“Never doubt that a small group of thoughtful citizens can change the world. Indeed, it is the only thing that ever has.” * Margaret Mead

User Controlled Research- What is it and how is it to be done?
Page..4

Computers and help with website for community groups – free advice
Page ..7 & 14

Organisations Profiles.
Page ..12

Company number 4382606
Shaping Our Lives led the service user consultation on the draft of this new guide produced by the Social Care Institute of Education. Involving service users and carers in the education and training of social workers is now high on the policy and practice agenda. In 2003, the government introduced regulations requiring universities and colleges offering the new social work degree to involve service users and carers in all parts of its design and delivery.

This was welcome news: service user involvement in the degree should mean that the next generation of social workers will be closely in tune with the experiences and expectations of the people they are supporting. In turn, this should lead to more effective social worker-client relationships and better supported more independent and happier service users.

However, the national Requirements for social work training do not prescribe how the universities and colleges should go about meeting these requirements. This new resource guide called Involving service users and carers in social work education has found that universities are using a wide range of approaches to the same activities and that while many programme providers have made a good start at working with service users and carers, progress is uneven across the country.

The guide focuses on how partnerships between the degree programme providers on the one hand and services users and carers organisations on the other, might be formed and sustained. It covers the values, principles and practicalities of participation, outlining a range of approaches to creating active and purposeful partnerships.
The guide also gives directions to useful documents, websites, contacts and places to secure funding and sets out nine steps to successful service user and carer participation.

If you would like a copy of this guide contact
SCIE Tel: 020 7089 6840
E mail: publications@scie.org.uk

Call for submission

The first anthology of writings and poetry by and for transracially adopted people

Personal stories, memoirs, reflections and poetry are invited from African, African-Caribbean, East Asian, Middle Eastern, South American, South Asian and South East Asian people (including those with one white birth parent and those born in other countries) who have been adopted by a white family in the UK (i.e. who have been transracially adopted), for the first UK anthology of writings and poetry by and for transracially adopted people.

The anthology is being edited by Perlita Harris, who is of Indian parentage and joined her white adoptive family as an older child.

It will be published by the British Association for Adoption and Fostering (BAAF) in 2005.

The deadline for submissions is 31 August, 2004. For further details and guidelines, please contact:

Email: Perlita.Harris@bristol.ac.uk
Tel: (w) direct line 0117 954 6726
Or write to: Perlita Harris, School for Policy Studies, University of Bristol, 8 Priory Road, Bristol BS8 1TZ.
User Controlled Research- What is it and How is it to be done?

Although there has been considerable discussion about it, there is not yet agreement about what constitutes a ‘user controlled’ organisation among disability, health and social care service user organisations.

This new, nine-month project is being carried out in the UK jointly by Shaping Our Lives and Folk Us with funding from Involve.

The project is starting with no assumptions about a ‘correct’ approach or definition of ‘user controlled’ research. There are likely to be a range of ideas about what constitutes user controlled research.

To achieve this we will be carrying out a literature review and some work with service users who are involved or have an interest in research with a questionnaire and some group interviews.

We would be very interested to hear from anybody with recommendations for documents to include in the literature review.

We also want to make contact with service users who are involved in research work who are willing to complete a questionnaire about these issues.

In the early summer we will also be holding three meetings with small groups of users interested/working in this area in the UK, so it would also be useful to hear from people who would like to take part in these meetings.

If you are interested in any part of this work, please contact the project worker, Michael Turner, via information@shapingourlives.org.uk please put ‘Attention Michael Turner’ in the subject line.
Contributing On Equal Terms, Getting Involved and the Benefits System

This report highlights the growing tension between service users and government commitments to get involved and contribute to local communities and the day to day working of the benefits system.

Shaping Our Lives was asked by Dr. Stephen Ladyman, Minister for Community, to write a report on problems with paying people who take part in user involvement who receive benefits.

Shaping Our Lives had a meeting with Dr. Ladyman, which we felt was positive. We are now waiting for an official response from Maria Eagle. We will keep you posted on further developments.

When available you will be able to read this report on our website, or contact the office.

Stephen Ladyman with representatives from Shaping Our Lives National User Group
The Edward Lear Foundation is looking for disabled people to take part in a consultation for the Disability Rights Commission.

Would you like the opportunity to tell the Disability Rights Commission about the barriers that you, as a disabled person/service user experience?

The Edward Lear Foundation is a disability think-tank, independent of the Disability Rights Commission or any other organisation. This consultation is being run entirely by disabled people, with a wide range of backgrounds and experience.

We would like to hear from you if you are a disabled person, or group of disabled people and willing to talk to us about your experience.

We are anxious to address issues of difference and diversity. We particularly want to involve such people as older disabled people, people living with HIV/AIDS, mental health service users and people with learning disabilities. We would value the perspectives of service users receiving direct payments, black and ethnic minority service users and people who communicate differently.

This consultation is trying to identify the barriers faced by disabled people, as a basis for a regular survey which will enable the Commission to check whether the Disability Discrimination Act is leading to real improvements for disabled people in the areas that really matter to us.

Working with Shaping Our Lives, we are trying to assemble as diverse a group of disabled people to interview as possible, so that we get as full a picture as possible of what barriers disabled people now face in their everyday lives.

Cont....
This will include people from England, Wales and Scotland, people from ethnic minorities and older disabled people as well as identifying the barriers faced by people with a large variety of impairments. We also plan to interview people whose voices are less frequently heard, such as disabled people who are asylum seekers.

If you take part, we will need about three hours of your time, to be part of a discussion group or be interviewed on your own. We will pay £30.00 plus travel expenses. (This is less than we would like, but we are limited by the budget for the project.)

If you would like to know more about this work, or would like the chance to tell of your experiences please contact the office, either by phone, E mail (please mark it For the attention of M. Shamash) or write to us.

---

**BT Community Connections new round for 2004**

BT Community Connections is a nationwide award scheme that aims to connect local community and voluntary groups to the internet. The scheme has already allocated 1,100 PCs throughout the UK during the past 12 months and there are a further 600 to be awarded.

Each award will give community and voluntary groups the ability to access up to date information via the world wide web, contact similar groups around the world by email and even create their own community interest websites. All you have to do is log on to the website – [www.btcommunityconnections.com](http://www.btcommunityconnections.com) OR request an application pack from BT Community Connections, PO Box 30775, London, WC1B 4QE. Email: btcommunityconnections@leaevents.co.uk
My name is Brian Maslen. I am a User of Social Services and a member of the Wiltshire and Swindon Users Network. It was through this network that I heard of Shaping Our Lives National User Network.

One of the founders, Clare Evans and June Sadd, manager at Wiltshire and Swindon Users Network, asked if I was interested so I went along to a meeting and have been attending ever since. I am involved with Older Peoples Groups, Charging Policy Group, West Wiltshire Primary Care Trust Older Peoples Planning Group, Wiltshire Older Peoples Advocacy Service, The Home Loans Group. The Users and Carers Meeting with Social Service councillors, as an older person recently elected to my second four year term. A member of the Rowan Review team on Direct Payments. Membership secretary of the Devizes Multiple Sclerosis Society.

My links with other organisations in Wiltshire are through invitations to their meetings. We also have groups of users from all over the country who come to learn or our experience with Social Services Health and Councillors and of course Finance.

What I like about being involved with Shaping Our Lives National User Network is being able to learn from other users throughout the country, their every day problems with people in authority and how they face up to them. To be able make a point of view and not feel embarrassed should I get it wrong. These few sentences are a very small part of being involved as a user with Shaping Our Lives.
People First and the Mental Incapacity Bill.

This article is written by Simone Aspis. Simone is a Disability Rights activist. She has undertaken a wide range of research projects. She has written many papers and articles around self-advocacy, issues around learning difficulties and on the topic of inclusive education.

People First are very worried about what the Joint Scrutiny Committee have said about the Mental Incapacity Bill.

“We were surprised that the committee didn’t feel it was necessary to ensure everyone must be required by law to support our human rights. Not being allowed to make lots of small decisions, like when to get up, what to eat and what to wear is degrading treatment.

They didn’t say that independent advocacy and circles of support must always be available when our ability to make our decisions is questioned alongside the provision of personal assistance, communication aids and interpreters.

Also they had said that anyone with an impairment of mind may not be able to make decisions for themselves. This would allow lots of people to think that people with learning difficulties have an impairment of mind and therefore we can’t make decisions for ourselves.

They have failed to see why People First feel it’s really important to recognize conflicts of interest between carers, service providers and Government bodies and people with learning difficulties.”

People First were concerned that many of the report’s ideas (recommendations) would take the self-advocacy movement back 20 years.
Moving On

After being in at the birth of Shaping Our Lives and seeing the Company develop and grow to its current influence, I have decided to leave and take up the offer of Participation and Membership officer with Disability West Midlands. The opportunity to work fulltime on a permanent contract is just too good to turn down.

But leaving is not easy, SOL operates to the sort of wide and innovative vision that is attractive to oppressed groups of people and I share their hope that one day, we will live in a society that is not only structured on the equality of opportunity but that has rid itself of the sort of political autocracy that merely nurtures self-interest and protects certain groups of people. I hope and expect SOL to challenge in its way, those ideals that rob us of our individuality and puts us in neat labelled boxes that social scientists in all its guises, whether political, educational, social and numerous others, can stack on shelves, unpack and repackage, throw policies at and restack according to their whim.

That vision is rare indeed, the introduction of ID cards is just another control fetish that bureaucrats will use to take something from us, will the cards include our disability, do YOU feel secure? Another underplayed plus of working for SOL is the opportunity for personal development. Directors of companies have to become responsible, there are legal implications, as there are with the employment of workers and the management of funds. Added to this is the undoubted benefits of peer support-meeting people who have some understanding of YOUR life experiences.

This is a real confidence-booster and can develop the self-determination necessary to find rewarding employment. I have met many people in my time with SOL and made many friends, I wish everyone well.

Phil Brough.
Phil was treasurer for Shaping Our Lives National User Network
we wish him well in his new job

Company number 4382606
There is now growing interest in user involvement in research and evaluation and in user-controlled and participatory research. There is also a new emphasis from government on ‘evidence-based’ policy and practice and the importance of basing public services on a strong knowledge base.

This new publication addresses the questions these developments raise. It explores a new practical and theoretical approach to including experiential knowledge in the development of policy and provision and suggests new ways of relating research to lived experience. Peter Beresford, the author, is Chair of Shaping Our Lives, the national independent user controlled organization and has a long involvement in issues of participation and participatory research as writer, researcher, campaigner and educator.
What does GLAD do?
GLAD provides advice and information to disabled Londoners. We do this by running an advice line on 020 7346 5800 ext 43 or e-mail info@glad.org.uk. The information line is available from 9am – 5pm, Monday – Friday. Please note that we do not undertake any individual casework.

Publications
GLAD publishes a variety of one-off publications and three main newsletters.

**London Disability News** is GLAD’s monthly newsletter, providing all the latest news, commentary and information on disability issues across the capital and contains information on GLAD’s projects and forthcoming events in London.

**Boadicea** is a bi-monthly national magazine written by disabled women, for disabled women. It is the only magazine of it’s type in Britain.

**Disability Update** is a fortnightly publication providing easy-to-read extracts from national newspapers, the Internet and a wide selection of disability newsletters and magazines, together with details of conferences, events, books and disability issues.

For more information about all of GLAD’s publications and Transcription Services please contact Ben Humphreys on: 020 7346 5800 ext 12 or email: b.humphreys@glad.org.uk

For information on all GLAD’s training courses Please contact Janet Nixon on: 020 7346 5800 ext 13 or email: j.nixon@glad.org.uk
What would you like to see in our next newsletter?

Here are a few ideas please feel free to send in any suggestions or pieces that you think would work in the newsletter.

- Opinion pieces
- Guides to key issues/reports/good practise guidelines
- Update on SOL activities
- Letters and questions
- Requests for help/information

Would you like to write an article about yourself or your organisation?

Maybe you have something you want to share with us or would interest other readers?

You can write to us at: Shaping Our Lives
Unit 57, Eurolink Centre
49 Effra Road
London
SW2 1BZ

Or e mail us:

information@shapingourlives.org.uk
BT Community Website Builder

The BT Community Website Builder allows registered UK charities, non-profit making organisations and volunteer led groups or organisations to build and maintain their own website free of charge, all you need is a computer, and internet connection and a web browser.

Contact e-mail: support@ik.com,
telephone: 08700 11 28 50
or visit their website at
www.communitykit.co.uk

Five members of Shaping Our Lives presented papers at a Disability Studies Conference. The theme was:

A Key Issue for the Future: Relating disability studies to the diversity of disabled people.

To read these papers go to the Previous Projects page on our website.
Networking Project.

We would like to say a big “Thank-you” to those of you who have returned the questionnaires that we sent to you. We wanted to give you an opportunity to tell us a bit more about what you think are important issues for user controlled organisations trying to operate most effectively and keep in contact with other service users at local level.

We would also like to ask you some questions about the development of service user knowledge. By this we mean that knowledge that we as service users have and can develop which is based on our direct experience as disabled people and service users.

If you would still like to share your views with us it is not too late. The questionnaire is also on our website, or you can contact the office if you would like us to send you a hard copy, or one in any other format.

We are going to be running some small discussion groups to talk about these issues. If you would like to come to one of these meetings, which we hope to carry out in different parts of the country, please let us know.

We will keep you posted on the development of this project.

information@shapingourlives.org.uk
Shaping Our Lives

Unit 57, Eurolink Centre
49 Effra Road
London SW2 1BZ
Tel: 020 7095 1159
TYPE TALK: 18001 020 7095 1159

Email:
information@shapingourlives.org.uk

Company number 4382606