On 22 November, we were all very excited and pleased to launch a new book called ‘We Are Not Stupid’.

This book was written by Jennifer Taylor, Maggie Brennan, Vanessa Williams, Ian Hiscutt and Raymond Johnson – otherwise known as the research team at People First Lambeth.

This unique book is about the experiences of people with learning difficulties, how they are treated and what needs to change. It was researched by people with learning difficulties who spoke to other...
people with learning difficulties. It tells their stories about being bullied and rude people, of racism and sexual abuse. But whilst some people will find it difficult to hear these truths it also talks of independence and choice, of some good relationships with staff and of standing up for your rights and yourself.

As the authors of the book say:

This is an important book for all readers. It tells people about the experiences of people with learning difficulties and what we think about the way people treat us. It will help some people without learning difficulties to understand us better, treat us with respect and think again about how they talk to us. This book is for everyone and we hope other people with learning difficulties will read it, or have support to read it, because it could help them to be more powerful.

Over 70 people attended the launch which started with speeches from the authors themselves, Peter Beresford as Chair of Shaping Our Lives and Judith Thomas from the Commission for Social Care Inspection. After a tasty lunch the celebrations continued with a disco!

A new series of books from Shaping Our Lives

The launch of We Are Not Stupid was important for Shaping Our Lives in more ways than one.

This book is the first in a new series of publications which Shaping Our Lives is publishing. We know that service users often have difficulties sharing their first hand knowledge and experience with each other and ensuring that these are readily available to inform and influence mainstream policy and practice. We know that service users and those who seek to support them frequently find it
difficult to get hold of such ‘service user knowledge’ and experience to help them increase effective user involvement and to improve the quality of services and support that people receive. At the same time, we know that they find such first hand evidence and information particularly valuable and helpful.

That is why Shaping Our Lives is producing this series of new publications. They will provide opportunities for service users to publish key findings and share knowledge and experience that can help improve the lives of service users and secure their rights and needs.

So look out for our second publication which should be following soon...

Fran Branfield

A beautiful day in Birmingham

Shaping Our Lives Annual General Meeting 2006–2007

Our Annual General Meeting, attended by members of our National User Group, was held at the end of October. We met on a beautiful sunny day at the botanical gardens in Birmingham. The venue was perfect for such a day as it allowed us all to go outside and appreciate the glorious autumn colours.

Peter Beresford, Chair of Shaping Our Lives, congratulated us all on the hard work we have done over the past year and reminded us of how far we have come in just a few short years! We all watched the DVD that was made as part of the Beyond the Usual Suspects: Developing Diversity in Involvement ‘Get Together’ day earlier in the year. We are very proud of this DVD which will soon be available as part of the resource pack that we are developing.

Photographs © Juan Romero
Lead policymakers and service users debate social care

Recasting the Future of Social Care Together: From existence to living, 14 November, London

This debate was jointly organised by Brunel University and the Commission for Social Care Inspection, with Shaping Our Lives playing a key role in inviting service users. It took place at The Resource Centre in north London.

The event was also supported by 18 key social care organisations across public, voluntary, private and service user sectors, including the Joseph Rowntree Foundation, Shaping Our Lives National User Network and the British Association of Social Workers.

The aim, successfully achieved, was to bring together a unique mix of lead policymakers and a wide range of service users to explore how to get the social care – and independent living for everyone in the future – that service users have been pioneering. The day focused on two key questions.

◆ Why are people still facing problems, being bullied and feeling lonely when we know what works to support people to live better lives?
◆ What can we do to make sure that many more people who use services get the support they need to have real choice and control?

Most time was spent in discussion, with presentations from David Behan, Director General for Social Care, Denise Platt of the Commission for Social Care Inspection and Peter Beresford of Brunel University.

A report is being published to be fed into the Department of Health consultation about reforming social care and this will be available from Shaping Our Lives.

David Behan, Department of Health, listens as Peter Beresford describes some of the difficulties that service users face. Photo © Brunel University.
Project updates

Beyond the Usual Suspects: Developing Diversity in User Involvement

Update from project worker
Michael Turner

Shaping Our Lives’ project Beyond the Usual Suspects, has moved into its final phase with work beginning on a resource pack for service users and service providers.

The resource pack will be based on the work of the project and what we have found out about diversity issues through the development work carried out for the project by four local service user organisations.

These four organisations are a group of black mental health service users, a group of people with learning difficulties, a women’s alcohol support group and a mixed user group with different types of service users from a range of backgrounds.

The pack will cover a range of issues around general good practice in user involvement and how to increase the number and diversity of service users who take part.

Topics covered in the pack will include:

◆ different ways of approaching user involvement;
◆ holding events;
◆ making events and user involvement accessible;
◆ promoting events and user involvement.

The four local service user organisations working with Shaping Our Lives’ project have had an opportunity to look at draft sections of the pack with some of their members and have given us feedback on the work so far.

This will help us to make sure that the pack covers issues that a range of service users have told us are important and useful. Work is still underway on the pack, so if you have any ideas about something that should be in it, please contact me.

A key part of the pack will be Shaping Our Lives’ new DVD on user involvement which was filmed at the ‘Get Together’ event held for everyone involved in the project in March. It was produced for Shaping Our Lives by the award-winning Arcadian Productions, a film-making company run by disabled people.

The DVD features a wide range of service users speaking about a range of user involvement and diversity issues. It will be available as part of the resource pack which will be launched next summer.

For suggestions about the resource pack please contact michael@shapingourlives.org.uk or telephone the Shaping Our Lives office.
Project updates

The Standards We Expect

*Update from project worker, Michael Glynn*

The *The Standards We Expect* project is working with eight partner services from across the UK. It is supporting their development of person-centred support.

The project is finishing its work with individual partner services. It is starting work on its final report.

Throughout the summer we arranged a programme of workshops for

- service users
- practitioners
- managers.

We held 25 workshops all across the UK. Over 140 people attended. Fourteen different trainers were involved. The trainers were either service users or practitioners. Feedback shows that people found the workshops very useful. They have already led to changes being made to make services more person centred.

We held our second national ‘Get Together’ event in London on 17 October. More than 60 people came along. This included 25 service users. We wanted to find out what people thought about some of our findings so far. We also wanted to talk about what happens after the project ends.

Some of the main things we talked about were:

- basic human rights of service users often not being met;
- many people who work in services don’t have basic support and supervision;
- most attempts to change services are still ‘top down’;
- service users and practitioners often have similar ideas about how to make services better;
- service user-driven culture change.

*Photograph © Shaping Our Lives*

If you would like further information about this project, visit the website at [www.standardsweexpect.org](http://www.standardsweexpect.org) or telephone 0116 257 7773.
Michael Turner tells us about this new report published by The Social Care Institute for Excellence. The report is based on a project carried out by Shaping Our Lives with the National Centre for Independent Living and the Disability Research Unit at the University of Leeds.

Developing social care – service users driving culture change (Knowledge Review 17) looks at how user involvement has brought about changes in social care and social work and how such changes have become part of the culture of organisations providing services.

The key findings of the project were:

- user involvement itself is the main area that needs to be improved and developed in social care. When user involvement is improved it can have a bigger impact on services. While the project found a range of good practice through true partnerships, it also found too many examples of tokenistic involvement;
- there appear to be different levels of user involvement for service user groups, with some groups being excluded from the process;
- service users and service providers need to have the same concerns and priorities in order for involvement to have a bigger impact;
- relationships between service user and service provider organisations and the individuals who make up those organisations are crucial to making positive changes and ensuring that those changes become part of an organisations’ culture.

Achieving this type of culture change is often a long-term process. Funding is a key issue in achieving change in several ways – this includes the crucial issue of funding for service user organisations so that they are
Developing social care
Service users driving culture change

able to be part of the process of change and making sure that service providers have the resources to make changes and improvements.

However, funding is not the only issue and the project found a range innovative schemes and initiatives that involved making better use of existing resources.

The key message from the project is that change and progress have to be linked to the development of service user involvement and that user involvement itself is the key cultural change that many service providers need to begin with.

Developing social care - service users driving culture change (Knowledge Review 17) is available to download as a PDF file from the Social Care Institute for Excellence website at:

www.scie.org.uk/publications/knowledgereviews/kr17.asp

If you are not able to download the report or need it in an alternative format contact the Social Care Institute for Excellence’s publications department on 020 7089 6840.

Stand up for your rights!
A win in court for SOL Director

On 7 December 2006, the Director of Shaping Our Lives, Fran Branfield (pictured left), was told by a mini cab driver in London that he would not take her guide dog in his cab.

Fran contacted the public carriage office who issue the taxi licences and they prosecuted the driver. The case finally came to court in October and the driver was found guilty and fined £650. We are really pleased with this result and would urge other disabled people who are discriminated against to use the Disability Discrimination Act to fight unacceptable and oppressive behaviour.

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Profile: Women’s Independent Alcohol Support

**WIAS (Women’s Independent Alcohol Support)** is a service user-led organisation which grew out of service user-led research in the field of women’s experiences of alcohol issues and of the treatment services.

Women who took part in the research said that they would value a way of socialising which enabled them to talk to other women and did not involve being told how they should be living their lives. Several of these women met up and decided what they would like to have happen at their meetings – for example outings, workshops, speakers, and most of all a chance to relax and chat in a safe environment.

**WIAS Helpline**

WIAS meets regularly on alternate Saturday afternoons but members also keep in touch and meet up outside those occasions. Our telephone line (0117 373 8797) was only set up to share information about what the group was doing, and about alcohol treatment in the area which we had heard was woman user-friendly. In practice it receives calls from all over the country from women who want advice and/or have been repelled by conventional alcohol treatment and the advice of some GPs.

We know from calls received on this line that many women are quite desperate to receive information which is not being provided elsewhere. They also feel better for talking to other women, all of whom have had severe alcohol problems but have overcome them, and are able to offer a variety of possible ways forward.

WIAS was funded for one year by Community Champions, but this funding has come to an end and we would welcome financial support, if only to enable us to keep our ‘helpline’ running.

If we had a motto it would perhaps be ‘no blame, no shame’.

Patsy Staddon
WIAS Joint Co-ordinator and Shaping Our Lives National User Group member.

To contact the WIAS helpline or if you have ideas about funding please telephone 0117 373 8797.
Disabled people raise issues through public art projects in Bolivia

“I don’t have a problem, the problem is theirs’

So said a participant in a research project recently completed in Bolivia. The work used a combination of traditional research methods and public art murals to investigate the priorities and demands of disabled people.

In each town, inauguration events were held at which local authorities, non-governmental organisations, media and the public listened to disabled people explaining the meanings of the murals.

One example of these murals is from Santa Cruz in the east of Bolivia. This design incorporates the ideas of many different disabled people.

On the right there is a tower. People from non-governmental organisations are seated on top drinking fine wine, with bags of money beside them supposedly for disabled people. A lonely figure reaches out, but he is too distant and isolated to reach the people organising on the ground below.

At the base of the tower, a blind man bumps into a pillar in his path. A
disabled woman searches in the rubbish to find some way of surviving.

Meanwhile, on the other side of the picture, disabled people are cultivating the ground, building an inclusive school and campaigning to get work, justice, equal rights and recognition of sign language.

In the sky above, there is a flock of geese. One participant described how the association he is involved with provides support in a similar way to the solidarity of geese. If one goose has a problem it comes down to earth with two others. They support each other until all are fit to fly again.

The sun represents equality. It rises and sets for everyone regardless of impairment or status.

To find out more...
Email: rebeccay@blueyonder.co.uk
Telephone: 07986 897234

Photographs © Andrew Bolton
Who or what has had the greatest influence in your life?
Religion has had the greatest influence in my life although at present I don’t have one.

What is your most treasured possession?
My mind.

If you had one wish, what would it be?
World peace and prosperity.

What, if it were up to you, would you ban?
Racism.

If you could change one thing in health and social care services what would it be?
The power dynamics between service users and professionals.

What makes you laugh?
Children being themselves.

What trait do you like least about yourself?
I can be wishy-washy at times (indecisive).

What trait do you most dislike in other people?
Forgetfulness.

What is your idea of perfect happiness?
Everyone living their lives in a way that doesn’t hurt anyone else (human, plant or animal).

What is your favourite film or television programme?
My favourite film is ‘Under cover brother’ and my favourite television programme is ‘Question time’.

What has life taught you?
That true love does not run smooth.

How would you like to be remembered?
As someone that cared and did something for her fellow man.

Patricia has worked with, and been involved with, Shaping Our Lives from its earliest days, ten years ago. She is currently joint treasurer. She is also the coordinator for BUGS, a black mental health service user group. Patricia is active in the disability arts scene and is a poet.
Graffiti Wall
Favourite sayings

Smile at the world and the world smiles back at you

The only way to predict the future is to invent it yourself

Don’t get mad, get even

You don’t need a weatherman to know which way the wind blows

I MAY BE CHAINED TO THE PORCH BUT THAT DOESN’T MEAN I CAN’T BARK AT THE PASSERSBY!

It’s amazing what you can do in a day

Pavements are for pedestrians!

Mind the gap!

Always look on the bright side of life

There’s now’t as queer as folk

Tra-la-la... Tomorrow is another day!

Nil illegatari carbarundum (Latin for: Don’t let the b*****ds grind you down!)

Follow your heart and be the person you want to be

For our next issue we would like to do something a little different. We would like to hear from you! Who or what has inspired you, and why? We will try and include as many contributions as we can.
**Over the top**

I am a lesbian  
Who makes people cringe.  
I don’t keep a low profile  
And I just love to binge.

Alcohol, chocolates, tobacco or jam  
If I think it’s tasty, it’s catch as catch can.

I used to feel sorry  
I was so diseased  
That I did what I wanted  
I did what I pleased.

What a terrible thing, to be giggly and fat  
When everyone knows that girls shouldn’t do that.  
I shouldn’t take drugs which allow me to fly.  
That’s reserved for the angels; you first have to die.

But I like to travel, to reach for the sky,  
So I use lots of caffeine, so I can get high.  
I paint and I shout and I scribble rude verse  
And as I get older...yippee! I get worse!

Patsy Staddon

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**Now it’s your turn...**

If you’ve got creative talent – for painting, cartoons or poetry – and you’d like to share it with a wider audience, why not send it in to our website? The redesigned Shaping Our Lives website at [www.shapingourlives.org.uk](http://www.shapingourlives.org.uk) has some gallery pages in the Get Creative! section, just waiting for your contributions.

We won’t be able to put up everything we get in, but if you send digital versions of your paintings, drawings, cartoons (as jpeg files) or poetry (as Word files), with your name and contact details, we will do our best to put them up on the website.

Just email them to Jenny at [jenny@shapingourlives.org.uk](mailto:jenny@shapingourlives.org.uk). (Don’t be shy – share your creativity!)
The Shaping Our Lives networking website, SOLNET, continues to flourish. It now has over 200 members and Friends. In September a regional event was held in Carlisle to promote the networking potential of the site. Twenty people from different parts of Cumbria got together to discuss how they might find SOLNET useful in their own work. If funding allows we would like to hold similar events in other parts of the country.

The Social Care Institute for Excellence generously funded SOLNET’s development for the first 18 months. That funding has now ended but we are committed to keeping SOLNET going from strength to strength. Please let us know if you have any bright ideas for future funding.

The noticeboard is a key feature of SOLNET and is updated frequently with information about events, publications, jobs, and other things relevant to service users. Please have a look! Members of SOLNET can post messages onto the noticeboard themselves, or they can ask the project administrator, Eamon Andrews, to help if they like.

Eamon can be contacted by email: eamon@shapingourlives.org.uk or telephone: 0845 241 2128. If your organisation hasn’t yet joined SOLNET, have a look at www.solnetwork.org.uk and get signed up!

Welcome, Nathan!

In the last edition of our newsletter we reported on the retirement of Shaping Our Lives’ Director Fran Branfield’s guide dog, Shep.

Shep is now happily settled in Yorkshire and new guide dog, Nathan (pictured at the Standards We Expect ‘Get Together’ day in October), has taken up the harness!
Shaping Our Lives National User Network is a national user controlled, independent organisation 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.

All photographs © Joanne O’Brien unless otherwise stated.