Addressing health inequalities together

Shaping Our Lives is working in partnership with the National Centre for Independent Living (NCIL) and RADAR, as one of 11 groups chosen last year 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.

As part of this Programme Shaping Our Lives was centrally involved in an event in March which was organised by the strategic partners. This event, ‘Marmot and The Third Sector – Addressing health inequalities together’, examined the impact of the Marmot Review, ‘Fair Society, Healthy Lives’ on the Third Sector or voluntary organisations and charities.

The opening keynote address was given by Gillian Merron MP, Minister of State for Public Health. Sir Michael Marmot, author of the review, spoke, as did Shaping Our Lives’ Chair, Peter Beresford. In addition four members of our National User Group ran workshops together. Maggie Brennan
and Jennifer Taylor spoke from their experiences of accessing health and social care services from the perspective of women with learning difficulties; Alison Black shared her experiences as a transgendered person and Amanda Wells spoke of the barriers encountered as a disabled person accessing mental health services. It made for two very interesting workshops.

User-led organisations in local authority areas

In our last Newsletter we asked you to tell us how you felt the government’s stated aim of developing a user-led organisation in every local authority area that was providing services was developing.

We would like to thank all of you who responded to our questions. We have now collected all your comments and put them in a report. This will soon be available on our website or from our office (see back page).

People had a lot of interesting things to say. Many reported that they did not think that this development was progressing well. This comment was typical: ‘I do not believe this initiative is making progress. Certainly not involving my local user led organisation.’
Other service users said that by developing and funding one service user organisation others, in the same area with different remits, were being forced to close. This, we were told, has meant that in some areas some specific impairment groups are left with no user representative organisation and in others has fostered competition rather than partnership working. Service users told us that they felt that groups which were less politicised ‘those groups that do as they are told and not seen as being awkward disabled people like us’ are much more likely to be funded than the ‘difficult and demanding rights based groups’.

But in general people said that it was a good idea but more thought needed to be given to how it was implemented in practice. Service users had many suggestions for developing this initiative. These included coalitions ‘where different groups were encouraged to work together in one area’ while ‘still keeping their own identity and autonomy’.

Don’t forget to keep a look out on our website to see this full report!
Keep an eye on the notice board on SOLNET, our networking website, to find opportunities to have your voice heard, to take part in discussions and to take part in some of our meetings! www.solnetwork.org.uk

A Better Life: Alternative approaches

People are always searching for the magic bullet, but there isn’t one. People want to live ordinary lives but that’s not headline news. (Service user participant)

Shaping Our Lives was asked by the Joseph Rowntree Foundation to explore with a diverse range of service users what, if anything we could learn from our experiences of being service users, that might inform alternative approaches to support the well-being of older people identified as having ‘high support needs’.

We wanted to discuss ‘alternative approaches’ to the more commonly available options of the traditional care home and the newer extra care housing model. The key questions the Foundation wanted answered were: What really exciting/promising approaches are already happening somewhere in the UK or internationally which might offer real hope for a better life (not just better care) for older people with high support needs, including approaches used with other groups that could be adapted for older people with high support needs?

What we quickly found out in the consultation was that such questions could not be asked in isolation. We could not helpfully think only of specific options for support. These had to be located in the broader context of attitudes and policies towards older people and how general developments, policies and practices might affect older
people. In the report we sought to highlight the insights that service users bring on both these issues.

1. Particular alternatives that might have much to offer older people.

2. Broader considerations that also need to be addressed, if older people are to have as good quality lives as possible and existing resources, policies and practices are to be consistent with this.

People had many ideas for making things better for older people, such as:

- Key ring communities where people living near each other are supported to look out for each other and have a support worker;

- People talked about overseas holidays and cruises as cost-effective means of offering supportive accessible living which could be in more supportive climates and environments.

- Cooperatives where people have their own houses and are independent but where they could get support and help.

- House sharing where older people could be put in touch with other people to offer accommodation in exchange for support.

- People said ‘telecare’ systems could helpfully be used to support older people in their own homes. But they were also worried that they might be used to replace contact with ‘real’ people as a cost-saving measure.

The Joseph Rowntree Foundation will use the report from this consultation to contribute to and inform their thinking when they came to identifying priorities in the 2010 funding stream.

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**Well done Patsy and Vic!**

We are really proud that two people closely associated with Shaping Our Lives, **Patsy Staddon** from our Management Group, and **Vic Forrest**, a service user and support worker for two members of our National User Group, have been awarded PhDs. They have both had to work very hard doing research and are now ‘doctors’!

Patsy’s PhD involved interviewing other women who had also had alcohol problems, running discussion groups with them, interviewing GPs and treatment providers, and then writing it all up. She found that the main cause of women needing alcohol was unhappiness caused by social inequality and abuse and that few health professionals knew what to do about it. Patsy hopes to do more service user-controlled research – watch the SOL website!!

Vic’s PhD thesis is about supporting people with learning difficulties to control their own self-advocacy groups and research projects. He supported one group through their project, researched his support role and wrote it up. Vic found that the user-controlled research supporter’s role can involve many support and research skills, and that it was important for the supporter to beware of taking over the group.
In March 2010, INVOLVE and Shaping Our Lives held a one day event to find out about how more people can get involved in research – in particular people and groups who are often overlooked or ignored by mainstream society. Ten service users attended the event with colleagues from INVOLVE joining the afternoon discussions.

When we talk about getting involved in research, we mean the active partnership between service users, patients and/or carers and the researchers in the research process. Involvement means people having an active part in deciding what research is done or how it is carried out. This would include, for example, advising on research project, assisting in the design of a project, or in carrying out the research and leading research projects.

The aim of the event was to find out more about the issues which might make it hard for people from a diverse range of groups to get actively involved in research. INVOLVE wanted to do this by learning from people who have experience in this area or ideas about it. INVOLVE felt that there may be common issues of concern, at the same time as diversity in the needs across a range of people and groups. They want to find out more about these.

This was the first event in a series to help INVOLVE think about including the views of the diverse population. They want to build on this work later in 2010 to find out more about researchers perspectives on this issue and give them information about service user perspectives.

These events are designed to contribute to an information guide to help greater involvement in research by people and groups who are often overlooked or ignored by mainstream society.

Watch this space!

For more information...
please contact Jenny Willis at Shaping Our Lives (her contact details are on the back page of this newsletter) or Lucy Simons, Public Involvement Advisor at INVOLVE, email: lsimons@invo.org.uk, telephone: 023 8065 1088.
Late last year Shaping Our Lives working in collaboration with the University of Sussex, The Social Care Institute for Excellence and a advisory group of service users and carers organised a conference around service users and carers involvement in educating social workers.

The event was attended by service users and carers together with social work educators, practitioners, students and others interested in social work education. It was an event full of energy and ideas and the participants brought a really wide range of experiences, knowledge and expertise.

The advisory group which organised the conference is now considering the conference report written by Alison Faulkner, an experienced user researcher who also took part in the day. This group has been listening to the pod casts and watching the videos and reading the evaluation forms. All this material will guide the development of the national forum for social work education participation. The National Forum will be set up during the spring and summer and the first meeting will be held in the autumn.

A special section of the website which will be about the development of the national forum will be created. The website (www.socialworkeducation.org.uk) will be used to update everyone on progress. If you need support using the website or you require information in an alternative format please contact SCIE (details below). The Conference report, the video, audio materials and a gallery of photographs will be posted up on the website soon. If you did not attend the conference but would like to receive email updates about this project please get in touch.

In the meantime please make use of the website. Its success depends on people registering on the site and using it to share good practice. It only takes a minute to register. If you have questions about registering or posting material please contact Michael Turner (who many of you will know as he used to work for Shaping Our Lives) at SCIE: Michael.Turner@scie.org.uk and he’ll be happy to assist.
Good news for part-time workers – Permitted Work disregard goes up from April

The Permitted Work disregard for Housing Benefit and Council Tax Benefit increases from £20 a week to £93 a week from 1 April 2010.

This applies to people who get:
- Incapacity Benefit
- Severe Disablement Allowance
- Employment and Support Allowance (contribution based)

Employment and Support Allowance (income based) already allows Permitted Work with earnings up to £93 a week, and neither Employment and Support Allowance, Housing Benefit or Council Tax Benefit are affected.

This means that people who are in receipt of any of the above benefits can earn and keep up to £93 a week providing they follow the rules for Permitted Work from 1 April (see below). For most people this will mean up to one year of earning £93 per week is allowed. The following year the limit reverts to £20 a week.

Unfortunately the benefit rules for people who get Income Support for incapacity are not changed.

**Please note**

People starting part-time paid work or involvement must notify Jobcentre Plus that they are starting Permitted Work as soon as practicable and preferably in advance, on a form headed PW1. If you don’t do this the work doesn’t count as Permitted Work and benefits can be suspended or stopped.

The Permitted Work disregard for Income Support for incapacity remains unchanged at £20 a week. People can earn up to £93 a week but £73 is deducted from Income Support.

**Who do the Permitted Work rules apply to?**

Permitted Work rules apply to people who get incapacity-based benefits:
- Incapacity Benefit
- Severe Disablement Allowance and/or
- Income Support for incapacity (with a disability premium) or
- Employment and Support Allowance contribution based (Work related group and Support group)
- Employment and Support Allowance income based (Work related group and Support group)

The rules also apply to people getting:
- NI credits for incapacity,
- Housing Benefit or Local Housing Allowance with a disability premium, and
- Council Tax Benefit with a disability premium.

This information is from the website of Judy Scott Consultancy. To find out more, visit: [http://judyscottconsultancy.com](http://judyscottconsultancy.com).
Shaping Our Lives has a new strapline!

After a lot of discussion Shaping Our Lives has decided to change its ‘strapline’. We have always called ourselves a ‘service user network’ or ‘a national network of service users’ but we have changed this to ‘service user and disabled people’s network’ or ‘a national network of service users and disabled people’.

Why have we done this?
Not everybody likes the term ‘service user’. Some people think that it does not really apply to them as they do not use any specific services. Sometimes ‘service user’ can be used to restrict your identity as if all you are is a passive recipient of health and welfare services. That is to say that a service user can be seen to be someone who has things ‘done to them’ or who quietly accepts and receives a service.

This makes it seem that the most important thing about you is that you use or have used services. It ignores all the other things you do and which make up who you are as a person. This is not what Shaping Our Lives means when we talk of ‘service users’. But we are aware that some people do not think all disabled people are service users.

What we mean when we use the term ‘service user’
Shaping Our Lives National User Network sees ‘service user’ as an active and positive term, which means more than one thing. It is important that ‘service user’ should always be based on self-identification. But here are some of the things we think it means:

- It means that we are in an unequal and oppressive relationship with the State and society
- It is about entitlement to receive welfare services. This includes the past when we might have received them and the present. Some people still need to receive services but are no longer entitled to for many different reasons
- It may mean having to use services for a long time which separate us from other people and which make people think we are inferior and that there is something wrong with us.
- Being a service user means that we can identify and recognise that we share a lot of experiences with a wide range of other people who use services. This might
include, for example, young people with experience of being looked after in care, people with learning difficulties, people who use drugs and/or alcohol, mental health service users, older people, physically and/or sensory impaired people, people using palliative care services.

We have added ‘and disabled people’ to our name so that everyone is very clear that we work with all disabled people and all service users, whatever your definition or understanding of these words... We want to be as inclusive as possible.

Knowing Me, Knowing You
Amanda Wells

Who has had the greatest influence in your life?
This is a difficult one. My English teacher at secondary school was very influential in terms of instilling in me a love of learning and of literature.

From 2001 to 2003 I saw an excellent psychologist who showed me that hope and happiness were possible for me; sadly, since he left I’ve had no further psychotherapy as it’s no longer available in my area, so the progress we made has been undone. However, I am lucky to have two very good friends who understand my experiences and we all do our best to support each other.

What is your most treasured possession?
My most treasured possessions are photos of my animals, past and present, and of my twin nieces.

If you had one wish, what would it be?
I’m going to be selfish here and wish for a house with land where me any my animals can live in peace and security. I should wish for a world where people are nice to each other and care about the environment, but I’m not sure it’s in human nature for people to be like that.

What would you like to ban?
I would like to ban prejudice and intolerance, and greed. Most of the world’s problems seem to stem from these things.

What one thing in health and social care services would you like to change?
Attitudes and power – we as service users know what we want from life and what assistance we require to get it,
but we are made to feel inadequate, a burden and a nuisance. Too often services forget that they are there to serve us, not us to serve them.

What makes you laugh?
My two dogs when they are playing together. Intelligent comedy such as Eddie Izzard and Jack Dee – I went to see Jack Dee at the theatre and was aching with laughter by the end of the show.

What trait do you like least in yourself?
Impatience – I get very annoyed when things seem to be needlessly inefficient or difficult. Trying to get the services I require springs to mind as an obvious example.

What trait do you most dislike in other people?
Narrow-mindedness. People these days seem to be too self-interested and to have lost their curiosity, not caring about, accepting or being interested in other people.

What is your idea of perfect happiness?
A house with land where me and my animals can live in peace and security!

What is your favourite film or television programme?
My favourite film is Terminator 2. If a machine can learn to be human, why can’t we? Plus the heroine has a diagnosis of schizoaffective disorder, the same as me, and people realise in the end that everything she says is true.

What has life taught you?
That things don’t always go the way you expect or hope, and sometimes the unexpected and seemingly negative twists and turns bring possibilities and opportunities that you had never considered, but which prove to be positive and fulfilling.

How would you like to be remembered?
As someone who tried to be kind.

Meet... the Disability Law Service

The Disability Law Service (DLS) has provided high quality information and advice to disabled and Deaf people for over 30 years. Disability Law Service is run by and for disabled people as an independent, national registered charity.

What we do
DLS provides expert legal advice and representation (for example, in complaints, using the Ombudsman, tribunals and courts) to disabled people, their families and carers. It is a national charity that specialises in the following areas of law:

◆ Welfare Benefits
◆ Community Care
◆ Disability Discrimination (in Employment, Access to Goods and Services, Further and Higher Education and the Disability Equality Duty)
DLS can also advise disabled people who are being discriminated against on other grounds such as their age, sexuality, gender, race, religion or belief and employs solicitors and caseworkers to provide **advice and information** by telephone and email and where necessary face-to-face **casework** and **representation**.

They publish a very wide range of **factsheets** on their website and run **training** courses in topics as diverse as Disability and Human Rights, the Disability Discrimination Act, Community Care, Disability Living and Attendance Allowance and Employment issues relevant to disabled people employing their own staff.

You can find more information on the Disability Law Service website at [www.dls.org.uk](http://www.dls.org.uk).

**Development Work**

Our aim is to use our knowledge of the law to support disabled people to manage and sustain their quality of life, improve their well being and realise their potential. To achieve this aim we try to conduct activities and projects which:

- ensure the most marginalised disabled people obtain sufficient basic support (for example, adequate community care support and welfare benefits);

- realise the aspirations and commitments made in existing laws (for example, helping individuals to use the Disability Discrimination Act and ensuring public authorities meet their duties to actively promote the best interests of disabled people);

- include future-focused work which looks beyond present legislation and/or practice (for example, cross equalities work recognising the multiple identities of disabled people).

Some examples of London work over the past year include helping to ‘unpack’ government proposals for the reform of the social care system and work with people with learning difficulties and disabilities to help them to understand discrimination law.

In national development we have been actively mapping and developing relationships with disabled people’s organisations and legal and advice providers. We have also been rolling out training courses outside London. We are aiming to link these contacts together in our future national development work and would love to hear from organisations interested in being a part of this.

If you have any ideas about how you could work in partnership with us please **get in touch**!

For London based organisations: Nick Clarke (email: nick@dls.org.uk; telephone: 020 7791 9819)

For organisations based outside London: Christine Goodhall (email: christine@dls.org.uk; telephone: 020 7791 9828)
Meet... CoolTan Arts

CoolTan Arts is a pioneering arts and mental health charity based in South London. It believes that mental wellbeing is enhanced by the power of creativity. It is run by and for adults with experience of mental distress.

CoolTan Arts has a lively and busy arts centre, with a public art gallery and daily creative workshops open to adults experiencing mental distress. The workshops offer visual arts and drawing, Batik and fashion, video editing and filming, creative writing and poetry, web design and podcasting, IT, photography, and sculpture.

Elephant & Castle Shopping Centre by Graham Newton, part of a Black History Month exhibition, Morley College

CoolTan is like creative jogging.

CoolTan Arts aims to empower people to move into the wider community, through creative workshops, public art exhibitions, fashion shows, poetry readings, ‘Largactyl Shuffle’ walks, websites, advocacy and volunteering.

Weird place that CoolTan - I have exhibited art work for the first time, been published for the first time and begun speaking instead of mumbling monosyllables. Be careful, it may be contagious.

CoolTan Arts challenges the stigma associated with mental distress –

Maggi Hambling by William Ball, part of the ‘Women that inspire you’ exhibition at CoolTan Arts Independent Gallery until 30 April, to mark International Women’s Day.
through art exhibitions in its own gallery and by showing the art work of the participants at other venues, including hospitals, libraries, City Hall, Dulwich Picture Gallery and will be taking part in the Alternative Fashion Show in April 2010 for the third year running.

CoolTan Art’s Largactyl Shuffle – one of the best 10 walks in London (Time Out magazine)

One of CoolTan Arts’ most ambitious projects to date is the Largactyl Shuffle, a monthly cultural walk through the Borough of Southwark from Maudsley Hospital to Tate Modern. The Largactyl Shuffle was named after an anti-psychotic drug that can have extreme physical side effects including a distinctive shambolic gait.

CoolTan Arts is developing the walks in other London boroughs, with ‘Largactyl two go’ as part of the Olympics/Paralympics in 2010-12.

CoolTan Arts has recently launched a ground-breaking self-advocacy skills training programme. This is based on one-to-one learning support tutorials covering topics such as housing, finance, the mental health act and personalization, assertiveness and employment. The courses have just started, and you can still sign up.

We are keen to hear from you to share best practice, put together conferences, have art exhibitions, show films, or work in partnership. Please get in touch, all individuals and organisations welcome.

Kathrin Kirmann

For more information...
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www.cooltanarts.org.uk
www.afunnyfarm.org.uk
Accepting Mental Illness

Feeling afraid, feeling alone
Accepting it all goes close to the bone
Accepting that you are ‘MAD’!
Wondering what happened,
finding all people feel you are BAD!

~~~

Your family and friends all feel upset
Realising you owe the doctors
and nurses a sort of debt.

~~~

Finding medication hard to take
Being told – it is necessary and for your own sake.
Having to accept being mentally ill
is hard. Then all feels still!

Siobhan Passmore

Photo by Peter Doyle
Reflections of an ordinary man

Pain is an ingredient of the painting of my life
Trembling hands make me interesting
The chair makes me bigger
Impairment is a fact of nature
Disability… is man made...

Iyiola Olafimihan

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Beautiful

I am beautiful in my own way
I am beautiful in my dark way
I am beautiful, in my sitting way
I am beautiful in my silent way
I am beautiful in my diverse mind way
I am beautiful in my legless body way
I am beautiful in my handless body way
I am an abstract of nature
I am disabled…

Iyiola Olafimihan
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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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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