do creative writing, to write poetry, to write prose, to have articles published, to learn skills, and all those things would probably have never happened in my life, if I hadn't actually had the good fortune to meet up with other service users and survivors and get involved in service user/ survivor action.

All of this hasn't made a tremendous difference to my life in terms of stopping me going into mental hospitals. I continue to do that regularly, but in every other way, it's transformed my life completely. I dislike people talking about service action as being therapeutic, that to me is not what service user action is about. But I have to say that it certainly has changed my life for the better, and I think we shouldn't overlook the transformation that being involved in action can have on individuals, regardless of whether we are actually changing anything.

Whether we've achieved anything, whether we've got anything to celebrate in terms of what we've achieved in the real world is a more controversial matter. But I think looking back at our history, the important thing to remember when we are trying to work out what changes have happened is that before the early 1980s, service users were not involved. We were not involved in our own care and treatment. There were no patients councils, no advocacy and very little information. I think it's worth remembering that now we talk about advocacy as being essential. We argue about the need to have a right to advocacy for people who are detained under the Mental Health Act. Indeed, a right to advocacy for service users as a whole. But in the early 1980s advocacy was

never talked about. There wasn't any. It wasn't on the menu at all. So we weren't properly involved in our own care and treatment because there was no advocacy. We were not involved in the development of services in any meaningful way either. We were not involved in consultation. We were not involved in training. We were not involved in research. We were not involved in providing our own services. We simply weren't involved.

If you look at the 1983 Mental Health Act, that was developed without any significant input from service users. And if you look at what is happening at the moment, when we've been arguing for years about amending the Mental Health Act, service users have certainly had the opportunity to be involved in this process and make a contribution. Whatever our influence has been is a different matter but certainly we've been there, we've had the opportunity to speak out about the Mental Health Act, and that certainly didn't happen when the 1983 Mental Health Act was being developed.

We were not involved in debates about understandings about what madness, distress, mental illness is. Nobody listened to us. Nobody thought we had anything worthwhile to say about our own experiences because we were mentally ill, we couldn't possibly have any 'insight' into what our lives were about. That has changed. We were not meaningfully involved in major voluntary organisations. National MIND in the early 1980s saw themselves as being the 'voice of the mentally ill'. But they didn't consult us, they had no mechanisms to make themselves sensitive to what service users really thought. Rethink, or the National Schizophrenia Fellowship, as it was then, was an organisation which basically represented the views of relatives. At that time all the major voluntary mental health organisations were not in tune with service users, service users were not meaningfully involved, they had no power or influence over these organisations. At the same time there were no service user organisations and service user controlled or service user only organisations. No independent organisations except very few.

Basically we were nowhere. Silent, excluded, outside the room rather than inside the room, that was it. And I think it's important now that service user involvement is established and accepted and seen as being a good thing, just to remember that 20 years ago – there wasn't any. I think the other thing worth being aware of is we had to fight for it. This wasn't something that the service providers

or the government suddenly woke up to and said, 'oh yeah this is a good idea, let's do it'. This was something that we had to fight for and struggle for. It was not of course just service users and service user activists who brought about this change. There were also people running the mental health system who thought it was a good idea. But service user involvement was not something that everybody thought was a good idea, far from it. It was not something that was granted to us, we had to fight for it.

During the early years, certainly most of the 1980s and the early 1990s, we were having to make the case for 'Why involve service users?' So almost every time I remember going to any event, the first five minutes at least of anything I ever said, was basically establishing the case for 'Why listen to service users?' 'What are the reasons for doing that?' and we had to go through that time and time again, and a lot of what we were doing, a lot of what I was doing as part of Survivors Speak Out, a lot of what Colin Gell and other people were doing in the Nottingham Advocacy Group was going around the country trying to persuade people, mental health workers and other services users, why it was a good idea to involve service users. And there was a great deal of opposition to this. The basic position most people took was sceptical. Most mental health workers certainly took a sceptical position. There was a great deal of obstruction. There were a number of techniques to obstruct what we were trying to do. One of them was the question of 'Who is a service user?' I don't know whether you have ever come up against that argument. But what used to happen was that you'd go to a meeting about service involvement. I remember going to one at the Institute of Psychiatry, where the entire morning was taken up with a debate by eminent psychiatrists about who a service user was. They decided that they couldn't do anything about involving service users, until they decided who a service user was.

To me it has always seemed obvious who a service user is. To me this debate was a clear obstruction technique. 'We can't do anything until we decide who we're talking about'. Representativeness was another one. 'Oh you're not representative, we can't listen to you because you're not a typical service user', all that kind of thing, and that's one that continues to this day. One of the things I remember, there was tremendous anger from many mental health workers about the idea that we wanted to set up our own groups, that we didn't want mental health

workers in our groups, we wanted service user only groups. I remember going to one conference, Colin Gell was at this one, in York. I remember the workshop I was in had to be abandoned because the mental health workers in it were so angry that we didn't want them to be involved in our groups. So there was a tremendous lot of scepticism, opposition, obstruction, anger. I mean there was a lot of 'Who are these people? Who are these people coming out of the woodwork and telling us you've done nasty things to us, why have you done this?' Being angry, being emotional, but not only being angry and emotional but actually having good arguments as well. And that's what's hard to take. If someone is angry and emotional you can dismiss them, but if they've actually got good arguments then it's more difficult. So there was a good deal of hostility and resentment.

I remember going to the Common Concerns Conference in 1998, a big conference in Brighton, with service users from other countries, and it was about half service users and half mental health workers. It was an extremely confrontational conference. For one thing service users took over the agenda, we changed the whole agenda at the beginning of the conference and said we don't want it done that way. But there was also a lot of hostility and most of the workshops were being run by service users. I remember being involved in one workshop, which I think was about Mind Link. We had a moderate, factual discussion about involving service users. But at the end of it a social worker came up to me and said 'You're typically psychotic'. I mean I was really shocked. It was like a head butt and meant that way. Maybe that happens nowadays, I don't know whether it does or not, but certainly I don't think we should believe this was all about common concerns, it was all about partnership, it was all about everybody working together, it wasn't. We've had to fight for these things, and I think it's worth remembering that, because there is quite a lot of rewriting of history going on and I think we should remember that we have our version of what happened, and it may not be what other people say happened.

When you look at advocacy, as I've already said, people forget there was not advocacy 20 years ago. People forget that the reason we have the advocacy we have is because service users fought for it. When other people weren't in favour of it or were distinctly unenthusiastic about it, the reason we have so much advocacy is because we took up the cause, we fought for it, we

started running our own advocacy groups, and that's worth remembering.

Advance directives, is another example, everybody now talks about what a wonderful idea an advance directive is and everybody using services should have one. In the early 1990s, nobody cared a damn about advance directives. Survivors Speak Out took up advance directives. We were the first mental health organisation to distribute a leaflet advising people how to write an advance directive. Nobody remembers that it was services users who took up that idea.

Let's look at harm minimisation in the field of self harm. The idea that instead of trying to prevent people from self injuring, you actually encourage them to minimise the damage they do when they self-injure. The Royal College of Nursing earlier this year suddenly announced they were going to start developing harm minimisation. Absolutely no acknowledgement of where the idea of harm minimisation came from. It came from service users, from the National Self-Harm Network. The very first conference in this country where mental health workers and people who self harmed ever came together was organised by self harming service users. So I think we need to remember a lot of the good things that have gone on that are now recognised as being good things. The reason that they're recognised as being good things is because service users took them up and promoted them. We shouldn't forget that.

We now have a kind of myth of partnership, 'oh yes we're all in partnership and we all should be in partnership and it is a good idea', but I think there's a myth to this extent that a lot of things that there is now a consensus about, is not due to partnership it's due to the fact that service users have been working in opposition, and service user involvement isn't just about working with people, it's sometimes about working against people.

I think of 1985-1995 as a pioneering phase. It is quite an interesting phase in the development of service user action, and it's also maybe a period that some of you here won't be that familiar with. One of the interesting issues is 'Did service user action really start in 1985?' The reason we've been celebrating this year, 21 years, is there is the perception that that's when things really started, and I think there is some justification in saying

that, but it's also clear there were things going on before 1985 and it's quite important to be aware of that.

Colin Gell has mentioned Perceval and the Alleged Lunatics Friend Society in 1845, and that's very interesting, if you're interested in the history of things. The Alleged Lunatics Friends Society was a unique organisation, it was an advocacy organisation, it was service user controlled and it did have quite a lot of influence on the development of legislation in the mid-nineteenth century, but obviously that's a long time ago. In the 1970s, there was a group some of you will have heard of called The Mental Patients Union (MPU), which probably could rightly be seen as the first service user involvement movement and some people who were involved in the Mental Patients Union, were also involved in the 1980s so there are direct links between the MPU and what happened in the early 1980s. Obviously there were also groups like Campaign Against Psychiatric Oppression, British Network of Psychiatry, which I've mentioned already, which were going in the early 1980s, which are sometimes overlooked.

A lot of the ideas of these groups fed into Survivors Speak Out, Nottingham Advocacy Group, and through them to the survivor movement as a whole. They were quite small groups and there were not a large number of them. One thing about groups like Campaign Against Psychiatric Oppression and British Network of Psychiatry was they were more political than we are now. They were also more separatist, they tended to stand back from services and criticise from the outside, and I think one of the things that changed in the 1980s, from 1985 onwards, was that the groups who started taking action then were much more involved within the system and prepared to work within the system, to reform the system rather than criticise it from the outside.

It's worth knowing that there were things going on before 1985 and some of those things fed into what happened after 1985. On the other hand I think in 1985-1986 significant things did happen. MIND has focused on the World Federation Conference held in Brighton in 1985, as a starting point. It's kind of ironic that they chose that, because the significant thing about that particular conference is there were hardly any service users from this country in it at all. In fact I'm not sure that any service users from this country were officially invited. There were a number of service users from other countries invited and the real significance I think

of that conference was that people suddenly asked 'Why aren't there any service users from the UK at this conference? We've got to do something about it because we know there are service users around who are taking action'.. And that's what led to Survivors Speak Out being formed the following year. So I think the MIND conference in 1985 in Kensington was more significant, because it was the first national mental health conference where much of the programme was being run by service users, many of the workshops were being run by service users and service user organisations. Then in 1986 Survivors Speak Out was formed, the first national networking organisation. Nottingham Advocacy Group was also formed, which was extremely important because it promoted advocacy and patients' councils and shortly after that Mind Link, the service user network within national MIND and National Voices, a similar network within the National Schizophrenia Fellowship was formed. So I think it's true to say that in the mid 1980s service user action moved up a gear from what had happened before.

One of the things that I think is interesting, having been involved in Survivors Speak Out, is that if Mind Link had got established before Survivors Speak Out got established, it is quite possible that service user action would have been channelled through mental health voluntary organisations like MIND and the National Schizophrenia Fellowship. But the fact that Survivors Speak Out was there promoting the idea of setting up independent groups was, I think quite important in retrospect to the development of mental health service user involvement.

1985 to the early 1990s was about spreading the word. Going out to people and saying 'Look it is possible for service users to take action, this is why it's a good idea and this is how we can do it', and I think a lot of what was going on was people doing that, Survivors Speak Out, Nottingham Advocacy Group and other groups, going to local meetings around the country. One of the things that I remember that was exciting about this period, was that as Secretary of Survivors Speak Out I would get a letter from somebody, say in Wrexham, saying 'I'm a service user, I've heard about Survivors Speak Out, I want to set up a group', and then a couple of months later you'd be invited to go to a meeting in Wrexham to talk about developing service user action locally, and then maybe a few months later there would be a group in Wrexham. You could see little dots on the map and groups being

set up where previously there had been nothing  at all.  So it was that kind of pioneering era.

What was going on was quite small scale compared to what happens nowadays.   In 1990 there were about maybe 50 independent service user groups. Nowadays we're talking about more than 600 groups in England and Wales!  We're also talking about quite a small degree of activity in 1990.  Many of the groups were small, most of them were unfunded, many of them didn't have offices, the majority of them didn't have paid workers.  This was the period before the user development worker. It was later in the 1990s that people were actually  employed by various agencies to help set up  user groups.

One of the striking things about the 1980s, was that you knew people in a way you can't do now.  It was quite possible if you were involved in a national organisation to feel that you knew a lot of the significant people who were involved in action around the country and nowadays things have got so enormous it isn't possible to know people in this way.   Things have got so much more complicated, it's very difficult to know what to do to move things forward nationally.   It's very difficult to know how to do things, because everything is so much more developed, more complex, whereas in those days it was much easier to say 'well this is what we need to do, and this is what we can do,  and there are a lot of the things we can't do because we simply don't have the resources and won't be able to get them'. So I think in many ways things were a lot easier than they are nowadays. One of the things that has changed as well is expectations.  In the early days we didn't have enormously high expectations of what could be done, we just thought, well we'll give it a go and see what happens, because it has never had been done before.  Nowadays there are higher expectations of what you can achieve, what you should achieve. There are particularly high expectations from outside service user/ survivor organisations and ideas about what service user/survivor organisations should be doing.  So I think things have changed quite a lot since the pioneering phase.

If you look at the last 10 years, what has happened is that service user involvement is now enshrined. It's not possible not to involve service users and those running the mental health system will not try to avoid involving service users.  Whether or not they actually listen to service users is another matter, but involving service users

is an absolute necessity.  I think you can see how in recent years voluntary mental health organisations like MIND or Together, have pinned their flag to the flag pole of service user involvement. Service user involvement has become a big industry, many people are involved in it.   We are involved in new areas of activity compared to the early 90s. For example, research.  Service user involvement in research is a huge area now. In the early 90s it wasn't  happening.  So service users are involved across a huge area and people can now make a career in service user involvement.  As a service user you can go out there and get paid work, sometimes quite well paid work. You can now pursue a career as a service user activist in a way that you couldn't 10 years ago.

Another thing that has happened is specialisation.  Because things have become so complex, there's a tendency for people to specialise in particular areas. In order to make any impact you have to spend all your time on self-harm, or on research, or on training and education. In some ways it fragments things and it's much more difficult to bring people together, because a lot of people are focused just on one particular area and may not be very aware of what's going on elsewhere.  And I think that's one of the reasons there is a difficulty in getting a national voice for mental health service users, and difficulty in getting an overall sense of direction and cohesion. Because there is so much going on it is difficult to bring things together.

I was going to say something about what has been achieved and what hasn't been achieved, but I'm going to leave that.  As I have been sharing my personal opinions, I have to acknowledge that when you look at what has been achieved and what hasn't been achieved, we all have different ideas about what the priorities really are.   But I think it is very important that we do  look at what has been achieved, why certain things have been achieved and certain things haven't been achieved, and how we can achieve things better in the future.

I think one of the things for me is that at least now there is an opportunity for people to take action in a way there wouldn't have been before.  I think for somebody starting off their career as a mental health service user nowadays, they do have the opportunity to take action, to try to change things, to work with other service users, to speak out in public, to discuss their experiences with

other people, to write, to teach, to do these things.  Certainly, when I started off in the system in the 1960s, that was inconceivable.  But I think it's very important that we do look at 'What are we trying to achieve?  What are the things that we believe in, what are the principal things we believe in?  What changes are we trying to achieve?  How do we work together to achieve them better?'  I think we do need to look not just at being here rather than nowhere but also at how we can make our presence more effective.

Thanks for listening.

# Evaluation by the Service User Involvement Co-ordinators, CEIMH

## Evaluation by the Service User Involvement Co-ordinators, CEIMH

The event was very successful because a lot of thought, time and energy went into organising it. Having the Centre as a venue was excellent, because of the welcoming space it provides and the resources available.

It was a good networking opportunity, both for us and for the participants. We made new contacts and got back in touch with people we already knew. This will help us to build user involvement capacity and also the user knowledge base. The content of the speeches, group and panel discussions was very good and there are plans to disseminate it on the Centre website, and the Suresearch website.

The panel discussion yielded frank views. It was good to have panel members with so much experience and was very balanced and down-to-earth.

We felt that service users had ownership of the day, in its planning, organisation and implementation.

We were given a treasure-trove of ideas of what is needed in the future for user development.

# Future events

## Future events

If we had another event next year, what would you like the theme to be?

Suggested themes for future events:

The service user experience

- Challenging stigma and discrimination
- Forced treatment
- To share the good practice that is going on in each area
- The way forward – possibly with commissioners
- How agencies (statutory and voluntary) can work in partnership with user groups and how they can better engage and effectively involve service-users within the development and running of services – more opportunities for professional/paid workers to engage with each other

**The user/survivor movement**

- Something around broadening the diversity of user involvement – CAMHS, older adults, LGBT, BME communities
- More examples of successful user involvement projects
- How to evaluate the progress of user involvement

**The importance of therapeutic approaches**

- "Well-being" as a theme
- More on personal/professional development
- More music at events
- Recognition of the importance of music
- Recovery

**… and last but not least**

## Excellent, let's have more!

# Everything but even bigger!

# Other CEIMH Publications

Ann Davis, Alex Davis and Martin O'Kane (2007) Claiming Disability Living Allowance:  An Information pack for people aged under 65 using Mental Health Service, their Carers and Advocates.


Jean Betteridge & Ann Davis (2007).  Mental Health & Incapacity for Work: An Information Pack for People Claiming Incapacity Benefit, Income Support & Severe Disablement Allowance.

Marion Clark, Ann Davis, Adrian Fisher, Tony Glynn and Jean Jefferies (2006) Transforming Services: Changing Lives : A Guide for Action

Copies of this report, as well as the above publications, can be downloaded from **www.ceimh.bham.ac.uk**

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