

Making user involvement work

Supporting service user networking and knowledge

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With contributions from

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This report provides the first in-depth examination of two key components for effective service user involvement – user networking and knowledge.

There is now both an increasing interest in and questioning of user involvement in health and social care. This study provides a timely exploration of the state of service user networking and knowledge.

The study reports the views of a diverse range of service users nationally. Networking is crucial for service users to be able to support each other and work together for change. By making their voices heard and sharing their experience, views and ideas, they aim to ensure that user knowledge becomes part of the evidence base of health and social care policy and practice. The report looks in detail at the difficulties facing service users and their organisations and the ways forward that they identify. It pays particular attention to issues of diversity.

This study was carried out employing a user controlled research approach, with the support of local service user organisations. It was co-ordinated by Shaping Our Lives, the national user controlled organisation and network. It will be of interest to user and non-service user researchers, educators, practitioners, managers, development workers and policy makers.



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This report is dedicated to Mairian Scott-Hill, who died in 2004, for all her support.

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Preface

One of the big new ideas emerging in public policy towards the end of the twentieth century was the importance of involving members of the public, patients and service users in public services. One of the areas where this has been most developed has been in relation to disability, health services and social care.

Movements of service users have taken forward both the idea and practice of user involvement. Such movements have included people with physical and sensory impairments, mental health service users/survivors, older people, people living with HIV/AIDS, people with learning difficulties, palliative care service users and other groups.

There is no doubt that major progress has been made in advancing this participatory approach to policy and services. The political rhetoric has had to change. Now the talk is of 'putting the service user/patient at the centre', 'empowering the public' and 'working in partnership' with people. Many health and social care service users have developed different, higher expectations. Many who would traditionally have been written off have become actively involved in trying to improve the support and services that they and others like them receive. New ideas, philosophies and theories have emerged and been developed.

But big question marks remain about how much change has actually been achieved in line with what people say they want. How real is that change? How many people do get actively involved? Do they truly reflect the diversity of the overall population they are part of?

Some troubling answers have been offered to questions like these, by both service users and other stakeholders. Little work has so far been done to find out how effective user involvement is (Carr, 2004). Service users repeatedly express their concerns about 'tokenism' and 'tick-box' approaches to participation. User involvement has not achieved equal involvement for all groups. Some groups still face particular barriers and exclusions and seem less likely to be listened to: for example, black and minority ethnic service users, people who communicate differently and older people. Service users continue to report major problems obstructing what they are able to do in their own self-run organisations and groups (Beresford *et al.*, 2005; Branfield *et al.*, 2005).

Yet since the movement for user involvement began, with its origins in the 1960s and 1970s, disabled people and other service users have stressed two things as fundamental to making participation a reality:

- 1 the importance of people being able to get together to do things together, work for change and support each other
- 2 the need to make their voices heard, to be able to speak and act for themselves (what came to be called self-advocacy) and to develop their own discussions, knowledge and ideas (Barton, 1996; Campbell and Oliver, 1996; Oliver, 1996; Barnes *et al.*, 1999).

In the years since, these concerns have continued to be priorities. While major progress has been made, so that, for example, Oliver and Barnes could write in 1998 about the way in which the disabled people's movement has been able to develop disabled people's own discourse, as a counter to traditional discussions coming from non-disabled people (Oliver and Barnes, 1998), other work has continued to show that the base on which such developments rest may still be fragile and insecure (for example, Barnes and Mercer, 2006). Thus disabled people's and other service users' achievements in taking forward participatory goals for social and public policy should not lead us to overstate these, or obscure the uncertain foundations on which they often rest. It is now time to explore these two issues – service users' capacity to work together and the degree to which they are able to advance their own voices and views – more carefully and systematically and also to begin to work out how both of these may be taken forward more effectively for the future.

That is the aim of this report and of the project on which it is based. It focuses on two issues and examines these from the perspectives of health and social care service users. It seeks to do this by exploring:

- how well service users and their organisations are able to network with each other, the obstacles they face and the ways in which they address these
- how well they are able to share their own 'service user' knowledge, based on their direct experience as service users and of being involved. This includes sharing such knowledge with other service users as well as in mainstream arenas.

These issues are both important for service users and important for user involvement. This has been a complex project to carry out. In doing so Shaping Our Lives developed a different approach to undertaking national projects which are based on engaging local service users, organisations and communities. We have involved local service users and service user organisations in undertaking some of the project fieldwork in association with Shaping Our Lives as a national organisation. This has had many benefits, particularly the opportunities it has offered

to build on the strengths of the local links and knowledge that local organisations have. In this way the process of the project, as well as its focus, has been concerned with networks and networking. We hope that this report will also play a positive and significant role in sharing the learning gained in the project and particularly that it will help both to disseminate and highlight the importance of service user knowledge.

Shaping Our Lives is an independent national user-controlled organisation and network. We are made up of and work with a wide range of service user groups, including older people, people with physical and sensory impairments, people living with HIV/AIDS, mental health service users/survivors, people with learning difficulties, young people with experience of growing up in state care, people with drug and alcohol problems and users of palliative care services. We are committed to increasing the say and involvement that long-term health and social care service users have over their lives and the support and services that they receive. We began as a project in 1996 and more recently became a democratically constituted organisation. We undertake research and development work as well as providing training and consultancy. We work with statutory and non-statutory organisations as well as with other user-controlled organisations and groupings.

Service user involvement is a complex and ambiguous idea. It is one of those aspirations, like partnership and empowerment, which can easily be degraded, diluted and devalued. But it is also important to remember that there is no one meaning attached to it. It is perhaps particularly important to remember this in the present context of networking and knowledge development. This project focuses on one of the stakeholders concerned with public policy – the people on the receiving end. This does not mean that any less value is placed on the role of other actors. Our concern has been that traditionally service users and their perspectives have been particularly neglected. Issues have been seen and understood from other more powerful perspectives, like those of politicians, policy makers and professionals. This heritage has also affected understandings of participation and user involvement.

Often user involvement has been framed in terms of seeking to involve service users in the service system's activities, ways of thinking, goals and structures. The most common calls have been to 'join our committee', 'send in your views to our consultation', 'fill in our questionnaire' and the like. That is still what most service user involvement is like. But from the beginnings of the emergence of new movements of service users, 30 and more years ago, first disabled people and then other groups of service users, began to develop a different understanding of what user involvement and participation might mean. They didn't necessarily want to get involved in existing organisations and services. They wanted to develop their own.

There is a big difference between feeding into someone else's ideas and organisations and developing your own. This distinction needs to be recognised. The first approach can be a very individualistic exercise, requiring no more than that people fill in a form or go to a meeting. But the second represents a new departure. It means people getting together and working things out for themselves and developing their own agendas. And it is here that the importance of user networking and user knowledge becomes most apparent. Is it enough for service users to get a space in existing service networks or do they want to develop their own? Is it enough for them to access existing knowledge or do they want to be able to develop their own?

There have long been indications that service users wanted the latter. It is because of this that we have undertaken this work – to get a clearer evidence base from service users' experience and knowledge about user networking and user knowledge.

An unexpected finding from this project was just how much the two issues on which we initially decided to focus, networking and service user knowledge, are interrelated and how important this interaction is for effective user involvement and if user involvement is to be taken forward successfully. We have tried in this report to offer an opportunity for a wide range of service users to report their experience on these issues. While the present situation that emerges seems to be a worrying one, at odds with political and policy commitments to participation, we hope that the evidence this report brings together will provide a helpful basis for change and improvement.

Acknowledgements

We would like to thank all the service users who contacted us and contributed to this research. We particularly would like to thank those people who took part in telephone interviews and those who attended focus group discussions.

We want to pay particular thanks to members of the Shaping Our Lives National User Group for their comments, suggestions and feedback, particularly on the construction of the interview schedules, but also at other key points of this research project. We would also like to thank non-service user organisations who contacted us during the course of this research project.

We owe our funders for this project, the Joseph Rowntree Foundation, a large thank you, not just for making it possible to undertake this work but also for their help and advice throughout critical points in the project. We would particularly like to offer our thanks to Alex O'Neil who was our link person with the Foundation. Thanks are also due to Jenny Willis, our office manager, for all her efficiency and administrative support in the Shaping Our Lives office.

Finally, we would like to take this opportunity to thank Phil Miller who sadly died earlier in 2005. Phil enabled us to run a discussion group with service users in Essex during this project and we would also like to acknowledge Phil's support to Shaping Our Lives more generally.

Summary

Background

There has been an increasing emphasis in recent years on user involvement in health and social care policy and practice. Lately, however, user involvement has come in for increasing 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 questioned the usefulness of getting involved.

Since service user movements began to emerge in the 1970s, service users have highlighted two activities as crucial for taking forward participation. These are, first, people being able to get together to work collectively for change and to support each other; and, second, making their voices heard and developing and making known their experience, views and ideas.

This project focuses on key expressions of these objectives: service user networking and service user knowledge. It seeks to establish from speaking to service users 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.

The project

This national project was based on a user-controlled research approach. It was undertaken through 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 implemented, 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.

Service user networking

Service users highlighted the importance and benefits of being able to network with each other, both as individuals and in user-controlled organisations, in terms of both improving their quality of life and sustaining a more effective voice and presence to make a difference.

Service user organisations and individual service users can be and often are isolated, with little knowledge of or contact with other service user organisations, locally, regionally or nationally.

Service users identify a range of obstacles in the way of networking as individual service users. These include:

- problems of mobility in rural areas
- the fragility of user-controlled organisations
- the effort of being actively involved.

For service user organisations, problems undermining networking include:

- 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, which can undermine their independence
- lack of adequate and secure funding which can be divisive 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, etc. 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
- 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.

Service user knowledge

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. One of the aims of this project was to find out more about service user knowledge, what impact it is able to make, how readily shared it is, what barriers it faces and how it can be most helpful.

Service users readily understand the idea of service user knowledge. They see themselves as having a particular role to play in the production of knowledge for health and social care, both because of the experiential nature of their knowledge and through seeing themselves as ‘experts in their own experience’.

Generally individual service users and service user organisations feel that they have difficulties impacting on health and social care policy and provision effectively. They identify a series of barriers in the way of their knowledge having the role and influence they want it to have. These 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 do not understand access issues and do not 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 do not seem to be genuinely interested in what service users tell them and do not 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, if their views are not consistent with what services want to hear, their funding may be put at risk. This is seen as an increasing problem.

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

- Education and training. Training and education (particularly if user led) for service users and providers were seen as both 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.
- 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. Thus user networking and knowledge development are seen as closely linked and mutually dependent.

Exploring diversity

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 was highlighted.

Contact between service users and service user organisations was limited, inconsistent and often hit and miss. Service users nonetheless 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 first-hand experience, and what was available. Many services and practitioners came in for adverse criticism as being unhelpful, unreliable, inconsistent and sometimes discriminatory. Flexibility in provision, user-led training, the availability of women-only services and support and the development of suitable standards and inspection were all emphasised as important for the future.

User networking, knowledge and involvement: ways ahead

During this project, it became increasingly clear that successful networking and the development, sharing and mainstreaming of service user knowledge are closely interrelated 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 contribution to improving people's lives, service users highlight two closely interrelated issues. These are, first, strengthening service user networking at individual and organisational levels and, second, the promotion of effective user involvement by service users.

- 1 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 a properly resourced national database of service user organisations owned and controlled by service users as helpful here. They see a national user network which offers support, information exchange, improved communication, contacts, advice on good practice and a national voice as having an important contribution to make.
- 2 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.

Introduction

At first I didn't want to know other people who were disabled, I didn't want to be one of 'them', but gradually 'them' becomes 'we' and 'us' and you realise that talking and being with 'us' is where we get our strength. We can have a more powerful voice and perhaps we can make a difference.

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.

(Service users who took part in this project)

This report looks at service user networking and knowledge. It is about the realities of service users working and learning together. It is concerned with what impact these activities are having, what problems they may face and what impact they may have for the future.

The twin principal aims of the project on which it is based were to identify the key issues around service user networking and involvement and around service user knowledge, as identified and reported by service users themselves.

The report sets out what service users say about service user-controlled organisations (see Appendix 1 for definitions of these terms) and networking amongst service user-controlled organisations. In doing so it highlights the fragile nature of so many of these organisations and the difficulties in the way of their collaboration and communication. We report what service users say are the difficulties facing such groups, their strengths and weaknesses, and we report what service users see as the best way forward for service user-controlled organisations and the role of networking in making this possible.

Involving service users and valuing their knowledge and experience are now part of the rhetoric of health and social care services and professionals. But as far as we are aware there has been little work done so far to explore with service users what exactly they understand by service user knowledge and what service users think of the value attached to their knowledge. This publication reports, from a service user perspective, what service users think, say and feel about their knowledge and the way it is treated, acted upon and valued.

This project then, has two equally important and often overlapping aims. These are:

- 1 to explore and support the development of local user-controlled organisations and their relations with each other and beyond
- 2 to explore and develop service user knowledge.

Our goal was to produce a report that would bring together what we learned in order to support, inform and develop other user-controlled organisations and to use this as a basis for Shaping Our Lives' own strategic development as a national resource for service users and others concerned with improving involvement and quality in health and social care. In line with our second focus we intended to report on service user knowledge and the issues around this as perceived and discussed by service users themselves.

This report represents the views of a substantial and diverse body of service users. Many of them have several years' experience of using health and social care services. From this perspective they are all experts by experience. This report is based solely on service users' views. In total 85 service users in England took part in the research. The participants were diverse in terms of the services they use, their experience of disabling barriers, their personal characteristics and identity and the geographical areas they come from. Everybody, bar one (a supporter working with people with learning difficulties), who contributed to this research, including all participants, facilitators, report writers and interviewers, identified as service users.

The report is divided into five major sections. Chapter 1 sets out how the research project on which this report is based was undertaken. Chapter 2 reports on the development of service user organisations and issues around networking. Chapter 3 discusses service users' views and perceptions around service user knowledge. While we have organised material in this way, these are not two discrete areas but in reality are inextricably intertwined.

Chapter 4 of this report is made up of three smaller reports of group discussions: two carried out by and with service users from black and minority ethnic communities and a third report of discussions with women who have had or still have experience of using alcohol services. While we have drawn upon material from these in the body of the main report, we also wanted to include them in their own right because of the specific issues they address and raise.

The final section of the report, Chapter 5, draws together the three key issues that service users discussed in this project – service user networking, user knowledge

and user involvement – and looks at their ideas for taking them forward for the future. It highlights the interrelations between the three. It explores service users' ideas for improving networking and confirms the importance that they attach to developing a national service user network and user-led database to help make this happen. It also reports on their ideas, experience and perceptions of improving participation and improving our lives, building on what we have learned about service user networking and knowledge.

The report's references are followed by a series of five appendices. The first clarifies our use of the terms 'service user' and 'user-controlled' organisations. The second provides the initial questionnaire which was sent out to obtain initial information from service users and service user organisations. Appendix 3 provides a short report of the data provided by this initial summary. Appendix 4 contains the schedule which was used to obtain additional information from service users in individual interviews and group discussions. Appendix 5 is the project brief, which provided information about the project for people interested in participating in it.

1 How we carried out the project

Introduction

This project was concerned with the networking of service users and user-controlled organisations and the development and role of service user knowledge. There is little consensus about the meaning of the terms 'service user' or 'user controlled'. Both terms can also be contentious (Beresford, 2005). In Appendix 1, we offer definitions of these terms. This project sought to be inclusive and to involve people on the basis of self-definition. What this tends to mean in practice is that participants have or have had long-term experience of health and social care services or would qualify to receive such services. The complexity of the concept of 'user-controlled organisation' emerged during the course of this study, but our starting point was organisations where formally control and power lay with at least a majority of people who identified as service users, whether disabled people, mental health service users, people with learning difficulties or others.

The research approach

This project sought to be user controlled and was based upon an emancipatory approach to research and evaluation. Such a research approach is generally associated with:

- focusing on research identified by and of importance to service users and their organisations
- involving service users in the research fully and in non-tokenistic ways
- seeking to equalise the relations of research production
- being based on a social model of disability approach
- being committed to the empowerment of research participants and service users more generally
- seeing the making of broader social change as a key goal for research (Barnes and Mercer, 1997; Beresford and Evans, 1999; Mercer, 2002).

As with all the work that Shaping Our Lives is involved in, we have viewed this project from the outset as a means of supporting the empowerment of service users rather than as an 'extraction' activity, merely drawing out what they know. That is to say that we have felt that participation in the project has to offer something to service users and user-controlled organisations. We are not seeking information primarily for our own or someone else's benefit, but for that of service users and service user organisations more generally.

The primary aim has been to support and develop service users' activities and organisations. We anticipated from the beginning of the project that it was likely to be based, especially in the longer term, on reciprocity – things that we can offer each other.

During this project we linked with a small number of non-user-controlled organisations and gave them access to user-controlled organisations and their members and (with agreement) enabled them to access information. However, this was essentially a secondary and subordinate activity.

The service users we spoke with

We sought to employ an inclusive definition of service user (see below and also Appendix 1). We included under the heading 'service user' people with physical and/or sensory impairments, people with learning difficulties, mental health service users/survivors, older people, people living with symptomatic HIV/AIDS, people who have used drug and alcohol services, young people who have used the care system and people who use the palliative care system. We sought to keep the definition flexible to be inclusive.

We also sought to reflect diversity, not only in terms of the different services that people use, but also in terms of age, culture, ethnicity, gender, sexuality and class. To this end we invited three service users/researchers to run discussions with two groups of service users whose voices have traditionally tended to be ignored or silenced: black and minority ethnic groups and women who have used alcohol and drug services.

The research participants were a diverse group of service users, in terms of age, gender, sexuality, regional location, services used, ethnicity and experience of disabling barriers and impairment. All people interviewed were service users as were the researchers. There was no screening process and participants 'opted in' rather than being defined by us through meeting certain, imposed, criteria. It was felt that if

service users expressed an interest in the topics under discussion then they should be given the opportunity to contribute.

The research methods we used

We wanted to get as wide a range of service users to participate in the project as was practically possible. To achieve this we used several different methods.

- 1 We decided to invite all service user members of our mailing list to participate in this research. We started recruiting people who might be interested in being involved by sending a short questionnaire to all individuals and organisations on our mailing list (see Appendix 2). Seventy-eight people responded to this call. For a detailed analysis of their responses please see Appendix 3.
- 2 We then sent a further request to the organisations and individuals who had responded to the first questionnaire. They were now asked if they would be interested in having the opportunity to tell us about what they thought were the important issues around networking, service user knowledge and service user involvement. We gave people the opportunity of contributing by email or post. We were also willing to conduct one-to-one face-to-face interviews if any of the respondents preferred this means of participating. No one took up this offer. In the event, people completed the questionnaire in writing and either sent hard copies or emails back to us. Thirteen people were interviewed on a one-to-one basis over the telephone.
- 3 In addition we organised a small series of locally based discussion groups. This offered both an additional way of involving service users – this time on an interactive rather than individual basis – and a means of drawing in a wider range of service users. Forty-eight people took part in six discussion groups held in different geographical locations. These were located in Essex, Leicester, Plymouth, London and Birmingham (two groups). Each group had between five and 12 participants. Three of these discussion groups were linked with user-controlled organisations. Participants were diverse in terms of age, gender, ‘race’ and ethnicity and sexuality. The groups were also diverse in terms of participants’ experience of services that they had used and disabling barriers they had experienced. For example, each group had participants who had personal experience of physical impairment, sensory impairment, learning difficulties, using the mental health system, and using services specifically for older people.

The three service user researchers who carried out the three other group discussions drew on their own existing networks to organise them. One group was with black and minority ethnic people with experience of the mental health system. A second black and minority ethnic group was made up of disabled people who use different services and the third group consisted of women who have experience of using alcohol services. The researchers' reports of these three group discussions are included in Chapter 4 of this report.

For email, telephone and group discussions we used the same semi-structured interview schedule (see Appendix 4). Participants were given the opportunity to look at the interview schedule before the interview or group discussion. Most participants welcomed having the questions in advance as this, as one person said, 'gave me time to really think about it all rather than just saying what came into my head'. Giving people the interview schedule in advance also allowed support workers to enable some participants to take part who otherwise might not have been able to. We sought to meet all access requirements of the people who contributed to this research project.

A total of 126 service users took part in the project in some way. Of these we had in-depth contributions from 85 service users. This report is based on what service users told us in response to the second, detailed interview schedule. Appendix 3, as we have said, provides information from the initial shorter schedule.

What service users said

It is important to recognise that people responded from both a personal and a political perspective. People talked from their own personal experiences and also from a developed philosophical and political understanding of their position as disabled people and service users. This does not lead to contradiction but rather is central to the understanding of many of the participants of service user knowledge, empowerment and the benefits of networking.

No names are used in the report, and any identifying comments have been omitted. All comments and quotations in the report, unless otherwise indicated, come from service users who took part in it.

2 Service user networking

Introduction

‘Networking’ is a idea that has become part of modern life and culture. People talk about networking in their personal, social and work lives. At the heart of the term are notions of linking up, connecting, making and retaining contacts, establishing new relationships, keeping informed, bringing together different groupings and tapping into helpful associations and ‘networks’. Networking is the opposite of being isolated. It is closely linked with concerns to communicate, share, exchange, cross-fertilise and keep in touch. While the potential of networking to exclude has always been recognised, as is reflected in talk of the importance of ‘the old school tie’, and male communication in ‘executive toilets’, its capacity to bring people together, join things up and synthesise is increasingly emphasised. Where once it was seen as an informal activity, a kind of add-on to the business of life (for example, during the refreshment breaks at meetings and conferences), now it is being formalised and developing its own discussions and literature.

So far limited attention has been paid to networking among service users and their organisations, yet the briefest of consideration highlights its importance. The movements of disabled people, mental health service users, people with learning difficulties, older people and so on have grown out of separation, segregation, isolation, institutionalisation and marginalisation. Historically, these have been the common themes of their experience. The disabled people’s movement grew out of the determination of a group of residential service users to live their lives in their own homes, rather than to continue to be segregated.

Service users have consistently emphasised the importance of doing things together – of collectivity – as the route to changing their personal situation and bringing about broader social and political change. The disabled people’s movement has long stressed that self-organisation offers the most effective route both to personal empowerment and to challenging social oppression (Oliver, 1996). Many service users, including the authors of this report, judge the strength and vitality of service user movements as most reflected in the state of local grassroots user-controlled organisations. This is where involvement starts for most service users. It is such local organisations and groups that are the first experience of getting involved for many service users. It is these organisations which offer service users their initial opportunities for linking up with others and being able to challenge conventional understandings and responses to them.

So far people's involvement in collective action has tended to be framed in terms of whether they do or do not get involved in service user or indeed other organisations. This is important and we need to know more about how such relationships and links do and do not develop. Much less attention, though, seems to have been paid to the nature of relations between service user organisations. We know there are different kinds of user-controlled organisations: for example, some that provide services, some that campaign and some that provide mutual aid and support – and some that do all these things. We also know that there are local, regional, national and international organisations. But much less is known about their relationships with each other and the potential for such links and relationships to develop.

Once there is recognition of the importance of collective action for service users and of its local foundations, then the issue of networking can be seen to be of central importance. We can expect it to raise many questions. For example, what are the issues involved? What problems and solutions have emerged? Are there particular networking issues for service users? What issues for networking do access issues, broadly defined, raise? And so on.

We clearly could not expect to deal with all these issues, but our aim was to make a start and put networking more clearly on the agenda as a matter that was likely to be important for the many service users who want to get involved and have more say and control over their lives and support services.

From the outset of this project we realised that we could not take the work forward by thinking in terms of developing a compendious list of user-controlled organisations as a basis for researching and exploring networking. There are many hundreds, if not thousands, of such organisations. We did not have the capacity to do so, nor would it have been a practical proposition bearing in mind the rapid changes affecting user-controlled organisations. It is widely recognised in the service user movement that user-controlled organisations are often fragile and insecure and 'come and go' all too frequently. We will find out more about the reasons for this in this report.

Shaping Our Lives set out to explore and support the development of networking among local user-controlled organisations. We started off with some initial objectives. These included:

- to identify areas where there are gaps in user-controlled organisations (for example, in particular geographic areas, for particular groups of service users and where user-controlled organisations are seen to face particular difficulties)

- to improve communication and contact between user-controlled organisations (consistent with Shaping Our Lives' commitment to work as a national strategic organisation, helping such organisations work together, learn more from each other, and have closer contact and greater strength)
- to provide a basis for a user-controlled database which Shaping Our Lives is developing, to support such contact and linking
- to strengthen links between Shaping Our Lives and local user-controlled organisations (consistent with our goal of being a grassroots-led, accountable and responsive organisation).

The meaning of networking

I think networking is about capacity building. By capacity building I mean things like training, training for service users in the social model [of disability], in equality and diversity training, issues around ethnicity. So that service users become more confident, so that they can become advocates for themselves and for others. There are a lot of people who have a lot of energy, a lot of determination for things to change but who don't know how to go about getting that change.

(Service user)

Almost all the people who were involved in this research felt that networking, both locally and nationally, with other service users and their organisations was or would be a very positive step both for individual service users and for the service user movement. This was true of all the group discussions we held, including those specifically with black and minority ethnic groups. Many suggested that there were a number of problems, most of which related to the 'capacity' of local organisations, that hindered linking with other groups.

This section reports participants' views on this topic. For clarity it is divided into two subsections:

- networking – what it means for the individual service user
- networking – what it means for the service user movement.

There is, as might be expected, considerable overlap between the two sections.

Networking – what it means for the individual service user

The benefits

Participants highlighted the benefits which they saw individual service users gaining from having links with other service users.

I don't know where I'd be if I hadn't found [name of local organisation]. I was just feeling sorry for myself and blaming myself for anything and everything rather than looking at it from a wider kind of angle if you know what I mean. And I think that's an enormous problem. You know you become disabled and you know nothing, where to go, who to talk to and it can be very isolating and difficult and lonely. You don't make sense of it ... I was just lucky that I found this group.

This service user was far from alone in talking about the positive benefits, on an individual level, of being involved with a user-controlled organisation. Others, for example, said:

I find it useful to have some sort of interaction, and it helps during the week to have a structure.

Without being involved in [name of local user-controlled organisation] I don't really know ... I mean it has given me an awful lot you see like I can now help other people in a similar position.

I've got time on my hands at the moment and so getting involved for me is a way of channelling information and knowledge into something with concrete outcomes.

Obstacles

For others, though, there had been obstacles in the way of making that contact. A large proportion of service users who were not involved in a local user-controlled organisation explained that it was difficult to find out what user-controlled organisations there were in their local area:

I would like to know and be more involved with a local group, but I don't think there is one in my area.

Service users referred to other problems too.

The problem is getting around. This county is enormous, it takes over two hours to get from the North down to the South and it's down there that all the organisations are and you know it is just impossible for me to travel there.

I would like to be more involved but it seems that it takes a lot of energy to be involved all the time ... and it is very difficult to actually find out what is going on. I mean if you are involved with a small local group they tend to have evolved ... I mean it can be difficult knowing where they are. You know they often just meet in people's own homes and so if you're not in the in crowd so to speak ...

The vulnerability of user-controlled organisations

People also highlighted the uncertain status of user-controlled organisations. One participant said that on returning to an area they had once lived in:

I am still trying to find out what has been happening to the organisations that used to be there. I think they have all folded because of lack of funding.

Several people, from different geographical areas, all made related points where they talked about user-controlled organisations either no longer being self-organised or not really 'user-controlled', even though they were offered as such:

There exists in my area a group who identify themselves as user controlled. But they are not. They are actually controlled by their able-bodied manager and workers.

My local organisation is meant to be user controlled but it is controlled by non-disabled staff.

In my area there have been problems in identifying what organisations actually mean in practice by 'user controlled'.

My local user group considers itself to be user controlled but in my opinion it is not. It includes carers as full members and the current co-ordinator is a social worker though others have been users.

Only one participant said that they were not in touch with any user-controlled organisation, but that they were networked with quite a few other service users. They went on to say:

But this is my choice. Sometimes the groups are run by a very dominant person who has their own agenda – well that's my experience.

The difficulty of engaging and maintaining involvement

Whilst no one else said exactly the same as the service user above, many did say that quite often 'it is all down to a few of us' and that it was difficult to 'get more service users actively involved'. The issue of recruiting service users to become active members in service user organisations was discussed by most participants. It became clear that problems in involving people were common. Thus:

You can learn from networking. I think we have common difficulties in establishing a large active membership. There always seems to be a nub of active people in any one service user network. I think we should put our heads together and wonder why it is and develop strategies to get round it.

What we want is a few more people to join us.

We haven't got any young people [in our group]. It is really hard to get new members and more people involved. It looks like we are going to have to finish the group.

The thing is that there are so few of us in our group who are active. It is the same core who turn up everywhere. We are beginning to lose our credibility. There are really only five of us who are active but we have over 75 on our membership and it is always the same three or four people who go to things and the providers are saying 'Is this representative?' So our credibility is in the air at the moment.

This service user sums up what many participants said:

For me it has made a big difference [getting involved in my local service user-controlled group]. And I suspect there are a lot of people out there who are isolated and lonely and depressed. I am sure. And they probably think there is no one else like them. But I found [the group] quite by

accident. How can we reach people? We don't, quite frankly, have the money – or the time. And then some disabled people don't want at first to mix with other disabled people. They can't imagine the benefits. But this has always been a problem for us.

From this study it is clear that service users who were involved in their local user-controlled organisation felt that their involvement added to their own quality of life at an individual level. The two reports which focused on members of black and minority ethnic communities also reflected this viewpoint. However, most people we spoke to, from whichever communities, thought that involvement with service user organisations was not only about the *personal* but was also much more about the *political*. Constraints in funding and other resources, however, meant that user-controlled organisations often had difficulty in involving people as they wanted to and meant that it was less likely that service users who would like to get involved would always be able to.

Networking – what it means for the service user movement

The importance of linking up

All the participants in the project, including those in the group discussions specifically with black and minority ethnic people, emphasised the importance of linking up with other service users. There was unanimity on this issue:

We need a collective national voice. If we are to succeed we need stronger collective grassroots activism.

It will give us all a stronger lobbying voice.

There is strength in numbers.

If we all come together someone has to listen.

There has to be strength in unity.

We can all work together as a team and make a difference.

It's always useful to have more of a national voice. Rather than just being a lone voice in the wilderness and it allows you to see what other groups are doing in other parts of the country, with regard to things like service user payment etc.

The potential for change

In all the group discussions, including the two specifically with black and minority ethnic people, there was a strong feeling that if all service user organisations were able to work together, real changes could be made. Again these comments were typical:

Making links and connections makes us stronger.

Yes exactly.

All contact is useful, exchange of information, sharing ideas and helping each other.

(Discussion between three service users)

And again in this exchange:

I think it is very important that we come together, learn from one another and become a voice that has to be listened to. You know like all political organisations ...

Absolutely I agree. And also so often we think we are the only organisation struggling with a particular problem when there might be a problem like ours which another group solved and could share how they did that or whatever.

Yes and it's like we think we have all different problems, like visually impaired people are different and have different problems from people who use wheelchairs and like older people who can't walk far or something and really our problems are the same, the same prejudices and barriers so it is important to talk and share and become stronger.

(Agreement from whole group)

One service user suggested that service user organisations needed to network with other oppressed groups, to learn from their experiences:

We have got to learn from each other and not just within the disability field. I think there are organisations that have a lot to teach us. That is organisations in the black and ethnic minority field. Because they are pretty good at getting the ear of the politicians ... Compared with what we get they are far more effective. Because they have a lot more experience of how to go about things and get things changed. I think they are far more politicised than disabled people generally.

This service user made a similar point:

I don't think we should just network with people with the same label as us. We should be networking with people who know how to campaign to change things. But there are so many of us [disabled people] who don't like to make a fuss, or not be grateful for what we've got.

Barriers to networking

Service users and service user organisations highlighted a range of barriers which restricted their capacity to network with each other.

Funding: the continuing barrier

The major stumbling block identified by participants as facing service user organisations was the lack of secure funding. This was identified as being a major problem among all the group discussions in this project.

These service users discussed their organisations' financial insecurity:

Really we feel we are being held up to ransom as every time we don't jump through the hoop that's placed in front of us then we are threatened – you know it's like the dog, you either get a treat or a threat.

We feel very insecure. Desperately insecure.

I think we feel the same. We may be OK for [this year].

Another group of service users said:

We are not secure at all. Our funding will end shortly.

Yes so will ours.

Security? What security? We are very much hand to mouth, always looking for money.

When I was the facilitator for a black and ethnic minority group it folded because of lack of funds. We tried to get more funding but you had to be a well-established group. It was a catch-22 situation.

The impact and implications of this lack of secure funding on local organisations are many. Here the focus is on the impact this has on staff, most of whom are service users:

It really does demotivate staff.

Sometimes you know there is just no incentive; you just think 'What are we doing?' Because you just feel like you're wasting your time.

We are all on short-term contracts, which obviously isn't good for staff morale.

Staff have to fill in application forms for funding. Fundraising for their own salaries!!

You know it can seem so hopeless. You want to set things up, support for each other and really feel you can make changes and then your funding is always under threat. It can be depressing for the workers. So you know it becomes a downwards spiral.

Although we are not too bad at this particular moment, I couldn't honestly say we are financially secure. But I am going to a finishing party tonight for a group I was more involved with who have lost their funding.

Funding: undermining user control

It is not just that funding issues limit what service user organisations can do. They also have the effect of shaping and biasing them. These service users talked about the political implications of a lack of secure funding for their organisations:

You know all the time you have to adjust your ideas to meet the funders' criteria.

Organisations have now been forced to be led by funders' priorities rather than by our own principles.

We have to spend so much time looking for potential funders, and then all the application forms to get a small amount of money, you can easily find yourself having forgotten what your organisation is actually supposed to be doing, why you all set it up and everything because all you do is look for money. It's very wrong really.

Perverse pressures to compete with each other

A recurring theme from participants in the project was that small service user-controlled organisations are competing amongst themselves for the same limited pots of funding. This can be damagingly divisive, as this discussion illustrates:

The way it works at the moment means that you have a feeling that you don't want any other group to hear of a funding opportunity. If you find one, particularly if it's a local based fund then you have to keep quiet or else they might get it and not your group. So the system doesn't exactly encourage networking.

No, that's right but it's nationally as well as just locally. We should all be sharing information about who to apply to get grants from. But everyone just keeps quiet about it in case they apply and get it.

So the system in a way makes you not co-operate with each other 'cos you are in competition for the same money.

Yes, competition for the same pot of money. And there are other organisations who say they are user controlled who, well actually the bottom line is they pinch our money. You know that is real to us.
(General agreement from group)

Participants also talked about another similar problem that discouraged them from networking on a local level with other user-controlled organisations. This was the fact that broader policy arrangements set them up in competition with each other. The following discussion illustrates this problem:

You know it all sounds lovely, everybody is friendly. But there is a lot of competition.

I think the whole contract culture is setting us against each other. Social services tendering processes – they are terrible in our area.

Organisations that used to work together are all set up against each other.

We also find that social services pit us as a user-controlled organisation against other organisations for carers. And we are organisations that have grown up together. And we find this very difficult.

David versus Goliath

Another related point was raised by many of the participants in the project. There is a tendency to talk about 'the voluntary sector' as if it were homogeneous. However, the term actually obscures enormous diversity, from typically small black and minority ethnic organisations and service user-controlled projects to the large charities with multimillion-pound annual turnovers. In the world of voluntary organisations, user-controlled organisations frequently feel like David, next to the Goliath of the big non-user-controlled organisations.

We are not [financially] secure at all. Basically these days, grants are drying up. You can't get core funding unless you bust a gut. And basically what you have to do is to provide services, and the resources you get for these services is never enough to actually meet the costs of providing those services. And we are also facing wide competition from non-disabled-controlled groups who pay lip service to disabled people. They can actually run a very smooth organisation and are often, more like than not in contact with the sponsors and they basically get the money and we compete very badly with these organisations. So our resources are not secure.

This service user's last point was made by many people we spoke to.

We are, of course, competing [for funding] with the large organisations and charities that we [service users] do not control, such as Scope and Mencap. They have whole departments whose job it is to just raise money and make grant applications. You see, they do it day in and day out. We, on the other hand, are usually understaffed, if we are staffed at all and don't have the time to do all this, so we can't even compete for money fairly.

We apply for grants again and again and again. Although we are reasonably well known locally we can't compete with these enormous national non-user-controlled organisations.

This concern over having to compete with extremely large and wealthy non-service user-controlled organisations and charities is, of course, not new. Many disability campaigners and theorists have long argued that organisations that are controlled by service users are essential if disablist discrimination and negative stereotyping of service users as passive and objects of charity are to be challenged (Barnes, 1991; Drake, in Barton, 1996; Oliver, 1996; Barnes and Mercer, 2006).

Lack of critical mass

Many participants identified a further problem that was integral to many service user organisations. It is a further expression of the under-resourcing and vulnerability of such organisations. This is their over-reliance on individuals because of their insecurity and inadequate budgets. This group of service users discuss what they felt often happens:

All too often I think that it all comes down to one individual who can really help to change things. But if that individual goes for any reason, like exhaustion, then the whole organisation can collapse.

That happens all too frequently.

It really is about capacity building so that it is not all reliant on one individual.

Other service users agreed:

In my area it comes down to one person, one person who tries to be representative. But ... whilst I think she does her best, it is difficult.

There are only a few core people who ever do anything. It is difficult to reach out to other people.

If it comes down to one powerful individual always fighting your corner ... it is not a good situation because what do you do when they don't want to be there [any more]. All their work goes with them and if a new person starts up something, they have to start from scratch.

Limited profile

Question marks also hang over the status and profile of user-controlled organisations, both over whether they are known about and how they are seen. When we asked user-controlled organisations how they felt they were perceived locally there were many different responses:

I don't think they give us much thought at all.

We raise our own funds and apply to the local trade unions in the form of donations to us ... we are reasonably well regarded in the local area.

We have a good strong reputation amongst disabled people and the local authority.

The following discussion encapsulates what many of the more politicised groups seemed to feel – that they were liable to be marginalised:

We are seen as being for 'The Severely Disabled'!

Yes, we are definitely seen as being run by disabled people for disabled people.

They see us as being the *really* disabled group!

But I think we are seen as activists therefore we are seen as challenging and so they go for the safer option – the do-gooders and not groups run by us ourselves.

In another group discussion, service users returned to the issue of having to compete with large non-user-controlled charities and the problems inherent in it:

The problem for us and I am sure you have heard this before from other groups, is that we do not have the capacity to market ourselves.

Or the money.

We think we are well known because we probably are in the disability world. So it becomes easy to fool ourselves. Outside that very small world no one has heard of us.

How can we market ourselves in the same way that Scope or the MS Society do ... we couldn't afford one billboard [advertising hoarding] let alone a marketing strategy.

Advertising! We can't even afford to advertise our services!

How user-controlled organisations felt they were perceived locally varied. In general the larger the organisation and the more funding it received, then the more regard members felt they had. This has worrying implications, given the general inadequacy of funding support.

Funding: inhibiting networking

The capacity of user-controlled organisations is clearly resource related. When we asked individuals and organisations if they had any difficulty or faced any obstacles when networking and collaborating with other user-controlled organisations we were told the same thing again and again:

It takes money to do all these things. To keep the thing rolling all the time, to keep the contacts constant and lively, you have got to have the funding, the staffing and everything else. And we just haven't got it.

The obvious one is resources both in terms of time and personnel. We are so busy it is unreal and often this is because we have to respond to other people's agendas. If we turn work or involvement opportunities down it is likely to back fire in terms of funding. Hence we do not often have the resources to do anything like as much work with other user-controlled organisations as we would like to.

Issues of access

Another key reason that service users gave for not networking effectively and successfully with other local user-controlled organisations related to issues of access in relation to people's impairments. This, as most participants explained, was again often due to lack of money:

Lack of time and energy of our volunteers, who are all service users.

Some organisations and groups use a lot of jargon words and for people with learning difficulties this is difficult. Some people cannot read.

We are not very good at using picture symbols and this is about workers' time and money.

There are impairment-related barriers. We are a visually impaired group and not all other user-controlled organisations can afford to make things accessible for us.

We do face a real barrier in that because we are user led a lot of our volunteers and staff [are] unable to travel because of agoraphobia. As we are based in the North of England we find a lot of meetings are held in London which results in our organisation being disadvantaged.

Networking: gaps in user-controlled organisations

We asked people what gaps in user-controlled organisations, if any, there were in their locality, for example for older people or people with learning difficulties. Participants identified a wide range of such gaps in their own areas. These included the lack of:

- active older people's groups
- self-run groups of people with learning difficulties
- groups of young disabled people
- groups for people living with HIV/AIDS
- disabled parents groups.

Inadequate provision for black and minority ethnic involvement

But the one gap that nearly all participants highlighted was organisations controlled by and/or fully involving black and minority ethnic service users. This didn't necessarily mean that efforts were not made to involve black and minority ethnic service users, but rather that there was a realisation that these were not adequate or effective.

I don't think there are any groups round here for black service users. We try to encourage them to come to our meetings, to get involved, but we haven't done that much and we don't have any black people involved in our work.

This is a multicultural city, but as far as I know there aren't any user-led groups of black or Asian groups.

There are a lot of Chinese people in this area and some of them must be disabled but there doesn't seem to be any user-controlled organisations.

Our research indicated that the lack of involvement of service users from black and minority ethnic communities was recognised as an issue by many service user organisations, and few seem to have been very successful at encouraging a more culturally diverse membership and involvement.

We have not got enough members from minority ethnic groups. We have tried to address this. I think this is a problem for all organisations.

Unfortunately our members are predominately white British, but that is a reflection of the make-up of this area in general.

We are not particularly attractive to people from a black and minority ethnic community and we are constantly struggling over that one.

There is a huge Italian community in our area but you wouldn't think so to look at us. It is not through lack of trying but we just don't have the funding and for other minority ethnic groups we are under-represented. There are big issues here.

Many people recognised that to involve people from black and minority ethnic communities took resources in both time and money. Many respondents' thoughts are summed up by this service user's comments:

To be inclusive on racial equality grounds needs two things. It needs the determination to be inclusive and it needs money. If you don't care it will never happen, but if you do try hard it will only happen to some degree unless you have the resources to reach out and involve people.

Indeed it was for this very reason that as we progressed the project, we felt it was crucial additionally to fund two service user researchers, both from black and minority ethnic communities, to draw on their own networks to involve more black and minority ethnic service users in this research (see Chapter 5).

3 Service user knowledge

Hypothesis: The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted.
(Beresford, 2003, p. 22)

Introduction

In recent years, governments have stressed the importance of public policy being 'evidence'- or 'knowledge'-based. What they have said they mean by this is that policy and provision in health, education and other areas of public welfare policy must be based on more than just doing what has been done before or relying on traditional assumptions and values about what is helpful and should be done. There has been an emphasis on finding out what works and what doesn't work. There has been some criticism about this 'evidence-based' approach to policy and practice. It has been argued that it wrongly suggests that policy is just a technical matter rather than one based on norms and values, to divert attention from the inherently ideological nature of public policy.

This debate continues, but it has helped to focus attention on why we have the policy and services that we do and it has brought to attention issues about the meaning and nature of knowledge and evidence which previously had tended to be taken for granted. We have preferred to use the term 'knowledge' in our discussion because it does not take for granted the complexities of how what people know comes (or doesn't come) to be seen as evidence underpinning or justifying something.

There is now much more discussion about *knowledge* in health and social care. It has raised issues about what knowledge is, whose knowledge we are talking about, how we come to know things, whether different approaches to finding things out result in different knowledge and so on. These are big, often complex issues and frequently they are discussed in ways which are themselves complicated and difficult to understand, using big words and professional jargon.

This has frequently meant that such discussions have excluded long-term users of health and social care or been very difficult for them to engage in on equal terms. We know that many people with learning difficulties, disabled people and mental health service users have had limited and inferior educational opportunities. We also know

that the barriers facing people included in these categories can make it very hard for them to participate in activities, including activities in the public sphere, which might be important to them and affect their lives.

This is clearly true for issues relating to the knowledge base of public and social policy in relation to disability, distress, ageing and learning difficulties. While such discussions may have been very difficult for many service users to engage in formally, it is important to remember nonetheless that right from the establishment of the disabled people's movement in the UK in the 1970s, issues of knowledge, 'evidence' and research have been important and have been highlighted. The grouping which formed a key basis for the British disability movement, the residents of a Leonard Cheshire residential home, came together around wanting to live in their own homes and trying to get an external research project to recognise what they wanted and that it was feasible. The search for knowledge – from other viewpoints – was key to service users right from the start of their coming together in collective action.

This has led to a stream of discussion, debates, research and publications, first by disabled people and then by other groups of service users providing *their* side of the story and developing and putting together *their* knowledge.

A key theme of such discussion has been that, for a long time, recipients (particularly long-term recipients) of health and social care services have been subjected to services and 'treatment' and been seen on the basis of 'professional/expert' ideas and knowledge of them, who they are and what should be done to them. This has been embodied in social policies and become part of political programmes. It has generally been based on medicalised, individual models of people, of disability, distress and so on. Service users have commonly experienced such approaches to them as inaccurate, oppressive and discriminatory.

Service users have always had their own understandings of themselves, their situation and how they are treated. Mostly in the past these were ignored, devalued and hidden. In the last generation, service users, based on 'the expertise of their own experience', have set out both their individual and collective views of who they are, what they want and how policy and services need to develop. Service users have developed their own knowledge, based on their own individual and collective experience and reflection. The social model of disability and the idea of independent living are important examples of this.

Service user knowledge has begun to make an impact and to make a difference in the lives of individuals and groups of service users. It has begun to influence policy

and practice. However, this influence is still limited and should not be overstated. We can expect that there are likely still to be powerful obstacles and barriers in its way. Many service users have limited chances to share and develop their ideas and views. Many, for example, are still unfamiliar with the social model of disability. Professional and academic traditions and interests are still powerful. We might expect that this would work to ensure that traditional approaches to policy based on traditional research and professional 'knowledge' would continue to exert a strong influence.

From its earliest beginnings, with the support and involvement of helpful non-service user collaborators, Shaping Our Lives has continued to receive strong messages from the many service users with which it has been in contact that is difficult for them to get their ideas, explanations, experience and views across and for these to be treated on equal terms. The message has been that service users' resources are very limited to be able to make perspectives more visible, to share them better and to challenge traditional understandings of them and their situation.

Shaping Our Lives' own awareness of these problems particularly grew through its early work on user-defined outcome measures, where we saw that professional and managerial understandings of what service users want from workers and services still predominated. We found that existing services had been shaped by service provider knowledge and research, rather than service users. We found from service users that direct payments, where service users can decide what they want and how they want it, were much more successful in providing the outcomes that they wanted, based on what they individually and collectively knew they needed to safeguard their rights and interests and to improve their quality of life. One of the ironies of this work was that Shaping Our Lives not only discovered that there was this inequality between the service provider/service system and service user knowledge, but that the strength of this continued to limit the influence findings like those of Shaping Our Lives could have and marginalise the development and implementation of user-defined outcome measures.

Because of this, Shaping Our Lives came to the conclusion that something needed to be done to support and strengthen the knowledge that service users have, based on their own individual experience, their collective discussions and increasingly their own research and evaluation.

Shaping Our Lives therefore organised a small national consultation focusing on service user knowledge, using a small sum of money from the Joseph Rowntree Foundation to see what service users more generally felt about this issue. An open invitation was made and, while it was a small consultation, participants were a

diverse group and brought a wide range of expertise and experience to the discussion.

At this consultation, service users emphasised that they thought the issue of supporting and advancing user knowledge in its own right and as a challenge to existing powerful non-user knowledge was important and should be viewed as a priority. They reinforced Shaping Our Lives' concerns that service user knowledge tended to be marginalised, stressing that they felt it had an important role to play.

As a result, Shaping Our Lives decided to include a focus on user knowledge as part of the proposal for work on service user networking which the Joseph Rowntree Foundation agreed to support. It was envisaged that this would be an initial phase of work, finding out more from a wider range of service users what they identified as key issues relating to 'user knowledge' as a basis for developing a large project proposal for funding. The areas for work identified in this project reflect those areas identified in the consultation. They are thus rooted in the goals and experience of a wider range of service users. In this sense, like the work relating to networking, they can be seen to fulfil the criteria of some definitions of user-controlled research that the ideas and impetus for the work come from the constituency concerned – service users (Turner and Beresford, 2005b).

Exploring service user knowledge: our aims

This second strand to this project, the focus on service user knowledge, set out to identify key issues for service users and their organisations regarding the development of user knowledge. Two overall objectives were involved here. These were to provide a basis for identifying:

- key practical and theoretical issues to enable the knowledges of service users to be developed and fed into mainstream policy, practice and debates
- how these knowledges can be shared effectively between different groups of service users and service users more generally.

These two objectives relate to four concerns which were identified by service users at the Shaping Our Lives consultation. These were:

- How can we share the knowledge we develop more effectively among service users and service user organisations?

- How can we ensure that our knowledge becomes a more powerful part of mainstream health and social care knowledge?
- How can we challenge the way that existing professional knowledge sidelines and seeks to take over our knowledge?
- How can we make mainstream knowledge more accessible to service users and their organisations?

There is a growing sense among people who use social and health care services that they are the 'experts by experience'. In other words service users can be the best people to tell the professionals what they want and need from any particular service, because it is intended for them and their knowledge of it is based on direct experience. Equally there is recognition that any judgement of whether a service constitutes good practice is likely to require the involvement of the views, experience and knowledge of service users, and that to achieve such provision it is likely to be necessary for service users and service user knowledge to be involved in the planning and delivery of such services.

Service user knowledge: making a difference

Significantly, while the concept of 'knowledge' can be a complex one, the majority of service users who took part in this project did not need the idea of 'service user knowledge' explaining to them. They readily related to the term. The general feeling seemed to be a taken-for-granted assumption that service users were 'experts by experience' or, as a service user put it:

Of course I am an expert on the services I receive. I have received services all my life, of one sort or another and you just get to be an expert. It's like you have to otherwise you don't get what you want. Not that I often get what I want but if I wasn't an expert it would be even worse. I mean you talk to anyone who has just started using services ...

We wanted to begin by trying to find out from service users what, if any, impact or difference they felt they and their knowledge could make on the services they received. The first question we asked them in the knowledge section of our schedule was: 'Do you think that you and/or your organisation is able to make as much impact on social care policy and provision ... as you would like to?'

Not one individual or group gave a simple 'yes' answer to this question. Instead, service users predominantly highlighted the difficulties they had in having any impact. They expressed many different opinions as to why they as individuals – and why they as part of the service user movement – were unable to have the impact and influence they wanted on their services. However, a few recurring themes quickly became apparent. These were:

- the devaluing of service user knowledge
- problems of access and tokenism
- the culture of health and social care organisations
- resource issues.

We will look at what people had to say about each of these.

The devaluing of service user knowledge

Most of the service users we talked to expressed the view that what they said and felt, what they *knew* and what they experienced, was not valued by professionals and the service system. This was true at both an individual and personal level, in relation to their own circumstances and broadly and more generally, when they commented on policy and provision. For example:

They don't give us the chance these days. There are all these people at the top who think they know everything about us and we are still having a job to explain who we are.

No, the more I have been involved the more it seems tokenistic. The government has put out provisos – they've got to have service user representation. A lot of the time you are not listened to, your ideas are not taken seriously.

I don't think they take us seriously. You have not just to have the right language and wear the right clothes – you have to look the part in all ways. If you don't and if you are not good at speaking and everything they just say 'yes' and practically pat you on the head and then just ignore what you say.

Service users are now involved in their [own] care but we are not treated as experts. It's always the case of 'Doctor knows best'.

I want to let them know what I think about me. What I want in my life and how I feel about them because they can't tell me what to do. They think you can't do things for yourself and you don't know nothing, but I do.

We have been able to make more impact in social care but we still encounter the professional power base that is reluctant to relinquish control to 'disabled amateurs'. It is much worse in health where the 'we know best' ethos is alive and well and disabled people's issues are barely on the agenda.

There has to be commitment from the authority. What they are not committed to is taking what we say seriously. It's like 'Oh here she is again ... banging on about how things should be and what's happened to her and people she knows' and it's terrible but they all act like what you are saying is really boring and they've heard it before and I am just being at best irrelevant or embarrassing. And it takes courage to talk in situations like that and they just belittle you.

This last point is important and worth highlighting. Many of the people who contributed to the project not only spoke of the way that service user knowledge is devalued and negated – deemed somehow less valuable or 'knowledgeable' than professional or so-called 'expert' knowledge – but also commented that the experience for service users of trying to promote their own knowledge and of trying to be treated equally can in itself be extremely disempowering. This is a significant distinction to draw. It is particularly important, given the degree of oppression and disempowerment that many service users experience anyway. Thus, for example, service users talked about the corrosive and disempowering effects of trying to challenge existing inequalities and discriminations:

We have not been able to make much impact – for the usual suspects of ignorance, stigma. But also a personal lack of drive to face the hostile reception that occurs when trying to enlighten folks. It is a double pressure and the struggle to keep at it is hard. The sense of it being a thankless task all of the time. And when you do something there is no one to share with or debrief you. It can be an empty feeling even if you are told you did well.

We have been quite successful in influencing health and social care policy and provision but this takes an enormous amount of time and energy from volunteers which is not then available to support and work with members of our organisation.

I don't have the will to fight any more. You see it is such an uphill battle and you have to be feeling so strong in yourself, to put yourself through it. It is not pleasant to be made to feel so unimportant. My wife and I, we talked about it and we decided that it was time for someone else to carry the banner. There is only so much you can do and it was beginning to tell on me.

The following two-way discussion between service users highlights the point that if professional knowledge is prioritised and valued over service users' experiential knowledge, then whatever service users say will not be treated as equal to the knowledge validated on the basis of conventional judgements and through professional bodies:

I used to be involved in far more things than I am now. Because it gets tiring just saying the same stuff over and over.

Well, it's not just that you're sounding like a stuck record, it's that they really don't seem to get the point of what you are telling them.

Exactly. You are telling them about something that happened to you and they think you are just telling them either an amusing tale or an embarrassing one. It's like they just can't see the point of it. And after a while you don't see the point of trying to explain it to them it's as if you are speaking a foreign language. It can be very frustrating and demeaning.

Yes, it leaves you feeling as if you are the stupid one. When it is them and their attitudes and the fact that they cannot listen.

Such devaluing of service user knowledge has far-reaching implications for both service users and service providers. For the service user, all too often the negation of what they know from what they have experienced results in them feeling devalued and disempowered as a person, who understandably gets tired of being involved. This helps explain the high attrition rate in user involvement and why service user groups and organisations frequently find it such a struggle to maintain broad-based involvement.

We should not forget the negative effects this also has for service providers. Seeing service users' knowledge as no more than anecdotal and of having little or no relevance to broader and mainstream discussions denies professionals the knowledge that service users have gained through their experiences over many years. They thus deny themselves a crucial knowledge source.

Problems of access and tokenism

If the devaluing of service user knowledge was one of the problems that service users highlighted, then an expression of this was the problems relating to tokenism and lack of proper access which they also talked about frequently. The two issues seemed to be closely interrelated. The failure to ensure good access for service users so that what they had to say could be listened to and learned from reflected the lack of real interest which many service users felt there was in it. Many service users in both the group discussions and individual interviews we carried out talked about service user involvement as being tokenistic rather than meaningful. Lack of support for service users and lack of understanding of access issues in their broader sense were identified as key ways in which service user knowledge is undermined. Thus, for example:

What do service providers think they are doing by getting some poor service user in off the street, so to speak, if they have no training, no support, no education, it is just the token disabled person sitting there so they can tick the box saying 'consulted with service users'. That is not consultation. It is terrible.

It often so much depends on the individual service user. On their experience and knowledge if you like. You know, whether they understand the bigger picture. Otherwise it is just tokenism and obviously that never works, well, not for us.

The more I have been involved with it the more it seems tokenistic.

Sometimes user involvement just seems like a cosmetic exercise.

Meetings are not easy. People don't talk slowly or in words we understand. They are boring. Some people can't read.

I find it very difficult to get things put into Braille in time for some of the meetings we are invited to. So then you are not prepared. You are disadvantaged before you even get there and you are just a token blind person and not really expected to speak!

Service users highlighted the problems resulting from current narrow understandings of access among many service providers:

One of the things we find is that although most places, but by no means all, are aware of having meetings in an accessible building ... we find all the time that they think that this means that there are no steps up it, or it has a ramp. And that is as far as it goes. They never think about other things. They don't think we might actually need to use a loo, that fire doors are too heavy, that the lights are too bright ...

And physical access is all they think of, they never think of the timing of meetings, how long they are, when we'll have breaks ...

But when it's things like working with people with a learning difficulty. I mean just forget access because they just don't have a clue how to include everyone in a meeting.

Getting to meetings can be very difficult for some of us.

It is worrying that at a time when there is a big official push towards participation and involvement that the service users to whom we spoke were frequently pessimistic about the impact that they were able to have on the health and social services that they received. Service user involvement and participation will always remain tokenistic unless service user knowledge is respected and treated with equality and on a par with professional knowledge.

[It's just] going through the motions.

The culture of health and social care organisations

Access works in two ways. First, as we have seen, it must mean that provision is made to meet the access requirements of service users so that they can participate and contribute on as equal terms as possible. But, second, organisations and agencies need to be receptive to what they have to say. Many individuals and

organisations told us that one of the main reasons that they felt unable to have the impact they would like to have on their health and social care provision was the *culture* of these organisations. They saw health and social care organisations as not being open to service user knowledge. These comments are typical of what service users said:

There is reluctance by health and social care departments to change.

We are strong representatives of our people. We know what the issues are and we say what they are. But nothing much changes due to an intransigent society that is hell-bent on supporting itself, the status quo, but not developing the equality, inclusion and participation of others.

Social services are quite scared of the professionalised service user. Their whole structure, their entire way of working is based upon the assumption that service users are 'in need' and pathetic, grateful. And when you challenge that they don't like it or know how to deal with you.

Providers are very entrenched in processes and policies.

It is not broken so why fix it seems to be their policy. But of course it is broken, but fixing would mean changing and it works for them but not particularly well for us.

These organisations are controlled by providers and they are largely run to meet the requirements of providers. Providers don't warm to the idea of consumer involvement. They see user involvement as a threat and they see user empowerment as provider disempowerment. Now, they are completely wrong in their view but I can fully understand why they hold it. I think that by empowering their users they are empowering themselves because they are target orientated and effective and they'd use their resources more effectively. But try telling them that!

Service users' perception of the culture or ethos of most service provider organisations is that generally they are slow to change and reluctant to shift the power imbalance that exists between service users and professionals. Service users repeatedly talked about their feelings of powerlessness and futility. One service user described his experiences of talking to his service providers as 'hitting your head against a brick wall', whilst another said:

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

The Government formally recognises that service user involvement in the planning and development of services is essential for appropriate and cost-effective provision. However, there was a strong perception among the service users we talked to that services were not truly embracing service user participation and generally did not regard service user knowledge as a tool for positive change. This was not seen as a problem of individuals, but rather a broader organisational and cultural issue. This resulted in a strong sense of disillusion and powerlessness among many service users.

Resources

Service users and their organisations have argued that their knowledge has its own particular qualities and a particular contribution to make. They emphasise that it is based on direct experience, offers unique insights because of this and as developed through user-controlled research is likely to focus on new and different issues which service providers may not have considered but which service users prioritise.

We have already seen that many service users saw the lack of service providers' receptivity to their knowledge as a continuing barrier to its development and inclusion in policy and practice development. However, they also highlighted another less obvious but equally important barrier – funding and resources.

Earlier in the discussion about service user networking, we saw how most participants in this project identified lack of resources and limited funding as key problems inhibiting networking. They raised similar issues in relation to service user knowledge. It quickly became apparent that, for many service user organisations, the question of funding was very closely linked to what the health and social care providers wanted from a user-controlled organisation. If user-controlled organisations and service users do not do what is wanted of them, indeed if they do not offer the views and information that are desired, then other views may be sought or their funding may be at risk. Thus funding emerged as a means whereby both service users and service user knowledge could be controlled and restricted.

This comment from a service user received agreement from all the other service users in one discussion group:

We get our funding. And they are telling us what they want us to do with it. We have no chance to argue – we won't get the money.

And later in the same discussion people said:

We quite often have to say 'Can we do this or not – or are they going to get upset and stop our funding'.

Are you saying it's getting worse?

Oh yes definitely.

It has got worse in the last two years in particular.

We have got to pay more lip service shall we say. We have got to fit in more with them or we won't get the money. They sat round the table and told us this.

Yes it is the same for us.

If we say what we want to say we won't get the funding.

So we are supposed to be independent user-controlled organisations but we are not really because we cannot be independent and it is worse than two or three years ago. I think since the Primary Care Trusts (PCTS) have come into being.

Other participants in the project made the same point.

There is a perceived threat to remove our funding if we don't give them the answers they want.

They say they want to consult us, but we are under enormous pressure to tell them what they want to hear. If we don't they will go to another group, probably not user controlled, but some 'gatekeeper' of service users, who will tell them what they want to hear. In other words they stop our funding and give it to someone else. We *know* this happens.

Thus the issue of resources in relation to service user knowledge emerged as a complex one. Lack of resources not only restricted the capacity of service users and their organisations to develop, share and input their knowledge. Resources can be,

and service users clearly think they are, used to undermine the independence of such knowledge – to support some views and disadvantage others. Whatever the intention, the effect clearly will be to limit the dissemination and impact of such knowledge.

Strengthening service user knowledge

Participants in this project painted a worrying picture of the constraints and barriers facing service user knowledge. The provision of adequate and secure funding which supports rather than constrains service users' independence is clearly crucial if service user knowledge is to be developed effectively and without bias. This means both financial and human resources. It is unlikely to happen so long as service user-controlled organisations continue to exist on the poverty line, with inadequate funding and limited resources. Service users emphasise that they want to influence change: they want to have a say in the services they use and they want their expert knowledge to be recognised and valued. However, until service user organisations have greater control of the purse strings, until there is greater recognition of the need for capacity building, they are likely to remain on the sidelines, without making the impact upon the services that they feel needs to be made.

We asked service users a series of questions about how they felt service user knowledge could make more impact on policy and provision, be shared more effectively between service users and service users' organisations, exert a greater influence on mainstream discussion and challenge tendencies to marginalise it.

While they had highlighted a series of major problems facing user knowledge, there was a lot of energy and enthusiasm in their responses to these questions.

Encourage and engage professionals who are also service users and carers and who are committed to service user involvement ...

Truth is our secret weapon. We need to speak the truth, tell it like it is, that is our strength.

Hopefully we can learn from people's life stories.

Four recurring themes for taking forward service user knowledge stood out in their comments. These relate to the importance of:

- education and training
- commitment to change
- ensuring diversity
- networking.

Education and training

Almost all the service users who responded to the questionnaire we sent out identified the need for education and training – training so that people both as service users and service providers could be more aware of and more prepared to use service user knowledge. Training and education were seen as both ways of challenging the barriers marginalising service user knowledge and ways of sharing and disseminating user knowledge. To a significant extent, the two were seen as inseparable. At the heart of most of the comments people talked about the need for Disability Equality Training (DET). But other issues relating to education and other forms of training were also identified as being important in promoting effective and inclusive participation. For example:

There needs to be a proactive approach to user involvement, with Disability Equality Training for professionals and empowerment training for service users.

Well, through training, through education. I mean if they did away with specialist schools and people were used to seeing disabled people, and they were seen just to be ordinary people with ordinary wants and needs . . .but yes I think it is about educating people.

There is such a need for training. Training done by other service users to service users, on empowerment, assertiveness, on equality on ... how to participate in meetings. So much training. And of course training for the professionals on an equalities, a political understanding of service users' position. On human rights ... so much training.

Expand and develop direct involvement in professional education.

I think there should be equality and diversity training.

We need to be involved at all levels. For example in research, in training professionals and psychologists in trusts and in universities. Remember we are experts by experience.

People don't just change. They have to be changed. Enlightened if you like. The only way I can think of doing this is by education and training.

We need to use the already existing education systems, such as the Learning and Skills Council, further education departments, WEA and trade unions. We need to get our message across in many different ways.

We, the service users, need to be doing the training. That means designing and delivering and evaluating the training of the care providers. They say we are now involved in the training of the new social work courses, but I am not sure if we are. I certainly haven't been asked!

We need to be involved in all sorts of training and education schemes and initiatives. But we shouldn't be an 'add on', we should be central to things.

While everyone recognised a need for training and education some groups and individuals were quite specific about how this could be a vehicle for spreading user knowledge and doing this in imaginative and effective ways – as this discussion illustrates:

We need to develop the full use of media.

We need to develop our own media including television and film. We need to develop skills in advocacy journalism.

We need to change the perception of disability, and I think he is right. Everyone has a TV; we need to be more of a presence and not just on these special programmes for 'the disabled'.

Yeah, we never see disabled people on the telly unless they are on because they are disabled. It could be very useful for getting our ideas across.

Most of the people who took part in this project recognised a need for education and training around service users and disabling barriers. The findings of this research suggest that people feel that non-disabled people and others who do not use

services, including health and social care providers, are shockingly ignorant of the experiences and everyday life of service users.

Under the heading of 'education and training' a second theme emerged. Whilst service users recognise that they are the experts on their own experiences, and that what they know is as valid as any professional knowledge, if they are put in a situation for which they are not equipped by training or education, then their knowledge will always remain subordinated.

One group spent some time discussing the involvement of service users in the new social work degree:

You see, this should make a difference. I think it is a really good step, but it has to be done right.

Well, that's about the size of it, isn't it. Because it won't be done right. Will service user organisations have the money, have the time, have the skills and really be in control? It seems a bit unlikely to me if I can say so.

Yes because we've already said about only getting the money if you say the right thing. So in that instance it could be a bad thing. Because it looks as if this is what service users are saying but in fact we have just become the puppets for the service providers.

I still think it could turn out and be good. But ... it's like all of these things, if it is done properly with proper service user involvement from the start and they have the freedom to say what they think is right then it will be good. But I don't think it is that simple.

I think it is a good step forward.

As I see it, it could do the service user more harm and make them look unprofessional. If you are not trained or educated to lecture or run a workshop or whatever and then suddenly you are teaching students who are doing a degree, you could end up with egg on your face.

Commitment to change

Just as the service users we spoke to saw the lack of commitment of services to user knowledge as a problem, so they identified a commitment to change as a way

of overcoming this difficulty. They felt this commitment was needed from both professionals and service users themselves. If services continued to be reluctant to change, then service users would need the determination to keep struggling to try to make things different. Their comments highlighted both issues.

It is not a level playing field. Control and power is in the hands of a minority. We need to be more aware and use tactics to achieve our strategy of needs-led user-controlled services. It is not pie in the sky.

We need concerted campaigning.

There has to be an acceptance by the power brokers that they need to rethink their policies.

We need mutual empowerment. Learning from each other and our history, mutual commitment to support and community development.

Such commitment from services would need to start at national level and address the practical problems that are still getting in the way of people being able to participate safely and without being disadvantaged (see also Turner and Beresford, 2005a).

I think much more of a commitment is needed on behalf of the health authorities for effective service user involvement. So that things do change. There needs to be much more support from both within the service user world and without for people who are involved. Service user payments, benefits and all that have to be sorted out.

I feel we must have the resources in order for this to be done properly and at the moment there is no real commitment from central government or elsewhere and everything has to be done on a financial shoestring and be short term.

I think it has to come through national policy really. It's the only way that things do seem to change.

I think we need a range of relationships with providers. The ideal is that we have the warm mutually supportive partnership which is based on trust and on evidence. At the opposite end you have got evaluating services from a user's point of view and putting the critical results in the public domain. Because I think it is necessary that shortcomings are

exposed and I think that providers will be frightened that their misdemeanours are exposed and reported.

Certainly advice on benefits and being involved and getting payments needs to be sorted.

Ensuring diversity

Service user knowledge is not only different to other more conventional forms of knowledge (for example, being based on direct experience rather than research findings) and takes different forms (for example, developing in informal discussion, collective action and through 'grey literature'). In addition the service users who produce it are a very diverse group (for instance, in terms of age, ethnicity, culture, sexuality, class, gender, disability, etc.) and one which has many access requirements. Thus if service user knowledge is to be widely available to both service users and non-service users, the process of its production needs to be an inclusive one and one which takes account of access requirements to ensure that it engages and can reach as many people as possible.

Participants frequently discussed the need for developing good practice to ensure diverse involvement. Service users were particularly keen to involve service users who traditionally have been excluded from any kind of involvement.

Many of our people are still excluded and not given access to tell their stories in a format which is appropriate to them.

We must make things available in alternative formats so that more service users can access them.

We know as an organisation we are not very good at getting information out in all the different formats some people need. This is not because we don't care. This is because we cannot afford to do anything properly. This then means that in effect we are excluding a percentage of service users.

There are a lot of people out there who never get involved. Because of their physical impairments they might not be able to speak or something and then people think they have nothing to say. But they probably have the most – just that nobody is listening to them.

There has to be an engagement with those least able to communicate [conventionally].

You have to talk to people in their own communities. Have a presence in those communities.

In the main people with physical impairments can be more coherent and speak up for themselves [more] than people with learning disability. The right support has to be in place. And for people with different needs. I mean some people just cannot leave their house for all sorts of reasons. Are these people's opinions ever sought?

We need representation from different communities.

Sometimes it feels that whatever meeting you go to it's the same service users who are there. This is not our fault but it is bad practice that the organisers are lazy and make no effort to consult with people who might actually mean they have to change their way of running meetings.

We find it difficult to engage a really diverse range of service users. We are aware that there is a large Chinese community here, but we don't have any ways of accessing them. We also assume there are a lot of service users who are very isolated and don't have the opportunity to get involved. They might be housebound ... or communicate in a different way, but we don't have the resources to try and involve them. Other non-service user organisations have the money but it is easier for them to carry on speaking to the 'usual suspects'.

Many people also talked of the need to make sure that if service users were invited to participate in something then all their access requirements should be met. As one service user, who was a wheelchair user, said:

Offering to carry me up two steps is not what I call meeting my access requirements.

Again, participants were clear that access means a lot more than just physical access:

It is always very difficult to get things put into Braille.

It is no good sending papers for us to read ... the amount of paper work some meetings send out is about a foot thick – it is just not possible for me to read that amount.

Some people can't read.

If they are having a meeting with people from a different culture they will look at having interpreters. But if they are having a meeting with us they assume – and that's if you're lucky – they just have to look at flat access and that's it. Sometimes people who don't speak English are also disabled people.

Sometimes the meetings go on so long and I can't sit for that long.

I fall asleep in the meetings.

Meeting service users' access needs must be seen as a crucial first step in any meaningful process of involvement. It is essential both for the generation of service user knowledge on an inclusive basis and for its effective dissemination across different service user groups as well as to service providers.

Networking

Our focus in this part of the report has been on service user knowledge. One thing that this study has highlighted, however, is that the activities of service users do not fall into neat separate compartments. Thus the issue of service user knowledge brought participants back to the matter of networking. Most of the service users we spoke to felt that networking was a vital 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. Service users repeatedly returned to this point.

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

We need to go round to other user-controlled organisations and see what they are doing in their organisations.

We need better national and regional networks.

It is important that more relevant information is sent to all groups. We need videoconferencing networks. We need to establish newsletters and magazines. We need websites where we can have chat rooms which allows interchange of ideas and experience.

[We need] access and unity.

The more we have unity, the more we speak from one voice, the larger and stronger we become.

If we stick together we could achieve so much.

We should write a newsletter about what we do. Visit people and go round meeting them and knowing what they do in their organisations.

We have got to be a voice together and you've got to direct it at the right people if you can find the right person.

We should have big groups doing things together not just people with learning difficulties, but all service users together. (*People with learning difficulties*)

Perhaps we could contribute to each other's newsletters. Time permitting, could groups 'talk' to other groups in their own meetings?

We need national user-led conferences, with workshops, newsletters, internet chat rooms.

Most participants were clear that while it was crucial for service users to network with each other, it was also important to network and develop a dialogue with service providers, educators and decision makers:

Let's not be precious about what we do. Let's work separately and together for the universal good.

We need more involvement with funders, attending meetings and speaking up as much as possible.

We need to be seen and heard at conferences, seminars, training ...

Demand reciprocity on each and every occasion, at meetings, at conferences, that we are there on merit.

Service providers seem keen to hear from service users. There should be plenty of opportunities to bring service users and providers together.

4 Exploring diversity

Introduction

This chapter is made up of three separate and discrete reports. Two of these report on service user discussion groups with people from black and minority ethnic communities, and the third is from women who have had or continue to have problems around the use of alcohol. As explained earlier in this report we wanted fully to address diversity in its broadest sense and so we felt that although the three other discussion groups we organised included people from black and minority ethnic communities, it was good practice to ensure actively that their voices were heard more fully. We thus approached two service user researchers from black and minority ethnic communities and asked them to draw upon their own networks to run these discussion groups.

We also wanted to be sure that this project took account of service users who face particular exclusions and marginalisation which tend to be overlooked. As an example of this we decided to organise a discussion with a group of health and social care service users whose voice is seldom heard – women who have used alcohol services. A member of the Shaping Our Lives National User Group who has strong networks in this area and shared experience agreed to carry out the discussion for the project. The following are the reports that came out of these three focus groups.

We were particularly concerned to support these groups to address the issues which concerned them and sought to avoid imposing an artificially narrow focus of our own. As readers will see, these discussions therefore, particularly the third, add to the stock of service user knowledge as well as addressing issues relating to service user networking and knowledge.

Report 1: A group of Asian disabled people (Grace Wise)

Introduction

Five disabled people based in the Midlands took part in this discussion. They were all recruited by word of mouth and informal contact. The group included three women and two men. One person was in their mid thirties, three were in their forties and one

in their sixties. Four people had physical impairments and one had a visual impairment. All were of Asian origin. They are not offered as a 'representative sample'. They speak from their own experience. Their views are offered instead to counter the frequent exclusion and marginalisation of black and minority ethnic groups in discussions about health and social care and participation in them.

Not all participants in the group were involved with service user organisations. Two women were on the management committee of the local centre for integrated living (CIL) which was defined as being 'exclusively' user controlled; one person had been a member but wasn't any longer because of other commitments; another person (woman in her sixties) chaired a disabled Asian women's group which was based at a social services-funded day centre. One man (in his forties) had no contact with any organisation, except to receive a newsletter from the Spinal Injuries Association. In terms of the ethnic composition of the CIL (the only sizeable user-controlled organisation within this Midland city), there were three minority ethnic people on the management committee out of a total of 15 and they were all Asian. Nobody was sure about the ethnic composition of the staff but they thought it was nearly half and half.

User-controlled organisations

Participants felt that a user-controlled organisation had to be 'exclusively' user led and not '51 per cent' or '90 per cent' as some organisations define it. It was felt that even when an organisation has a management committee that is user led the staff can make it non-user led:

... it's the staff that control it – as opposed to the management committee. Do you see what I am saying?

One organisation was based at a social services-funded day centre but it was still defined as user controlled because 'they have to do the things we ask them'.

In this Midland city, there are three main organisations that participants were aware of and only one (the CIL) was felt to be truly user controlled. One organisation focused on advocacy for people with learning difficulties and another on practical help with employment advice, benefits, direct payments and holiday clubs. The user-controlled organisation focused on more political aspects such as providing training on the Disability Discrimination Act and campaigning, for example, on inclusive education. Participants said that when the local CIL first got established, they had a

vision that it would be an umbrella organisation bringing all the other organisations together under one roof and the CIL would be the training arm of it. This did not happen because of different approaches to disability. Some people had a more traditional attitude to disability. Thus:

The organisation wasn't service user led. It was a more provider-led mentality and philosophy and the funding was – they were very rich basically – and they wanted to have, you know, autonomy and not really empower us as an organisation. But we didn't want to compete. That was the ultimate way forward – that we did not want to compete. But we would provide [a] service that was going to be of benefit to disabled people ...

Problems of networking

When asked if user-controlled organisations talk to each other to share information, the response was 'I have just seen a pig fly past'. There was consensus that there is no or little communication between organisations, user controlled or otherwise. It was felt that part of the problem was that organisations are competing for limited resources from the same pot of money: 'There is this element of competition which is getting there first'.

The importance of unity

There was strong consensus that having one organisation would be more effective for the cause of fighting disability than several.

[It's] not about politics personally, I would fight the cause all the way because I think disabled people together would have a much better say and we would have much much more funding, yeah, if we weren't going for the same projects and things like that, if we were one ...

Another benefit identified was that there would be strength in unity:

Unity, strength, I suppose to give you a focal point to actually campaign on, to put pressure on the politicians, providers – so there is – the old phrase – singing from the same hymn sheet, as it were.

Resources and inclusion

Another major concern was the lack of funding for user-controlled organisations. It was felt that this impeded their work in reaching out to disabled people and other service users in the community who have not heard of them. So people said:

There has been debates within the management committee too, on many times, that we need to get people like yourself who have not heard of the organisation to know about the organisation and to be supported and helped. But to do that we need the funding and people to be able to do that but we never had that sort of luxury to work directly with local community. Not really to the extent that we wanted to ...

Some people felt very strongly that some disabled people in the community were isolated and not being reached by disability organisations:

It makes me so angry that there are so many people isolated out there – we are okay – I am okay Jack, but how it gets left the feeling is I don't really care about people out there and that is what [is] bothering me.

Some people also felt very concerned that disabled people from minority ethnic communities, especially smaller groups such as the local Chinese community, were not being represented at all.

How do we get African Caribbean and disabled people involved? ... It is difficult to get involved. How do you get involved with the Chinese community and not only that, there is sort of growing population from Eastern Europe, Poland, Rumanian? In Leicestershire, we don't even know how to tap or get into those communities.

Lack of links between user-controlled organisations

Lack of funding was also the reason given for there being no links between the different organisations locally, though it was felt that such links would be beneficial.

The will is there, we would like to work and make that effort and see how we can work together because we can always make it possible, but resources are so tight within this organisation. You know what we have is all spoken for in terms of human resource. People have got those

projects to deliver, to target for those funding that [what] we have so we don't have the capacity to actually give that time to create that interlink and working together.

The clash of principles and sometimes personalities were other reasons given for the lack of links between different local organisations of and for disabled people. So for example:

If we work with such and such organisation, that will go against our principles, so we can't do that. Secondly, I think we have to admit there are personality clashes, certain people can't work with other people, and that, in a way, affects how the general [run of] disabled people can come together. And thirdly I think there is this lack of [an attitude of] let us forget personal issues and be pragmatic and see what is best for disabled people.

Links with national user-controlled organisations

When asked about links with national organisations, the British Council of Disabled People (BCODP, an umbrella organisation) was mentioned by participants. However, it was felt that links with the BCODP were of little benefit to their local organisation. This feeling was strong enough for a decision to cancel the annual subscription for membership.

We are paying I can't remember what subs it was and getting nothing – nothing from the national user led organisation at all, so no, we are not actually [members].

What [people] wanted was proper information and participation in different areas of BCODP's work because you don't actually get that.

Other issues identified for national organisations to be working on with local organisations were awareness of the social model of disability and campaigning to strengthen disability discrimination legislation. It was felt that there are many disabled lay people who still do not know about the social model and that disabled people's organisations are not able adequately to raise awareness of this principle.

Participants felt that a national organisation's role should be to inform local organisations of the national agenda and share the benefit of each other's experience:

About awareness of what the ... national agenda is because we could be sort of battling away in our own area or in our own city and not be aware that that is a national issue and it is a wider picture and there is something happening elsewhere which we are not aware of. But if we were made aware that we could work with another city, [or] organisation in other part of England or whatever, [some other part of] the country that we could work and liaise with – it is that interaction to create links, interaction, whatever you want [to] call it but enabling us, it could be an enabling role.

A national database and network

When asked if they would find a national user-led database useful, participants responded that it *could* be, but that it would only be as good as the organisations maintaining it and that lack of funding would impede it again. For example:

I am not going to find anything in [this city] because the organisations [here] haven't fed into it. If our local authorities are not inputting into it, then the information on there is dead information.

There was consensus that people would like to be, and benefit from being, part of a national user network:

There would be definite interest because it would be good to work with other organisations.

It was also felt that what would be more important than a database would be an increase in people's capacity (through greater numbers and skill development) to do the actual work of outreach and applying for funding. Otherwise these would continue to be problems.

Participants in the discussion also identified several other issues they saw as important here. These included:

- the need for there to be an individual in an organisation locally who can help people with discrimination cases and obtaining compensation
- rethinking government plans to merge the Disability Rights Commission into a single equalities body

- continuing segregation in the disability community in terms of impairment: for example, people with learning difficulties are generally separate from other disabled people
- because of the limited funding of user-controlled organisations and projects, disabled employees get trained and then move on elsewhere (often to non-user-controlled organisations) and take the valuable resource of their skills away with them.

Participants also felt that there should be more peer support groups with transport provided to enable people to network better:

Run properly, regional or national or local, if it was run properly I think would be a way forward.

Perhaps the most worrying response from this group of minority ethnic service users came when they were asked how much impact they felt they had on health and social care policy from their direct experience. Their answer was none at all:

It's like a brick wall.

I spent seven weeks in hospital over my broken leg, I couldn't have a shower or bath and ... other people were in the same situation [and complaints were made] but not one, one person actually heard or listened to [them].

I spent three and a half years in hospital I see how they treat people – disabled people – they don't really look after you properly.

Conclusion

Overall, there was considerable pessimism among participants in the group discussion about user networking and knowledge because of their feeling that power and funding were concentrated in organisations which are not user controlled. User-controlled organisations, from their experience, had very little funding. Such funding was also often project funding specific to particular activities, such as providing information technology (IT) or skills training to disabled people. This meant that they did not have core funding to operate their organisation, develop it and strengthen their relationships with service users and other organisations. This also gave rise to an immense feeling of frustration because service user organisations tend to lose

valuable disabled people in whom they had invested training as employees, who had inferior opportunities in user-controlled rather than traditional organisations because of the former's financial insecurity.

Local organisations tended not to co-operate with each other because no one seemed to want to make the first move. This was either because of differences of principles or personalities, or because of the limited time and funding available. The net result was that individual disabled people either accessed services from one or another user organisation if they were fortunate enough to know about them or they did not access services at all. Those who did not get to hear about them remained isolated and left to struggle on their own.

A frequent finding from any research with minority ethnic service users is the lack of appropriate provision and people's heavy reliance on relatives. For example, one person who participated in the discussion spent three and a half years in hospital because it took that long for his wife to obtain adaptations to their house so he could live at home. In terms of service user knowledge impacting on health and social service policy and practice, participants' views were bleak. They felt that despite the rhetoric of involving more service users in consultation and so on, the reality was still that disabled people were patronised, not listened to or cared and provided for adequately. As one person said:

Social workers or doctor. We are just a piece of meat at the end of the day.

Report 2: A group of black mental health service users (Patricia Chambers)

Introduction

This discussion group was a black group, used in the political sense to mean it was inclusive and included a range of different black people. It was made up of men and women who were all mental health service users and based in London. Some members of the group belonged to a user-controlled organisation, while others were individuals who used services and were quite vocal about their thoughts on the services that they used and how they were treated.

The group also had quite clear ideas about what they saw as the way forward for well-linked and informed service users as part of mainstream service provision. Within the focus on networking and service user knowledge, participants also discussed some negative things, like why users didn't network or use the knowledge that they already had in a more effective way.

Contact with other user-controlled organisations

Debate was lively, candid and colourful. It began with the question of contact and communication with other user-controlled organisations. While some members of the group said that they didn't have any contact with user-controlled organisations, others said that they did. For example:

User-led organisations are thin on the ground and that when and if contact is made it is often not followed up.

Because of difficulties with finance, service user groups were often coming and going out of existence. Sometimes at conferences and other meeting places, you find service users in employment and this sometimes led to networking but generally user-led organisations and projects were quite 'rare'. Another service user said that there was some contact with user-controlled organisations, but it was sporadic and not joined up and did not continue as an ongoing thing.

Benefits of networking

One of the benefits and gains that group members felt that networking could offer them and their organisations was the exchange of ideas on funding, growth and progress and the chance not to be proud and to ask for help. Sharing information on weak points and how to combat them was regarded as another benefit of networking; also sharing solutions. Some of the problems and obstacles experienced by members of the group and their organisations with keeping in touch with other user-controlled organisations included the fact that the organisation more often than not was not run full-time. This meant a delay when doing things. For example, if the group met once a week, anything not done on that day either had to be left till the following week or taken home by one of the group members. Office space was also a recognised difficulty, along with keeping details up to date and safe and not losing them. Knowledge of current technology was also a real problem for members of the group who were involved in service user organisations.

Re-education is needed to bring people up to date with the techno world.

The limits of existing networks

As for links with national user-controlled organisations, there was some contact by some participants, but this was with a national survivors' poetry group, not an activist group.

Members of the discussion also identified other practical obstacles limiting their ability to network. For example:

Our organisations don't have the finance to send us to conferences where we could network because you often have to pay to attend conferences.

Lack of awareness also stops us from networking. Quite often user conferences or conferences in general aren't widely advertised and people didn't know they were taking place – plus the fact you have to pay.

Although Mind annual conferences were seen as 'a good event' and the fact that they were held in different places was also seen as good:

You have to be very active and 'in the know' to be up to date with what was going on.

Service users said that contact with service agencies and involvement in their events was often on very unequal terms:

There is no point in going to council-run conferences because they had already made up their minds. They take our ideas for their own or on the other end of the scale they totally ignore what we have to say.

They are rude and arrogant towards us and looked down their noses at us.

... like a bad smell and they keep on doing this. They seem to only have their own career interest at heart and they keep on making cuts. We always get the same thing from them.

One service user said that a group of users had tried to organise a user-led evening drop-in for black people but so far nothing had come of it and it was felt users could not be solely be blamed for this.

What contact there was with other user-controlled organisations tended to be with other black user groups or at least other user groups or organisations dealing with mental health issues. One service user said that his contact with another user-led group came about because it was a 'breakaway group'. Links didn't extend beyond London and contact had been made through going to conferences. These were conferences that were held and organised by other mental health groups. Participants didn't mention any networking arranged or organised by the local health and social care authorities although they did say that they had been able to network at activities organised by the local authorities.

The purpose of links

As far as the type of contact that had been developed was concerned, members of the group said that this tended to include contact for both campaigning and social activities. For example, service users had gone to another user group's black history month celebrations. Members of the group also said that contact included sharing of information, such as who it would be helpful to contact in an organisation if you wanted something specific and who to contact in the local authority depending on what you wanted. Getting advice wasn't specifically identified as a reason for networking, but service users agreed that groups and organisations did 'brainstorm' together. One man highlighted the difficulties due to the way service users had to work:

Contact is made at conferences and things, but nothing is done about it in between and then people then meet up two years later and start all over again.

Barriers to networking

People also said that their desire to develop stronger links with other service user organisations was greatly hampered because generally childcare was not provided, to enable individuals to attend meetings, groups, conferences and so on. There was a common feeling that these service user organisations and activities tended to be for people who did *not* have children and participants said they wanted something

done about this as they felt they could and would be more active if childcare needs were properly addressed.

Gaps in user-controlled groups

The kind of gaps that people saw as existing in the field of user-controlled organisations was something for single mothers and fathers. They thought that there was a gap in the evening for black users and in the provision by user organisations of outings and organised leisure activities. They also talked about the lack of service user organisations which engaged people who had dropped through the net (who had mental health problems but did not engage with services) and were not in the system and therefore not networking within it.

The desire to develop networking

There was strong support in the group for developing stronger networks and links between service users. The group also thought if links were stronger, it would be possible to gain a wider range of views from service users. One person said that stronger networks would be useful to get 'more diverse opinions from users'. It was also felt that it would:

- give groups firmer reciprocal foundations and make them stronger
- bring new energy and ideas
- bring new and more activities
- create opportunities to meet new people.

The price of support

People also talked about the issue of the security of the user organisations that they were attached to. Some participants said that were attached to an organisation which felt secure. It was funded by the local health and social care authorities, who had some degree of regard from them, but this security came at a price. The service user organisation was expected to attend meetings and events and write reports on its progress and keep good records in the way of finance and minutes. This created a lot of work.

Helpful support

The sort of support that people wanted from a user-controlled organisation and thought would be helpful included help with funding, finding premises, campaigns and attendance at events, and support and help with advertising things such as drop-ins, conferences and social events. Other useful help could be with legal issues and statistics to help assess need. Service users felt that this support could be provided via email, telephone, letter or correspondence and internet. They also thought that it could be offered at all levels, local, national and regional, as well as by people coming directly to them.

The kind of help that service users said they would like a national user-controlled network to offer them included:

Adding weight to our voice, [giving] collective strength.

A database of information so that individuals requiring information on something could contact the organisation and it would have this information to hand on their database.

... the benefits of contacts i.e. if someone wanted to find out about palliative care or people with learning difficulties, this organisation would have information on these things.

It would also be useful to carers, as they could contact any organisation that is part of the network and from their database be put in contact with who or what they required.

You would also have the benefits of the collective knowledge of all the organisations in the network and also a ready network to spread information. News would spread faster.

Participants thought the idea of a national database, which service users owned, would be a very good way for users to share information and be supported in their work. Information about jobs for service users could be put on the database and so could other information, for example about medication. People were agreed that if it had the potential to achieve something, they would like to be involved in a user network, although one mother in the discussion said that her involvement would be limited because of her children and lack of childcare. People taking part in the discussion also talked about ways in which they would like to be involved. Some said they would like to design the network website and represent the network at

conferences and meetings and with public relations. One member said they would like to be involved in an educational role, especially with young black men who were service users.

Service user knowledge

Members of the group shared a strong view that their knowledge was important and that it should have a big impact on health and social care policy and practice. For example:

We are the experts. They are the learners. We are the experts because we go through it.

They've got no experience of what we're going through. They only know what they know through books.

How can they help us when they don't know what it is with us? One doctor will say you've got clinical depression, another will say it's mild depression and another will say you've got schizophrenia and this is where they fall down. We need to educate them.

We could be helped to write testimonies on what it's like to be mentally ill, what it's like to be locked up and what it's like to take medication and the professionals could learn from them.

However, participants felt that both as individual service users and service user organisations, they did not have much or enough impact on health and social care policy. They saw this as unfair and frustrating.

When you speak up, they see you as a troublemaker.

One woman said that her psychiatrist listened to her. Another person felt that service users should empower themselves as individuals and then go on to influence policy on a wider scale.

On the issue of sharing knowledge more effectively between service users and service user organisations the group stressed that:

Contact should not be lost.

There needs to be more talk between the groups. Groups should be encouraged to link up more and make use of modern technology like internet and email.

Participants also suggested that conferences be held:

Educate the people and make them more aware.

Start small and let things grow.

They felt the pressure had to come from them.

Participants identified a range of issues which they felt were important for making what people knew as service users have impact on their lives and the services they used. They talked about the importance of stopping tokenism. Housing was seen as important, since people have to be settled in order to be able to make a contribution to things. Support for service users to be involved was also seen as a priority along with improvements in the care system to provide adequate day-to-day support, including more social workers and better sharing of information. One member said that things should be improving now that government has stipulated that service users should be involved in policy making and strategic planning. She also felt that change would take time and we should attend meetings and be vocal.

To ensure that people's knowledge as service users becomes a more powerful part of mainstream health and social care knowledge, participants said that service users needed 'major representation at the top', something like an MP who was a service user. There also needed to be better organisation at the grassroots level.

In order to challenge the way that existing professional knowledge often sidelines and takes over service user knowledge, members of the group said service users needed to be more vocal, more involved in training professionals, so that they would learn to listen to service users from the beginning of their careers. One person repeated that our own documented accounts of our experience could add weight to our voice if used in the same way as the textbooks that professionals use for learning and studying.

The group went on to discuss how to make mainstream knowledge about health and social care more available and accessible to service users. They felt that education about mental health issues more widely was essential. Everyone should be educated about mental health: families, carers, schools and professions. They also said that knowledge could be spread through the internet, letters, DVDs, talking to people, phone, texting and video. Better information and communication were key.

Conclusion

The group was enthusiastic about the idea of a user network and what it could achieve. The consensus was that they would all like to be involved in some capacity such as promoting the network, working for and with the network and helping the network to run. Their impression, that there were not many user-led user groups or organisations, worried them. They felt these were rare. The contact that they had with other user groups or organisations was all in the field of mental health. There didn't seem to be any exchange or cross-fertilisation between different groups of service users, for example with people with learning difficulties or physical and sensory impairments, and this also concerned them.

Where there was contact with other groups it was usually limited to the local or immediate area. All the groups that they said they were in contact with were in London. One reason for not venturing further afield was lack of finance. Contact also mainly came about through conferences, either run by local services or by other user groups. This is a very limited and formal way of networking, which doesn't encourage ongoing and informal contact and the development of relationships. Local services were not very active in helping users to network or to get organised although this was changing with the increasing emphasis on user involvement in government legislation.

Where participants had made contact, this contact tended to be sporadic and 'bitsy'. Lack of childcare was identified as a major obstacle to networking in an inclusive way. This needs urgent attention as user organisations are denied an important resource so long as they are unable to engage and draw on the skills of service user parents – who in turn are denied contact and support. Some participants thought that professionals were condescending towards them and wanted this challenged, although at the same time they said: 'there are good and bad people in mental health'.

Service users thought that if networking was to work, people needed to be made aware of what was going on. It was thought this could be done through all the means of communication now available, including email, internet, leaflet and letter.

For service user views to have more weight, people thought that education about mental health was essential. This meant education across the board, for carers, professionals, family, schools etc. It was felt that this would create more empathy and understanding for mental health service users. Everyone agreed that the benefits of a properly resourced national user network were almost limitless and wanted to see one set up and running as soon as possible. And they were willing to work towards the realisation of such a network.

Report 3: Treatment and control – competing understandings and knowledge (Patsy Staddon)

Introduction

While we offered this group the same agenda as the other two, the group discussion focused on their feelings about the treatment they received. What this highlighted was the lack of fit between their views about what was helpful and unhelpful based on their own experience and knowledge and the way that the system worked based on conventional professional knowledge sources. This discussion, therefore, offers particular insights relating to the differences between service user and ‘expert’ knowledge from a group facing particular exclusions.

This group discussion included nine women and the facilitator and was based in a West Country city. All, including the facilitator, had a background of alcohol misuse. All were contacted through the facilitator’s networks. They focused on their experience when they went for help with their alcohol problems. Some of the women were fully recovered and some still had a drinking problem. They ranged in age between 30 and 60; most were in their forties.

This report is based on the comments of participants in this discussion. First, participants discussed their views and experience of different professional staff.

General practitioners

Three out of ten GPs were seen as helpful, supportive and knowledgeable. The other seven were felt to display ignorance, prejudice, malpractice and cruelty. For example:

Mine was very good – does acupuncture and allows me to do my own detox – very understanding.

I’ve never had a good one – sent away with tablets and made to feel a nuisance—male and female GPs have done this.

My GP said not to come any more as I was too much trouble and I ought to pull myself together.

Mine didn't seem to know what to ask or say – never considered alcohol as source of my other illnesses.

Told to go away and sort myself out – once they know you drink, they treat you differently.

Mine was very supportive.

Didn't take mental health problems seriously and brushed me aside – told there was a long waiting list.

Psychiatrists

Only one woman described a positive experience of seeing a psychiatrist. The rest were described as strange, uncommunicative, inconsistent, detached, opinionated and hard to access. For example:

He was in a hurry and unhelpful.

He couldn't communicate. I don't know what he was after.

I saw several, got different diagnoses, different pills, got sectioned, and was told I had a personality disorder. Actually I was just a very angry woman!

I couldn't trust mine. He made me feel like a specimen.

Mine liked to pin labels on people and was very cutting.

I saw one who was helpful once – made me feel at ease.

Mine told me I was just a masochist.

The waiting lists are appalling.

Staff generally in NHS and voluntary alcohol treatment units

Participants referred to three local alcohol services/units. These have been given the pseudonyms 'Poplar House', 'Mountain View' and 'Riverside'. 'Riverside' received only positive comments, but is only available to people in a particular part of the city as it is part of a neighbourhood project.

All participants thought that women should have the choice of mixed-sex or women-only groups at units (which they don't) and most thought women only should be the norm at first, until women were clearer about what help they needed. Negative and threatening approaches such as 'you'll drink if you do such and such' were seen as unhelpful, as were large 'treatment groups'. Social class was seen as a factor, with Mountain View in particular being seen as 'snobby' and 'uncomfortable' by working-class women while Poplar House was seen as very male-oriented. Two other centres (Riverside and one outside the city) were highly praised for their attitudes, atmosphere and success. At this point in the discussion only a few negative criticisms of staff were made. But it became clear that what service and support women received could be arbitrary and hit and miss, according to the particular agencies to where they were referred. Comments included:

At Poplar House they treat you differently as a 'patient' from how they do if they think you're someone official. Like you aren't worth so much.

Poplar House is good because if they smell drink on you they breathalyse you and send you home – that actually helps.

There's no disabled facilities at Poplar House, so when I broke my leg I was told I had to stop going ... it wasn't safe for me to be going up and down the stairs on my backside.

At Poplar I hated the groupwork and I was told if I left (I'd been having problems with another group member) I'd drink. These are AA tactics. You're told you're heading for relapse.

Mountain View was hopeless for me – really middle-class and pearls – I felt completely out of place.

Class is a really serious issue in treatment and especially for women.

I saw a man at Mountain View – he gave me an instant diagnosis, some AA information and didn't seem to take me seriously as a person. I didn't feel he understood and came away feeling hopeless.

Mountain View has good groups, well facilitated – I learnt a lot there.

I went to a day centre in [another county] and it was so different! They helped me design my own treatment plan, including counselling, acupuncture and meditation and I felt a truly active person in my own healing. And it's lasted too!

The private clinics treat you better, at least to your face.

Yes, paying gets you a semblance of humane treatment.

My nearest place is an hour and a half's journey each way by public transport, and I used to get anxious about the journey and drink.

Most alcohol treatment centre staff are respectful although you get the odd person who isn't.

Yes, I was mostly treated well.

Counsellors and psychologists

Counselling and psychotherapy outside the alcohol treatment centres were seen as relatively helpful, but erratic in availability and quality. At the treatment centres, people offering counselling were often men, who were frequently felt to have strong prejudices, limited awareness and an unhelpful attitude, or women with very fixed ideas. For example:

I see a psychologist now and that's very helpful. I do meditation too.

I've had good counselling from Mountain View and from Poplar but they won't support me taking time out for binges, even though the binges are getting shorter and wider spaced. Ultimatums like that are lousy psychology.

Sometimes so-called counsellors are just CPNs who are very hard line and can cause people to kill themselves in despair. Then the treatment centre and AA say, 'Isn't it sad, the alcohol got her'.

You don't always get offered counselling and NHS counselling isn't very good anyway.

They don't believe in open-ended counselling at Poplar and that means you can't relax with a counsellor and work at your issues.

My doctor once offered me a psychotherapist – called it 'a talking cure'! – it was open-ended and that really, really helped.

Only offered it once in 15 years of drinking.

I've had excellent and poor – it's luck really.

Poplar House doesn't believe in counselling unless it's AA! They said it was for life – there was no cure – you could never trust yourself.

Receptionists and administrative staff at treatment centres

Women also discussed their views and experience of related non-clinical staff. Again wide variations emerged between different centres and different women's experience. For instance:

Mostly okay if you don't look like you'll give them a hard time.

Mountain View reception's helpful and gives you time, but they do tend to suggest you ring AA!

Well Mountain View is gentle and sympathetic on reception but Poplar House is terrible – arrogant, pompous, dismissive.

Yes, at Poplar I rang once and I was put straight through to one of the blokes there who's a real control freak and so arrogant ... I thought he must be a psychiatrist ... I didn't go back.

Poplar, they keep you waiting and sit behind that glass screen, like you're nothing, you know?

Reception at Riverside is first rate.

The police

Alcohol misuse and the problems associated with it can lead people to increased contact with the police. They, in turn, can play an important part in people's experience. All but one woman had had bad experiences of police behaviour and agreed that the police needed retraining about how to help women with alcohol issues as opposed to making things worse by treating them unhelpfully and sometimes abusively. Women's comments suggested that gender discrimination is still strong in the police service.

Well they despise drunken women, full stop. They're rough and disrespectful to us, like we've lost our rights as human beings.

They've got a disgusting attitude towards women who are drunk. They like to see you feeling shamed.

They didn't care I was injured. I was drunk – that was the point for them. It was the following afternoon I finally got taken to Casualty.

They don't care about drunk women; we're the pits to them.

They treated me okay.

They think drunken women are a sort of joke. They've zero understanding of how we feel.

Condescending, patronising, hypocritical. I mean you can see from how they look that they like to knock it back themselves.

I was told to go home and be a good girl.

They – well all men really – assume a woman being drunk is the same as her being sexually promiscuous so it's okay to treat you however they like. And they do.

Residential care

Four participants had experience of residential services for alcohol problems. Their views of them were very critical, particularly their lack of understanding of women's

vulnerability and their willingness to accept a woman as a resident even if she was the only one there. For instance:

If I'd been together at the time I'd have asked for a women-only centre but of course you aren't together and by the time you realise mixed-sex residential is a disaster it's too late. Anyway I don't think there are any women's residential treatment centres are there?

In the group sessions we were told to be honest and I was but then the men came on to me later.

Violent men used to seek me out to confide in me. It was horrible! – I didn't want it.

How can you heal in those circumstances? You curl up inside and hide.

I never felt safe for one moment.

I stuck it out because I was afraid if I didn't do as I was told I'd never see my children again. I wasn't allowed to see them while I was in there.

I had a male counsellor! It was so unsuitable it was mad.

It was okay if you kept your head down.

I'd have been dead if they hadn't taken me there but it was bad – counsellors behaved inappropriately – sometimes sexually, sometimes getting a high out of bullying you. If you complained no one ever believed you.

A lot of the residentials are just money-making, they don't care at all really and it shows.

They all do the 12 Step thing [AA] too.

Other sources of support

Alcoholics Anonymous figured significantly in the discussion, but not generally as helpful. Significant gender issues emerged in relation to it.

Service users were often advised to join Alcoholics Anonymous (AA), rather than seek counselling, even at treatment centres which described themselves as 'independent' or 'eclectic'. This meant accepting that their problem was 'alcoholism', rather than that 'alcoholism' could be how they were currently dealing with painful experiences or mental distress. Poplar House describes itself as 'eclectic' yet out of the ten women present, seven had gone there, and six had been instructed or encouraged strongly to go to AA. Mountain View describes itself as 'independent' yet out of the ten women present, five had gone there and four had been instructed or strongly encouraged to go to AA. Mountain View even runs extra short rehabilitation courses for people who promise to go frequently to AA meetings. Poplar has more than one staff member who is said to tell people he can do nothing for them if they do not go to AA.

Women found it hard to resist this pressure but those present did not find the organisation very helpful, particularly in the long term. Thus they said:

Well AA certainly tried to control me! – I'd say they kept me drinking 20 years longer than if I'd had ordinary counselling instead, in my twenties, to deal with the bad experiences I was drinking on. They made me think it was my fault because I drank, rather than the fault of people who had sexually abused me, tormented me, and made my kids see me as dirt. That 12 Step philosophy may be great for blokes, but it just pushes women further down into more shame and self-hatred. I'd like to sue them – ban them, stick them in a dungeon. I feel they were instrumental in taking away my life.

I found it helped having an 'alcoholic' label. It helps me to stop.

I think it's very unhelpful. It's not true that we have to be like that for life. It really isn't. But AA tries to keep you in sort of treatment forever.

AA – it's all control, control, control. Then you have to rebel, don't you? – so you drink, you slip. It's crazy.

Wherever you go almost, they try to get you to go to AA. It doesn't work but it might keep you off the streets! Then you're less trouble – but does it help you?

I was effectively forced into hospital for treatment because of the kind of job I had. I used to pretend I'd got better and didn't have a problem any more, to keep my job. They never looked at the issues.

I used to try to use AA but there are people there, well, men, they pretend to be alcoholics to get access to vulnerable women. It's a terrible trap.

Sexual and domestic abuse

Only one person had been asked about sexual abuse and she said that this had been helpful for her but she did not want to say more about it in the discussion. No one else had been asked about sexual abuse or domestic violence, including people who entered treatment this year.

However, the Department of Health recognises an overlap between domestic violence and other forms of abuse, mental health problems and substance misuse issues (Department of Health, 2000, 2002). For example, the Department's resource manual for health care professionals suggests that health workers should be aware of these issues and should enable disclosure.

Conclusion

The women identified a range of changes in services and support which they would like to make, based on their first-hand knowledge and experience. These included:

- women having the choice of a range of different treatment options
- counselling only being offered by properly qualified counsellors
- women's family responsibilities being taken seriously and flexible treatment times offered, including evenings and weekends; assistance with childcare and awareness of the prevalence of abuse within the family
- women having access to safe places to get well
- the universal availability of single-sex groups and same-sex key workers
- mandatory training in gender awareness and women's specific alcohol issues for all GPs. Such training should be run by women, and should include information about a variety of treatment ideologies and approaches.

In addition, women in the discussion group agreed a set of proposals which they wanted the Government to implement:

- no treatment without ongoing appropriate and independent counselling
- all treatment providers to have their procedures inspected by an independent service user-led body
- licensing for such inspection by an independent service user body to be mandatory
- funding to be withdrawn from treatment centres which do not meet these criteria
- one-stop shops to be set up offering women with alcohol problems counselling, childcare, benefits advice and support to deal with domestic violence.

5 Service user networking, knowledge and involvement: ways ahead

There can be little doubt that service users and their organisations value the idea of networking: of making connections with other service users and other service user organisations. This holds true for all the groups and individuals we spoke to including those specifically from and engaged with members of black and minority ethnic groups. Networking is valued at a personal as well as a collective and political level. However, this study has highlighted that from service users' perspectives, meaningful involvement and participation in the services they use are in their infancy.

At the same time, what became increasingly clear during the course of this project was that successful networking and the development, sharing and mainstreaming of service user knowledge were closely interrelated and that the two are inextricably involved with meaningful user involvement in most service users' minds.

Two strong interwoven themes emerged when we asked service users three interrelated questions:

- 1 How do you think that we, as service users, can share the knowledge that we develop amongst service users more effectively?
- 2 What do you see as the most important issues for making it possible that what we learn and know from our experience as service users can have more impact to improve our lives and services?
- 3 How can we ensure that our knowledge as service users can become a more powerful part of mainstream health and social care knowledge?

People said that:

- 1 Networking between service user organisations and individuals must be strengthened.
- 2 Service users must keep promoting meaningful involvement in the services that they use.

We will look at each of these themes in turn.

Strengthening service user networking

We repeatedly heard from everyone we spoke to, including the black and minority ethnic groups, that the best way forward for service users was to meet with each other and learn from each other. Thus participants said:

We need to have our own conferences, seminars, training, electronic discussion boards, publications, campaigning. In a word: networking.

Better national and regional networks.

More relevant information sent more often to groups. Establish a videoconference network. Establish newsletters, magazines, a website which allows for an interchange of ideas and experience.

It is imperative that we improve users' networking. We should share and build on international experience. We could develop sharing through various user groups. It is only through developing, sharing and networking that we can strengthen international user knowledge.

It is difficult, because even at conferences and events you can only cascade to so many people. We should contribute to each other's newsletters. Groups could 'talk' to other groups at their own meetings. It is all about better networking.

We could write a newsletter about what we do. We could visit people and go round meeting people and we could tell each other what we are doing in our organisations.

Hopefully we can learn from people's life stories.

We need to develop and maintain a database for users and our organisations.

We should strengthen ties between local, regional, national and international levels on issues that affect us as service users.

We need to just try and work together, that is all people, service users and non-service users, and work things out.

We need to support and encourage other users within the system. We need a central database where we can find out where we all are and what we are doing.

We should be developing a common body of knowledge based on service user research based on our perspectives. A network of practitioners and knowledge sharing networks.

We need to make more use of existing groups and networks.

It is clear that for most participants, including those from the black and minority ethnic groups, networking is the key to empowerment for service users.

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.

Almost all the people we talked to identified networking – that is, communicating with each other – as being fundamental if service users want to share and promote service user knowledge, to strengthen their collective voice and to successfully impact on the services they use.

Ways forward for networking

Service users in this project, as has been seen, were universally supportive of the idea of improving networking with each other. When we asked them if they and their organisations would like to develop stronger links with other service user organisations, the response was an unqualified 'yes'.

We wanted to find out from them how they felt such networking might be taken forward to become more effective and extensive. We asked two particular questions to follow this up:

- Do you think that a national database which service user organisations owned would be a useful way for people to share information and to support the work of local user-controlled organisations?
- What kind of benefits would you like a national network of user-controlled organisations to offer you/your organisation?

We already had some evidence that service users were interested in both a national service user database and a national network of user-controlled organisations. In 2003, Shaping Our Lives in association with the Social Care Institute for Excellence organised a national workshop which highlighted the importance of these issues for a wide range of service users (Carr and Branfield, 2003). Key recommendations of the workshop report included:

- It is important for service users to share knowledge and good practice in an empowering way and to be able to come together about particular interests or campaigns.
- A user network database could allow people to find and contact each other in order to share knowledge and work as a strong collective.
- Users should have ownership of a user network database.
- Sustaining and updating the database is vital and it needs to be properly funded and resourced.
- It is essential to address issues of confidentiality and privacy so people feel safe to give their details. People need to know enough about the database and how it will be used to make a choice about sharing their information.

When we asked service users in this project if they thought a national database would be helpful, they responded enthusiastically, making very similar points. For example:

Definitely. Yes.

Providing there is finance and support to keep it up to date, otherwise it is not worth having.

It has to be confidential to service user-controlled organisations. I wouldn't want the information to go outside without permission.

It has to have levels of security and password-controlled access.

We are all learning from this and have a lot to learn from each other and need to utilise this nationally.

But only if it is adequately resourced so that it can provide local organisations with a consistent and regular quality of information.

In Northern Ireland it can be isolating and a database would be beneficial for contact.

Yes as long as it is updated and accurate. Free phone number to access and on the web.

Great minds think alike.

Yes, Yes, Yes!

The benefits of a national service user network

Service users identified a wide range of benefits from developing a national service user network. They saw the benefits as practical, organisational and political. The network would encourage and enable solidarity and unity. For example:

I think it is a very positive move to be involved in numerous organisations.

To have more links with other user-controlled organisations.

A voice to the national decision makers – government.

It has got to be the best way forward for the service user movement. Well, for people who want us to be involved as well as for us as it would all give us access to each other.

Makes them part of one group, so that all the different groups can work as one team.

Strength in numbers.

Commitment to campaigning.

It could be an opportunity to discuss issues.

It would give us a national perspective that could be adapted locally which would identify common issues and needs, so national guidance could address them at national level. This would avoid various people working on the same issues at local level, for example the issue of paying users who are on benefits for involvement work.

Such a network could help ensure better access to information, including service user knowledge and information as well as other forms of support:

All sorts of information from updates and information about what Bills are going through parliament, we haven't all got time to read and learn ourselves.

There is so much information we could share. From funding possibilities to managing direct payments to knowing the best way of complaining about the service you might be getting.

We could learn from all over the world. And help all over the world.

All manner of things. Shared information, shared knowledge.

Instant access to any information required.

General exchange of information. The more you know about other user-controlled organisations the more you can offer advice, and the same in the opposite direction.

Very often we don't know about how to go about getting information.

I think by mixing with other groups you get extra knowledge and can share information. All the professionals hold information and this is a way of sharing our information.

Support and encouragement.

Help, information and contacts.

Cheaper goods and services.

Free events.

Information exchange could help service users find out more about good practice in participation and share it better:

[We could find out more about] Good practice.

You can learn from other organisations about good practice. And about bad practice. There is a wide range of knowledge out there.

Promoting meaningful service user involvement

The service users who took part in this project were aware of involvement that does not work. As this report has already explored, service users told us of involvement that was tokenistic and inaccessible and which meant no more than that 'the right box had been ticked'. This was a constant concern. And yet service users told us again and again that the best way for them to have more say and more impact on the services they use and for their knowledge to become meaningful and valid in the eyes of service providers was through better and sustained involvement. As these service users said:

We need proper involvement in everything that affects us.

Reiterate in practical terms 'nothing about us without us'.

Expand and develop direct involvement in professionals' education.

To be effective you need co-operation from both sides.

I think [there is a need] for much more of a commitment on the behalf of health authorities for effective service user involvement so that things do change.

We need to be involved in implementing things.

I think we need to get involved at all levels in policy and planning and I think we need to set our own agenda.

We need to have service user conferences to which we invite statutory services and where we set the agenda instead of the other way round. That puts us at the centre for involvement.

Service users need to be involved. We need to attend things. I think by being genuine, by telling our own stories and other people's stories and showing where the mistakes have been made, what has helped us most and what has not helped us. This will give an idea of what it's like to be on the receiving end, to look at things from a different angle.

We need to attend forums and discussions and meetings. At first you can think you are having no effect. You sit there and it feels like you say the same thing at each meeting. But it's like the drip drip effect. You just have

to keep chipping away and, in my experience we are now, after over a year, beginning to have some sort of effect.

The two dominant themes that service users talked about were clearly those of networking and meaningful service user involvement.

Campaigning

However, other themes also were discussed. These included campaigning. For example they said:

We need organised campaigning. We must make Them listen to us, our needs, what we know. We have to be more Political with a big 'P'.

More campaigning.

Campaign. We need to be more demanding.

If you see what other oppressed and minority groups have done in the past to successfully make changes it is lobbying, marching on parliament, campaigning. We have to fight for change to make them listen to bring about changes that are good for all service users.

Concerted campaigning.

Negotiation

Other people said they thought the best way forward was through a process of negotiation.

Keep channels of communication open. Try not to see it as a 'Them and Us' situation. We need to be working together and listening to each other.

Through negotiating.

We need to encourage and engage professionals who are also service users and carers and who are committed to service user and carer values.

Although many people talked about how difficult it was to bring about change, to influence the support services that they use and to have their experiences and knowledge treated with equality, there is a large amount of energy and determination within the service user movement to effect change. Many people told us:

Don't get downhearted. Does it matter if they take over our knowledge if it is acted upon and brings about changes for the better?

It is difficult, but most things worth doing are! We just have to keep knocking at the door until they let us in.

We will work seven days 24 hours to drag mental health services kicking and screaming into the twenty-first century.

It is a big task and it will take time. But it is our lives we are talking about and we will keep talking, shouting.

Drip, drip, drip. Eventually the hardest stone is changed. You just have to do what you can and not let the bastards grind you down!

I think sometimes you can get really deflated and feel like giving up but at the end of the day you've always got to look forward and try not to look back. You can feel like you're wasting your time. But it is the smallest things that can make a real difference, that can be an achievement. 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.

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Appendix 1: Terminology – the language we use

Service user

What do we mean when we say ‘service user’?

Shaping Our Lives sees ‘service user’ as an active and positive term that means more than one thing. It is important that ‘service user’ should always be based on self-identification. But here are some of the things we think it means:

- It means that we are in an unequal and oppressive relationship with the state and society.
- It is about entitlement to receive welfare services. This includes the past when we might have received them and the present. Some people still need to receive services but are no longer entitled to for many different reasons.
- It may mean having to use services for a long time which separate us from other people and which make people think we are inferior and that there is something wrong with us.
- Being a service user means that we can identify and recognise that we share a lot of experiences with a wide range of other people who use services. This might include, for example, young people with experience of being looked after in care, people with learning difficulties, mental health service users, older people, physically and/or sensory impaired people, people using palliative care services and people with drug and alcohol problems.
- This last point about recognising our shared experiences of using services, whoever we are, makes us powerful and gives us a strong voice to improve the services we are given and to give us more control and say over what kind of services we want.

What people sometimes mean by the term ‘service user’

The term ‘service user’ can be used to restrict your identity as if all you are is a passive recipient of health and welfare services. That is to say that a service user can be seen to be someone who has things ‘done to them’ or who quietly accepts and receives a service. This makes it seem that the most important thing about you is that you use or have used services. It ignores all the other things you do and which make up who you are as a person. This is *not* what Shaping Our Lives means when we talk of ‘service users’ (see also Beresford, 2005).

User controlled

What do we mean when we say ‘user controlled’?

There is a range of meanings attached to the term ‘user controlled’. Here are some of the things the Shaping Our Lives National User Network thinks ‘user controlled’ could include:

- that service users decide what things they want done and how
- that the majority of the controlling group (usually the management committee) of the organisation are users of the organisation or members of the group for whom it was set up
- that the group or organisation strives to work from an equalities approach to service users, addressing diversity and rejecting any hierarchies of impairment or other difference.

Appendix 2: Initial questionnaire

Questions for an individual

1. I would like to become an individual member of Shaping Our Lives (National Users Network)

Yes ☐ No ☐

2. I would be happy to be included on the Shaping Our Lives (National Users Network) database

Yes ☐ No ☐

3. Contact details:

Name:

Address:

Telephone:

Minicom:

Fax:

E-mail address:

4. I would like to communicate with Shaping Our Lives National Users Network through (number 1, 2, 3, etc. in order of importance and/or need):

Printed material (14 point font) ☐ Larger font (state...) ☐

Braille ☐ Telephone ☐ Pictures supporting words ☐

Minicom ☐ Typetalk ☐ E-mail ☐

Disk ☐

Questions for organisations

5. We would like to become part of the membership of Shaping Our Lives (National Users Network) as a service user-led organisation

Yes ☐ No ☐

6. As an organisation we consider ourselves:

Local ☐ Regional ☐ National ☐

7. We would be happy to be included on the Shaping Our Lives (National Users Network) database

Yes ☐ No ☐

or

8. We would like to be included on the Shaping Our Lives database as a non-user-led organisation

Yes ☐ No ☐

9. Contact details:

Name:

Address:

Telephone:

Minicom:

Fax:

E-mail address:

Please send information to (position in the organisation)

Making user involvement work

10. We would like to communicate with Shaping Our Lives National Users Network through (number 1, 2, 3, etc. in order of importance and/or need):

| | | | |
|----------------------------------|--------------------------|---------------------------|--------------------------|
| Printed material (14 point font) | <input type="checkbox"/> | Larger font (state...) | <input type="checkbox"/> |
| Braille | <input type="checkbox"/> | Disk | <input type="checkbox"/> |
| | | Pictures supporting words | <input type="checkbox"/> |
| Telephone | <input type="checkbox"/> | Minicom | <input type="checkbox"/> |
| E-mail | <input type="checkbox"/> | Typetalk | <input type="checkbox"/> |

11. We would be happy to have information about our organisation on the Shaping Our Lives (National Users Network) database

Yes ☐ No ☐

12. We would be happy to have information about our organisation given to other members

Yes ☐ No ☐

13. We would be happy to write the information about our organisation that will be given to members

Yes ☐ No ☐

14. Our members or people we work with are: (Tick as many as needed)

| | |
|---|--------------------------|
| Older people | <input type="checkbox"/> |
| People with learning difficulties | <input type="checkbox"/> |
| Mental health service users/survivors | <input type="checkbox"/> |
| People with physical and sensory impairments | <input type="checkbox"/> |
| Young people who have experienced the care system | <input type="checkbox"/> |
| People from minority ethnic service user groups | <input type="checkbox"/> |
| Palliative care service users | <input type="checkbox"/> |
| Other | <input type="checkbox"/> |

15. Do you hold regular meetings?

Yes ☐ No ☐

Please give details

16. Do you produce any publications?

Yes ☐ No ☐

Please give details

Questions for everyone

17. As a member of Shaping Our Lives (National Users Network) would you welcome:

| | | |
|-----------------------------|------------------------------|-----------------------------|
| A newsletter 3 times a year | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
|-----------------------------|------------------------------|-----------------------------|

| | | |
|----------------------------------|------------------------------|-----------------------------|
| A members section on our website | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
|----------------------------------|------------------------------|-----------------------------|

| | | |
|-----------------------------|------------------------------|-----------------------------|
| E-mail updates about events | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
|-----------------------------|------------------------------|-----------------------------|

| | | |
|---|------------------------------|-----------------------------|
| Information about other service user groups | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
|---|------------------------------|-----------------------------|

| | | |
|--|------------------------------|-----------------------------|
| Contact with other service user groups | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
|--|------------------------------|-----------------------------|

18. Would you be interested in playing an active role in the National Users Network

Yes ☐ No ☐

19. Shaping Our Lives National Users Network is often invited to take part in meetings and events – would you be happy for us to send you a list of subject areas and invite you and/or representatives of your organisation to tell us which ones, if any, you would be willing to attend

Yes ☐ No ☐

20. Is there a question you would like to ask us about the National Users Network?

Thank you for your time. Return this form to:

Shaping Our Lives
Unit 57, Eurolink Centre
45 Effra Road, Brixton
London SW2 1BZ

Or e-mail information@shapingourlives.org.uk

Appendix 3: Analysis of Shaping Our Lives initial questionnaires

Introduction (based on a report by Bob Williams-Findlay)

Shaping Our Lives sent out initial questionnaires to both organisations and individuals who had been in contact with us or who have worked in partnership with us. The twin aims of the questionnaires were to discover the number of contacts who were interested in the idea of, and issues surrounding, user networking and to explore with them the best ways of taking it forward.

Below is a detailed analysis of the questionnaires, followed by the actual results. Before highlighting the findings it is worth noting that not all respondents replied to every question.

Organisations

Forty-one organisations responded to the questionnaire, 36 of whom were user-controlled organisations. The remaining five questionnaires were either from non-user-led organisations wanting to be members of the Shaping Our Lives database, or they failed to supply information about whether or not they were user controlled.

- 35 out of 36 organisations said they would like to become part of the Shaping Our Lives network.
- 20 said they were local organisations.
- Three said they were regional organisations.
- Nine said they were national organisations.
- One said it was an international organisation.
- The geographical spread of the organisations suggests no overall pattern.
- 23 organisations said that printed material was their first choice and 13 said email.

- All but one respondent said they would be happy to have information about them on the database and to have information given to other members.
- 33 said they would be happy to write information about themselves that would then be given to members.
- 19 organisations work with older people.
- 12 organisations work with people with learning difficulties.
- 16 organisations work with mental health service users/survivors.
- 20 organisations work with people who have physical and/or sensory impairments.
- Seven organisations work with young people who have experienced the care system.
- 12 organisations work with people from minority ethnic service user groups.
- Three organisations work with palliative care service users.
- Three organisations specifically mentioned disabled people, young people, carers and socially excluded groups.
- 32 organisations said they held regular meetings.
- 12 said that they had a meeting once a month.
- Three organisations said that they did not have regular meetings.
- 25 organisations said they produced publications.
- Seven said they did not produce any publications.
- 15 said they produced a newsletter.
- Six produced information sheets/leaflets.
- One organisation produced videos.

- Four produced internal magazines.
- Two produced an annual report.

Shaping Our Lives

- 34 organisations welcomed the idea of a newsletter from Shaping Our Lives three times a year.
- 25 respondents were interested in a members' section on our website.
- 36 were happy to have email updates about events and contact with other service user groups.
- 33 would like information about other service user groups.
- 23 organisations said they would like to be actively involved in Shaping Our Lives.
- Four organisations said it would depend on the levels of commitment required.
- Four were not interested.

Individual questionnaires

There was a total of 30 questionnaires from individuals. All were keen to become involved with Shaping Our Lives.

- One individual said that they would not want to be included on the database.
- The division between male and female was fairly even with 13 men and 14 women identified.
- 16 individuals preferred information via email.
- Ten people indicated printed material as their first choice.

- The geographical location of individuals was widely dispersed around the UK and beyond. However, there was also evidence of clusters: for example, there were three people from the Manchester area.
- 18 people said they would welcome a newsletter three times a year and a members' section on the Shaping Our Lives website.
- 15 people said they would welcome email updates about events, information about other service user groups and contact with other service user groups.
- Two people said they did not want email information and updates sent to them.
- 12 people said they would be interested in playing an active role in Shaping Our Lives.
- Four said they would not.

Appendix 4: In-depth follow-up interview schedule

We would be very grateful if you would have a look at the following questions. We are asking these questions in order 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.

This is a small-scale project with limited funding. It is user-controlled and based on an emancipatory approach to research and evaluation. Its main aim is to explore with other service users their views, ideas, experience and proposals for developing and supporting local user-controlled organisations. It aims to identify the key issues around this topic as reported by service users themselves. We include under the heading 'service users' people with physical and/or sensory impairment, people with learning difficulties, mental health service users/survivors, older people, people living with symptomatic HIV/AIDS, people receiving palliative care services and young people who have experienced the care services. We are seeking to keep the definition flexible to be inclusive. We will also seek to reflect diversity in terms of race and ethnicity, gender, sexuality and class.

The project is independent and is based at Shaping Our Lives. Shaping Our Lives is a service user-controlled organisation that has a track record of undertaking independent user-led and user-controlled research and evaluation.

This project will rigorously seek to abide by principles of total anonymity and strict confidence. By this is meant that whatever you may say to us will not be attributed to you personally in any way. Everything you say will be treated in complete confidence. Absolutely no names will be used and we will seek to ensure that nothing anybody says could ever be traced to them. We will not mention to anyone what you have individually said. If there are any questions you would like to raise about this we will be happy to discuss them. If you would be happy for your name to be used we would be happy to discuss this too.

If you would like any further information about this, please get in touch. We will feed back to you the results from this work and we will also be working hard to make sure that it is heard by policy makers and can make a difference.

Definition of user controlled

We are taking as our definition of an organisation that is user controlled to be that at least a majority of the management group and/or people controlling the organisation are defined/self-define as disabled people/service users.

Name of user-controlled organisation:

Contact details:

Questions

1. Do you have contact with other local user-controlled organisations?

YES/NO/DON'T KNOW/DETAIL

If Yes:

2. What kind of organisation are they? (older people, disabled people, mental health service users etc.)
3. Do you know how this contact with other user-controlled organisations came about?
4. Can you tell me about the type of contact you have with them? (Sharing of information? Social? Advice? Campaigning?)
5. Would you and your organisation like to develop stronger links with other service user organisations?

YES/NO/DON'T KNOW

If yes:

6. Can you tell me a bit more about why you think it might be useful?
7. How secure does your organisation feel it is in terms of resources, funding and the way it is regarded locally?

DETAIL

8. What benefits/gains do you feel networking with other user-controlled organisations can offer you/your organisation?

DETAIL

9. Are there any problems/obstacles for you/your organisation networking with/keeping in touch with other user-controlled organisations?

DETAIL

10. Do you or your organisation have contact with any national user-controlled organisations?

YES/NO/DON'T KNOW

11. What sort of support, contact or information would you/your organisation find useful and helpful to get from other user-controlled organisations at:

A. Local

B. National

C. Regional levels

DON'T KNOW/DETAIL

12. Are there any gaps in the kind of user-controlled organisations which exist in your area? (for example, for particular user groups/doing particular things, etc.)

YES/NO/DON'T KNOW/DETAIL

13. What kind of benefits would you like a national network of user-controlled organisations to offer you/your organisation?

DETAIL

14. Do you think that a national database which service user organisations owned would be a useful way for people to share information and to support the work of local user-controlled organisations?

YES/NO/DON'T KNOW/DETAIL

15. Could you tell us something about the ethnic composition of members/people involved in your organisation?

16. Is there anything you would like to say about service users networking that we haven't talked about?

YES/NO/DON'T KNOW/DETAIL

17. Are there any questions you would like to ask me?

18. If we are able to develop the user network would you and/or your organisation like to be involved in any way?

YES/NO/DON'T KNOW/DETAIL

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.

19. Do you think that you/your organisation is able to make as much impact on health and social care policy and provision from what you know from experience as service users as you would like to?

YES/NO/DON'T KNOW/DETAIL

20. How do you think we as service users/service user organisations can share the knowledge that we develop among service users and service user organisations more effectively?

DETAIL

21. What do you see as the most important issues for making it possible that what we learn and know from our experience as service users can have more impact to improve our lives and services?

DETAIL

22. How can we ensure that our knowledge as service users can become a more powerful part of mainstream health and social care knowledge?

DETAIL

23. How can we as service users challenge the way that existing professional knowledge often sidelines and seeks to take over our knowledge based on direct experience?

DETAIL

24. How can we make mainstream knowledge about health and social care more available and accessible to service users and our organisations?

DETAIL

25. Are there any additional points you would like to add?

DETAIL

26. Are there any questions you would like to ask us?

We hope that you will fill this in. If there is not enough space on this form please use more paper. If you would like more information or any help or if you would like to fill it in on the phone please contact the office on 0207 0951159 and we will get back to you. We will keep you posted on our findings. Thank you.

Appendix 5: Project brief – invitation to service users to take part in group discussions

Service users' networking and knowledge project brief

We would like to invite you to take part in a small discussion around service user knowledge and networking. We would like to give you an opportunity to tell us 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.

This is a small-scale project with limited funding. It is user-controlled and based on an emancipatory approach to research and evaluation. Its main aim is to explore with other service users their views, ideas, experience and proposals for developing and supporting local user-controlled organisations. It aims to identify the key issues around this topic as reported by service users themselves. We include under the heading 'service users' people with physical and/or sensory impairment, people with learning difficulties, mental health service users/survivors, older people, people living with symptomatic HIV/AIDS, people receiving palliative care services and young people who have experienced the care services. We are seeking to keep the definition flexible to be inclusive. We will also seek to reflect diversity in terms of race and ethnicity, gender, sexuality and class.

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