

Shaping
Our Lives

National User Network

NEWSLETTER

ISSUE 15 Spring 2009

New strategic partnership launch

STRATEGIC PARTNER PROGRAMME
WITH THE DEPARTMENT OF HEALTH



Members of the programme at the launch event, including (front row) Care Services Minister, Phil Hope (centre), Sue Bott, National Centre for Independent Living (second from left), Liz Sayce, RADAR (third from left), and Peter Beresford (second from right) and Fran Branfield (far right) of Shaping Our Lives.

The partnership of Shaping Our Lives, RADAR and the National Centre for Independent Living is one of 11 groups chosen by the Department of Health to take part in the new 'Third Sector Strategic Partner Programme'. The programme was launched on 21 April by the Care Services Minister, Phil Hope.

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New strategic partnership (cont)

Shaping Our Lives is particularly interested in increasing the impact of service user's voices in influencing health policy and practice. We will be using the strategic partnership to enhance two-way communication

between service users and the Department of Health on a number of important areas such as personalisation, transforming adult social care and the development of the current care and support Green Paper.

Relationship Matters Building our knowledge and networks

During the autumn of 2008 Shaping Our Lives supported five service user and/or disabled people's organisations to hold networking events in their own regions. They each invited other local service user organisations to give presentations and participate in these 'get-togethers'. Each organisation told Shaping Our Lives what people had said during these events and a report was written. The summary of this is included with this newsletter.

Service users highlight the importance of actively supporting a diverse range of long-term users of health and social care services to network with each other. The importance of networking for service users and their organisations cannot be over-emphasised. It is through networking that long-term users of health and social care services can share experiences and consolidate a service user identity. This allows service users from diverse backgrounds and understandings to recognise shared barriers to equality and full human rights.

This form of empowerment allows service users to move forward together to influence change and promote good relations among and between groups. We think these ideas are very important and other service users agree with us.

- ◆ "These inter-group meetings are important to identify similar issues."



Relationship Matters (cont)

- ◆ “Events must enable service users to come together to share with, and empower, each other. It is essential to have a unified voice that comes from service user meetings through user-led organisations that can feed into the system. To have any influence on policy it is essential to have a unified approach. Organisations need to be able to put pressure on commissioners to influence change and commissioners need to be able to feel the pressure so that they respond effectively.”

People gave many reasons as to why service users should have service user-only meetings.

- ◆ “More accurate priorities are identified.”
- ◆ “More choice and control over what the groups want to do.”

People said it was good to talk to many different types of service user.

- ◆ “We should share newsletters and bulletins.”
- ◆ “Information is key to independence.”

But people also said there were many barriers that stopped service user groups from working and sharing their ideas.

- ◆ “Many groups and individuals are often so overwhelmed with their own work that they do not know what others are doing.”
- ◆ “Sharing ideas is difficult because of competition. Now there is tendering instead of grants.”

The summary report and the full report can be downloaded from our website. You can also ask Jenny in our office if you would like either report in a different format. See contact details on the back page.

This project was funded by the Equality and Human Rights Commission.



News

National Skills Academy for Social Care

The National Skills Academy is a new national organisation with a responsibility to advance leadership in social care.

There are two exciting aspects to its development. First, it has involved real service user involvement from the start. Shaping Our Lives has a representative on its shadow steering group, who we hope will become a member of the board when this is set up. Second, it is interested in supporting leadership at all levels, not just at the top, and is also interested in supporting capacity-building and user issues in service user organisations.

The Academy has been given the go-ahead and granted funding by the



Government. A Chief Executive, Liz McSheehy, has just been appointed. It is already starting on its work programme.

One part of this is a project concerned with what it calls 'micro employers'. By this it means people using individual budgets and direct payments and service user-controlled organisations. It has

set up an advisory group for this project with a majority of service users, including some highly experienced and assertive service users.

This group will be looking in fresh and positive ways at taking forward roles like that of personal assistance from a

user-focused perspective. We hope this will be a helpful challenge to some of the traditional ways in which these issues have been approached in the past.

Local authorities working with user-led organisations

Shaping Our Lives is happy to be supporting a paper, produced by the Department of Health, called 'Working Together with User-Led Organisations'.

The paper was launched in March by the Minister of Social Care Services, Phil Hope. The paper is aimed at local authorities and explains why it is good for them to work with user-led organisations and how this helps disabled people, carers and others who need support.

The paper shows local authorities:

- ◆ how they can build important relationships with user-led organisations
- ◆ what support the Department of Health will give them to do this, and
- ◆ where they can go to get more information about user-led organisations.

The paper also talks about making changes to adult social care. In 2007 the government wrote 'Putting People First'. They said that local authorities should give people more choice and control over

News

their lives and the services they use. They said that all councils should have a plan to set up user-controlled organisations in their areas, if they don't already have one.

Shaping Our Lives thinks this paper called 'Putting People First: Working Together with User-Led



Organisations' is good. You can download it from the Department of Health website – www.dh.gov.uk – or from ours. You could send it to your local authority and you could ask your local authority what they are doing about these ideas and what their plans are.

Farewell to long-time disability activist Ken Lumb



Ken Lumb was one of the early founders of the UK disabled people's movement. We report his recent death with great sadness.

I don't think he would have called himself a 'leader', but I think

he was one in the best sense. He was an inspiration and a source of great wisdom, experience and knowledge. Most of all, for me, he was a person of great determination, commitment and experience.

In a world where disabled people and other service users face routine discrimination, oppression and double-dealing, he was principled and always kept in sight the ideals

of the disabled people's movement – to achieve people's rights and bring about broader change in society.

Ken had a long association with the Greater Manchester Coalition of Disabled People, which is how I got to know him and, especially important I believe, he was editor of its journal or magazine, *Coalition*. *Coalition* is one of the things that keeps me going. Loads of humour, but also real honesty and no pretence. For me it was the disabled people's equivalent of *Private Eye*, telling truths others didn't mention and helping you to feel you weren't on your own.

We send every good wish to his partner and survivor activist Anne Plumb and daughter Hazel on their sad loss. We won't forget the contribution of people like Ken.

**Peter Beresford
Chair, Shaping Our Lives**

Thanks to Anne Plumb for the photograph of Ken.

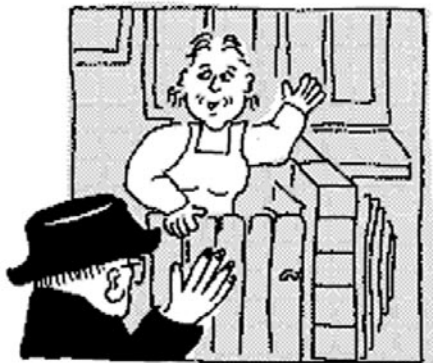
Housing and Support Services

Finding out older people's views

Early in the year *Shaping Our Lives* was invited to carry out a small piece of research for Cumbria County Council and Cumbria Primary Care Trust.

They wanted to get an idea of what type of housing and support services older people living in their area might want and need in the future. We spoke to over 70 older people. Some people we talked to on the phone but most of the people we spoke to came to meetings where we all discussed the pros and cons of different kinds of housing schemes and options.

They were a very diverse group of people with different life experiences. Yet there was a remarkable degree of consistency in what they said. The overall message that we got, almost without exception, was that no one wants to have to live in a residential home. People's preferred choice is to stay in their own home. This person's comment sums up what a lot of people said:



“Home is more than bricks and mortar. Home is memories. Home is a lifetime's collections...of life, of love, of loss, of happiness, of pain, of joy, of peace. Everything is in my home. My house, my home, is me.”

Barriers

People identified common barriers that often prevented older people from being able to remain in their homes. These included:

- ◆ concerns over standard of care
- ◆ lack of accessible, reliable and frequent appropriately-timed transport
- ◆ lack of affordable and reliable services to help with house and garden maintenance and repairs, particularly small jobs
- ◆ delays to adaptations to home, and
- ◆ fear and isolation.

If these barriers meant people could not stay in their own homes then people contemplated a move to what they considered to be more suitable 'mainstream' accommodation. Some people for example, considered a bungalow and for others it meant a move to a less rural and isolated location. It was only after these options had been explored that people thought they would start looking at housing options specifically for older people. Of these,



extra care sheltered housing was the most positively viewed.

Other findings included the following.

- ◆ People recognised that in some circumstances there was a need for nursing homes.
- ◆ Independence and security are valued very highly by older people. It can be achieved in different ways.
- ◆ Older people whom we spoke to did not want to become disengaged from the wider community. Most people emphasised the importance of maintaining relations with their local community.
- ◆ Feeling safe in your local community and in your home is of great importance to older people. Fear of crime might exceed actual

incidence of crime, but fear can have a disabling impact on older people's lives.

- ◆ Older people value easy access to facilities such as shops, doctors' surgeries, hairdressers, and post offices. Easy access to leisure and social facilities are valued as a means of combating isolation and loneliness.
- ◆ A person-centred approach to care provision can contribute towards social wellbeing.

This report will soon be made available via our website or, for alternative formats, via our office. See back page for details.

Meet...Groundswell

Groundswell is an organisation committed to supporting client involvement for people who have experienced homelessness. Like *Shaping Our Lives* we were set up in 1996 and work across the UK, and our beliefs are similar too.

Groundswell's core beliefs:

- ◆ Homeless people need to be part of the solution! The only way to genuinely tackle homelessness is with the expertise of homeless people themselves.
- ◆ There is no **Them** – only **Us!** Groundswell brings everyone together – policymakers, staff and homeless people – to create effective solutions.
- ◆ Involvement works! When everyone is involved, the process creates more effective services

and enables people to regain their independence.

- ◆ The whole community benefits when we tackle homelessness effectively.

Getting Skilled Up

Let me tell you more about our actual activities. To support client involvement in services we run training to help set up service user groups, and to help service users get directly involved in commissioning. We also offer training to frontline staff and management to help them get better at involvement.

One of the main ways we try to kick-start involvement is through Peer Research. This is a type of research which actually involves people with experience of homelessness in all parts of the process. From designing questions, conducting interviews, analysing the results and delivering presentations on what we have found out.

Research can be the essential first stage of involvement – before you can start making changes you need to know what everyone really thinks. Some people prefer to discuss issues with friends in focus groups, others prefer the privacy of one-to-one interviews; some people like to write their thoughts down, others like to speak to camera. We find that using a range of techniques enables everyone to have their say – not just those who love going to meetings!



Do It Yourself!

As well as supporting client involvement in services, we also run a programme to encourage people to bypass services and Do It Yourself! Sometimes as a service user you can get trapped in the way of thinking that you need

support for everything, and you lose sense of your own ability to get things done.

Our Grant Award Scheme gives out awards of up to £700 to people to set up their own projects or enterprises. Some people run art groups, gardening clubs, set up companies designing T-shirts, building yurts, taking photographs... anything! Over the years we have had over 400 winners some of whom have set up projects that are now bigger than Groundswell.

Let's Work Together

Increasingly our research is finding that people are unhappy about the way that services try and compartmentalise our issues. This is more useful to the providers than it is for the actual service users. People who are homeless often use some or all of the specialist services around drugs, alcohol, mental health, learning disabilities and others. People find



themselves repeating their stories endlessly and getting bits of support here and there in a disconnected way.

Groundswell is trying to respond to this by broadening our focus away from just homelessness and more to meet the needs of people who use support services. So we are looking outwards to work in partnership with other organisations who share our mission and beliefs and we hope that there might be opportunities for Groundswell and Shaping Our Lives to work more closely together.



Contact us at:
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5 Stockwell Mews
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Tel: **020 7737 5500**
www.groundswell.org.uk

Hate Crime

Hate crime has become a serious issue for the disabled people's community. The term is recent; the actual issue is nothing new. A hate crime is a crime that is committed against a person or people simply because they are seen as different, subhuman and a threat.

Hate crimes against disabled people have been a part of the lives of disabled people for far too long. They are the most extreme manifestations of diasablism, oppression that stems from the view that disabled people are inferior. The hate crime can take many forms from abuse in the street to grisly murders. In 2008 Scope published a report on the subject of hate crimes called 'Getting Away with Murder' that focused on these vile acts. These were dreadful events that needed to be recognised by the police, courts and penal institutions.

However, most disabled people have experience of hate crime of a less extreme nature. In a report written in 2005 for the Disability Rights Commission Scotland in association with Capability Scotland, it was found that 47% of respondents had experienced some form of hate crime, 73% had received verbal abuse and 35% had been attacked physically.

This will come as no surprise to any disabled people reading this piece.

When I spoke to a small discussion group for a report that I was writing on this subject everyone had a story about some act of violence that they became involved in. Take, for example, this incident.

"I was walking in the park; four or five youths on bikes came up to me. One said he would kick away my sticks. If they'd done this I'd have fallen over like a sack of spuds. Since that day I've never walked in the park".

Yet if so many disabled people can identify with this, why has so little been done so far? There are many reasons. Firstly, there is the fear that disabled people can have of the police. There is a risk that if they take the matter further there will be retaliation.

There is the complexity of the reporting procedure. There is the inaccessibility of so many police stations. Neutral third party reporting centres may be a solution to these barriers.

There is also the lack of willingness on the part of the police to identify a crime against a disabled person as a hate crime. Until 2008 there were no means of pinpointing a record of a hate crime against a disabled person. Additionally, Section 146 of the Criminal Justice Act gave the right to increase the sentence if it was felt that the hostility was centred on disability.



However, even in the most extreme murder cases this has not been done.

A priority is publicising these criminal acts with a campaign to raise awareness. All agencies – housing, social care and criminal justice – must work together. This work is starting to be done with various local authorities but it is piecemeal. A national campaign backed by political will is needed to ensure that hate crime is tackled effectively.

Michael Shamash is a disabled researcher currently working on a project to develop user involvement of disabled people in East London. He is also active in broadening service users and carer participation in social work education. The report on Hate Crime in East London can be obtained at www.ditoh.org or by contacting Michael Shamash at michael.shamash@ditoh.org.

SOLNET – The networking website

Since its launch in 2005 SOLNET, Shaping Our Lives' networking website, has provided a space for service user-controlled groups around the country to come together to share experiences, to let each other know what is going on in their areas and, importantly, to give a presence to the service user movement.

Groups have been able to share their newsletters, have links to their blogs and encourage service user participation in research and development initiatives. SOLNET is a unique resource for us as service users. It is where we can share issues and disseminate our own research. It is where we can strengthen our united voice and inform social care and health services that shape our lives daily.

Over the coming year we would like to ask our members if they have ideas that could improve the website and what areas are of particular interest to them. We want to continue to develop the noticeboard into a dynamic and useful site where groups can see what research, events

and requests for participation are going on locally, regionally and nationally. We are also beginning to develop international links.

At the moment there are 306 members of whom 281 are controlled by service users. Each day, on average, we receive 483 'hits' with an average of 97 different visitors. Since its launch we have had over ½ million hits from 25,000 individual computers that have visited the site. We have had over 135,000 visitors to the site.

Shaping Our Lives is delighted with the success of SOLNET. We would like you to encourage any group, big or small, to join the networking website. You can join as a friend if you are not a user-controlled organisation or group. Get involved and increase your say in the services you use.

Eamon Andrews
SOLNET Project Worker



Meet...Disability Wales



Disability Wales is the national association of disabled people's organisations striving to achieve the rights, equality, and independence of disabled people in Wales.

Disability Wales promotes the adoption and implementation of the Social Model of Disability, which in contrast to the Medical Model of Disability identifies that it is environmental, institutional, and attitudinal barriers that disable people and prevent them from full participation in society, not their medical conditions or impairments.

Disability Wales is an independent, not-for-profit organisation established in 1972 and managed by a voluntary Board of Directors drawn from disabled people active in local and national disability organisations across Wales.

We receive core funding from the Welsh Assembly Government Directorate for Older People and Long Term Care. Most of its eight staff members are disabled people with many years' experience working in both a professional and voluntary capacity for various disability organisations in Wales and beyond.

Disability Wales occupies a unique position within Wales. It is an umbrella organisation that champions the rights and equality of all disabled people regardless of physical or sensory impairment, learning difficulty or mental health condition. It recognises that many disabled people have multiple identities and consequently may face

multiple or intersectional discrimination.

As a representative disability organisation Disability Wales has an interactive role between statutory bodies and its member organisations. In line with the Social Model of Disability, and through consultation with its members, it influences the development of policy and practice to truly address the needs of disabled people on a basis of equality.

Our aims are to:

- ◆ develop and support the work of organisations led by disabled people
- ◆ be an effective advocate for the views, priorities and interests of our members
- ◆ influence policy and decision makers at all levels, and
- ◆ develop and deliver services that benefit disabled people.

Disability Wales is recognised as a lead organisation in Wales in promoting the understanding, adoption and implementation of the Social Model of Disability. It has provided a model to other disability organisations in Wales on how a traditional organisation set up for disabled people can transform itself to become one that is of disabled people.

Streets Ahead

Streets Ahead is Disability Wales' current campaign for inclusive access to high street shops and services.

Disability Wales carried out a survey of members in November 2008 to find out what issues concerned them most in the broad area of access, and barriers to access to the high street emerged as the number one priority issue. Disability Wales wants to address these concerns and find out the true picture across Wales, report on findings and influence those with the power to change things for the better.

To find out more visit our website at www.disabilitywales.org and look under the 'activities' section. Alternatively contact Rhyan Berrigan Policy Officer on rhyan.berrigan@disabilitywales.org or through Typetalk dial **18002 029 20 885 834**.



Knowing Me, Knowing You Jennifer Taylor

Who has had the greatest influence in your life?

I think my Grandmother really. She taught me how to do the washing up, the housework, the cleaning. She told me about the birds and the bees and took me to school and kept me safe as a kid. She told me how to keep away from trouble and how to be a good person. I thank her for that so much. If it wasn't for my Grandmother I wouldn't be here today – she's the one I look up to.

What are your most treasured possessions?

My music, really, and my clothes.

If you had one wish what would it be?

My one wish is to go and visit my Mum and my sister in New Jersey. My Mum has been saying to me to visit her on a holiday. Maybe in the future I would like to go, but I need someone to come with me. Because she does miss me I know, and it is a long way for me, and I miss her. I write letters to her and she writes them back to me.



Knowing Me, Knowing You (cont)

What would you like to ban?

I would like to ban all the cuts in services and stop all the cuts in Lambeth.

What one thing in health and social care services would you like to change?

I would like to see health and care services be better for everybody. I would like social care to treat people with respect no matter what their disability is.

What makes you laugh?

Some of the people in People First Lambeth make me laugh because they are happy most of the time and we chat together and laugh together about the good and the bad.

What trait do you like least in yourself?

I am not a bad person because my Grandmother brought me up good. Put it this way, I like helping people. I can't think of anything I dislike about myself.

What trait do you most dislike in others?

I don't like when people argue with one another for no good reason.

What is your idea of perfect happiness?

Being a woman and being proud and being a Mum as well.

What is your favourite film or television programme?

My favourite film is *Dirty Dancing*. I've seen it so many times.

What has life taught you?

It has taught me how to stand up for myself. It has taught me how to take control of my own life. It has taught me how to keep safe. It has taught me how to be independent and to speak up to people.

How would you like to be remembered?

I would like to be remembered for being myself as a woman with learning difficulties, a very nice person. I would like to be remembered for going to a lot of meetings and speaking up for a lot of people with learning difficulties who can't speak up for themselves. I am proud of the book that I have done with my mates, called 'We Are Not Stupid'. I would like to be remembered as a woman who kept out of trouble and away from nasty people, and for being a Mum as well, with two boys Martin and Jason.

My name is Jennifer Taylor. I am a black woman with learning difficulties. I work for People First Lambeth in South London. I love going to meetings and speaking up for people with learning difficulties who can't speak up for themselves. I like looking after people with learning difficulties as well. I am also involved in Shaping Our Lives meetings and SCIE meetings. I am a member of the Partners' Council at the Social Care Institute for Excellence. Sometimes I like to socialise. I like to chat to people about what is going on in their lives, what they are going through.

Poem

Our year begins in September

Following Shaping Our Lives' recent work (see page 6) we thought it would be good to include this poem on getting older.

by Trevor Hewett

Years ago, somebody had the sense
to place these wooden seats around
the edges of the village, facing west
into the evening sun over the bay,
where you could stroll then sit and feel the wash
of sunset after each long working day;
and, every year, as summer fades
into the calm fruition of September,
old men, like flocking birds,
come, gather, wearing ties and polished shoes,
to sit and talk, remember, laugh and sigh
for other times, lost childhoods that they shared;
as if the intervening sixty years
were just a lengthy trial to labour through,
and maybe that's exactly what they were –
apprenticeships for this maturity.
Now, as they sit and talk in cooler air –
the urgency of life behind them now,
as is the pace and heat of summer days –
the evening breezes drift in from the sea
to bathe their optimistic, hopeful mood
with the nourishment of light and air.
And free of all the piercing awareness
that the end of something always brings,
they speak of next year, new springs, summer growth,
understand the cycles of the land,
and that this cool, long-shadowed autumn light
heralds a beginning not an end.
Now, as harvests gather in,
the ever-turning season spins,
and, once again, the year begins.



Source: 'Poems and Prose' – <http://poemsandprose.blog.co.uk>

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.

Photographs pages 11, 13 and 16
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