# Spring 2013 Newsletter

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We all expect our personal information to be kept private. A recent report by Dame Fiona Caldicott says how health and social care information should be kept private and when it can be shared.

The report says that you should have the right to

- read your own personal records
- privacy and confidentiality
- be told how your information is used
- to say if you don’t want information about your care and treatment to be shared. If your wishes can’t be followed you should be told why.

The report also said that training for staff needs to be better. Sometimes staff don’t share information because they are afraid of getting into trouble. This is even when it’s in the best interests of the patient to share information about them. Staff need to be a bit less worried about keeping to the rules in every situation and feel they can use some common sense.

The story of a blind member of Shaping Our Lives was used in the review. He wanted information about his partner who lives with Parkinson’s disease and dementia. He was told that information could not be sent by email because email is not secure. Email is the best way for him to get information so this was not helpful. He fought a long battle but eventually got information which was accessible to him. Shaping Our Lives are proud of our member for what he has done.
Munir Lalani

Munir Lalani

Shaping Our Lives were very sad to hear that Munir Lalani had died. Munir, or Manny, had been on the board of Shaping Our lives for a long time.

He was deputy vice chair and also a member of the National User Group.

He was involved with many other groups and organisations. He was chair of the black health forum achi-Zindagi.

We all miss Manny deeply. He was a positive human being, bright and witty. He was committed to equality and social justice. He represented all that is good about user led organisations.

Peter Beresford
Chair Shaping Our Lives

Beyond the Usual Suspects

Shaping Our Lives has written 3 new reports. These are to help organisations get better at involving people who use their services.

Look at our website for these and other free reports.

http://www.shapingourlives.org.uk/ourpubs.html#Beyond
PowerUs involves organisations in Norway, the United Kingdom and Sweden. In the UK the organisation is Shaping Our Lives. It is funded by the European Education and Culture Programme.

The aim of the project is to improve service user and carer involvement in social work training. Shaping Our Lives has worked with South Bank University to try out a new approach. They ran a course called Advocacy, Partnership and Participation. Students, service users and carers all learnt together.

People who took part said it worked well.

Find out more at www.powerus.se
Pooling Personal budgets

Some people now get a personal budget or direct payments from their local authority. This gives them more control over how they are supported. Many people find this helps them to live their lives as they want.

Recently some people have started getting together and “pooling” their money. By doing this they have been able to do things like –

- employ a personal assistant between them
- buy equipment they can share
- go on respite breaks
- live together
- run a social group
- set up their own business together

If you live in Hull and want to talk about pooling your personal budget or direct payment please contact –

Luke Caldwell
01482 878 778
Or if you have a hearing impairment
01482 370 986

luke@choicesandrights.org.uk
Earlier this year Lucy Meadows was found dead at her home. Lucy’s change from male to female was reported in the newspapers. Many people were angry at how her story was told in some newspapers. This is an example of Transphobia – a foolish fear of transsexual people. Transphobia can show itself in different ways. At its worst it can lead to people being beaten or killed. This is called a hate crime.

In law a hate crime is any crime committed by someone because they have a prejudice against certain other people.

This can be because they are –

- of a different religion or belief
- disabled
- of a different race or ethnicity
- transgender,
- bisexual, lesbian or gay

Name calling can be a hate crime. It is important to report it because it can lead to worse things. If you don’t report hate crime nothing can be done to change things.

If it happens to you report it
0800 138 1625

http://www.report-it.org.uk/report_a_hate_crime
or tell someone at a Hate Incident reporting centre
Poetry

Diagnosis Hysteria? Prescription Hysteria?
Is a book of poems by
CoolTan Arts Women’s Poetry.
You can get the book from
sara@cooltanarts.org.uk or
020 7701 2696

Below is a poem from the book

A spoonful of medicine
Depression, a tablet they give to you
Post a letter through the door
Trauma, an incident that just happens
Stress:
Living every day
Disorder a label given to people
Personality:
Behaviour learned
Disorder a label stuck to you
Auditory illusions, a conversation one has with one’s self .............
waves on different frequency
Telepathy does exist
Illusions, aspirations, delusions, misconceptions
Here comes the 6th dimension
You tread on egg shells
You walk on glass
You are not here
Your blood leaking out across the broken glass but you cannot see
and do not feel
By the medication you were wounded
By the sword you are killed

Michelle Bahrier
Spectrum

Southampton Centre for Independent Living (SCIL) has changed its name to SPECTRUM Centre for Independent Living.

SPECTRUM is run and controlled by disabled people. SCIL started in 1984. We are working for a world which celebrates and includes all disabled people. We provide services for disabled people, to help them manage their own lives. SCIL has a long proud history of being one of the strongest and most successful user led organisations in the UK.

www.spectrumcil.co.uk

Art by Disabled Asylum Seekers

RAPAR is a human rights organisation based in Manchester. They worked with the UK Disabled People’s Council on an arts project in Bristol. They produced a piece of art by disabled refugees and asylum seekers. The mural will be on a big roundabout in Bristol.

www.disabilitymurals.org.uk
About Shaping Our Lives

Shaping Our Lives started in 1996. It is a national network of user led organisations.

It wants to see a society that is fair and where disabled people have choice and control over the way they live and the support and services they use.

Over 425 user led organisations are already members of Shaping Our Lives website. It is free to join. The website puts you in touch with over 1,200 service users.

You can use the website to
• tell people about your work
• advertise events
• advertise your services
• tell people your news

5 good reasons to join SOLNET:

1. hear news
2. be part of a national network
3. share ideas with similar groups
4. find out what other organisations offer
5. help people who use services find the support they need
Our aims

- to support the development of user involvement
- to give a shared voice to organisations controlled by people who use services
- to support user involvement at a national level
- to work with all user groups
- to improve the quality of support people receive
- to help user led groups to link to each other
- to develop links with groups led by disabled people around the world

www.solnet.org.uk
## Contact us

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