



**Shaping Our Lives Newsletter  
Winter 2010 – Issue 18**

**Big Changes, Big Worries, Big Challenges, New Ways of Working**

by Peter Beresford  
Chair, Shaping Our Lives

These are times of massive change. It's difficult to be clear about or take on what all the changes will mean for disabled people and other health and social care service users that follow from the Coalition government's spending cuts announced on 20<sup>th</sup> October with the 'comprehensive spending review'. Most independent commentators think that poor and disabled people are likely to be hit the most and come off the worst from these cuts in services and benefits. While the government talk has been about 'fairness', service users fear that they have been singled out for attack because of their lack of political clout. Our user controlled organisations are especially important and especially vulnerable at such times.

These difficult times will mean that disabled people's and service user organisations and networks like Shaping Our Lives will probably need to find new and effective ways of ensuring that people have a say, that their voices are heard and their rights and quality of life are not reduced.

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## **Big Changes, Big Worries, Big Challenges, New Ways of Working.....**

We are on the case and also welcome all ideas and comments from our network and readers. Please make contact with us through our networking website SOLNET.

### **Changes at Shaping Our Lives office**

This has also been a time of big change for Shaping Our Lives itself. Two of our long term and much valued workers, Fran Branfield and Jenny Willis have moved on. We wish them well, hope our paths will cross again and meanwhile we're all working hard to meet the massive challenges that face us and all disabled people and service users. We will be making new appointments soon, so watch out as there may be opportunities here which interest you.

## **Count us in! Involving everyone in health and social care - a report of a workshop run by Shaping Our Lives for INVOLVE**

This is the report of a workshop held in March 2010 with a diverse group of service users interested in health and social care research. The aim was to find out how more people can be actively involved in research, especially groups and people whose views are heard less often in wider society.

This report details the ideas and perspectives from the service user participants, summarises the discussion between the service user participants and INVOLVE and sets out the service user identified recommendations for future work to improve and expand the groups and people getting involved with research.

This report is available on the home page of:

[www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)



# “Assisted Dying: Be careful what you wish for!”

**Baroness Campbell of Surbiton DBE**

Calls for Assisted Dying to be legalised have grown from a background murmur into a roar since I first became involved in the campaign to defeat Lord Joffe, who tabled his Assisted Dying for the Terminally Ill Bill in 2003. Although we were successful then, the assisted suicide campaigners did not go away. We have witnessed the high profile Court cases of both Diane Pretty and Diane Purdy, who wanted the assisted suicide to become legal; there have been numerous accounts of Britons going to Dignitas and recently a high profile celebrity, Terry Pratchett has given his financial and celebrity support to Dignity in Dying campaigns.

These developments, combined with the fact that we are witnessing the biggest financial cuts to public support services, is beginning to have a serious effect on the lives of disabled people. Disabled people are alarmed by the enthusiasm of the public to help severely ill or disabled

people to die, and less proactive when it comes to saving the support services we need to live with dignity. The consensus would seem to be that it is more humane assisting another person to die, than it is to go on trying to alleviate pain, incapacity, isolation and dependency that is often associated with progressive conditions. Assisted suicide campaigners say this is not true, that they only want to offer ‘a choice’ after all suicide is not illegal. The proponents of legalising Assisted Dying, very few of whom are terminally ill or disabled however hardly ever think of the environment in which we are asked to make this so-called ‘choice’.



**Jane Campbell and Rachel Hurst**

An environment where the majority of the public believe to be severely disabled is worse than death. Certainly It is not unusual for me to be told, “I couldn’t live like you ” or “You’re so brave, I know if I were in your position I wouldn’t cope ”. I wonder how you would feel if others thought you’d be better off dead? Well, you may rebel, but more likely you will eventually give in to the drip drip negativity that suggests/demands you consider this death option.

After all, you don't want to be a burden on your family or the state, do you? OK, that might be a bit strong. How would you feel if people assume you want to die because, in their eyes, your life must be unbearable? That's their mistake you might say. But if they are the doctors and nurses treating you when you're seriously ill and fighting for your life, it's a mistake you might not live for them to regret. What if they've already assisted 1, 2, 5, or 20 people like you to die, how hard are they going to fight to keep you alive? Research in Holland has shown that what began as a very unusual end-of-life choice for those in the last few weeks of a terminal illness, soon became a routine option for disabled people without a terminal diagnosis. It is all too easy to make assumptions about lives very different from our own; All too easy to believe that another life has less quality than our own because it is different; All too easy, to believe that we wouldn't be able to cope if our circumstances were to change dramatically; All too easy to assume difference means less and change can only be negative. The reality is dramatically different. Disabled people whatever their conditions are as happy and sad as the rest of the nondisabled population. Working alongside disabled people and listening to their stories, I understand why they fear the slippery slope. Legalising premature death as a treatment option plants a seed of doubt about one's right to demand help to live with dignity – and undermines the state's responsibility to ensure all citizens can live with dignity. If it becomes legal to assist people to die, I believe it will place a new and invidious pressure on disabled

and terminally ill people who **think** they are close to the end of their lives. Some will consider death as preferable to fighting for support to live with dignity. It will be the cheapest, quickest and simplest option. Think of older people who are anxious not to cause their families any distress! Evidence from research in this country and abroad shows that most people who seek assisted suicide give, "not wanting to be a burden" as the principal reason for seeking death. The increased choice argument is not valid, until we live in a society that values us equally, where we can live with dignity and not feel burdens. A society, whose health system offers genuine pain relief for everyone, not a society which is on the brink of public service bankruptcy. That is why I set up not dead yet UK. I realised the voice of the disabled and terminally ill people collectively, was not being heard in the debate on assisted suicide. We believe we can help by showing how important it is to debate this issue in the context of society's cultural response to illness and disability; in a society that does not target essential health and social care support services for cuts. I hope this article helps you to understand my and other disabled people's fears. A change in the law would not only be dangerous for disabled and terminally ill people, it would be bad for our culture and humanity.

**[www.notdeadyetuk.org](http://www.notdeadyetuk.org)**

If you have views on this issue or this article please get in touch with us at: **[information@shapingourlives.org.uk](mailto:information@shapingourlives.org.uk)**

# Shaping Our Lives

## Current Initiatives

Shaping Our Lives has been keeping busy during these difficult times working on existing projects and taking on new ones. Here are some of the things we are now working on:

### **Shaping Public Spending Priorities for Adult Social Care**

Shaping Our Lives has been working with the Joseph Rowntree Foundation and Ipsos Mori, the well known survey organization on a national project to find out what effect current and planned spending cuts are likely to have on service user involvement and how best this can be maintained.

More information on the [www.jrf.org.uk](http://www.jrf.org.uk) website

### **The Strategic Partnership**

Alongside the National Centre for Independent Living and Radar, Shaping Our Lives is involved as a strategic partner for user involvement with the Department of Health. The aim is to improve and increase two-way communication between service users, disabled people and our organisations and the Department. In these difficult times this is especially important and we are working to ensure that the Department knows what is happening at local and grassroots level.

### **International Collaborations**

Shaping Our Lives now has three possibilities for future international collaborations with overseas organisations and service users. One of these is for an exchange next year with Italian service users. The two others are linked with Sweden and should also mean exchanges. One of these involves linking up with Lund University to produce an application for European 'Leonardo' funding which can help promote contact and capacity building.

### **Wiki Access Project**

Shaping our lives have also been supporting the Social Care Institute for Excellence (SCIE) in its development of an innovative 'Wiki Access Guide'. What this means is that using the same principles of co-producing knowledge and information as was developed by Wikipedia, service users will be involved in developing, testing and improving a new access guide to be produced by SCIE for organizing events.

More information with links to the various reports are available in the on line version of this newsletter. The newsletter is on our publication pages of:

[www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)

## **Network of Networks**

Shaping Our Lives along with a small number of other user led organisations, joined the Office for Disability Issues Network of Networks. Its main objective so far has been consultations on the United Nations Convention on the Rights of Disabled People in order to monitor its effectiveness and the Government's Independent Living Strategy. The United Nations Convention is to be consulted on in further depth in the following months and we will be making sure that you have a chance to be involved through our website and SOLNET. The reports will soon be on our main website.

## **Social Work Education Participation**

This is a national strategic project which Shaping Our Lives is a joint partner in alongside other service user and carer organisations and the Social Care Institute for Excellence. We are working to set up an inclusive and diverse advisory group nationally to advance user and carer involvement in social work education and we have funding to work to take this forward from the Department of Health. We are currently developing the website. Please check it out and we hope you will send contributions to it.

Check out the SWEP website at:

<http://www.socialworkeducation.org.uk/>

## **Co-Production Group**

This is a national group of service users and carers established by the Department of Health to advance co-production. Shaping Our Lives is a member of this group which is diverse, lively and active, working hard to try and ensure that co-production can become a reality rather than just be another jargon word.

## **The Standards We Expect**

Shaping Our Lives is joint partner in this action research Consortium, supported by the Joseph Rowntree Foundation, with three other organisations. Its aim is to advance person centred support for all service users. Its main publications are due to be published in Spring 2011. They include practical resources which will be helpful for service users working to improve the quality of support they can access. Watch this space for further information.

See Shaping Our Lives web site for more information.

If any of these projects particularly interest you or you would like further information, please get in touch with us at:

[information@shapingourlives.org.uk](mailto:information@shapingourlives.org.uk)

# Canerows and Plaits a new service user-led group based at Sound Minds

Canerows and Plaits is a service user-led group based at Sound Minds, a mental health arts project in Battersea, south London. It aims to improve the experience of mental health service users from Black, Asian and Minority Ethnic (BAME) backgrounds both in the community and on the Wandsworth wards of Springfield Hospital, Tooting and Queen Mary's Hospital, Roehampton.



Although the group has a BAME focus no one is excluded from the service because of their ethnic background. The group's activities focus on two methods of engaging service users. The first is by holding meetings every six months called Have Your Say Forums. BAME service users meet health professionals, volunteers and carers to discuss issues, listen to guest speakers and exchange views. These events always have music and food as part of the proceedings. The second is the Ward Visiting Service, which has the aim of supporting people on the wards by showing them kindness, compassion and understanding, while also ensuring their cultural needs are addressed.

The fact that the visitors are of BAME heritage with experience of staying on the wards helps them to relate to people who are receiving the service. Canerows and Plaits is governed by a steering group made up of four service users (including the author), the Chief Executive of Sound Minds, and a community development worker employed by South West London and St George's Mental Health NHS Trust to work with BME groups.

The service was positively evaluated earlier this year involving staff, training for Ward Visitors is now accredited with the Open College Network and Canerows will soon be able to provide this for other organisations. The group has recently been awarded a 3 year grant from Comic Relief to expand the service locally and to pilot a Community based Peer Befriending service.



Thanks to Paul, Rima and Dwight at Sound Minds. [www.soundminds.co.uk](http://www.soundminds.co.uk)

**Allan Sutherland,**

**I have for several years been working at making transcription poems about the lives of disabled people.**

**I make these poems by carrying out a long oral history interview. I transcribe the recording (painful work, but a good way to get to know the material), then edit it to produce a set of poems. I have found this to be a remarkably productive way of working.**

**The first works created by this method were 'Paddy: A Life', with Paddy Masefield, a major figure in disability arts, and 'The Explorer' with artist Nancy Willis. These can both be found on the Disability Arts Online website, as can Nancy's film**

**'Transformations, made using 'the Explorer':**

**I am currently poet in residence at the Centre for Citizen Participation, Brunel University, creating four more sets of poems. So far, I have worked with Jennifer Taylor, a member of Lambeth People First, and Catriona Grant, who developed aphasia (language loss) following a stroke.**



The trap

It's a trap isn't it it's like a horrible trap  
to admit that there are things that are difficult  
about being disabled  
things that are really hard to deal with.

But you don't want somebody to think  
oh well it would be better  
if they hadn't been born  
wouldn't it.

It's a really difficult thing to get..  
to be able to deal with.

I think to be able to be truthful is hard.

Allan Sutherland

(Transcription poem from the words of Nancy Willis.)

## Tattoo

By the time I got to 60  
I'd also got the terminal cancer news. Okay,  
if this is not a situation where you go for something  
then I don't know what is. It's going to be subtle and funny  
and Caroline my wife is going to design it for me.

I found out by accident off the back of a kitchen tea towel  
that, used by the royal navy,  
there was a flag which is one half of my tattoo  
a red diamond on a white background  
and the exact and only translation of this is  
'I am disabled please communicate with me'  
and I don't think this is an appropriate message for a ship to run up  
if it's been run out of action  
but I thought that the notion of ever meeting somebody in a hospital  
who was able to translate that flag  
would be wonderful, if unlikely,  
so we then decided that the single flag would look ridiculous on an arm  
so we thought we'd go for the crossed flags.

We managed to find one that was vaguely interesting  
which meant 'you are running into danger'  
so the two flags on my arms mean  
'I am disabled please communicate with me'  
and 'you are running into danger'.

It was only when we'd decided on that  
that I discovered that each of these flags  
also represent a letter of the alphabet  
and if you read my arm  
it's unfortunate that they just happen to read  
F.U.

Allan Sutherland

(Transcription poem from the words of Paddy Masefield.)

## An urgent letter to the government.....

People First Lambeth  
336 Brixton Road  
London SW9 7AA  
23/11/10

David Cameron  
and Nick Clegg  
10 Downing Street  
Westminster  
London SW9 7AA

Dear David Cameron and Nick Clegg,

We are a group of people with learning difficulties from People First Lambeth...We are called Jennifer Taylor, Maggie Brennan, Wenda Gordon, Christina Watkins and Susan Laffey (Jennifer) and we are not happy with the way the government is working at the moment (Maggie). People with learning difficulties are not happy with your government (Wenda).

There is a lot of people who don't understand where we are coming from. David, you told us you are a parent who had a son with learning difficulties. We are surprised at the way you are behaving towards people with learning difficulties (Jennifer). And if the cuts start where is everyone going to go (Christina) and what are they going to do (Jennifer)? Plus, how do you expect everyone to get jobs who has got a mental health problem and who has got learning difficulties?

It is hard for them to get a job (Maggie). Maggie said this: 'I know a lot of people who hasn't got jobs who have got a mental health problem and learning disabilities as well. They want a job but the government is stopping them getting a job. The employers are stopping people getting a job'.

It feels like we are getting punished by the government because some of us haven't got jobs (Jennifer).

Some of the people who are writing this letter have got a job. They feel angry in case they might lose their job. Some people are frightened about it because their jobs might be cut (Maggie).

What about the support workers, cause they work in residential homes with people with learning difficulties and we don't know what's happening with them. And the same thing for all the residents in residential homes. If they go, the staff, we are going to get no support (Wenda).

I say from my point of view the government is talking rubbish. I watch the news all the time at home and they talk pure rubbish (Jennifer).

They shouldn't be in power in the first place. They let us down (Wenda).

The government has not given us a proper choice with the cuts and everything (Susan)

The cuts could leave us with nothing. We could have no choice in our lives and no power. If the government are cutting all our jobs we have no say in the matter. They should have talked to us first [about] what we want in our lives because this is ridiculous (Jennifer).

Maggie said 'I am worried that I will lose my flat, my job, my independence, my support I get and I'll end up back in a residential home and I don't want that – going backwards'.

If the government stop the benefits how would some people survive or live (Christina)?

You have got to remember as well that people with really high needs that go to day-centres what will they do? If the centre is closed where will they go...? The carers need a break in the day. It gives them time to do what they want to do while people with learning difficulties and high needs are in the centre. If the centres are closed what will happen to them...the carers (Maggie)?

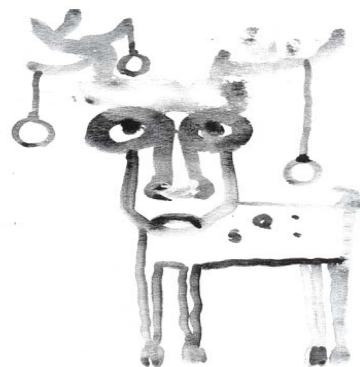
We want you to give us a change out of it...I suppose like a new life or something (Susan) and better power in our lives (Maggie).

It doesn't look like it's changing for good...It seems like it's going down the drain (Jennifer).

Since you got in to government it's gone sort of like pear shaped. Since you have got in you haven't done anything for us (Christina).

You want to cut everything. It seems like you want to stop everything and take everyone's lives away. You want people with learning difficulties to have a job, but you don't want us to have a life of our own... The way you're going on it seems like you want us out of the planet all together and [to] just have normal people on the planet instead of people with learning difficulties as well, mixing in the community. Because people with learning difficulties have got lives to lead as well, not just normal people...Do you want us to stay at home and do nothing and be bored stiff (Jennifer)?

From all of us at People First Lambeth Training Group:  
Jennifer, Wenda, Susan, Christina and Maggie (Jennifer).  
We are just saying our views, that's all (Maggie), how we feel about the government (Jennifer).



Do you want the opportunity to build confidence in developing your voice on the visual arts, theatre, music or literature?

## **The New Voices Project**

### **Disability Arts Online (DAO)**

DAO is looking for individuals with a range of experience and interests. Over 2011, we intend to develop groups of writers from London, Brighton and the Bristol area. Each arts writer will receive a bursary of £750 to spend three months, working one day per week. To support this process New Voices writers need to attend workshops once per month over the duration. The groups will run in Brighton [at Lighthouse], Bristol [at Spike Island] and in North London, [at Shape Arts].

Do you want the opportunity to build confidence in developing your voice on the visual arts, theatre, music or literature? Do you want experience of having your unique viewpoint and experience of the arts published on DAO? Do you want to learn about getting your voice heard through social media? Do you want to connect with an audience from within the disability arts community? Would you like the opportunity to get an inside view of how artists and arts organisations work? You may be an artist looking for advice and feedback on your writing skills. You may be a writer looking to widen the scope of your practice, who wants to get some journalistic experience.

Or you may simply be someone who is passionate in communicating about the arts.

If you think this opportunity is for you then let us know!

### **What to do next?**

Please submit an expression of interest, telling us what areas of the arts you are familiar with and are passionate about. Let us know what experience you are looking for. And let us know what access needs you may have so we can look at how best to support you.

Please send an email to DAO editor Colin Hambrook:

**[editor@disabilityartsonline.org.uk](mailto:editor@disabilityartsonline.org.uk)**

with New Voices in the subject heading.

### **What happens next?**

Those selected will be asked to submit some original, recent arts writing – either in text or audio formats.

**[www.disabilityartsonline.org.uk](http://www.disabilityartsonline.org.uk)**

Disability Arts Online (DAO) is a unique online journal for discussion of arts and culture. We publish blogs, reviews, profiles, creative writing and galleries, working across art forms with artists and writers who identify as part of the disabled, deaf, survivor / marginalised communities. DAO has a growing national and international audience.

# Sandwell's Vision Strategy

The UK 20/20 Vision Strategy, launched in 2008 has three aims.

1. Promote eye health care to prevent avoidable sight loss.
2. Provide good quality health and social care services to support people coping with sight loss.
3. Promote the independence of people living with sight loss; encourage and enable them to engage in civic and community activities.

**Sandwell Visually Impaired (SVI)** an organisation run by visually impaired people and a member of SOLNET [www.solnetwork.org.uk](http://www.solnetwork.org.uk) is working with Sandwell Council's Adult Services, to develop a vision strategy for Sandwell. The questionnaire will ensure the recommendations for future service provision is evidence led.

## How we are consulting

**Sandwell Visually Impaired** will be visiting existing groups and forums across the borough, in addition to organising a range of focus groups and carrying out a questionnaire to gather local views.

They are using creative ways to reach out to the six towns in their area. World Sight Day is an annual day of awareness about blindness and visual impairment held on the second Thursday in October. It will be an exciting day of razzmatazz under the slogan 'make a spectacle of yourself', where we intend raising the roof on sight loss with eye catching spectacles, posters, balloons galore and music

To know more about this project please visit :

[www.sandwellvisuallyimpaired.org](http://www.sandwellvisuallyimpaired.org)



It is with great sadness that we have learnt that Cora Jones died last month. Cora joined the management group of Shaping Our Lives in October 2008. She was a director/treasurer of Birmingham Disability Resource Centre. Cora also worked with Birmingham City University on the new Social Work degree as a service user, putting forward the needs and viewpoints of service users to student social workers and teaching staff. Despite having to cope with high levels of almost constant pain, Cora had a good word and a warm smile for everyone; she had a lively, generous spirit that she was happy to share with all she knew. We will miss her wise counsel greatly; our heartfelt condolences are sent to her family and close friends.



“MARTHA ROBINSON” POETRY COMPETITION 2010  
is open to all mental health (ex-)service users in the UK  
Organised by National Perceptions Forum

The winning entries will be published in  
“Perceptions” Magazine

**P R I Z E S   1 s t   £ 1 0 0   2 n d   £ 5 0   3 r d   £ 2 5**

For an entry form please write to: Rachel Brett, Poetry Competition, National Perceptions Forum, Rethink, 89 Albert Embankment, London, SE1 7TP  
Or Email: [rachel.brett@rethink.org](mailto:rachel.brett@rethink.org)

Deadline for entries Monday 28th February 2011

# Rethinking Mental Health for the Twenty First Century

As the government embarks on a high profile campaign to get many thousands of mental health service users off benefits and into employment, it may do well to listen to what they have to say if it is serious about wanting to support them to live more independently.

A new service user-led study, which explores mental health service users' own views, suggests that prevailing approaches to thinking about and treating them are actually making things worse. They see the medicalised approach to understanding mental wellbeing issues which they feel still dominates UK political, professional, public and indeed, most service users' understandings of mental health issues, as having few benefits to offer and as largely negative in effect. This is because it stresses that 'something is wrong with you' and 'blames the individual'.

They see this kind of 'medical model' approach as being at the heart of the stigma and negative stereotyping which continue to create problems for those service users trying to lead ordinary lives. They are not saying that nothing's wrong, or they don't have problems or need support. Instead they stress the value of a more social approach to making sense of their difficulties and responding to them, which addresses the barriers and material problems that they face.

The disabled people's movement developed the 'social model of disability' to challenge discrimination and help them live on more equal terms. It has become embodied in public policy and legislation. Mental health service users don't have an equivalent. Our project suggests that some have doubts about whether framing themselves in terms of disability necessarily offers an answer.

But what they do make clear is that a more rounded way of thinking, which takes account of the 'whole person' and which doesn't just see the person as a set of symptoms to be fitted into diagnostic categories, is needed for the twenty first century.

Old ways of thinking have increasingly cast mental health service users in terms of dependence and danger. The message from this study is that discussion needs to develop to explore more helpful and robust ways of thinking. This can most helpfully start among mental health service users and their organisations, as well as drawing in professionals and policymakers, to look at how new social approaches to mental health issues, policy and practice may provide a basis for improving the life chances of mental health service users.

*Taken from Peter Beresford's blog entry on the Joseph Rowntree Website where you can find a link to the study mentioned.*

[www.jrf.org.uk](http://www.jrf.org.uk)

# Recovery from Alcohol Addiction

By Patsy Staddon

I wanted to write about this because I know people are frightened of being called alcoholics and even the well-known 'Alcoholics Anonymous' (AA) embodies the very idea of shame and secrecy in its very name—anonymity; hiding your identity behind a life-long condition. I was called 'an alcoholic' for most of my life and certainly my drinking, which I did initially to help me deal with manic depression, but subsequently to deal with unhappiness and isolation, came to take over my life. I lost jobs and my family; I ended up drifting around the country and living in abandoned buildings.

That was 22 years ago. I don't drink any more—just don't fancy it---and I deal with my mental health issues, and my epilepsy, using prescribed drugs and alternative remedies. How did this happen? Is it unusual?

The truth is that there are as many roads to recovery as there are people to take them. In my case, I got 'adopted' by a couple of groups of what I suppose you'd call alternative people; one group were lesbian women with many friends and contacts, the other a mixed household who were--well, very alternative. The big deal for me was that they seemed to want my company and to talk to me but although not really drinkers themselves, they never at any point tried to stop me from drinking.

Nor did they show disapproval. I drank less and less over about a year, as I got to feel safer and more confident among them all. They also took me to social events where people talked about interesting things—politics, social deprivation, new music, alternative sexualities. I could tell them of the many adventures my downbeat life on the road had led me into, and found I could still make jokes even without a drink in my hand.

Later, when I no longer drank at all, I went to an alcohol recovery unit, but I will have to write about that another time. Let's just say it was an experience.

What I want to say here is that we can both drop labels—I hardly ever use the word 'alcoholic'; after 22 years it seems a bit of an anachronism---and adopt them. I do call myself a service user, because I may need help with my mental health and epilepsy issues at any time, even though the initial 'presenting issue' of alcoholism has disappeared.

What we must try to avoid is having our lives bound down by these labels and that can happen if you are being



called 'an alcoholic'---someone who will never recover; someone with a 'relapsing condition'.

I now hold a PhD in the sociology of women's alcohol use, and the news is that most people do recover from alcoholism and that they do so without the help of any of the known 'authorities' such as medical treatment and AA.

Anyone who is doubtful about this is welcome to email and I will send them academic references which evidence this. The reasons the old information about alcoholism is still taught in many medical schools and colleges are complex and interesting but would take up too many words to lay out here.

However recovery does take the sort of kindness and unconditional positive regard shown in more enlightened treatment centres and certainly in Shaping Our Lives. This regard can be hard for relatives and 'significant others' to give. During my research a women's group developed to try to provide the kind of support I had received myself, and it ran for several years. Now I am seeking funding to run a special social network online which can offer this to women but also to other groups; to anyone who has not felt comfortable with traditional treatment. If we get the money, you will read about it, and be able to join, here in the SOL newsletter!

Patsy Staddon

One of the directors at Shaping Our Lives.

[Patsy.staddon@plymouth.ac.uk](mailto:Patsy.staddon@plymouth.ac.uk)





**BDA Conference & AGM  
25<sup>th</sup> – 26<sup>th</sup> March 2011  
Hilton Hotel, Bradford**

To mark the British Deaf Association's New Era, following a structural review of the organisation, join the BDA as it transforms into a modern, vibrant organisation at the heart of our Deaf Community.

Unite with us as we celebrate the Deaf Community and our beautiful language. Join us at this special Conference as we come together to unveil our plans for the future of the BDA.

Enjoy a spectacular **Gala Dinner** with fantastic entertainment on Friday 25<sup>th</sup> March, followed by the Conference and AGM on Saturday 26<sup>th</sup> March – you won't want to miss it!

Book your place now to avoid disappointment – places are limited.

Booking forms are available on the BDA website [www.bda.org.uk](http://www.bda.org.uk) Please print and complete your booking form and return to: BDA, Bushell Street Mill, Bushell Street, Preston, Lancashire, PR1 2SP.

Exhibiting stands are also available for Saturday 26<sup>th</sup> March – please visit our website for more information and an Exhibitor Booking Form.

For more information:

email: [bda@bda.org.uk](mailto:bda@bda.org.uk) // text: 05603 115295 // fax: 01772 561610 // tel: 01772 259725

The British Deaf Association is the largest organisation of Deaf people in the UK that is run by Deaf people. We represent the British Sign Language community, which is united by shared experiences, history and, most importantly, by language. We celebrate Deaf Culture, Deaf Identity and British Sign Language.

**Shaping Our Lives has produced a number of publications which are available as downloads on our main website**

**[www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)**

**Relationship Matters: Building our knowledge and networks (2009)**

This report highlights how important service users, both as individuals and in groups, see networking as being, if they are to be involved as active citizens in their communities and society.

**Examples of User Controlled Research -**Changing Our World****

This important new report is now available from Involve and it includes as one of its examples Shaping Our Lives' 'Relationships Matter' project. It is available free from Involve: **[www.invo.org.uk](http://www.invo.org.uk)**

**It's Our Lives: A short theory of knowledge, distance and experience**

by Peter Beresford (published by Citizen Press in association with Shaping Our Lives, 2003)

This small book is concerned with supporting people's empowerment by valuing their knowledge and experience. To do this it explores a new idea.

**Making User Involvement Work: Supporting service user networking and knowledge**

(Fran Branfield and Peter Beresford, published by Joseph Rowntree Foundation, 2006)

**Service users have highlighted two activities as central to making user involvement work. These are: people being able to get together to work collectively for change and mutual support, and the importance of making known their own experience, views and ideas.**

This is just a selection of titles available from the Shaping Our Lives website.

For more information go to [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)

Or e-mail [information@shapingourlives.org.uk](mailto:information@shapingourlives.org.uk)

All Shaping Our Lives publications are developed by service users and are available in different formats on request.

# About Shaping Our Lives



Shaping Our Lives National User Network is a national user controlled, independent organisation, 'think tank' and network that was started in 1996. It wants to see a society that is equal and fair where all people have the same opportunities, choices, rights and responsibilities, a society where people have choice and control over the way they live and the support services they use.

## What are our aims?

- to support the development of local user involvement that aims to deliver better outcomes for service users
- to give a shared voice to user controlled organisations
- to facilitate service user involvement at a national level
- to work across all user groups in an equal and accessible manner
- to improve the quality of support people receive
- to enable groups to link to other user controlled organisations
- to develop links with worldwide international user controlled organisations

**This newsletter is available in different formats on request.**

## Contact us



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