Foreword

Peter Beresford, Chair, Shaping Our Lives

Long term users of health and social care services are a group who face many barriers and exclusions. It is important therefore that there is now growing public and political recognition of the need to involve them in the shaping and running of policy and services. Successive governments have committed themselves to greater ‘user involvement’. But service users are also a very mixed group. If their involvement is to challenge existing barriers rather than just reflect them, then it is crucial that everybody can be involved on as equal terms as possible. That means prioritising access and ensuring diverse and equal involvement.

There are many important expressions of diversity. The Equality and Human Rights Commission brings together the key equality issues of age, gender, race, sexuality disability and belief. Service users also experience other barriers and exclusions. Some groups we know are especially marginalised, for example, because they communicate differently and have multiple impairments. Others face additional difficulties, for instance because of experiences of homelessness, as travellers, through being in the penal system.

So it is especially important to make every effort to address all these issues of equality and inclusion. This report highlights how important service users, both as individuals and in groups, see networking as being, if they are to be able to be involved as active citizens in their communities and society. They also stress how valuable it is to make contact with the wide range of different service users. But it also shows that there are many problems currently restricting networking and isolating service users.

The project reported here starts the process both of exploring this issue and seeing how networking can be improved and ensure more diverse involvement. The many different service users who have been involved in the project have important things to say about securing rights and equality. We hope that this report will help share their views and experience, to bring about positive change to achieve greater diversity and equality in involvement.
Introduction

"We strongly believe that a key element to the further development of organisations led by disabled people is the dissemination of information and opportunities to discuss shared experiences in order to strengthen and promote partnership working."

"The Disabled People’s Forum meets each month and we share some of what we are doing, we ask each other for help. It is good to belong to a group in sharing their work and our own. Also, sometimes we need numbers to push things forward."

Service users highlight the importance of actively supporting a diverse range of long term users of health and social care services to network with each other. The importance of networking for service users and their organisations cannot be over-emphasised. It is through networking that long term users of health and social care services can share experiences and consolidate a service user identity. This allows service users from diverse backgrounds and understandings to recognise shared barriers to equality and full human rights. This form of empowerment allows service users to move forward together to influence change and promote good relations among and between groups.

In the autumn of 2008 Shaping Our Lives supported five service user and/or disabled people’s organisations to hold networking events in their own regions. They each invited other local service user organisations to give presentations and participate in these ‘get-togethers’.

Events must enable service users to come together to share with and empower each other. It is essential to have a unified voice that comes from service user meetings through user led organisations that can feed into the system. If there is to be any influence on policy it is essential to have a unified approach. Organisations need to be able to pressurise commissioners to influence change and commissioners need to be able to feel the pressure so that they respond effectively.

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"Quotes" are from service user participants and reports of the regional events.

"These inter-group meetings are important to identify similar issues"

"It costs us, one of the first vital steps is to be counted, people bob in and out, but we need something more solid. Professionals get paid for their label, unless we say you pay our out of pocket expenses, the outside world recognises us as outside. It should be written in ALL information."
The main things people said and what people told us during these ‘get togethers’

"People need space to develop their own ideas, to get involved [with other service users], to understand the concepts and to be able to share their ideas."

- **Service users are unanimous** in their agreement that the opportunity to network with other organisations of service users, however different from themselves they all at first appear, has many benefits. These include:
  - Sharing experiences
  - Telling their own stories
  - Information exchange
  - Signposting
  - Gaining a stronger, united user voice

"Often small organisations only have a small voice, even when they have a very important message to get across. Collaboration and ‘joined-up thinking’ between groups can amplify this voice and increase the possibility of change being effective"

- **Service users were clear** that it was important to recognise the common issues that all service users face.

- **Service users said** that they have limited opportunities to network with other organisations.

"Many groups and people are often overwhelmed with their own work that they do not know what others are doing."

They never meet with local groups. They often do not know that other organisations exist. Service users identified a major reason for this: Service user organisations’ general lack of capacity. This is manifested in terms of:
  - too small a workforce to allow for networking
• an already overworked workforce with no time to explore networking opportunities
• Insufficient and insecure funds to allow for networking
• Some user controlled organisations are, for their very survival, funding-led and this does not allow for networking
• Lack of information, limited promotion and profile of groups

• Service users identified a lack of knowledge about other service user groups as a barrier to networking with each other. Service users repeatedly said that they had not realised the common ground shared by so many different groups until they attended a networking event. Participants recognised that many of the barriers their specific group encountered were shared by other groups of disabled people and service users.

"It is important to have mechanisms to share experiences and practical ideas with other disabled people and that disabled people who do not have the confidence are encouraged to speak out and to believe that what they know is worth sharing and valuable."

Language and communication

Disparate groups of service users all identified language and communication as a barrier to networking. These included people with learning difficulties, people with visual impairments, people with hearing impairments, people with speech impairments, people for whom English was not their first language (this included some people from Wales) and older people, many of whom were sight and hearing impaired.

"Some don’t see themselves as a disabled person, don’t get involved in groups and don’t get the information they need."

"Professionals - they may know what they are talking about but they cut you out of the conversations"

"If you get worked up or cross your seen as having ‘challenging behaviour’.

Stigma

Many different service user groups identified the negative ways in which they were often seen by the wider community as a barrier to getting involved and networking with other service user groups.
This included mental health service users, people with learning difficulties, older people, gay, lesbian, bisexual and transgendered people, travelers, asylum seekers, and people who used alcohol and substance misuse services.

**Physical access**

It was suggested in some of the groups that service users and in particular disabled people did not want to participate by going to venues that they did not know as they believed their access requirements would not be met. This was borne out by their experience and many participants repeated the view that access meant far more than flat access for wheelchair users.

"When you don’t feel welcome, when you don’t feel listened to, when there is no support. Accessibility. Not being able to get into the building, when the information is too hard for you to understand"

**Fear and apprehension**

Some of the people who attended the ‘get togethers’ said that many service users and disabled people had a ‘lack of confidence’ and were ‘nervous and apprehensive’ about attending meetings with other groups.

"Be welcoming and listen. [...] Don’t underestimate the power of a cup of tea. Acknowledge that some people need a social outlet and that that social occasion may be the stepping stone towards engaging them in your work."

"We also talked about when approaching some people it may be the first time that someone has actually listened to what they have to say. It may take time to develop trust that we are genuinely interested in what an individual has to say. Shaping Our Lives has used pre-meeting meetings to build people’s confidence."

"Fear seemed quite a common theme [of the ‘get together’]. Fear [and] insecurity and apprehension. And a shyness and nervousness about being in new situations, or being around"
people they are not used to, and having the confidence to deal with new people."

**Transport**

Lack of accessible and reliable public transport was seen by many as a reason why it was difficult for people to network. This was true in towns and cities as well as in rural locations.

**Insecure funding**

Insecure funding for service user and disabled people's organisations affects organisations and groups in many ways. People said that it can make organisations:

- suspicious of each other because they have to compete for the same funds.
- distrustful and reluctant to share ideas ‘in case they are stolen’

Yes more networking opportunities would be good. But lack of resources, including finance is a stumbling block.

"Sharing ideas is difficult because of competition. Now there is tendering instead of grants."

**Service users' ideas on improving networking**

Participants in all five networking events valued the opportunity to meet other local and regional service user organisations. People also valued the chance to network with national organisations. They had many suggestions for how to improve networking.

"Get out and sell your wares – outreach work you travel to them, as leaflets are not enough – some people can’t read. This way you inform people ‘leaflets’ give information but by talking to people you inform them."

Ideas included:

- **Web based meetings.** Although everyone recognised that the internet was not necessarily accessible to all, many felt it would be an effective
tool to aid networking. SOLNET, Shaping Our Lives' own networking website was cited by some participants as a good tool that could help organisations network, share information and promote their own organisations. It can be found at www.solnetwork.org.uk.

• **Training.** It was recognised that training on various topics could be an interesting and informative way of building links with other service user groups and organisations. Participants said training could be offered by service user groups to other service user groups. They offered the following training topics:
  • Our rights – the Disability Discrimination Act, the Disability Duty, Human Rights legislation
  • Empowerment
  • Assertiveness
  • Direct payments
  • Individual budgets
  • The benefits system

### Raising the profile

Many organisations who participated in the five events had not heard of the other organisations who attended the same regional events. Participants had many ideas for raising the profile of service user organisations. These included:

- Advertising on local radio, television and in local newspapers
- Fliers and leaflets left in doctor's surgeries, libraries, post offices etc.
- Development and outreach work
- Word of mouth 'actually go out and talk to people'
- Offering different types of involvement
- Offering free transport

### Making networking fun

Service user organisations and individuals clearly say that networking events must be enjoyable for the participants. All five events reported the importance that people place on networking as both an individual
social activity as well as being a commitment to having their voices heard. The five organisations who hosted the events all adopted different strategies to make their event fun and to ensure everyone talked to each other.

Throughout the course of this one year project it has become increasingly clear that service users value the opportunity to network both as individuals and as organisations. The importance that service users place on networking was demonstrated by the level of commitment placed on this project, shown by both our advisory group, and the five host organisations, the hard work that went in to organising and facilitating the ‘get togethers’ and the success of all the events.

It is through networking with other service user controlled organisations and individuals that service user knowledge, that which is known through service users own day to day experiences, can become stronger, more powerful and ultimately more influential.

"By sharing knowledge we build our capacity."

During each event we heard how important service users viewed the opportunity to network and share knowledge and experiences with other individual service users and organisations.

This short project has reaffirmed that for most participants, regardless of who they are seen to be, regardless of barriers encountered and services used, networking is the key to empowerment for service users.

Shaping Our Lives, with technical support from the Social Care Institute for Excellence, has developed SOLNET, a website for service user organisations, with a notice board and other facilities, to support service user networking and knowledge exchange. This is a relatively new development and was used exclusively in the early stages of this project to recruit host organisations, and contact local groups. This project has highlighted the importance of such a web tool and how this can be used to strengthen service user networking and knowledge.

"Not to duplicate, lots of individuals putting a lot of passion into a project, forming informal partnerships with others who are doing something similar, it’s not about re-inventing the wheel. Possibly being absorbed into a group that is doing similar work to yours. Have a pat on the back when we do achieve something."

"It is important that people from your organisation share information, that it is all the same."
But, as was also made clear during this work, a web tool is not in itself the answer for all service users and their groups. Participants in this project were clear that a web tool can be useful but what service users really want and see as a necessity, is the opportunity for face to face networking. Service users value the chance to meet, talk and share experiences and knowledge with other service users.

This small scale study has demonstrated unequivocally the priority that service users and their organisations place upon being able to communicate with each other. It is only through this kind of diverse networking that service users can share and promote service user knowledge. It is through networking that the collective service user voice can strengthen; it is through networking that service users can gain the power to influence and change the services they use. It is through networking that a truly diverse range of service users can be involved.

"The feedback throughout the day was that local groups would welcome more opportunities to meet and network with other organisations in the area. Many participants were able to extend their contacts and widen their knowledge regard to the valuable work of others."

"More events like today!"

"[Networking means] you can pool resources, share information and have a stronger voice, some groups may have to overcome suspicion of other groups. And groups must have respect for other groups and not stand on other groups' toes. Topics and barriers are: Transport, Housing, Welfare to Work Reforms, Access to local services/physical environments/accessible venues, finance, travel distances."
In work Shaping Our Lives has already done we found that there are a lot of things that stop service users and their 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, 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 groups.

We looked at these important ideas in this project.

Shaping Our Lives tries very hard to work with and support and help as many different types of service users as we can. All the time we are trying to find different types of people we can work with, so that we can try not to leave anybody out.

One of the ways we try to tell as many service users 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.

For our new project we wanted to work with some other groups of service users and disabled people.

The Advisory Group

Shaping Our Lives National User Group was the Advisory Group to this project. The group is made up of 16 service users, who come from a variety of backgrounds and beliefs, different genders and sexualities, and who all experience a range of disabling barriers. Being a member of the Advisory Group was an important job. This meant that for one year at every National User Group meeting we talked about this project and asked the diverse members of this
group to think of this project as we went along. We took what people said very seriously.

**Five service user groups to be hosts**

The first thing we had to do was to put an advert on SOLNET. The advert was for groups to work with Shaping Our Lives. We needed to find five very different types of groups, in five different regions or parts of the country. We asked people to tell us about their group, and if they were networked with other groups in their area. We also asked them to tell us about work that they had done to make what service users and disabled people say, heard by other people.

**Regional seminars or ‘Get Togethers’**

Next we worked with the five groups to run regional ‘get togethers’ - a day event for local and regional service user organisations and groups to come together and tell each other about their work and activities and to talk and share ideas with each other. After each regional get together we asked the people who came to fill in a form and tell us what they thought of the day. We asked the host organisations to write a report of the day.

**Summary of what people said**

Service users think it is very important to talk to other service users both on their own and in groups. It is important because:

- Sharing ideas and what has happened to you with other service users makes you feel stronger.
- It is good to be with people who understand you and what you want so you can join in.
- When you are with other service users you can shout with a louder voice.

Service users said they often don’t have a chance to talk with other service users.

People said that there are things that stop service users from joining in. These are:
• People might not speak English
• People use jargon words
• People sometimes are not nice to service users
• Sometimes service users are frightened to join in
• Some buildings can be difficult for some service users
• Sometimes getting to a meeting is difficult
• Sometimes service user organisations don’t have enough money to help people

People who took part said that it was important to talk with other people and groups who were different from you. Service users who can at first seem very different to you often face the same types of problems such as:
• Other peoples’ attitudes
• Communication
• Transport
• Money, benefits and payment
• Feeling shy and fearful
• Access needs not being understood or met

Service users had ideas about making it easier to talk with other service users. They said:
• Use the internet
• Do some training
• Let people know what you do by advertising, fliers, radio etc.
• Talking to people
• Having different types of meetings
• Making meetings fun

Ways forward or what should happen now?

Service users who took part in this project all thought networking, that is, talking and sharing ideas with other service users is very important.

Shaping Our Lives has a website that is for service user organisations to network. This is good. But it is not the same as meeting face to face. If we want service users to take part in things, to have a say in the services they use then we must find a way of helping service user organisations to network with each other.

"Don’t feel appreciated."

"Information not accessible or too overwhelming, professionals answer these questions before you."

"It is about recognition and groups, not a pat on the back."

"Be clear about what you’re doing, people are passionate about what they want."

"The power of the group in here, we should be able to do something about this."
The organisations who took part in the regional events

**Bradford:**
- CONTACT Peer Support Service
- Bradford District Supporting People
- Service User Involvement Group
- Bradford Association of Visually Impaired People (BAVIP)
- Bradford People First
- Bradford Access Action

**Wales:**
- Disability Wales
- DEWIS centre for Independent Living
- RCT People First
- Fifty Plus Older People's Forum
- Valleys Women's Ethnic Minority Support
- RHADAG
- Taff Ely Access Group
- Interlink
- Cynon Older People Forum

**Gateshead:**
- Gateshead Access Panel
- Dyslexia Action (via e-mail)
- Durham Disability Voice
- Gateshead Cerebral Palsy Group
- ADAPT
- Leonard Cheshire Disability
- Sight Service Gateshead
- Sunderland Visual Action Group
- New Vision Gateshead
- Castle Morpeth Disability
- Sunderland Physical Disability Alliance
- Pathways User Involvement Forum
- Vision Sense
- Gateshead Visual Impairment Forum
London:
Independent Living Alternatives
Surrey Coalition of Disabled People
Equality 2025
RADAR
Richmond AID
Catch – a – Fiya
Southwark Direct Payments Service
DAN Coalition
Disability Law Service
Harrow Association of Disabled People
Greater London Authority
Age Concern England
HAFAD
Disability Croydon

Lancaster:
FOCUS (Forum of Carers and Users of Services)
Lancashire Deaf Society
George House Trust
Lancaster ME Organisation
Bolton Active Disability Group for Everyone
Making Space & Harvesters Resource Centre
Thumbprint
Visual Impairment Forum
Warrington Disability Partnership
One Voice

This report is available in different formats on request.

A copy of the full report which includes the five reports of the regional get-togethers, can be downloaded from www.shapingourlives.org.uk or by contacting the Shaping Our Lives office.

Acknowledgements

We would like to thank all the service users who took part in this project.

We want to pay particular thanks to the five service user organisations that facilitated the regional events. Without their commitment, hard work and enthusiasm this project would not have happened. We owe a special thanks to key individuals at the sites, namely Joanne Williams, Nicole Drake, Julie Earl, Miranda Evans, Tracy Jannaway and Paul Anderson.

Thanks are due to Jenny Willis, Shaping Our Lives’ office manager and Ro Thomas.

Finally a big ‘Thank you’ to Molly Barrett from Em En Designs.

We are grateful to the Equalities and Human Rights Commission who funded this project.

All illustrations are from the CHANGE Picture Bank www.changepeople.co.uk

Photos were taken by CONTACT Bradford, Disability Wales, One Voice Lancaster.
About Shaping Our Lives

Shaping Our Lives 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.

SOLNET is a networking website run by Shaping Our Lives for service user controlled organisations. There are over 300 organisations on SOLNET including user controlled organisations and non user controlled organisations who have joined as friends.

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 world wide international user controlled organisations

Contact us

Postal address: BM Box 4845, London WC1N 3XX
Telephone: 0845 241 0383 (a local rate telephone number)
Type talk: 08001 0845 241 0383
Email: information@shapingourlives.org.uk
Websites: (main) www.shapingourlives.org.uk
(networking) www.solnetwork.org.uk