Now we are 10!

On 7th November 2006, Shaping Our Lives celebrated ten years of championing user involvement.

The ten years have seen Shaping Our Lives develop from a project based at the National Institute for Social Work to a fully independent organisation working in partnership with service users all over the country. Speakers at the party included Shaping Our Lives’ Chair, Peter Beresford, and representatives from the National User Group. Other speakers were David Behan from the Department of Health, Daphne Statham formerly of the National Institute for Social Work and Denise Platt from the Commission for Social Care Inspectorate. Guests were entertained by Caribbean drumming. To read comments on our first 10 years, please have a look at page 13.
Joseph Rowntree Foundation published our new report at the end of last year. The report is called ‘Making User Involvement Work: Supporting service user networking and knowledge’. Fran Branfield, Director of Shaping Our Lives, tells us more.

We talked to a lot of service users who told us that they thought it was very important that service users could get together to support each other and work together for the things they wanted. They also said it was very important that service users could talk about their experiences and that other people listened to their views and ideas. This project talked about the problems and difficulties and things that got in the way of proper networking and knowledge. The report talked about things that could be done to make it better and to give service users more opportunities to be listened to.

Here are some of the problems that you told us about:

◆ Service user organisations and individual service users are often isolated and do not have enough money to involve a wide range of people.

◆ Service users see user networking as very important for positive participation.

◆ Service users feel that what they know is often not taken seriously by professionals, policy makers and services.

◆ Service users said there must be user led training in services, and this also means including all sorts of different service users, to hear what everyone has to say. Service users should be supported more so that what they know is listened to by the people who make decisions over their lives.

To find out more about this project, or to download a copy of the report please either contact the office or go to our website: www.shapingourlives.org.uk.
Beyond the usual suspects: developing diversity in involvement

Michael Turner brings us up to date on this Shaping Our Lives project which is looking at ways of increasing diversity in user involvement.

All four local groups working with Shaping Our Lives on this project held events aimed at attracting service users who have not taken part in user involvement before.

The events were:

◆ A social happening held by the Black user group with entertainment from African drummers and discussions about issues around user involvement;

◆ An open day held by the women’s alcohol support group - this included workshops in music and reflexology and the opportunity to socialise with women with similar experiences.

◆ An open day held by a group of mixed service users – this included workshops in alternative therapies, a poetry reading and a visit from the mayor.

◆ An event at a college with people with learning difficulties with karaoke, singing and dancing, and talks and discussions about how to get involved.

The number of service users at the different events varied but all of the groups did very well in terms of reaching service users who have not been to user involvement events before.

As well as being successful events in themselves, they have highlighted a range of issues and pointed to a number of important lessons that the project will need to address, such as how to publicise work and reach new service users and how there are often ‘gatekeepers’ who you have to get through to reach many service users.

The events could not have happened without a huge amount of time and effort from the members of the four groups, and particularly their co-ordinators – thanks to them all from Shaping Our Lives.

In addition to the work of the four local groups, we sent out a large questionnaire about the issues covered by the project. Although it was a difficult questionnaire to fill in we had 120 returned and are doing work with groups to reach people who may not have been able to complete it, including an interview with a group of people with communication impairments and an interview at a residential home. Plans for the rest of the project will be drawn up in March.
Networking

Networking Website
Our networking website continues to grow. It is supported by funding from the Social Care Institute for Excellence which lasts up until the end of March. We are currently seeking funding to continue developing the site. If you belong to a user controlled organisation which has not yet joined please have a look at www.solnetwork.org!

Providing inspiration for Norwegian service users
Last June a group of mental health service users from Norway came for a meeting with Shaping Our Lives to find out what we do and get ideas for setting up a similar network in Norway.

Shaping Our Lives meets Minister for Social Care, Ivan Lewis

Shaping Our Lives is increasingly being recognised as the national voice of service users. On 21st November 2006 five of us from the Management Group met with the new Minister for Social Care, Ivan Lewis (pictured centre). We made clear to the Minister that we shared the government’s stated commitment to service users being in control, to self-directed support and to effective user involvement and the resourcing of a strong network of service user controlled organisations.

We stressed that we were keen to help the government take forward this agenda in all ways possible. We highlighted the work we have been doing on enabling diverse involvement in social care and how we could help the government by drawing on this experience in any consultations or activities for involvement it undertakes.

The Minister listened as we reported on our progress, asked questions about our work and responded by saying that he would be very pleased to speak at an event which we organised. We said we would be very pleased to take up his offer and are currently working on how best to do this. Watch this space for further information!
Shaping Our Lives conference at St Martin’s College in Cumbria

St Martin’s College, based in Lancaster, Ambleside and Carlisle, contacted Shaping Our Lives to ask for our help to run a conference about promoting service user involvement in social work education. The conference took place on Tuesday 7 November 2006 and we organised and ran five workshops. These were about involving young people with experience of the care system, older people, people with learning difficulties, people from black and minority ethnic backgrounds and also one on student placements in service user controlled organisations. A wide range of people took part in the conference including service users, students, academic staff and some practitioners. Entertainment was provided by ‘Positive Spirit’, a West Cumbrian group, and we reprint one of the poems that was performed at the conference overleaf, introduced by its author, Lynda Kirkbride.

A full report of the conference is being prepared. If you would like a copy please contact Shaping Our Lives – see back page for contact details.

Funding cuts to independent user-controlled organisations

At Shaping Our Lives we have heard from a few independent user controlled organisations who have had their funding cut. We are very worried about this. Please can you let us know if this has happened to your organisation so we can find out more about the situation in different parts of the country? Please send any information to Jenny Willis at Shaping Our Lives – see back page for contact details.

Recruitment of new members for INVOLVE

INVOLVE promotes public involvement in NHS, social care and public health research. It is funded by the Department of Health. The group has been in existence for ten years and meets four times a year, usually in London. Members sit on the group for three years. We think that we will be advertising for new service user members in late Spring.

If you would like to know more and make sure you hear from us when we are advertising please contact Roger Steel by telephoning 023 80 626 233, emailing rsteel@invo.org.uk or writing to him at INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hampshire SO50 9FD.
My name is Lynda Kirkbride and I am a mental health rights campaigner and member of a group called **Positive Spirit**. We use creativity to raise mental health awareness and promote well-being. We aim to challenge stereotyping, break down barriers and reduce stigmatisation through art, poetry and drama. The remit fits my personal aims and aspirations around mental health awareness, social inclusion and the promotion of well-being through creative means.

**Just so vain**  
© Lynda Kirkbride

It takes guts to sit here,  
With you looking down your nose.  
I can do poetry,  
I can do prose.  
I've got a brain in my head  
But you, you're **just so vain**.  
You think you've got the upper hand  
You've got all this power at your command  
You decide if I stay or go.  
Incarcerate me, lock me up,  
Throw away the key.  
Friend or foe are you?  
– I don’t know,  
**Who** my friends are.  
How could I?  
I'm insane  
But you –  
You're **just so vain**.  
You're up there,  
In the air.  
Psychiatry is your forte  
Your domain  
You're 'da main man'.  

You're revered,  
You're a success  
You sit there  
At your desk.  
You tinker with my pills  
Like you're Merlin,  
King of wizardry.  
Puff, and then I'm gone  
Disappeared  
Off the face of the earth.  
But hang on,  
Wasn't I all along?  
Isn't that the point?  
I'm not really here at all!  
I'm a figment  
Of **your** imagination.  
It's **you** that's delusional.  
How can I be the one?  
I don't exist.  
I'm invisible.  
I was all along.  
Get it?  
Oh, you will,  
Because it's catching.  
Here!  
Take your own damn pill!
Patricia Chambers, the Co-ordinator of BUGs, tells us about the group, including how it started and what its main activities are.

BUGs was started in 1996 it came out of what the head of mental health services at the time saw was a need in our borough for a black user group. It was funded by the then EHHHA (Ealing, Hounslow and Hammersmith Health Authority) and had six management members and regular attendees. The remit of the group was to advise black mental health service users on matters of mental health and, if we could not help, to refer them on to the people or the agency that could.

We also wanted to carry out advocacy on behalf of black mental health service users, co-ordinate between groups of black mental health service users and have a joint voice. Another service we wanted to offer was to visit black mental health service users on the hospital ward to see whether there was anything that we could do for them and invite them to visit us. When visiting we tried to take little items in for them such as soap and fruit juice. These visits were very popular with the clients and made us some lasting friendships.

Today we hold a drop-in once a month and still try to do the ward visits. At the same time, we are involved in user research and join with other black service users to do this. We feel that this is a vital area of mental health that deserves our support.

We believe in encouraging black service users to realise that there is a life after mental illness and that it can be lived to the full. We are also willing to work with any others who will encourage and support this ethos.

To get in touch with BUGs, contact Shaping Our Lives – see back page for our full contact details.

Shaping Our Lives Chair gets OBE

We are all delighted and extremely proud that Peter Beresford our Chair is to receive an OBE (Order of the British Empire). Peter is being honoured for ‘services to social care’.

This is the second award this year for Peter as he was placed in Disability Now’s top ten of most influential disabled people. We are very encouraged to see this recognition of a service user’s commitment and hard work. Well done Peter!
What is the Standards We Expect? It is a research and development project that lasts for two years. We are funded by the Joseph Rowntree Foundation.

◆ We want to find out what stops the support people get from being person centred.
◆ We want to know how we can get over these barriers.
◆ We want to find solutions based on what service users say.
◆ We hope our work will influence the people who design and run services.

What is person centred support?
That is one of the questions we are asking! It means different things to different people. We think it is about asking each service user what support they need and making sure that services are flexible enough to provide it. It is not giving the same things to everyone.

It is not ‘one size fits all’. A person centred service provides the right support that a person needs to live independently.

Why is the project important?
It is important because lots of people find that services are not person centred. We want to find out why that is. We want to find ways to improve services based on what service users and front line workers think.

Who is running the project?
It is run by a group (called a consortium) made up of:
◆ Shaping Our Lives
◆ De Montfort University
◆ Brunel University, and
◆ Values Into Action.

The consortium also has researchers who are experts at working with:
◆ older people
◆ people from black and minority ethnic groups, and
◆ social work practitioners.

Can anyone take part?
The project is working with 20 projects across the UK. Eight of these are project partners who we are working more closely with. These projects were chosen by the Joseph Rowntree Foundation. There were lots who wanted to take part.

We are interested in what everyone has to say so please get in touch if you want to tell us something about person centred support.

What has the project done so far?
In our first year the project has gained ethical approval, appointed a Project Worker and been working with people
from our eight partner sites in England and Scotland. We have held lots of meetings and interviews with managers, front line workers and service users at these sites. It is important we understand what local people think of their service and how it could get better.

**What was the Get-Together?**
We held a big meeting in London in November. We invited people from the 20 projects across the UK. We called it the Get-Together. It was a chance for the people involved in our project to meet and get to know each other. It was a chance for service users, front line workers and managers from different projects to talk and swap ideas. It helped our project to find out what people think. We wrote a report about the event and will be writing more about it next year.

**What happens next?**
We are supporting the 8 partner sites to make changes to their services. We are doing this by giving training, advice and sharing good practice. Each site is different but they have a lot in common. We will be holding another event in the autumn to talk about what has changed. We will be writing a final report at the end of 2007.

**Contact details**
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**Workshop participants at the Get-Together meeting**
Knowing Me, Knowing You
Munir Lalani

Who or what has had the greatest influence in your life?
My brother, Rustam, who humbly donated his kidney to me, without question. That’s real unconditional love.

What is your most treasured possession?
A book of prayer which we brought from Uganda, handed to my mother from her mother. It has been in my family for at least five generations or perhaps more.

If you had one wish, what would it be?
To make poverty history. It creates strife.

If it were up to you, what would you ban?
All war, and conflict and weapons of mass destruction. Just imagine a small percentage of weapons spending being spent on development or health and social welfare. Imagine what could be achieved!

If you could change one thing in health and social care services what would it be?
I would put service users at the centre of all decision making processes. After all if people like me were not mad some of these people would be out of a job.

What makes you laugh?
I laugh at the irony of life. I’d rather laugh than cry.

What do you like least about yourself?
I am too easy going. In the past I have been taken advantage of by unscrupulous people.

What trait do you most dislike in other people?
People’s pettiness, jealousy and hypocrisy – the green-eyed monster. People forget the old Indian saying: ‘Shrouds have very tiny pockets’.

What is your idea of perfect happiness?
The idea of perfect happiness is a misconception. If it existed life would be extremely boring. A bit of unhappiness keeps us going, so that we can have a moan, then go about our business.

What is your favourite film or television programme?
There are many. My favourite three are firstly Casablanca, then Spartacus, and lastly a more recent film Schindler’s List. I also like The Two Ronnies!

What has life taught you?
That tenacity and perseverance can overcome the most ardent of foes.

How would you like to be remembered?
As a tenacious activist who worked hard for marginalised service users, especially within the black and ethnic minority community, particularly the new and emerging communities, who died at 120 surrounded by his friends and family.
Graffiti Wall:
Shaping Our Lives is ten!

Here are some extracts from comments written in Shaping Our Lives’ birthday book:

More power to your collective elbow.

I have grown and been supported and allowed to express myself. Thank you, Shaping our Lives.

Inspirational and influential...thank you for sharing your experience and expertise and making an impact.

Lovely ethos and ambition

I hope SOL does not become SOS.

Shaping Our Lives is leading the way in service user involvement. I hope the next 10 years are even more successful.

Congratulations on 10 years, here’s to lots more.

So much to achieve, so much has been achieved – here’s to another 10 years!

Your contribution to transforming social care is very special.

Fantastic achievement - keep going strong.

Huge congratulations – you’ve been a real inspiration and a hope for me both professionally and personally – thank you. Here’s to another decade!

It’s great to see such diversity of membership and commitment to furthering service user issues.

Keep going strong!
People are saying they want to take control of their lives and choose the way they are supported. To help people make their own decisions, the government is clear that self-directed support is the future for delivering social care.

This will put people and their families in control by offering personalised services and giving them the freedom to choose the type of support they want.

The work on the Individual Budget Pilot Programme is an important part of this, and it sits alongside the work to increase the number of people who receive their care services as a direct payment, and the In Control programme. The Department of Health is leading the programme and working closely with the Department for Work and Pensions and the Department for Communities and Local Government. The pilot will run until the end of 2007.

Individual budgets put people in the centre of the planning process, and recognise that they are best placed to understand their own needs and how to meet them.

It is a flexible way of doing things that lets people who are satisfied with existing services to keep these, but also gives a range of options for building up more tailored support, using direct payments and other routes.

Individual budgets bring together funding from more than one agency. People are given a clear, up-front idea about how much money there is and they can use it in a way that best suits them.

Thirteen Local Authorities are taking part in the pilot. Each site is trying Individual Budgets in different ways, with different people and using different funding streams. The work will be independently evaluated to check how individual budgets work for the people who get them, and everyone else involved. The results of this should be ready by April 2008.

Many organisations – including Shaping Our Lives – are interested in this work. Because it is important we hear everyone’s views, we have formed an Individual Budget Reference Group and two sub-groups made up of organisations that have a user focus and a provider focus. They meet regularly to discuss what is happening in the pilot sites and

Jaimee Lewis, Communications Advisor for the Individual Budgets team at the Department of Health, writes...

Individual budgets:
Two views

to share information. Changing from how things are set up now, to a system where Local Authorities can provide self-directed support and give people individual budgets means massive changes. A team from the Care Services Improvement Partnership (CSIP) will help with this.

With things moving as fast as they are, it is important that people whose expertise in using the social care system can be involved in steering and communicating the changes. Last December, CSIP arranged for 30 disabled people and family members, with a wide range of experiences and backgrounds, to come together for two days in an ‘Academy of Self-directed Support’.

They heard about the history of the care system, about the ideas behind self-directed support and had the chance to learn what is happening across the country. The Academy was run as part of CSIP’s ‘Having a Voice’ programme and paid for by the Department of Health and the Social Care Institute of Excellence. Everyone who went worked hard, but came away feeling excited that it could be the start of something bigger.

They are now working with others in the regions they live in to build the expertise of more disabled people and to build new alliances with people and services developing self-directed support.

If you would like further information about self-directed support or the Individual Budget Pilot Programme, please visit www.sdsnetwork.org or www.individualbudgets.csip.org.uk.

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**Back in the year 2000** Shaping Our Lives published a leaflet called ‘The Outcomes We Want and How We Can Achieve Them’.

This was based on work that found that service users who had the most positive outcomes from support services were people receiving direct payments, and the leaflet said:

‘It is important to ensure that direct payments should become available to everyone who wants to use them. However, this should in no way detract from the need to ensure that traditional services become empowering and responsive to users’ needs.’

It seems that individual budgets – which are also called self directed support – might just be the response to this challenge.

People supporting the development of individual budgets say that service users can make better and more realistic plans. There is also meant to be a lot ...continued overleaf
more flexibility in what the money can be spent on. For example a man could use part of his budget to pay for a season ticket for a friend to take him to see his favourite football team, rather than having a personal assistant to do this. It’s hard to hear about individual budgets without getting a feeling of having heard it all before: the things being said about giving service users real choice and control are very much the things that were being said about direct payments when they were first started 10 years ago.

Direct payments have delivered a lot but only for a relatively few people. In many areas social services have been very restrictive about the way users are allowed to use their payments. It is not clear whether this is because there is a problem with direct payments or whether they have not been properly supported by social services at a local level.

Individual budgets are not meant to be a replacement for direct payments – they are meant to remain an option within the individual budgets system – but there does seem to be an implication that the new system is some sort of replacement. There is also a feeling that while many service users have been involved in the development of individual budgets, it is receiving such vigorous support from the government and those involved in the pilot areas that are testing out the new approach that it feels like a ‘top down’ approach.

The team supporting the introductions of individual budgets is working to involve more service users in this process and is keen the highlight the undoubtedly good experiences of service users who have been part of the pilot schemes.

Part of what makes it so difficult to believe that individual budgets are going to be as good as they sound is that there are so many other negative things happening at the moment with cuts in services and particularly with cuts to service user organisations.

This causes the real fear that system could become too focused on the individual and that people could be too much at the mercy of professionals and carers/relatives who may dominate the individual budgets process, even with the best of intentions.

Michael Turner

What do you think?

If you have any experience of direct payment or individual budgets that you would like to tell us about, please contact Jenny at Shaping Our Lives (contact details on back page).
New members join our National User Group

Alison Black

I would like to thank Shaping Our Lives for being invited on to the National User Group. I hope I will bring some good work and support to the network.

I am Alison, from Northern Ireland. I have slight learning difficulties and I experience mental health difficulties. I have been a cross dresser/transvestite for over 12 years. In 2005 I lived as a woman for 11 months, but I had to stop due to the problems I had from people. I was happy but society was not, so I reverted back to male gender but I wear all female clothes and attire. I would be lost without my handbag!!

Even though I am male I consider myself to be female; instead of ‘Mr.’ I prefer to be called ‘Ms’. I am 33. I like walking, socialising, pen-palling, surfing the internet, and lots of other things.

I have recently raised money for Marie Curie, Macmillan Cancer Support and Barnado’s. I am a member of Disability Now, Values Into Action, Amnesty International and The League Against Cruelty to Animals.

Amanda Wells

Originally from Yorkshire, Amanda moved to Mid-Wales in 1983 to study English at Aberystwyth University. Apart from a year travelling in Europe, she has been in Mid-Wales ever since, and now lives in Newtown, Powys.

Amanda began using mental health services in 1991, and became involved in voluntary work as a service user/survivor representative in 1996. Over the years she built up her experience and skills, and in 2003 became self-employed as a survivor trainer/consultant. She still uses mental health services, and also has a physical impairment.

Amanda enjoys writing, and has recently had her novel *The Dispossessed* (under the pen-name Rosamund McCullain) published as a paperback by Chipmunka Publishing. She also loves animals, and has two cats, two dogs and a horse who help keep her going when times get rough. With two survivor colleagues, she recently established Ffenics Ltd (Welsh spelling of ‘phoenix’) a co-operative social enterprise ‘by and for’ people with mental distress (www.ffenics.coop). Amanda is looking forward to working with Shaping Our Lives, and has a special interest in how to improve services in rural areas.
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 in this edition, except those on page 6, © Joanne O’Brien.

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