



Shaping
Our Lives

National User Network

NEWSLETTER

ISSUE 13 Summer 2008

Relationship matters: building our knowledge and networks

We are delighted to report that we have been successful in our bid to the Equalities and Human Rights Commission to fund a small scale one year project to develop service user networks and strengthen service user knowledge.

In work Shaping Our Lives has already done we found that there are a lot of things that stop service users and our groups from taking part in things and finding out what other groups of service users are doing.

We thought of some ways of helping service users and disabled people and their groups and organisations to take part in more things, to join in and get in touch with other different, service user and disabled people's groups.

We want to look at these ideas in this project.

Trying to reach people

Shaping Our Lives tries very hard to work with and support and help as many different types of service users and disabled people as we can. All the time we are trying to find different types of people we can work with, so that

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New one-year project launched



Shaping Our Lives' National User Group will be the project's advisory group.

we can try to not leave anybody out.

One of the ways we try to tell as many service users/disabled people as possible about our work is through our networking website SOLNET. This also lets groups get in touch with other groups and it lets people tell each other and groups what they have been doing and what they are going to do.



Five seminars around the country

For our new project we want to work with some other groups of service users and disabled people. We want to run five different 'get togethers' or seminars with different groups of people around the country. At these events we want other groups of service users and disabled people to come along and tell others about the work they have been doing. We will then collect all the different things people tell us about and make sure even more people get to hear about them.

Have a look at the opposite page and see whether you and your organisation would like to host one of these days or whether you and your organisation would like to attend an event in your area.

New one-year project launched

Relationship matters: building our knowledge and networks

WANTED: Five host organisations

Shaping Our Lives is looking for five service user controlled/disabled people's organisations who can organise a one day regional event. We want to work with five different organisations, in different parts of the country. The host organisations will work closely with Shaping Our Lives to invite other regional groups of service users to attend an event and give presentations about themselves and the work that they have been doing. The host organisations will identify who to invite, organise an accessible venue and refreshments and ensure participants' access needs are fully met.

All expenses will be reimbursed plus a management fee of £1500 will be paid to the five successful organisations.

In selecting the host organisations Shaping Our Lives will be taking into account issues of diversity, locality and equality. We will be seeking to ensure that a wide range of service users will be able to contribute to each event.

If your organisation would like to apply to become a host organisation for this exciting new project then please contact:



Jenny Willis

Shaping Our Lives

BM Box 4845

London WC1N 3XX

Tel: **0845 241 0383**

Email: **jenny@shapingourlives.org.uk**

Type talk: **08001 0845 241 0383**

The deadline for applying to be a host organisation is **7 July 2008**.

Please get in touch if you would like information in alternative formats.

If you do not wish to apply to be a host organisation but would like to take part in a regional event then please also contact us and let us know you are interested.

News and Events

Shaping Our Lives in the Dragons' Den

We know in Shaping Our Lives that service users and their organisations have real problems getting equal access to funding and to ensuring that their ideas and innovations get real support. That's why we decided to enter for the social care version of 'Dragons' Den' sponsored by the Guardian and the Royal Society of Arts in February this year.

We put forward the idea, backed up by service user research, to produce a wide range of service user-produced books and other materials to develop and share service user knowledge to improve support services and involvement. We know from service users that there are real barriers stopping this happening and at a time when government is highlighting 'personalisation', involvement, choice and control, it is clearly important.

We are proud to report that of more than 140 entries, we were selected to be among the last 16 to go forward to the Dragons' Den. This gave us the chance of being shortlisted to get £20,000 worth of advice and funding to take forward our idea. Projects like us which were

'longlisted' were promised advice from funders and consultants on the day and help improving our presentation. We took notice of the help offered to make our presentation. Other bigger projects tended to use prepared and costly videos.

Yet when it came to the announcement of the shortlist, we noticed that only one of the user-led projects got through; two others were from the same large voluntary organisation, one was from a commercial organisation and another from a local council. To be truthful none of the last four offered anything really new

and we wondered why such organisations couldn't find money from other sources, for example, from their local authority, if they were any good. We were only told we would have to pay our own costs for this stage when we had been longlisted and no funder or consultant made

contact with us on the day, so for us the Dragons' Den meant a lot of effort, some cost and absolutely no benefit.

When we expressed our concerns to the organiser, they said they were only 'amateurs' at this and made excuses for not including service users among the judges and for not meeting our costs.



News and Events

This has been a painful business for us, because it has highlighted the routine nature of barriers in the way of service users and our ideas and innovations, however good they are. But we don't intend to take it lying down. We will continue to work for the good ideas that service users have.

Peter Beresford
Chair of Shaping Our Lives

Registration of Domiciliary Care Workers – a consultation

Earlier this year the General Social Care Council asked us to talk to a range of service users and disabled people to find out their views, concerns and opinions about plans to register domiciliary care workers. These are the people who come into your home to help with things like getting up and washing. In February we held two focus groups with people who used domiciliary care workers to find out what they thought about such a registering process. The aim is to feed into a piece of research that the General Social Care Council is going to be carrying out later in the year.

United Nations Convention of the Rights of Persons with Disabilities

The United Nations Convention of the Rights of Persons with Disabilities went

into force on 3 May this year. If you want to know more about this and what it means for disabled people then go to the United Nations website:

www.un.org/disabilities

User Involvement in Public Services – report of House of Commons Select Committee

On 7 May the Public Administration Select Committee published the first parliamentary assessment of user involvement in public services. They were particularly looking at a new model for public service delivery that should lead to improved services and greater user satisfaction. The committee considered a range of different types of involvement, including service users consultations and user directed or user driven services.

'The Committee concludes that achieving high-quality, responsive public services means empowering and engaging with service users as much as simply addressing their needs...People that want to be more involved in public services should get the support they need to do so.'

We are very pleased that our Chair, Peter Beresford, was invited to give evidence to the committee and some of this has been included in the final report which can be downloaded at www.parliament.uk/pasc or you can access it by going to the publications

News and Events

page of the Shaping Our Lives website at www.shapingourlives.org.uk.

Printed copies are available from the Parliamentary Bookshop (12 Bridge Street, Westminster, London, Tel: 020 7219 3890) or The Stationery Office (Tel: 0845 702 3474), for £10 each.

Independent Living Strategy Consultation

The Independent Living Strategy was launched on 3 March 2008. Consultation on the monitoring and implementation of the strategy runs until 20 June 2008. The office of disability Issues held a consultation event on 12 May in York. Munir Lalani, Vice Chair of Shaping Our Lives went to the event and commented that there was a distinct lack of representation from black and minority ethnic communities. Shaping Our Lives is very anxious to ensure that the voices and views of groups which face particular barriers and exclusions

are included, as well as ensuring that all aspects of diversity are addressed and that the wide range of disabled people who can benefit from the effective introduction of the Independent Living strategy can have their say in the consultation.

Another event will be held on 4 June at The Oval, London. If you are interested in attending this event contact the Office for Disability Issues in one of the following ways.

Website

www.officefordisability.gov.uk

Email

office-for-disability-issues@dwp.gsi.gov.uk

Post

Office for Disability Issues
Post Equality 2025
c/o The Secretariat
6th Floor, The Adelphi
1-11 John Adam Street
London WC2N 6HT

Project updates

The Standards We Expect



Update from Project Worker, Michael Glynn

The Standards We Expect is a three year research and

development project funded by the Joseph Rowntree Foundation. Over the past two and a half years it has worked with eight services across the UK to support the development of person centred support.

We are currently working on several publications based on what we have found.

Project updates

Person Centred Support

The first guide we have written is called 'Person Centred Support: A guide for service users'. It was written for service users who took part in our project to explain what the project found out.

We wanted as many service users as possible to see it. It has lots of information about person-centred support. It has contact details if people want to find out more about any of the things it talks about.

We have tried to make the guide accessible. Please let us know if you would like to get it in a different format, like large print or on CD.



If you know anyone who might want to read the guide they can download a copy from our website (see the box at the end of this

article). Or they can get in touch with us (see box) and we will send them a copy.

Making a Change

We have been working on a guide for people who want to arrange accessible training. It is based on our experience of arranging events for service users, including our national programme of workshops called 'Making A Change' which took place last summer. We hope it will be published soon.

Contact us

Michael Glynn
The Standards We Expect
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Hawthorn Building
De Montfort University
Leicester LE1 9BH

Email: standardsweexpect@googlemail.com

Telephone: 0116 257 7773

Website: www.standardsweexpect.org

INVOLVE User-controlled research survey



Update from Project Worker, Michael Turner

Shaping Our Lives is carrying out a survey of user-controlled research projects with the Social

Perspectives Network and the Centre for Citizen Participation at Brunel University.

We are finding out about user-controlled research projects that have been completed since 2002 and any projects that people are currently working on.

We have already had good response from projects run by mental health service users so we particularly want to

Project updates (continued)

hear from other groups such as disabled people, older people, people with learning difficulties, people living with HIV/AIDS and other service users.



The project has been commissioned by Involve, which works to increase user involvement in health, social care and public health research. They will look at putting details of the projects we find out about on their web-based database of research projects that involve service users.

You can fill in a questionnaire online at www.pmhcwn.org.uk/involve.asp or contact Michael Turner on michael@shapingourlives.org.uk.

Consultation with older people

Consulting older people in Cumbria about their residential homes

At the start of 2008 Shaping Our Lives carried out a consultation for Cumbria County Council. The Council is proposing to modernise its residential care homes for older people. We were asked to find out what local people and current residents of six care homes felt about the plans.



We conducted a public survey and we spoke to all the residents of the care homes who wanted to participate in the project. We worked alongside an advocacy organisation to ensure that the older people had every opportunity to make their voices heard.

We found that residents were broadly supportive of the Council's plans and recognized the need for change. Within this the following issues were particularly important:

Residents like their home to 'feel homely'. This meant:

Consultation with older people

- ◆ having friendly and helpful staff
- ◆ keeping the size of the home relatively small

People want opportunities to enjoy the company of others. This can happen by having:

- ◆ an active activities and events programme
- ◆ a day centre on site
- ◆ spaces within the home for people to meet

Most residents want a meaningful community life. This can be helped by:

- ◆ encouraging links with the community ie coffee mornings, church concerts, school plays.
- ◆ siting the home in the community so residents can see 'the world going on'
- ◆ having local homes so people remain in the community they have always been a part of

The proposal to develop care homes with additional capacity for nursing was considered by most residents to be a good thing. However this is only true if the nursing section is quite separate and distinct from the residential side. People thought it would be depressing to be surrounded by ill patients and if they themselves were taken ill they felt it would be more appropriate to receive nursing care in a separate wing. Some said that by going to a separate nursing wing they would be able to keep their dignity.



Residents also feared that the homely atmosphere for residential clients would be lost if the nursing and residential services were not provided as two distinct units.

Residents had many ideas for an ideal home. These included accommodation for guests; accommodation for married couples; better use of outside space; meeting of access requirements and more information about their rights and entitlements. Most residents thought a shop in their home would be a very good idea.

We also found that many residents do not have information about domiciliary support services and some were unhappy that they had to move from their own homes.

We have just submitted this report to Cumbria County Council and we have had a very positive response. Acting on our recommendations they are preparing an action plan to take forward the proposals from the consultation. There is also the possibility of Shaping Our Lives talking to more residents from different Cumbria Care homes in the future.

Fran Branfield
Director of Shaping Our Lives

Hi, I'm Alice...

Alice, a member of our National User Group, tells us about her life as a transgendered person.*



Hi, I'm Alice...

I class myself as a female but I am male gender. I am a transgendered person. I am in my mid-thirties. I have a mild learning difficulty and I am a mental health survivor.

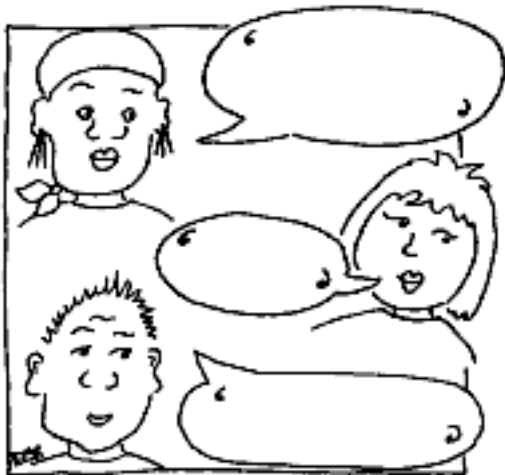
I am an active woman – I am a member of various different advocacy and disability organisations and I have met quite a few special people over the years, most recently Desmond Tutu.

I love fashion shopping, car boot and jumble sales and charity shops. I adore handbags – I have about 340!

Trying to be me

In 2005 I started to live fully as a woman in society because I felt that was me. 'Society' had other ideas! I was the victim of so much intimidation, discrimination, hassle and verbal abuse. Sadly, I had to stop living fully as a woman, even though I feel I am female and consider myself female.

Whilst I like to wear all female clothes I have learnt to go for a more unisex look. I find that if I wear a wig, fill the cups of my bra and put on high heels and make-up people react badly and are much happier if I wear just a little make-up, flat, but female shoes and trousers. That seems to be OK. Wearing the right-size bra is important but I find it a problem getting properly measured because I would be laughed out of the shop within seconds!



Girls and boys

It is easier for woman to get away with wearing male clothes than it is the other way round.

I know women who wear male type clothes, who don't use handbags or wear jewellery and who never wear skirts or dresses. They don't get hassled because they have chosen not to follow the stereotypical female role models.

It is not the same for me. I can really only be myself when I am away from home. I dress fully as a woman as much as I can because I feel that's me and to deprive myself of that is not good.

Born and bred

I was born male but as I entered into my teens I found myself increasingly drawn towards female clothes and accessories. If I now deprive myself of being feminine then I am depriving myself of the person I wish to be or have become.

I still suffer from discrimination. When I was in hospital recently the staff repeatedly refused to call me Alice even though I have had my name legally changed. I believe they were purposely trying to goad me into losing my temper. I suffer discrimination in work as well. I find it extremely difficult to get voluntary work which I would love to do. People are not prepared to take on someone as different as myself.

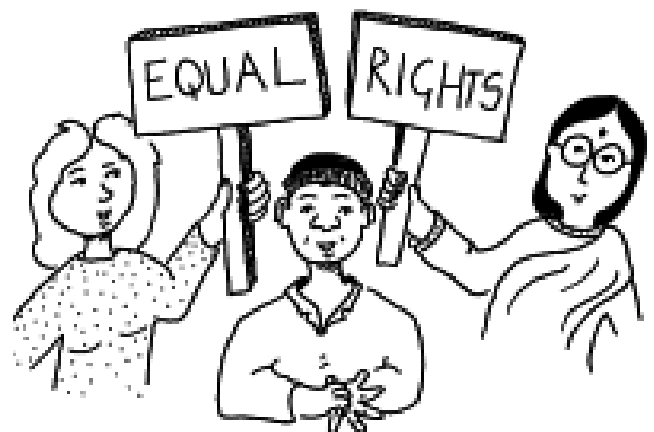
I want to be accepted just as I am. For every person I have met who was not so pleasant or nice to me I have found the next person to come along is kind, polite and good to me. That has lifted my spirits.

I feel that our society as a whole has a long way to go to reach acceptance regardless of race, age, colour, illness or anything or anyone who is different or unusual.

*Extracted from **Ability NI** Vol 1 No 5.*

Photo © Joy Gregory.

* Alice is not the author's real name.



CHANGE project to do new research on sex education

CHANGE, an organisation that campaigns for the rights of people with learning disabilities, is working in partnership with the Centre for Disability Studies at Leeds University to undertake a three-year ground-breaking research project to find out from young people with learning disabilities what their knowledge, hopes and dreams are in relation to sexuality and personal relationships.

The project came about because, in previous work with parents with learning disabilities, CHANGE found that many people with learning disabilities said that they were never told about sex and relationships. People with learning disabilities said that if they had learned more about sex and relationships when they were younger they might have made different choices as adults.

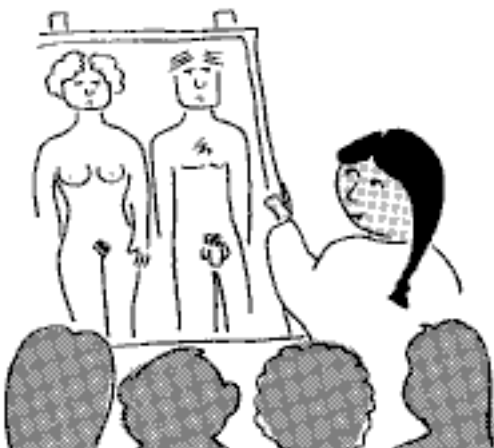
The professionals with whom CHANGE has contact also said that

sexuality and relationships were a priority area to be developed now that people with learning disabilities are living, working and taking their leisure with everyone else in the community. This led CHANGE to put in a bid to carry out research about sex and relationships for people with learning disabilities.

They were successful in their bid and the research project based at CHANGE started in January 2007. It includes the following aspects:

- ◆ a series of drama workshops with young people age 16 to 25 over a period of 18 months to find out their experiences and views;
- ◆ a national survey of special schools and colleges to find out what is taught in relation to sex and relationships education and what difficulties schools have in teaching it;
- ◆ interviews with 20 parents of people with a learning disability to get their views; and
- ◆ focus groups with teachers to discuss some of the wider issues that come out of the survey.

At the end of the project, the young people from the drama group will put on a play to highlight some of the issues that have come out of the project. There will also be reports written in an accessible format, seminars to disseminate the



information and articles written for magazines and journals. The outcomes of the project are expected to influence changes in policy and practice for people with learning disabilities around sex and relationships education.

If sexuality and relationships is an area in which people with learning disabilities have been excluded, then the importance of this study cannot be underestimated. It is an innovative, large scale piece of research that CHANGE hope will have implications for changing attitudes and ways of working with people with learning disabilities and will contribute to making relationships and sexuality a positive experience for them.

For further information about this research, please contact the Sexuality Team at CHANGE.

Telephone
0113 243 0202

Email
ruth@change-people.co.uk

Post
CHANGE
Units 19/20
Unity Business Centre
26 Roundhay Road
Leeds
LS7 1AB

Graffiti Wall

Home is...

Members of the national user group completed the phrase 'home is...' for this graffiti wall. We wondered how many of these would hold true for people in residential homes. Something for service providers to think about?

Home is where I most want to be.

Home is where the heart is.

Home is where I can really be myself.

Home is with my family.

*Home is... somewhere to relax
be warm, be comfortable
and think.*

Home is topsy and turvey!

Home is my comfort zone.

Home is a warm blanket, keeping out the cold.

Home is full of dreams won and lost.

Home is an interactive place where excitement abounds.

Home is where my garden is.

Home is where lots of DIY needs doing!

Knowing Me, Knowing You

June Sadd



Who or what has had the greatest influence in your life?

My two sons Ben and Joe.

What is your most treasured possession?

My mum died 25 years ago and I still have her anorak – I can't bring myself to get rid of it.

If you had one wish, what would it be?

Social justice for everyone on the planet.

What would you like to ban?

War, corruption and exploitation.

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

They should really listen to us and act on it. (That's two but they go together.)

What makes you laugh?

Not a lot.

What trait do you like least in yourself?

Not having a sense of humour (ask my partner, he'll vouch for that).

What trait do you most dislike in other people?

A patronising attitude.

What is your idea of perfect happiness?

To spend Saturday morning in bed catching up on the previous four weekends' broadsheets (it's never ending!)

What is your favourite film or television programme?

'Strictly Come Dancing'

What has life taught you?

I never stop learning.

How would you like to be remembered?

Kindly.

June has been involved with Shaping Our Lives from its earliest days, over 10 years ago. She is a disability consultant involved in training and research, and she has also worked with universities to promote the involvement of service users in social work education.

A qualified Practice Assessor for social work students, she holds the postgraduate Practice Teaching Award. She had to show her knowledge, skills and values in the same way as qualified social workers. As she is not a social worker this was a considerable achievement. Her values are well rooted in her experience as a survivor of the psychiatric system. She lives in Wiltshire, and has been part of the service user movement for the last 14 years.

Get creative!

You and I

I am a 'resident'. You just live at your place.

I live with seven others, a couple of whom I don't really like. You just got a new place with a couple of friends because you didn't like the people you were sharing with.

I'd like to leave my room a mess but staff tell me I'm learning something when I clean it up every day. You tell me your room is a disaster area.

I am aggressive. You are assertive.

I have behaviour problems. You are rude.

I'm non-compliant. You don't like being told what to do.

I am on a special diet because I am five pounds over my ideal body weight. Your doctor gave up telling you.

When I ask you out for dinner it is an outing. When you ask someone out it is a date.

I want to talk with the nice-looking person behind us at the grocery store. I was told that it was inappropriate to talk to strangers. You met your husband at the cheese counter. He couldn't find the brie.

I think some of the people who are paid to work with me are my only friends. You have lots of friends; none of them are paid.

I don't have anything that says who I am. You've got your driving licence.

My Case Manager, Psychologist, Occupational Therapist, Physiotherapist and House Staff set goals with me for the next year. You haven't decided what you want out of life.

I don't know how many people have read the progress notes people write about me. I don't even know what is in there. You didn't speak to your best friend for a month after he read your journal.

from The Advocate, newsletter of the United Kingdom Advocacy Network, late Spring 1995

*United Kingdom Advocacy Network
Premier House, 14 Cross Burgess Street
Sheffield S1 2HG*

And for those of you planning your holidays, a cartoon by Dave Lupton...



About Shaping Our Lives

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

This newsletter is available in different formats on request.

All photographs © Joanne O'Brien unless otherwise stated.

Contact us

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(networking) www.solnetwork.org.uk

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