Relationship Matters: Building our knowledge and networks

We are already half way through our new project ‘Relationship Matters’, funded for one year by the Equalities and Human Rights Commission.

This project is about helping service user’s own groups and organisations to find out what other service user and disabled people’s groups are doing locally – it is about networking and sharing with each other what we know from our own experience, as individuals and as groups.
We were very pleased that so many of you responded to our request for organisations who could host a networking event – a Get Together. We could only choose five groups and that was difficult as we felt everyone who contacted us could have done an excellent job. In the end we went with organisations who were in different regions and who were networked with a range of different service users. These groups are Disability Wales, Contact (Bradford), One Voice (Lancaster), Gateshead Access Panel, and Independent Living Alternatives (London). At the time of writing three of the organisations have already held their ‘Get Together’ day and, so far each one has been very successful!

Here are some of the things that service users who went to the networking events said:

- It was a really good opportunity to meet other people and groups who you never have the time to meet.
- It was very interesting and we will be able to signpost people to other local groups.
- If we are all singing from the same hymn sheet our voices are more likely to be heard.
- Disabled people can be ‘too busy trying to get by day-by-day’, especially when they don’t get the right support. They don’t have the time or energy to get involved.
- Build trust between groups and build communities.
- Work together, but it is important to maintain our own specialist roles and identities too.
- Build on contacts and keep lines of communication open.
- Combining different specialist knowledge, skills and experiences for a stronger voice.

The Equality and Human Rights Commission want to know what people think about plans for a new grant funding programme. Have your say by going to their website: www.equalityhumanrights.com
The Social Care Institute for Excellence (SCIE) has been funded by the Department of Health to think of ways to support service users and carers to take part in social work education. Fran Branfield reports.

Shaping Our Lives has been working with the Social Care Institute for Excellence and with service users to find out where examples of good practice are taking place and where more work needs to be done. We finished this stage of the project last year and two reports were produced based on what service users told us. The first report is called User Involvement in Social Work Education (Fran Branfield, Shaping Our Lives 2007). This is the report of five regional consultations with service users who met and talked about the best way to support service users to take part in social work education. You can order a printed copy by contacting the Shaping Our Lives office.

The second report, published by the Social Care Institute for Excellence in 2007 is called Common Aims: A strategy to support service user involvement in social work education. This identifies good practice and also the barriers and possible ways forward for service users working together with colleges and universities. This can be ordered from www.scie.org.uk

A new phase
We have now moved on to the second stage of this project and again we have involved a diverse range of service users to tell us what their thoughts and experiences about getting involved with the education of social workers has been. This time we have asked people to think about these questions:

◆ What do you see as good practice in user involvement in social work education?
Social Work Education (cont)

- Can you give examples of good practice?
- How can you measure good practice?
- What is being achieved from user involvement in social work education?
  - For service users
  - For students

- Is user involvement in social work education changing practice?
- What is being done to build capacity (for organisations and individuals) and what can helpfully be done to do this?
- What barriers are people facing which stop good user involvement in social work education?

We are working with the Social Care Institute for Excellence to develop a web tool for service users and carers who want to know more about being involved in social work education. This web tool was also discussed during the consultations and we will be working closely with Social Care Institute for Excellence in its design and development.

The consultations took place during November 2008 and a report of what people tell us will be available in the New Year. If you have any comments that you would like to make please contact the Shaping Our Lives office.

New Job for Michael

In early October Michael Turner started a new job with the Parliamentary and Health Service Ombudsman, as a case worker dealing with social care issues and complaints across government departments. Michael has been with Shaping Our Lives since it began in 1996, working as a project worker, development officer and researcher. He has always been a member of the management group and the wider National User Group where he was always a supportive colleague and, for many of us, a close friend. Whilst we wish him all the very best for his future he will be really missed.
New members on the Management Group

We are delighted to introduce two new members of the Management Group, Patsy Staddon and Cora Jones. Patsy and Cora were elected to join the Management Group by members of the Shaping Our Lives National User Group on 14 October. Here, Patsy and Cora introduce themselves.

Patsy, once alcohol dependent, has been researching sociological factors affecting women’s alcohol dependence at the University of Plymouth. Her research projects were funded by her local NHS Trust, and she was assisted by other women, many of whom had recovered using alternative methods from the more traditional 12 Step programmes. She also runs a group called WIAS (Women’s Independent Alcohol Support), a service user controlled 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, and this is one of the needs WIAS seeks to address. Patsy is also involved with a number of other organisations including the West Hub of the UK Mental Health Research Network, Bristol Lesbian Gay and Bisexual forum, INVOLVE, and the Social Perspectives Network.

Cora is a permanent wheelchair user and a user of the services provided by Health and Social Care and the NHS. She is a member of a Direct Payments User Forum and a director/treasurer of Birmingham Disability Resource Centre, a user led organisation providing information, advice and guidance services to disabled people and their support network across a range of issues throughout the city of Birmingham.

She has also worked with Birmingham City University since the beginning of the new Social Work degree as a service user, putting forward the needs and viewpoints of service users to student social workers and teaching staff, and has been involved in the development, planning and delivery of teaching, together with the recruitment of staff and students.
In late summer 2008 Shaping Our Lives undertook two consultations for the Department of Health. One on the Adult Social Care Workforce Strategy Board, based on the Department’s Interim Statement: *Putting People First – Working to make it happen*. The other considered the role and task of social workers. A diverse group of adult service users with experience of social care workforce issues took part.

**Improving the Adult Social Care Workforce**

Service users identified the following key issues:

- “Capacity – both in terms of adequate funding for social care and recruitment, retention and training of social care workers; and the capacity of social care staff at all levels to understand the whole point of social care, which is to improve the lives of service users.”

- “Improving pay, terms and conditions.”

There was agreement with the priorities in the statement, but service users doubt that they will lead to real change:

- “These workforce priorities have been the same for many years and there is very little evidence how the change from outputs to outcomes will be funded so that all the grand aspirations for the workforce can be achieved.”

- “Yes – but what’s missing is the crucial involvement of service users in developing, delivering and monitoring progress on these priorities, at whatever level they wish to be involved. It is too easy to produce endless lists of strategies, policies and priorities without any of it ever actually happening.”

In addition service users generally do not feel that the present workforce is well equipped to meet the new priorities:

- “Key to the whole transformation policy is a change from providing generic services where disabled people have to fit the services, to the other way round, with disabled people being in control of the services that they receive. For many people working in the social care profession, this is a revelation, a massive mind-shift. This is the key challenge in realising personalisation. It is absolutely critical that this is done right, with gusto, with commitment and with true understanding from social care workers. Anything less and the personalisation agenda will fail, to the detriment of everybody. Achieving this mind-shift has to be
the key priority; everything else will then hopefully follow on from it.”

Service users recognise the difficulties experienced by the social care workforce and are keen to help facilitate change:

◆ “We need to support a workforce any of us would feel happy to turn to for support.”

Roles and Tasks of Social Workers in England

A number of key points were highlighted:

◆ “I would like to see social worker training be made open to a wider range of people, in order to attract the right kind of people. This would include disabled people and those with relevant experience and attitudes but maybe not the academic qualifications. The ‘fitness to practice’ issue must be addressed.”

◆ “Who becomes a social worker? This is crucial – why people choose to go into this profession. We need more service users as social workers and it needs to improve its public image. Training must involve service users in a meaningful way.”

◆ “It is very important that training, staff development and supervision etc. place the greatest emphasis on the empowerment of service users.”

In answer to a question about career frameworks to support social workers to stay in front line practice, service users were positive:

◆ “Absolutely! Of course promotion should not mean you lose the best practitioners so they can progress up the career ladder.”

◆ “People should be able to get the recognition (personal and financial) they deserve for providing the support that they do at the front line.”

◆ “Yes. It has always seemed paradoxical and even nonsensical to me that successful health and social care workers must move away from practice if they are to gain promotion. Their skills and experience are then lost, to the detriment of their colleagues and service users.”

Service users again raise the issue of the fundamental need for practice to be value-based.

◆ “National Occupational Standards seem to be very action rather than value based, yet they need to be value based. Prior to National Occupational Standards there used to be practice requirements and also value requirements. The value requirements are now in the code of practice – more like a second place and they have been diluted.”

For a copy of either report please get in touch with the Shaping Our Lives office.
Hidden Barriers to Involvement

User involvement in services for women who have experienced sexual abuse or rape

Eleni Chambers, User Researcher University of Sheffield tells us about her work.

I am a user researcher and was on the advisory group for the Shaping Our Lives project “Beyond the Usual Suspects”, which looked at how to increase diversity in involvement. I have continued my interest in this area by carrying out user led research into user involvement for women who have experienced sexual abuse or rape.

Even though there are very many women with such experiences, user involvement has seemed to miss out this group of people. This is similar to other marginalised groups including users of substance misuse services, refugees and asylum seekers or women who have experienced domestic violence. Often these groups of people have experiences which have particular implications for user involvement.

For my research study I interviewed both users and staff of a specialist organisation that provided counselling services for women who have been sexually abused or raped. I also examined any relevant documents from the organisation, contacted other similar organisations and looked at other research on the subject to see what could be learnt from elsewhere.

Some of the things I found were the same as those found for user involvement in other settings. However, some of the new issues that haven’t been considered much are:

◆ **Stigma** This can have a very powerful effect on whether or how users want to get involved. It also means that there are few groups that users can become part of. It is vital that any involvement does not reinforce any already existent feelings of stigma or powerlessness.

◆ **Confidentiality** It is important to respect whatever level of confidentiality or anonymity users want. Therefore a range of involvement opportunities and mechanisms are needed that take this into account and enable the involvement of any user.

◆ **Boundaries** This is important in such services where counsellors have a responsibility to keep safe boundaries for their clients. Workers were worried that being involved may be upsetting for users as they may re-experience painful memories. However, it is important that users don’t feel patronised, they are capable of making responsible judgements about when and how to get involved and have the right to choose to do things that may be upsetting if they wish.

Interestingly I found no other research had been done on user involvement in such services in the UK, perhaps yet another effect of the stigma?

Email: e.chambers@sheffield.ac.uk
Knowing Me, Knowing You
Graham Price

Who has had the greatest influence in your life?
Gladys Sealey, an inspirational friend, 55 years my senior who taught me to shun image and know contentment.

What is your most treasured possession?
Happy memories, if that counts because there’s more than one but they are stored in one place.

If you had one wish, what would it be?
That I remain strong enough to protect my wife for as long as is necessary.

What would you like to ban?
Injustice and insincerity.

What one thing in health and social care services would you like to change?
That we achieve the provision of services that are truly user led.

What makes you laugh?
Many things, for instance The News Quiz on Radio 4 particularly when Andy Hamilton is on the panel.

What trait do you like least in yourself?
Being obsessive at times; the outcome is to deny the needs of others close to me.

What trait do you most dislike in others?
Selfishness.

What is your idea of perfect happiness?
A difficult one to answer but bliss is time to relax and reflect with members of my family in a good country pub with a pint of real ale.

What is your favorite film or television programme?
Good drama; currently it’s ‘Little Dorrit’.

What has life taught you?
Unwelcome experiences often present good opportunities.

How would you like to be remembered?
As being a helpful person who has striven to ensure all people are treated well.

Graham is a relative newcomer to Shaping Our Lives becoming an elected member two years ago. He trained and worked in public administration and landscape architecture. An inherited gene caused him to become blind and he is a founder member and chair of the Sandwell Visually Impaired group whose membership has risen from 12 to 420 in its four-year life.

Graham believes in co-operation rather than confrontation. He sits on his council’s Disability Equality Board; he was the ‘Expert Witness’ on his council’s Equality and Diversity Scrutiny Panel; he is the lay member of the local PCT Practice Based Commissioning Board, chairing their Stakeholder meetings; and he is a member of Birmingham University’s recruitment/selection/assessment panel for Applied Social Work students as well as engaging with them in lectures.

Graham believes getting around to raise awareness of our strengths and support needs is key. Ability is recognised if we accept the challenge; it’s demanding but rewarding work.
A lot of the work we do brings service users, including disabled people, to meetings with other service users – a service user only meeting. We are often asked to say what is different about these meetings compared to ones where non-service users and professionals are present. Here are some of the things that service users have said about this:

[People without learning difficulties] treat you as an equal and don’t talk down to you.

Tell me what’s going on and I can understand it better, understand what they are talking about.

As a service user you can feel isolated, so it is a good opportunity to meet other service users, that in itself can be very empowering, whatever the meeting was about. It is good when they allow time for service users to network with each other.

You feel empowered, everyone respects you and that feeling carries with you.

At first I didn’t want to know other people who were disabled, I didn’t want to be one of Them, but gradually ‘Them’ becomes ‘we’ and ‘us’ and you realise that talking and being with ‘us’ is where we get our strength. We can have a more powerful voice and perhaps we can make a difference.

For me it has made a big difference [getting involved in her local service user controlled group]. And I suspect there are a lot of people out there who are isolated and lonely and depressed. I am sure. And they probably think there is no one else like them. But I found [the group] quite by accident. How can we reach people? We don’t, quite frankly, have the money. Or the time. And then some disabled people don’t want at first to mix with other disabled people. They can’t imagine the benefits. But this has always been a problem for us.

Getting involved takes you out. Better than medication.
with Other Service Users

There needs to be atmospheric access. 
You need to feel welcome.

There is a huge difference. Service user only meetings are always friendlier. Access is far more likely to be met for one thing. But you don’t have to explain yourself.

You might all, at first seem to be a very mixed group of people, but soon you always discover you have so much in common – we all share barriers, we are all stigmatised, we are all seen to be different.

You have a kind of common shared understanding with each other. There is a kind of acceptance which is never there even when people want to make you feel welcome they don’t really get it.

And also so often we think we are the only organisation struggling with a particular problem when there might be a problem like ours which another group solved and could share how they did that or whatever.

It’s like we think we have all different problems, like visually impaired people are different and have different problems from people who use wheelchairs and like older people who can’t walk far and really our problems are the same, the same prejudices and barriers so it is important to talk and share and become stronger.

It is difficult to put your finger on the difference but it is enormous. It’s about not having to explain yourself, it’s about having freedom to say what you feel without being made to feel stupid, or you’re being emotional.

It’s about recognising that if you talk about your own personal experiences, that is valid. That is OK. That is what you know and that is worth sharing with others.
Get Creative!

**Friend** by Eleanor Ward

Bumped arms
Unexpected smiles
Small talk
Long talk
Nothing's changed
Same her
Same you
Same distance
If not more
Now you're standing
Face to face.
Shop counter
Between you
Change given
Goods received
Common ground
Disappeared
She glances at the ground
Two wheels below you
Means
Too far apart.

**Stigma** by Steven Kirkbride

Stupid;
- Is how the doctors make you feel.

Tired;
- Of being treated like a second class citizen.

Irate;
- At the old school treatment.

Give;
- Nothing away, because of the repercussions.

May;
- We have some help?

Away;
- With the blues!
The government plans to make big changes in social care. It uses the jargon word ‘personalisation’ to describe these changes and says this means that service users should have more say, control and individual budgets. That’s what the government says, but what do service users say?

Shaping Our Lives helped enable a wide range of service users to get involved in an event organised by Brunel University and the Commission for Social Care Inspection bringing service users together with policymakers to say what kind of social care they want for the future and how it can be achieved. The report is now being published and here you can now read the main things people say. This is going into the government’s own consultation about future social care.

People spent a lot of time discussing how good change can be brought about. This is vital. After all, if you don’t have ways of getting the change that’s needed, it will never happen. Service users and policymakers identified six ways of getting better social care and support. First – and this is a bit of a chicken and egg situation – social care will have to change to become more attractive to gain more support. It’s status and profile will have to be raised. Second, there needs to be more joined up campaigning and lobbying which service users are centrally involved in.

Third, everyone will need more education, training and capacity building from childhood onwards to recognise the importance and value of social care. Next, the media must play a more active role in helping people understand social care issues, by raising its profile while no longer stigmatising social care service users. This links with the key need to challenge the stigma now faced by service users and indeed often those working with them, which has meant that they are now often not seen as valuable or worthwhile. Last but not least, user controlled organisations must have a stronger voice to bring about change with increased and more secure funding.

continued on page 14
Transforming Social Care (cont)

The kind of social care people want is one that has much greater user involvement; a better workforce with improved wages, conditions and training; better, more improved services and of course improved funding generally to make all this possible. People call for a universal service everyone is entitled to, not one restricted by charges and eligibility criteria. They want services based on the values of independent living and people having rights. They want services that see service users as whole people, locally based where all the services people need are linked up – housing, health, benefits, education, leisure and so on. Finally they call for better organisations to provide social care support – less bureaucratic, more accessible and not concerned with making a profit.

Let’s hope government now listens to these key recommendations for the future.

Peter Beresford
Chair of Shaping Our Lives

Transforming Social Care: changing the future together by Peter Beresford and Frances Hasler
For further information and copies, please contact cit-participation@brunel.ac.uk

Gaining Experience, Getting a Job

I have been involved with Shaping Our Lives since 1996 when I went to a meeting that they held with Pauline Abbott-Butler. I thought they were very good to me then.

That was only a one off meeting. But in 98 Michael Turner contacted me and asked if I would be involved in some service user research. I said yes and the happy union has taken shape from there. The research was about service user expectations and outcomes from the services. It was published. I really enjoyed the work and I felt then that it had stretched me and helped me to prove to myself that I was good for something. I had lost a lot of confidence because of my illness and this work was the beginnings of regaining some of it. The service user outcomes research ended in 2001. I had a relapse that year but I was determined to bounce back
and Shaping Our Lives stayed in contact and then in 2004 I joined the management committee.

Things really took off then. I was asked to speak at conferences and panels and I attended more meetings. Not just for Shaping Our Lives but for my local borough. I became more at ease with public speaking and more skilled at PowerPoint presentations. I began to gain a new confidence in my skills to assess and report back on a situation. I stopped sleeping in till noon and felt great about the coming of the morning. My life was going in a direction of recovery and meaningfulness. And I was loving every minute of it.

That’s not to say that I didn’t have my ups and downs but Shaping Our Lives has been patient and supportive and helped me achieve my goals. These are skills and achievements that Shaping Our Lives has helped me gain and acquire and I now have secured a job as Project Manager for the Catch-a-fiya Black Minority Ethnic service user network and I represent the organisation at conferences and speak on their behalf. Something I never would have been able to do if I hadn’t been involved with Shaping Our Lives. And I absolutely love what I do, it’s helping others and it’s helping me. The things that I was doing for Shaping Our Lives seem like they were on the job training for the position I hold now, it’s great.

I would recommend joining a user group to every service user, it gives you purpose and hope again and gives some light at the end of the tunnel. It’s a social network as well and its peer support. I feel more able to take on the challenges of the world and my life with my users group behind me. My life has definitely taken on a different and better shape to the way I thought it was going to go.

Thank you Shaping Our Lives.

Patricia Chambers

Catch-a-fiya is a survivor-controlled forum for mental health system survivors, funded by the Big Lottery Fund to facilitate positive change for survivors over 3 years.

Their primary purpose is to establish and maintain contact with survivors from Black and Minority Ethnic communities and support them to learn, teach and grow (personally develop). To find out more go to their website: www.CatchAFiya.org

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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

Contact us

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Please feel free to get in touch with your comments on articles in the newsletter, your own contributions or suggestions for future editions. We are sorry that we can’t include everything we receive.

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