Involving service users and carers in social work education

W

e have been working closely with the Social Care Institute for Excellence and Sussex University on an ongoing project about involving service users in social work education.

Earlier in the year, as part of this project, four regional/local groups held consultation events to find out from service users what has been happening in terms of service user involvement in their areas in the new social work degree. At the same time Sussex University was carrying out similar work with carers and carers’ groups.

Throughout the past year service users and carers from these events have been meeting as a ‘reference group’ for this work, and with support from the web team at the Social Care Institute for Excellence (SCIE) we have designed a web tool that we hope will really help spread good practice in this area.
Social work education (continued)

The aim of the website is that everything you need to know about participation in social work education can be found on one website.

Social work education participation (SWEP) is a user-generated website designed to enable the sharing of good practice in service user and carer involvement in social work education. This means that the more people who use the site and who ‘post’ information on the site, the better and more useful it will become.

Please give us your views
User generated means that to make the site work we need your contribution so please upload your good practice example, share your experiences and get involved in making social work real.

Mental Health Self Reforms (Part 1)
by Philip Pashley

Breaking down the isolation, returning self esteem,
People sharing information, no it’s not a dream.
Service users training others,
Professionals stand and stare.
Roles reversed, one soon discovers,
The buck does not stop there.
Everyone just work together,
It’s important that we do.
Because those who think they know it all Just haven’t got a clue.

The home page of the new Social Work Education participation website

The website is the only one of its kind where people can swap ideas, experiences and examples of good practice. The site is for service users, carers, educators, students and other people and organisations interested in making sure the involvement of service users and carers in social work education is meaningful.

Access the website for free at www.socialworkeducation.org.uk or follow the link from our own site at Shaping Our Lives.

In December this year there will be a seminar where service users, carers and other stakeholders will come together. The reports from both Shaping Our Lives and Brighton University will be launched and after this event they will be available to download from our websites and from SCIE.
We need your help, please!

Shaping Our Lives is working in partnership with the National Centre for Independent Living (NCIL) and RADAR, as one of 11 groups chosen by the Department of Health to take part in the ‘Third Sector Strategic Partner Programme’.

Our role in this work is to improve and strengthen two-way communication between service users and our organisations and the Department of Health. From previous work we have carried out and from listening to and meeting with many service users we have identified two areas which seem to us to concern service users above other issues.

We want to check these priority areas out with you.

1 Feeding from service users to the Department

The Department of Health has said that they want to see a national network of user-controlled/user-led organisations in every local authority area.

Questions

◆ Do you and/or your organisation feel this is making progress?

◆ If not what are the problems and the barriers to making this a reality?

◆ What should we be doing as service users and service user organisations to highlight the barriers and challenge them?

◆ What message do we want to get to the Department of Health from our localities about this?

2 Feeding from the Department of Health to service users and our organisations

The government has committed itself to transforming social care to enable person-centred support (personalisation offering choice and control) and self-directed support (methods like direct payments and individual budgets, giving people choice and control over their support through having control of funds).

Questions

◆ Are present financial arrangements making this possible? Do you and/or your organisation feel you have enough resources to ensure equal access to funding to provide the support to make possible independent living?

◆ Are there barriers?

◆ If so, how can these be overcome in addressing social care funding for the future?

Please get in touch. You can phone us, email us or write to us. Full contact details are on the back cover of this newsletter.

Thank you all very much.
Free personal care plan makes a mockery of the adult Green Paper consultation

Peter Beresford, Chair of Shaping Our Lives first wrote this report in his blog at www.communitycare.co.uk.

The Prime Minister’s conference commitment to introduce free home care for people with the highest needs has made a further mockery of the government’s Green Paper consultation. This plan wasn’t even in the Paper. The government said it wanted the Green Paper to foster public debate but it is only increasing controversy.

Already, thousands have signed up to a petition opposing the green paper proposal to divert money from universal benefits, such as Disability Living Allowance and Attendance Allowance, into councils’ discretionary funds for care, to which people so far have little entitlement.

Tax funding
Service users have made clear their concern about the green paper ruling out funding social care through general taxation. Many people consulted in preparing the green paper said they preferred this option. It describes it as probably the simplest and fairest option.

It has never been clear from the Green Paper what its calculations were based on.

All three funding options offered require people to make a contribution. But those contributions seem suspiciously low. The full calculations have not been provided. So how can we make a judgement? How can we have an informed public debate?

Calculations
At a recent users’ and carers’ consultation organised by Hampshire Council, the Department of Health representative told me that the London School of Economics would this month publish the figures on which the calculations are based.

This means that the public, carers and service users will have less than one month to make an informed judgement about proposals for the future of a policy that affects more than one million people. Already underfunded, the demand for social care is set to increase enormously.

Consultation answers
How can this constitute a legitimate consultation? What basis does it provide for social care for the future, especially at a time when every major political party is
Shaping Our Lives was asked by the Crown Prosecution Service to run a consultation event to explore with people who have mental health issues, including alcohol and other substance users, their views, perceptions and ideas on the draft policy prepared by the Crown Prosecution Service on prosecuting criminal cases involving people with mental health issues. As a result of this consultation substantial changes were made from the draft to the final document.

One delegate at the event said: “I am pleased to have been asked to take part in this day. I am pleased that the Crown Prosecution Service have put on this day because it shows that perhaps they know the judicial system is prejudicial towards certain sections of society. Let’s hope we can begin to change that.” “There is a lot that I don’t like in the draft policy,” said another, “but, saying that, it is good that they want to hear what we have to say about it. And it is really good that they are doing this day today.”

During the course of the day we had some very interesting discussions. These included talking about when a
witness is seen to be credible or not, the importance of language and the need to clarify the difference between the police and the Crown Prosecution Service and the need for both organisations to adopt best practice procedures and policies towards mental health service users.

You can receive a copy of the policy, 'Supporting victims and witnesses with mental health issues', by contacting CPS Communications Branch (tel no 020 7796 8442; email publicity.branch@cps.gsi.gov.uk).

Latest reports from the Highland Users Group

Recently the Highland Users Group (HUG) has published a report called ‘When it all goes wrong’ which looks at the police in particular, as well as other parts of our justice system. It is a powerful illustration of those times when the police can be a calming and life-saving presence as well as those situations when their intervention is traumatising and deeply disturbing to those of us that have to be subjected to compulsion or force.

The Highland Users Group’s main aim is to improve the way in which we, as users of mental health services, are treated, by campaigning to improve the rights, services and treatment of people with mental health problems, and to challenge stigma and discrimination.

Over the last few months the Highland Users Group has produced some other interesting reports:

◆ **The Impact of the Diagnosis** – in other words, what does it do to us when we are diagnosed with a mental illness? Is it always a negative label or can it have a positive effect? What is the impact of the diagnosis on our lives and self esteem? And finally what is it like to have mental health problems and no diagnosis at all?

◆ **Local Issues in NHS Highland Area** – a series of reports that give a perspective on what is important to us in our local areas. NHS Highland is the same size as Wales but has as population of 300,000. It may be interesting to groups that live in other rural areas or cities.

Recent talks from HUG have been on HUG itself, user involvement, peer support, welfare reform, personality disorder and personalisation and the contract culture.

To receive copies of these reports and talks email us at hug@hccf.org.uk or visit our website www.hug.uk.net.
News and Events

Breakthrough Independent Living Award 2009

Chief Officer Jayne Horton and Mrs Pamela Thompson went to this year’s Breakthrough Independent Living Awards held at Manchester Town Hall on 18 July, where Warrington Disability Partnership received the Kevin Hyett Award for Best Independent Living Initiative.

The awards recognise and celebrate organisations in the North West who have ‘gone the extra mile’ in promoting and supporting independent living. The keynote speaker Jonathan Shaw MP, Minister for Disabled People, said “Government can put legislation in place, but it is organisations like the ones we celebrate who make change happen in reality. I congratulate each and every one of the nominees for the fantastic work they do.”

Warrington Disability Partnership is a user-led voluntary organisation with charitable status, which promotes independent living. We employ 40 paid staff and over 100 volunteers who deliver a range of services for disabled people, their families and carers. Services include shopmobility in two locations, a disability information point at Warrington Market, direct payments schemes, employment services, leisure, recreation, access advice, equipment loans and training. The Discover IT suite has recently launched its UK Online training course facility to add to the long list of training courses on offer. Our DISC sports club also offers children the opportunity to join in with sports that they otherwise would be unable to play, bringing new meaning to the lives of the children and their families.

At the moment our independent living centre is going through major renovations, after a grant from the Big Lottery Community Assets funding, and we are at a temporary address. We hope to be able to move back in early 2010 and when we do our services will grow. We will have a community café on site to encourage the local community to join WDP and access all our services.
Our history

The idea for BADGE (Bolton Active Disability Group for Everyone) originally came about at the ‘Bolton Café’ event in July 2006 and, after a series of meetings, its founding members quickly set about agreeing its terms of reference, creating its constitution, formally electing its officers and applying for funding.

At large meeting at the Bolton Town Hall in May 2007 BADGE then gave a presentation to key people from all different types of public service such as Bolton Primary Care Trust, the Police Service, Greater Manchester Passenger Transport Executive as well as many Council departments. This explained that BADGE was an important group to contact when planning services for disabled people and when making their Disability Equality Schemes and so on.

What we do

BADGE wants to...

◆ help services in Bolton to engage, plan, communicate and consult with disabled people in a positive and mutually beneficial way

◆ see the creation of an Independent Living Centre in Bolton planned for and with disabled people

◆ be part of creating an equal society for everyone in Bolton and welcomes the Government’s 2025 agenda.

Our committee and group has voices from all areas of the disabled community. We have people who try hard to represent the voices of people with various disabilities including physical difficulties, learning disabilities, sensory impairments, mobility problems, mental health conditions, speech difficulties and neurological disabilities such as MS, stroke damage and spinal injuries.

Join us!

BADGE welcomes new members from all areas of the disabled community who either live, work or study within the borough of Bolton. To become a member you must consider yourself to be a disabled person and agree to work within the social model of disability.

Being a member of BADGE can be fun, powerful, busy and hard work. Sometimes we do surveys, attend meetings, take part in consultations with services, run open days, attend forums and help plan services for disabled people. For a membership pack please contact the Secretary, Ian Cooper, Doyle Road, Hunger Hill, Bolton BL3 4SA.
SOLNET goes international!

SOLNET, the Shaping Our Lives networking website, continues to grow. Hundreds of user-led organisations are members along with other friends and allies. The network is set to increase its reach even further as SOLNET develops new international links. New members include:

♦ WIBS – Wir Informieren, Beraten und Bestimmen Selbst – an Austrian People First Group, who meet from all over Austria, South Tyrol, Switzerland and Germany to work together.

♦ Disabled Peoples’ International – a network of organisations of disabled people, established to promote our human rights. Their work extends over five regions: Africa, Asia/Pacific, Caribbean, Europe and Latin America. They are in the process of developing a sixth region to include the Middle East.

♦ European Network on Independent Living (ENIL) – network which aims to increase awareness of independent living, and the solidarity of disabled people, throughout Europe.

If you know of any other groups who have not yet joined SOLNET please tell them to contact us! We would love to hear from them!

SOLNET’s online noticeboard is ever-changing and packed full of interesting debates, events, conferences, campaigns, job vacancies and much more! Every SOLNET member and friend can place items on the noticeboard. This makes it an exciting and up-to-date place to find out about what’s going on in the service user movement.

Here is a taster from the SOLNET noticeboard.

♦ Debates and blogs on topics such as...

“Social Care Funding: Is the private sector pulling the strings?”

“Does technology make it easier or harder for disabled entrepreneurs?”

♦ Projects and Involvement

Involve have produced a short film, which outlines why and how people are getting involved in research and highlights some of the differences that public involvement is making.

The noticeboard also has news bulletins, job vacancies and newsletters including Disability Arts Online which showcases disability and deaf arts, profiles artists and offers reviews, arts news and reports the latest from the disability arts world.

If your organisation would like to become a member (or a ‘friend’ for organisations that are not user-controlled) or know an organisation who would be interested then go to www.solnetwork.org.uk and click on ‘Join Network’.
This September 440 people from 21 European countries met in Strasbourg for the Freedom Drive. The group included disabled people with their personal assistants. The common cause was independent living: deinstitutionalisation, the right to personal assistance and the approval of the UN Convention on the Rights of Persons with Disability.

“The segregation of people with disabilities in long-stay institutions is a violation of disabled people’s human rights” says Freedom Driver Ines Bulic of the UK. She was one of the speakers at a European Network for Independent Living (ENIL) conference on Monday 14 September at the Youth Centre in Strasbourg on ‘Implementing the UN Convention on the Rights of Persons with Disability’ which kicked off a week of Freedom Drive events in the city.

The UN Convention is the first legally binding instrument with comprehensive protection of the rights of disabled people and so one of the eight demands of the Freedom Drivers handed over to European Parliament President Jerzy Burzek and to Richard Howitt MEP was for the European Community to approve this human rights convention.

Freedom Drivers also asked for a continuation of the development of community-based services to achieve deinstitutionalisation across Europe and called for the implementation of the human right to a personal assistance service, which is fundamental to guarantee the enjoyment of independent living.

As they received the demands, Jerzy Burzek and Richard Howitt said they were committed to fight for the rights of disabled people. They also encouraged Freedom Drivers to keep lobbying their national MEPs.

Freedom Drivers ended the week with a celebration of the 20th anniversary of the European Network on Independent Living (ENIL), one of the organisers of the Freedom Drive. The Freedom Drive week in Strasbourg is one important event in ENIL’s ongoing campaigning for disabled people’s human rights.

To see the Freedom Drive Demands in full go to the European Network on Independent Living website at www.enil.eu and click on Projects and Campaigns and then Freedom Drive 2009 – Demands (at the bottom of the page).
Shaping Our Lives had a strong presence in the fourth annual conference of the Social Work Action Network (SWAN), which was held at Bath University early this autumn. Peter Beresford (Chair), June Sadd (Management Group member) and Fran Branfield (Director) all gave presentations and took part in discussions during the two-day event.

The Social Work Action Network is made up of social workers, social work students, educators and academics and, importantly, service users. There were many interesting discussions and talks. Some people talked about how they had chosen to become social workers because they thought they might be able to improve things for some people, even if it was just in a small way.

Getting harder to help

But people also said that over the last 15 years it was becoming more and more difficult to have a positive impact on service users’ lives. Some people said that now all decisions were made on how much money it would cost, whether the right forms had been filled in and the right ‘target’ met. They were concerned that the people who were the poorest and most oppressed were not being helped.

Social workers at the conference said they joined the profession to make a good and positive difference to service users’ lives. They said they didn’t become social workers so that they could be ‘case managers’ or have to make decisions based on money rather than on what was needed.

Some social workers were very fed up with the way they had to work. They said they were fed up because they could see that social work didn’t have to be like this and they thought working all together with students, with academics, with others from the welfare services and with service users and our organisations was the only way that social work could get back on track and be a profession we would all be proud of.

Fran Branfield
Director, Shaping Our Lives
The ‘Being the Boss’ website – www.beingtheboss.co.uk – has been created to address the lack of peer support available to disabled people who employ their own Personal Assistants (PAs).

We aim to do this by sharing information based on the experiences of disabled people who employ PAs, and by providing a safe forum to discuss and share ideas. It is very important to appreciate that there is no one correct way of working with PAs. We all have our different approaches and we must respect and value this. However, we can all learn from and support each other to become better employers.

With the introduction of Direct Payments in 1996, the Personalisation Agenda and the new government consultation ‘The Right to Control’ it is more important than ever to make sure disabled employers have the support they need. Who better to provide this support than disabled people? One of the most crucial factors when recruiting Personal Assistants is whether you feel their personality matches your own. However, this is difficult to tease out during an interview. It is easy to teach a person to cook your favourite meal, but getting the relationship right is more tricky. Understanding what makes a good PA and how to make the relationship work is often about having good ground rules.

There is a lot of support available from service user-led organisations, but peer support at a national level is very scarce. Even at a local level, many peer support groups have now closed due to lack of funding or have been taken in house by the local authority. This website is intended to address this need.

At Being the Boss we are also launching a handbook for disabled employers and their personal assistants which looks at:

- terms and conditions of employment
- policies on employment
- disciplinary procedures
- supervision/appraisal information

and includes useful telephone contacts and much more.

Through our organisation, the Association of Disabled Employers (ADE), we believe we will give disabled people a louder voice. If you are a member of ADE the handbook is free. The price is £10 if you are not.

You can contact ‘Being the Boss’ on mail@beingtheboss.co.uk or write to: BM, Being the Boss, London WC1N 3XX.

Anne Pridmore
Meet...Molly Barrett

Molly has worked with Shaping Our Lives for a number of years and has produced the designs for many publications including this newsletter and the Shaping Our Lives logo. She designed the book ‘We Are Not Stupid’ written by the research team at People First Lambeth. Here she tells us a little bit more about herself.

For almost 30 years I’ve been self-employed, under the name of Em En Designs, working on graphic design projects for commercial and not-for-profit organisations from sole owners to departments of the European Union.

The first in my family to experience education at university level, I’m incredibly lucky to have benefited from not only that golden age of mandatory grants, but also the computer age which gives me the chance to carry on working while my condition accelerates.

All this is good for morale, which is just as well, since there’s enough obstacles out there to knock the self confidence of most women in the workplace, and most disabled women in general. Being five foot two – and shrinking – gives an added edge to the situation, which sometimes gets me a reputation of being somewhat stroppy – largely among tall non-disabled men, it has to be said!

Luckily it doesn’t happen too much in my work life, partly thanks to the very good grounding I had at Norwich School of Art in understanding print production processes. The first time a printer sucked on his teeth and shook his head at me I was able to suggest “What if we do it like this?” at which he gave a relieved grin, and I haven’t looked back since. Now I get comments like “Why couldn’t they have got you to design this, Molly? It would have made our job a lot easier.”

Isolation is a big problem, especially when you think that a considerable amount of informal training in the workplace is done among colleagues. So there’s a constant sense of running to catch up with the rest of the industry – or at least where one imagines it’s up to.

So you can appreciate that working for (or should that be ‘with’?) Shaping Our Lives gives me a great sense of belonging, a sense of purpose and comradeship.

I shouldn’t have said that, should I? They’ll see the chink in my armour and be getting me to work for nothing next. Whatever will my accountant say?

For details of Shaping Our Lives’ publications, many of which have been produced with Molly’s expert help, go to www.shapingourlives.org.uk and click on Our Publications in the menu on the left hand side.
Who has had the greatest influence in your life?
My grandmother and my mother who put the seeds and gave me the roots of the person that I am now, from them I have the good side of my existence. They both left long time ago but manage to teach me my most beautiful lessons.

What is your most treasured possession?
My friends, from my family up to my newest one, they are the most valuable treasure that I possess.

If you had one wish, what would it be?
A world more tolerant and with more compassion, without the mask of extremism, violence and hate.

What would you like to ban?
Intolerance.

What one thing in health and social care services would you like to change?
I would like to change the system to a more human and individual approach as their services are for humans and all humans are unique.

What makes you laugh?
Children playing and having fun in the streets or parks and a happy friend doing silly things.

What do you like least in yourself?
My impatience sometimes and the fear of failure...my worries taking over my decisions.

What do you most dislike in others?
Being selfish and intolerant, the use of violence...and not listening.

What is your idea of perfect happiness?
To be under a cherry tree in blossoms with a glass of a good wine, smelling the flowers and looking to nowhere with a mind full of peace and a heart full of joy.

What is your favourite film or television programme?
All the ones that make me laugh...and there are many.

What has life taught you?
That everything good and bad happens for a reason and I must learn from them. When I get the lesson then life seems easier to carry on. Also that ‘present moment, beautiful moment’ and the here and now must be my priority and the key of my happiness.

How would you like to be remembered?
As a funny old lad...
An Open Book
by Anne Pridmore

My life is like an open book for all to come and see.
I long to find a secret place where I can be just me.

Perhaps it may be strange to you that this is how it seems,
For many disabled people who only have their dreams.

I long to find some hidden spot away from prying eyes,
To carry out my fantasies and write my book on life.

We have our lives looked into from birth to death you see.
It’s hard to find a part of life that belongs specifically to me.

~~~

I long to be a mother whose children are full grown,
Their children all around me and then I’d send them home.

My dreams are all that’s left to me that no one else can see,
I treasure them so fiercely because they’re just for me.

The tune of life’s mapped out for us but mine’s an open book.
Sometimes I feel quite naked, my heart is laid quite bare.

But then I stop and wonder is there anything to reach?
I’ve travelled to the Orient, danced naked on the beach.

~~~

The mind’s a truly wondrous place that just belongs to me.
No one can know its secret place and dreams are always free.
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

Contact us

Jenny Willis is our Office Manager and you will speak to her when you ring.

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Websites:
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(networking) www.solnetwork.org.uk

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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