

# **OUR MAD HISTORY**

A Community History of the Lothian  
Mental Health Service User Movement

# Oor Mad History

**CAPS** (The Consultation and Advocacy Promotion Service) is an independent advocacy service working in Edinburgh, East Lothian and Midlothian with people who use, or have used mental health services. CAPS works with groups and individuals to set their own agenda and have a stronger voice.

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## FOREWORD BY MALCOLM CHISHOLM, MSP

This is a very important history for both the people involved and the wider public. It shows how the experience of those using mental health services has been an agent of positive change and as such has wider lessons for mental health services and health services more generally.

Lothian has for a long time been in the vanguard of these developments. I saw this at first hand through organisations such as Edinburgh Users Forum, CAPS and Advocard that met or were based in my constituency. It is brilliant that people involved with these and other organisations have now recorded their stories so that we can all have a better understanding of this very important movement. I believe this will also inspire people to carry forward and build on the successes of the past.

One such success was the establishment of a crisis centre in the community. This was based on the view that mental health wasn't just a medical issue and shouldn't be based on a medical model. This has underpinned the movement from the start and was one of the many lessons I learned from it. Moreover Lothian service users always emphasised the importance of advocacy in general and collective advocacy in particular and it was in no small part their campaigning, along with that of others, which led to Scotland's landmark mental health legislation including new rights to advocacy.

Involving users of mental health services in the development of services has progressed but there is still a long way to go. At times there is too much lip service paid to it and too little genuine engagement. I hope this history will help to convince sceptics as well as inspire those who are already committed to this way of working.

Congratulations to everyone involved with this project. It is an honour to write this foreword and a privilege to have learned so much from you over the years. **Malcolm Chisholm MSP**



## ACKNOWLEDGEMENTS

Above all thank you to the many service user activists, supporters and allies who have played a role in the history of the Lothian mental health service user movement. Many are represented in these pages, but it is important to remember the people whose voices have not been heard for whatever reason. Some people we have been unable to contact, others have not taken part for a variety of reasons. Some voices are sadly no longer with us. So we wish to acknowledge the valuable contribution to the movement of those whose voices are not heard in these pages. Thank you.

Thank you to everyone who has contributed to the project by telling their story, for sharing their experiences and memories of the movement. Please know how much your goodwill and contribution to Oor Mad History has been valued.

Thank you to all the service users and advocacy groups throughout Lothian who have supported and contributed to Oor Mad History, including Edinburgh Users Forum, The Patients' Council, East Lothian Involvement Group, Service Users Midlothian, West Lothian Mental Health Advocacy Project, Saheliya Peer Advocacy Group and the Edinburgh Carers' Council. Thank you to everyone who has donated to the archive.

Thank you to Linda Irvine and the Mental Health and Wellbeing Programme, NHS Lothian for supporting Oor Mad History.

Oor Mad History is managed by a steering group made up of service users/survivors and supporters from the community/oral history field. Thank you to all steering group members, past and present, for their guidance and support.

A huge thank you to Anne O'Donnell, chair of the steering group, who played a key role in the early development of the project and writing the original proposal. Thank you to Jim McGill, for his



dedication and enthusiasm for the project in so many respects – particularly for his contribution as speaker at many events publicising the project and for his participation in the Canada trip. Thank you also to Jenifer Booth for her committed work as steering group member and oral history interviewer.

Thank you to John McCaughie from the Living Memory Association, Susan Pollock from NHS Lothian and Margaret Mackay from the School of Scottish Studies, Edinburgh University for all their support and input as members of the steering group.

Oor Mad History has benefited from the hard work of volunteers, thank you to volunteers past and present. Thank you especially to Alistair, Phil, Jenifer, Jim, Terry, Garry, Kenny and Peter.

Thank you to Kirstie Henderson for her important role in the early development of Oor Mad History.

This book has been a collaborative work. Thank you to everyone who came along to the Book Workshop to help out with choosing material to go in the book and the CD. We hope the book meets your expectations.

Thank you to Anne O'Donnell, Jim McGill and Jenifer Booth for their work on reading highlighted transcriptions from the book workshop and assisting with editing the oral history material for the book. Also thank you to Anne, Jim and Jenifer for their work on finalising the book structure and for contributing to the first section of the book. Thank you to Jim and Glen Faulkner at CAPS for proof-reading work.

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Thank you to Jimmy Osborne for his photography advice and skills. Thank you to Maggie Keppie for allowing us to use her image on the front cover.



Thank you to Andrew Roberts and The Survivors History Group, their research has been a valuable resource to us.

Thank you to our transcribers, Jacqueline Hall, Phil Barnard, Joanne Murray and Shula Hawes.

Thank you to all our survivor colleagues in Toronto, Canada. Thank you to David Reville and Dr Kathryn Church for hosting us on our research visit with such generosity and kindness, to Ryerson University and to Mel Starkman and Geoff Reaume at PSAT (Psychiatric Survivors Archives Toronto). Thank you to everyone at A-Way Express Couriers and The Raging Spoon Café, to Jenna Reid and Jen Poole, JiJi Veronka, Diana Capponi and Lucy Costa, all of whom went out of their way to make an itinerary we will never forget.

Thank you to Laura Brouard at Lothian Health Services Archive for all her advice. Thank you to David Brown and Susan Corrigan at the National Archives of Scotland. Also thank you to Jaime Valentine from Ourstory project for his invaluable advice around the oral history archive. Thank you to Sarah Cowie from East Lothian Libraries and Museums Service for all her assistance.

Thank you to everyone who plays a part, no matter how small, in supporting and encouraging our work. We hope you enjoy the book.

**Kirsten Maclean, Community History Worker**



## INTRODUCTION

People with mental health problems have often been silenced and stigmatised by history and by society. As a whole, history related to mental health is dominated by the history of asylums, psychiatry or medicine. Little has been recorded of the histories of those who have experienced the system first hand or who have come together to change it.

Community history and oral history are powerful tools for reclaiming the histories of groups who have been marginalised by society and by mainstream history. Oral history is one way of democratising history, of putting history in the hands of those who have created it. What is more relevant to a community than its own history?

Oor Mad History is an innovative community history project gathering and promoting the history of the mental health service user movement in Lothian. We are based at CAPS Independent Advocacy and supported for the first two years by the Mental Health and Wellbeing Team, NHS Lothian. Oor Mad History is managed by a steering group made up of service users/survivors and supporters from the community history field.

### **Aims of the project**

- To remember, record and promote the history of the Lothian mental health service user movement
- To highlight the key role service users have played in developing mental health services in Lothian
- To challenge current ideas about people who use mental health services
- To enable service users to see themselves and to be seen by others as active agents of change
- To celebrate the achievements of the movement
- To strengthen the service user voice and movement, today and in the future



Over these first two years of the project we have worked together with service user volunteers and groups to create a paper-based and oral history archive which is unique in Scotland. We recruited a team of service user volunteers and provided training in oral history skills. At the moment we have 70 recorded oral history interviews and a growing paper archive of photographs, t-shirts, leaflets, posters etc. We are working towards a permanent community archive overseen by a group of service user volunteers. We see the archive as an important resource and a focal point for sustainable service user involvement and ownership of the project.

During the course of the project we also had an opportunity to build on links with similar work in Toronto, Canada when the community history worker and a volunteer participated in a research trip to Toronto in November 2009.

This book is only a beginning and can never be the “whole story” or the definitive history of the movement. We see Oor Mad History as a living, ongoing process and this book is only one part of this process. We hope that it will serve as a lead-in to the wider archive and that it will encourage people to visit and contribute to the archive and get involved with Oor Mad History.

There will be gaps in the book and many voices will not be heard, sadly some voices and people are no longer with us. We have just begun the process of recording Oor Mad History and many voices are still to be heard.

The book is divided into two parts. In the first part we look at the background to the project and why it is important to record this hidden history: Anne O’Donnell, service user and chair of the Oor Mad History steering group writes about the background and theory to the project in, ‘Why Oor Mad History?’ Next the community history worker writes about the project process and methodology, how we went about recording Oor Mad History. This includes the learning generated by a research visit to Toronto, Canada to learn from similar work and projects there. Two oral history interviewers, Jim McGill and Jenifer Booth then write about their experience of volunteering.



In the second part of the book we turn to the many voices of the movement itself, to quotations and images from the Oor Mad History archives. We hear memories and stories from service users and supporters who have been interviewed as part of the oral history project and the history of the Lothian mental health service user movement comes alive. Interviewees talk about the early days and beginnings of the movement, the collective advocacy groups which make up the movement and the campaigns/issues they have been concerned with. They describe what they consider to be the main achievements of the movement, what could have been done differently, the influence of the movement on mental health services, why people got involved and what they got out of their involvement, the importance of collective advocacy and hopes for the future.

We have tried to include as many quotes from the interviews as possible, but it has not been possible to quote everyone due to the amount of material generated. Apologies if we have been unable to include a quotation from your interview. All interviews will be available in full as part of the Oor Mad History oral history archive, which will be deposited as part of a community archive based at CAPS. Please get in touch if you would like to listen to any of the interviews.

We have done everything we can to source appropriate permission for all images and photographs used in the book and to abide by copyright legislation. Please accept our apologies if we have been unable to contact you or have inadvertently sourced insufficient permission.

Thank you to everyone who has made this book a reality in such a short time scale, thank you especially to those who have been interviewed for the project, whose words tell the story of this unique history. We hope you enjoy reading this piece of Oor Mad History.

**Kirsten Maclean, Community History Worker**

## **PART ONE**

# **BACKGROUND AND PROCESS OF RECORDING OOR MAD HISTORY**

## WHY OOR MAD HISTORY?

*I think that recording our history is a really good idea because when the ones that founded it get on a bit, it'll be great to know it's been recorded and it's not all going to be forgotten about and it's not all been for bugger all really. **Maggie Keppie***

For many years, mental health collective advocacy groups have argued for being involved in every aspect of mental health policy and service development. In recent years, we have been in great demand to take part in consultations and planning groups. However this has meant we have less and less time and energy to focus on what we think is important, rather than what service providers think is important.

Some of us involved in collective advocacy had been casually reminiscing about events and people from our past, and it was always noticeable how much more energy we had when remembering way back when compared to how we talked about current demands. Perhaps a focus on our history as activists would help us in our current work? By re-connecting us to the reasons mental health service users had set up our groups, by learning from the past, and by working together, we could use the past to change our future...

*It's 16, 17 years down the road and then, you look back and you think, god, we have got a history, we've done all this stuff. You don't see it necessarily as that when you're involved in the middle of it. I think it's a good point to actually look back and see what we've done and here are our pointers and our purposes. I'm really pleased this is happening. **Adrienne Sinclair Chalmers***

In October 2007, Canadian mental health 'consumer' and academic, David Reville, visited Edinburgh. David teaches a course at Ryerson University called Mad People's History, which caught our attention and our imaginations. This course looks at 'madness' from the perspective of those who were, or are, labelled as 'mad' rather than the history of psychiatry or the history of mental illness. David spoke



at a daylong meeting of the different collective advocacy groups in Lothian and sowed the seeds for what has become Oor Mad History.

Language is significant - we chose each word in the project's name carefully: 'Oor' emphasises the collective nature of the project and the Scottish context. 'Mad' is a difficult word, one that challenges the medical focus of much of the language in this whole area. No term is neutral, not mental illness, mental health problem, madness, or any other term. We liked mad because it can mean angry and fun as well as mentally ill. 'History' - because we wanted to look at our past.

We learnt from our history in two ways - collecting oral history and an archive. Service users have interviewed a huge number of activists and allies who have been involved in the service user movement in Lothian in the past two decades or more. We have also organised the wealth of papers and other objects that the different groups and organisations had built up over the years.

We have learnt a lot from listening to people and by what we are finding in the archive. We have also learnt by doing Oor Mad History - interviewing and organising and reading and listening. Both have challenged our own ideas about what we, the 'mentally ill' can and have achieved. We hope it will let everyone who uses services and who works in services, as well as the general public, appreciate that we can work together to make positive changes and that this will challenge stigma and assumptions.

*There's lots we can learn from the past; that a lot of voices are stronger than lone voices standing screaming on each street corner. We can learn that just because people have mental health problems doesn't mean that they can't take a full part in society.*

**Maggie Keppie**

Learning about the early days of the service user movement in Lothian - the commitment, passion and determination to improve the experience of using mental health services - has helped us renew our own commitment to collective advocacy.

*Well, hopefully when people see some of the achievements that have happened, it will encourage other people to get involved and the more people get involved the stronger the voice becomes and the more they have to sit up and take notice of what we actually say. Alistair*

One way of looking at how collective advocacy groups work in the context of user involvement policy is to think about 'political space'[1].

A definition of 'spaces': opportunities, moments and channels where citizens can act to potentially affect policies, discourses, decisions and relationships that affect their lives and interests.

There are three kinds of political space - claimed, invited and closed.

Closed spaces: When decisions are made by authorities behind closed doors, without any pretence of broadening the boundaries for inclusion. Within the state, another way of conceiving these spaces is as 'provided' spaces in the sense that elites (be they bureaucrats, experts or elected representatives) make decisions and provide services to 'the people', without the need for broader consultation or involvement.

Invited Spaces: As efforts are made to widen participation, to move from closed spaces to more 'open' ones, new spaces are created which may be referred to as 'invited' spaces, i.e. 'those into which people (as users, citizens or beneficiaries) are invited to participate by various kinds of authorities.

Claimed/created spaces: Finally, there are the spaces which are claimed by less powerful groups. Cornwall refers to these spaces as 'organic' spaces, which emerge 'out of sets of common concerns or identifications' and 'may consist of spaces in which like-minded people join together in common pursuits'.

When users of mental health services began to demand our inclusion in all the big decisions that shaped our lives, we created a 'claimed' space. However, now this has become 'invited' space, where we



have been invited to participate on the terms of the providers, policy-makers and politicians. And, as you will read in this book, there are many of us who feel 'closed space' still makes the key decisions about mental health services and policies.

It is important that we remember that the policies about service user involvement are not something that the government or professionals have given us. We came together, made the case for our voices being heard and have worked hard to get to where we are today.

We can reclaim and recreate 'claimed' space and become more aware of our own power. While it is clear from what people have told us that much has changed for the better since the late 1980s, there is still a strong sense that more needs to be done. We hope that by remembering our past, we can work for a better future.

As for Oor Mad History, we feel we have only just begun - there is so much more that we want to learn, more people who we want to interview, more questions that we want to ask... and why stop at Lothian?

*I think it's fantastic that you are doing this project. I would like to see the history of the service user movement documented for the whole of Scotland. It is a really important part of our culture. And I am a big fan of history... there is probably a Rosa Parks out there. A Rosa McParks in Scotland that we don't know about!*

**Shaun McNeil**

**Anne O'Donnell, Chair of Oor Mad History Steering Group**

[1] This idea comes from work done by people working in international development, such as Andrea Cornwall. You can read about it in this paper, available free online: Cornwall, A. (2002) Making Spaces, Changing Places: Situating Participation in Development, IDS Working Paper 170, Brighton: IDS <http://www.ids.ac.uk/go/idspublication/making-spaces-changing-places-situating-participation-in-development>.



## OUR MAD HISTORY - PROCESS AND METHODOLOGY

### Paper Archive

We are gathering paper-based material from all over Lothian and beyond. Initially we began by sorting the papers by date order and by group. We approached the Lothian Health Services Archive (LHSA) for support and Laura, one of their archivists, came in to help. We also sought advice from other archivists and museums including National Archives of Scotland and East Lothian Museums Service.

We decided to order the collections in a way that would reflect the chronological story of the movement as much as possible. We wanted the paper archive to illustrate the vibrant history of the movement. We also wanted there to be a strong inter-relationship between the paper and oral history archives.

We met with collective advocacy groups throughout Lothian and collected archive material from them. This is still an ongoing process. We are very grateful to all the groups and individuals who have donated to the archive.

We are a living, community archive and welcome donations of any memorabilia relating to the movement. Please get in touch if you find anything lurking in your filing cabinets or loft at home!

We have been lucky to receive lots of donations to the archive. These include:

- a poster for the first ever public meeting held in Lothian with a view to setting up a user movement
- A fascinating recording of a presentation given by Glasgow Link Club members to the 1984 MIND conference, courtesy of The Survivor History Group

- 
- 
- West Lothian Patients Council material never seen before
  - Tapes of radio interviews
  - Photographs of the first Scottish service user conference
  - Books written by local service users
  - A book on the history of the New Brunswick survivor movement in Canada - a contact made on our visit
  - A-way Express DVD from Toronto and lots of other material including a menu and magnet from The Raging Spoon, survivor run café
  - 8 boxes of material from East Lothian Involvement Group
  - A video training pack, newsletters, A Brief History of the Patients Council and other material from the Patients Council at Royal Edinburgh Hospital
  - Newspaper articles
  - A directory of mental health services dated 1987

After the initial sort through of material a catalogue of the archive was started, using the Lothian Health Services Archive system. Work has continued on developing this catalogue and continuing to sort through the material. Volunteers have been involved in this process and in deciding which images from the paper archive would go in this book.

Following debate at the steering group and also learning from our research trip to Canada, community ownership of the archive has been highlighted as a significant issue. It is important that service users retain a sense of ownership over their history. This debate has been part of the process of Oor Mad History.



OMH volunteer, Jim, with a tower of archive boxes from East Lothian.



## **Service user involvement and developing the oral history archive**

This project is service user led and service users are involved with all aspects of the work. Oor Mad History grew out of a desire from within the movement itself to record its history and the management and direction of the project has been service user led. Meeting with service user groups has been a big priority. It was important to meet with service user groups to find out what they wanted and expected from the project. We attended Edinburgh Users Forum (EUF) meetings, Service Users Midlothian (SUM), Seasons, North West/Threshold, West Lothian Mental Health Advocacy Project (MHAP), East Lothian Involvement Group (ELIG) meetings and the Patients Council at Royal Edinburgh Hospital. It has been important to maintain good links with service user groups, and several are represented on the steering group and as volunteers. Also in these meetings it has given us a chance to ask service user groups who they would like to see interviewed for the project and to volunteer to be interviewed themselves.

At the start of the project we also carried out research meetings with early activists and supporters of the movement. This was vital in building up good links with potential interviewees and also in developing our understanding of the movement.

Both these meetings with key activists and supporters/allies of the movement provided numerous further contacts and material. This process was ongoing as the project grew, publicity and word of mouth spread, more people got in touch and in turn suggested other good contacts. This allowed us to interview a far greater number of people than initially anticipated.

### **Oor Mad History Volunteers**

At the heart of Oor Mad History are service users researching their own history. To enable effective service user involvement the recruitment, support and training of service user volunteers has been



central to Oor Mad History. Time was spent developing the volunteer recruitment process. In order to encourage people to get involved and potentially to volunteer with the project, an 'Oral History Taster' was held on 6 March 2009. This was publicised widely. The session was run by John McCaughie of the Living Memory Association. Feedback was really positive and the session was hands-on and fun. Service users had a chance to see the recording machines we would be using and to get trained in how to work them. We had role-play sessions which people really enjoyed.

## **Volunteer recruitment**

After receiving completed application forms, we carried out interviews for the volunteer oral history worker roles.

## **Volunteer workshops**

With the team of volunteers in place and following the 'Oral History Taster' the next stage was to have a workshop with the new volunteer group.

This workshop was a chance for the volunteers to draw up themes and questions that we would use in the oral history interviews. Ethically it was important that service users developed the themes to be researched in the interviews and also were involved in constructing the interview questions to engender a sense of ownership and control over the process. Again it is linked to the central ethos of service users researching their own history, as opposed to an outsider.

During the workshop the group came up with lots of themes. The community history worker did some input on different kinds of questions. Next we explored one theme in more detail and the group came up with different kinds of questions for this particular theme.

The second workshop was held on 11 May 2009. This session was longer and the focus was on interview practice. Utilising feedback from the last session we began with a short history of the service user movement in Lothian. Next there was a session on refreshing oral history interviewing skills. Then the volunteers worked in groups of three for interview practice. This enabled a pair to be role-playing an interview and the third member acting as an observer. This worked very well. Each observer had a sheet to take notes and feedback to the pair.

There was also time in the big group to feedback and to discuss experiences. Feedback from this session was very positive. People would have welcomed more time to spend on this process.



**Volunteer workshop, practising oral history interview skills**



## Drawing up the interview schedules

Using input on themes and questions developed in the volunteer workshops, schedules for the first oral history interviews were put together. It was important for volunteers to have a schedule to support them in the interview process, although there was always room for flexibility within the schedule. Each schedule was individually tailored to the interviewee, although certain questions were repeated throughout all interviews. As the interview process progressed we responded to feedback and the interview schedules evolved according to what was most effective.

## Beginning the oral history interviews

First of all the volunteers interviewed each other. This generated interviews for the archive and gave volunteers invaluable interview practice in a comfortable setting with someone they were familiar with. Peer support between volunteers has been an important part of Oor Mad History.

After that we began the formal oral history interviews. We do everything we can to be flexible in terms of venue for the interviews, to ensure that people are being interviewed in a space they are comfortable with. Volunteers are supported at all interviews by the community history worker.

## We held interviews in:

- Local libraries
- Community centres
- COSLA offices
- People's living rooms
- Scottish Parliament
- Universities
- Advocacy projects
- Mental health projects
- Patients' Council offices
- Royal Edinburgh Hospital ward
- St Johns Hospital, Livingston
- A church
- Dunfermline
- Glasgow
- Dumbarton
- West Lothian
- East Lothian
- Midlothian



**At the Scottish Parliament, following an interview  
with Malcolm Chisholm**



**An oral history interview in full swing**

We held a peer supervision session for volunteers to share learning and to feedback their experiences of interviewing. Another peer supervision session was held in February 2010 to feedback on experiences and also to think forward to the next stage of the project. Two new volunteers came forward at this point.

We continue to carry out interviews for the archive and if you would like to tell us your story, please get in touch.

### **Transcription of interviews**

As the interviews progressed we began to transcribe them. This is an enormous task. Volunteers were involved and we also recruited sessional staff to transcribe interviews. Ethically it is important to fully transcribe the interviews as they were recorded. This will be a key part of the Oor Mad History archive, as each interview will be

archived on disc alongside its full transcription. Transcriptions were also invaluable in the service user workshops involved in the process of writing the book. We printed off transcripts at the book workshop to allow people to engage with the material and choose quotations to go in this book.

## **Archiving of the interviews**

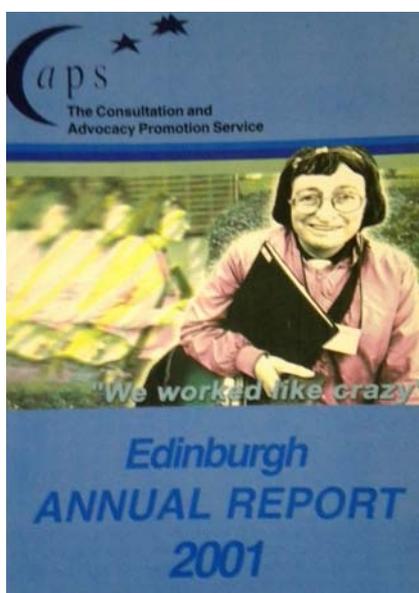
At the end of the first phase of the project all interviews done so far will be archived on CD alongside their full transcription. The full set of interviews will make up the oral history archive which will be deposited as part of the whole Oor Mad History archive. We aim to deposit one set in the community archive room based at CAPS office and another set with the LHSA. This is a living archive and we intend to continue interviewing and add many more voices to the archive.



**Some of the Oor Mad History volunteers after a workshop**

## Research visit to Toronto, Canada

The movement here has had a link with Canada since 2001, when a group of Canadian survivors who had been involved in the film 'Working Like Crazy' came to Scotland. 'Working Like Crazy' is a documentary about the survivor run businesses in Toronto and the people that work in them. 'Working Like Crazy' struck a chord with many service users here and despite being nearly 10 years old it still has a strong influence. It was screened in Lothian as part of the 2009 Scottish Mental Health Arts & Film Festival.



**CAPS Annual Report featuring Working Like Crazy**

Dr. Steve Tilley from University of Edinburgh has been instrumental in building and maintaining links with Canada. In 2007 Dr. Tilley was part of a group, including CAPS and Abertay University, who hosted a visit from David Reville to Scotland. David Reville is a Canadian mental health 'consumer' and academic who teaches the Mad People's History course at Ryerson University in Toronto. In October 2007 CAPS hosted an event for service users to meet David Reville and hear about his work.

Service user groups came from all over Lothian and gave presentations about their history and what they thought were important achievements for them. People were very inspired by this event and it reignited a spark to build on the work already done and begin to record the history of the movement locally. It was following this event that a steering group was formed to take Oor Mad History forward and a project proposal was developed.

In November 2009 the community history worker and an Oor Mad History volunteer had the opportunity to visit and learn from the movement in Toronto. We were able to meet with a fully survivor run archive based over there and learn how the archive relates to David Reville's Mad Peoples History course at the university.

We also learnt about a fascinating exhibition they held over there about the history of disability and the mental health survivor movement. We also visited many of the survivor businesses in the community and also in the local psychiatric hospital, such as The Raging Spoon Café and A-Way Express both of which featured in the Working Like Crazy film.



**The Raging Spoon Cafe - a survivor-run business**

## **Key learning areas for Oor Mad History Psychiatric Survivor Archives Toronto (PSAT)**

One of the most useful meetings was with Geoff Reaume and Mel Starkman, volunteers who are responsible for PSAT, the equivalent of the archive we are creating in Lothian. This is a fully survivor run archive and they also work hard to raise public awareness of survivor history, Geoff for example runs public tours of a wall built by ex-patients at the old Toronto asylum.



**Geoffrey Reaume giving a tour of “The Wall”, built by patient labour at the old Toronto asylum**

This meeting raised important issues for Oor Mad History around depositing of the archive and maintaining community ownership and how these relate to the Oor Mad History archive. The meeting inspired us to work towards creating a community archive room based initially at CAPS and to support a group of service users to act as guardians of the archive.

## Out From Under Exhibition

One fascinating meeting was about the exhibition which Kathryn Church co-curated – ‘Out From Under’. This was an exhibition that came out of a short summer course at Ryerson University about representations of disability in museum collections. Course participants were asked to bring along one item that represented their experience of disability or the disability/mental health movement. They then explored their objects in the group and went on to design how they would like to see it displayed. The project culminated in a high profile exhibition at the Royal Ontario Museum.

This exhibition was extremely powerful and this meeting had many lessons for Oor Mad History. An exhibition using this community development model could be viable and exciting for us here. It would provide a direct way for service users to get involved and have ownership of a major exhibition about mental health. It would also be a fascinating combination of object, archive material and biographical information.

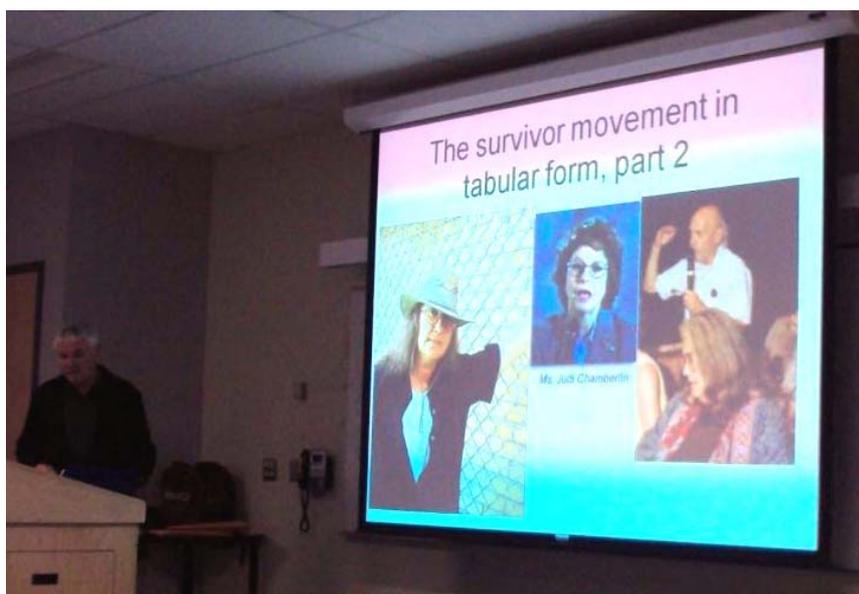


**This installation is a suitcase, an image of the old asylum and a description from the service user as to what the significance of the object is to them (photo courtesy of School of Disability Studies, Ryerson University)**

## David Reville's Mad People's History course

We also had the opportunity to attend one of David Reville's Mad People's History lectures at Ryerson University on our first day in Toronto.

It was inspiring to be physically in a lecture theatre where this knowledge was being taught. It made it easier to visualise a similar course locally. We continue to be involved in discussions around developing a course locally similar to Mad People's History. David's Mad People's History course is now available online and the uptake has been tremendous. David has also been involved in creating advanced film-making techniques as part of the online learning experience.



One of David's lectures in Mad Peoples History at Ryerson University

## Oor Mad History - The Book!

As mentioned earlier, this book has been a collaborative process. We began by holding a service user 'Book Workshop' on 16 April 2010 to enable service users to engage with archive material and choose quotations to go in the book and CD. At the workshop service users were also able to input ideas on the structure of the book and on the front cover. As part of the workshop participants took highlighter pens and stickers to highlight quotes they thought were important to go in the book. A smaller sub-editing group, or 'Team Book', made up of service users/survivors was also formed.



**Highlighting transcriptions at the book workshop**

As a group we decided to write to Malcolm Chisholm, as a central ally of the movement, to ask if he would consider writing a foreword for the book. We were delighted when he said yes.

Following input from the book workshop a draft structure was decided. Next the community history worker took all the highlighted transcripts from the workshop and pulled out the key quotes under headings in the agreed structure. This was a vast amount of material and a lot of work was done by the members of the sub-editing group in editing this down. Volunteers also proof-read sections of the book. As you have read members of the group have also written sections of the book.

A group of service users and the community history worker then met to look through the paper archive and decide which photographs and pictures would go in the book and on the front cover. One volunteer with professional photography skills advised us on the front cover and photographed key documents from the archive to go in the book.



**Jimmy photographing documents from the archive**



## **The Future**

We see this book and the archive as an important, living resource and we are keen to sustain Oor Mad History in the future. We are working towards setting up a community archive based initially at CAPS and plan to develop and support a group of service user/ survivor volunteers who will act as guardians or safeguards of the archive in the future. This archive room will act as base for Oor Mad History, be an intermediary between the community and LHSA and a first port of call for service users who wish to deposit material or get involved in Oor Mad History. The digital recording equipment will be stored here, so further oral history interviews can be carried out and voices added to the archive. Also we would like to develop clear guidelines on archiving and how the archive can be added to. We also see the archive as a way of widening participation in Oor Mad History in the future. We are keen to develop and publicise the archive as a source of voluntary work opportunities, peer support training in archiving, oral history and survivor history as well as a research and community resource.

We are also keen to develop other opportunities such as discussions around developing a course locally based on David Reville's Mad People's History course in Canada and exciting arts based outcomes/partnerships such as exhibitions. Please get in touch if you would like to make an appointment to view the archive or listen to the oral history interviews. Also please contact us if you'd like to donate to or be interviewed for the archive or if you'd like to get involved with Oor Mad History in any way.

**Kirsten Maclean, Community History Worker**



## **OUR EXPERIENCE - WHAT IT WAS LIKE BEING AN ORAL HISTORY INTERVIEWER**

### **JENIFER BOOTH**

I became involved because I was interested in the fact that patients were doing oral history. I stayed involved because of the extraordinary things happening in the mental health service user movement.

As interviewers, Kirsten the Community History Worker made us feel part of a team. She organised training led by the Living Memory Association in how to do oral history interviews. Then we had a session where we interviewed each other. She came with us to each interview and discussed the questions with us beforehand. Towards the end she organised a session where we all discussed what we had done.

It was also good to be part of the book workshop where an invitation had gone out to the mental health service user movement to come and help choose quotes for the book. Anne commented on the studious atmosphere in the room. It made us think that this book is uniquely interesting to people because it is their history.

It is a privilege to learn about all the things the movement has achieved and to interview some of those who have been involved.



## JIM MCGILL

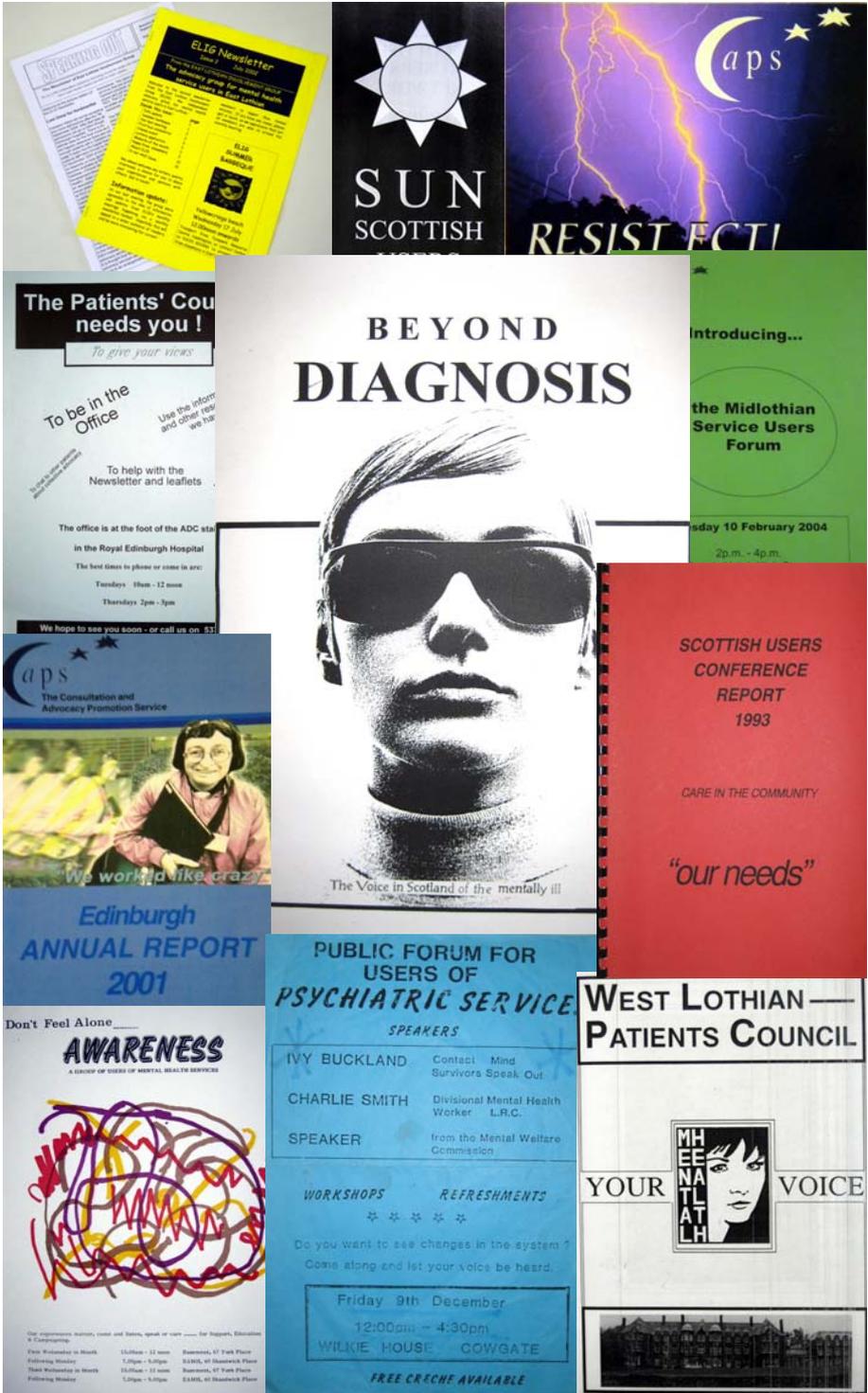
Going from being part of a group who decided the final make up of the questions for the oral history interviews, to actually asking these questions during an interview was an absolute treat. To witness interviewees reacting positively and, in a lot of cases, enthusiastically to the questions and realising that you had given them the opportunity to dig into their memories and come up with wonderful stories was an added bonus.

I learned skills such as engaging with people through eye contact, nodding my head encouragingly at what I hoped were appropriate moments and eventually managing to stop saying 'uh-huh' and 'I see' throughout the interviews! On more than one occasion people thanked us for the opportunity to share their stories and for finally having an appropriate place to tell them and that felt really special.

The whole process was beneficial to my confidence. It encouraged me, hopefully, to speak clearly, to pay attention to the sequence of questions, to take notes of issues which I might have wanted to come back to and really useful disciplines for someone with a short term memory disorder.

Being part of a process which supported people to share their involvement in a history in which I had also played a part felt really rewarding. If another piece of work came up in the future involving oral history I would feel much more confident about taking part.

I have recently become involved in archiving and cataloguing some of the paper archive. Again I have learned new skills from this process, skills upon which I can build and become part of a team of volunteers who will ensure that the Oor Mad History archive continues to be added to and updated both accurately and meaningfully.



**PART TWO**

**VOICES AND IMAGES FROM THE OOR  
MAD HISTORY ARCHIVE**



## EARLY DAYS OF THE MOVEMENT

This section looks at why people who used psychiatric services came together in the late 1980s to work for positive changes in psychiatric services, and what they hoped to achieve.

What we had in common was that we weren't getting treated very well by psychiatric services, just some basic things like nobody ever listened to a damn thing you said. **Adrienne Sinclair Chalmers**

*I think we literally just wanted to be heard.*

**Anne Bardsley**

I could see there were things wrong with the way people were getting treated and the way the hospitals were run. Basically if you had a mental health problem you were a second class citizen.  
**Maggie Keppie**

There was certainly a growing awareness in mental health particularly that people with mental health problems were stripped of all dignity and human rights when they were taken into hospital. There was a whole range of very seriously worrying human rights issues when people went into the 'psychiatric sausage machinery'. There was a growing concern that something had to be done. **Jeff**



Definitely the main thing was the 'power thing'. Feeling disrespected, not listened to, feeling that people were only interested in a set of symptoms and medicating them. People were extremely angry and they just felt they were seen more as their illness not as their person. I think it has changed enormously since that time, but at that time people's anger was mostly directed towards psychiatry. **Be Morris**

It was difficult times. It was a Thatcher government. Public expenditure cuts were deep and incisive. So the political climate was difficult and not very encouraging, although I do think within that it always creates a better campaigning user movement because people are more angry that nobody is listening to them. **Jeff**

*...right we're here, listen to what we've got  
to say!*  
**Anne Bardsley**

I think we were trying to achieve being noticed, saying we're here, we belong in the community. The Community Care Act had just come in, they're saying they wanted consultation with service users, we're saying 'right we're here, listen to what we've got to say'.  
**Anne Bardsley**

Powerful meetings, a lot of anger, strong voices coming out of the dark and into the forum of public meetings. For people in the '80s, to come out and nail their colours to the mast and say, 'I'm proud, I'm a human being. I'm not afraid to say I've got a mental health problem'. **Jeff**



Most of us were exceptionally angry at the way we had been treated and very keen to make a change. We didn't trust psychiatrists, we didn't trust most workers and we thought that life, once you had been labelled with a diagnosis of mental illness, was pretty awful. We wanted to change the stigma, we wanted to change the services, to have a say in everything that happened, to be equal people, to be respected for who we were. We didn't want to be put on medication or sectioned or put in hospitals, we'd have liked the hospitals to be torn down, sectioning abandoned forever and the psychiatrists put into re-education camps. **Graham Morgan**

*Just warts and all, farts and all, that was what was good about the movement. How ordinary, basic, fantastic, brilliantly funny the movement was and I'll never forget that and I was part of it.*

**Jeff**

My strongest memories of the early days are how alive and energetic it felt and how committed and how exciting it felt. It really felt as if it was something major happening. It was a movement along with lots of other movements that were very vocal at the time like the women's movement, the black movement. It felt like at last, folk were standing up, forming a strong alliance and making strong statements that were going to make societal changes. **Be Morris**



## BEGINNINGS OF THE MOVEMENT

Following inspiration from attending early MIND conferences key supporters and allies set up public meetings in Lothian and this was the beginning of a movement forming locally.

*It was like suddenly you had lifted  
the lid off something and it just went  
'boom!'* **Colin Murray**

One of my strongest memories, is of a very elderly chap at that first MIND conference. He'd had RD Laing as his psychiatrist and I remember his name was Joseph and he stood up and he bellowed right down the auditorium to the platform 'When are you going to stop locking us up?' and I think he put an expletive in there as well. You could feel the shock. I don't think most people had ever heard a service user actually stand up and be vocal like that. And slowly a small ripple of applause that eventually rose to a crescendo and the panel just looked completely nonplussed, just by the energy of the thing I think, as much as the question. It stays with me and has kept me passionate about the whole thing. **Be Morris**

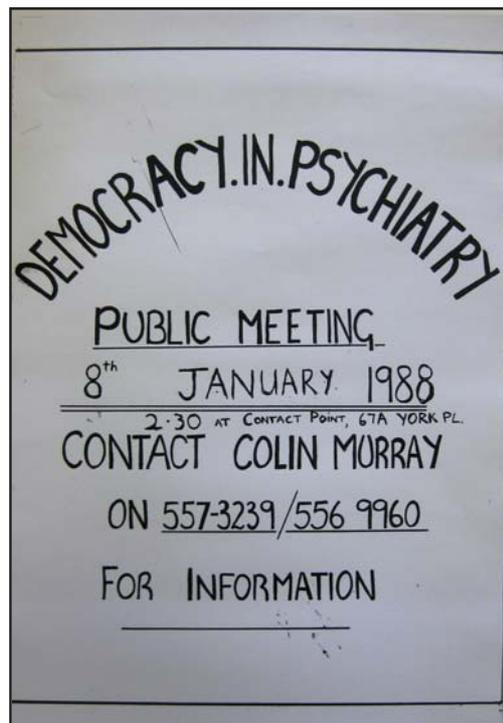
*When are you going to stop locking  
us up?*  
**Be Morris**

There was change going on and people recognising that new services had to have a user influence. That didn't go down particularly well as you can imagine. **Shulah Allan**

*There was a sense of energy around, that this was revolutionary. Colin Murray*

I remember a Mind conference, in Brighton I think, and people who used services talking about the need for things to be really different and how unjust things were, it was all about medication and feeling that we had to come back and do something about it in Edinburgh.  
**Shulah Allan**

### The first public meeting: Democracy in Psychiatry



Democracy in Psychiatry meeting poster, 1988



It must have been about 1985 and there was a student on placement at Barony called Colin Murray, who was very inspired by the 'Survivors Speak Out' movement in England and was aware that there was nothing like it in Scotland. He called a meeting called Democracy in Psychiatry, and that had a huge turnout in Contact Point, people came from all over Scotland. **Be Morris**

I remember there was a stage and rows of seats which were mostly occupied. There was some heckling but the chairperson handled it very well. At the public meeting people didn't talk much. People were asked questions. 'Do you think there should be something done?' I remember hands went up, quite a few. **LR**

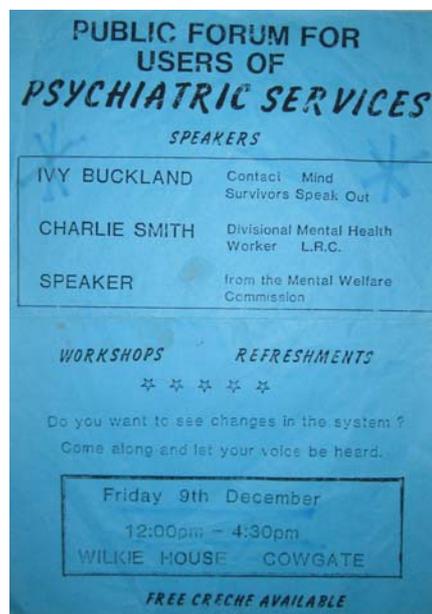
There was quite a sense of energy around, that this was revolutionary. In mental health there was this very, very radical opposition movement going on and everywhere else was wanting to become more consumerist, make more money, drink more champagne. **Colin Murray**

*Democracy in Psychiatry had a huge turnout... people came from all over Scotland. **Be Morris***

To my horror and delight, seventy people turned up, everybody crammed in. Although it had been advertised in Edinburgh, people from Glasgow and from Aberdeen came... People just snarled off at their experiences and how wrong it all was and the injustice of it. Nobody was saying 'let's do a, b and c and that'll give us x y and z', it was too early for that. People were coming into a room together and actually hearing other folk speak and their experiences were being mirrored and that in itself was probably huge for folk. **Colin Murray**

## The second meeting:

By the time the second meeting came around I'd found out about Survivors Speak Out. They had started the previous autumn, they were just months old, so that was really exciting - oh my god we're not alone here, we're in tune with something else, bigger. **Colin Murray**

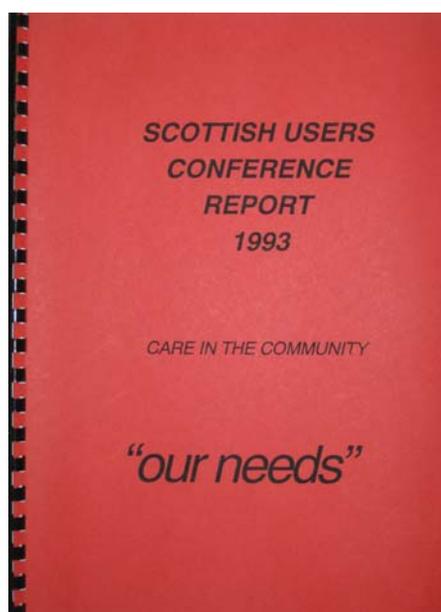


**Poster for the second public meeting in 1988**

It might have been '89 or so, that MIND conference, the theme of it was user involvement and advocacy. We started a bit behind them but we had got ahead and things were more advanced here than they were down South. I think it was me and Be and Anne sat pounding the table, 'We are doing just as well as them in fact we're doing better' 'Let's have a national conference in Scotland for users' there is something to celebrate and shout about and bring more people together. **Colin Murray**

*The second meeting was a bit more chaotic than the first one. People were a lot stroppier; they were a lot more demanding...*  
**Colin Murray**

When we got together again, it was about six months later. We called a bigger public meeting. And again people came from all over Scotland and we'd got folk from the survivor movement down south up, primarily Chesterfield. They told us how they had set up a user movement there, we'd met them at the MIND conferences. That's where it all kicked off really, in the '85, '86 MIND conferences, where users were very vocal and very angry about how they had been treated in psychiatric hospitals. We were a bit stunned at how many folk were there. **Be Morris**



There is clearly a need for it. Funders want something, people who use services want something, those two things don't necessarily meet up but how can we use what the funders want to get money to do what we want? **Colin Murray**



## COLLECTIVE ADVOCACY GROUPS

In this section we hear about people's memories of the collective advocacy groups that make up the Lothian movement and some of the issues they have been involved in.

*Everything seemed to be going off  
in tandem. There was a lot  
happening at once.*

**Be Morris**

It was such a big achievement getting everyone together in the first place. It was something that we had to work out for ourselves and we had to establish our identity, because we didn't know who we were because it hadn't been done before.

**Adrienne Sinclair Chalmers**

We'd never been asked what services we needed. We'd never been asked what we needed to do this or that or the next thing. We'd never been asked 'do you need administrative back up, do you need the use of telephones, do you need the use of a photocopier?' This was a brand, brand new concept of being asked. Whereas up until this point in time you were told. Now you were asked, totally different area. **Anne Bardsley**

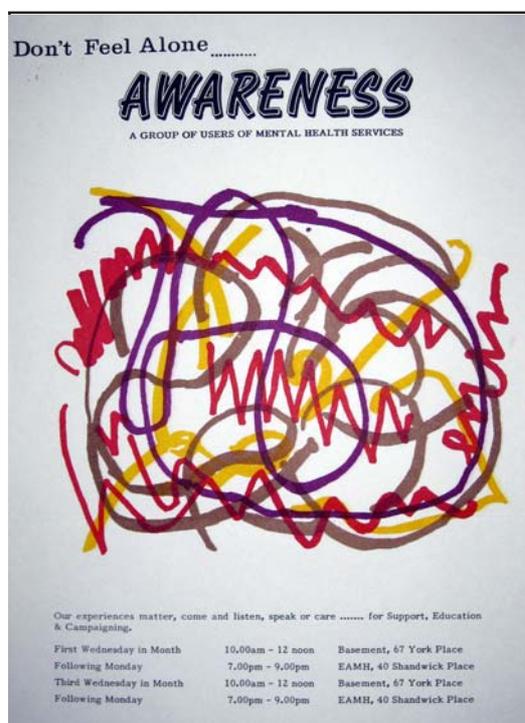
*We'd never been asked what services we needed.*

**Anne Bardsley**

## Awareness

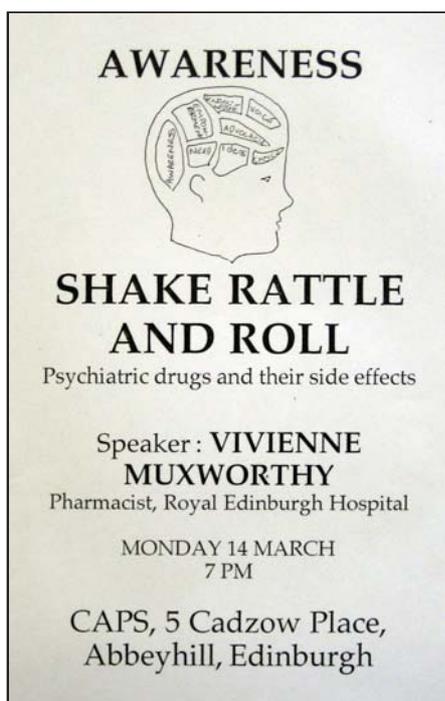
**Awareness was the earliest campaigning service user group in Lothian.**

Awareness met regularly in a dingy little room in EAMH. And we smoked and shouted and argued and generally had a really good rant. Then we went to the pub and did more of it and went home exhausted. **Colin Murray**



Awareness was a small group of people. It knew it was basically self-appointed and it was quite a small group and this was the time that Care in the Community was coming in and it was just getting absolutely inundated with consult on this and consult on that and can you send someone to this meeting and someone to be a member of this group and it couldn't cope. **Adrienne Sinclair Chalmers**

Awareness was before community care, all there was was the hospital, many people were discharged with no access to services and had to suffer the rehabilitation themselves. We wanted to campaign, to make improvements. **LR**



Awareness was meeting at that point in EAMH which is now called Health In Mind and it used to meet on the very, very, top floor of Shandwick Place and you'd have to get oxygen masks by the time you got up there. **Adrienne Sinclair Chalmers**

*...no one had ever been asked what they thought about services or care before. **LR***

The other place we met was a little place called Contact Point, and it had a wee fire, I remember it had armchairs and a wee fire and a wee kitchen. It was like a real fire. It was a nice wee cosy place and it was a nice wee happy place, and you could just actually really quite relax there. **Anne Bardsley**



Awareness met to raise issues, to talk about things that folk weren't happy with. To talk about how people might want to challenge the status quo. Then we found that suddenly listening to the service users' voice had become paramount in terms of lots of different people's funding applications, and Health and Social Work were all being told they had to listen to the service users' voice. **Be Morris**

I remember I was the minute writer and I had my rickety old typewriter. I'd tap away on it very, very, badly with one finger. There were the two different aspects to Awareness and some of it was very much directed at campaigning. It was not focused in the way the user movement is now. We were meeting and learning and changing our minds and getting cross with things but we did come up with opinions and we did make some changes. **Graham Morgan**

I remember attending Awareness meetings at EAMH on Shandwick Place. We were struggling to work out what to do, no one had ever been asked what they thought about services or care before. We got to talk about how we were feeling and of our experiences of the psychiatric system. I suggested that there wasn't enough talking to people, between nurses and patients, doctors and patients. Graham Morgan suggested a questionnaire. It felt great – it was going forward. We were reaching an audience. There was a draft questionnaire made. Quite a few replies came back all saying they wanted counselling and talking more. We didn't know what to do with it then. **LR**

Awareness turned into a steering group really. It was supported at that time by Lothian Mental Health Forum which was very active and had some quite big hitters on it in terms of professionals and so on. But it was the amount of requests that were coming in to Awareness, that's where the thinking started that maybe there was a need for an organisation that can consult on things. That was the very beginning of CAPS. **Colin Murray**

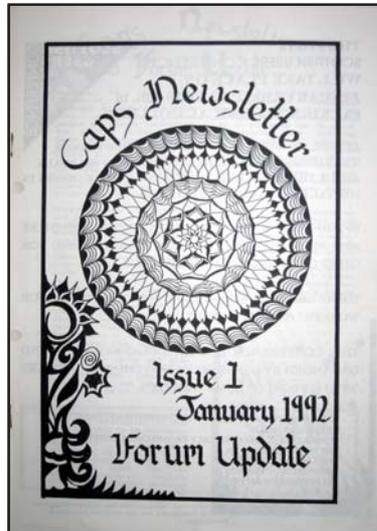
## CAPS - The Consultation and Advocacy Promotion Service



CAPS first office was based at The Engine Shed

*...there should be a group that was more accountable to service users.*  
**Adrienne Sinclair Chalmers**

It was a tiny office in the Engine Shed and it was like being thrown into a complete whirlpool, you had no idea what to do.  
**Graham Morgan**



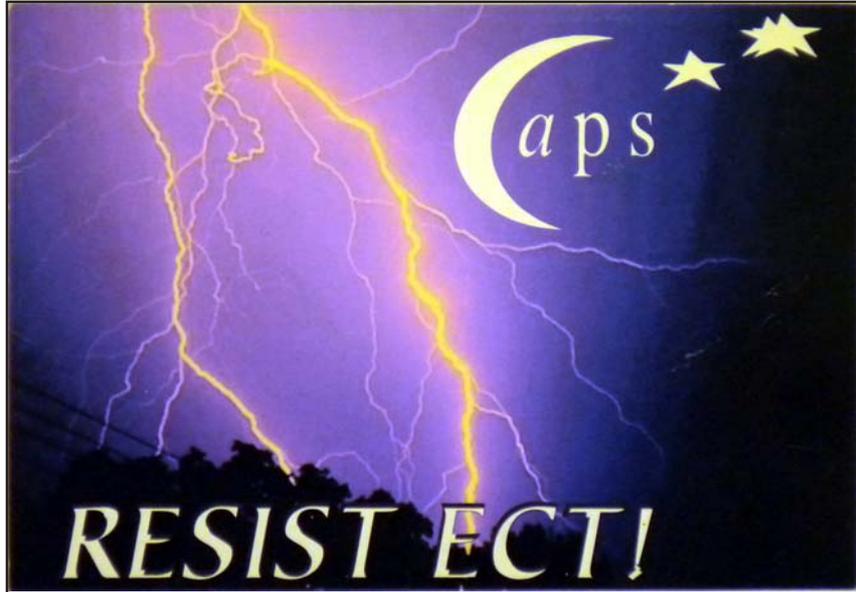
**CAPS first newsletter**

That was partly why CAPS had been set up, as I understand it anyway, because the idea was that there should be a group that was more accountable to service users. I think it was 1992 that we had a big meeting at Wilkie House and decided we would go off and create a thing which at the time was Lothian Users Forum. And that was it, we created a monster.

**Adrienne Sinclair Chalmers**

I don't even remember the early days, I remember being in the office and I remember slowly meeting people, going out to different places and talking about setting up a group. It was very exciting, it was exhausting and we were all pretty ignorant and we were learning as we went. **Graham Morgan**

Awareness didn't have a mandate from the larger user movement but were being asked to represent users on all sorts of different committees, consultations, 'what do you think of this before we do it?' We really needed to look at getting something more organised and structured. So Awareness and at that time the Lothian Mental Health Forum got together and put a funding proposal together to form CAPS. **Be Morris**



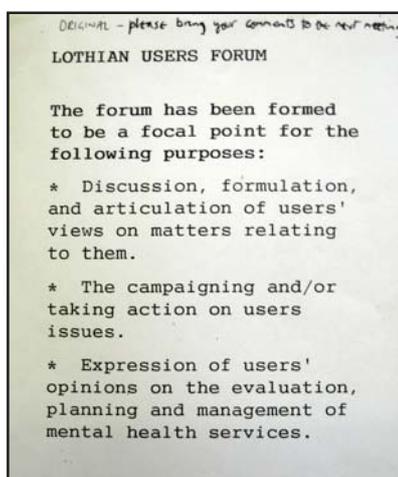
A rare postcard from CAPS 'Resist ECT' campaign

We had a little room and we bought tables and eventually bought a computer and eventually we got an admin person who could use a computer. It was just very, very basic. **Graham Morgan**

CAPS got 10,000 postcards printed and addressed to Malcolm Chisholm and he said every day he would open his post bag and another of these cards would fall out and he was sick of seeing them! It was actually the day before the stage 3 debate in the Parliament and he phoned me up and I was in the bath, unbeknownst to him! So, I was having a conversation with the Health Minister when I was in the bath and he was saying 'we're going as far as we can'. He is a good bloke Malcolm, I think he was the first Health Minister who had read RD Laing! **Adrienne Sinclair Chalmers**

## Lothian User Forum

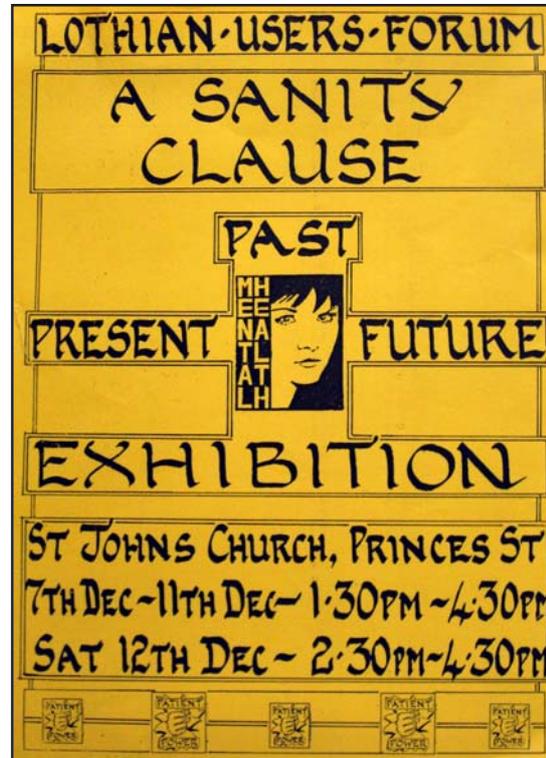
My strongest memory of the movement is of Adrienne suggesting a Lothian wide forum, it was so bold. No one had thought of a thing like that. I thought it wouldn't work! **LR**



*It made the way that services pigeon-hole people, it just made it all so damned irrelevant.*

**Adrienne Sinclair Chalmers**

I can't even remember when our first meeting of LUF was held. I think it was in Contact Point and it was crowded, with people sitting on tables. We weren't quite sure what we were doing or why we were doing it or how we were going to do it, but we were very excited with lots and lots and lots of talking. That went on for quite a few months at that intensity and then it stopped, I think because we didn't know how to do it. **Graham Morgan**



A poster from a LUF exhibition

I don't think I've ever come across a wider cross section of folk as in the then Lothian Users Forum. There was people who had been in hospital for decades, there was people who dipped in and out, there was people who had never been in hospital. It made the way that services pigeon-hole people, it just made it all so damned irrelevant.  
**Adrienne Sinclair Chalmers**

The next thing I remember is Graham from CAPS organising a party at the South Side Community Centre and there was some kind of alternative band called 'Elephant Noise' who were very good. Everyone was seated around the walls. After the band there was a meeting to talk about LUF and to appoint office bearers, I enjoyed the party. **LR**

We were trying to get groups of people to change the world. In the initial days it was a wonderful, wonderful buzz of activity and talking and rushing around and feeling that everything was going to change. There had been a lot of suspicion of us from the professionals where this was just so brand new to them they just assumed we would fail and would be no use. In many ways we proved what we were doing is good, and could work and was correct. **Graham Morgan**



*In the initial days it was a wonderful, wonderful buzz of activity and talking and rushing around and feeling that everything was going to change.*

**Graham Morgan**

Aye, I do remember it all started off with cups of tea, there was a sort of social element first and then the meeting would start. And again I can remember quite good attendance. I can remember us having discussions and I can remember us going to the pub afterwards. So there you go, I remember the cup of tea and the pub afterwards more than I can remember a meeting! **Allison**

This was a user led agenda, this wasn't professionals holding a meeting for service users, this was service users holding a meeting for service users and that made it feel very different. **Jim McGill**



I can remember one AGM or event that we had at The Filmhouse where we had a local singer. It was just an ordinary social event that any other group would have, only we were all wearing 'Glad to be Mad' T-shirts. That felt like quite a powerful thing. So that stands out as an enjoyable memory. **Allison**

*We were all wearing 'Glad to be Mad' T-shirts.*

**Allison**



LUF was off our own backs, it was something that was important to us, it was our own agenda. **LR**

*Several hostelries must have been absolutely delighted to have a bunch of mad people in their pub screaming about ECT! It's amazing how many laughs you can get sharing your top ten worst failed suicide attempts! We'd be rolling around on the carpet by the time we'd finished!*

**Adrienne Sinclair Chalmers**

Someone cycled from the Borders to come to LUF meetings! There was a lot of enthusiasm around. **LR**

Words like collective advocacy would not spring happily to your lips way back in those days, it was a 'user group' and suddenly we realised that was what we were doing, 'oh it's collective advocacy'!

**Adrienne Sinclair Chalmers**

I remember just being amazed by the people that were there, everyone had loads to say and there was a great energy.

**Anne O'Donnell**

## Beyond Diagnosis Magazine

We just knocked our pan in trying to get it off the ground.  
**John MacDonald**

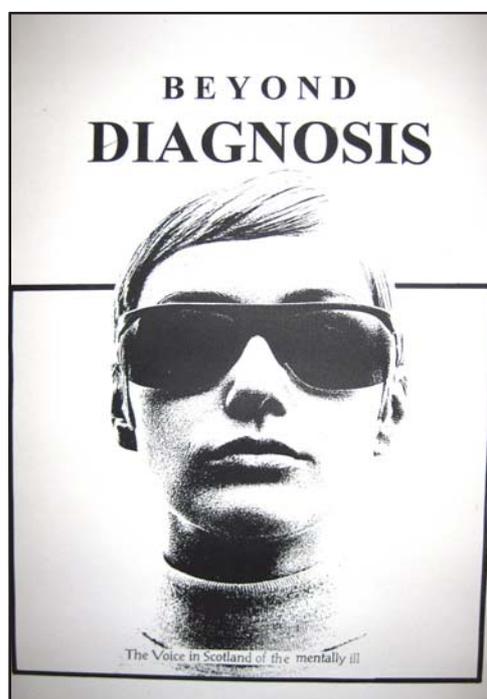


I kind of came in towards the end of Beyond Diagnosis. It was a magazine that offered creative opportunities for people with mental health problems and used mental health services. There was photography, poetry, fiction and autobiographical pieces.  
**Anne O'Donnell**

I think it gave people a space to be open about having mental health problems. **Anne O'Donnell**

It was to express the talent, experience, to enable people to be greater than they were maybe being pigeon-holed as being. So there was a healing element in it which I'd felt the need for myself having being incarcerated. Finally I verified with myself that I had recovered from the bitterness of the way I'd been treated.

**John MacDonald**



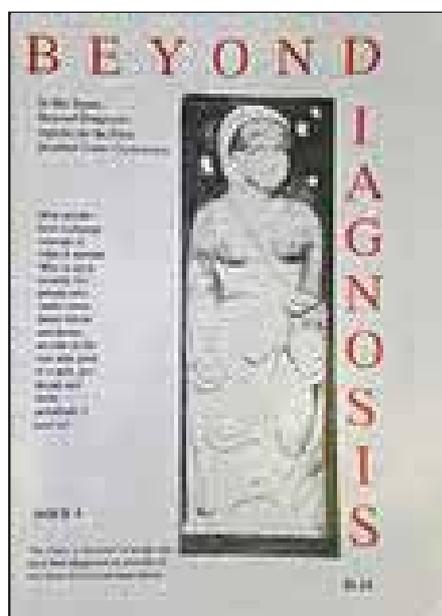
My strongest memory is just being in the basement with all the paperwork and trying to sort it into some kind of sense. I'd very little experience of admin stuff at the time, so I was learning as I was going along. **Anne O'Donnell.**

It was the magazine that I was first involved with, mainly my photographs were used on the front cover and to illustrate some articles on the inside. That was my first introduction to the movement.

**Jimmy Osborne**

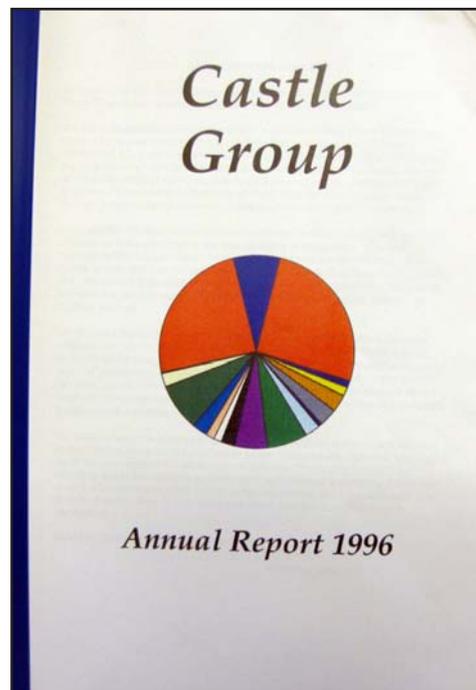
I don't think I would have got involved with the user movement directly if I hadn't gone through being involved with Beyond Diagnosis. It meant that I got to see people and got comfortable in the CAPS office, so it wasn't such a big step, whereas I don't think I would have got involved as directly otherwise. **Anne O'Donnell**

Being in the fashion world during my career as a photographer I was in continual company of magazine editors and writers and so on and was fairly knowledgeable about the structure and what made them tick and what made them work. **Jimmy Osborne**

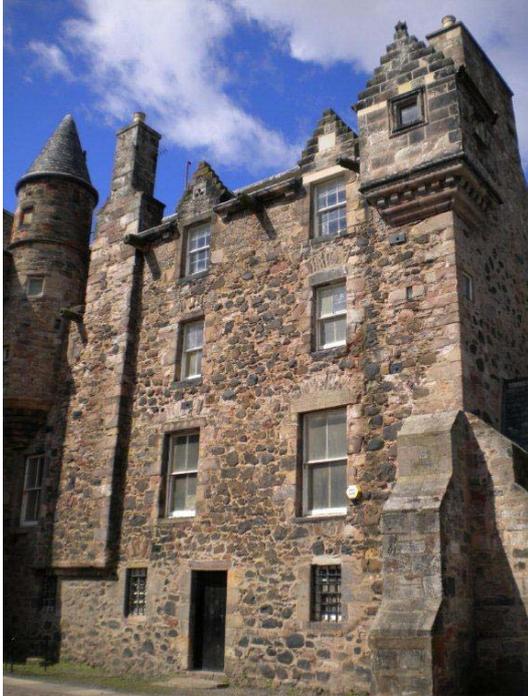


## The Castle Group

The Castle Group got interested in the concept of advocacy. We didn't know it was advocacy, we kind of worked it out for ourselves. We had a group member who was having a difficulty with his consultant. We kept saying what a shame one of us couldn't go with him just to make sure he didn't get sidetracked by this guy. So we immediately grasped the point of advocacy because we'd sort of worked it out for ourselves. **Adrienne Sinclair Chalmers**



The Castle Group was an early model of an attempt at having a user led organisation. The Castle Group was very valuable to the people who used it. A place to go, it was warm, it was welcoming and it was accepting and it wasn't judging. But really what happened there in my view was it became very closed and was very difficult for new people to go into. **Willie Paxton**



**Craigentinny Castle - home of the Green Lady and the Castle Group**

The idea started at The Castle Group of having a Crisis Card with your name, your next of kin and a little bit about what meds you're on and what needs really done when you're ill and that. Whether it be, somebody feed the cat, somebody water the plants. That's where Advocard came from.

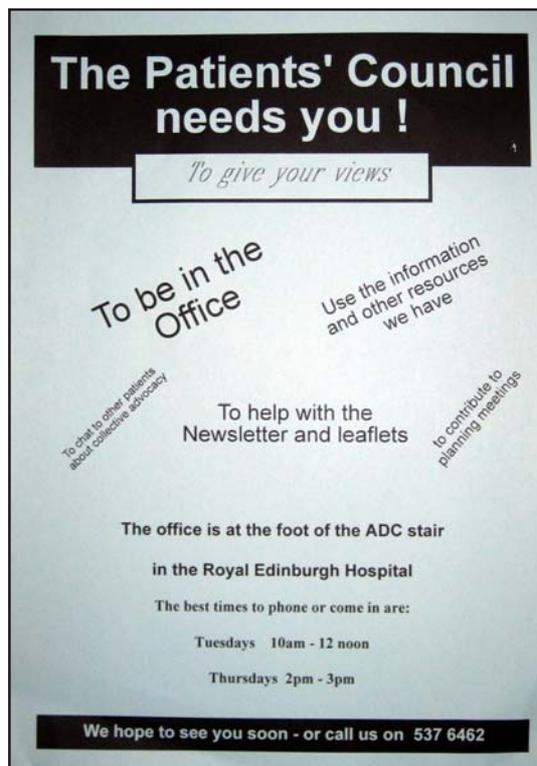
**Adrienne Sinclair Chalmers**

*When the Castle Group were in Craigentinny Castle there was supposed to be a green lady that the janitor used to meet - he claimed - on dark nights. It was really interesting when we did relaxation and when people were totally relaxed they would claim to have visions that were consistent with the green lady who they had never even heard about at the time, I never met her myself!*

**Lami Mulvey**

## The Patients' Council, Royal Edinburgh Hospital

What I understand is that the Patients' Council started when the Director of Edinburgh Association for Mental Health went down to a MIND conference and there were some people from Holland there who had started up Patients' Councils and there were also some people from Nottingham. Nottingham Patients' Council was set up and the director of EAMH heard these people talking about Patients' Councils and thought we needed one in Edinburgh. **Allison**



A Patients' Council poster

I think everybody in the hospital was very, very suspicious because it was a user group. I think they all had the image, oh, are the loonies going to take over the asylum. But after a couple of years people noticed it's not only for the patients' benefit, because if the patients are being treated with dignity, being respected, having the basic things like food that you can actually eat, staying in a ward that the cleanliness is high, there was actually a better atmosphere on the wards. Other things benefited the whole of Morningside, because we got the council to drop every kerb for wheelchairs, so it wasn't just the people in the hospital that were benefiting from that, everybody in the community that had a wheelchair, whether they had a mental health problem or not, benefited as well. **Maggie Keppie**

*And I think that one of the things that I do remember is thinking how uncomfortable the nursing staff looked actually when they were escorting people to the Patients' Council. I think that was because they felt they might be under attack. I think they were quite surprised at how business-like the meetings were. And also how reasonable people could be, despite having had very negative experiences.*

**Allison**

The very first memory was of Margaret Temple sitting in her room, it was an office with a chair which might have been missing a leg. And the chair doubled as a table for her typewriter or a seat for her. So if she was doing typing she'd be sitting on the floor and if she wasn't she could sit on the chair! And she would wander around the Thomas Clouston Clinic, talking to people who had been there for years and years and years, and trying to find out their views around the closure of the clinic. Then it all moved down to the Royal Ed.

**Graham Morgan**



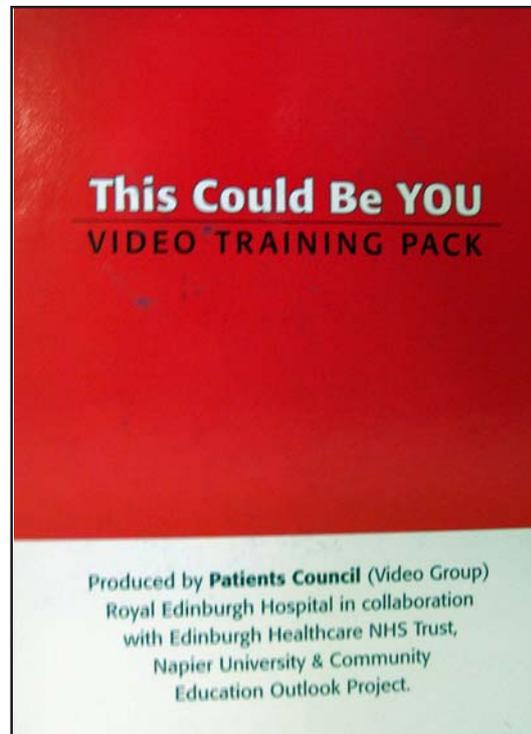
I can remember us thinking well we have to launch this Patients' Council and thinking "oh my god" ...because we were doing it by the seat of our pants. There was nothing that said to do it any particular way and were we going to get it horribly wrong? And that felt a hell of a responsibility because if we get it wrong we'll be setting the thing back. **Shulah Allan**

*The first meetings were in the boardroom which was quite... 'the inner sanctum', like 'Oh my god we're in the boardroom, we better no put our cups on top on this table', you know, it was really strange to be in the boardroom.*

**Anne Bardsley**

It was like 'horror on horror'. It was very much a case of 'Oh my god, the lunatics are taking over the asylum' which wasn't the case at all, and for some Patients' Councils it was simply 'We want a tuck shop that's open at seven o'clock at night, that sells more than Mars Bars and Bounties'. **Anne Bardsley**

One of the things that I was involved in was a video that we made called 'This Could Be You' which is a training video and it was in response to some concerns about how people were being treated on the acute wards. It won first prize in this 'Pavilion Publishing' competition. **Allison**



*One thing I was quite careful to do was not to go to a meeting when I was in hospital. Basically I was too scared there would be a backlash from the care in the ward.*

**Les**

I did wonder whether the Patients' Council was actually going to survive or whether it was going to be destroyed from within. Which was very sad at the time. You had users fighting users, you had users saying workers had done this and workers had done that. It was a really hard time. But luckily we got through it and the council is twice as strong now. **Maggie Keppie**



The NHS has been fantastically supportive of the Patients' Council and at times I think the Patients' Council might not have survived without the support of the NHS and the Royal Edinburgh Hospital in particular. And the other thing I want to say is how amazing service users are to come back into a hospital environment where some of them have had some pretty devastating experiences, and they come back in to try and improve the hospital experience for other people, I really take my hat off to them being able to do that. **Maggie M**

For a start it was getting across to staff and taking staff with us and getting them to appreciate that patients had a right to raise issues. Not just the tea and toilets, but also methods of treatment, the need for more talking therapies. **Jim Kiddie**

There were quite a lot of issues at that time about conditions on the wards, about over-use of medication as members saw it, about treatment and care and about, well, the influence that consultant psychiatrists had on a person's treatment and care. **Ruth Rooney**

We've been involved in ICP's, integrated care plans that have been produced over the last two or three years, and we've had service user representatives' involved in most of those. **Maggie M**



I think some of the work that is going on around privacy, safety and dignity is also positive, especially around things like looking at single-sex facilities, for people who are in hospital. I think that is really important that that's being looked at, though some might say it is long overdue. **Allison**

One issue that we had when I was there was there used to be some sort of café drop-in place that wasn't very successful and I think we got SAMH involved and it became the Church Centre, it became a good social centre in the hospital. **Jim Kiddie**

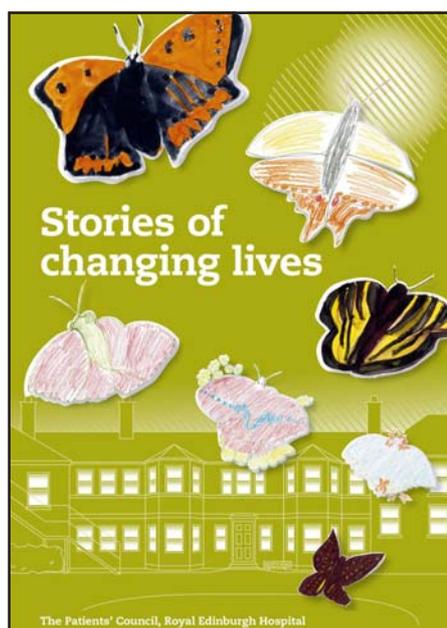
*I can remember some years ago we hosted a  
'suicide workshop', that was way before  
'Choose Life' was established.*  
**Maggie M**

It's important that we don't become an institution and become institutionalised as we work together with hospital managers but we must also be able to challenge them. **Pat W**

I remember they had a few barbecues, when it rained usually. I went away to Yorkshire with members, we stayed in Harrogate and it was the coldest night of the year. Things like that kind of stick in your mind really, oh just hundreds of things. **Ruth Rooney**

There are whole lists of campaigns. I've been very much involved in changes within the hospital, very much involved with the kaizens and the intensive home treatment teams being established, and the mental health assessment service. I am just adding the service users' view. **Pat W**

The Patients' Council has been involved with plans to redevelop the Royal Edinburgh Hospital since I've been here, which is 13 years now, and the current re-provisioning process is the third one we've been involved in that I can remember. **Maggie M**

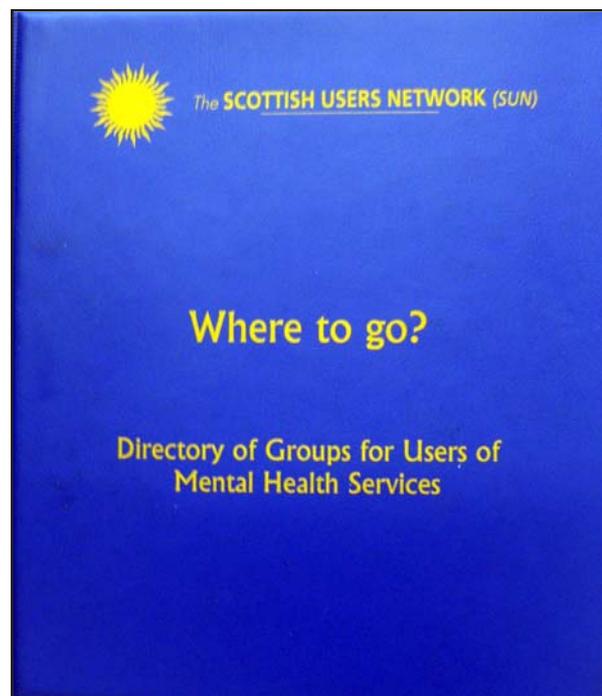


**'Stories of Changing Lives' a book published by the Patients' Council in 2010**

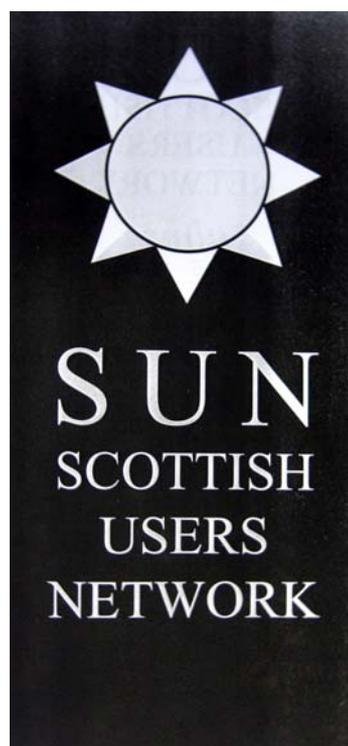
I think places like the Royal Edinburgh Hospital, I think they should have rebuilt it years and years ago, you know. Speaking personally I was in there myself and it's not a very nice place to be in, it's nothing to do with the staff because the staff are really friendly but for instance when I was in there I'd go and have a shower and the shower was in the same place as the urinal and the curtain was hanging off the shower and I just really felt degraded, you know, and I hated it. **Gordon Mackay**

## Scottish Users Network (SUN)

The Scottish Users Network was an organisation that was intended to provide a national user voice, and various collective advocacy groups were members of SUN. Lothian Users Forum or Edinburgh Users Forum... was a member of SUN and various other groups were as well... I think a lot of energy was taken up trying to set up the infrastructure for that organisation, trying to ensure that the funding continued... trying to get user groups to join, trying to sort out some of tensions between people in the executive, some of the members and it folded. It went under... and of course we now have Voices of eXperience folks. **Allison**



Well, one of the strongest memories was just the length of time the management committees, the advisory committees used to take! So that's one memory of how much hard work it was and then the other memory I suppose is the less pleasant one which is how it came to an end. **Stephen Maxwell**



Part of SUN's job was to create a proper users movement throughout Scotland. And that really proved the most difficult bit of the job because although there was a small network of users or organised users groups with funding of some sort or another, SUN set itself the target of actually establishing new users groups in areas where there weren't any. So that was the main criteria I think or the main objective of the organisation for which money was given. And that was where the Scottish Office hoped to see results and they proved pretty difficult. **Stephen Maxwell**

There was a lot of consultation going on in the late 90's and 2000's around the end of the Tory government, the beginning of the Labour government, the beginning of the devolved government, in fact it was 'consultitus land' you know, but it kept going on and on. Also the care standards were being established, clinical standards, you name it. So SUN was putting people in there with experience.

**John MacDonald**

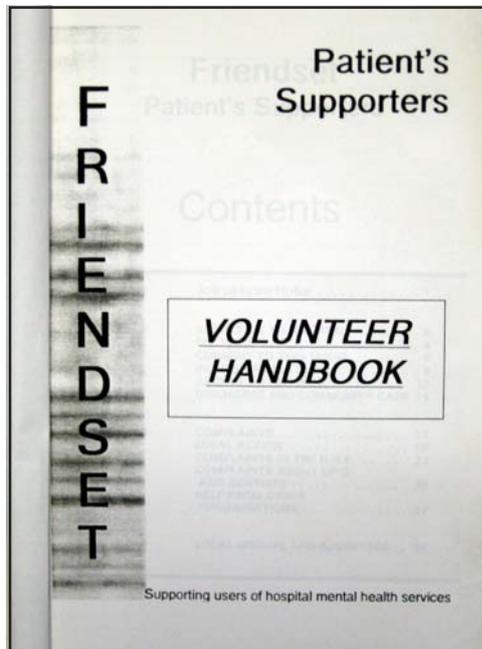


Now after I decided to retire really from the Patients' Council it was going through some real difficulties and I remember Allison Alexander suggesting to me maybe I could be of some help there. Ultimately I became convenor of the Scottish Users Network. Now there was some pretty nasty stuff went on there and I mean service users can maybe be nasty to each other at times, reflects what goes on in general society, and I had to resign from that because I thought I'm going to have another mental breakdown if I don't get out. I do feel there has to be a strong national voice and I think there now is an organisation called VOX. I hope it's effective because I think it's critically important. **Jim Kiddie**

## West Lothian



West Lothian Patients' Council started from Friendset. There was a meeting in the big church at Bangour. It was mobbed. They wanted to make things better for other people. It was advertised about users' rights about setting up a Patients' Council and from that the first steering group was set up. **Anon**



Friendset was around before I came and it was a befriending project for people with mental health problems.

**Chris Galbraith**

When I arrived in West Lothian there would have been ward meetings and meetings took place in the day hospital for users of the service. My first recollection of that being more formalised into a movement was the development of Friendset; where volunteers would be recruited to befriend people with a range of mental health problems. And that really evolved over time into a much more user led organisation, really the start of advocacy. But it grew out of initially a befriending project. **Dr James Hendry**

Friendset went through a name change and was called the Mental Health Advocacy Project West Lothian. And as the staff of MHAP we also facilitated the local service user group in West Lothian which met on a Saturday in one of the local centres. We could talk to them and gather their views and there was a social element to that as well in terms of we put on food, rolls and cakes and things like that partly to try and attract people to come along. **Shaun McNeil**

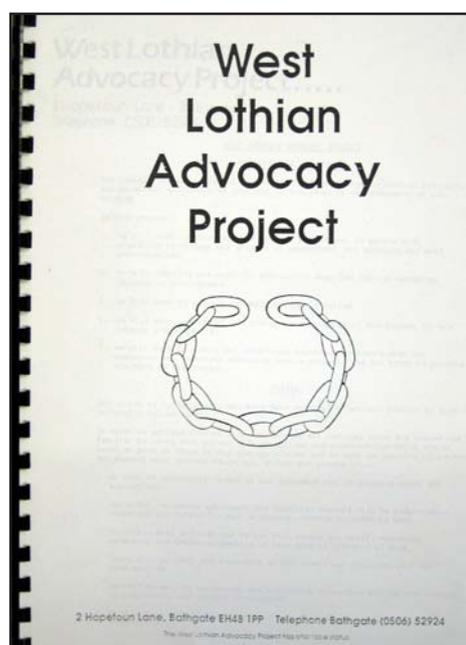
Obviously the biggest issue was the closure of Bangour Village Hospital and that was monumental in many ways, it was the on the ground reality of care in the community. **Chris Galbraith**

*If valuing ethos is not done for the most forgotten about person in the very back wards, that no one ever ventures into, never gets any of the great and the good visiting, if it doesn't work for that person then there's still more to do.*

**Chris Galbraith**

At the moment we support the West Lothian Service Users Forum and they meet once a month on a Friday afternoon. MHAP also supports the Community Reps Group, that's a group of service users who attend day services in West Lothian.

**Kathy Hamilton**





We are involved in the Inpatient Forum which is fairly new, we've been involved in the development of the acute care and support team which has been up and running for a couple of years now. At the moment we're involved in the development of a rehab and recovery service. We were involved in the campaign for CPNs for people with hearing impairment, we did quite a lot of work on that. We have the mother and baby unit here which I know service users campaigned for a long time ago. Just now the service users main goal in West Lothian is to protect and to keep collective advocacy because that's probably an area that people feel most under threat.

**Kathy Hamilton**

*...the service users main goal in West Lothian is to protect and to keep collective advocacy...*

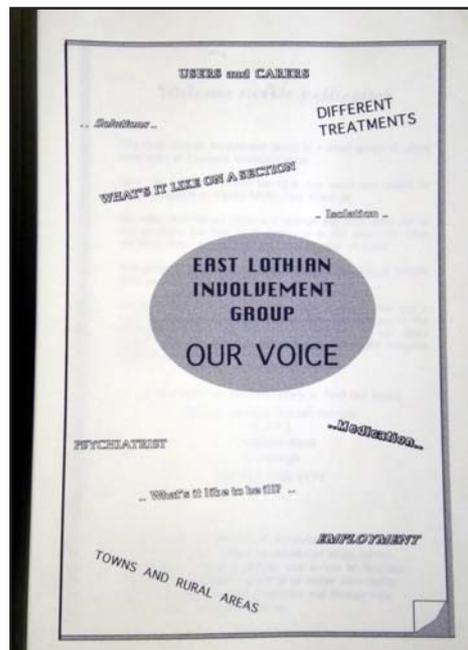
**Kathy Hamilton**

We have had issues around things like staff wearing uniforms in the hospital... So service users were very strong in their views that they wanted staff wearing ordinary clothes and it did seem like harking back to the past. So we did a bit of work on that. One of the other issues we had was actually the continued care ward in St John's. Now the people who were in that ward were not detained, but the ward was kept locked apparently for their own safety and service users weren't happy about the fact that the ward was locked because there was no real need. So...whilst we maybe haven't been participating in national campaigns, we do an awful lot more on a local level and that's where the bulk of our work in collective advocacy has been.

**Kathy Hamilton**

## East Lothian

Myself and another couple of folks went to Jewel & Esk Valley College. They tailor-made sessions for us around how to organise a group, how to make sure that you were constituted, the main roles for office bearers, what were their responsibilities... So taking it from, 'yeah this is a great idea', to 'how are we going to do this?' Demanding but exciting. **Jim McGill**



Some of the earliest ELIG members had discussions with Napier in terms of the involvement of people with experience of mental health difficulties in the development of the psychiatric nurse curriculum. These early consultations predate the review that was Rights, Relationship and Recovery report, and that was to do with individual members of ELIG having expressed a particular interest in relation to stigma. **Fiona Macdonald**



The work on medication which resulted in the report 'Because it Will Help You'. The work that was done on suicide and self harm which again was Lothian wide, and that predated the Choose Life campaign. **Fiona Macdonald**

*One of the biggest issues that we've been tackling over the last few years is reducing stigma. Labelling people in society is very damaging.*

**Ian Stevenson**

I think in terms of East Lothian, it's a large rural area and by definition there will be people with mental health difficulties who don't stay in Haddington and who don't use Tynepark, there's going to be people out at Dunbar and Cockburnspath... how do we get them involved? So it's about identity and about people seeing this as being centralised. **Jim McGill**

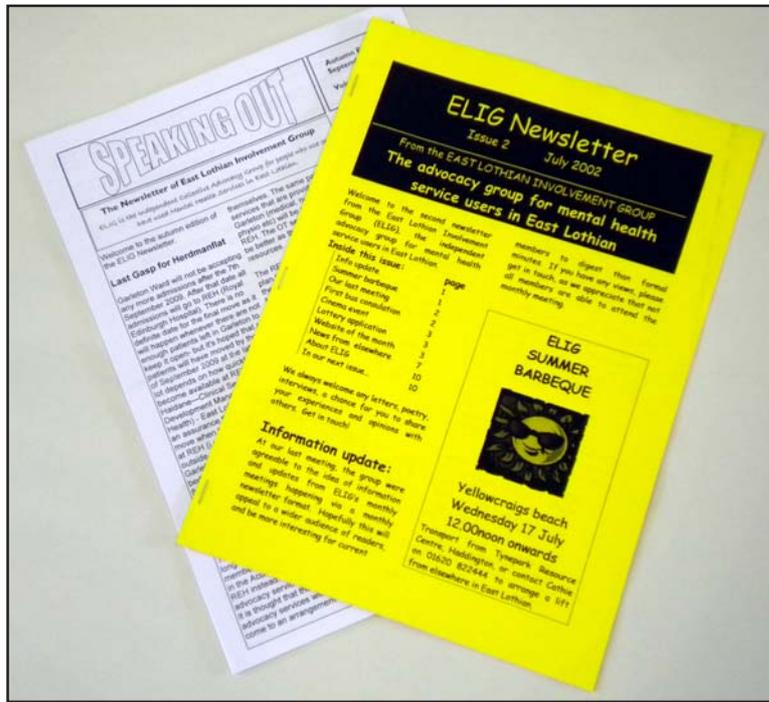
At that time there was a big hoo-hah about NHS Lothian wanting to close down the acute ward at Herdmanflat Hospital and there was a huge petition got up against it. **Ross McPhail**

There's also the issue of Garleton ward at Herdmanflat, which first became an issue 5 years ago and at that time lots of meetings were held. There were many meetings held and service users and the professionals made it crystal clear at the time that they were dead set against the closure of Garleton ward. **Veronica Forrest**

Way back when I first joined there were talks about big changes happening and how people would be able to access getting support and help within East Lothian. Also there was issues about people's benefits because ongoing changes happening with them, things like people needing support at home, how do they access that, who will help them, who will guide them, who will show them the way forward. Also there were issues surrounding advocacy, how do you get advocacy because when I first joined advocacy was quite a new way of people getting help and not many people really understood it. **Ian Stevenson**



**Garleton Ward at Herdmanflat**

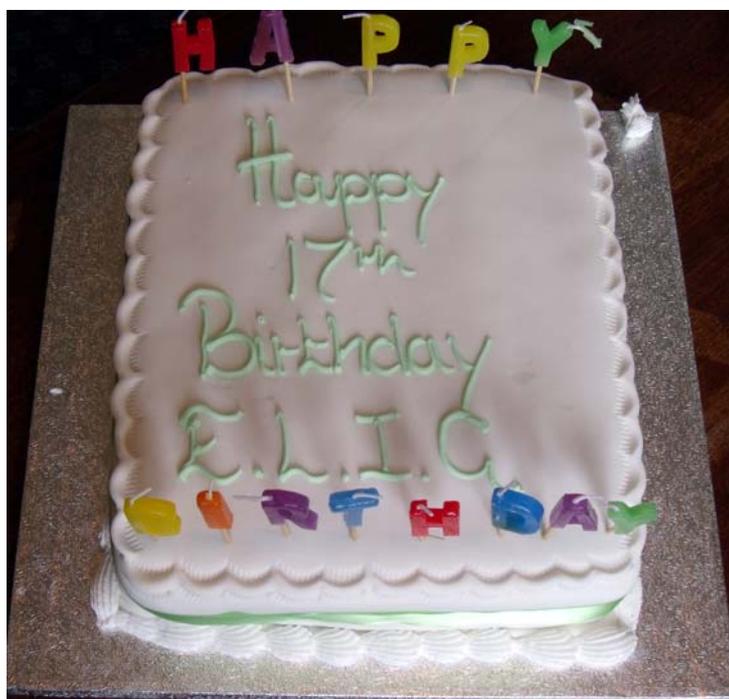


*‘Working Like Crazy’, was the opener at an AGM. It was the film where I first come across social enterprise and it fired up my interest.*  
**Veronica Forest**

I think ELIG members deserve a lot of credit for giving a profile to the voice of people with mental health difficulties as well as some of the reports that have been produced and a newsletter. As in most groups there are peaks and troughs of activity, and I hope there will be more scope for a next era for ELIG to have influence.

**Fiona Macdonald**

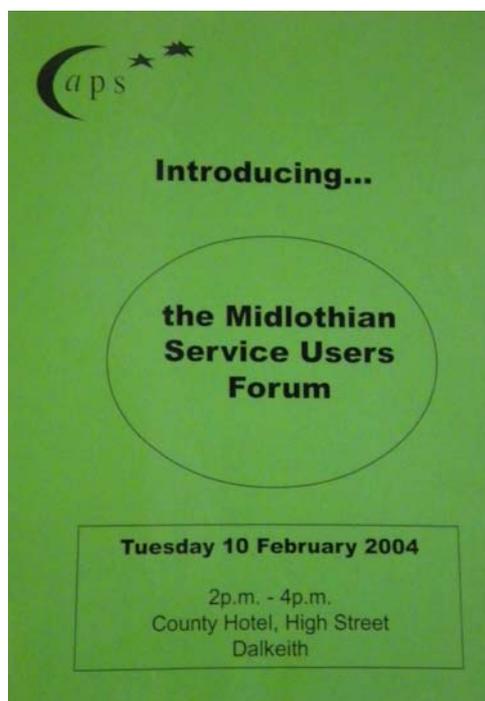
There's been problems over people's benefits, how are people supposed to cope if they haven't got the money to go and get the help because the helps been taken away from them? Or people that were stuck at home, how are they going to get the help in the house? What phone numbers are available? Will there be round-the-clock help if I have a crisis in the home? **Ian Stevenson**



Why should anybody have to travel to Edinburgh by taxi, who has got no money, or to St John's Hospital and why should people have to do without vital services in East Lothian where they live because public transport, quite honestly, is sometimes nonexistent and not straightforward. **Ian Stevenson**

## Midlothian

I can remember one time in Midlothian, service users had got together and they said they wanted advocacy in Midlothian and there wasn't any there. I informed the Lothian Health Commissioner of this, he was quite a nice bloke, and he said "well they can't have it because that's not one of the priorities in the local plan". I don't care what you've got written in your little local plan! This is what the service users want, it's their priority! **Adrienne Sinclair Chalmers**



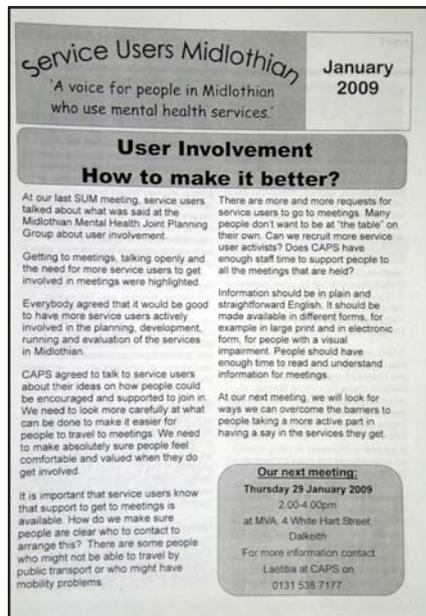
At the 'Have Your Say' Days we got really heard and we did a booklet and that went out to different people. It got them to realise that we weren't just mental health patients to get treated and that was it, that we had views and thoughts of our own. **Irene Rooney**

Rosslynlee closing down was a bit of a shock, certainly for me it was a loss, there's no question. It was probably just by luck that I fell in to SUM. I find the whole thing exhilarating. Aye, some of the meetings were superb. **Pat**



There's a feeling I've got good input to make in these meetings and I'm usually stimulated into thought, about innovations in the psychiatric field and aye, taking more control of your own mental health. **Pat**

You hear service users in Midlothian saying, 'yeah, we have 24/7 telephone access to crisis service.' Fantastic, fantastic, these were the things that people were banging the drums for years and years but didn't think it was going to be possible. **Jim McGill**



Mental illness has got to be faced straight on, if it hadn't been for an organisation like SUM it might have taken years and years to get to the point where we are now, it just seems to me to be straightforward that an organisation like SUM should exist. **Pat**

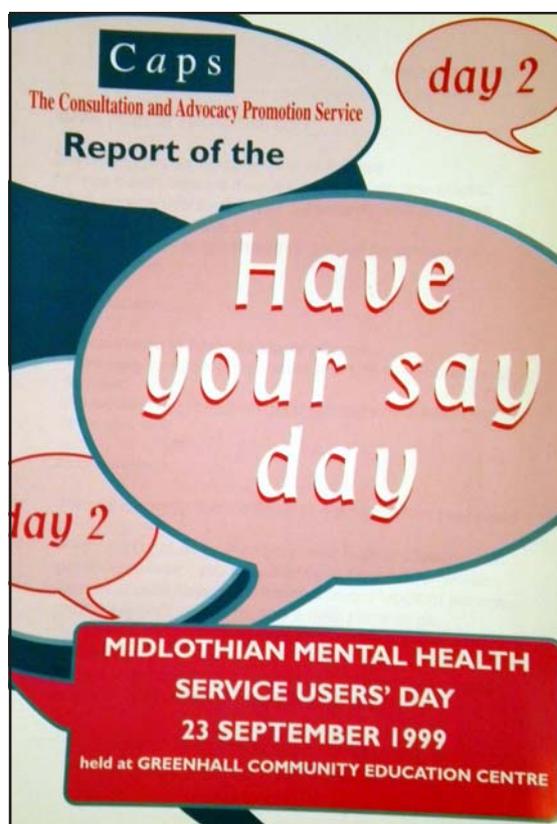
We set up a collective advocacy group in Midlothian, SUM, Service Users Midlothian and I was at the very first meeting. A short time after that the individual advocacy took over in Midlothian too, CAPS did individual advocacy in Midlothian and had a pool of volunteers. I had done the training and was one of them. I think it's a much smaller group than obviously in Edinburgh because Edinburgh has a bigger population. But we've plugged away at much the same things that EUF does you know. **Terry**

*I think the SUM meetings are good because people are getting a chance to have a say and listen to other people as well.*

**Irene**

I think the advocacy service was really good. That's helped a lot of people. It's helped me to get across to officials that maybe the diagnosis or the medication they were giving me wasn't quite right. And I was able to get a better say and better confidence having somebody there with me to do it. **Irene**

The success in Midlothian is definitely without doubt collective advocacy. Everyone is listening to SUM now. For instance when Rosslynlee closed down, SUM has been involved in that from the beginning. We had put our views across, what we would like and what we would want in a perfect world. It remains to be seen if it was taken into account because there is always money involved. And individual advocacy, the changes in professionals in Midlothian is quite astounding over the years from open hostility to welcoming you. **Terry**



I think we are listened to more. I think people listen more to us than they did when we first began. At first it was a bit like you weren't sure if the professionals were gonna be listening to us. Now you have the meetings and something's said or something's decided on, then we try to take it forward to deal with it. **Irene**

## SMOKE

So everything's smoke, I can remember now a few people who didn't smoke and they must have sat in this stinking environment with the rest of us all smoking away. Just amazing when you think of it. I'm surprised you can't still smell it on the walls! **Shulah Allan**



And the other thing I remember is the amount of smoking that went on and when rules were brought in that only two people at any one time could smoke or only the person who had the ashtray could smoke and people just staring at the ashtray waiting for it to become free. **Anne O'Donnell**



There was still things going on like a token economy – if you are a good patient today you'll get two fags instead of one. I can't underestimate how huge a thing cigarettes were. Cigs were the currency. People's whole day revolved around cigarettes. How many cigs they could get, what they could swap their cigs for etc. That's something that is really strong with me. **Shaun McNeil**

*So everything's smoke.*  
**Shulah Allan**

One of the big changes was smoking policy and people obviously think that smoking is dreadful and awful... but the thing that was good about it was if there was a nurse who was a smoker and if there was somebody who was in the hospital who was a smoker, it was a form of human contact, lighting up. Having a displacement activity is incredibly useful and now that has been removed. **Jonathan**



## THE STRUGGLE TO BE HEARD – reactions and resistances to advocacy and an emerging service user voice

Things have got better, but initially it was practically a closed door. You are knock, knock, knocking and they're saying no. It was literally getting your foot in that door. Once you had your foot in that door it made things a lot better. It was like squeezing your toes in that door to start off with. It was literally being determined enough to not let that toe get out that space, and just keep it there and keep it there and push, push, push until you were in the door. **Anne Bardsley**

Initially the professionals were aghast that the patients even had opinions. You know, its 'wait a minute, mental people can't have opinions - they're mental, they are'. **Anne Bardsley**

I can remember the first time I sat down with the charge nurse in ward \_\_\_ in 1987 to try and tell them about what we were all about, he turned his back on me shut his eyes and puffed on his pipe and refused to acknowledge me, I mean how rude was that? Within a couple of years he was out and there was new people coming in who were a bit more enlightened. **Lami Mulvey**

25 years ago we had to fight for that right and we had to be cleverer than a cart load of monkeys. We had to be cleverer than the people we were speaking to and be politer and kinder and nicer and more courteous, because otherwise they would chuck us out. They wouldn't give us the time of day. I'm not making this up. It really was shocking. **Anon**



The other thing was worker hostility. There was and still is a lot of resistance to advocacy, of course. But it was intense, very, very intense then. **Colin Murray**

Oh I can remember going up to the Royal Ed and we were just laughed at, just ridiculous. I can remember when I went to the Scottish Office to talk to somebody about advocacy and being told “Don’t come in here talking about advocacy, advocacy is about lawyers. Find another word for what you want to do.” So you know we were just pooh-poohed but all that did was make you more determined. **Shulah Allan**

Although there were a lot of allies out there, the service user movement still had a lot of people who still didn’t really think there was any value in terms of listening to service users. **Keith Maloney**

I think it was very slow. Most staff I think recognised there was a need for advocacy but often considered that the need was greatest in other people’s wards and not their own. **Chris Galbraith**

We were once sitting in the Patients’ Council members’ room when a female consultant came barging into the office waving one of our posters and said ‘These things are causing an eyesore in the hospital, remove them all immediately’. So the Patients’ Council had to write to the Medical Director and point out advocacy is part of the hospital actually. I couldn’t imagine that happening now, there is more respect. **Ruth Rooney**

## CRISIS CENTRE CAMPAIGN

One of the most significant campaigns of the Lothian movement was the campaign for a crisis centre. Crisis services have been on service users' agendas since the early 1980's.

We sent a letter to all the people standing for parliament saying 'we want our crisis centres!' The heading of the letter was 'We're mad as hell and we're not going to take it any more.'

**Adrienne Sinclair Chalmers**

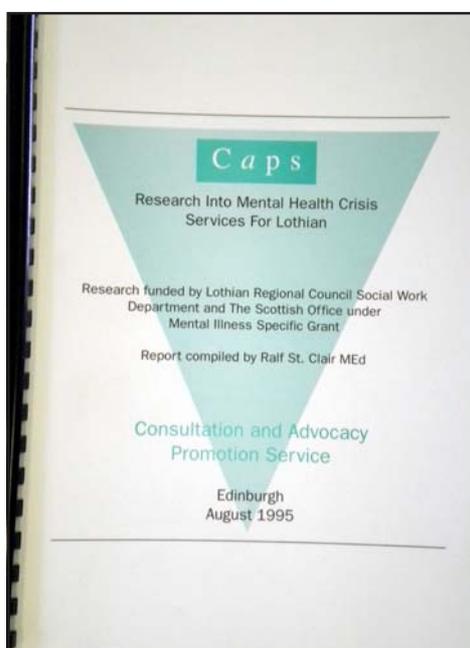
*'What do you want?' 'We want a Crisis Centre!' 10 years later, 'What do you want?' ' We want a Crisis Centre!' it went on and on and on.*

**Willie Paxton**

One of the things we did want was a crisis service. Because it was very much any treatment availability was 9-5 and nothing at the weekend and the CPN's didn't cover the weekends either and we were saying, 'look...are you not allowed to have a crisis between 5pm on a Friday and 9 o'clock on a Monday?' **Anne Bardsley**

If I go back to the Castle Group days, what we thought would help us and something very loosely approaching the crisis centre was something we all had, it wasn't properly formed in our heads but it was something we knew we wanted. **Adrienne Sinclair Chalmers**

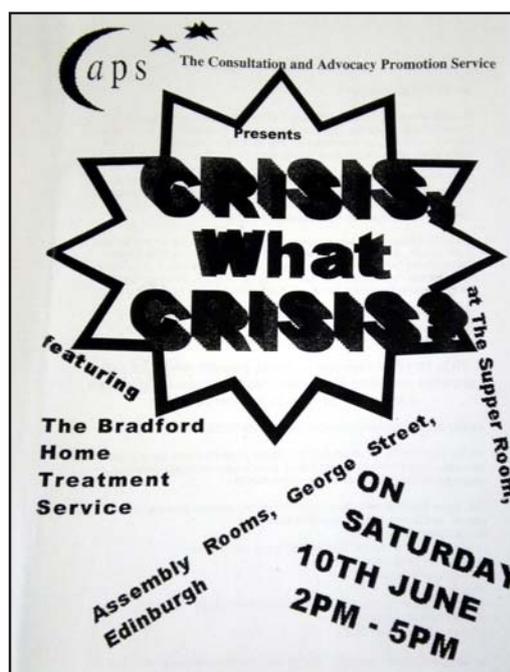
They couldn't get it into their heads that when service users say crisis they don't mean blue lights job at two o'clock in the morning they mean a stage before that and it was just like bashing your head against a brick wall and you tell them until you're blue, blue in the face. **Adrienne Sinclair Chalmers**



I think the other thing that stands out is the sense of frustration. I can't think about the Crisis Centres campaign without feeling a sense of frustration at the length of time it took and the number of obstacles that were put in the way. **Allison**

We met with quite a bit of resistance; I remember we met with a psychiatrist who basically said 'But how would they cope if someone came and they were drunk and they had an axe with them?' Well, I remember thinking, why are we having this conversation? Presumably if someone is drunk and turns up with an axe at the Royal Edinburgh Hospital they have to deal with it. In the same way you would deal with it if you were in Lothian Road on a Friday night, and you met somebody who was drunk and they had an axe with them. **Allison**

Yes, the Crisis Centre campaign went on for at least 17 years from the actual thinking of 'We need a crisis centre' to the day I actually stood in the Crisis Centre and they pulled the plaque over, so it was a long hard fight. We did lots of things - we were sending leaflets telling them how much we need a crisis centre. We just wouldn't let it go. **Maggie Keppie**



Well nothing moves fast in politics or in health. I think the constant pressure that EUF put and other people in Edinburgh put on, that's what swung it. **Maggie Keppie**

People were very clear from the mid-nineties exactly what they wanted to see and how that could happen. When there was a stage that there was real possibility of some money coming through from the Act, Crisis Services were being put on the agenda through a great deal of political nous through the users forum.

**Christina Naismith**



But something like that's just going to get hijacked. The ideal way of doing it would be to have some sort of '70s hippy commune type nonsense and that's not going to happen anymore. **Jonathan**

Aye so it's quite a major thing, I'm sure it will save quite a lot of lives. **Alistair**

I think people would celebrate the fact that EUF and the user movement got the Crisis Centre. I'm not so sure about that. I think they waited a long time to get it. That was where it had an influence and that's where it was really helpful but then it got taken over. And yeah the users forums sit round that table but I'm not sure how much influence they really have, because at the time I also sat on that group for a while but I just got frustrated with it. **Les**

I suppose it linked to the whole sense that mental health wasn't just a medical issue and shouldn't just be based on a medical model. **Malcolm Chisolm MSP**

*I thought it was a tremendous testament, more than anything else to the patience of service users. They just kept plugging away.*

**Willie Paxton**

It was like a dripping tap, like Chinese water torture for both sides. A consultant was heard to say at a meeting 'Oh let them have their crisis centre, it'll be shut in a year and then they'll shut up about it!' **Adrienne Sinclair Chalmers**

Malcolm Chisholm was invited to numerous Edinburgh User Forum meetings mainly around the Crisis Centre agenda. So when he then became the minister for Health and Community Care he was very sympathetic to the case that was being made by the mental health service user movement. **Keith Maloney**

# Compassion needed in face of despair



**Malcolm Chisholm** says providing a mental health Crisis Service in Edinburgh will save lives and reduce the burden on hospitals

**H**OW many of us have faced an overwhelming crisis - with no prospect of help at hand? The following poignant words from one of my constituents graphically illustrate the feelings of despair that some people suffer.

"It's mainly to do with an overwhelming feeling of desperate misery that you need someone else to pull you out of it. For me it usually gets bad at night and the later it gets the bigger the crisis becomes. You sit there running through all the people in your mind that you can't phone.

"You get to the point when you are sitting there at 3am with 100 paracetamols whizzed up in a blender because you know if you swallow them while you wait for them up before you get poisoned enough.

"You end up biting yourself you can survive another five minutes and, if

because this is one subject that people have raised with me time and again both as a constituency representative and as honorary president of the Edinburgh Mental Health Users Forum.

But those words from my constituent make the case for Crisis Services far more compelling than I could

someone's home, and a safe place to go, otherwise known as a crisis centre.

The phone-line would aim to provide information and support to callers. Functioning as a gatekeeping mechanism for the other two elements, a single number for the whole of Loth-

residential and medical support would be available if necessary.

Crisis Services are not there just to prevent people from killing themselves, although we have to ask in advance how many lives could be saved if these services had been in place. They would also help many people who are in extreme situations and many who would otherwise end up in hospital.

Indeed, people who have used Crisis Services in Birmingham in England argue that not only do they provide a better service to the people who need them but that they are a money saver because of the reduction in number of beds that are needed in psychiatric units.

I

It reminds me of several letters received not too long ago in relation to a superb example of a mental health project in my constituency was under threat. "It's the Royal Edinburgh if it wasn't this project," more than one person wrote. One woman even told me it was a death sentence.

A central part of mental health care is involvement of users in

Edinburgh Evening News

Certainly our feedback from the Intensive Home Treatment Team is that this service has prevented people going into hospital. It's provided something that wasn't there before, that people have found useful, so prevented a deterioration in mental health which is great because that's a key reason for us being here. **Jacquie Nicolson**



I think it takes a great deal of commitment, enthusiasm and energy, and skill, and I don't always think that is recognised but I think in the partnership group it has been recognised and that's one of the great benefits of having CAPS supporting EUF. It's been a lot of work for users and they could have quite easily got quite exhausted with it as well and I think CAPS' involvement has helped keep the momentum, keeping people involved and supported. **Jacque Nicolson**



## CAMPAIGNING FOR ADVOCACY AND GETTING ADVOCACY INTO THE MENTAL HEALTH ACT

Individual advocacy in Edinburgh, East Lothian and Midlothian came as a result of campaigning by the service user movement. Later there was the work around the review of the 1984 Mental Health Act. Lothian service users were involved in giving evidence to the Millan Committee and pushed for the right to independent advocacy being named in the new legislation.

*I think the movement was very important in terms of advocacy getting written into the legislation.*

**Malcolm Chisholm MSP**

When I first came to CAPS in 1997 in Edinburgh there was only CAPS and a very, very young Advocard that had been around for a couple of years and only worked in the North East of Edinburgh. Over the next 10 years I watched advocacy becoming more and more rooted in the Lothians. CAPS were instrumental in establishing individual advocacy in East Lothian and also in Midlothian as well, so really it's been gradual haul over 10 years up until about 2005 and the final stage in that was the Mental Health Act. **Keith Maloney**

The movement bombarded politicians, it bombarded human rights campaigners, I mean it literally bombarded everybody, it had to. And the day that got enshrined in law, it wasn't a won battle. I don't think the battle is ever won, it is always a continuous battle but the users won that particular war. **Anne Bardsley**

I went to the Health Committee and I gave evidence to them and one thing that really bugged me was that at that time any relative in your family could sign you into hospital, but now in the new mental health act it has to be a doctor, two doctors or a doctor and a mental health officer. OK my family can still go to my shrink and say 'I don't think Maggie's too well' but it's the shrinks' decision or the mental health officers' decision which is a big thing for me. **Maggie Keppie**

We have the distinction of having the only two guide dogs ever to be in front of the Scottish Parliament. Adrienne was giving evidence and she stood up and said, 'We'd like it noted this is the first time there has been two guide dogs in the Scottish Parliament, one on the floor and one up in the gallery'. I must admit we were treated like Royalty. They had to get searched and all that, not us. We just sailed through the whole system. So they treated us very well. The other thing is it's actually written in the minutes, the actual names! Poppy and Zeus. **Dot**



**Poppy, one of the first guide dogs to enter the Scottish Parliament**



I think a lot of people did a lot of work round and about the mental health act, not least service users in Edinburgh and it meant that we got the right to individual advocacy in the mental health act and collective advocacy and that's the first time that ever happened in the world. **Adrienne Sinclair Chalmers**

I was one of the people that was involved in the campaigning and giving evidence and pressurising for there to be a big inclusion of advocacy in the legislation itself which eventually led to us having a right of access to independent advocacy. It was a really, really difficult battle to actually get that right of access to independent advocacy in there because people the lawyers were saying you can't put 'a right' of it to anything in legislation and were very reluctant. **Shaun McNeil**

EUJ provided written and oral evidence. I remember Maggie Keppie in particular, Willie Twyman, going along to the Scottish Parliament and saying this is what our concerns are about from the perspective of people who use services. **Anne O'Donnell**

So there was a kind of driver for change in the Mental Health Act, service users were part of that drive for change. Advocacy was something else that was happening at the time. It was way back in 1997 that the very first guide to advocacy was published in what was then the Scottish Office and the support for the development of advocacy, advocacy for all groups in society was moving parallel to the review of the Mental Health Act. People like Malcolm Chisholm who was the then minister for Health and Community Care was absolutely instrumental in all this. **Keith Maloney**

So we found ourselves on the Millan Committee and I think that without our involvement there we wouldn't have had anything on advocacy in the Act. So that's why I say it's important that service users are involved at all levels to influence the debate, to influence the outcome, and that was an important two years in my life. **Jim Kiddie**

## CLOSURE OF BANGOUR VILLAGE HOSPITAL, WEST LoTHIAN

Many people interviewed talked of the closure of Bangour Village Hospital as a significant landmark in the history of the West Lothian movement. Service users were involved in befriending long-stay patients and preparing them for the move.



An aerial view of Bangour Village Hospital, photo courtesy of MHAP

Service users developed a kind of volunteering group that visited people in Bangour and befriended people in the hospital and discussed care in the community from their perspective. They're still involved in working with service users and visiting service users who were long-term people in Bangour Village Hospital.

**Kathy Hamilton**

These men, some of them had been in hospital for 30 or 40 years. I think it was in November or December and I went into this gentleman's flat at about six or seven in the evening and he was sitting in darkness and he was totally freezing. Of course you don't appreciate that when you are in a ward, you don't have control of the light switch and you don't have control of the heating. We just thought we need to emphasise to this chap, its up to you when you want the light on and the light off. It's up to you what temperature you have, if you want to open or close the windows that's OK. It was just a real stark illustration of the change that was made and while it's still something that's positive and empowering for the individual, yes it's great, but people need to be aware of those choices and need to know how to utilise those choices. **Shaun McNeil**

I think things generally do progress, I think we had a big risk with care in the community just being care on the cheap and I think there was a lot to fight over. **Chris Galbraith**

*...you don't appreciate that when you are in a ward, you don't have control of the light switch and you don't have control of the heating...*

**Shaun McNeil**

I think that the service user movement in West Lothian was growing in number and confidence and I think having that involvement in the reprovioning and having some of those small successes made service users locally think 'well maybe sometimes we are listened to and maybe my views can have some influence'. People's views do count and your view as a service user may be equally as important as the view of the nurses locally or the view of the doctors.

**Shaun McNeil**

I think both patients and staff felt it actually reduced stigma being in part of a general hospital and then of course in the case here, in the centre of a general hospital rather than being in a more isolated environment. **Dr James Hendry**

*Generations of people had worked there... Generations of people had been in and out as well.*

**Anon**

They [the grounds at Bangour] were absolutely beautiful. You could walk for miles and you could be by yourself if you were feeling everything was too much for you. You could go into the woods to take time out. The likes of St John's all that you've got is a car park to walk around. **Kenny**

The big, big issue at that time, was it had already been agreed that Bangour Village Hospital would shut and that the new unit would open at St John's, the new hospital in Livingston. Feelings ran very, very high about that. Generations of people had worked there, people knew the staff. Generations of people had been in and out as well. So everybody felt that from that point forward it was bound to be worse and that it wouldn't be familiar and it wouldn't be nice and it wouldn't be peaceful. It would be in the middle of Livingston ugh... Even people who came from Livingston said 'Ugh, we don't want to be in the middle of Livingston, stuck in a horrid modern building'. **Anon**

I always remember one guy saying to me there's nothing more distressing than being distressed in a public place. He'd been detained or brought by police through the front entrances of a general hospital to get into the secure acute wards. So again it was looking at things like access. **Chris Galbraith**

There were quite a few service users who just went straight from Bangour over here into like IPCU and the rehab ward, ward 2. I think the main thing would have been the restriction of it, because in Bangour it was a village basically. Folk had the run of the place, they could go out and walk in the grounds and go to the shop. It was actually a lovely place to be. To go from that to a general hospital where you're very restricted in what you can do. Basically people can have a wee walk round the hospital or they can go to the garage to buy whatever but that's about it. **Julia McCafferty**

*You could get a cup of tea in the shop in Bangour Village for 5p but when we moved over to St John's it cost 60p a cup.*

**Kenny**

Being in what's supposedly a rehab ward and expecting to be rehabilitated if you like but coming over to the same conditions, things like meals at the same time, you can't go and help yourself to a cup of tea or coffee, your cigarettes are kept by the staff and they're handed out, you know, that kind of thing. So I think that was a big challenge for people because they expected it to be different and it wasn't really. **Julia McCafferty**

I think there's no doubt that for people requiring a more acute period of care, I think having access to the full range of services, medical services, investigative services, A&E's occasionally, I think is a huge help. People recognising that they are coming in to exactly the same building with a mental illness as people with a physical illness. I think that's very positive. And as I've said before I think the way in which everyone, all staff at St John's Hospital welcomed us, made a big difference. **Dr James Hendry**



## ACHIEVEMENTS OF THE MOVEMENT

Crisis centre, the right to access advocacy, the right to be involved in where you stay, the right to be involved in the kind of day services that you use, the right to have a care plan that's around the whole of your life and the right to have a support worker who listens to what you're saying. I think all of these things are major achievements of the user movement. Also to have a seat at the planning table is really massive, and not only to have a seat but to have a seat that's important, not just a tokenistic seat. People, I think, listen to what service users are saying, take heed of what we're saying and that would be a major achievement from the early days of the user movement. **Jim McGill**

*I think the main achievement of the early days was the creation of Advocard.*

**Adrienne Sinclair Chalmers**

The main achievement, I'd say there's been quite a few. It's hard to say the main one. I'd say change, change for the better. Change, being listened to, being heard, advocacy enshrined in law changing of the Mental Health Act. Having an actual recognised user movement. **Anne Bardsley**

It's difficult to say what is an achievement because sometimes if you achieve something but you're on the wrong path I'd like to be upbeat about this but I'm not, so I'll just be brutal about it. **Jonathan**

One in particular which always stands out and I usually get very emotional about this, but we had a corridor patient, as they were called, but this particular patient couldn't read, couldn't write, he was maintained in the community on a drug called Redeptin.

One day he was in tears in the corridor and spoke to me and said, 'Jim, I've just been told by my CPN that Smithkline Beecham have decided to stop this drug and I don't know what I'm going to do.'

So the Patients' Council took up that cause and we went through all sorts of hoops, we went as far as the health minister of the day, we met Malcolm Rifkind, we met so many people, we met Nigel Griffiths the local MP and ultimately we were getting nowhere. We decided to go to the press and I went to Scotland on Sunday and the next weekend there was a two page spread.

Now what multinational companies don't like is bad publicity. On the Monday I had a telephone call from the managing director of Smithkline Beecham in Geneva, assuring me that this drug would be continued on a named patient basis.

Now several hundred people throughout Scotland benefited from that. Now that's one of our major triumphs. There's a nice end to the story and this is where I get very emotional because Nigel Griffiths sent this patient a letter congratulating him on what he had done on behalf of others.

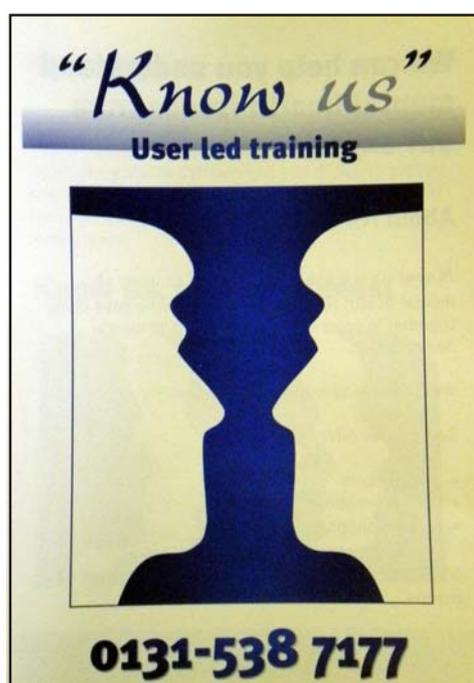
Now he couldn't read the letter so I had to read it to him, but he got it framed and it was kept above his bed and I think isn't that what life is all about, you know, I mean trying to do something for the most vulnerable people who deserve to be heard.

**Jim Kiddie**

I think for example CAPS itself is a massive achievement and I think Advocard is a tremendous achievement, I think Advocard have really genuinely made a massive difference to people's lives. You probably get them taken for granted now as they're part of the landscape. For a long time there was nothing really like that for people.

**Willie Paxton**

I think maybe when I was there one of the main achievements was probably the setting up of Know Us [Service user training branch of Edinburgh Users Forum]. **Karen MacDonald**



I think there is that sense that through having a consistent user movement that's vocal and also starts to develop credibility. It changes the statutory services. It changes the big providers and I know that's done on a constant basis and I really appreciate the kind of energy level that requires. **Akin**



Going back a bit, because I'd been going through the rehab service, I felt that patients should not be locked out of their rooms during the day, and that was very much part of a campaign. We achieved the fact that they wouldn't be any longer. **Pat W**

I genuinely think that the user movement in Lothian has made a massive difference to individual people who have mental health problems in their lives. In the really core stuff around how they interact with the people responsible for treating them, or housing them or providing them with other services and the difficulties they can get into, I think they've made a massive difference, and I think that's a really important achievement. I think they have also had a really significant influence on how services have been shaped and you know how they are delivered and they're how they are managed in an ongoing way. And I think these are tremendous achievements given where things were. I think you could look back and say it's been well worthwhile and it's been a significant achievement.

**Willie Paxton**

*So I think that Lothian has had a key part to play in setting an example to the rest of Scotland in how things could be done.*

**Jim Kiddie**

From our own point of view on the Patients' Council we frequently get items in the Evening News so we've got public recognition for the work we've done and also for bringing mental health services into the public arena has been important. Showing that people can live in the community with mental health problems or illnesses and you know that we don't need to be locked away or ignored. It's possible to live with symptoms of quite severe and enduring mental health problems. **Pat W**

## Fast Track

Now, Fast Track is something that if you get discharged from a unit or from hospital, you can phone one number and for the next 2 years you can get back into the system. It saves a lot of time... that took a long time to get off the ground. It's made a big difference because they know it's there, you know, and they know it's not just there for the next 3 months or something; it's actually there for 2 years.

**Gordon Mackay**

## Service User-led Research

The poster features a blue rounded rectangle at the top with the text 'Much More Than A Label'. Below this is a white box with the heading 'Just a phrase?' and the question 'Would you like to have your say about information and support for people with personality disorder?'. The main text of the poster states: 'From mid-April until the 30th June 2009 we would like to speak to anyone who has experience of personality disorder. We want to know your views about what is helpful and what is not helpful when getting treatment for personality disorder.' Contact information for Naomi at CAPS is provided: '0131 538 7177 — ask for Naomi' and 'naomi@capsadvocacy.org'. Logos for CAPS (independent advocacy), NHS Lothian, and funding information are at the bottom.

**Poster from service user led research project to develop a Personality Disorder toolkit**

Quite a lot of the interviewees have said the fact that this is being done by someone else with the same diagnosis has made me more likely to take part, it's not this kind of paper exercise of professionals, it's made it a lot more real and they're very positive about that fact.

**Naomi Salisbury**

## Crisis Services in Edinburgh

The Crisis Centre, finally after how many years? Twenty? It's a great thing. That's a really tangible outcome. That's one of the things that got talked about right back in the early days, we need asylum in the proper sense of the word. A safe place of refuge. **Colin Murray**

*It's phenomenal. To actually have a Crisis Service within Edinburgh is a tremendous achievement to the movement.*

**Pat**

Well I think the Crisis Centre obviously was a success. I think that the movement towards the home treatment teams as well, the idea of that was something that was very much supported by them as well. But maybe the Crisis Centre was the biggest success.

**Malcolm Chisholm MSP**

To have survived and grown I think is a big achievement in itself in the climate that we have had. I remember right at the very start being told that it's something called a Crisis Centre and being given an evaluation of the need for that and I was hugely impressed when a good 10 or 12 years after that the crisis service came into being. And I think that's evidence of the clarity and vision that CAPS and EUF and the other user movement have displayed. They saw early on that this was one of the big changes they wanted to see in service provision and they held on to that and they didn't let it go, and they made it happen, I think that was hugely impressive. **John Bonnar**



I think certainly the Crisis Centre was an achievement and I know there are a lot of negativity to a service like this but I think through campaigning through research, putting together the argument for this type of service, and then being very involved in the development of it, I think that's helped. Hopefully it's helped the movement as well, service users have got what they've argued for and hopefully that gives them something to feel proud about, that they've achieved a service that they fought for for a long time. **Jacquie Nicolson**

*I'm smiling here because my own view is it is very, very, very largely down to the user movement that we have a Crisis Centre.*

**Fiona Macdonald**

The willingness to engage with things that are difficult and people know there isn't any one answer and people are willing to persist with that, one example is the Crisis Centre. I'm smiling here because my own view is it is very, very, very largely down to the user movement that we have a Crisis Centre. The support for that was ongoing for a long time and there were allies who held that and the people with the power to make decisions. I imagine that most people would say at that latter stage of decision making, the holding of that is very much to do with the user movement. **Fiona MacDonald**

## Seat at the Table

Having a seat round the table but I think it's more than just the collective advocacy groups that have managed to achieve that. I think that's also come from providers, from policy makers. So I don't know. But people do have a seat around the table. I certainly think from my time with the Patients' Council, we earned that seat at that table. I felt that we were listened to. **Les**

I think it is an achievement that now service users are involved and the fact that organisations like CAPS, and EUF and the Patients' Council and other organisations are inundated with requests either to go and speak to groups or to be involved in things is a positive thing. **Allison**

*Well the fact that The Patients'  
Council is here and it's eventually  
being listened to.*  
**Albert Nicolson**

I suppose the good thing is that service users are very much at the table and valued for what they have to say and are able to draw on all manner of experiences and still make a commentary on things, and refer back and make things better and actually offer amazing insights to people who simply haven't had that particular set of experiences. So I think the impact has been profound, at one stage they wouldn't be there. **Christina Naismith**



I think the growing strength is an achievement, that more people feel that they have a right to be heard and can express that right to be heard both individually but also collectively. **Jane Rubens**

We have managers, we have the Care Commission, we have quite a few voluntary bodies as well as from the private sector, nurses and doctors that come to the Patients' Council to actually hear the response of the Patients' Council acting on behalf of the patient. **Kate**

*You can't keep people voiceless here.*  
**Ruth Rooney**

It's taken as read that the service users voice has to be heard and involved now before any decision making is taken. I think people in hospital have more access to advocacy and folk can't make quite such sweeping decisions as they could before. That's grown into being included in the Mental Health Act and that's all come from the user movement. I think that's a major, major achievement. The users have swayed public opinion hugely. **Be Morris**

Well I think the biggest one is now we have the choice, we actually help to employ nurses because we sit on the recruitment panels with NHS Lothian and West Lothian Council. **Kenny**

I think that's to do with Patients' Council helping to change attitudes. You can't keep people voiceless here. **Ruth Rooney**

## **The Mental Health Act (Care and Treatment) (Scotland) Act 2003**

The day it all became a reality and the day I then thought 'My work is done for now' is the day advocacy became enshrined in law. I was the first national advocate but I won't be the last. **Anne Bardsley**

*The proudest thing that I have is the Mental Health Act because it doesn't only affect Patients' Council, Edinburgh Users Forum, it affects everybody in Scotland and not only now but in the future as well.*

**Maggie Keppie**

One of the main achievements of CAPS and EUF and the user movement in general was getting advocacy into the Mental Health Act. We put a lot of work into that. At one stage it wasn't going to be in the act directly. I can't remember who it was but one of the MSPs said 'oh it'll be understood to be in the act because of the principles'. I wasn't involved much at the time, but the people who were involved were saying 'no that's not good enough, we want it in the act'. And what went in the act was the best possible way of putting it in, and that was a huge achievement, and EUF played a huge part in that. **Anne O'Donnell**

Getting advocacy into the new Mental Health Act as something that every service user has a right to access, I would say that was the most important achievement of the service user movement. **Alistair**



I do think the Mental Health Act 2003, the fact of there being people on the Millan Committee who had experience of using services and then were involved in the debate about how the Act should be framed. I think that was just wonderful, fantastic. Although the Act's maybe not perfect, I think it's really positive legislation. It's quite forward thinking legislation and that's why advocacy is in it, I think, because service users raised the whole thing about advocacy and why that would be worthwhile being in the Act. **Jane Rubens**

It seems to me that the whole concept of advocacy has been embraced certainly in Edinburgh and the East of Scotland. The concept has been embraced, and welcomed and strengthened and valued and while that in part comes out of government policy, you could also say that's a testament to the work that's been done and that's a real achievement. **John Bonnar**

*Getting advocacy into the new Mental Health Act as something that every service user has a right to access.*  
**Alistair**

I think it's probably been when we had the Millan Report for the Mental Health Act coming in to play, we did a lot of work on that ... which we found really quite effective because we felt that service users were being listened to at the time when they were starting to put the Act together. Then of course we had the Act came out in 2003 and the service users in general felt that they had quite a big input into the Act being put together. So I think that's probably our biggest achievement. **Julia McCafferty**

## Bangour Village Hospital, West Lothian

*I think the service user movement had  
a major influence...*

**Shaun McNeil**

Well I hope we made the Bangour closure and move a bit easier. I think for me looking back it was just getting advocacy recognised and accepted that it was a legitimate. I hope we've championed and supported the good practice and we've highlighted bad practice and hopefully eliminated as much bad as possible. I think that's probably the main thing, just, having it there, having it accepted.

**Chris Galbraith**

I think definitely some of the achievements were influencing the way the reprovisioning was done in terms of making that as best as it could be for many of the people who had been in Bangour Village Hospital for a long period of time. I think the service user movement had a major influence in that area. **Shaun McNeil**

I find it very hard to say that there has been one single achievement. I think that it is that there has been a very clear voice of service users and I think it's generally taken account of and I think it has a reasonably high profile through the Mental Health Forum which has helped to collate views. I think that the active involvement of service users in patients moving on from Bangour Village Hospital to the community has been exceedingly positive. **Dr James Hendry**



## SERVICE USER DEVELOPED SERVICES

A significant achievement of the user movement was campaigning for increased individual advocacy. For example members of the Castle Group were responsible for setting up Advocard.

Also, we see the how influential service users have been in the development of community based services such as PROP – Pilton Reach Out Project.

### Advocard

*One thing I remember is answering  
the phone and someone asking,  
'Hello is that Applecart?'*  
**Karen Anderson**

That's when the Mental Illness Specific Grant as it was known as then had come on stream and people were acknowledging the need for advocacy. Sometimes it's the right time for something - service users wanted it, the professionals were receptive to it and the funders were willing to fund it. It was a really opportune time, it just seemed to be right at the time. **Lami Mulvey**

Anne Bardsley had gone to a Mind conference in London and had heard about crisis cards. So she came back and did a presentation to the Castle Group members about this idea and they felt it was such a good idea they wanted to have something similar here in Edinburgh. So a group of people from the Castle Group put in an application to Lothian Regional Council for funds to start up this project. So that was where Advocard came from. **Karen Anderson**

The original project was a tiny project, supposed to be a pilot project just working in the north east of Edinburgh, so 3 part time workers doing half a week each, so 18 hours each. **Karen Anderson**



**Advocard Office**

As I remember Lambeth Link cards, they more or less just gave them out to service users and you gave them to your pair, somebody you found to represent you. The idea was that if you were in a crisis you could hand this card over to a professional and say this is who you can contact to help me out. Well Adrienne and Maggie and everybody, I think they were a bit horrified by the fact that there was no support for those people that are doing advocacy or no training. I think they could see from a very early stage how you needed a good infrastructure of your organisation. **Karen Anderson**



And the Castle Group itself started getting interested in the whole concept of mental health advocacy and that was the beginnings of the thinking that led to the development of the establishment of Advocard. **Lami Mulvey**

We started in a very tiny office in East Norton Place, just a few doors along from the Castle Group premises of the time which was very, very tiny - a single room with a toilet and a washbasin.  
**Karen Anderson**

*Hello, is that Advocaat? Wasn't that a drink?*  
**Jane Rubens**

My favourite story was when there was a consultant psychiatrist with a lot of influence who was very, very in favour of Advocard and advocacy and helped it probably get its funding. But one of the first people who happened to need advocacy was a service user who wanted to bring an advocate to see *him* and it was absolutely... 'Why do you need Advocard? Haven't we got a good doctor/patient relationship?' So it demonstrated the difficulties around that.  
**John MacDonald**

'Hello, is that Advocaat?' Wasn't that a drink? We used to get that all the time at the very beginning and people wouldn't quite know what Advocard was all about and perhaps some still don't.  
**Jane Rubens**

Certainly not everybody at the hospital was on board to begin with I would say, there were some doctors who were very resistant, and nurses. We did have occasions with doctors refusing to see a person if they had an advocacy worker with them, that happened more than once. 'We're doing that, why would you need to have anybody else come in to do that?' **Karen Anderson**

## Prop Stress Centre – a service user developed service

*It was very, very much their place. Anne*

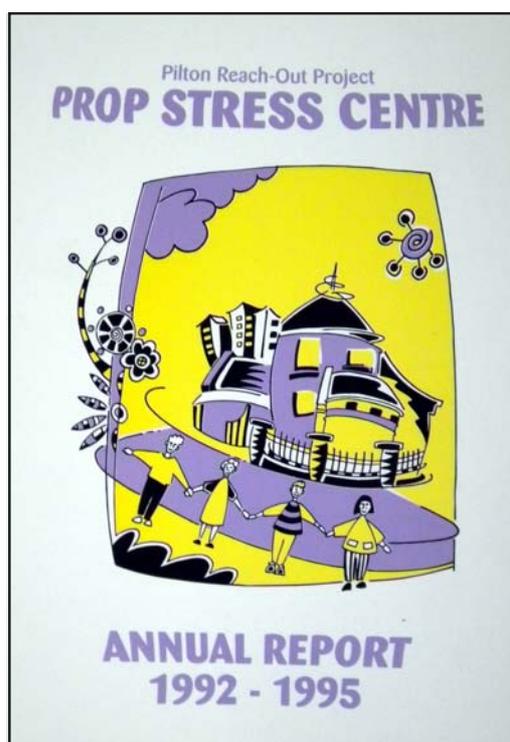
It must have been about 25 years ago, there was a women's group running at Royston Wardieburn community centre. Quite a few of the women had also been on tranquilisers so there was quite a lot of talk about that. So we said, right okay well obviously we're not the only ones in the area. At that point Jane was the one that had all the confidence because we certainly didn't have the confidence. She said, "Right, what we'll do is we'll leaflet the whole area and we'll have a phone in, we'll ... man the phones." So we leafleted the whole of Royston, Wardieburn, Granton. We arranged that people could phone in. We probably had maybe 8 or 10 phone calls which was really good because it's a big step for anybody to take.

The two end houses were used for janitors and the middle house had been used by the school for domestic science but obviously rooms were free at night. Jane somehow managed to persuade them to let us have the house, which was good, 2 nights a week just for a couple of hours. So we started off like that.

We were getting bigger and the two hours a night weren't enough and we needed more room. So Jane had had the idea of applying for Urban Aid. Miracles of miracles she managed to get money. So this building here was actually purpose built, it was what the members wanted. They wanted a fireplace because unfortunately some people had had bad experiences with hospitals and they wanted something that was a bit more homely and that did not feel threatening. They've still got the fireplace, they picked the colour of the carpets, what colours they wanted the walls painted, everything, so it was very, very much their place.

When people were moving from like the middle house and across we actually made a wish for the centre, the member's wishes and the workers wishes for the stress centre. It went in between the bricks. I put it in there, it was like a time capsule.

For the opening we made the cake in the shape of the building. I'm no a very good baker but we had to make it all and measure it all and make it. But it was absolutely brilliant and just gradually getting people just to feel safe and own the building because it was very, very much member led. **Anne**



So the stigma...was sort of broken down and people would think, oh my mum goes there or my dad goes there or my aunty or my uncle goes there and that and it's actually okay, you know.

**Anne**

There were two things happening in parallel I think. One was around the concern of over-prescribing tranquilizers and one was around this mighty structure in the Royal Ed. People got chucked in, chose to go in or got told to go in. And then when one day somebody said, that's fine – you don't need to be here anymore, cheerio, no bus fare, no contact with family if indeed there was any family, no contact with GPs, carers or nothing and it's a good hour or two hours walk to get back to Pilton or Granton or Royston. So local people were very concerned about that. **Anon**

## WHAT COULD HAVE BEEN DONE DIFFERENTLY?

*My biggest worry about the user movement in Scotland as a whole is that we haven't been radical enough.*

**Allison**

I can't remember a time without conflict, some of which was very difficult for people. I would love to think, as a user movement we can learn from that. **Fiona Macdonald**

The conflicts and tensions in the movement were the same as in any movement, though for people in the service user movement they could create real alarm. There were tensions where people thought we all have to stay together, there were tensions when some people thought 'no we don't'. Some people were totally anti-medication and some people were totally for. Some people were totally anti-psychiatry, some people were totally for. So huge differences of opinion. **Be Morris**

*A lot of people come to a user group because it's somewhere to go, it's a cup of tea and that's great, but that should be afterwards. So, yeah, it's like herding kittens.*

**Jonathan**

Quite a bit of fear was around. People often felt they needed to be extremely brave because they were very worried that if they became unwell and went into hospital they would be treated differently. If their voice had been up above the parapet, being too critical. So it took a great deal of bravery for an awful lot of people to speak out.

**Be Morris**



As the movement grew there could have been an argument maybe it should have split into more, you know, the women's branch or the black and minority ethnic branch or the anti-psychiatry branch or whatever, rather than it constantly trying to hold together with these tensions. I think there was a lot of difficulty in accommodating all those different voices and all those different standpoints. **Be Morris**

I think it's been inclusive to the people who have presented themselves generally and it's been exclusive because certain people have been in it who have manipulated situations, who have used an accessible policy to behave badly and to create problems and to have a venue to be tossers. **Jonathan**

I wasn't welcomed, I wasn't part of it. There seemed to be this group of people who all knew each other and they had their 'in' conversations and I felt ostracised. You are there for a meeting to be inclusive, not to have your matey conversations. They might welcome me and say hello and everything; but it was 'until you're part of the in crowd you're not part of this'. **Les**

I think a lot of people who used mental health services believed and thought they couldn't change anything themselves or collectively. **Anne O'Donnell**

The tension that made me despair a lot in the latter stages of the user movement was that I feel that advocacy and some parts of the user movement were professionalised. I think early stages it was very much controlled by the user, very much led by the user, very much owned by the user and that's important, it's still a value that I hold dearly, that it should still be. **Jeff**

*I felt worn out, not listened to and unappreciated. That's why I left. It was too difficult not being supported and not being appreciated. It kind of put me off the user movement, it certainly did. LR*

You reprovise a hospital and you're going to get 101 views on what should happen, what shouldn't happen. You can never represent everyone's views and there'll be arguments about whether you should represent anything because you can't represent everyone's views and therefore you should just say 'here's all the different views and you make up your mind'. **Chris Galbraith**

I think we could have looked after each other and ourselves a lot better. Because people were very impassioned by it, I think they could be intolerant about people who didn't quite see things the way we did and there was some personality conflicts and I wish we'd handled them a lot better. That was in the late '90's. I remember at the start being impressed by the sense of community and solidarity, but I don't know if that was me being idealistic and finding a space where I felt safe or whether it was there and it got diluted by increased demands and the differences that can arise when people work together. **Anne O'Donnell**

*I think we could have looked after each other and ourselves a lot better.*  
**Anne O'Donnell**

I would like the benefit of having the opportunity to meet with some people who share a similar experience but not for it to take over my life. I just fear that sometimes I got frustrated with services or places where people meet. It's just that people are stuck or they are quite happy in a certain place but I don't feel part of that. I want something more, I want something different and I can't get it there and I don't know where to get it. **Les**

*Aye, psychiatry could have been a lot more open. If psychiatry had got off their damn high horse and heard what folk were saying about what they do to them.*

**Colin Murray**

I think the parliament does provide a great opportunity to lobby MSPs and it's not just MSPs it's councillors as well. So perhaps lobbying a larger number of politicians, because that is going to become very important around the advocacy review, so it may be that there needs to be a bit more emphasis on that. **Malcolm Chisholm MSP**

So internally there's been difficulties and I don't think anybody could deny them or wish to deny them or fundamentally you should deny them. I think that's the nature of being human, it's the human condition and it's also part of being involved in this [movement]. Externally I think the relationships that the user movement have had with professionals and others has gone through ebbs and flows and there have been high times and low times and a lot of the time, there's been some of the times when people haven't listened to what they've been told, or they've listened and they've just ignored, or platitudes have been offered, but other times whatever you want has just been written into an act. Then your very words have been written on the page. So absolutely, highs and lows. **Christina Naismith**

What could have been done differently would have been to have given the movement more acknowledgment of what it was about. We had to fight for many years to get that acknowledgement before any funding started to become available and when you're trying to create a movement and a collective voice at the same time as having no money then that's when some of the tensions started to happen and people fell by the wayside because they just couldn't cope with the amount of work. **Jeff**

*There's no reason why the Africa Centre  
Scotland or the Pakistani Centre, or the Sikh  
Gurdwara isn't sent some of this information.*

**Akin**

When we go to the hospital reprovisioning environment meeting it's predominantly white, I'm the only one ethnic minority and it's when we were in the last meeting there was a plan for two years and this plan for a lecture on the hospital and lectures on two topics and there was nothing for ethnic minorities. There is a history of psychiatrists from different countries being trained in this hospital and there is also a history in the 1970's of people who were employed from Asia, India, Pakistan coming to work in nursing, there is a history and so we can be more inclusive, so they welcomed that, so I explored that, who could be giving a transcultural psychiatry lecture. **Rashpal Nottay**

There are also times when that the service user movement shouldn't feel too constrained to send things to certain minority ethnic communities if they exist in number. There's no reason why the Africa Centre Scotland or the Pakistani Centre, or the Sikh Gurdwara isn't sent some of this information. **Akin**

I don't know that's for me to say. I don't think it could be done differently from how it was done, because it had to evolve in the way it evolved with the people that were involved with it at the time and what their voice wanted it to be. **Be Morris**



Often when we talk about user involvement, we talk about users responding to what service providers are asking them. But the movement was different in that it was service users saying ‘This is our agenda, this is what we think is important, this is what we want. You’re saying that you listen to us and we should be involved in developing services, designing services and evaluating services, so there you go, that’s the service we want, and we’ve researched it and we’ve got the evidence so please can we have it’. And I think the amount of time it took between that kind of demand and it actually being delivered is really illustrative of how we haven’t really got there. Lots of people say ‘Oh we have user involvement’, it’s a thing now. Of course you wouldn’t set up a service now without thinking about user involvement. But when it comes to actually addressing service users agendas’ I don’t think we have got there at all. **Allison**

*I think it is very important to say that a lot of people are not involved in the user movement.*

**Fiona Macdonald**

It is like the other side of the same issue. People bring tremendous passion to the work. The huge amount of work that has been done by people on a voluntary basis is just absolutely phenomenal. Alongside that people have very, very strong feelings, so sometimes the anger that people feel can find it’s way into the discussions or become personalised and it’s very, very difficult to unpick all that when you are in the middle of trying to change things for the better. There has on a number of occasions been very challenging and difficult fall-outs for people when there has been conflict. I hope as a movement that as we mature we will learn how to handle these situations in a different way and that’s not about avoiding conflict, it’s trying to find ways through that, that we can use that energy in a positive way. And not let our own fora become a battleground for what are our own issues. **Fiona Macdonald**

## HOW INFLUENTIAL HAS THE MOVEMENT BEEN?

*Probably the main contributory factor to how services and how policy has evolved is because of the user movement being there, nipping the ankles like a wee terrier, not letting people get away with things.*

**Jeff**

Huge, enormous, I think that the mental health services in Lothian would be a pale shadow of what they are if it hadn't been for the movement. **John Bonnar**

Lot's! Without the Patients' Council, the services in the Royal Ed would be back 10 years. I think people now know to speak up when they are unhappy about something. Now there's more services getting tailor-made to service users needs. **Maggie Keppie**

I mean I'd like to say it's an all singing, all dancing service now and everybody's h-a-p-p-y and they're sweetness and light and everything's a bed of roses, but it's not. It's a lot better than it was and I think that's the impact the movement has had. There is an improvement in the way services are delivered, it's much more individual, needs led, human-oriented. There's much more consultancy and involvement and information for the patient. So in a way that's probably the main contributory factors to how the service and how the policy has evolved because of the user movement being there, nipping the ankles like a wee terrier, not letting people get away with things that were unsavoury practices, keeping at it, keeping the bit between the teeth. **Jeff**



I think there is a very real impact on the way services develop, and I think particularly in terms of some of the broader decisions that have been made. We have a Lothian-wide Mental Health Strategy that both the Health Board NHS Lothian and the Local Authority have signed up to, and there was very considerable user involvement in the development of that and in setting out the principles. There has also been a lot of discussion largely in the rest of Lothian about the future of hospital provision firstly with the future of Rosslynlee and Hermandflat Hospital and now a lot of discussions around the future of the Royal Edinburgh Hospital. I think it would be fair to say, it hasn't been the view of all service users for example that Rosslynlee and Hermandflat hospital should close. I think there probably have been some decisions taken that were probably in direct opposition to what might have been the consensus view. **Dr James Hendry**

I think the adoption by the government of campaigns such as 'See Me', '1 in 4', raising awareness in the commonality that most people are going to experience a period of mental ill-health. I think that's come from people collectively actually making that known to the officials, just saying 'look, there are so many of us saying this. There's got to be some truth in it'. **Akin**

*I think a good service is shaped by the service user. **Akin***

The longer The Patients' Council is running the more they're coming round to the fact that we've got the lived experience. So-called experts in the field have only done book learning and observation, lectures and all that; they've never actually been there at the coalface. **Albert Nicolson**

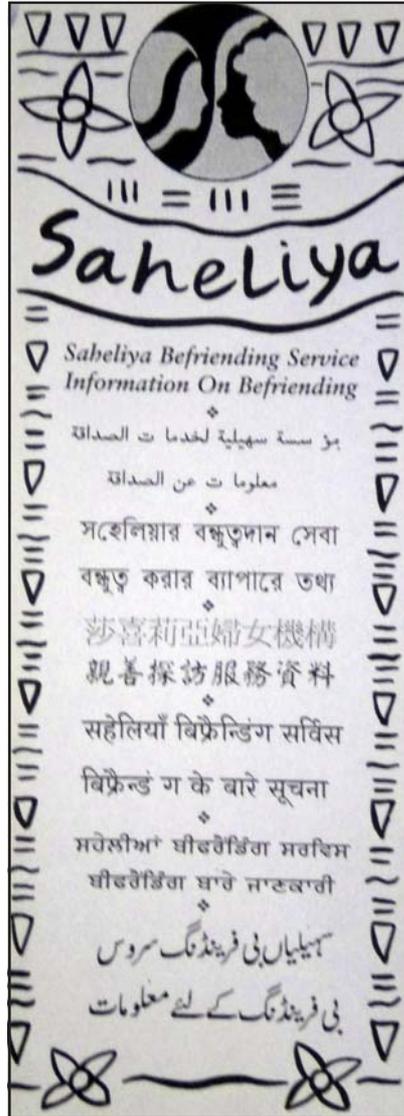
The Patients' Council also cover the Orchard Clinic and we have been able to bring about changes for the patients there. In actual fact the service that the patients receive in the Orchard is very, very good and is an example to the rest of the hospital. **Pat W**

*I think the fact there's a real bent for training that involves service users, things like recovery network is starting to open up.*  
**Naomi Salisbury**

If there are any issues where The Peer Advocacy Group feel we need to get involved like immigration or asylum seekers, we are there. We support, write letters... One of the asylum seekers was returned to Afghanistan so we wrote a letter of campaign. So we are also a campaign group in issues of mental health, wellbeing of minority ethnic groups and mothers and children. We campaign for change. We get politicians to come in to tell us about how the parliament works and we visit places to just see how the whole system works in the UK because most of the ladies who are in the Peer Advocacy Group are not from here. So we are trying to find out what's going on, what happens, influence any decision making. **Alice**

I think there are service users who I would consider to be part of the movement, part of a wider movement but they don't necessarily engage with groups such as CAPS. But actually they operate in the same spirit. **Akin**

Well I think the Patients Council has influenced [care and treatment] a great deal. I think the fact at this point in time that all service changes within the hospital always now come to involve and consult with service users and carers, means that that is now the norm, whereas 15 years ago it was the real exception. So it's kind of established collective advocacy as a way of working in partnership over change in the hospital. **Ruth Rooney**



I think we've influenced the attitudes of staff, because when The Patients' Council started going to wards sometimes we went into rooms that weren't adequate, sometimes the food wasn't actually edible and our managers had to work really hard with the team leaders of a ward. So staff have made the effort and I think the influence of the Patients' Council is quite big. We can influence the changes that can occur within a ward through regular meetings. **Kate**

I would say there's probably the beginnings of a BME movement, but again it's just a question of time or need. **Akin**

I think from a West Lothian perspective we're fairly well recognised and respected by mental health services. **Kathy Hamilton**

I think the specific things would be some of the changes to the ward with the safety privacy and dignity agenda, where they actually physically changed the wards – they put things in like a family visiting room. They opened up the nurses and instead of the nurses huddling in wee nursing stations they did away with those and made a bigger wider open area where service users can actually see the nurses and actually talk to them. **Ruth Rooney**

Well I think they've had a massive influence if you think of things like the growth of the recovery movement, the recovery network, peer support workers, Crisis Centre, all those things came out of service users saying this is a direction that will be most beneficial. I don't think that would've happened without the service user movement. It certainly wouldn't have happened in a decade. **Ruth Rooney**

The Mother and Baby Unit at St John's hospital, Livingston came about specifically as a result of the requirement in the 2003 Act, to provide a service and my understanding is that that decision was made as a result of service user pressure. **Dr James Hendry**

*I see a real change in NHS Lothian staff as well.  
It's going to take another 10 or 15 years but  
there's a recognition now that professionals need  
to change their attitudes and their values, they  
need to be working with people.*

**Keith Maloney**

Well the NHS has made it clear that they'll listen to us, they'll hear us out and then they'll simply go away and do their own thing anyway. They have absolutely total disregard for what the service users want. So, in answer to your question, service users have absolutely no say, nobody will listen to them. **Veronica Forrest**

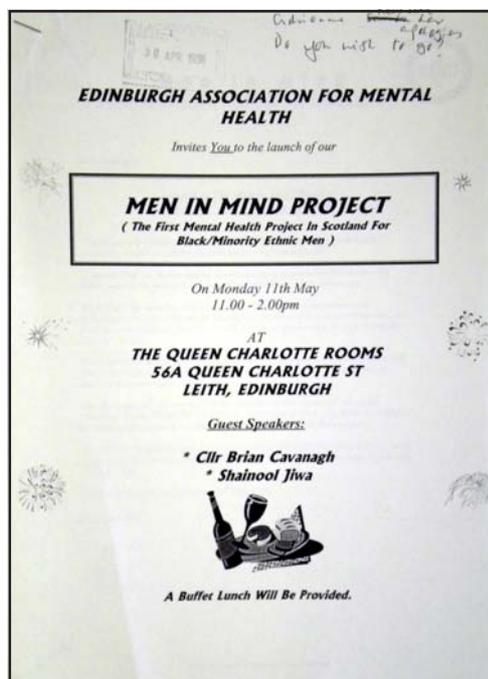
I was just one of the users to inform Men in Mind that you need this drop-in, people need it. And a few years into the future, they are doing excellent - they have a boxercise class, they go out for walks, they have an additional one or two drop-ins and they have forums. So all I can say is well done to them. Well done to the Men in Mind organisation but equally well done on me, well done to the users for forwarding and suggesting to them 'What do we want, what do we need?' **Tony Chan**



For example in Scotland we have the Scottish Recovery Network set up around 2004/5. And some of the key recovery ideas have been introduced through a national initiative where for example a lot of that grew up from the grass roots. So the drivers for that have come from different sources but the ideas have their ideas in the user movement largely. **Fiona Macdonald**

I think they've had a profound influence. The declaration of Alma Ata of 1978 The World Health Organisation said that people have a duty and responsibility to be involved in the planning and development of their local health services or words to that effect and I think organisations like PROP, Edinburgh User's Forum, the Patients' Council at Bangour, have had a huge impact on taking some of that rhetoric and making it reality. I do seriously think that. **Anon**

There was a conference which took place, the 'Who Cares Who Decides' conference. Service users shouted, 'When we go to mental health services we don't get access to early treatment but when we are in crisis we are enrolled at the Royal Edinburgh Hospital. When we go there our services are not culturally sensitive, there is no interpreter and there is no ethnic food, no spiritual care'. So these were the gaps and staff attitudes. So I came into this post in 1994, we looked at the sensitivity of the services, we looked at the dietary needs, the spiritual needs, the linguistic needs, we looked at the information needs, we looked at advocacy, we looked at service user involvement. And at that time there was a strategy under development and there was information for a booklet that we were working on and there was a 'Feeling Better' video which was translated in four different languages so we used a lot of it to empower the community or to de-stigma mental health. **Rashpal Nottay**



When you think about some of the campaigns for people to access psychological services and a range of interventions, moving beyond medication that's something else that the user movement has played a very important role in.

**Fiona Macdonald**

## HOW MUCH HAS CHANGED?

*In those days speaking to someone like that was rather like getting an audience with the King or the Queen.*

**Graham Morgan**

### The User Movement

I think the fact that the groups are still going is testament to the people that set them up and helped them keep going. **Maggie Keppie**

There's less room for the kind of people who would be saying "oh we should just knock down the hospital and we should have safe places for people" ...that kind of radical edge just seems to have been crowded out. **Anne O'Donnell**

*Oh, it's gone soft.* **Colin Murray**

We're only talking 17 or 18 years and yet we were involved in the consultation around the new Mental Health Act, we're involved in all kinds of consultation and I think that says a lot about the power of the user movement. **Jim McGill**

Oh, it's gone soft. There isn't that really radical element anywhere that's making a lot of noise, making trouble and getting itself into bother. Any kind of movement that is about this sort of change needs those different levels of it. You need the people who are going to sit down with the suits and do the nice chit-chat and try and influence things that way. You need the radical people out there giving them a kick up the bum and any kind of social change has got that - the civil rights movement in the States in the 60's, The Black Panthers. And I fear that's missing. **Colin Murray**



I think the early activists would be on the whole delighted with where the movement is today, I don't know if we could have conceived how much things would have changed for the better in such a short time. I think in the early days we probably thought that we might have been banging drums for a lot longer. I mean to see the Crisis Centre up and running is just wonderful, it's a source of inspiration I think for people, as is the new Mental Health Act and the input which service users had into that and the fact that a lot of that was taken seriously and that a lot of it is now in legislation. So from that point of view we've possibly surprised ourselves. **Jim McGill**

I think again in the early days people were saying, 'You're backing a loser, things will no change, the power imbalance is far too great and people might be tokenistic and say, yeah, yeah, yeah, but will anything ever change?' Well I think now I think things do change, I think people listen to what you've got to say. **Jim McGill**

## **Mental Health Services**

In a way the opposing forces were much clearer and hard-line then. 99% of psychiatrists said 'So what? Poor women, poor little things. They would go mad wouldn't they'. There's two generations of new people, new medical ideas come through in psychiatry and the education of doctors has been very heavily influenced by the user movement. **Anon**

Well I think it's changed for the better up to now. When I first got involved with services which was in 1994 I knew nothing about anything because there was no information about and you never heard anything about advocacy...or anything, it was just basically the hospital and that's all. **Alistair**

I would hope we've reached the point now that if somebody said to their doctor or their nurse or their social worker 'I would like to bring an advocate with me to the next time we meet' they wouldn't sort of throw their hands up in horror and refuse which is what used to happen. **Willie Paxton**

*...the education of doctors has  
been very heavily influenced by  
the user movement.*

**Anon**

I remember when Adrienne and I had started, we raised an issue with the chief psychiatrist at the Royal Ed. Firstly we were completely and utterly shocked that he agreed to see us, we found that incredible, I think it was over crisis services. Then we met him and then we went to a cafe and spent the rest of the afternoon giggling. We just couldn't believe that a psychiatrist would sit down in the same room as us and not only listen to us but agree with us and take us seriously! Nowadays you would just take it as a matter of course, but in those days speaking to someone like that was rather like getting an audience with someone like the King or the Queen. It was just completely unheard of and we just couldn't believe it was going to happen. **Graham Morgan**

I hope there is not a psychiatric hospital or a long stay department in the NHS that serves teas and coffees with the sugar or the milk in it already, that was definitely the case in Bangour Village Hospital in 1988. 'Lunacy,' they thought, 'how will we control these people?' Sharing underclothes, sharing towels, sharing facecloths, these were all the norm. One telly, STV, the majority football. **Anon**

When I think about the environment I went into in 1987 and the environment I left a dozen years later, I think they're unrecognisable. The environment I moved into, service users weren't seen as anything other than patients and clients. I think that the move away from hospital services and into community services changed the whole way they were identified and they were all of a sudden they were "service users". They were people with some autonomy, and some influence and control of their life instead of being patients and clients. I suppose that's the biggest change for me. **Lami Mulvey**

*I think we might be sitting round the table but  
still things are decided elsewhere.*

**Anne O'Donnell**

God, it's the same old same old shit that's still going on to my mind. I'm not convinced that the Royal Ed's a better place or has better practices. I think there's some things that have changed that are probably a bit better but the fundamental problems about institutions remain. I think for that to change it's going to have to come from more than the collective advocacy movement. I think on its own the movement can't achieve that sort of fundamental change.

**Colin Murray**

I ain't saying the Royal Ed is perfect 'cos it ain't. I think the difference to me is if somebody in the Royal Ed says 'Hello, hello, I'm not entirely convinced this is lickety split', 25 years ago mostly people would have gone 'up their medication,' or 'they're talking rubbish,' or 'away with the fairies,' or 'go and sit down in that corner'. Now people working in the NHS will sit down and give that person the time of day. It is quite fantastic the change really. **Anon**



I personally feel a bit disappointed in the way mental health services are going and I think we've less influence in that than I would have hoped. I think we might be sitting round the table but still things are decided elsewhere. **Anne O'Donnell**

The sad thing though was a lot of things that they were saying about privacy; safety and dignity were things people had been saying when I was an advocacy worker. And there was a good 11 year gap between when I was an advocacy worker and recent times, and that really upsets me. We are still talking about people who don't have lockable spaces to put their personal possessions, people can't get access to drinking water despite being on medication that makes them thirsty. People can't get access to a cup of tea or a cup of coffee when they want it. These were things as an advocacy worker that I battled and battled to try and secure and the Patients' Council battled and battled and they are still not happening, and this is 2009 and I find that incredible, because these are small things but they are small things that make a huge difference to people, so while I think yeah, there's been a lot of goodwill over the years between staff and Patients' Council members and there's been a lot of working together on things, I think when it actually comes to real results then at times I have been disappointed by the lack of results. **Allison**

People are talking about it more, they never used to know about Saheliya or Men in Mind. So now they talk about it, even to their GP. They never used to, so at least now it's quite comfortable for people from the minorities to speak to another person of colour. It's quite rewarding these days that at least people are getting help and the communities are getting help and the communities are moving on with better mental health awareness. **Alice**

## User Involvement

Well we haven't got lip service now, they actually listen to us, we get invited to take part in things by Lothian Health and West Lothian Council. The likes of now we've got joint training with nursing staff and users. **Kenny**

Oh there was initially a lot of resistance by staff feeling that patients should just be told what to do and just get on with it. It's actually quite hard to remember that attitude now, I think to a large extent it's gone. On the whole I think the expectation is patients have something to contribute and are much more involved than they used to be.

**Maggie M**

I think we are listened to more. I think people listen more to us than they did when we first began. At first you weren't sure if the professionals were going to be listening to us, that it wisnae going to go anywhere, just going to be a meeting and that was it. Now if you have the meetings and something's said or something's decided on, then they try to take it forward to deal with it. **Irene Rooney**

*...we need to be continually  
hammering home the point that we  
need more say in services.*

**Alistair**

I think there's less lip service about, I think people are more genuinely listened to and hopefully there seems to me to be a commitment from the services to do an awful lot more listening to what service users are saying. So I think the movement has probably influenced a heck of a lot. **Kathy Hamilton**



I think that it's come a long way since I first went to mental health services but I think there's a lot of room for improvement. I think we need to continually hammer home the point that we need more say in services and until we're listened to and until it doesnae take years for the things we're campaigning for to come about. Until it comes to the point when a group of service users say, this is what we think we need because we think this will be better for us... and then people look at it seriously rather than leaving it for years and years and years and letting somebody else come up with the idea and stealing the idea as if it was theirs. **Alistair**

*There is certainly a recognition in policy that service users should be centrally involved.*

**Malcolm Chisholm MSP**

I think the whole atmosphere has changed, I think the backdrop against which service user groups are operating now has changed, I think it's far less confrontational if you like. I think service user groups, service user representatives are much more welcomed at bigger forums now and I think they're given their rightful place, I don't think you have to battle so much. **Jim McGill**

Obviously everybody's learning through time, having a lot more experience and confidence now than what they did back then. I mean we were just... pioneering really. **Anne, PROP**

I think we probably have moved on quite a bit, even over the last 10 years. There is certainly a recognition in policy that service users should be centrally involved. I suppose the challenge is to make sure that happens in practice, but I think it has been relatively successful in Lothian but I think the fact that people came together to argue for these issues collectively, I think has been quite effective and so I think it has demonstrated collective advocacy in action. And I think in that way it has been important. **Malcolm Chisholm MSP**

Now you hear of more organisations looking for service users to join their board. Yes it's a good thing but I'm a bit suspicious, because why are you doing it now? Because the Care Commission will give you a better grading? Slightly cynical, but are you doing it well? Is it a bum on a seat or is it true involvement? **Les**

Oh dramatically, certainly in the LUF days it was very much on the outside and we were trying to make the case for user involvement, for people having a say about what happened to them individually and collectively, and now that's more or less accepted.

**Anne O'Donnell**

In some places we are further on, in other places things have stood still. I think I'd say we've got quite a good representation of advocacy in the community and in the hospital. The Patients' Council is a very good spokes-body for the hospital. I think things have stood still because half the time they are still using the same medications that we were using 20 years ago. People are still dying and still getting pretty screwed up by the side-effects. And the fact that it's 2009 and we still have lobotomies. **Maggie Keppie**

*We should be quite proud about Scotland.*

**Shaun McNeil**

When I first went to hospital you were basically just a patient and they told you how you were going to be treated and what you would do and what you wouldnae do and that was about it, but now there's a lot more say and a lot more choice. **Alistair**



We should be quite proud about Scotland, some of the articles that have been published recently have shown and demonstrated that we have been quite innovative in terms of the mental health service user movement in the UK. **Shaun McNeil**

I think it's changed in that it's taken for granted now that it's one of the voices to be heard and one of the prime voices to be heard. It probably has the biggest influence of any of the voices once it's galvanised and organised and making enough noise. Folk ain't for lying down anymore. **Be Morris**

*Folk ain't for lying down anymore.*  
**Be Morris**

I think that the difference between now and then is now we've got our own parliament. Scotland is responsible for its own health. Therefore Scotland is responsible for mental health. There is a lot more opportunities for that kind of engagement. Whereas then, there was possibly less so. **Shaun McNeil**

Well I think the culture has changed a bit. Certainly in policy terms the situation has changed and there is more recognition of the importance of advocacy but that reflects the fact that there is more recognition of the importance of involving users of the service in developing services but there is obviously a gap between policy and reality. I do think the policy and the culture have changed significantly. **Malcolm Chisholm MSP**

## WHY AND HOW I GOT INVOLVED WITH THE MOVEMENT...

In this section we hear from a selection of individuals about their journeys into the movement - what motivated service users to become involved in collective advocacy.

My main issue that I had, the biggest problem was with medication. They medicate you up regardless of what's going on or what you're trying to say because they don't have the time and they don't have the staff. So we're on the road to nowhere while you're in the Royal Edinburgh, you're on the road to nowhere. There's not enough staff and there's not enough education amongst the nurses. That's changing. **Marie Jenkins**

*Injustice. Injustice against service users... the way people were treated in hospital, the way people were treated in the community, the way they were stigmatised, the way they were discriminated against.*

**Anne Bardsley**

I wanted to see change. I didn't think the services were good enough. There was nothing after discharge from hospital. Psychiatrists were not listening, there was no emotional support. It was very isolating coming out of hospital and also isolating being in hospital. Being in hospital makes you ill and then coming out makes you isolated and then that made you ill. Round and round in circles. I felt that it wasn't just me, that other people probably felt the same. **LR**

It was 1994, I'd just been diagnosed as having depression and I was also interested in creative writing and I saw a poster in the Central Library for Beyond Diagnosis. So I just wandered along to the CAPS office one day and asked about it. Graham Morgan was there, I can't remember who else was there at the time but Graham was definitely there and we had a big long chat about mental health problems and the user movement and different things CAPS was doing and about Beyond Diagnosis. So that was like my main reason for getting involved. **Anne O'Donnell**

*I'm at a loss to answer that. Anger. Anger,  
that'll do for it.*

**Jonathan**

I think I was frustrated with being offered pills. I wanted more. I was frustrated being on the ward surrounded by people who were going nowhere. I didn't feel that people were getting truly helped or that I was getting truly helped and I didn't know how to get help. I just thought there must be more than this. **Les**

I was aware of the Patients' Council. But I didn't know what they did, I didn't know who they were. They were just these vague figures floating about. And somehow I wanted more from what psychiatry was offering. But I didn't know how to go about it. I had a very good Social Worker who would listen to me moan or complain or say I wasn't happy about certain things, to the point that she was saying 'If you want things to change, you've got to be part of it.' 'Well how do you do that? If you want to change something you've got to get involved. Well that's why I got involved, dipping my toe into the Patients' Council. **Les**

I wanted better care for people and I wanted to see something that actually made a difference... I couldn't believe that people didn't have access to kitchens whenever they wanted. Basic stuff like that, I just felt it was wrong for certain. You saw too many people who were in hospital for long, long periods of time and sometimes you just wondered why. I've seen people who I was friendly with who took their own life. I've seen people with eating disorders and the way they were treated I was disgusted by. You're forcing somebody to lie in bed with their hands above the quilt, on a 24 hour watch at night. Sitting with people while they eat, what are you trying to achieve? I didn't see it achieving anything, it just felt wrong. **Les**

Wow! Well many things I think; my experience as a general manager in the health service in charge of mental health in Aberdeen and the rather unfortunate and at times bizarre experiences I had working with consultant psychiatrists was one motivating factor. Then of course what happened to me, because that working experience was very bad for my mental health and wellbeing and I ended up as a patient in three different psychiatric hospitals, including finally the Royal Edinburgh Hospital and I think warts and all, as all psychiatric hospitals have them. **Jim Kiddie**

I received some pretty good care at the Royal Edinburgh Hospital and that sent me on the road to recovery. But there were a number of negative aspects as well and I remember being visited by Margaret Temple when I was a patient in the North Wing and I had a number of grievances, including the food which was pretty awful and the fact that there was a general election that year and I had been disenfranchised and I'm a political animal, so that annoyed me Margaret was trying to get me involved in the Patients' Council that she was just setting up at that time and I really didn't have the strength to do it then. Some time went by, I was eventually discharged as a patient. Then I was approached to get involved. **Jim Kiddie**

I saw the abuse of power in Aberdeen by consultant psychiatrists, I really did, and that angered me terribly because I think we're dealing with very, very vulnerable people. The disgraceful conditions in 1987 when I went to Cornhill Hospital upset me and I was appalled at how some psychiatrists didn't seem to care.

So it's R D Laing I think, I always quote him, hated by psychiatrists still in Scotland but revered internationally, who once said 'I am more frightened by the fearless pursuit of power in the eyes of my fellow psychiatrists than I am by the powerless fear in the eyes of my patients.' So, you know, that is a very telling quote and I love quoting a psychiatrist to psychiatrists.

I think we need a lot more humility on the part of not just the psychiatric profession but other professions and particularly in the mental health arena to realise that the real experts are those who are experiencing the problems, their own personal problems, unique to the individual, and that they have so much to contribute and in my view, at that time in the '80s, they just weren't being listened to. **Jim Kiddie**

*I am more frightened by the fearless pursuit  
of power in the eyes of my fellow  
psychiatrists than I am by the powerless fear  
in the eyes of my patients.*

**RD Laing**

I was still a patient in the hospital and there were notices up about a meeting with the Patients' Council. I thought that sounds quite interesting so I just went to listen and I thought that's really quite a good idea but didn't feel confident enough to actually ask if I could join, and it took probably two meetings and then I put myself forward for the management committee of the Patients' Council. I think that was probably the year 2001-2002 and so I've been with them for well, eight years now. **Pat W**



I wanted to change what was available and for people to know what should be available and I wanted to see whether you could fight from the inside and the outside and get other people to understand what the motivations were and what you could achieve and what you couldn't. **Jonathan**

What got me involved with the mental health service users was because of my long stay in hospital. I got to find out what the Patients' Council was like and I thought it would be a great idea to actually join. **Kate**

Well when I was banged up in 1973 there was nothing like that, that I was aware of, so there was nobody to take up your rights. There was so much negative about the various experiences I had in psychiatric hospitals in the early 1970's that I found it a very brutal process. Even the day hospital the year before when I'd been depressed was very, I wouldn't say it was brutal, it was just almost deathly. There was nothing real that could inspire anything, 'string designs' was the most creative thing you were offered to do. So in the late 70's and early 80's I was involved with politics, campaigning politics, left wing politics, anything, you name it I'd support it. Then I began to get fed up, sort of 'what's happened with the people like me?' So I went to see and there was nothing. It was like there was this hidden thing. **John MacDonald**

I'd always wanted to change attitudes towards people with mental illness, not just society but even doctors, you know. Some of the things I used to get involved with was going and speaking to junior doctors, trainee psychiatrists, who we used to call baby doctors and go and speak to them about our experiences and about the things we were wanting to change in the hopes that they might change. **Karen MacDonald**



I remember in the early 1990's I was staying in a supported accommodation in Musselburgh called Cameron Cottage. I remember we used to have a weekly residents' meeting and at one of these meetings a couple of folks from an organisation called CAPS came down to talk to us about user involvement and about the idea of supporting service users to get organised to become collective advocacy groups so that service users could have a voice heard, to get organised, to learn how to campaign, to try to make sure they were involved in the planning process. I was quite unfamiliar with the concept of collective advocacy and the user voice at that time didn't mean a great deal to me. So that would be my earliest memory of the user movement. **Jim McGill**

It's very diverse, you can find immigration issues, isolation, depression. I used to have post-natal depression in the beginning. But I think it's quite a culture shock. This is what I think, also because when I arrived here in two months I got pregnant. **Anon**

*Keep taking the tablets Mr Nicolson.*  
**Albert Nicolson**

When I started coming to Tynepark I had personal issues and problems that I needed to address and the best way to do that as a service user was to be involved with the movement. This has greatly helped me in moving forward in my life and understanding the difficulties that other service users have experienced or have had difficulties in dealing with in their own personal lives. **Ian Stevenson**

Well I think it was the beginnings before the movement really got started I wanted to know what was wrong with me and nobody could ever tell me. The only mantra they used was 'Keep taking the tablets Mr Nicolson'. **Albert Nicolson**

I wanted to think about psychiatry, I wanted to learn what they [Edinburgh Users Forum] did and I was interested in how they were contributing to psychiatry. I was interested in the fact that they wanted to tell their own story of how they had contributed and I wanted to think about the nature of psychiatry and the nature of the user movement. **Jenifer**

*...by being admitted to the Royal Edinburgh,  
I was just given a place to freak out.*  
**Marie Jenkins**

It was through word of mouth. I heard about the project through my involvement with the Africa Centre Scotland. So I used to come for events. Last year when I separated from my husband, that's when I became a service user. And at the same time being a volunteer with the Peer Advocacy. So that's how I got involved with Saheliya.  
**Alice**

It was when all the changes were happening to mental health services and my key worker at the time thought that everybody should get involved in this and just fight it, otherwise there were possibilities of losing it. **Gordon Mackay**

The fact that I wasn't helped by being admitted to the Royal Edinburgh, I was just given a place to freak out and that didn't come cheap! I had to recover at my own leisure by going out and getting books, talking to other people. So with that in mind I would like to potentially help who are going to go through the same processes that I did and maybe give them pointers along the way that the Royal Edinburgh should be actually doing. So what I'd like to do is help others and if god forbid this ever happens to me again then I'll have to help myself as well. **Marie Jenkins**



I had been diagnosed with borderline personality disorder when I was living in Germany the general message seemed to be that this was a diagnosis you did not want to have attached to you when you were in the UK. There certainly seemed to be quite a lot of stigma, a lot of people had trouble getting services, they had trouble getting support.

I had some really, really negative experiences. I just felt very trapped in that situation because I felt that everything I did was seen through this veil of a diagnosis, I didn't exist as a person. Nothing I did or said was right. I had never felt so trapped in my life and so frustrated and so upset.

I actually had blood clots in both my lungs and that was really frightening because I actually could have died because of someone else's attitude, because they couldn't believe that there was something else wrong with me and in a way that was the catalyst because I was so angry I thought for the first time in my life, 'nobody gets to do this to me, I've got to stand up for myself'.

I think that the more I got involved with online peer support, the more I began to realise that this isn't just happening to me. I [now have] a job doing a research project speaking to people who have personality disorder and writing a resource for staff based on their experiences. **Naomi Salisbury**

I went down and made an appointment to go in and see CAPS and and met Graham, who I was extremely impressed with. He told me about a magazine that they'd put out a few issues and he thought that I might with my kind of background be helpful to the lady who was editing it and putting it together. **Jimmy Osborne**

Well I wanted to get better and also at the time I was living alone, kids had all grown up and left home and I had lost my job and so I was pretty much unemployable and I didnae have any family round me, I didnae have any friends because I'd cut them off over the years and I found myself sitting behind four walls pretty much going off my rocker and so I really needed as much help as I could get. I had taken an interest in what ELIG was doing and I was going to go to one of their, well, it was actually the Annual General Meeting and just as I was going in the door Harry, the then convener, said that he really wanted to step down but he would only do it if I would be willing to take his place. So I agreed and that was that. **Veronica Forrest**

Well Midlothian Text was the first place I went in to... that is set up for teaching computer skills; it was more to bring me back into the employment world... a superb rehabilitation first of all and then to teach you computer skills. That would be the very first point I found service users movement, so that's why I then moved on to other aspects of what SUM were interested in doing. **Pat**

How I actually got involved with the service users movement was to put something back into the service what I actually got out of it and that was up in Highland because that was in the days of the Patients' Council. I was asked if I'd be interested to start the Patients' Council up in Inverness at Craig Dunain Hospital. Well I moved down from Inverness to West Lothian and I was on Bangour at the time and the co-ordinator of Friendset came and asked a few service users would they like to get involved in making decisions and I said yes because it was to put something back into the service and make it better for the newer people coming through. **Kenny**

This is going back years ago and I wasn't doing much with my life and I felt really bad and guilty and I just couldn't help myself. And then I thought to myself they're always telling me the good experiences, positive experiences they have from the Patients' Council and how much benefit they get from it, so I thought to myself, well I want a little bit of that, I want a piece of that. I want to feel good about myself, I want to contribute in a positive way, I want to give back to society instead of just taking all the time and receiving help. So I thought, ok, I'll just go there... just as a user, attend the drop-ins, talk to people, get to know people. Then from there I started to enquire about if it is possible if I could attend the management meetings.

Gradually as I understood the process and as I understood what they were talking about and their agendas, their ideas I was able to contribute in a positive way, give my ideas and I felt great, I felt fantastic, I felt it really benefited my mental health in a fantastic excellent way, and then I found myself looking...more to the future, I found myself almost volunteering and electing myself when it came to asking people 'Who wants to be elected to the Patients' Council?' I just said I would like to do it. **Tony Chan**

*I... asked for my rights and I was given them, I had absolutely none.*

**Terry**

I had quite a bad experience of mental health issues, I was sectioned I think very unreasonably... I was frightened when I realised and asked for my rights and I was given them, I had absolutely none... I felt that the professionals involved in [the] mental health service were not listening to me. I felt very alone, I thought it was wrong, I thought it was wrong then and I think it's wrong now. I just wanted things to be better for the service user. People that go into hospital, I found that the way they were treated was shocking to me to be absolutely honest and that it was wrong. **Terry**

## THE IMPACT OF BEING INVOLVED WITH THE MOVEMENT

In this section people talk about the impact, both positive and negative, of being involved with the service user movement.

*I can only give a mixed picture of the good the bad and the ugly and the exceptional.*

**John MacDonald**

There was something about people who had used mental health services getting support from each other, and getting that sense of peer support, which has now been formalised and we have peer support workers. But at that time we didn't have such things and I think user groups whether it be the Users Forum or the Patients' Council actually did provide quite a bit of peer support for people. That sense that you weren't on your own, that there were other people going through similar experiences to yourself. **Allison**

*There are very many heroes in the user movement.*

**Fiona Macdonald**

Positive is the human interaction, I've met some good people that I'd happily spend time with and hopefully they would have time for me. The negative aspects are endless, so you've got to work within that and you've got to be working in activism, understanding that you can't change or influence everybody or you can see somebody going downhill and you know it's wrong and there's nothing you can do about it. **Jonathan**

Oh god, I think that can be hugely liberating for people, hugely and it can be enormously damaging for people and everything in between. Both things at the same time probably. **Colin Murray**



You can get sucked into the emotions and you can get sucked into a movement and the meaning of the movement becomes too much. If you don't know how to get out of it you are trapped in a situation that can be so damaging. So I can only give a mixed picture of the good the bad and the ugly and the exceptional because there were exceptional times. It was a close community at times, the community spilled into the pub, we enjoyed it. **John MacDonald**

Remember you're dealing with human beings and that can be positive and that can be negative, people can have horrendous things happen to them and they can still be obnoxious! **Jonathan**

When I first started going to the meetings I felt quite intimidated, I just felt I'm out of my depth here, these are all professional people and then there's me who had never really been to a meeting like this in my life and didnae really know what to say. **Alistair**

And as I say, actually when I started off supposed to be working 30 hours and I was finding I was working about 60. If you've had a mental health problem you've got to work twice as hard just to feel half as good as everybody else, and I don't think that's right. **Anne Bardsley**

Sometimes I could end up spending 80 hours a week at different meetings, different conferences. I also was with Know Us for a while as well, that's the training branch at Edinburgh Users Forum. And I helped write the training pack with Adrienne and a few others and we used to do training sessions to doctors, baby nurses, baby mental health officers, Joe Public if they wanted to know more about mental health problems. So burn out. A couple of times I ended up in the Royal Ed. because I just pushed myself so far and used every brain cell in my head and every ounce of energy in my body.  
**Maggie Keppie**



I think with the passion and strength of feeling involved in the movement, people put maybe too much of themselves into the movement and as a result probably adversely affected their mental health and that created tensions between people. **Jeff**

Difficulties emerge because campaigning is exhausting. Being involved as a service user activist is a real big ask for folk. And whilst there is a huge number of very committed and very able people, there are also some folk who have really burnt themselves out. **Christina Naismith**

*On an individual level it has actually made me feel quite proud of myself.*  
**Anne Bardsley**

Committees just suck the soul out of you. Sometimes you think ‘to hell with this, let’s have a benign dictatorship’, because at least you know things will get done. **Jonathan**

My strongest memories are just the fantastic spirit that people brought to the work and the passion that people had. I’m very, very conscious of the time and effort that people have put in on a voluntary basis which will probably never be captured and a lot of humour that there was with that. **Fiona Macdonald**

I think there’s a lot of things I’ve done in terms of participation or involvement, in a wider sense I don’t feel part of some user movement. When people talk about a user movement I don’t feel part of that. **Les**

*As I've been doing it I've grown as well,  
because I've sort of tapped into my old  
South African activist days when I was  
fighting Apartheid!*  
**Rosita Rhode**

It's just exhausting, that's why it's really important that there are structures around currently CAPS and other bodies to support people through those times. **Christina Naismith**

Within a group some of the things you believe will have to be compromised and it can be difficult respecting somebody's viewpoint when it's stupid and destructive and it's just going to carry on helping support the status quo or something restrictive that's coming up in the future. **Jonathan**

People go to meetings and they are totally out of their depth. It's inappropriate; they've not got a scooby what they're there for. I think it's unfair. It's a bum on a seat and that's user involvement, we've ticked the box. That's not fair. **Les**

I got frustrated with always being the volunteer and sometimes doing an awful lot of work. Sometimes being placed in positions where I'd be going to a meeting with some senior NHS staff and I'd never in my life been before, and I was scared. Then I had to just go and do it and it paid off in a way. I gained in skills, in confidence, in knowledge. But I was frustrated because I couldn't use it or I was still stopped because people were paid to do that. **Les**

I was a general manager of mental health services... I actually feel I've had much more influence through my patient experience and the work I did with the Patients' Council and learning from so many people in CAPS and Advocard and other organisations. So a great journey and I'm now trying to get advocacy developed in Aberdeen, it's been a very long haul but I think other parts of Scotland have a great deal to learn from what I would call my Edinburgh experience.

**Jim Kiddie**

*I think I have got quite a lot of confidence, especially as English is my third language, not a first or second but a third language.*

**Anon**

When you first discover you have a mental illness you feel like are the only one in the whole wide world that's got it, until you go into hospital and you discover there's another 1,500 patients inside. Just to realise that you weren't alone, that there were others in the very same situation, possibly losing their houses, running up rent arrears, whatever. It was really quite frightening. **Anne Bardsley**

I've learned a hell of a lot more skills, I've learned how meetings work, how to chair a meeting properly, how to minute a meeting. How to write a report on something and I've also learned how to deal with people that are screaming in your face. I've learned at that moment you just sort of stop the meeting, go outside, have a fag, have a moan to somebody, come back and start the meeting again. I mean I would have never learned any of these things if I hadn't taken mentally ill. **Maggie Keppie**



I think it's really good and its part of your restoration as a human being and your recovery to be around people who have similar experiences as yourself. **Shaun McNeil**

It's my passion I think it gives people a sense of worth, it allows people to cry and laugh and share, it gives people the support that they need, it gives people inspiration, it gives them motivation, it allows people to think that they're not just in this hellhole on their own, that there's other people that share similar experiences and similar stories, it gives a sense of strength and worth to your existence even though sometimes that existence is difficult **Jeff**

Just knowing that there are other people who think the same way that you do, totally mad. **Adrienne Sinclair Chalmers**

*When I first went to meetings I didn't  
say anything, I didn't feel I had  
anything to say. In recent years it's  
been difficult to shut me up!*  
**Anne O'Donnell**

That was one thing that the user movement gave me, that connection between what happens to me as an individual and what happens in broader society. So it's not just me feeling crap because I'm not a strong person or I've got mental health problem. **Anne O'Donnell**



My main interest is just a commitment to advocacy for everybody, especially people with mental health problems. I'm also on the board of directors of the Patients' Advocacy Service at the State Hospital and I wouldn't have got involved with that except through my experience through CAPS. **Anne O'Donnell**

Aye definitely, aye, it gave me a lot more confidence to speak up for myself and for others. When I first got involved in collective advocacy I suppose it was others that were doing most of the talking. For me it helped my confidence particularly, aye, my confidence. **Alistair**

People said this to me over and over again that their involvement in the Patients' Council was in itself therapeutic and perhaps more therapeutic than some of the drugs that folk had to take. **Jim Kiddie**

I'd certainly say it increases confidence. I think it is a useful way more generally of improving communication and I think it can increase the level of information that people have and I think it does allow them to recognise that what they say will make a difference. I don't think it is without its potential difficulties and I recognise it can become quite demanding. **Dr James Hendry**

When I get to be a very old man then I will look on the 5 years that I was with the Patients' Council as being one of the happiest and most productive periods of my life. So thank you very much to the advocacy movement in Lothian and in particular to the Patients' Council for enriching my life. **Jim Kiddie**

Sometimes the agenda of somebody coming along to a group like this is that actually they have a voice and they may not actually have anything to say and that can be very disruptive. It can really spiral out of control. So in a way you have to be fairly strong to do any of this because it's not always a nurturing experience. That's a hard, difficult lesson to learn. **Jonathan**

It seemed a lot of the times that the service users had one agenda and the service providers had another. But I felt that my role as the service user rep was to represent what the service users had told me and I used to just stick up for that and just stick by it but it wasnae always easy. **Alistair**

I think it helps people's self esteem and building confidence back up. When you've been unwell or your mental health's not been great I think one of the first things that suffers is people's confidence and their feeling of self-worth. **Karen Anderson**

*I learned as much from working in the  
Castle Group than I learned from  
anybody anywhere in my life and it was  
the service users, not the workers that  
taught me.*

**Lami Mulvey**

So I feel far more confident. But like I left school at 15 and I think I've always been hungry to learn and I always am and I think that's really good because I think we learn all our lives anyway, it's whether you're given the chance to, you know, and I wasnae given the chance then. **Anne, PROP**



Well I've met some really good-hearted people, that are here to stay and support the patient because they've all been through it before, they've all been mentally ill. I feel that we will challenge directly or indirectly how the hospital is in the future and its plans are for meeting the patients' needs. **Kate**

*It gives people a bit more confidence, you're not alone.*  
**Albert Nicolson**

Bringing people closer together to share the experiences in their lives. It's also very important for people who are lacking in confidence to rebuild their lives. **Ian Stevenson**

ELIG has helped me in dealing with problems I've had in a friendly and relaxed atmosphere to talk confidentially to other people who also suffer the same problems as me and it's also helped me in my road to recovery from mental illness. **Ian Stevenson**

I think we've had a few casualties along the road, people who don't come anywhere near user groups because they say, 'crikey, you end up doing 10 meetings a week and you're out there on your own, out on a limb'. I think that's something we always need to keep an eye on, supporting enthusiastic people so they don't get that knocked out of them. **Jim McGill**

I think it's kind of helped me to be a lot less angry about some of the situations I've been in because I can see that very slowly things are starting to change. **Naomi Salisbury**

I'm mainly very proud to be a member of that group of people. I think some of the people there are brilliant and amazing and it's a privilege to know them. **Jenifer**

People get discriminated against. I'm sure everybody's had the experience where you tell someone you've had mental health problems and they just change their attitude to you, just very subtly and you know that they have and there's nothing you can do about it. One of the nice things about being involved in the user movement is that you don't have that. That you're all just human beings and that's nice. **Jenifer**

*It's given me a new lease of life, it's taken a long time but I've got a lot of confidence back.*

**Gordon Mackay**

I'm able to give back my experience, you would not believe the experience some of us have in all sorts of walks of life. I've got that much experience I'm bursting, I'm bursting to give it back.

**Marie Jenkins**

I think that's it can be a very, very equalising thing in a positive way. People suddenly feel 'well actually my view does matter and I'm not the only person with this view'. **Naomi Salisbury**

*It's influenced me because I've felt empowered, a wee bitty.*

**Kate**

I felt really good because it meant that I was able to help not just myself but help other people as well. **Irene**



I quite often hear about service users talking to staff about what's going on and the service users know a hell of a lot more than what the staff know. It's really quite powerful for them. So it's a bit about confidence building and a bit of power as well I think.

**Julia McCafferty**

Going to the Patients' Council, to EUF meetings, to the AGMs of Advocard, CAPS and Patients' Council really helps me, it's very beneficial to me. It gives me focus, direction, a goal and aim in life instead of me staying at home every day and watching TV which I've done, which gets me nowhere. I've got something positive to do, engage in a positive me and it's going to help me and help other people. **Tony Chan**

*...it made me feel that I have a voice.*

**Tony Chan**

I feel like I've developed confidence, self esteem, communication skills, coping skills, strategy, dealing with people. It's given me a destination like a goal, an aim to constantly improve myself.

**Tony Chan**

Actually it worked and it demonstrated well here's somebody who you only see in this context as somebody who is risky, who services think has to be very tightly corralled and there they are on a Thursday night sitting chairing a meeting. I think that's really quite significant.

**Willie Paxton**



It's been the best thing that I came in to advocacy services because it gives you a bigger voice when you want to make changes, you can't actually make these changes yourself. **Kenny**

It's given me something to live for, I'm doing the kind of work that I really want to do. I feel like I've got the freedom to pick up on issues and bring them to people's attention and if ELIG can intervene in any way to try to help or improve whatever situations arrive then that's what I want to see. I'm not getting paid for anything, but I enjoy the work so much and I get so much pleasure out of it and also bearing in mind that I do have mental health problems, this is something that allows me to keep my mind active and feel worthwhile and useful and in some cases maybe even appreciated instead of just sitting at home suffering terrible depression and loneliness. So this has improved my life dramatically. **Veronica Forrest**

Well I think it's been good for me... because of services that are actually developed and it's good to be involved in the decision making. **Kenny**

*So this has improved my life dramatically.*  
**Veronica Forrest**

It made me feel great and fantastic, but not just that though, it made me feel that I have a voice. I've learned that it's not just about me. What I loved about the Patients Council is we really supported each other in our strengths and our weaknesses. You didn't feel alone or isolated or not listened to or snubbed... There's a 'feel good factor' that you are doing something good with yourself, with your life and other people's life. Thank you. **Tony Chan**

The fact that I can contribute in this way – it's a miracle. A couple of years ago I couldn't do anything. I was just so paranoid and so anxious. It was like a self-fulfilling, self-perpetuating nightmare. I didn't do anything with my life, I wasn't going anywhere. I had skills and abilities, yes, but I didn't use them, so I was just going round in circles. **Tony Chan**

People have chosen to give huge amounts of time and effort with no question of payment. There are very many heroes in the user movement. **Fiona Macdonald**

I got satisfaction from service users being heard. It was so important to hear what we thought about our care, it didn't use to be taken into consideration. I also made friends through it and I avoided being in the house too much, or being in a day centre. It seemed so much more important to be making progress. I had the opportunity to work in the CAPS office for 10 years which I enjoyed. I enjoyed taking responsibility, mostly through being secretary of LUF. **LR**

*It's given me far more confidence, without a doubt. I feel I can speak to consultant psychiatrists or council officials, anyone, on an equal footing, without being afraid that I'm going to get locked up, or be put back in.*

**Terry**

I can think of people who through their involvement have moved on into paid employment. If I think of that in terms of confidence building, knowledge, connection with other people within the user movement. Knowledge of how the system works. **Fiona Macdonald**



## THE IMPORTANCE OF COLLECTIVE ADVOCACY

It's absolutely vital. There's no point in running a service that's not any use, or isn't what people want or how people want it. **Be Morris**

Where I think collective advocacy is so powerful that an individual patient has very little voice, but when you get people acting together in support of each other, there's nothing more powerful.

**Jim Kiddie**

*I am a survivor, because I have survived  
the mental health system, and not  
everyone does. Allison*

It's important for the statutory sector because it helps them to get it right. It stops them spending money inappropriately it helps ensure that the services that are delivered are the best they possibility can be. It helps them to meet their targets, priorities and policies, and so that's what's in it for them and that's why it's important

**John Bonnar**

I think down south have taken a more political stance and radical stance. In Scotland we've kind of worked on reforming the service from within so we have sat in groups and been consulted on things. I introduced myself at a meeting and said 'In Scotland I am a user of mental health services but as soon as I cross the border I become a survivor'. I am actually personally much more comfortable describing myself as a survivor, because I have survived the mental health system, and not everyone does. **Allison**

There's no point in running a service that's not any use, or isn't what people want or how people want it. Lots of professionals can get swept away with fashions and approaches and almost take them out of the hands of service users as if they have invented them. Personally I have a lot of concern about that in terms of the recovery movement which actually came from service users but the way it is talked about now you would think it had come from professionals or the Scottish Government. **Be Morris**

A consultation is only meaningful if there is an intention to be influenced and that's pretty clear that that doesn't often happen. But at least people are being asked. **Colin Murray**

But I think the kind of real nub of it all is people coming together in a collective user movement and being successful and being victorious in that. Those people who had the bravery and the guts to stand up and be counted, everyone that did stand up actually did huge amounts to break down discrimination and stigma for people with mental health issues. **Jeff**

*A consultation is only meaningful if there is an intention to be influenced and... that doesn't often happen.*

**Colin Murray**

One of the things about the 'User, Survivor, Consumer, Refuser' conference we had in Dundee that moved some people to tears was there was a woman who attended who hadn't been out of her house for five years. **Shaun McNeil**



People, regardless of being stripped of dignity and rights and dehumanised and desensitised, can still actually come together and have a strong voice and do something about that and change things. That the human being is so resilient, that she or he will still find somewhere at the bottom of that bottomless pit to get up and stand up and be counted because without that we're lost. **Jeff**

*...it's collective advocacy that's made the changes in mental health services.*  
**Keith Maloney**

I think has kind of been really, really important. It's collective advocacy that's campaigned, it's collective advocacy that's made the changes in mental health services and in the development of advocacy for all service groups in Scotland. **Keith Maloney**

The voice of people's own lived experience are as valuable as and as important as somebody doing three years professional training or somebody having worked in a profession for years.  
**Shaun McNeil**

I think it has allowed those of us involved in planning and implementing changes in services to at least aim to improve things from the point of view of the service user. **Dr James Hendry**

We are collective animals and that's what makes it important for collective voice and collective action to happen, because so many times we're deprived of that kind of community, we're shut in our wee boxes or we're shut in a ward or we're shut away in front of a telly and that's not good for us. I think that's what the movement has given people, is the opportunity to do that. **Jeff**

I think the more people you have behind a movement, people take that more seriously. Pay attention. **Helen**

I think for the sake of being human really. The institutions and particularly the profession of psychiatry are very dehumanising in their tendencies and practices and that's why advocacy exists - to be human again. **Colin Murray**

*If it's good enough for psychiatrists, it's  
good enough for service users.*

**Jim Kiddie**

I think it's made them listen, they have taken up some pointers and that's very important to both sides, I think. **Clare**

Well I think it is absolutely fundamental, I think it probably has a lot of lessons and other potential in other health areas. Its absolutely fundamental to what happens in mental health that people should listen to the views of people who are using the service and people coming together to do that is more powerful and more effective than people just doing it individually. So I would like to see a strengthening of collective advocacy and more support for it because I think that's really absolutely essential to developing mental health services that are genuinely responsive to what people need.

**Malcolm Chisolm MSP**

Collective advocacy is not just important, it's essential and after all, the Royal College of Psychiatrists is a collective advocacy body. If it's good enough for psychiatrists, it's good enough for service users.

**Jim Kiddie**



Just hammering away and keep telling the people that are running the services what we want. Basically as long as we dinnae get silenced and split up and keep together we should be able to influence them because they can only ignore us for so long really and the louder our voice is the harder it is to ignore. **Alistair**

Advocacy is not an instant, it's part of a whole process of change and it's chipping away at the attitudes that support the traditional ways of working with mental health issues, but it's not an overnight kind of change. **Jane Rubens**

The movement really needs to concentrate on enabling people to feel they're worthwhile, even when they don't feel they're worthwhile and society doesn't feel they're worthwhile. **Ross McPhail**

I just worry how much the traffic goes in the other way. That when you've got an issue or if you want something to change, how willing people are to listen to that? So I don't think it's a two-way flow yet. **Allison**

It will continue to be important for a long, long time because I do think although there's progress and one of the things that strikes me as I go round the country is the distinction between Edinburgh and other places. I know there are some other places probably who are as advanced as Edinburgh was, but there are many places that weren't. Some areas are still in the very early stages, I can think of one or two in other parts of Scotland where that's the case. **Willie Paxton**



Yeah, collective advocacy is important. I remember my darkest day, when I was in hospital, I didn't feel like I was listened to or paid attention to and you get into this routine morbidity. You think nothing's ever going to get better and I think we're hearing a lot of people like that who would like to see the changes of the role of the nurse in the future. **Kate**

I think ELIG's very important for firstly getting people together who suffer from mental health problems, secondly ELIG is a very important service because they can make changes in both individuals' lives and to what happens with the services in East Lothian, thirdly ELIG is always involved in getting service users involved in some of the planning groups or being given the chance to go to any conferences which hold various workshops and have speakers, to be able to go along and even have a say at a conference as to how it's affecting them or how they feel. **Ian Stevenson**

To me the important thing is that collective advocacy is very important, collective movements are very important but the individual support is also critically important. **Anon**

*People can quite easily say, well,  
you're just crazy.*  
**Naomi Salisbury**

I think if you've been around the movement long enough and seen some of your dreams and beliefs come to reality then I think you can go away and think well we were operating in the right areas after all, the things that we were saying were important. **Jim McGill**



I've noticed that there were people who when there seemed absolutely no point in standing up for patients' rights because they would be bullied or whatever, still did that and now their story is being told. It makes me think that it is worth standing up for something even when the odds seem to be against it because you never know what good it might do. **Jenifer**

*Who better other than ourselves to  
speak up for ourselves?*

**Fiona Macdonald**

I think it's really, really important. I think because when you're just one person it's really difficult. People can quite easily say, well, you're just crazy. But when there are a lot of people saying the same thing over and over again it's possible to actually make a change and be well represented. **Naomi Salisbury**

I'm not sure that there is a particular Lothian movement, I feel at the moment that feels like that's a possibility. I think West Lothian always seems to have been a very sort of separate entity over the years but it does seem at the moment that the potential is there for more of a Lothian movement. **Kathy Hamilton**

I think it's much more difficult, these days anyway, for councillors or MSPs, or MPs, or officials to face down claims from a credible users movement. **Stephen Maxwell**



In some ways it I think it's more important, it's certainly as important as Individual Advocacy, so although Individual Advocacy can really help somebody in their own situation and help them to have a voice. The collective voice is much more powerful I think. **Ruth Rooney**

*I think it's been the best thing that's actually happened since sliced bread.*  
**Kenny**

Collective advocacy is so important. It's a sharing together of experience and it's a building of a community. You've got a whole community bringing together their issues, their common cause and their differences and saying 'listen to us, believe in us, show us respect, we are not going to go away. We are not going to disappear. We've been here all along. We were missed and ignored for centuries and we're now going to be visible. We're not necessarily going to be angry but we are going to be proud of who we are. We may be disgusted by what we go through but we can find the vigour and the hope and the strength to speak out and support each other and know we've got something to give. **Graham Morgan**



## THE FUTURE

*Speak up and be proud!*  
**Karen MacDonald**

So often as people who use services we get defined by the language of psychiatry and the labels that they give us. I think it is quite important that we take ownership ourselves of the language that defines us, and how collectively we want to be as a group. So I would like to see a bit of the survivor movement getting a bit of a hold on Scotland. But I know that is quite a radical view. **Allison**

My hopes are that the movement keeps going and it is perhaps able to address things a bit more radically again. **Be Morris**

That we can be seated in the Scottish Parliament when they pass legislation and say 'well for black and minority ethnic people this is what happens to our mental health, would you please note that. That our people want better access to services, we don't want it yesterday, we want it today!' **Rosita Rhode**

I think it will be a challenge to continue to be relevant to people and let people see what can happen if they do get involved in collective advocacy. I would think particularly young people would have a lot to say now. And I'm not sure how involved the young people are, and it is also important that the black and minority ethnic communities are heard. **Be Morris**



If there are threats of cuts we might want as a movement to be a bit more radical and a bit more 'activist'. One of the things as well that I think is important is that we need to connect more in a cross-disability way. **Shaun McNeil**

I look to what I've heard about the movement in Canada. And feel that that teaches us quite a lot.  
**Pat W**

I think there has been progress but there's a long way to go, so I'd like to see more support for user groups and more genuine involvement of them in developing services. So we've got a good platform but there's a long way to go and there's particular risks with the public expenditure situation so you know it is quite a critical point, but I think we just want to see the movement develop and become stronger. **Malcolm Chisolm MSP**

Pushing forward user participation in recovery and enabling users voices to be heard through VOX. **Ross McPhail**

I would very much hope that an organisation like CAPS and the users groups that it supports can be sustainable in the long term because they've been so good at what they've done. They've got a track record, they've established relationships, they've built on those relationships, and they have made a real difference and those things are of inestimable value and no matter what the changing funding scene is, it will be crucial that those positive aspects are sustained.  
**John Bonnar**



I think it's also important that we are able to continue to be able to negotiate to continue our growth as full human beings and for that not always be pathologised or linked to illness. **Fiona Macdonald**

My hopes for the future are that service users are taken seriously without having to go through great big campaigns to get what they want, that what they say is considered immediately. **Alistair**

By still striving towards greater recognition. There needs to be more champions, figureheads and that should be irrespective of whether or not someone identifies themselves as a service user. They are people who are supportive of a service user movement. But they need to be influential. That's why I think that looking at all equalities campaigns in the past is very interesting. It's not just the black people of South Africa who defeated an Apartheid regime. It was all the people round the world who didn't think Apartheid was a good idea that's what did it. **Akin**

I hope that the movement and myself, other service users, other organisations will be positive and use their skills, attributes in a positive way to not just help themselves but to help other people. That we will look at the bigger picture, the wider movement and not just think of it in a small way. **Tony Chan**

I suppose the main issue for collective advocacy at the moment is to maintain itself and its importance. Because it would be a huge loss if the voice was diluted in any way. **Lami Mulvey**



I feel that the Patients' Council should get wider and I think the movements within the Patients' Council are objective just now but I feel that there could be more advocacy work done within the Patients' Council, on the wards establishing advocacy work. **Kate**

*...advocacy provision should be increasing, not being squeezed.*  
**Adrienne Sinclair Chalmers**

Well my hope obviously is that the work of CAPS continues and I'm hoping that the mental health service user movement becomes stronger and stronger. My fears are that the advocacy movement is under threat at the moment and financial issues are being used in fact to undermine what is a more fundamental issue. **Keith Maloney**

Certainly I think that we should never rest on our laurels, I think that's important because I think the movement then becomes complacent. People perhaps might begin pointing the finger and saying the movement's no radical anymore, accusations of selling-out and just becoming part of the thing that we were questioning, we were questioning the system. **Jim McGill**

*Collective advocacy will need to fight its corner.*  
**Ruth Rooney**

One of the challenges is will collective advocacy be able to hold its own, will it be seen as important as say statutory individual advocacy? That shouldn't be a problem in my view, because collective advocacy is part of mental health legislation as well as individual, but we're in a world where finances are being squeezed Collective advocacy will need to fight its corner. **Ruth Rooney**

Be positive and get involved with campaigns and speak up and be proud, not be ashamed. **Karen MacDonald**

*Wow! The user movement has been happening for centuries, yahoo! We've always been there. Get in there! We need to dae something about this, this is shite. Nobody's going to treat me like that, let's get together, let's stand united and let's move forward and change things. Jeff*

Well, I've been really concerned to hear the City of Edinburgh Council's plan to review advocacy provision and to look at retendering or reducing the number of advocacy providers. I'm quite concerned about that because we fought, oh I nearly swore there, we worked really, really hard to get the advocacy provision that we currently have in Edinburgh and in Lothian and I would hate to see that being reduced when we know it's not enough as it is. We know there are other groups of people who are also vulnerable and need advocates and as a matter of fact advocacy provision should be increasing, not being squeezed. **Adrienne Sinclair Chalmers**

The rhetoric is currently very, very good in many directions. It's full of respect and autonomy. But the reality and the credit crunch has just put the tin lid on it, times are going to be very, very, very, tough and priorities are going to be sharpened up and mental health has usually been at the bottom of the shopping list so I think we're going to have to fire ourselves up again. **Anon**

*I think we're going to have to fire ourselves up again.*  
**Anon**

We need a new hospital with single rooms, en-suite. We need nurses that can actually spend time with the patients and not with the paperwork, we need less red tape. We need sectioning to be outlawed, we need lobotomies to be a thing of the past and we need psychiatrists to all to retire. I mean, we'll never get it but we can hope for it , eh? **Maggie Keppie**

Generally, I would want to acknowledge all the things that I've learned since I've been involved, huge amounts, and that people are simply amazing and I know the cost that's come for some folk but keep on doing it if you can because it's just so vital, so important.

**Christina Naismith**



## AFTERWORD

History really comes to life in the voices of those who have made it and participated in it. The history of the Lothian service user movement is a vibrant, rich one and we hope to have captured some of that vibrancy.

There is power in taking back and reclaiming history. By gathering together some of the many voices and memories of the movement this book is a powerful statement in itself.

What really comes through for us is the energy of this movement. There is a strong, tangible sense of the passion and belief, of the will of service users and allies to come together and work towards change. It is inspiring to hear about the initial struggles to establish the movement and to hear about the early public meetings where service users were coming together and sharing experiences for the very first time.

It is easy now to take service user involvement in decision-making for granted, but it is so important to remember that it has not always been this way. By researching this history we can see that in the early days of the movement many decisions about policy and people's care and treatment were made in 'closed spaces' where decisions were often taken *for* service users by those with more power.

There are powerful messages in this book about the achievements of the movement and how mental health service users have demanded their own spaces. Collective advocacy has been, and still is, instrumental in creating these spaces and supporting service users to claim their own power in arenas where policy and legislation is created and where decisions are made about their care and treatment. In the spaces created by the service user movement the idea of crisis centres, independent advocacy and recovery have been developed.



Mental health policy in the past twenty years has made spaces into which, increasingly, service users are ‘invited’, to be consulted and involved in planning and decision making processes, but this is rarely on their terms. Often though there is a complicated balance between ‘closed’, ‘invited’ and ‘claimed’ spaces, with many service users feeling that still today in 2010 many decisions are made behind closed doors. Service users may have ‘a seat at the table’, but how influential is that seat really?

It is important to celebrate the changes achieved by the movement, to honour the tremendous journey of the movement from its early inception to today where user involvement is at the centre of policy delivery. There is a lot to celebrate. However there are still critical questions to be asked about truly meaningful service user involvement, we should not allow ourselves to become complacent. Many people in the book talk about a need to reinvigorate the movement and to continue to ‘fight our corner’.

There are strong messages in this book about collective advocacy and its central role in enabling service users to have a voice. People have a right to mobilise collectively and have a say about decisions that affect their lives. We hope this book is testimony to the many people who have fought for a stronger service user voice and have campaigned for increased advocacy. We recognise and commend the struggle of the early days of the emerging movement – the tenacity, passion and anger of early activists who came up against huge barriers in attitudes and bureaucracy and yet continued to strive for equality and respect as well as improved care and treatment. It is truly inspiring to hear about people’s involvement with the movement and by learning about our past we gain new energy for the future and renew our commitment to collective advocacy.

**Kirsten Maclean, Community History Worker**