SOLNET turns one

At the end of May we celebrated a year in the life of SOLNET, our networking project.

SOLNET is a website where service user groups can network with each other, share information and let people know about their organisations. It was important for us that this website was owned and controlled by service users before we opened it up to other types of organisations. Once we had over 150 service user-controlled member organisations we felt it was time to think about inviting non service user groups to join as ‘friends’ of the network.

During the day, chaired by Peter Beresford, we heard Mayo Marriot from Independent Living Alternatives and Shaping Our Lives talk about what the network means for service user organisations. Then Kate MacMullen from the General Social Care Council and Roger Steel from INVOLVE talked about the benefits, from their own organisations’ perspectives, of joining SOLNET.

Eamon, the SOLNET administrator, was on hand to demonstrate the website and show people how they could use it. If you haven’t joined SOLNET then take a look at it now! It is free for service user organisations to join and we are asking ‘friends’ who want to join to make a suitable donation to the running costs.

To find out more go to www.solnetwork.org.uk or contact Eamon on 0845 241 2128 or Jenny on 0845 241 0383.
The end of the first phase of the Beyond the Usual Suspects project was marked by a ‘Get Together’ event in March which brought together people from all the service user organisations taking part in the project. Project Worker Michael Turner tells us more.

These four groups – a black mental health user group, a group of people with learning difficulties, an independent support group of women who have had problems with alcohol and a group with a mix of users of different services – have all worked with us on this project.

They were joined at the Get Together by members of the project Advisory Group and members of the Shaping Our Lives National User Group.

This was an opportunity for everyone involved in the project to share their experiences and discuss what has been learned from the work that each group has carried out on increasing diversity in user involvement. There was a particular emphasis on under-represented groups such as users from black and minority ethnic communities, young people, people who communicate differently, and people whose support needs are expensive.

Each group gave a presentation about their experiences and we talked about the responses to the questionnaire that has been carried out for the project. Workshops in the afternoon were an opportunity for everyone at the day to discuss and explore the issues further.

The findings so far

The work so far has shown that, if we want to increase the number and diversity of service users taking part, it is essential to make involvement a positive and accessible experience for everyone. Once this has been done, specific work can be undertaken to reach and involve under-represented groups.

Feedback from the day has been extremely positive, with most participants saying how useful and positive it had been to meet with such a wide range of service users from such diverse backgrounds.

A particular highlight of the day came at lunchtime when the booked entertainer was unfortunately unable to come and two members of the black user group stepped up without even pausing for breath and wowed everyone with their poetry – all from memory.
Developing the resource pack
The whole day was filmed and a DVD is being produced which blends the events of the day with interviews with many of the people involved. This DVD will be a key part of the second phase of the project which is the production of good practice guidance and resource material on increasing diversity in user involvement.

Work is already underway on this material but we are also keen to hear about any other training and guidance material on user involvement so that we can learn from others’ experiences.

If you have any material like this – or would like to find out more about the project or tell us about anything that might be useful – please contact Michael Turner at michael@shapingourlives.org.uk or ring Jenny on 0845 241 0383.
The Standards We Expect
The project moves forward

The Standards We Expect project has been moving forward quickly in 2007. It seems like a long time since our last update in January. We have been busy with lots of things.

◆ We have written our first major report. This tells people what we found out at our Get Together event last year. It is about what people said to us. They were service users, practitioners and managers from our 20 project partners.

◆ We have launched our website (www.standardsweexpect.org). This has lots of information about the project and good practice examples from our partner projects. It has a forum where people can ask questions and send replies to each other.

◆ We are in the middle of giving a programme of workshops for groups of service users, workers and managers at our project partner sites. This is an important part of the development work our project is doing. The workshops are a chance for people to come together in groups and talk about what makes services person centred. We talk about people’s rights and look at practical changes that people can make to make services better.

Background

The Standards We Expect project is guiding and supporting the development of person centred services in 8 areas of the UK. We are trying to find out what stops services from being person centred and how these barriers can be overcome. We are funded by the Joseph Rowntree Foundation.

We are working with lots of different types of services. They include:

◆ a service for young adults with physical impairments
◆ services for people with learning difficulties
◆ a partnership of services working with people as they approach the end of their lives.

The project is run by a group (called a consortium) made up of:

◆ Shaping Our Lives
◆ De Montfort University
◆ Brunel University
◆ Values Into Action

The consortium also has researchers who are experts at working with:

◆ older people
◆ people from black and minority ethnic groups
◆ social work practitioners.

To find out more please visit our website: www.standardsweexpect.org.

Michael Glynn, Project Worker
Social Policy: An important event for service users

On 5 June 2007, with the support of the journal *Critical Social Policy*, Shaping Our Lives organised a seminar focusing on service user views and ideas about welfare reform. Service users talked about their experience of existing policies and services, across health, housing, education, social care, children’s services, benefits, planning and so on. They also identified the kind of social policy they want to see for the future.

The day worked really well and participants were very positive about it – both about having the opportunity to contribute and share views and about having the chance for their views to be included in the journal and also highlighted elsewhere. People are very anxious that something should follow from the day. A report of the event is being written and we hope it will be possible for Shaping Our Lives to negotiate with *Critical Social Policy* over the best ways of including what service users had to say in the journal. We hope we may begin to produce a service user manifesto.

A very diverse range of service users took part in the seminar. Participants included a strong representation of black and minority ethnic service users; an out-lesbian who raised the problematic response of social policies faced by lesbian, gay, bisexual and transexual communities; and people reflecting belief and class differences and members of community and service user organisations.

Significantly, people reported predominantly negative experiences of current social policy. One exception was direct payments. For the future, people want to see social model and rights-based approaches to social policy, which effectively involve service users and are truly user led. Participants emphasised the importance of getting involved with policy and decision makers at the highest level and for policy that truly starts with service users. We will keep readers in touch with what happens next.

Role and task of social work

Following the government’s decision to look at the work of social workers and see how it might need to change to fit the needs of the 21st century, Shaping Our Lives was asked by the General Social Care Council to run a seminar to explore service users’ views.

The event, which was held on 28 February, formed part of a larger consultation on the role and task of social work. As part of this work Peter Beresford, Chair of Shaping Our Lives, prepared a ‘literature informed discussion paper’ which can be seen on our website at [www.shapingourlives.org.uk/ourpubs.html](http://www.shapingourlives.org.uk/ourpubs.html) along with a report of the event.
Some of you may not know this, but Shaping Our Lives has two websites. The first is www.shapingourlives.org.uk. This site has all the main information about Shaping Our Lives, including news, publications, events, policy papers and so on. The new design and layout has made it easier to use and also easier for us to update, so keep looking out for news and events! We have done our best to make it accessible but we’d like your feedback – please let us know what you think.

The second website is the SOLNET site – www.solnetwork.org.uk. This is the networking site for service user organisations and ‘friends’. The site has over 150 members and the noticeboard lists lots of events, publications and other information useful for individuals and organisations. Have a look and even join this online community! (For more details see the front page of this issue.)

Welfare to work

National User Group member, Amanda Wells, reports on the Welfare to Work Convention in Birmingham in June, organised by Inclusion (Centre for Economic and Social Inclusion).

I felt a little out of place at this event as there were very few service users present out of 800 delegates. But I was very glad I went when I realised how little awareness of equality and diversity issues the presenters and the delegates had. These people will be putting Incapacity Benefit reform into practice and they need to learn more about the issues. So I shamelessly promoted both Shaping Our Lives and my own training/consultancy services.

I put the first question of conference to John Hutton, Minister for Work and Pensions, asking whether the ‘responsibilities’ of disabled people to do what work they can will be first met by a duty on services to provide the support that people need before they can work. His answer showed that he didn’t really know what I was talking about, which is worrying. Perhaps we should all write to Gordon Brown, as these reforms were his idea in the first place?

One thing that did give me hope was the attitude of staff from JobCentre Plus, who wanted to know more about disability issues and want to do their best but need more influence to do it. They, too, worry about how the reforms will work in practice.

Overall, it was an interesting experience, but there is an urgent need for more campaigning by all of us to make sure that the new system will work for, and with, us.

For the full version of this article, please visit www.shapingourlives.org.uk.
New member says Hello...

Abandoned at three weeks old 67 years ago, I entered adult life with an indifferent education but blessed with plenty of energy and a steely determination to succeed.

Living in the West Midlands and happily married for 43 years, I’ve two sons, both of whom have inherited my disability; blindness caused by RP.

Trained as a horticulturist, becoming the group leader of landscape architecture in the West Midlands County Council I retired from paid work in 1986. NVQ studies in furniture craft and computer skills followed. The latter enabling me to become fully engaged in my passion; striving to improve the lives of disabled people by increasing awareness of issues facing them.

I’ve chaired the Sandwell Visually Impaired group since inception in 2004; since when, we’ve achieved national status in promoting a partnership with the council in moving towards a user led service.

Warmly welcomed to my first SOL meeting last May, I’m looking forward to playing an active role in meeting the needs of us all.

and a familiar face says Goodbye!

A very familiar face at Shaping Our Lives events and National User Group meetings, Fran’s guide dog Shep has now had to say Goodbye to Shaping Our Lives to enjoy his retirement. Although we will miss him, he is looking forward to chasing rabbits and becoming disobedient at his new home in Yorkshire.
Hazel Peasley explains the history and purpose of SCIL.

Southampton Centre for Independent Living (SCIL) is an organisation of disabled people firmly rooted in the British and international disability movement.

Our structure
We work to the Social Model of Disability which defines disability in terms of negative attitudes and discrimination caused by a society which fails to meet the needs of people with impairments. We are a company limited by guarantee; have a membership comprising ‘full members’ (disabled adults) and ‘associate members’ (non-disabled allies); and operate a committee structure fully accountable to our membership. Our catchment area is the county of Hampshire.

Our aims
Since our formation we have worked to fulfil our aims by two means: campaigning and providing user-led services. Thus we not only have a commitment to an accountable network through which disabled people can voice their views, debate issues that concern them and find representation and mutual support as well as a sense of their common history and culture, but also to the creation of services which support and enable disabled people to take full advantage of whatever avenues exist to secure high quality lives by their own definition. Both these functions are seen as essential if not always easily combined and are explored further in our website.

We believe that many services traditionally provided for disabled people have resulted in segregation, creating systems which actually increase passivity and dependence. We aim to work towards creating real opportunities for disabled people to live independently and participate in the community.

Our services
Our services are directed at empowering or enabling disabled people. They include: direct payments support, independent living support scheme, disability equality training, consumer audit, personal development and peer mentoring, outreach and volunteering, peer support, individual support, advocacy (towards self-advocacy), mutual support information, counselling, representation and training.

To find out more...
Visit www.southamptoncil.co.uk
Email ian@southamptoncil.co.uk
Phone 023 8033 0982.
Sign the petition for the European Parliament’s Disability Rights Directive.

In 2003, during the European Year of Disability, the disability movement tried to get the European Parliament to adopt a Disability Rights Directive, but failed. Now in 2007 (the European Year of Equality), the European Disability Forum has launched a new campaign for a Disability Directive.

In December 2006 the United Nations (UN) adopted the Convention on the Rights of People with Disabilities. The UN Convention covers all aspects of life, including the development of an inclusive education system, the need to get more disabled people into work, women and children’s rights and the right to supported decision making for all rather than guardianship. However, disabled people and their allies will have to struggle to get these things into British Law, but a really effective way is to get them into a legally-binding European Directive.

Support the campaign, sign the petition and make a change.

The UK is lagging behind other countries in collecting signatures. Please do all you can to get signatures online: www.1Million4disability.eu or on paper (contact Jenny at Shaping Our Lives for a paper petition to sign, see page 16 for contact details). Anyone of any age can sign as long as they are European citizens.

If you can, why not come to Brussels on 4 October to show your support? Contact your MEP who may be able to pay for your attendance at the demonstration and lobby.

For more information contact...

Richard Rieser
UK European Disability Forum Representative
Unit 1M, Leroy House
436 Essex Road
London N1 3QP
Telephone: 020 7359 2855
Email: r.rieser@btinternet.com

Vicki Raymond

It is with great sadness that Shaping Our Lives has to report the recent death of Vicki Raymond.

Vicki was an important member of the reference group that worked on the development of the Shaping Our Lives networking website, SOLNET, as well as a valuable contributor to Shaping Our Lives work more generally.

Her positive attitude, great sense of humour and ability to put people at ease, even when tackling difficult issues, was a great asset to any group she was part of and we will all miss her. We send our sincere condolences to her family.
Service users and those working to involve them repeatedly highlight the barriers the benefits system puts in the way of people getting involved.

While the government rhetoric is about putting service users at the centre and involving them in all aspects of their services and communities – in research, planning, practice, management, education and training – the reality is that benefits policy and practice are making it almost impossible for service users to be involved safely, equally and without risk.

The evidence that the existing system is unworkable has been growing for some time. Whether you are paid or not for getting involved, your benefits may be put in jeopardy because benefits practice and policy are so complex, inconsistent and difficult to make sense of – for both service users and for benefits workers themselves.

Taking action

That’s why Shaping Our Lives, as a member of the Joint Participation Steering Group, which includes key health and social care organisations, was keen to be involved in organising and holding a national seminar which took place on 22 May 2007. This brought together key stakeholders, including a strong representation of service users as well as representatives from the Department for Work and Pensions, which has responsibility for this issue. Service users spoke first hand about the problems benefits pose if you live in residential services, how they stop you getting involved, the fear they generate and the need for radical reform of the benefits system.

A report of the event is to be published and a commitment has been made that the Minister for Disabled People will meet with the Chairs of Shaping Our Lives and the Commission for Social Care Inspection (who jointly chaired the event) to discuss the findings from the day as a basis for further action. Shaping Our Lives will keep you posted about further developments.

Peter Beresford
Graffiti Wall: Equality is...

...an uphill struggle but worth fighting for.

...part of your quality of life.

...being enabled to do the same things as anyone else – any time, any place, anywhere.

...just like you and me.

...missing in life.

...being listened to and taken seriously.

...respecting diversity or difference, equality is celebrating difference or diversity.

Equality should be for all and everyone.
Equality should be equal for all and everyone.
Equality should be for all society.
Equality shouldn’t be judgemental but it is.
Equality should be free but it’s not.
Equality comes at a price but it shouldn’t.
Equality for everyone is best regardless of disability, gender, race or any other.

EQUALITY – EQUALITY – EQUALITY

Equality is achieved when no one need seek favour.
Equality is knowing that justice has been done.
Equality is when words and deeds need no special expression.
Equality is when everyone’s thoughts, words and deeds are non-judgmental.

Equality is achieved when we all really do love our neighbour.
Equality is a right to have access to information and resources in society: being included and treated without judgment.
In all the projects that we are involved in, we are finding that service users share and identify many of the same barriers that prevent us all having the control, choice and power over our lives that we would like.

For example, in our project Beyond The Usual Suspects: Developing diversity in involvement, we are working closely with four quite distinct and very different local service user groups: black mental health service users, a group of people with learning difficulties, a mixed service user group and a group of women who have formed an alcohol support group.

These are four groups who people might think had little in common with each other. However, we have found that they share many barriers to full inclusion and to being able to participate in society as full and equal citizens. These barriers include stigmatising assumptions made about who they are seen to be, how they live their lives and what they can and cannot do; they also include ideas of fear and ignorance about ‘people like us’ and the ways in which they are made to feel ‘less than human’. Other barriers around access, media portrayals, employment and housing were also identified as being experienced by all the service user groups.

The same, but different
This is not to say that our experiences of barriers is the same. Indeed, two people with exactly the same ‘label’, the same impairment, might have very different experiences and manage their impairments and their experience very differently.

The disabled people’s movement has recognised for many years now that as a social movement it is important to unite as disabled people and to move away from the medical classifications that for so long defined who we were: the insane, the cripples, the blind, the idiots and so on. The disabled people’s movement was accused in its early days of being dominated by younger, white, middle class men who used wheelchairs.

But over the past three decades it has learnt to embrace all disabled people – people with physical and/or sensory impairments, people with hidden impairments and conditions, people with learning difficulties, older people, mental health service users, people with fluctuating conditions and so forth.
By embracing diversity and difference the disabled people’s movement has grown and developed.

Shaping Our Lives believes that it is equally important for the service user movement to develop in this way. Different groups within the user movement do have distinct and different histories. We do not want to deny these or our differences but we believe it is time to move away from divisive practices and speak with a united powerful voice.

This is an extract from a longer article by Shaping Our Lives Director Fran Branfield on ‘Strengthening the Service User Voice’. For the full text of the article please go to our website at www.shapingourlives.org.uk.

Who or what has had the greatest influence in your life?

I’d like to think everyone I meet has a certain amount of influence on me. If I had to pick anyone I suppose it would be my parents never expecting less of, or from, me than they did my brother and sister.

What is your most treasured possession?

Probably my house but that’s really because it contains my family. At a bricks mortar level (literally) it is where I’m happiest and most comfortable – it’s probably true for many disabled people that your home is where you have most control over your environment and you’re able to do things as you want to.

If you had one wish, what would it be?

If I only had one wish, the obvious thing would be to wish for more wishes. Otherwise it would be world peace or ending poverty – something substantial.

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

I’m not keen on the idea of banning something – it’s difficult to justify banning one and not another. I could be persuaded to make exception for ‘EastEnders’ and ‘Big Brother’ though.

If you could change one thing in health and social care services what would it be?

Put service users in control.
What makes you laugh?
Spelling something so appallingly wrong that the spell checker cannot even make a suggestion for the word I am trying spell always makes me smile. My children have made me laugh a lot down the years and our cats do some pretty silly things – one was attacking the computer mouse just before I wrote this. I think he’s a bit confused.

What trait do you like least about yourself?
I hate getting cross. Even when there’s a good reason for it I always regret it afterwards.

What trait do you most dislike in other people?
Lack of respect and consideration for others. It’s such a basic thing that would make everyone’s lives better.

What is your idea of perfect happiness?
Probably the times I’ve had with my family as my children have grown up. I look back fondly on when Rachel and Abigail were younger – I was very lucky to be able to work from home at that time and build a house out of lego instead of commuting and watch ‘Sesame Street’ or ‘Teletubbies’ with them in my lunch break.

What is your favourite film or television programme?
Hard to say. I remember being amazed by Powell and Presburger’s ‘A Matter of Life and Death’ when I was quite young and still enjoy this film. Of more recent things it would have to be the ‘Lord of the Rings’ films.

What has life taught you?
Make the most of what you have, in every sense of the phrase.

How would you like to be remembered?
Just being remembered – in a good way – would be something.

Michael has worked and been involved with Shaping Our Lives from its earliest days, 10 years ago. He is also a disability consultant and freelance trainer. Michael lives in south London with his wife, two children and two cats.
Poetry

Bite the hand that feeds you

Bite the hand that feeds you
Make the bugger bleed
Then maybe they’ll notice you
And ask you what you need.

Allan Sutherland has, for thirty years, been one of the most passionate voices on the disability scene, as writer, journalist, standup comic and performance poet.

He was once described as ‘the first political stand-up on the disability arts circuit’. His book ‘Disabled We Stand’ (1981) won awards in the UK and the US, and is still required reading on some university courses. His Radio Four play ‘Inmates’, set in a long-stay institution for disabled people, won a Raspberry Ripple award. Allan is also available for poetry readings. You can contact him via Jenny at Shaping Our Lives (see back page).

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 newly-redesigned Shaping Our Lives website at www.shapingourlives.org.uk has some new 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. (Don’t be shy – share your creativity!)
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.

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