On June 25th over 250 people attended our first national conference. This event “Improving Quality, Increasing Involvement, Making it Real” was the launch of two major projects that Shaping Our Lives has carried out.

We were very pleased that the newly appointed minister for Community, Dr. Stephen Ladyman, was able to give the opening speech. He was warmly greeted and managed to spark off a lively debate and feedback session from the delegates.
We asked people at the event:
Are there any things that you would like Shaping Our Lives to do in the future?
This is what we were told:

- “Campaign for a better benefits system in what that allows service users to get paid more by being involved. This will encourage more service users to get involved and feel valued.”

- “Keep everyone informed!”

- “A tour of workshops. Go ‘on the road’ to disabled groups and a Newsletter”

- “It’s a must we keep SOL a regular conference.”

- “Produce ‘how to do it’ guide to effective user involvement. Get the eyes and ears of government to listen and act on user involvement issues. Need national data base of ‘good practice’ in user involvement and training and support.”

There were ten workshops looking at lots of different issues.
The event marked the publication of two research projects funded by the Joseph Rowntree Foundation.
(Available on their website www.jrf.org.uk)
These publications titled “Our Voice in Our Future” and “Shaping our lives – from outset to outcomes” explore and highlight the need for user controlled involvement in the provision of services and for us to have a voice in the future of the welfare state.

Shaping Our Lives Stewards
What did you like most about the day?

- “Meeting different people, talking to others with different disabilities about how they cope and the fact that they have similar problems to me – An excellent day”
- “Great to see a broad representation of users, professionals & academics debating in partnership issues that are of importance to everyone in the drive towards involvement + ultimately inclusive. Very encouraging and stimulating.”
- “Such a mixture of people with varieties of experience. Brilliant. Stimulating. I felt like I was the beginning of the development of a civil rights movement.”
- “The Minister’s speech and questions and answers. Good to see that so many service users were present, and that they were valued.”

“At the centre of it all must be you, not Whitehall, not the Government. I’m here. I’m listening and I look forward to hearing your comments.”

Dr. Stephen Ladyman.
Read the full speech on our website!

Stephen Ladyman MP and Peter Beresford chair of Shaping Our Lives

We would like to thank our sponsors for helping us make this event such a success.
Many of you will be aware that rules around benefits—particularly disability benefits—are making it difficult for service users to be paid for taking part in user involvement initiatives.

At the recent Shaping Our Lives launch event, Dr. Stephen Ladyman, Under Secretary of State for Community, heard a number of users express their strong concerns about this issue.

As a result of this, he asked Shaping Our Lives to produce a report to tell him about the problem and the difficulties it is causing. We are now doing this with funding from the Social Care Institute for Excellence.

To help us do this we have been asking you for any information that you have about this issue.

Our worker on the project, Michael Turner, has been putting your comments together to form a Report for the Minister. As soon as this is ready we will be putting this on our website. We would like to thank everybody who took the time and trouble to share their experiences with us for this very important report.

(We still want your experiences. You can write or e-mail them to:

information@shapingourlives.org.uk

Shaping Our Lives
Unit 57, Eurolink Centre
49 Effra Road
London
SW2 1BZ)
Shaping Our Lives (National Users Network) has initiated a project called Shaping Our Users Network Direction (SOUND) to help us build up the membership of the national users network and its database.

People who use services and their organisations have a great deal of knowledge and experience – by being service users we have seen what works and what doesn’t, we have found ways of getting our points across or have helped to create and/or change service provision.

Developing Our Knowledge

As part of our work on strengthening the collective voice of service users we want to find out directly from service users and their organisations what kind of lessons they’ve learnt, examples of good practice and different ways of doing things. The idea is to hold a series of focus groups and interviews with people across the country. The interviews, for example, will be carried out using a variety of formats – this will be done in an attempt to meet people’s access needs. Bob is keen to hear from any user organisation or individual users who might be interested in taking part. Please could you let us know as soon as possible via the office.

Building Up The Membership Of The National Users Network

By working together it is hoped that we can play a central role in shaping services to meet our needs, influencing ‘good practice’ and creating a national voice of service users capable of both influencing policy makers at local, national and international levels and laying the ground for partnerships.

To help us with this project a small questionnaire has been written. This questionnaire will ask questions about you and/or your organisation. Once we have all the information returned to us we will be able to organise our membership and create a useful database.
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
Rights to make your own choices

By Nico Mac Given. National People First Campaign Officer

The government is trying to make a new law which will mean that people without learning difficulties will be able to make choices for people with learning difficulties. If the draft Mental Incapacity bill becomes law it will be a very big step backwards for people with learning difficulties rights.

The draft bill says nothing about how the government will make sure that choices are being made for people with learning difficulties that are best for them rather than best for their relatives or carers. The Government is putting too much faith in our carers, relatives and other people without learning difficulties to make decisions for us that are really in our best interests.
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.
OUR FIRST AGM

Shaping Our Lives held its first annual general meeting and a great time was had by all. It was a huge success in its attempt to involve everyone in a meaningful and democratic way. The band, Creative Connections sang a number of songs with some clever percussion. We had discussions in small groups about involving more people with Shaping Our Lives and that our AGMs shouldn’t be just about putting our hands up and voting. Lambeth People First gave us a very interesting talk on their experiences of being involved in the government’s white paper “Valuing People.” They said that they enjoyed being involved in working on this paper but that nothing at all had changed for them in the services that they got. The two people from Lambeth People First will be writing more about this in our next newsletter.

We want to keep our AGMs fun, as well as a business event.

!!Look out for next year’s AGM!!
Shaping Our Lives updates:

Everybody who came to our conference will receive a copy of the Launch Report.

Please note this Launch Report will be by e mail and will also be available on our website.

Shaping Our Lives tries to make information available to all people please let us know if you need information in a different format by contacting the office with your details below:

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