

Making user involvement work: supporting service user networking and knowledge

Service users have highlighted two activities as central to making user involvement work. These are: people being able to get together to work collectively for change and mutual support, and the importance of making known their own experience, views and ideas. This project, by Fran Branfield, Peter Beresford and a team from Shaping Our Lives, focuses on key expressions of these activities: the development of service user networking and knowledge. It highlights major barriers facing both, and ways service users see of overcoming these.

- Service user organisations and individual service users are often isolated. Inadequate and insecure resources, low profile and the need to compete with big charitable organisations and each other are major problems. They limit involvement, particularly of black and minority ethnic service users and those with significant access requirements.
- Service users see effective user networking as crucial for positive participation. They see as helpful here a properly resourced national database of service-user organisations controlled by service users and a national user-led network which offers support, information exchange, improved communication, contacts, advice on good practice and a national voice.
- Service users feel that their knowledge is generally not valued or taken seriously by professionals, policy-makers and services. The closed culture of health and social care services and their own inadequate resources restrict service users' capacity to develop and share their knowledge.
- Service users see user-led training and education, a commitment to change in services, the inclusion of diverse service user perspectives and more support for service user networking as key to strengthening service user knowledge and enabling it to have greater impact on policy and provision.



Background

There has been an increasing emphasis in recent years on user involvement in health and social care policy and practice. However, it has come in for growing questioning. Service providers and researchers have begun to ask what evidence there is that it improves services. Service users and their organisations have raised the issue of what they are actually able to achieve by their involvement and to question the usefulness of getting involved.

This project has sought to establish from service users how effectively they are able to get involved by exploring two key concerns of service user movements with them. These are how well they are able to link up and work together and to develop, share and make an impact with their experiential knowledge. It explores their views and experience as individuals and organisations, looking at what barriers they face, what helps and what they think will improve things for the future.

All comments are from service users taking part in the project.

Networking

“Making links and connections makes us stronger.”

“I think networking is about capacity building.”

Service users highlighted the importance and benefits of being able to network with each other, as individuals and in user-controlled organisations, both in terms of improving their quality of life and sustaining a more effective voice and presence to make a difference. Key obstacles they identified in the way of individual networking included transport problems in rural areas, the fragility of user-controlled organisations and the effort of being involved.

“We are, of course, competing [for funding] with the large organisations and charities that we [service users] do not control, ... They have whole departments whose job it is to just raise money and make grant applications.”

Barriers in the way of service user organisations networking included:

- Inadequate and insecure funding and resources. Service user organisations generally do not have secure or reliable funding. Because of this, many service user organisations are liable to become funding-led rather than led by their own concerns, priorities and principles, undermining their independence.
- The divisive effects of inadequate and insecure funding as service-user-controlled organisations are placed under perverse pressure to compete with each other for the same inadequate funding.
- The unequal position of service user organisations in competition with big charitable organisations.
- Inadequate resources leaving user-controlled organisations dependent on a small core of activists.
- Limited profile.
- Lack of resources to ensure full and equal access for all service users.
- Lack of local user-controlled organisations generally and for particular user groups, for example, young disabled people, people living with HIV/AIDS, disabled parents. There are major gaps in the types of user-controlled organisations that exist in most areas.
- Inadequate provision for black and minority ethnic involvement because of restricted funding.
- There is a strong perception among some service users that, in practice, not all organisations which claim to be user controlled are actually controlled by service users.

“We need a collective national voice. If we are to succeed we need stronger collective grass roots activism.”

Service user knowledge

“People think the only thing we know is how to moan. But they are not listening. We know what needs changing, what works and what doesn't work. We know this because we live it 24/7, 52 weeks a year with no days off.”

“Trying to get them to listen is ... well let's just say it's a Herculean task and I aren't no Hercules!”

Increasing political and policy interest in 'evidence' or 'knowledge' based policy and practice has highlighted issues relating to knowledge and different knowledge sources, including service users' experiential knowledge. Service users see themselves as having a particular role to play in the production of knowledge for health and social care, as 'experts in their own experience' and because of the experiential nature of their knowledge. Both individual service users and service user

organisations feel that they have difficulties impacting on health and social care policy and provision effectively. Barriers they identify in the way of their knowledge having the role and influence they want it to have include:

- The devaluing of service user knowledge. Service users feel that their knowledge is generally not valued or taken seriously by professionals and services. Trying to make an impact with their knowledge is also frequently a disempowering experience. This also means that health and social care frequently deny themselves a key source of information and evidence on which to base their actions and decisions.
- Problems of access and tokenism. Service organisations frequently didn't understand access issues and don't make it possible for service users with a wide range of access needs to contribute on equal terms. They tend to interpret 'access' in its narrowest sense. At the same time they often don't seem to be genuinely interested in what service users tell them and don't treat their knowledge with the same respect they give to professional knowledge.
- The culture of health and social care organisations. Service users generally feel that these organisations are not open to service user knowledge. They are reluctant and slow to change.
- Resource issues. Limited resources restrict service users' capacity to develop and share their knowledge. Also they feel their funding may be put at risk if their views are not consistent with what services want to hear. This is seen as an increasing problem.

Strengthening service user knowledge

Service users identify four key ways to strengthen service user knowledge to make more impact on policy and provision and to be better shared between service users and their organisations. Three of these are:

- Education and training. Training and education (particularly if user led) for service users and providers were seen both as ways of challenging the barriers marginalising service user knowledge and ways of sharing and disseminating it. They were seen as ways of changing people and cultures.
- Commitment to change in services and among service users was seen as a prerequisite for challenging barriers in the way of user knowledge.
- Ensuring diversity. The diversity of service users needed to be recognised if the full range of service user knowledge was to be engaged, included and developed.

The fourth, significantly, is developing networking. Most service users thought that networking was a key route to strengthening service user knowledge and increasing its credibility and visibility, both in services and policy and among service users and service user organisations.

“To share our knowledge better we have got to have networking.”

Making progress for the future: integrating issues

“The more we network the more powerful we can become and the more united our voice will be. We will be stronger. To develop a strong voice is important and from other groups we must learn to develop our own networks.”

“I think it is very important that we come together, learn from one another and become a voice that has to be listened to.”

It became increasingly clear in the project that successful networking and the development, sharing and mainstreaming of service user knowledge are closely related and that the two are inextricably involved with meaningful user involvement in most service users' minds. When asked how user knowledge can make a more powerful impact to improve people's lives, service users highlight two closely interrelated issues. These are:

- strengthening service user networking at individual and organisational levels;
- the promotion of effective user involvement by service users.

Service users suggested a wide range of ways of improving their contact with each other, highlighting the importance of involving black and minority ethnic service users in such networking. They see as helpful here:

- a properly resourced national data base of service user organisations owned and controlled by service users;
- a national user network which offers support, information exchange, improved communication, contacts, advice on good practice and a national voice.

Service users see two routes to effective involvement – campaigning and negotiation. Service users repeatedly stated that the best way for them to have more say in the services they use and for their knowledge to become valid in the eyes of service providers, was through better and sustained involvement, as opposed to ‘tick-box’ exercises.

“I’ve managed to get the time that you wait for a blood sample to be taken at the cancer centre shortened from one hour to ten minutes. And that affects so many people everyday and every week. So it might only be a little thing, but for me – I feel as though I have moved a mountain.”

Exploring diversity

“This is a multi-cultural city, but as far as I know there aren’t any user led groups of black or Asian groups.”

The project included three local studies to ensure that diversity was addressed fully. Two were with black and minority ethnic service users, the third with a group that has tended to be neglected in health and social care discussions, women with alcohol problems.

There was considerable consistency between the views of black and minority ethnic service users and service users overall. Issues relating to the powerlessness and lack of adequate funding of user-controlled organisations were again highlighted. Lack of resources militated against networking and lack of appropriate support and services for black and minority ethnic service users were highlighted. Contact between service users and service user organisations was limited and inconsistent. Service users again stressed the importance of networking and of a national network.

Women with alcohol problems highlighted the lack of fit between what support they wanted, based on firsthand experience and what was available. Many services and practitioners came in for adverse criticism as unhelpful, unreliable, inconsistent and sometimes discriminatory.

About the project

This national project was based on a user-controlled research approach. It was undertaken using individual interviews and group discussions using a schedule. Building on an initial survey of service users and service user organisations, a diverse range of 126 service users took part in the project in different parts of the country. As part of the project, three additional discussion groups were carried out, two specifically with black and minority ethnic service users and one with a group of women with experience of alcohol problems, in order to maximise diversity.

For more details

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