

Celebrating our history

Valuing ourselves



A mental health service users' conference with historians -The Report

Part of the ongoing work of the *Survivors History Group* to record and document the history of the survivors' movement.

Thursday 29.5.2008

Our day of meetings with historians and a journalist, on what survivor history is for, were held crowded into the office of Anne Beales and Mandy Chainey (both absent in the new world) and continued in a pub-restaurant on Old Street. Conversations began before the meetings and reflections continued afterwards.

Present (in rough order of arrival) were Helen Spandler (Manchester historian), Andrew Roberts (Hackney), Peter Campbell (London), Ian Ray-Todd (Hackney), Phil Ruthen (Brockley), Mark Cresswell (Durham historian), Catherine Jackson (journalist), Frank Bangay (Hackney), Sophie Mirrel Moakes (Hackney), Clare Ockwell (Sussex), Joan Hughes (Hackney), Roger and Felicity Lansdowne (Hackney).



Different points of view

The emphasis was on the rich rainbow colours of the users' movement and the need to record the different perspectives on what has been done. *Survivors History* needs its manifesto, but should not have a party line on history. There were a lot of challenges, but it was contained. No blood was spilt and no one had tantrums. We remained good friends. Key features picked out by Phil Ruthen were the sociability of the meeting, the openness of discussion, and the emphasis on establishing the facts of our history and considering them from different survivor points of view.

Getting the facts right

It is important that different views of our history can co-exist - We can live with multiple histories and versions. However, Helen Spandler (left) comments, we can get key dates, facts, and events right, as far as possible. Using the *Survivors History Timeline* and the *Mental Health History Timeline* seem crucial here.

Why the history group started and where it might go

Peter Campbell outlined our early history. The group formed as a response to a meeting '**What are we going to do about the history of the mental health service user movement?**' called by Thurstine Basset and Peter Lindley on **30.11.2004** at the *Sainsbury Centre for Mental Health*. About twenty people attended, including a number of leading figures in the survivor movement.

This meeting was memorable because it centred on showing films. These included one on the history of psychiatry and one that Thurstine Bassett made of a tape slide presentation by members of Glasgow Link Clubs to the *Mind* Annual Conference in 1984. This user group had compiled a series of photographs and drawings to illustrate tape recordings of their stories and what they thought was wrong with the Scottish mental health system. They were determined to see changes for the better that included respect for patients. Link club members were amongst the founders of *Survivors Speak Out* in the winter of 1985/1986, and they used the presentation at many subsequent workshops.

A lot of interest was generated by the films, with many potential ideas for collecting together and somehow preserving the history - and also making it accessible. Various people undertook to look through their papers and search through cupboards and lofts to see what they had got.

One of the user celebrities who attended was Anne Beales, who had just been appointed as *Together's* first "Director of Service-user Involvement". Anne offered *Together's* Board Room as the venue for an inaugural meeting, and has remained active in the group ever since.

Other celebrity survivors who were active in getting the group launched, and have remained involved, include Colin Gell, a founder of the *Nottingham Advocacy Group* in 1986; Terry Simpson (Leeds), active in the *United Kingdom Advocacy Network* from 1993, who preserves its archives; Peter Munn, a pioneer of groups in Wales; and Peter Beresford, Professor of Social Policy at Brunel University.

Our inaugural meeting, on Thursday 21.4.2005, was also memorable. The founder members brought items from their own archives to show. Exhibits included T-shirts, badges, videos, books and posters from many organisations over many years. At this point we learnt a painful lesson. No one recorded what was brought and that record is lost. When the group launched its full manifesto, in January 2006, the final commitment was to "be conscious that we are making history as we work and seek to record the activities of the group."

Peter Campbell spoke of the need to bring more people into the history group and into history activities. He also said we should discuss the value of history to survivor/users, both to those who take an interest and those who may not (at present) think it relevant.



Survivor History Treasurer, Anne Beales, received a medal from Prince Charles in November 2007 for services to mental health.

Peter also thought we need to reflect on what we want to do. What direction do we want to go in? Do we want to create a physical archive like the *National Disability Arts Collection*? Or do we want to concentrate on a web history and web archive? Or do we want to concentrate on writing history in a more conventional sense?

Value of History

We heard about the excitement of a group of younger user activists at *Together*, about a year ago, when they were introduced to the histories on the *Survivors History Timeline* and the *Mental Health History Timeline*. Working in pairs, they selected five areas to pursue for their own further research: world war one soldiers being shot for cowardly behaviour - the alleged link between insanity and sexually transmitted diseases - the Nazi party eliminating people deemed to be mentally ill - military and naval asylums - an Archers radio programme where a character was treated for mental illness in 1954. Some of these activists have established and maintained contacts with the history group.



Clare and Catherine listen to Frank.

Clare Ockwell was a founder of *The Capital Project Trust* (Clients and Professionals in Training and Learning). This is a West Sussex user-led project, set up in 1997, to train users in service user focused training, consultancy and research. Being part of the history group and learning about our heritage had made a lot of sense of her own life and experiences. Clare told us how she had been using material on the survivor movement history in her teaching within CAPITAL and the interest that has aroused. One person who took part in one of Clare's groups wrote to the history group with information about the users' movement in New Zealand, Ireland and elsewhere that has added valuable new dimensions to our web history.

We hear from other people about the inspiration of having heard Peter Campbell, or others, speak about the significance of history at conferences. One of these, Lizzie Maitland, is a member of a group who have written a booklet and are touring Leicestershire and Rutland with a history exhibition. Their book begins

"A user group was started specifically at the beginning of the 21st Century by Peter Campbell in London to write the history of user groups and the effect they have had on the treatment of mental health. In 2004 the Rutland Healing Group, some users, past-users and carers, decided to campaign for freedom and a voice in their own mental health treatment. This led to the start of this Heritage Mental Health project,

The Progress In Our Age Exhibition, the book *Our Local Heritage of Mental Health* and the two pamphlets of *Life-Stories*."

We need to reflect on what we are doing in creating our own history. We need to listen to those who are inspired by the history and to learn from them what they relate to and how it motivates them to action. If we can hear what is said, it will help us to tell our stories in ways that inspire others.

Catherine Jackson asked Helen Spandler why she was involved with the group. Helen said that she thought the remit of the group was really important (survivors developing their own histories) and wanted to find ways to support this. She also wanted to contribute to the emerging histories of the movement, as well as potentially developing collaborative projects with the group. She has been discussing with Anne Plumb and others a history of the survivors' movement in the north west of England, where she is based.



Conversations and incidents

Recording our history provides material for many conversations, most of which we will not hear about.

But we need to hear about all the different groups and events that are the substance of the story. The members active at the centre of the history group aim to be open to, and interactive with, others, so as to record what is remembered and archived about the movement. The website is an important tool for this. The web history is created from the material that is sent into us by its readers.

We also seek, through exhibitions and post, to communicate with those who do not use the web. In this way, the conversations become richer as more and more incidents are recorded as part of our history.

Knowing what has been achieved

It was suggested that one value of history is to know what has been achieved. This led on to a discussion about what had been achieved.

People listen - do we want to speak?

It was suggested that, in the past, people would not listen to users, but that now they will.

Andrew thought there was another side to this. There was a period when groups like PROMPT did not want to discuss issues with the people they saw as the enemy. At the same time, the users working through *Hackney Workers Educational Association* were setting up

user controlled forums in which users, psychiatrists, anti-psychiatrists and others, could debate issues on equal terms. A big step forward was the *Mind* conference to which CAPO (inheritor of PROMPT) went. We (rightly) put a lot of emphasis on the fact that English users' groups were not invited, but we should also remember that, previously, some had not wanted to go. Frank Bangay, later, commented on and corrected Andrew's statement.



British Network of Alternatives to Psychiatry

Peter Campbell (left) spoke about the importance of the *British Network of Alternatives to Psychiatry*. In the 1980s, this brought radical survivors and radical professionals together. It included forceful characters like Shulamit Ramon and David Hill, who had both recently completed their Ph.D. theses (Shulamit in 1972). David was very important because of his trade union and political links. He got users into the Houses of Parliament and into conferences in Chesterfield organised around Tony Benn. These links were lost after David left.

Frank Bangay on PROMPT (*Protection of the Rights of Mental Patients in Therapy*), **CAPO** (*Campaign Against Psychiatric Oppression*) and **Mad Pride**

Frank spoke about the history of the movement, including the first PROMPT meeting he went to.

PROMPT (*Protection of the Rights of Mental Patients in Therapy*) was a small, but vocal campaign group started by Julian Barnet in the **summer of 1976** to

"protect the rights of mental patients, and to form ourselves into one massive pressure group to lobby MPs, inform 'mental patients' about what really is going on, vis-a-vis the true nature of their 'treatments', to bring together all our experiences and to say with one voice '**Psychiatry belongs not in the realm of medicine - but more in the realm of politics**'."

At some time, Julian Barnet joined forces with Eric Irwin. Prior to the national Mental Patients Union's formation in March 1973 Eric was one of the co-authors of a document called *The Need for a Mental Patients' Union*, known because of its cover as the Fish pamphlet. The first part of this argued that "psychiatry is one of the most subtle methods of repression in advanced Capitalist society". The second part set out what a union could do, and was built on by the Mental Patients Union, which otherwise disassociated itself from the Fish pamphlet. Eric always remained loyal to the ideas set out in the Fish pamphlet, which was eventually resurrected as parts of policy statements by PROMPT and CAPO.

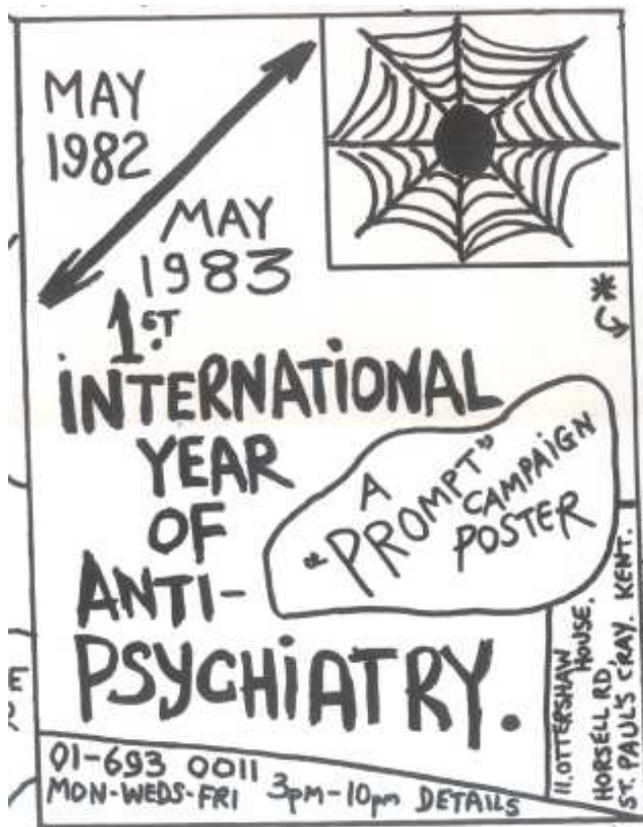
Frank Bangay became a close friend and colleague of Eric and in 2000 AD it was Frank Bangay who suggested the Fish pamphlet be re-printed as part of Mad Pride's anthology. By the time Frank joined PROMPT, most of the small group of members were patients. Frank said

"My first introduction to PROMPT came in 1979 when I found some PROMPT booklets in a bookshop either in Brixton or in Stratford. I might have found booklets in both places. My first PROMPT meeting in 1980 was a conference at Conway Hall."

PROMPT met first in Dulwich then in a pub in Farringdon called the Metropolitan.

Frank recalled the early days when he met Eric Irwin. Eric's deep bitterness and anger with services influenced both Eric and Frank's approach to activism. Frank changed a little when Eric died, as did the focus of his activism, as it adapted to a changing context.

Frank talked about the PROMPT/CAPO relationship with *Mind*



Part of a "Poster Printed by: Trojan Printers, 47a Grayling Road, London, N16. Published by: Kent Prompt as part of Human Rights Campaign".

The poster included a note that "* Spiders web is the symbol by which the anti-psychiatry movement is recognised." The symbol had been appropriated from the mental patients unions

"When I first got involved with PROMPT, in 1980 The boss of national *Mind*, Tony Smythe, was very supportive of Electro Convulsive Therapy (ECT). I know this because I heard Tony Smythe speak. This of course made *Mind* the enemy - at the time. There was one occasion I remember when *Mind* held a fete at the Maudsley Hospital in south London. We went along with our petitions and campaigns. Then Julian Barnett grabbed the microphone and started saying 'come and get your free E.C.T. here'. *Mind* then phoned the police to have us moved from the premises."

"When the Italian experience came to England, a few years later, we went along. We had heard a lot about it and about the work of Franco Basaglia (1924-1980). However we were disappointed to find the meetings run by mental health professionals speaking on the patients' behalf. No patients from the centre seemed to be there to speak for themselves. This caused us to be a disruptive voice from the audience."

CAPO (Campaign Against Psychiatric Oppression) was formed out of PROMPT in March 1985. CAPO met in a pub called *The Wheatsheaf* on the Edgware Road.

In **July 1985**, *Mind* ran "Mental Health 2000", a *World Federation for Mental Health* conference, in Brighton. Apart from Glasgow Link, no users/survivors from Britain were invited. Eric Irwin, Barry Blazeby and Frank Bangay, from CAPO, attended, uninvited

"We set up a stall by the door to show that we mattered too. Following this, with a little persuasion, we got involved with the **autumn 1985** annual *Mind* conference. Here we ran a stall and gave a well received talk, Eric was on fine form. I also organised the poetry and music entertainments for the conference."

"In **1986** we again ran a workshop at the *Mind* conference. I organised some poetry and music entertainments for that conference as well. After this we did from time to time take part in *Mind* events."

"Our relationship with *Mind* was not always harmonious. I would argue that the friction took place on both sides. It did not just come from CAPO."

"I know we were quite critical of the move to work together with mental health professionals. But the mid 1980s was a time of change in the survivor movement. It can sometimes be hard to adjust to these changes."

***Asylum A Magazine for Democratic Psychiatry* started in the Spring of 1986.** This sought to be "the freest possible non-partisan forum for anyone in any way involved in mental health work" The first issue had substantial material on or including the *Campaign Against Psychiatric Oppression*. The second included some opposite points of view. Frank made clear that the publication of alternative views was a problem for some members of CAPO. However, he persisted in providing material.



Eric Irwin (1924-1987) drawn by Colin Hombrook. From "A CAPO Tribute to Eric Irwin" in *Asylum*

Towards the end of his life Eric Irwin spent a lot of time in the library at the Westminster *Mind* headquarters on the Harrow Road. It was here in the **autumn of 1987** that he collapsed and was rushed to hospital. Eric died in St Joseph's Hospice, Hackney **Just before Christmas 1987**. CAPO was continued until 1991 largely by Frank. After Eric's death it decided to affiliate to *Survivors Speak Out*.

Frank's tribute to Eric was published in *Asylum* Volume 3, No 1, Summer 1988. Julian Barnet, who was not too happy about the involvement in *Mind*, was also quite angry about the tribute appearing in *Asylum*. As Frank recalled

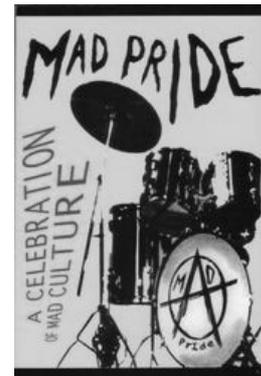
"He had his reasons as Professor Alec Jenner, the editor of *Asylum*, supported E.C.T. It was a difficult decision to make, but Eric did not altogether denounce *Asylum*, and at this point in time I felt the need to try and work with others. CAPO had become quite isolated. I will however say that there were times when I did enjoy working with Julian, and I respected the work he did as an activist and campaigner.

After Eric died, Frank's involvement with *Mind* continued. He also got heavily involved with the **London Alliance for Mental Health Action**, or **Lamha**, which was formed in **October 1987**. Frank found that "some of the younger activists in Lamha criticised me for not being radical enough".

"The days of PROMPT and CAPO are a long time ago now. Some of my memories from that period are quite painful. Other memories are easier to come to terms with. I have been through a lot since then, so I obviously see things a bit different now. But I feel honored to have known and worked with Eric."

Mad Pride

For Frank, a major focus of activity in the 1990s continued to be poetry. On **Monday 15.3.1999**, a day of protest against compulsory community treatment orders ended with some poetry from Frank Bangay, and a minute's silence for people who had died in the mental health system. The day had been organised by the group called **Reclaim Bedlam**. This was formed in the **autumn of 1997** to carry out street protests as a counter-culture to the celebration of 750 years of Bethlem Hospital. Its politics and tactics were inspired by the direct action of the anti-road building Reclaim the Streets movement.



Reclaim Bedlam organised its first cultural event ("gig") under the title **Mad Pride** on **20.6.1999**. "Frank Bangay, veteran of Campaign Against Psychiatric Oppression and survivor poet read from his latest book" and "Ted Curtis - co-author of punk novel *Seaton Point* - did some assorted storytelling".

In June 2000, Ted Curtis, with Robert Dellar, Esther Leslie and Ben Watson, edited *Mad Pride: A Celebration of Mad Culture*, with a selection of twenty-four essays, including one by Frank, "An Uphill Struggle, But It's Been Worth It", telling the history of poetry and the survivors' movement. At Frank's suggestion, the 1973 Fish pamphlet was also included with the following introduction

"Originally published in 1974, this now rare document, also known as "The Fish Pamphlet", is said by some to mark the beginning of the organised 'survivor movement' in Britain as it can be recognised today. The document is therefore of great historical and political importance. According to folklore, survivor activism was at the time particularly strong in West London, where a network of squats was established to provide 'safe houses' for people in distress. The Mental Patients Union evolved during the 1970s into PROMPT (People for the Rights of Mental Patients in Treatment), which eventually turned into CAPO (Campaign Against Psychiatric Oppression) in the early 1980s. CAPO went on to issue a seminal manifesto which is still regarded by many as inspirational; however; we include instead here the original MPU document, which predated and provided a template for the CAPO manifesto. Although some of the following material and the language used may appear dated, it is a timely reminder of where it is that the 'survivor movement' has come from, and sets the context for this book in more ways than one"



Phil Ruthen was so busy taking everybody else's picture that his own was not taken. This one is at a conference at Essex University, where Survivors History ran a bookstall

Phil Ruthen described Mad Pride as having an iconic and romantic status. Was it something of its time? - It has not all been recorded - people have memories of events they thought to be significant of which there appears to be no written record (yet). However, Mad Pride, like PROMPT and CAPO, have made a firm imprint on the minds of historians.

There was some discussion about why certain parts of the movement are remembered like this, and other parts overlooked, and it was suggested that involvement in "chipping away at services" is not very glamorous.

Mad Pride considered itself an art form. Ben Watson wrote "Madness is just Modern Art without the authoritarian intimidation". There was creative drama in both the protests and the culture, although the reality behind the drama became cruelly clear when Peter Shaughnessy killed himself on **14.12.2002.**

We discussed the possibilities of people acting madness for whatever reason, and whether there are realities of mental distress that are marginalised by the drama?

Complexity of the history

There are different versions of survivor history. Eric Irwin's innovative version in *Asylum*, Volume 3, Number 3 (published after his death), sees the Mental Patients Union as a branch of "anti-psychiatry". A similar interpretation is given (briefly) in *Mad Pride: A Celebration of Mad Culture* (2000) and in an expanded version in Nick Crossley's and Helen Spandler's histories. Extended forward in this way, it draws a *Need for a Mental Patients Union* (Fish pamphlet) - PROMPT - *Survivors Speak Out* - Mad Pride trajectory. This presents the 1972/1973 pilot committee's Fish pamphlet as if it was the unions. That is, it analyses a pamphlet (and one not written by a mental patients' union) in place of analysing the real unions. Criticising this version, Andrew Roberts (who was not anti-psychiatry) argues against ignoring the activities of the real mental patients' unions, from Scotland down to Portsmouth, before and after 1973. He argues that histories developed from Eric's version tend to be London centred, not usually mentioning the *Federation of Mental Patients Unions* formed in Manchester, for example. The "branch of anti-psychiatry" argument leads to a focus on the activities of ex-patients and anti-psychiatric "allies". This means the unions and user groups inside hospital, from which much of the momentum came, are overlooked. The interpretation also omits the subsequent activities of user groups, (apart from the *Campaign Against Psychiatric Atrocities*), prior to the 1985 World Congress at Brighton.

Andrew wants us to use empirical, archival and other, materials to create a more complex version of different histories, including collective activities in hospitals, and action in Scotland, Manchester, Leeds, Bristol and east and south (as well as west) London. This more nuanced version must include, but not be pre-occupied with, the very political groups, and the anti-psychiatry tradition in the movement. It should make space for local groups of patients; for housing schemes run by patients; for women's groups and black and ethnic minority groups; for groups that include users and carers; for the development of self-advocacy by people with learning difficulties; for mental distress in old age activities; for grass roots activities as well as sensational media events; for activities that defend, reform or develop services, as well as for those that attack them, and for the quiet voices underneath the loud.



Catherine notes Frank's point

Radical or assimilated? Abolition or improvement? For or against psychiatry?

Is the movement more or less political now? Are there clear trends in our history or a complex interweaving of diverse themes? Catherine Jackson and Peter Campbell argued that there is now more focus on involvement and improving services and less radical anti-psychiatry action. In the early 1980s (especially) some people wanted to abolish psychiatry or mental health services and, possibly, replace them with alternatives. Nowadays we hear less of this approach. The users' movement may have been assimilated.

Ian Ray-Todd spoke of his own experience of the movement in Hackney in the 1980s: People did not want to abolish services. If anyone talked about abolishing psychiatry it was in the context of challenging the hegemony of the medical model. People were critical and challenging of assumptions, but one aim was, nevertheless, to improve services. Clare Ockwell pointed out that this included the prospect of providing our own services. Ian and Andrew were both involved in efforts to secure funding for a "user controlled mental health centre for Hackney", for example .

GRAMME
Sector Application Form

Reference number: V94
AT

Completing this form, please read the guidance notes at the back

Name of project: Hackney Community Mental Health Centre

Name of Organisation: Hackney Mental Health Action Group (HaMHAG)

Name of Contact: Cathy Pelikan
c/o Hackney Health

Contact address: Emergency, 5 Telephone: 254 6689
Liberty Hall,
489 Kingsland High Road, E8

Summary & main aims of project: To establish a user-controlled community mental health centre for Hackney, providing a social and cultural centre for mentally distressed people and their friends. Services to include recreational and 'quiet room' facilities, facilities and support for self-help groups, counselling and advice sessions, relevant educational classes and creative/expressive therapy groups.
To research the feasibility and work towards the establishment of a linked but self-contained 'crash pad' unit providing crisis containment/emergency accommodation within the community.

Everyone seemed to agree that some trends could be identified - But we could not agree about what the trends are.

It always seemed to be more complex when Andrew described the history. He argued that there was a well documented involvement in improving services dating back, at least, to the late 1970s. He also pointed out that Mad Pride, which used direct action against psychiatry, claimed that it was "set to become the first great civil liberties movement of the new millenium" - that is the 21st century.

Participants also disagreed about their attitude to psychiatry and treatment. In describing the action around the 'celebration' of 300 years of Bedlam, Peter characterised the history of the mental health services as "300 years of oppression". Andrew said that his own experience of mental health services had mainly been positive.

Mark Cresswell spoke about the pressure to simplify and distort issues when writing in an academic context. He feels that a "good story" is wanted, rather than something that corresponds to the diversity and complexity of what actually happened. Academics, if 'left to their own devices' will always over-simplify, so we cannot rely on these histories alone

But simplicity had its champions. Ian cautioned us "lest we shoot the project in the foot". We should bear in mind Samuel Johnson's dictum that a degree of compromise with simplicity is essential to communicate crisply.

Hidden histories and neglected geographies.

We talked about the hidden histories of the movement, including the ones in people's memories and in archives preserved by individuals up and down the country. The web project is seeking to list and explore these. Much may be lost if we do not succeed in this.

On the train back to Lancashire, Helen Spandler wondered whether we could also look into a funded Ph.D. studentship to research the hidden histories. This would be a good way to get someone, preferably a survivor researcher/historian, to spend three years researching the material.

Helen also noted the geographical dimension in our analysis which was highlighted by the contrast between the users' movement east and west London. Peter Campbell suggested research would be useful into why groups persisted in one form in some areas and mutated in others. Andrew Roberts thought the relevance of geography was even more salient in the absence of discussion of the movement outside London. Hardly any mention was made of Scotland, Lancashire, Yorkshire, Nottingham or Bristol, although the significance of what happened in each of these areas was as great as that of anything that happened in London. Helen mentioned the work of Glasgow based social geographers in our field of study and will attempt to make contacts for us.



Sophie, Ian and Mark did a lot of listening.

Quietness

Sophie Mirrell's presence was much appreciated. She said she wanted to keep quiet for her first meeting, but has promised to come again. Like Ian and Mark, she spent most of her time listening and learning.

Clare Ockwell talked about people who are quiet at meetings for other reasons, and about the kind of meetings that we need to have if everyone is to find a voice. She said that the groups we speak about in the 1970s and 1980s would have been far too loud and outspoken to attract her. She became involved in the survivor movement in the mid-1990s. The day centre she attended were looking for users who could be representatives. She suspects she was selected because she was quiet and reasonable, and not likely to cause any trouble. She only became assertive when Andrea Linell introduced users to training programmes for West Sussex mental health professionals. Jim Read, a user professional, was employed to train them. Jim had developed consciousness raising programmes in Hackney during the 1980s. In his classes, Clare learnt that she had something valuable to say and how to say it. She is now a manager of the *The Capital Project Trust* (Clients and Professionals in Training and Learning) and is encouraging others users to be self-assertive.

Spaces closing

Clare Ockwell spoke about the spaces closing in which users can associate. She mentioned day centres. National groups need to be aware of this and to work towards maintaining and developing areas in which people can associate locally.

Length of histories

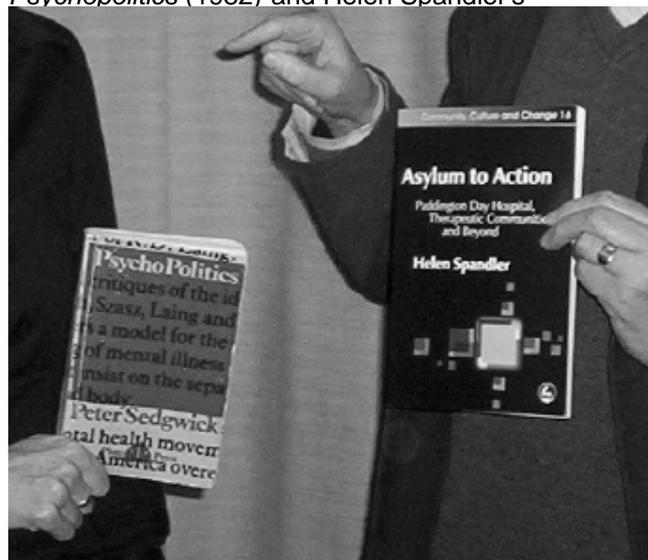
How many words are needed to write the history of our movement? Can it be done in 3,000? Or will that over-simplify? Peter has been asked to update an Open University text that he wrote ten years ago, summarising the whole movement in 3,000 words.. He felt that asking someone to update a chapter to cover a further 10 years of activity and still keep it within the same word limit of 3000 words is quite cheeky...!!

Ian was pleased that Peter had done it – because at least it contributed to the number of histories available to people.

What history will survive us?

Helen Spandler has warned that unless we write our own history, a few expensive books, like the collection of Michel Foucault's lectures, the one by Nick Crossley and Helen's could be what people read about us. Our history, written by others, may be studied in university

Two of the best professional histories of the mental patients' movement in the 1970s are Peter Sedgwick's *Psychopolitics* (1982) and Helen Spandler's



Asylum to Action (2006) But Helen thinks we should find ways to critically evaluate histories such as hers.

libraries, but closed to the users outside the universities. We need ways of enabling users to write their own diverse stories, and we need ways to preserve and make those stories available to future generations. Helen also thinks that the group should be finding ways to record any inaccuracies in the official accounts and histories – so that they do not get repeated.

What kind of history?

Phil Ruthen has argued, at an earlier meeting, that the Survivors History Group works in many ways as a social science project with a historical perspective. He made reference to the "mutually beneficial" links we have made with university departments and individual researchers, with Survivors Poetry, and networks of survivors. Since the conference he has helped to establish a web forum in which survivors and academics can document and discuss history. Given this, Phil suggests that we should subscribe to the ethics and other norms of the social science disciplines

Frank Bangay having asked for clarification on what was meant by social science in this context, Ian Ray-Todd had submitted reflections on the "scientific" aspect of our ongoing research and the nature of the "history" that we are constructing. He thought we could discuss whether to seek standards of objectivity that would make our research acceptable to the social science community or whether to emphasise the "intrinsic worth" of what we do to the users and others who take part in constructing it, or who come across the end result. The two approaches might be combined.

Ian read from and elaborated his notes on this idea:



To Phil it was a picture of some of the food before we ate it.. To Ian it was "The fruits of the Survivors History Group, and its sustenance!" Ian wanted to know the value added by the first fruits of our work.

Thinking: Social Science: 'Normal' or New Paradigm?

* What does the Survivors History Group understand by social science? Are we content to treat social science and its standards, such as 'objectivity' and 'professionalism' as not worth contesting?

* What is the meaning of 'history'? How do we define it? How do we describe it? What are its implications?

Value addition

Must the fruits of the Survivors History Group's first substantive research project be sufficiently original to add real value - in the opinion of competent, respected, professional historians - to society's store of self-knowledge and understanding?

If not, would their intrinsic worth, to the people nevertheless subjectively interested in the fruits, be quite enough to justify the project? Ian thought it would, but also asked:

Would there then be a sufficient element of public (as distinct from user) benefit, educationally or otherwise, to secure funding? How much would this matter?

Ethics and methods

Ian challenged us to reflect quite carefully on "the most appropriate methods of realising the aim of an ethically sound, yet subjectively resonant, authentic mapping of the terrain which the various narratives testify". He laid down some principles:

* To separate opinion from fact, reasonably clearly, without becoming stylistically robotic, is virtuous.

* To think that the unalloyed facts speak for themselves is to indulge in a delusion.

* We cannot be inclusive if we use a jargon quite as impenetrable to ordinary folk as medieval clerical Latin.

* We should value the respect of academics but decline their services as amanuenses (people who write for people who cannot write for themselves).

Class

Mark Cresswell and Phil Ruthen had a brief discussion about class and mental health. They concluded that class is a dimension that has dropped out of recent research, however much they might lament its disappearance. This discussion concerned class as a socio-economic concept, as in research about working class mental health. A broader issue concerning Phil is the idea of users and ex-users of mental health services as a class (group, category) in government policy, and their eventual class-excluded position in socio-economic life. He has provided the group with a 6,000 word summary of his thesis on this.

Restaurant Meal

By Joan Hughes

My friends Roger and Felicity called at about 5.45pm in their car and drove me to the restaurant where members of the Mental Health History Group had arranged to have a meal. Roger had some trouble in finding the way, but we arrived there eventually. I did not want to climb the steep steps, so we walked round to the front of the restaurant and came in that way.

Helen Spandler had come down from Lancashire to attend this meeting and I was really interested to meet her, having seen her once at my home about twenty years earlier. Helen has since written a book, but we talked about articles that we both wrote in the magazine *Asylum*, and about articles I published elsewhere on the history of the mental patients union and other groups. We had our photograph taken together.

I had curried vegetables and rice. Most people had this and it was very nice. Helen and Mark (from Durham) had to leave early to catch trains. Andrew had arrived under his own steam [like one of those old trains!], but as Roger and Felicity were driving me home, we took Andrew as well. I had ice cream when I got home and then Roger and Felicity took Andrew home. It was an interesting evening.



Joan Hughes (aged 80 - left) talks to Helen Spandler (aged 38 - right) about their articles in *Asylum A Magazine for Democratic Psychiatry*. Helen is pointing out the significance to her of one of Joan's comments.

Reflections on a mental health service users' conference with historians

by Mark Cresswell

Problems with academic writing on the history of survivor/user activism

The meeting was not only enjoyable but also a real eye-opener for me. I guess I was listening with a particular perspective in mind: as an academic who works on the history of user/survivor activism; who thinks academic work in this area is important but worries all the same about its 'credibility', about the issue of whether it can ever 'do justice to' the movement itself etc. My memories relate very specifically to this perspective so apologies if it comes across as a bit self-indulgent.

As I said at the meeting, often academic writing comes from a particular theoretical perspective (Marxism, feminism etc.) and this is used as a way of imposing a certain order upon what can seem to be the infinity of historical facts. But as a part of this process a number of simplifying manoeuvres occur which threaten to do violence to grassroots activism. I do not think this means that we should do away with 'theory'; I think that is neither possible nor desirable. But I do agree that over-simplification has taken place.

An example: one of the most prominent and comprehensive histories of the British movement to have appeared in recent years is Nick Crossley's *Contesting Psychiatry* (2006). I know this work well. I worked with Nick for many years at the University of Manchester and also know his previous work on the movement which stretches back over a decade now. I do want to defend the quality, the significance of this work. But it seems to me that the discussions that took place at the meeting raise a number of issues about the incompleteness of this work and, consequently, for academic writing in general, which obviously implicates my own work on the self-harm survivor movement between 1986 and 2000. The meeting has stimulated me to specify some of these thoughts.

First, I do not think we should tar all academics with the same brush. Some have only ever been within academia; others come to academia by a circuitous route which may involve all sorts of political activism and social movement participation. Nick would be an example of the former; Helen and I of the latter. Nick is a sociologist in the 'pure' sense of seeing sociology as an important discipline that makes claims that may even be regarded as 'scientific'. This has definite consequences for his work on the movement, which he tends to regard as an 'object' of research rather than something he believes in, cares about, and is a part of. Put it another way: the movement is not part of his 'identity'. His work lacks an obvious political, or ethical, dimension. What he does do is take the movement seriously as an 'object' of research and he provides an intelligible 'story' about its history and its changing patterns of political activism.



I want to move on to my specific memories of the meeting, but first I want to say what I think that ‘story’ is that Nick presents in his work. I am doing this because one of my abiding memories of the meeting is that it highlighted some of the inadequacies of the academic approach. At the risk of gross over-simplification, I think the ‘story’ Nick presents of the period 1970 – 2000 (ish) is this:

Political activism in mental health *mirrors* wider features of society and *tracks* socio-cultural change. In other words, when you have a political culture that stresses left-wing activism, Marxism, the legitimacy of trade unionism, you will get mental health activism that follows suite. In terms of the history of user/survivor activism in Britain this sets up a series of ‘correspondences’ of the following kind:

- 1970s – there is successful left-wing activism/trade unionism (the miners' strike, a three-day week, beer and sandwiches with the Prime Minister, etc.), *therefore* the Mental Patients Union and the Fish pamphlet with its Marxist theoretical frame.
- 1980s – Marxism declines, there is the rise of the ‘New Right’, an assault on trade union power in which the miners are defeated, the ascendancy of consumerism and managerialism in welfare, *therefore* Survivors Speak Out, partnership, collaboration, user involvement in service planning/audit, ‘experts by experience’ etc.;
- 1990s – the rise of anti-globalisation/anti-capitalism movements, direct action as a pattern of activism (Reclaim the Streets) influenced by anarchism, *therefore* Mad Pride, ‘separatism’ and a positive revaluation of the ‘madness experience’.

Now, what struck me most at the meeting was the way in which the contributions of Andrew, Frank, Ian, Phil, Peter and Clare exposed the *incompleteness* of this historical perspective. Andrew’s comments on the MPU, its origins and activism, for instance, imply that a revision of this history is an urgent task. I think that Andrew’s account implies that the relation of the MPU to later activism contains strong *continuities* as well as *discontinuities*, which Nick Crossley’s account emphasises. Presumably, the archive that is being collected would support Andrew’s perspective. So, I guess the first thought I had as I wended my way back up North was this: a revisionist history of the MPU is urgently needed, one which perhaps takes as its point of departure, not the Paddington Day Hospital-MPU relation (as Helen and Nick do) but, rather, the SUMP-MPU relation, which we know far less about. This ‘revisionist history’ would also stress the autonomous nature and localised activism of the various MPUs. I do not think this new account of the MPU need necessarily stand in complete opposition to the other accounts but it would show that they are, as they stand, incomplete. I think, for this revisionist account to work, everything turns upon what we can find in the archive, especially regarding SUMP and the autonomous MPUs. One of the problems here is that Nick and Helen have already unearthed material that has been ‘hidden from history’; now we face the daunting task of uncovering material that has been even more submerged. Not for nothing did Michel Foucault call historical work ‘archaeology’.

The question of ‘what we may find submerged in the archive’ raises another issue. I want to summarise this in terms of the fascinating exchange which took place between Ian and Andrew who can, of course, correct me if I have misinterpreted them. Briefly: Andrew stressed the *objectivity* of the attempt by the group to compile its archive, referring to the efforts of keeping boxes, files etc. often over many years. Frank said that the boxes in his flat are piled high. I agree with the essential ‘objectivity’ of this task. But Ian’s response was equally persuasive: we should not devalue the *subjective* side of the archive in the name of

‘objectivity’ – it possesses its own value and this is in no sense some kind of ‘second-rate’ knowledge. This point has to also be correct: medicine and psychiatry have an ignominious history of denigrating the knowledge produced by users/survivors as being ‘merely subjective’.

This issue is difficult to disentangle because it does go to the heart of the task of historical writing. Briefly, historians (and historical sociologists of my type) have taken two contrasting perspectives on the issue of the ultimate ‘truth’ of what they do. Either:-

1. They see their task as being to ‘reconstitute the past’, to ‘tell it how it was’, and they do this by compiling an exhaustive collection of ‘facts’ about a given period. History, according to this account, is seen as ‘objective’; that is to say, it could only be altered if a new set of ‘facts’ were uncovered which refuted or altered the original collection of facts. Or:
2. They see history as being about ‘multiple perspectives’ each of which may contain a certain limited ‘truth’ but which cannot be aggregated together to produce one ‘ultimate truth’ of an historical period or subject. According to this account, history is always ‘subjective’ and always open to interpretation and reinterpretation.

Somehow, it seems important to hold both of these perspectives in mind, though in practice it is very difficult. An example from my own work: I think the ‘facts’ really matter and it can be shown objectively that self-harm survivor activism arose as a combination of mental health activism (e.g. Louise Pembroke through Survivors Speak Out) and feminist activism in Bristol (e.g. Maggy Ross and the Bristol Crisis Service for Women) in the period 1986-1990. I am happy to defend these as ‘facts’. But fast-forward ten years and we find that the movement actually contains two very different *types* of activism: that associated with the campaigning of Louise and the National Self-Harm Network and that associated with Sharon LeFevre in North Wales around the Action, Consultancy and Training Group. These are both equally ‘facts’ and they do share some points of similarity; but they are also very different *perspectives* on self-harm survivor activism.

The other issue from the meeting that really struck me – it relates to the issue of ‘multiple perspectives’ – was the significance of ‘localism’. This is, perhaps, very hard for an academic to grasp because we are constantly being implored to adopt an ‘international perspective’ in our work, and certainly publishers like and expect that. But the recollections of Andrew, Frank, Peter, Clare, Phil and Ian also stressed the importance of a *local* perspective. Maybe I am demonstrating a certain Northern bias here – I tend to see ‘London’ as just one (very big) thing! But what is very clear is that local histories and patterns of activism may actually be very different in Hackney, Ealing etc. Why? This, it seems to me would be a different and innovative way of doing the history of the movement: not in terms of a national perspective; not in terms of an international perspective; not in terms of a subject-specific perspective (hearing voices, self-harm, anti-ECT etc), but in terms of a *geographical locale*. In my own work, for instance, it is very clear that Bristol feminist activism and its links with mental health activism was very important in the period 1985-1990; but actually, there has never been a detailed grassroots account provided of this.

Finally, as I wended my way back up North, I found myself thinking of the words of the Czech writer Milan Kundera. ‘History’, Kundera said, ‘represents the triumph of memory over forgetting’. That sums up the significance of the day and of the group’s efforts for me.

There can be no doubt that the history of the movement has been ‘hidden’ – there has been a lot of pressure applied to ‘forget’ - and that when it has seen light of day in the work of academics, say, it has been and remains incomplete. This places a definite ‘responsibility’ upon academics who work in this area and that ‘responsibility’ is in the nature of a political and ethical commitment, not a ‘scientific’ task. At the same time, users/survivors have so far been given only minimal opportunities to record their own history – I am thinking here of Peter being given just 3,000 words to recount the history of the movement when he has been its most exemplary chronicler for twenty years or more.

So, it seems to me, that if ‘memory’ truly is to ‘triumph over forgetting’ for the history of the movement, two imperatives seem to apply:

First, and most urgently, more opportunities for people with *direct experience* of psychiatry need to be pursued to recount *their historical experiences and their analyses of those experiences* whether through written publication, public exhibition or multi-media work. I am thinking here of something like an ‘activist’ equivalent of the ‘Testimony’ archive of experiences in the old Asylums compiled by Mental Health Media, digitised and stored now for all time in the British Library. Clearly, the work of the History Project would be central to this, however we choose to take the manifesto forward. I am stressing the importance here of ‘experience + analysis’ – not only ‘experience’ - because I worry that sometimes the powers-that-be are quite happy to embrace the ‘survivor’s voice’ tokenistically without taking any notice whatsoever of the *criticism* contained within it. I have found the work of the Mental Health Media ‘Testimony’ project to be powerful precisely because the cumulative testimonies contained within it amount to an extensive and overwhelming *critique*. One of the reasons the powers-that-be want people to ‘forget’, it seems to me, is that ‘remembering’ can be so very *critical of them*.

Second, I do not think we should give up on academia, though, of course, I would say that wouldn’t I! Rather, it is important to identify and work in alliance with ‘academic-activists’ who accept the sorts of ‘responsibilities’ I have outlined above. Such ‘academic-activists’ reject both the idea of the ‘ivory tower intellectual’ and the ‘academic in the service of government’ function and, instead, embrace the idea of being ‘embedded’ within the movements they write about and whose democratic goals they work to promote. There is a limited and secondary role for academia in this project; but it is not an altogether meaningless one.

Explanatory Notes

In case it should not be clear from the introduction, this is not a verbatim report but a report that includes the reflections of participants on what they said. A recording of the main meeting (with Catherine Jackson) was taken, and will be preserved in our archives. All participants in the conference have had the opportunity to contribute to and make editorial comment on the report. Final editorial responsibility for faults in fact or phrasing, layout or content, rests with Andrew Roberts. The meetings before and after this were not recorded. The explanatory notes provide references for some of the story told in this report. Fuller references will sometimes be found by consulting the *Mental Health History Timeline* and *Survivors History Timeline*, or by writing to Andrew Roberts.

Andrew Roberts A mental patient since he had the waves of his brain measured in Runwell Hospital in about 1955 (aged 11+). He was the husband of Valerie Argent who was confined (aged 14, in 1962) in "a hospital for mental defectives"(quote from her medical case notes). Together, they established Robin Farquharson House, the mental patients union's Hackney headquarters, collective living scheme and emergency accommodation (1973-1976). Valerie gained her Masters' degree from Bedford College in 1984. She then worked as a lecturer some days and attended a psychiatric day hospital on others. She died in 1992. During the 1980s and 1990s Andrew was an active member of *Hamhp: Hackney Action on Learning Disability*, one of the first organisations to include people with learning disabilities as fully participant members.

Anne Beales is a registered social worker, who has worked within the statutory and voluntary sector. She first worked "as a survivor" with CAPITAL, joining in 1998, eventually becoming the Director. She is also part of a regional group of people who access services in the South East called the 'Dream Team' (soon to change its name). She first heard the idea of linking groups locally and regionally across England from members of these groups. They gave her the vision of "people coming together, and briefing and debriefing their leaders with their 'collective perspective'" (*Service-users Together* page 16). Anne was appointed "Director of Service-user Involvement" by Together in December 2004. The directorate was set up "to strengthen the voice" of Together's service users and to "support service-user involvement nationally". One of her first acts was to support the Survivor History Group. Anne found that her idea for a survivors' network was "almost identical" to one developed by survivors and others involved in the Sainsbury Mental Health Centre's *Our Own Terms* project. In fact, some people referred to the idea as "Jan Wallcraft's project" after the Sainsbury Centre's senior researcher in user focused research, who set up the *Mind Consumers Network* in 1998. Sainsbury money having run out, this project was nurtured, from early 2006, by David Crepaz-Keay, another celebrity survivor, who was appointed as Head of Patient and Public Involvement for the Mental Health Foundation in June 2005. Anne and David called the *Our Future* conference in Birmingham, on 8.3.2006, which led, eventually, to the establishment of the *National Survivor User Network* (NSUN). Anne is a member of the NSUN management committee and is currently involved in efforts to establish *Interrelate*, a service user/survivor led international network. Together's service user policy was set out (about May 2006) in *Service-users Together. A guide for involvement*, edited by Thurstine Basset, with substantial contributions from Anne Beales. NSUN has disavowed being the voice of users, but Anne is still inspired by her original ideal. She writes "We should know our history and our combined expertise will make our voices louder, more influential and provide leadership based on our experience."

Anne Plumb lives in Manchester. As a student, in the late 1960s, she was not helped by two psychiatric hospitals, but was helped by reading. So she has been collecting books, pamphlets and articles ever since. Her collection is woven into her memories of her life as a survivor activist and she is recording both in emails and catalogues. Her writing could provide the core for a survivor history group project giving north of England perspectives on the movement. Anne, Helen Spandler and Andrew Hughes are also working on a Manchester history timeline and have been discussing a north of London group, centred on Manchester. Similar groups might form with other centres.

Asylum A Magazine for Democratic Psychiatry Founded Spring 1986.

CAPITAL *The Capital Project Trust* (Clients and Professionals in Training and Learning) is a West Sussex user-led project, set up in 1997, to train users in service user focused training, consultancy and research.

CAPO (*Campaign Against Psychiatric Oppression*) was established in March 1985. Its core activists included, Eric Irwin, who suggested and prompted the change of name, Frank Bangay, who worked in very close association with Eric, and Barry Blazeby. The group replaced and developed PROMPT. Frank Bangay discontinued CAPO in the early 1990s.

Catherine Jackson is a journalist and former editor of *Mental Health Today*. She asked to interview the group for a forthcoming article she is preparing, so she was the instigator of our conference, which grew around her interview.

Clare Ockwell In the last series of *Mastermind*, in 1997, contestant Clare Ockwell chose *anorexia nervosa* as the subject for her heat. Anticipating the interest that this would generate, the BBC made it the first of the final series. Clare's first experience of using the mental health services was when she was only nine years old. She turned her experience as an anorexic to good use in 1982, when she and her mother formed the *Society for the Advancement of Research into Anorexia* (SARA). Clare ran this for ten years, before merging it with the *Eating Disorders Association*. in 1992. She was a founder member of *The Capital Project Trust* (Clients and Professionals in Training and Learning) in 1997 and the *Survivors History Group* in 2005.



Fish pamphlet: *The Need for a Mental Patients' Union - Some Proposals* is a four sheet, stapled, foolscap pamphlet written by Eric Irwin, Lesley Mitchell, Liz Durkin and Brian Douieb. It was circulated in the spring of 1973 by a small group that also included Andrew and Valerie Roberts. The picture and quotation on the cover (below) led to its nickname as the Fish pamphlet:

"An individual having unusual difficulties in coping with his environment struggles and kicks up the dust, as it were. I have used the figure of a fish caught on a hook: his gyrations must look peculiar to other fish that don't understand the circumstances; but his splashes are not his affliction, they are his effort to get rid of his affliction and as every fisherman knows these efforts may succeed." - Karl Mennenger.

The pamphlet was not a Mental Patients Union publication.

Frank Bangay Born Wandsworth in 1951. In his early twenties he started suffering from severe depression and anxiety. Expressing himself through poetry helped to disperse the gloom and he performed at *Troubadour Coffee House* in Earls Court. At the end of the 1970s, he collaborated with musicians in the *Fighting Pigeons Band*. He first read PROMPT booklets in 1979.

Glasgow Link Clubs Glasgow Association for Mental Health was founded in 1978. Its Link Clubs are self support groups of service users and carers.

Hackney Workers Educational Association A radical branch of the WEA in which classes were often autonomous study groups. The branch gained a national reputation for innovation. The first class promoted by mental patients was *Mental Health and the Community* at the Centerprise Community Bookshop in Dalston. It grew out of discussions at Centerprise about how to cope with customers with mental health problems. The ex-Hackney MPU members who ran it were bored with people shouting about one another, and sought to create a space where people could discuss divergent views. The principle was that people could talk without agreeing and without compromising the purity of their respective principles. Psychiatrists, for example, could debate with anti-psychiatrists, and mental patients talk to mental health workers, on equal terms. Between the autumn of 1977 and the autumn of 1984, Hackney *Workers Educational Association* was involved in meetings on alternatives to prisons (with Alan Leader) - the local psychiatric unit - mental handicap - alternatives in mental health - mental distress in old age and a series of meetings with speakers who had physical or communication disabilities (*Everybody's Hackney*). Ex MPU members were active in all of these. In 1985, Jim Read "ex-mental patient" ran a course specifically for anyone who "had ever been a patient in a mental hospital - attended a day centre - had electric shock treatment - taken tranquillisers or anti-depressants - or felt you were going mad". It was called "Your Mind in Their Hands".

Helen Spandler began research in the Mental Patients Union archives in October 1989. In July 1990 she wrote an (unpublished) paper "An attempt to analyse the anti-psychiatry and mental patients movements with regard to the social and political period of the sixties". Her research on the Socialist Patient Collective was published in *Asylum* in Autumn 1992. Helen Spandler's thesis (2002) and book (2006), both called *Asylum to Action* include a fairly detailed account of the origin of the Mental Patients Union. She is currently working with Anne Plumb on the history of the survivors' movement in Greater Manchester, and with Mark Cresswell on the legacy on Peter Sedgwick.

Ian Ray-Todd was an active member of *Hackney Mental Health Action Group*, which was formed in the summer of 1984 by local patients, ex-patients and other people sympathetic to "the aim of increasing the self-determination of mentally distressed people in Hackney". This was the most successful of a series of associations formed in Hackney in the 1980s by mental health service users, including *Hackney Mental Patients Association* in 1981 and the *Phoenix Patients Collective* in 1983. These groups all engaged with services to the extent of being represented on committees and entering into a dialogue. All "past or present user of the psychiatric services" could be members of *Hackney Mental Health Action Group* and attend meetings. Others had to be sympathetic to the aims of the group, and professionals had to be invited by the group before they could attend meetings. Ian helped to formulate a "Charter of Rights for Victims of Mental Distress", intended to become the basis of Hackney Council policy. He was also involved in the group's efforts to secure funding for a "user controlled mental health centre for Hackney".

Italian experience Law 180 of 1978 was known as "Basaglia's law" after Franco Basaglia (1924-1980) the psychiatrist who founded *Psichiatria Democratica* in 1974. According to this law, all psychiatric hospitals were closed to new admissions (and, after three years, also to readmissions) and were replaced with community-based services and psychiatric units based in general hospitals. In the same year a new National Health Service, providing free health care to all Italian citizens, replaced the existing national insurance system. Some of this

sounds like what had already happened, or was happening, in England, but in Italy it was sudden and revolutionary, and had a democratic and socialist philosophy attached. Basaglia explained the relations between national experiences in England, France and Italy in a speech to a European workshop on "Alternatives to Mental Hospitals" held in Ghent, Belgium between 31.3.1980 and 3.4.1980 ("Crisis Intervention, Treatment and Rehabilitation" in *Alternatives to Mental Hospitals - Report of a European workshop*, MIND, London, 1981, pages 23-25). In July 1981 the Conservative government in Britain released the, hitherto secret, "Parkinson Report", and initiated the policy of closing all old style hospitals, moving long-stay patients into the community accompanied by the money used on their hospital care. Discussing the final end of the asylum seemed, quite suddenly, realistic, and the Italian experience was thought, by many, to pave the way. The first edition of *Asylum A Magazine for Democratic Psychiatry* (1986) stated "within the editorial group there is an admiration for the work of *Psichiatria Democratica*. We are agreed amongst ourselves that the use of coercion, locked doors, violence, and ECT is, at the very least, regrettable. But exactly how to organise therapy remains the fundamental problem. And so this issue continues with the theme of Italian reform..."

Joan Hughes wrote "Mental Distress - Short talk on the history of mental patients' movements" for a meeting on 4.2.1986. It has since grown into a longer talk. She helped to preserve the archives of the *Mayola Mental Patients Union* after 1976. As Joan Martin, she co-authored *A Directory of the Side Effects of Psychiatric Drugs* in October 1975 and re-published it in October 1977. Her autobiography (much of it unpublished) and articles in the alternative press (*Asylum*, *Lawletter*, etc) are important sources of information on the history of the movement.

Mad Pride Street demonstrations in October 1997 as a counter publicity-stunt to the 750th anniversary celebrations of Bethlem Hospital were organised by Pete Shaughnessy (1962-2002) and other user/survivors who had recently taken over *Southwark Mind*. They adopted the name "Reclaim Bedlam" and carried out other headline-catching demonstrations in the following years. In June 1999 they organised a festival of music and poetry ("gig") under the name "Mad Pride". Others followed. In June 2000 the anthology *Mad Pride: A Celebration of Mad Culture* was published by Spare Change Books.

Mark Cresswell is a sociologist based at Durham University. He has researched and written about the self-harm survivors movement 1988-1996 including. "Self-Harm 'Survivors' and Psychiatry in England, 1988-1996" *Social Theory and Health* 3: 259-285 and is currently working (with Helen Spandler) on the legacy of Peter Sedgwick.

Mayola Road Mental Patients Union When the *Federation of Mental Patients Unions* was formed, 37 Mayola Road, Hackney, which had been the national centre and remained a coordinating centre, was named Mayola Road instead of Hackney to make clear it was not a Hackney only group. Any patient from anywhere in the world (in practice) had a right to attend its meetings and vote. The *Hackney Hospital Mental Patients Union* was an autonomous union. Only Hackney Hospital patients had a right to attend or vote at its meetings.

Mental Health History Timeline An internet history started by Andrew Roberts on the Middlesex University website in June 1999. In May 2007 it moved to its own website at <http://studymore.org.uk/mhhtim.htm> - From this site it will be regularly archived by the *UK Web Archiving Consortium*.

Mental patients unions were associations of mental patients (and/or ex- patients) working for their common good. A suggestion for a union of patients was made by Archie Meek (Scotland) sometime in 1969/1971. The *Scottish Union of Mental Patients* (SUMP) operated by means such as a common petition of grievances and may never have had a general meeting (which would have been difficult to organise inside a mental hospital with locked wards). The English based unions began with general meetings in 1973 and 1974. Unions were active, inside and outside of hospitals, and throughout Britain, in the mid-1970s. Archives of the Scottish union, national and some local unions are preserved by Andrew Roberts.

Michel Foucault (1926-1984) French theorist who explores the relationship between ideas systems, which he calls discourses, and power. One of his early books was translated into English in 1961 as *Madness and Civilisation. A History of Insanity in the Age of Reason*. The student uprisings in France, in May 1968, opened intellectual minds to the broader concept of political power that Foucault was interested in. On Dutch television, in November 1971, Foucault argued that power is not just something "in the hands of the government... local government, the police and the army", but is also exercised through idea systems, including sciences. "Psychiatry, for instance, is ... meant to improve mankind, and the knowledge of the psychiatrists", but it is also "a way to implement a political power to a particular social group." From 7.11. 1973 to 6.2.1974, Foucault gave weekly lectures in Paris on psychiatric power. In these he used the term anti-psychiatry to describe a movement critical of psychiatry, that arose within psychiatry. The way that this movement arose was rich and complex. It included disease, because hysteria in the late 19th century was seen as a patient protest engendered by psychiatry, but it also included all movements away from asylum psychiatry that were made, in the twentieth century, by mental health professionals. A translation into English, by Graham Burchell, of Foucault's lectures was published as *Psychiatric Power. Lectures at the College of France 1973-1974* by Palgrave Macmillan, (London and New York) in 2006. It includes an introduction by Arnold Davidson; detailed notes by someone other than Foucault, who is not identified; and a "Course Context" by Jacques Lagrange. The additional material is detailed, and relates Foucault's text to the genesis of the French movement of mental patients.

Milan Kundera (1929-) Czech born writer (novelist, poet, essayist, dramatist) living in France and writing in French.

Mind: *The National Association for Mental Health* (now *Mind*), was founded in **1946**. It was a combination of existing organisations, partly merged in **1939** as the *Mental Health Emergency Committee* for war-time coordination. Its components were the *Central Association for Mental Welfare* (formed in **1896** as the *National Association for the Care of the Feeble Minded*), the *National Council for Mental Hygiene* (founded **1918**) and the *Child Guidance Clinic* (founded **1927**). The Association worked closely with the *Ministry of Health* and the *Board of Control*. In the **1960s** it was associated with media work to overcome the taboo of silence about mental health in the press and on television. In **1958** Christopher Mayhew MP, a supporter of the *National Association*, persuaded the BBC to record *The Hurt Mind*, the first television programme to do with a mental hospital. But the cameras were not allowed to film patients' faces, only their hands and feet. Mary Applebey, (Director **1951-1974**), speaking of the problems of getting *The Hurt Mind* broadcast, commented that "last week a patient was filmed who was frankly demented". In the autumn of **1969** the Scientologists tried, unsuccessfully, to take over the Association. This conflict, originating in efforts to prevent overseas Scientologists entering the United Kingdom, led to the formation

of the *Citizens Commission on Human Rights* (1969) by Thomas Szasz (author of *The Myth of Mental Illness* (1961) and the Scientologists. The National Association was seen as the representative of psychiatry which had demonised scientology, in turn scientology sought to demonise psychiatry. Most mental patients unions kept well away from the Citizens Commission. The exception was a union formed by Kenneth Wood, who was not a patient. In the meantime, the Association was becoming much more of a campaign body, and adopted the name "*Mind*" from one of its campaigns. From **March 1973**, when *The Mental Patients Union* was formed, *Mind* was generally supportive. Its new magazine, *Mind Out*, published helpful reports and news, and encouraged articles by union activists. The new director, Tony Smythe, attempted, unsuccessfully, to secure funding for the unions. Relations with Tony Smythe became strained in **May 1974** when the MPU side-effects list was blamed for the negative professional response to *Mind Out's* "consumer's issue". Within the unions there were those, like Andrew Roberts, who were willing to work with *Mind*, and those who saw it as part of the problem. Eric Irwin saw it as part of the problem. In **May 1975**, *Mind* included COPE (*Community Organisation for Psychiatric Emergencies*) as a workshop in its conference on "Psychiatry and Alternative Support Systems". Mary Hutchinson and Eric Irwin from *West London Mental Patients Union* also took part. COPE and West London MPU used the occasion to launch an attack on *Mind* and to formulate the idea of RAM (Radical Alternatives to *Mind*). "We were able through the conference to meet fellow RAMers - to confer and conspire... and to develop a critique not just of *Mind* but of the state of mental health - or rather lack of it - in Britain today and to recognise the political and other implications of psychiatry. From now on we need to take the offensive and build a solid grass roots mental health movement". (*Heavy Daze*, number six, page 6 "Mind Games and More"). In the **late 1970s** and **early 1980s**, *Mind Out's* coverage of the patients' or consumers movement became virtually non-existent. On the other hand, *Mind's* legal department vigorously pursued issues, such as the absence of controls on treatment, which had been raised by the union movement. This culminated in the *1983 Mental Health Act*, the passing of which may have freed *Mind* for other activities. In **1983**, members of Glasgow Link Clubs attended *Mind's* annual conference and "were somewhat amazed and angry" that none of the presentations, seminars or workshops were by patients. They made their own presentation at the conference in **1984**, which they later turned into a tape and slide show which was used at many users' gatherings. In **July 1985**, *Mind* was host to the World Federation of Mental Health Congress in Brighton. Judi Chamberlin, author of *On Our Own. Patient-Controlled Alternatives to the Mental Health System* (USA, 1978) was a speaker, and Hans Wiegant, from the Netherlands, spoke on *Clients participation in Psychiatric Hospitals*. Thurstine Basset presented a video about user involvement in Scotland, England and the Netherlands in which Glasgow Link members expressed their enthusiasm for attending the conference, if they could raise the money for the fares. No users' group from England or Wales was invited to speak, but Eric Irwin, Frank Bangay and Barry Blazeby, from CAPO, attended uninvited.. "We put up our stall in the entrance and it was there that the Dutch patients' group (invited over by *Mind*) met us, and negotiated our stall into the conference. They helped us a lot, and we brought to *Mind's* notice that no English recipients had been invited to MIND's conferences, yet there were many professionals talking about the 'mentally ill'". Survivors united. Judi Chamberlin wrote "I got quite involved in Brighton, working out a declaration on 'self and citizen advocacy'... Most of it is liberal but I think our section (Part 2) is pretty radical" That autumn (1985), *Mind's* annual conference was for service users and about service users. Peter Campbell, David Brandon and Service Users from Glasgow Link and others ran workshops. There were workshops from CAPO (*Campaign against Psychiatric Oppression*), The *British Network of Alternatives to Psychiatry*, *North Derbyshire Mental Health Services Project* (Tontine Road Centre), *42nd Street* in Manchester and *Camden*

Mental Health Consortium. Frank Bangay organised a poetry and music session for the conference, in a pub near Oxford Circus. Peter Campbell recalls that there was a meeting of service users immediately after the conference and from that meeting *Survivors Speak Out* was founded. Late in **1987**, Jan Wallcraft was employed in *Mind's* national office to set up ways in which people with direct experience of psychiatric services could have a bigger say in *Mind*. The main way she tried to make this happen was by setting up a network of recipients or users of psychiatric services. (*Progress report after the first three years* - January 1991). "*Mindwaves: The Newsletter of the MIND Consumer Network*" first appeared in **August 1988** and the network was being called *Mindlink* by **1989**. The new network had a potential to think of itself as an autonomous user movement and *Mind* struggled to keep it under control. By **1990** there were three major survivor networks, *Survivors Speak Out*, *Mindlink*, and the *National Advocacy Network* (which became the *United Kingdom Advocacy Network*). Each had its virtues and vices, from different user perspectives, so users were able to join the network or networks they felt most comfortable with. Anne Plumb comments "had there been just one organisation we would probably have fallen out ". As it was, the three networks had overlapping membership, and they often cooperated to provide a united user voice.

National Disability Arts Collection Holton Lee, East Holton, Holton Heath, Poole, Dorset BH16 6JN.- <http://www.ndac.org>

Nick Crossley Author of (1999) "Fish, field, habitus and madness: the first wave mental health users' movement." *British Journal of Sociology* 50, 4, pp 647-670 and (2005) *Contesting Psychiatry: Social Movements in Mental Health* London: Routledge.

Nottingham Advocacy Group A funded, user run, service established after 1985 and continuing until after 2006, when it lost its main contracts to the local NHS Trust.

Peter Campbell was named *Mind's* "Diamond Champion" in May 2006, in recognition of his "excellence in campaigning for people with mental health problems".

His work telling the story of the users' movement in the United Kingdom includes:-

1987: "Giants and Goblins: A Description of Camden Consortium's Campaign to Change Statutory Plans" in Ingrid Barker and Edward Peck, editors, *Power in Strange Places - User Empowerment in Mental Health Services*. London, Good Practices in Mental Health.

1996: "The History of the User Movement in the United Kingdom" in T. Heller, J. Reynolds, R. Gomm, R. Muston and S. Pattison *Mental Health Matters: A Reader*. Buckingham: Open University Press.

1999: "The Service User/Survivor Movement" in C. Newnes, C. G. Holmes, C. Dunn (editors) *This is Madness: A Critical Look at The Future of Mental Health Services*. Ross on Wye, Herefordshire: PCCS Books.

March 2001: "The role of users of psychiatric services in service development - influence not power" *Psychiatric Bulletin* of the Royal College of Psychiatrists, volume 25:pp 87-88.

2005: "From Little Acorns - The mental health service user movement" in *Beyond the Water Towers: The Unfinished Revolution in Mental Health Services 1985-2005* edited by Andy Bell and Peter Lindley and published by Sainsbury Centre for Mental Health.

Peter Lindley was working for the *Sainsbury Centre for Mental Health* when he helped to form the *Survivors History Group* in November 2004 and April 2005. The Sainsbury Centre had published a substantial review of the movement's history in June 2003 as part of *On Our Own Terms - Users and survivors of mental health services working together for support and change*, by Jan Wallcraft.

Phil Ruthen: Phil was being treated for anxiety and depression in Whitchurch Hospital and the University Hospital of Wales, Cardiff, when he began to write his thoughts down. Twenty years later, in November 2007, he published part of the documentary manuscript of those experiences as *One Hundred Days War*, a collage of thoughts, poetic prose, and straightforward account of what was happening to him. Since the early 1990s, Phil has been active in the disability civil rights movement. He has been development worker for *Mid Surrey Mental Health User Group* (SWAY), and has worked for *Sutton Centre for Independent Living* and *Sutton Alliance for Disabled People*. He was a representative on the "Mind Link National Advisory Panel" forum March 2004 to August 2005. Since 2007 he has been a Trustee, acting Secretary and mentor for *Survivors Poetry* and Administrative Co-ordinator of *Sutton Mental Health Action Group*. He was appointed a researcher for the *Survivors History Group* in March 2008, paid for from a small grant from the Hamlet Trust. He is preparing applications for funding for the histories and archives that the group seeks to develop.

PROMPT (*Protection of the Rights of Mental Patients in Therapy*) issued its first newsletter in June or July 1986. It was the project of Julian Barnett who had devised the title in 1975. He was stimulated by Alan Saint's *Patients Protection Law Committee* which issued a newsletter in May 1986. Julian's aim was a campaign organisation that would treat psychiatry as more of a political than a medical activity. PROMPT would lobby parliament and inform patients of what was really happening to them. Julian produced a series of booklets, often reusing material produced by others, which he distributed as widely as he could. He was joined (at some stage) by Eric Irwin and, in 1980, by Frank Bangay.

Roger and Felicity Lansdowne Friends of Joan Hughes.

Sophie Mirrel Moakes is a Gospel singer.

survivor/user: There is no agreement in the movement about the language we use to describe ourselves. The full title of the history group is *The History of Mental Health Service User/Survivor Movement Group*. The *National Survivor User Network* (NSUN) "brings together groups and organisations in England that are run by users and survivors of mental health services in one national network". The titles and descriptions are a compromise. In this document, the term "survivor" is not intended to imply anti-psychiatry, and the term "user" is not intended to imply that the mental health services are beneficial.. Those discussions continue.

Survivors History Group: Short title for *The History of Mental Health Service User/Survivor Movement Group*, established April 2005..Contact via <http://studymore.org.uk/mpu.htm> or c/o the Secretary, 177 Glenarm Road, London, E5 0NB. The original group is London based, but networks are forming in other parts of the United Kingdom. Details of meetings and newsletters will be sent on request.

Survivors History Timeline <http://studymore.org.uk/mpu.htm> A history and digital archive organised by the *Survivors History Group* in association with the *Mental Health History Timeline*. The website includes: The story of the movement in the form of a timeline - Information boxes about particular features such as *Survivors Poetry* - Reviews and summaries of books, articles and other printed material that record and discuss the history - Copies of articles about the movement and its history - Copies of documents from the movement's history - Lists of paper records about groups in the movement that individuals and others have preserved - Book and pamphlet lists - Records of where papers, books and pamphlets are preserved. As well as being regularly archived by the *UK Web Archiving Consortium*, a Trust is being established to preserve the website itself for a minimum of twenty five years.

Survivors Speak Out was founded in 1986 by a group of mental health service users and workers. The term survivor was chosen to portray a positive image of people in distress and people whose experience differs from, or who dissent from, society's norms. The main aim was to promote self advocacy. Peter Campbell was an officer of *Survivors Speak Out* from 1986 to 1996.



Thurstine Basset is an independent mental health training consultant who lives in Brighton . In 1975, as a student social worker at the London School of Economics, he invited a mental patients union speaker. - and his involvement in the patients' movement continued throughout his career. In the summer of 2004 he decided to clean out his loft space and discovered a video copy he had made of a presentation by service users in the Glasgow Link Clubs. The original presentation., in the autumn of 1984, may be the first time that service users collectively addressed an Annual Conference of *Mind*. It was the spark of *Mind's* consumerism.

Struck by the fact that it was 20 years since the presentation was made, Thurstine emailed twenty seven other people who he thought would be interested, and many were. Peter Lindley was amongst those who responded positively and the two of them called the meeting at the *Sainsbury Mental Health Centre* that led to the *Survivors History Group*.

Together

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UKAN: United Kingdom Advocacy Network

UK Advocacy Network, Volsolve House, 14 - 18 West Bar Green, Sheffield, S1 2DA
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This report can be downloaded from <http://studymore.org.uk/mpu.htm> or ordered from . the Secretary, 177 Glenarm Road, London, E5 0NB. Copies are free. We welcome any donations towards our work from those who can afford to pay.