“Think for yourself and let others enjoy the privilege of doing so too.” Voltaire

Disability Rights Festival-returns to London September page 2

Service user led research in Bristol – a report Page 5

User controlled research project – update – page 7

Job vacancy at Shaping Our Lives National User Network – page 15

Company number 4382606
Liberty – UK’s largest disability rights festival returns to Trafalgar Square

Title: LIBERTY – London’s Disability Rights Festival

Time: Saturday 4th September, 1.00pm – 6.00pm

Venue: Trafalgar Square

Entrance: FREE

Liberty is a free Disability Rights Festival for all Londoners on September 4th 2004. Following on from the success of last year, the event returns to the heart of the capital, and will be one of the highlights of the 2004 Trafalgar Square summer programme.

The festival will feature a high profile and contemporary programme with disabled artists, musicians, dancers and performers from the UK and abroad. Additional attractions will include stalls and displays from a variety of organisations.

The festival is organised by the Greater London Authority (GLA) in association with Greater London Action on Disability (GLAD).

1. Details of the event, including programme and access information, are currently being finalised and once confirmed will be available on the GLA website www.london.gov.uk

GENERAL PUBLIC/NON-MEDIA ENQUIRIES: Call the Public Liaison Unit at the Greater London Authority on 020 7983 4100
The Voices and I

I live in the presence of the voices, Ancestors, Satan and God.
I know I shouldn’t hear them, because people tell me it’s odd.

Sometimes they’re a comfort, saying things of cheer.
Some of the time they are nefarious, saying things I’d rather not hear.

Sometimes we have good conversations and they make me laugh out loud.
But I know that hearing voices sets me apart from the crowd.

I don’t mind being different but it seems to be a problem for some.
I think that they should hear voices and have a little fun.

I don’t see that hearing voices means you have to take a pill.
I don’t see that hearing voices means you are forever mentally ill.

I don’t see that hearing voices means that you are demented.
Even though at times by these voices I am tormented.

The voices have become for me a part of daily life.
They even give me companionship like a husband or a wife.

They often entertain me, give me knowledge, make me wise.
In fact they’ve told me lots of things that have opened up my eyes.

Don’t inject me because I hear voices leave me to be free.
I think they’re a part of nature like the wind, the sky, the sea.

Oh when will hearing voices be something that’s not bizarre
Maybe when the voices confess and tell us who they are.

O.K. I hear voices a phenomenon of today.
And to tell the honest truth I don’t want my voices to go away.

I like listening to my voices, they’re like the radio.
And I think that I’d be quite sad if my voices should ever go.
You don’t have to lock me away for an experience that’s strange.
Don’t say that I’m mad, psychotic and deranged.

I think that hearing voices is just a paranormal thing.
I don’t want to be told I’m disordered, like my voices are a sin.

You can’t control the voices with drugs and medication.
I don’t think it’s humanly possible to be rid of them, I’ve tried with dedication.

Only God can get rid of the voices and maybe it’s his way of getting through.
Don’t be so quick to judge me because God’s next choice could be you.

Let me enjoy the phenomena, let me see where it could lead.
Take me off the medication I shouldn’t have to plead.

I think the voices are spiritual, voices from heaven or voices from hell.
I have notions that they’re my ancestors which ones I cannot tell.

Lots of things come to mind for me about the voices that I hear.
But more than the voices it’s the medication that I fear.

It stops me from brushing my teeth, having a bath and keeping clean.
When they say it’s better for you, I don’t know what they mean.

I don’t feel better drugged up and unable to think.
I don’t feel better not washing for days and beginning to stink.

I don’t feel better not working and playing with the rest.
I don’t feel being in hospital of all my talents is the best.

Let me live my life the way it’s meant to be.
I think that this is what God has ordained for me.

So once again before I go, I don’t think I’m mad.
And once again before I go, hearing voices isn’t bad.

**Patricia Chambers**

Patricia Chambers is a member of
Shaping Our Lives National User Network
Patsy Staddon used to be classified as “an alcoholic”. After struggling with various mental and physical health problems, including addiction and epilepsy, for 28 years she was finally able to stop using alcohol 16 years ago. However her experiences of society’s treatment of women with similar problems had convinced her that there were many issues which were not being addressed, or even recognised. She returned to University, taking an M.Sc. in Sociology at the University of Bristol in 1994; the particular areas she studied were Disablement, Gender and Methodology. Before she could continue her studies further, her epilepsy became very much worse and she had to retire from academic work for a few years. However in 2002 she registered for an MPhil/PhD at the University of Plymouth, supervised by Professor Elizabeth Ettorre.

Patsy’s research, into Women’s Alcohol Dependency: Some sociological factors is itself currently funded by the Avon and Wiltshire Mental Health NHS Trust, which supports the concept of service user led research. Apart from a small honorarium the work is voluntary and Patsy is assisted on a voluntary basis by a Research Advisory Group of other women who have also been addicted to alcohol but all of whom have been well for between two and sixteen years. These women meet with her monthly and have input into all stages of the research, from design through practice and support to discussion and analysis.

After a year spent studying what had already been written about women’s alcohol issues and visiting a variety of alcohol treatment centres, Patsy submitted a Report to the NHS Trust which concluded that what seemed to be particularly lacking locally was (i) awareness of the need for provision of one-to-one counselling with choice of gender of worker (ii) women-only groups (iii) flexible opening hours (iv) help with childcare (v) acknowledgement of particular risks to women with alcohol issues from within the family (vi) awareness of the lesser suitability for women of the Twelve Step programme.¹

¹
Over the last year Patsy has been running her own research programme, together with the Research Advisory Group. This involved advertising locally for women who had had alcohol problems to phone her in confidence, and hopefully meet up with her for an in-depth interview. There was an excellent response and Patsy conducted 23 interviews, usually in the women’s homes. She then ran focus groups for the 16 who were prepared to meet each other and the most pressing issues were discussed. So far, interviews and groups have steadily confirmed that women want and need the changes mentioned above. Particularly clear were the links between alcohol misuse and childhood and adult sexual abuse and violence. When Patsy has finished analysing and writing up the research, copies will go back to the interviewees so that they may add their comments, before the Report for this year is sent to the local NHS Trust.

Several of the women who responded initially have now formed a self-help group for friendship and support, independently of the research, and independently of any particular treatment philosophies.

In the coming academic year Patsy has requested funding for a further research project which asks doctors and other health workers involved in the treatment process to talk to her, in confidence, in order to investigate the apparent gulf between stated goals of treatment and their application and efficacy in practice. She will be basing her questions on information received from her interviewees, and will be sending them a copy of the subsequent Report.

1 The Twelve Step programme, still very common in treatment, particularly residential treatment, and derived from the philosophy of Alcoholics Anonymous, asserts that alcoholism is a disease which can only be treated, never cured, and that the best solution is heavy exposure to groupwork, usually mixed-sex, abstinence, and dependence on frequent attendance at AA meetings. It does not believe that there are social or psychological causes, or that such issues should be addressed until long-term “sobriety” is attained---if then.

Patsy Staddon is a member of Shaping Our Lives National User Network
User-controlled research project - update

Shaping Our Lives’ project looking at user-controlled research started in February. It is called User-controlled research - what it is and how it should be done.
The project is looking at the different views and perspectives that people and organisations have on user-controlled research and user involvement in other research on social care and health services.
We are doing the work with Folk Us which is based in Exeter and it is funded by Involve, which used to be called Consumers In NHS Research. Michael Turner is the worker on the project.
We have done three focus group meetings for the project - one in London, one in Birmingham and one in Leeds. Lots of different service users came to the meetings to tell about their work and what they think about research.

We are also sending a questionnaire to people who want to tell us about what they think - please contact the office if you would like a copy.

The report of the project will be written in the early autumn and the project is due to be finished at the end of October.

The Lesbian Community Project in Manchester kindly let us reproduce this cartoon.
For information about the project and more cartoons
Contact them via e mail:

mail@manchesterlcp.org.uk
Last September Shaping Our Lives presented a paper at the first Disability Studies Association Conference (see our website). We said that a wide range of service users should be able to be involved in discussing disability studies.

Going to the Conference was difficult because it wasn’t very accessible. I have just come back from the Second Conference of the Disability Studies Association. It was much better. Access had been improved. I met a lot of other disabled people and service users, made some new contacts and went to some really helpful discussions, for example, about human rights, the killing of disabled babies and what people want and hate from professional practice. There were people there from all five continents. I was able particularly to highlight issues facing mental health service users/survivors.

I learned a lot. But I think the conference still highlights big problems. Some academics and researchers – both non-disabled and disabled – just seem to want to have arguments about theory, which have little to do with people’s lives. Some still don’t think, for example, that people with learning difficulties have much to offer. There are tensions between them and service users who want real change. This is a worry at a time when people don’t have good services or enough support; when the old charities are becoming very powerful again and when disabled people still face many barriers.

In my opinion we need to keep involved in the Disability Studies Association to help make sure with other people that it focuses on issues that really concern us. We need to have a real say in how it develops.

The Second Annual International Conference of the Disability Studies Association was held in Lancaster, July 26-28 2004.
INVITING ARTWORK
FOR AN ANTHOLOGY OF WRITING AND POETRY
BY AND FOR TRANSRACIALLY ADOPTED PEOPLE

Transracial (including intercountry) adoptees, who were adopted in
the UK, are invited to submit artwork for an anthology of writing and
poetry by and for transracially adopted people being published in
2005 by the
British Association for Adoption and Fostering.

The artwork should look striking as a black and white image.
(It will be reproduced in black and white only).
This could include, for example, painting, sculpture and
photography.

The piece of artwork should relate in some way to transracial
adoption.
It could address, for example, identity, loss, racism,
searching for birth family etc.

Contributors should send either a photograph of their piece of
artwork
or the image in jpg format, together with the title of the piece
and their contact details (ie. name, postal address,
telephone number(s), email).

Deadline for submission of artwork: 15 September 2004
Deadline for submissions of writing and poetry: 31 August 2004

I look forward to hearing from all transracial adoptees
With warm wishes, Perlita

Email: Perlita.Harris@bristol.ac.uk

Perlita Harris
School for Policy Studies
University of Bristol
8 Priory Road
Bristol BS8 1TZ

Tel: (w) 0117 954 6726 (from 1st September)
At the end of April, Peter Beresford gave the keynote address at a conference organized by Essex County Council. The conference was for voluntary organizations who, increasingly are taking on the role of service providers. In the afternoon Shaping Our Lives’ Manager, Fran Branfield and Shaping Our Lives National User Group member, Jennifer Taylor ran a workshop. The following paper was written and presented by Jennifer at this event.

I’ve done a piece of writing for Community Care magazine with Vanessa Williams about what we think about Social Services.

How can staff give service users what they want in their lives?
Staff can boss service users around. Like when I was in a hostel they were telling me how to clean and tidy up. I know how to do that. Telling me to tidy up the house before I go to college; telling me I’m not allowed to stay out late; telling me to take my medication and I know how to do that. Telling me to do things I already knew. My Mum told me how to do all that.

This is what service users want now. They want to do their own thing. They want to go out and stay up late and that. They have got a brain and they know how to make decisions and choices. It’s about time the service users stood up to the staff. That’s what I did. That’s why they have key workers now. They can tell the key worker and the key worker can tell the manager and sort it out for them.

My name is Jennifer Taylor and I work for People First Lambeth. I am on Shaping Our Lives National User Group. I do speeches and go to conferences and meetings. I’ve done a few conferences and I get paid to do it. I’m in the Research Group at People First Lambeth. We have just done a book called We Are Not Stupid. We are working with the publishers to publish our book for us. I’m training to be a receptionist at Lambeth Accord. I was on the Management Committee for People First Lambeth as a chairperson and for Lambeth Accord as well.
Staff should understand people with learning difficulties and treat them fairly. Staff are not giving them a chance to do their own thing. This is why they are complaining. They want to go out and mix with people and go out at night and have a good time.

My friend in the hostel wanted to go out. She didn’t want to go to college. She didn’t want to learn new things. She just wanted to enjoy herself. The staff wanted her to go to college but she didn’t want to do that. The staff wanted her to do something but she didn’t want to do it. She lost her temper with the staff. She was swearing and cussing and God knows what.

She wanted to be like everybody else, mixing with people and going out. My friend went out and didn’t take her medication. She had a seizure in a night club. She was well tipsy. She was over the limit. She was drinking and mixing with men. She didn’t know what she was doing. She got pregnant. Staff just told her off. It didn’t help because she wanted to do what she wanted to do.

Sometimes staff don’t listen to the service user. You know, when they want to go out and have friends come round and visit them, or their family come round and visit them; specially at the weekends, not during the week.

Staff can be controlling sometimes over the service user and a bit rude. I find when the service user wants something they are like “you are not allowed to do this, come back, you’ve got to do as you’re told”. Do what the staff wants not the service user wants. They might want to go shopping or go to the cinema. They are not allowed to do that.

Some people, staff are with them all the time just in case anything happens to them. This is why they have got to stand up and tell the staff what they really want. Say they want money or to live in their own house, they can’t do that. They say it’s a big wild world out there you might get raped, you
might get abused or anything like that.

The service users need support. If they want to go to a night club they need support just to be safe because there are a lot of nasty people out there, horrible people out there. They can call you nasty names and be weird to you. This is what I was saying to my friend. She was in danger because of her seizures. She was in danger because of her drinking and because of the way she was behaving. I had to look out for my friend. I said to her be safe there is nasty men out there. You can’t just keep getting yourself pregnant all the time. She has already lost one baby as it is and she is scared that Social Services might take this baby off her as well.

Staff should not control people like my friend a lot. They should learn how to be friends with her and talk to her nicely and go out with her when she wants them to. Services have not helped her, probably because of the way she was behaving in the hostel. She didn’t want no one to help her because she just wanted her own way all the time like some people do. She could have been like me, doing training, getting a job, settling down, but she didn’t want none of that. She thought that life was all about night clubbing and that, about getting tipsy. I tried to put her on the right path but she wouldn’t listen to me. Some people get into a right mess because they don’t know what they are doing half of the time. She wants her way. The staff want their way.

My friend ended up in a bad relationship with the staff. The staff should have listened to her properly and understood her. Probably they weren’t treating her right as a resident. That is why she was acting like that all the time, keep coming in late, keep staying out, keep coming in the next morning. The staff couldn’t cope with her. It is difficult for staff to help a service user who is in a temper because they want this and they want that and they want to be like everybody else.

Staff should like have a friendly relationship towards service users. When I was in the hostel I got on with my key worker and the manager. We would go out shopping and for a cup of
coffee. My friend wanted a friendly relationship with the staff but they were too busy working, like working in the office. She tried to talk to them about her problems. They said if there are any problems just come into the office and sort it out with me. Staff were too busy typing and sorting out bits and pieces and they would say come back later because we are busy. Or they were having a staff meeting

**Now I will talk about having good meetings and bad meetings with staff there.**

**A bad meeting with staff there**

It’s difficult for me to understand what’s going on. There was jargon words. They were talking too fast like they do. They could have talked a bit slower so I can understand what they are saying. Some meetings I don’t understand what people are talking about.

They start talking about different things. They don’t ask you no questions or anything. They don’t say “Jennifer would you like to say anything”. They just talk amongst themselves. With their big folders and paper and so I just dozed off. You can’t read what they put down on a piece of paper.

I felt left out as a person with learning disabilities. All they were interested in was among themselves. They could say “how did you like the meeting” and I could say “a bit boring and that”.

**A good meeting with staff there**

A good meeting is when I go to the Women’s group or the Management Committee at People First. I used to be the chair person at People First. You know what you’re talking about there. But some service’s meetings you don’t understand them. Because they talk in jargon words. You can’t understand jargon words.

I can understand what is written in the minutes at People First. You can understand it better. The words are not jargon words. In the Management Committee the service users are in control. In the Women’s Group we are supported by a woman with learning difficulties. She has a supporter who
supports her. In the management Committee or the Women’s Group it doesn’t go too fast for me. I can understand what they are saying.

I like the Shaping Our Lives meetings because they are good. You get good money. You get paid for it, put it that way. You get involved. It’s a good friendly atmosphere and they care about what you think as well. And it’s like being part of a family. They also listen to you as well. You get involved like when they said to me do you want to do a conference I said yes because I’m good at speaking out to people.

A question for the people in this group
The question is: how can staff help service users be in charge of what happens in their lives?

Our colleagues at GLAD brought this to our attention

![Ask Your Neighbour](https://www.askyourneighbour.co.uk)

Often a big dilemma among local groups and not-for-profit organisations is finding ways to spread the word about their activities WITHOUT having to spend money.

One answer is to take advantage of our totally FREE but highly effective [Good Neighbour](http://www.askyourneighbour.co.uk) scheme on [www.askyourneighbour.co.uk](http://www.askyourneighbour.co.uk)

[askyourneighbour.co.uk](http://www.askyourneighbour.co.uk) is one of Britain's fastest growing websites where neighbours pick each other's brains on just about any topic you can imagine.

Quite simply, every time you ask or answer a question on the site as a [Good Neighbour](http://www.askyourneighbour.co.uk), there is a link to your own full-screen Profile – where you can promote your group’s aims and activities.

No expense whatsoever is involved and we benefit from having more good people involved in the site. The scheme is really taking off among local groups.
PART- TIME VACANCY

FLEXIBLE HOURS

Salary: £23,550 pro rata
6 months contract in first instance

Shaping Our Lives National User Network

is looking for a

COMMUNICATIONS OFFICER

To work 17.5 hours per week at its office in South London. The successful candidate will have experience in office administration, organising meetings, and knowledge & experience (in work or non-work capacity) of website and database work.

To download more information please go to
www.shapingourlives.org.uk

If it is not possible for you to access information on-line it can be posted by leaving your name and address at this telephone 020 7095 1159
( this method may take a few days )

Deadline for receipt of completed applications:
Friday 17th September

Interview date: Thursday 23rd September

Company number 4382606
Fran, manager presenting a leaving present to Eamon one of our communication officers.