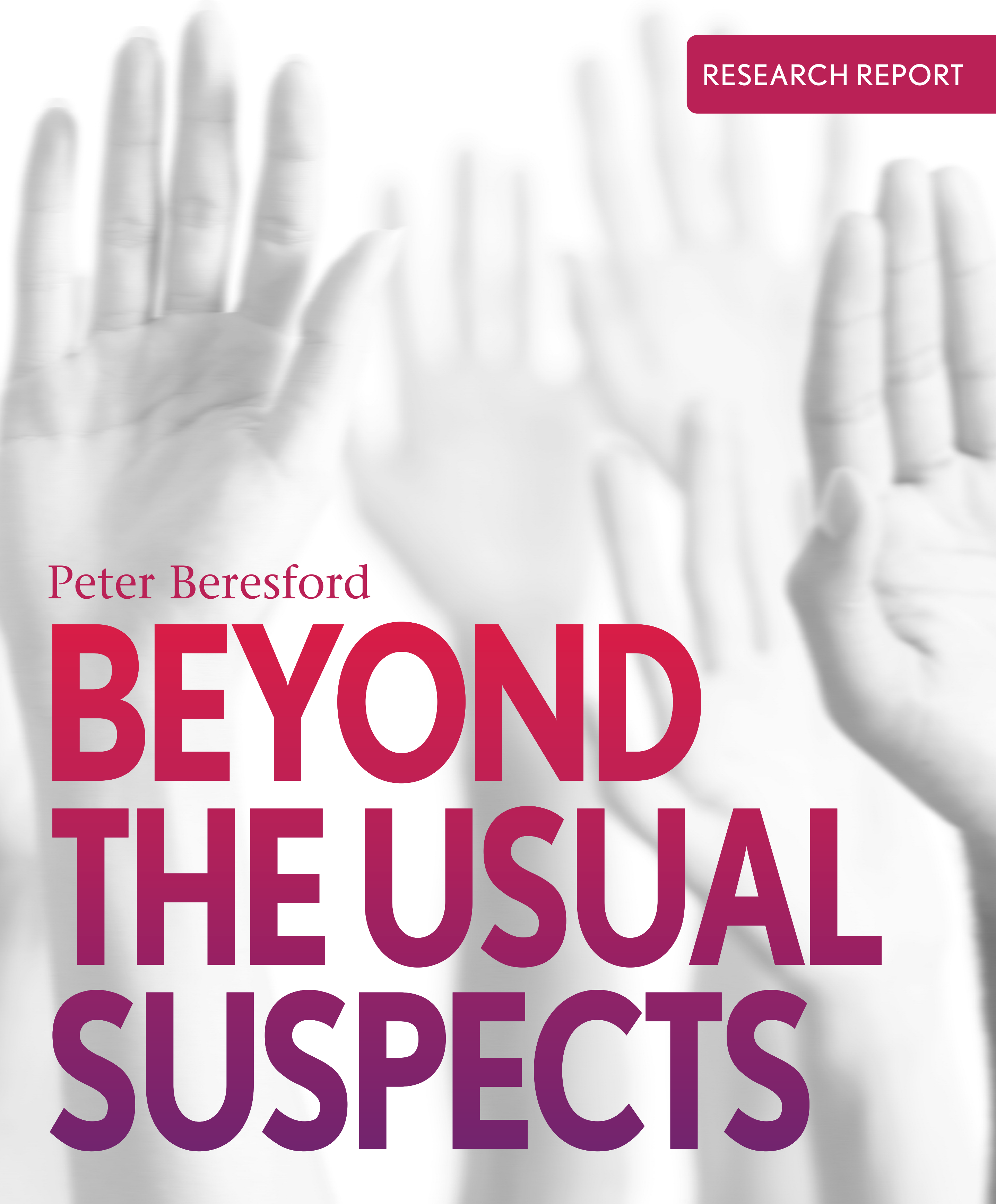
TOWARDS **INCLUSIVE** USER INVOLVEMENT

RESEARCH REPORT



Peter Beresford

BEYOND THE USUAL SUSPECTS

Published in 2013 by
Shaping Our Lives
BM Box 4845
London WC1N 3XX
www.shapingourlives.org.uk

ISBN 978-1-906498-01-6

Front cover image Moodboard, Cultura, Getty Images

Designed by Julie Rimmer

Printed by Pureprint Group

With thanks

We have many people to thank for making this publication possible. First, the many service users who took part in the project which is reported here. Thank you for taking part in group discussions, undertaking interviews, getting involved and contributing your ideas and expertise. Second, we must thank the four service user organisations which organized local initiatives to help involve people who had previously not got involved in their activities. We would also like to thank the Shaping Our Lives National User Group for their input and to the project's advisory group which helped guide its work and Fran Branfield, Michael Turner and Eamon Andrews, who played key roles in undertaking it. Thanks also to our designers, Molly Barrett and Julie Rimmer and finally to Becki Meakin and Debbie Vickers of Shaping Our Lives for helping to bring the project to fruition.

Dedication

For my grandparents Dora and Barnet Kaufman who came to this country as immigrants and refugees, before politicians made these dirty words, and amongst their many contributions gave me my home and nationality.

THE PURPOSE OF THIS REPORT IS TO OFFER PRACTICAL HELP TO DEVELOP MORE INCLUSIVE INVOLVEMENT FOR THE FUTURE SO THAT EVERYONE WHO WANTS TO BE INVOLVES HAS EQUAL OPPORTUNITIES TO DO SO.

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FOREWORD

Involving service users has become a repeated mantra. For decades official reports, service reviews, plans for new developments have, as if by rote, included the phrase 'services users must be involved.' And more recently, the gloss on this has been 'service users must be at the centre of all we do'. Too easily these phrases have been seen as sufficient. A generalised plea for a new approach which could be best delivered through finding a handful of more or less interested service users, and ensuring that they were consulted, brought into the process and in the name of engagement asked to contribute.

The Joseph Rowntree Foundation and many others, including Shaping Our Lives, have long argued that this is unsatisfactory all round. The few service users involved in this way have been exhausted. Planners and professionals have had an uneasy feeling that they are only hearing partial and inevitably individual views. And critics have muttered about the reliance on 'usual suspects' and the risk of capture by the system. What has been more worrying, has been the tendency to ascribe a simple homogenous view to service users, as if all service users are the same, share the same histories, and have identical views.

In this publication Peter Beresford challenges this approach, and does it with passion, analysis and knowledge. Arguing for an inclusive approach to engagement, he develops a compelling, thoughtful and genuinely inspirational approach. He challenges received wisdoms, while at the same time remaining absolutely focused on the need to involve the widest range of users at all levels of the decision making process. But what is most important about this publication is that Peter brings his considerable experience to bear on the issue, providing the tools and the expertise to ensure that in future user involvement really does involve all users, and does it in a way that makes a difference.

Julia Unwin CBE
Chief Executive, The Joseph Rowntree Foundation

SUMMARY

There has been growing interest in modern times in people being able to play a more active part in their society, community and lives, as citizens, service users and patients. Such 'user' or 'public/patient involvement' has become a shared goal across all shades of politicians and policymakers. However it has become increasing apparent that some groups face many more barriers than others getting involved and this reinforces the difficulties that they may face and excludes their important perspectives from consideration.

This report, based on a national research and development project funded by the Department of Health explores why some groups tend to be left out in this way and how they may be fully and equally included in the future. We know that some groups, particularly from minorities often experience generally inferior access to and support from services. The same groups are likely to have inferior opportunities to get involved in schemes to strengthen their voice. The combined effect of these two factors is likely to be to exacerbate and perpetuate inequalities faced by some of the most disadvantaged groups in our society.

Shaping Our Lives, a national user controlled organisation and network, with a strong commitment to diversity, equality and inclusion, carried out this project to find out how to ensure that all groups of long term health and social care service users could have a more equal chance of having a say and involvement in their lives and society. To do this it worked with four local user controlled organisations and carried out discussions and individual interviews to find out which groups and individuals tended to be excluded and how they might better be supported to get involved in the future. The project was user controlled and carried out entirely by service users, guided by a service user advisory group.

THIS REPORT EXPLORES WHY SOME GROUPS TEND TO BE LEFT OUT AND HOW THEY MAY BE FULLY AND EQUALLY INCLUDED IN THE FUTURE. WE KNOW THAT SOME GROUPS, PARTICULARLY FROM MINORITIES OFTEN EXPERIENCE GENERALLY INFERIOR ACCESS TO AND SUPPORT FROM SERVICES.

Existing exclusions

Service users seem to be denied equal opportunities to get involved for five overall reasons. These relate to:

Equality issues

Service users report barriers they face getting involved on the basis of gender, ethnicity, culture, belief, sexuality, age, disability and class. Older people are conspicuously under-represented.

Where people live

This includes people who are:

- Homeless
- Living in residential services
- In prison and the penal system
- Travellers and gypsies.

This group also includes people whose rights may be restricted. It also extends to a related group: asylum seekers and refugees; people who do not have citizenship rights and status.

Communication issues

This relates to barriers on the basis both of ethnicity and impairment and includes:

- Deaf people
- Blind people and people with visual impairments
- Deaf and blind people
- People who do not communicate verbally
- People for whom English is not their first language.

An additional recent group often facing exclusions are those who are not computerate, who do not use the internet, who can now face some of the same difficulties as people who do not read or write.

The nature of impairments

People with complex and multiple impairments are frequently left out. This can be because their involvement is seen as expensive and difficult, or because of unevidenced assumptions that they are not able or interested in being involved. It can also happen where people are seen as 'awkward' or 'difficult' (for example, the growing number of people with dementia). This is a category in which people who see themselves within the range of neuro-diversity are sometimes included.

Unwanted voices

Service users frequently comment that some points of view are more welcome than others – particularly those of people who agree with what's on offer. More confident and assertive service users are often unpopular among those organizing involvement activities and often dismissed as 'the usual suspects'. To ensure diversity these more experienced and determined voices which agencies may not want to hear, need to be included as a key part of the overall picture.

Why people get involved

User involvement is most likely to attract a wide response if it takes account of why people want to get involved. Most people want to get involved to bring about positive change. Involvement that doesn't offer this prospect is unlikely to have a wide appeal. It isn't enough to hear what people say. It has to be listened to and acted upon.

People may get involved in one of two ways. They may get involved in their own User Led Organisations (ULOs) or Disabled People's Organisations (DPOs). Alternatively they may respond to requests from agencies and services to get involved in their schemes or arrangements for involvement. Each of these approaches has strengths and weaknesses. They can offer different appeals. It can be most effective to get involved in your own organization before responding to invitations to get involved in services and other people's invitations.

The barriers

Service users identify a series of external barriers preventing or making it difficult for them to get or stay involved. These can work in complex relation with people's own personal difficulties to magnify their problems of exclusion. Key barriers included:

- **Devaluing service users** – not valuing or listening to what they say
- **Tokenism** – asking for their involvement but not taking it seriously, making it an unproductive experience
- **Stigma** – the stigma associated with their service user identity discouraging them from associating themselves with it and getting involved on that basis
- **Confidence and self-esteem** – low levels leaving people to feel that they don't have much to contribute or are worried about whether they will be able to do it. Their disempowerment is sometimes misread as apathy
- **Language and culture** – the frequent reliance on jargon and other excluding arrangements for involvement, puts off many service users who are not confident in or used to such situations
- **Inadequate information about involvement** – this is made worse by the frequent lack of appropriate and accessible information about getting involved, discouraging many from taking the first steps to getting involved.

There is a real fear amongst some service users that if they say anything critical about the services they use, then this may result in some kind of reprisal. Although this fear is not universal, the project's findings suggest that it does seem to be widely experienced among some seldom heard groups and individuals.

Key problems

Service users identify three further major barriers in the way of their involvement, which also particularly exclude some groups. These are:

Gatekeepers

Such self-appointed gatekeepers can serve both to prevent service users getting involved themselves and obstructing people and organisations trying to involve them. They can do this by denying them information or support. We ourselves encountered such gatekeepers undertaking the project. Effective ways of overcoming this problem are educating such gatekeepers, getting them 'on-side' and ensuring that service users have support to deal with them.

Financial barriers

Financial barriers play an important part in the inclusion and exclusion of service users. They seem particularly to militate against the involvement of groups identified as ' seldom heard'. Service users highlighted the obstructing effects of money in relation to:

- **Meeting service users' expenses** – when all participants' costs weren't met and paid speedily, particularly off-putting people with limited resources
- **Paying service users for their involvement** – recognising this widely accepted principle for participation, signifying service users' worth
- **Problems with the benefit system** – which is over-complex, suspicious and unclear and can discourage people from being reimbursed or getting involved at all, for ear of losing their benefits
- **Covering the costs of involvement** – where people may have high costs because of the nature of their situation or impairment.

Overcoming the barriers

To overcome the barriers in the way of diverse involvement, service users highlight the importance of recognising them and adopting a realistic approach to responding to them, rather than simplistic calls to be 'more diverse'. Two essentials emerge as crucial for inclusive involvement, both of which need to be in place. These are:

- **Access** – ensuring all service users effective ways into organisations and decision-making structures to have a real say in them
- **Support** – for example, building confidence and skills, offering practical help and opportunities to get together to work collectively to support people's empowerment and build their capacity so they are in a realistic position to respond to invitations to get involved.

Different forms of involvement

Service users also stress the need to develop innovative approaches to involving people which can work for the widest range and move beyond traditional reliance on meetings and surveys, written and verbal skills. They prioritise developing a variety of methods of involvement that can work for different people and are based on different forms of communication. They highlight the helpfulness of meetings and activities that are organised by service users and/or are for service users only, offering them safe opportunities to develop their ideas and agendas.

Where meetings are still used, there are many ways in which these can be made more attractive and inclusive. Service users place an emphasis on:

- Service users having a good time and ensuring that they enjoy themselves
- Providing good, free food and refreshments which are culturally appropriate
- Offering a warm, safe and supportive environment
- People gaining knowledge, awareness and understanding from the events or meetings.

They identify a wide range of ways of doing this, for example, through providing entertainment (particularly by service users), supportive activities, informal and appropriate venues and encouraging networking.

Outreach and development work

Service users emphasise the importance of reaching out to involve service users, especially those identified as 'hard to reach', rather than expecting them to come to you. In this way people who were isolated or weren't 'joiners' were more likely to be engaged, although service users do not feel this currently happens enough. Suggestions for outreach work included:

- **Reaching out directly to service users** – checking out their views and what works best for them;
- **Reaching out to their communities** – for example local black and minority; ethnic communities, travellers' communities, people in residential services
- **Reaching out to community leaders** – who command trust and can support service users to engage.

Advocacy

Advocacy is a key but under-developed component for supporting people's participation. It is especially important for people who are disempowered and isolated and this is true of many of those excluded by existing arrangements for user involvement. Five forms of advocacy are identified all of which help people speak and act for themselves. They are legal advocacy, professional advocacy, lay or citizen advocacy, peer advocacy and self-advocacy. Service users stress the importance of advocacy and also the essentials of advocacy if it is to make a difference and enable everyone to be at the starting line for getting involved, becoming empowered and making a difference. They also make clear that it is generally in short supply and not given enough priority by policymakers and services.

Ensuring sustainable involvement

Key to ensuring the involvement of 'hard to reach' service users is providing on-going opportunities to get involved which over time make it possible to build trust and relationships with them. Such an infrastructural rather than ad-hoc, one-off approach to involvement makes for sustainable arrangements which are likely to attract new people as well as retaining others. This makes it possible to build up interest, experience and expertise. It supports the constant need to balance the mixture of new people and old hands, new participants from seldom heard groups and those more established activists, often dismissed as 'the usual suspects' with a track record of successful involvement. Inclusivity and effectiveness. Both are key for effective and inclusive involvement.

Involvement from outside

Many service users have become increasingly wary of getting involved with statutory and service organisations as often little may come of it. This has been exacerbated by cuts in services and major welfare reform policies which seem to take little notice of what disabled people and other service users say. Service users' organisations have also become more insecure and over-stretched.

There are three key expressions to this change. First, service users seem increasingly to be trying to get involved to make change outside of formal arrangements for user involvement, in more oppositional and conflict-based approaches, explicitly challenging government policy. This is taking the form of campaigning for and taking direct action to achieve change.

Second, service users are developing new collective forms of involvement which are accessible to them and take account of their impairments and barriers they may face. Many new campaigning and mutual aid groups have emerged. They are both working together to campaign with people with shared experience and also linking up with allied groups and causes.

New forms of service user campaigning and protest are often based on social media and social networking technologies. These also enable people to get involved in 'virtual' ways which can overcome many of the traditional barriers relating to 'access' and inclusion, requiring people to go to participation, rather than participation coming to them. Such service users are, blogging, vlogging, podcasting, tweeting and have their own facebook and other groups. They are impacting on mainstream media, as well as policymakers and the political process, influencing wider discussion and public consciousness.

INTRODUCTION

The focus of this report is making it possible for everyone who wants to, to be more involved in and have more say over their lives and the services they use to live them. This aspiration has come to be framed in terms of 'user involvement'. The report draws on findings from a national research and development project the Developing Diversity in Involvement project supported by the Department of Health, which aimed to find out how this could be achieved.

Over the last 20 – 30 years there has been a growing interest among both policymakers and service users themselves in developing user involvement (Beresford and Croft, 1993; Barnes and Mercer, 2006). As this policy has been taken forward, there has been an increasing recognition of some abiding limitations (McLaughlin, 2010). A key one highlighted is that not everyone seems to get involved on an equal basis. Some, often more advantaged groups, tend to be more involved than others. Other groups facing particular barriers in their lives generally also seem to face additional barriers when it comes to getting involved. A growing body of literature and research has highlighted these issues. It has emphasised the importance of challenging such barriers. Otherwise a vicious circle is likely to operate. The most disadvantaged groups and people are likely to be further disadvantaged by being less likely to be heard and listened to when they try and highlight the problems they face.

Two developments in user involvement have drawn attention to this issue. First as user involvement has become more established as policy and practice, it has been subjected to more detailed examination. This has led to an increasing concern with considering its impact and effectiveness. This has resulted in concerns that such user involvement frequently overlooks and leaves out particular groups. Meanwhile as attention has been paid to the rights and needs of a widening range of groups of service users, it has emerged that some groups seem to face particular discrimination and barriers when it comes to getting involved. Thus a picture has begun to emerge that:

- Some groups of service users, particularly from minorities, often experience generally inferior access to and support from services
- The same groups are likely to have inferior opportunities to get involved in participatory initiatives
- The combined effect of these two factors is likely to be to exacerbate and perpetuate inequalities in support received by some of the most disadvantaged groups of service users. (Allan, 2001; Robson et al, 2003; Begum, 2005 and 2006; Ahmed et al, 2006; Rainbow Ripples and Butler, 2006; Moriarty et al, 2007; Hernandez et al, 2010; Kalathil, 2011; Whiteford, 2011; Morrow et al, 2012).

THE FOCUS OF THIS REPORT IS MAKING IT POSSIBLE FOR EVERYONE WHO WANTS TO, TO BE MORE INVOLVED IN AND HAVE MORE SAY OVER THEIR LIVES AND THE SERVICES THEY USE TO LIVE THEM.

Getting involved can be especially difficult for groups facing more than one set of barriers or exclusions, for example, mental health service users in the prison system (Samele et al, 2008) or homeless people associated with substance misuse (Begum, 2005). Service users and their organisations have sometimes been criticised as 'unrepresentative' by services on the grounds that they are not fully inclusive (Beresford and Campbell, 1994). On the other hand, as will be seen from this study and other evidence, service users frequently feel that the opportunities that they are offered to get involved more generally are often excluding and don't deal with access issues well. Jabeer Butt has examined the characteristics of social care organisations that successfully promote diversity and concluded that:

> Diversity means taking account of the complexities of the lives of individuals, of groups of people, and the impact these complexities have on their experience of discrimination and disadvantage. (Butt 2006).

In other words, organisations need to address all equality issues rather than focusing on one aspect of a person's identity. The interplay between age, disability/impairment, sexuality, gender, social class, religion and faith, race and ethnicity all contribute to a person's lived experience of oppression and inequality.

When ideas of participation and 'user involvement' were first highlighted in the latter part of the twentieth century, there was a strong sense that they were a 'good thing' in themselves. Ethical, moral, democratic and emotional arguments were used to justify and support them. The point was made that it was only 'right' that citizens and service users should be involved and have more say. Governments increasingly argued that such 'consumer involvement', made sense in the new market driven politics that emerged from that period. More recently, however, there has been increasing pressure to evidence the benefits of user involvement and for these not to be taken for granted. This pressure has come from researchers, policymakers and service users and their organisations. It is reflected in a growing body of interest and work focusing on such impact of involvement in policy, practice, research, planning and management (Carr, 2004; Cotterell et al, 2010; Adebayo et al, 2011; Barber et al, 2011; Cotterell and Morris, 2012; Staniszewska et al, 2012). Such research and evaluation of user involvement has explored the possible impacts on both policy change and on service users and their lives; both those getting involved and intended beneficiaries. As yet though, its focus on the diversity of involvement has been relatively limited.

This and the other developments described above have been the impetus for this project and its outputs. Its aims are simple; to find out more from service users who tends to be excluded or discouraged from involvement; what the barriers are in the way of their involvement and how these in practice can be overcome. It draws on empirical evidence from service users themselves; both those who have got involved and also those who haven't. It aims to support action for change and improvement, which is why this report of the project's findings only represents one of its outputs and the others have a clearly practical purpose. This is to help people who want to be involved and to involve others, do so, regardless of obstacles and difficulties that may previously have discouraged this.

BACKGROUND

Shaping Our Lives is an independent national user controlled organisation and network of disabled people, service users and their organisations. It was set up about 15 years ago and has gained a strong reputation for working with service users and their organisations in an inclusive and accessible way. Its aims have been to increase the say and control service users and disabled people have over their lives, over services that intervene in them and over the support that they may need to live their lives on as equal terms as possible. To achieve this, Shaping Our Lives has carried out numerous research and development projects, consultations and information gathering exercises, campaigning to support the rights and interests of disabled people and other long term health and social care service users (Beresford and Branfield, 2012).

Shaping Our Lives is made up of and works across a wide range of user groups, including people with physical and/or sensory impairments, people with learning difficulties, older people, mental health service users/survivors, people living with HIV/AIDS, people living with chronic and life limiting conditions and young people with experience of living in care. Shaping Our Lives works at local, national and international level, both with other service user organisations and with government and non-statutory organisations to achieve both bottom-up and top-down change. It has developed its service user network, SOLNET to improve networking and extend the reach of service user knowledge, both among service users and their organisations and more broadly. Shaping Our Lives has a strong track record of involving a broad range of service users. It has worked to enable diverse and effective user involvement in health and social care to influence and improve policy and practice. It has supported the involvement of service users in a wide range of statutory and non-statutory initiatives.

In doing this it has gained valuable experience about the obstacles in the way of truly inclusive and diverse public and user involvement which moves beyond a narrow group of activists and is able to address difference and diversity effectively. Barriers to diversity have so far seriously inhibited the degree to which government and indeed service users themselves and their organisations are able to engage with a wide range of patients/service users and members of the public as they seek to and be truly inclusive. Service workers and providers have long experienced real difficulties in fulfilling the requirements placed upon them to enable such diverse and effective involvement. It is for all these reasons that this project came into existence.

SHAPING OUR LIVES HAS A STRONG TRACK RECORD OF INVOLVING A BROAD RANGE OF SERVICE USERS. IT HAS WORKED TO ENABLE DIVERSE AND EFFECTIVE USER INVOLVEMENT IN HEALTH AND SOCIAL CARE TO INFLUENCE AND IMPROVE POLICY AND PRACTICE.

Access and inclusion

This project: *Developing diversity in involvement: Getting beyond the usual suspects*, sought to address this issue in a systematic way, building on the significant body of work Shaping Our Lives has been able to undertake to involve and include a very wide range of service users; both as individuals and in groups. Issues of access have tended to be defined very narrowly in terms of physical access for people with physical and sensory impairments, often ignoring broader cultural, communication, social and other barriers. Despite the fact that resources have been dedicated to promote inclusion and participation, from the perspective of some service users groups, successful inclusion and meaningful participation is rare. This is particularly true for some groups such as people with learning difficulties, people with chronic (and life limiting) illnesses and conditions, black and minority ethnic communities, frail older people; people without their own home or in residential services and people who communicate differently.

Shaping Our Lives has been piloting more effective approaches to access and inclusion. The aim of this project was to work with a diverse range of service users and service user organizations and highlight barriers for specific groups and find new ways of overcoming them.

THE PROJECT

The purpose of this project was to find out more from service users' perspectives about who tends to be excluded from user involvement initiatives, including both general opportunities and those offered by service users and their organisations. We then wanted to explore new and innovative ways of involving a truly diverse range of service users.

To carry out the project and to inform this practical guide, we did five things:

1. We worked with four local service user controlled organisations through four 'regional coordinators' and a national coordinator, all of whom were service users. All four organisations were concerned with groups of service users who tend to be excluded. We asked them to look at who they felt was missing from their own groups, in terms of the broadest understanding of diversity, and then to look at the key barriers to their involvement. They then carried out practical developmental work to address these barriers, for which each had control of a significant delegated budget. The groups were:

- A black mental health user group – a group of black and minority ethnic mental health service users
- A self-advocacy group of people with learning difficulties
- A support group of women with alcohol problems, offering mutual support and friendship
- A mixed service user group from a wide range of backgrounds and who use a wide range of social care and health services.

These four groups worked to identify which groups of people they felt they did not reach and then they developed a programme to reach them. Through this project, Shaping Our Lives was able to offer both financial and practical support in order to do this.

2. We carried out a national questionnaire survey to gain the views of a diverse range of service users, which included people who were not involved in any service user or disabled people's group or organisation. The questionnaire for these individual interviews (see appendix 1) was designed by the project team and piloted with Shaping Our Lives National User Group. Changes were made according to their feedback. This was a semi structured interview questionnaire allowing participants to respond as fully as they wished. The questionnaire was widely distributed, with 800 copies sent out with Shaping Our Lives own newsletter. An online version was available on the Shaping Our Lives website. It was also available on request in alternative formats. Copies were given out at three 'shopmobility' schemes as this was identified as one way of reaching disabled and older people who might not be active within service user organisations. 130 questionnaire responses were returned, including 47 completed online.

3. We established a steering group of service users who reflected the characteristics associated with 'seldom heard voices' to guide us with their experiential knowledge and expertise.

WE WANTED TO EXPLORE NEW AND INNOVATIVE WAYS OF INVOLVING A TRULY DIVERSE RANGE OF SERVICE USERS.

4. We carried out two group discussions specifically to involve people using residential services and people who communicate differently – groups recognised to face particular exclusions.
5. We checked out our findings with other well networked and experienced service users through Shaping Our Lives National User Group, an established group that is strongly networked with wide experience of user involvement.

In addition further information was also collected from service users involved in user involvement initiatives and user led and disabled people's organisations during 2011-12 to provide as up to date a picture as possible.

The report draws on the voices of all the service users who participated in this project, whether as individuals, part of a local group working closely with Shaping Our Lives throughout this project or as part of a one off group discussion.

In addition to the 132 service users who provided individual interviews, just over one hundred other service users contributed through participation in group interviews and via the project advisory group. This report is based on the experiences and thoughts of these 232 plus service users. Because of the way in which we carried out the project, many of the service users who were part of it are just those who might ordinarily be thought of as 'hard to reach' or 'seldom heard voices'. Thus, we were able to get particularly valuable insights into why people are excluded and who is excluded, from people who themselves had such first hand experience. There was also remarkable consistency in what people told us in the different research methods we used; the group discussions, interview survey and the one-to-one interviews. This was true both of the groups that they highlighted as facing particular barriers and the reasons for this.

WHO GETS EXCLUDED

While the policy rhetoric, since at least the 1980s, has been of participation and user involvement, it has become increasingly evident over the years, that some groups are much more likely to be heard and listened to than others. We know that some people and groups face particular barriers and are especially likely to be excluded (for example, Robson et al, 2003; Begum, 2005; Rainbow Ripples and Butler, Kalathil, 2011; Morrow et al, 2012; Beresford and Branfield, 2012). The evidence from this project highlights that a very wide range of service users tend to be left out. The reality is that people who face barriers to their involvement in wider society and are more likely to be socially isolated are also more likely to be excluded from participatory arrangements in society. There are barriers to their involvement both in service users' and disabled people's organisations and in service-led schemes for involvement.

Such exclusions seem to be linked with five key issues:

- Equality issues
- Where people live
- Communication issues
- The nature of impairments
- Unwanted voices.

Service users highlighted the way in which prevailing discriminations and exclusions also seemed to be mirrored in participatory arrangements. We will look at each of these issues in turn.

Equality issues

It is clear that service users are facing barriers getting involved around the wide range of issues of equality and diversity, including, gender, sexuality, class, culture, belief, ethnicity, disability and age. Examples of all of these emerged in this project. But the three most often mentioned related to ethnicity and age (we discuss impairments separately).

Black and minority ethnic service users

The group of people most often identified as being excluded by people taking part in the project were people from black and minority ethnic communities. This reflects findings from other research (Blakey et al, 2006; Bowes, 2006; Trivedi, 2009; Begum, 2005; Morrow et al, 2011). This also included faith groups:

> Chinese people. There is a large community of Chinese people where I live but you never see them getting involved.
>
> Culturally specific religious groups: Muslims, Hindus, Sikhs, Jews …

One of the four regional groups that Shaping Our Lives worked closely with as part of the project was run by and for black mental health service users. They discussed their own opportunities for involvement, compared to white mental health service users. They felt that personally, they had the same opportunities, but that this was a relatively recent development.

PEOPLE WHO FACE BARRIERS TO THEIR INVOLVEMENT IN WIDER SOCIETY AND ARE MORE LIKELY TO BE SOCIALLY ISOLATED ARE ALSO MORE LIKELY TO BE EXCLUDED FROM PARTICIPATORY ARRANGEMENTS IN SOCIETY.

One member said:

> For too many years, while you people were enjoying the welfare state and freedom of benefits, my friends, my brothers and sisters were being locked up in prison. They weren't even considered to have a mental health problem. They were just seen as bad people and locked up … I think black history in the mental health system has not been a good one so we need more situations where there is user involvement in terms of black people, black voices being heard and black services – there are not enough black services. There's more in America. We're a bit slow on the uptake here I don't know if that's because of our colonial past but a little thing like this little forum [their own organisation] here is a start.

Participants agreed that even where people from black and minority ethnic communities were involved, they were generally people who spoke English or for whom English was their first language and that it was difficult to get interpreters for people who did not speak English. There was a feeling among them that members of black and minority ethnic (BME) communities were often excluded from both service users' own groups and organisations as well as from involvement initiatives set up by the care system. However there was also general agreement that certain BME communities were increasingly getting involved and taking part in things. One way in which people thought that this was happening was through groups like the one which took part in our project which was specifically for black mental health service users. However, significantly this has subsequently lost its funding and had to close.

Gender and involvement

Many of the women who participated in this project highlighted problems of sexism in participation. These seemed to apply to all kinds of involvement, from calls to get involved in local services to getting involved in service user organisations. One woman described going to see what a group was like and finding:

> I had my say, but this girl was really being bullied by men in the group.

Another woman said that in user groups involving both men and women it can be difficult to talk about issues that are specifically relevant to women. One woman said:

> I think I'm getting a bit of a reputation. I noticed at a meeting last night that a bloke kept goading me about women's issues and I got to a point where I wanted to turn round and tell him to shut his mouth.

Another woman said:

> I go to a meeting where all the different user groups meet up but … I don't feel supported within it. I have comments made about me because I'm into women's rights and everything that I've said has been thrown back at me in a very sarcastic way. … I've tried to talk about safety issues for women and things like that, but it all goes over the top of their heads. I've decided to back off and wait for the right time.

Others had had similar experiences with men in mixed groups when talking about women's issues. One gave the example of a group of people with alcohol problems:

> It's sexual harassment – you're feeling vulnerable, you're trying to get sober and you're getting sexually harassed. Women are seen as fair game.

Another woman said:

> I've had a lot of problems being bullied by men and it's very difficult to get support to deal with it. Men rule in groups – they have the power.

Sexuality and involvement

The project included participants from the gay, lesbian, bisexual and transgendered/ing community. Some, reflecting broader evidence (Rainbow Ripples and Butler, 2006), said that they had experienced harassment when they raised issues related to sexuality in mixed groups. One woman described how it can be an issue even in supposedly more progressive groups:

> You get shunned … You start talking about being a lesbian and you get a look on people's faces, you get a 'tut'. You know it's because you are talking about being gay …

Another service user said:

> I was at a training meeting a few weeks ago and everyone there was an employee of the mental health trust. They were professional people. We were talking about different experiences and in the course of one I mentioned being a lesbian and one person, who knows me quite well, said 'I don't see why you always have to bring sex into everything. All I'd done was to talk about the issues, but to her as a heterosexual woman, I was talking about sex and I find that makes me very angry. Being a lesbian isn't just about who you want to screw, it's about who you are and how you want to live and the different things that might apply to you.

Age and involvement

Older people make up the largest group of social care service users. Yet they tend to be under-represented in arrangements for involvement. Given also that older people make up the largest group of disabled people, of physical, sensory and intellectual impairments, this is a gap in involvement. It may not only be difficult to get frail older people to get involved. There has also been a widespread failure to encourage and support their involvement. The growing numbers and proportions of older and very old people have also been associated with concerns about the increasing number of people affected by dementia. The latter have been identified as another group facing particular barriers in the way of being involved (Allan, 2001; Williamson, 2012; Weaks et al, 2012).

People taking part in our project were equally concerned about the barriers that prevented younger people from getting involved:

> It is difficult to get younger people to come to our meetings.
>
> If you look around you [in this service user group] you can see the youngest person is probably in their forties.
>
> Who's lacking? Young disabled people, between the ages of 16 and 30. It is rare to see younger people taking part in things.

Service users have lots to say about why young people don't get involved; they don't appreciate the need to, they have grown up in a more individualised society than they themselves did, they are more interested just in living their lives. Yet at the same time, there is a lot of experience of involving children and young people in policy and services (Dynamix and Save The Children, 2002), for example, in the fields of child protection and looked after young people to learn from, where a wide range of young people have been actively and successfully involved. As one young service user said:

> To be truthful, often they don't seem to make much effort to connect with us. You don't necessarily want to spend a lot of time with middle-aged people. They might not want to with you. But you've got to make it a bit less 'middle aged', a bit more in line with how we do things in the rest of our lives, if they want to involve us really.

Where people live

Where people live emerges as having a significant bearing on the likelihood of them getting involved or not. Several groups seem to face particular barriers on this basis. This project highlighted this in relation to people who were:

- Homeless
- Living in residential services
- In prison and the penal system
- Travellers and gypsies.

Related to this were people whose rights were restricted in some way. Exclusions also extend to a related group: asylum seekers and refugees, who do not have citizenship status and rights to live where they are.

Residential service users

While there was reference to each of these groups in this project's research, it was most often associated with people living in residential services or institutions – homes for older and disabled people. A disproportionately large number of service users, nearly half a million, are still located in such residential services. Yet this project highlighted that they tend to be left out of schemes for involvement. Service users told us that it was very unusual to meet service users who were receiving residential services, in any kind of event or meetings regardless of who was running them.

> People who are marginalized by their care treatment, like people living in [residential] homes – they don't come to things.
>
> The only time I have met with residents of a care home was when I went to it specifically to talk to them as people in receipt of residential services.
>
> It's like they [residential service users] inhabit a different universe.
>
> They are the most disempowered of us [service users].

In order to redress this, as part of the project, we set up a discussion group in a residential home. It was important to hear what residents themselves had to say about taking part in involvement initiatives, and getting involved in service users' own organisations. This resident sums up the difficulties for people living in such services:

> It is difficult to even get to hear about things. If we go to the local disability group, it is not really talking about things that are of interest to us in the home. And then you have to arrange transport to get out … We do get involved in our own things … We have a residents committee. And some of us are on staff interview panels and such. But if we wanted to go out and join other disabled people it would be very difficult for us really.

Another service user who had personal experience of the residential care system said:

> It is sad to say, but many people living in these places are completely institutionalized and so would have little in common with those of us who are lucky enough to have a more political awareness of our situation.

The service users referred to above were people with physical impairments living in residential homes. However, two other groups of residential service users were highlighted in this project as frequently being excluded. These were older people and people with learning difficulties. Older people, whether living in residential homes or not, were often excluded from taking part in involvement initiatives. This could include service user organisations, as these service users involved in one explained:

> We don't have the facilities or experience to support frail older people particularly if they have dementia problems.
>
> People who can't leave their homes because they are very frail and old. It is not just the effort of arranging transport and that but it is not having the energy. The journey itself could be too long and tiring.

Many people with learning difficulties receive residential care. Service users in the project said that they were often excluded from getting involved and taking part in many things that they might enjoy, if they only had the opportunity.

We repeatedly heard from people with learning difficulties about lack of support to enable residents to speak up for themselves. We heard how people can be nervous to speak out about things in residential homes. One person said:

> People are afraid to speak at my house.
>
> It is difficult for people in a residential home because the home becomes your world and in that world there are people with more power than others and bullying happens and you can get afraid to speak. You can't complain.

It is important in residential services for people to be able to meet without staff being present Some people with learning difficulties talked about the important role they had speaking up for others who weren't able to speak up for themselves.

> If people can't speak up themselves we have to help.

The group of people with learning difficulties that Shaping Our Lives worked with during this project, acknowledged that they themselves did not reach all residential care service users in their area. It was for this reason that in this project, they focused their attention on increasing the numbers of residential care service users with learning difficulties who were in regular contact with their group. Other groups of service users who are routinely excluded from involvement initiatives include people in prison and the criminal justice system (Samele et al,2008). It is now well established that mental health service users, people with learning difficulties and people with drug and alcohol problems, all significant social care service users, are over-represented within the criminal justice and prison system. Equally people with experience of the care system, mental health service users, people with learning difficulties and people with alcohol and drug problems make up a disproportionate number of those living on the streets, without shelter or permanent homes. While efforts are now being made to increase their involvement, these people's voices are seldom heard in mainstream participation schemes or even in service user organisations.

People whose rights are restricted

The rights of many disabled people and service users are substantively restricted; that is to say, regardless of what their human and civil rights should be in a society, these are not in practice actually secure or safeguarded. But some service users have their rights additionally deliberately and formally restricted. This includes some:

- Mental health service users
- People seen as not having 'capacity' to make decisions for themselves
- Parents believed to be abusing their children.

While it may be necessary sometimes to restrict some people's rights to prevent them abusing those of others, this does not justify them being denied opportunities for involvement and to express their views and share their experience. Where people's rights are restricted, service users feel that their views are often less likely to be sought or included. Yet it is clearly particularly important that they are. This is especially important as more people, particularly service users are brought within the orbit of child protection provision and the emphasis in mental health policy has shifted significantly from providing support to restricting people's rights (Faulkner and Morris, 2003). This not only relates to the growing numbers in forensic services, but also those whose liberty is limited in mainstream mental health provision and service users on whom community treatment orders have been imposed. All need to be heard if abuse is to be prevented, their rights safeguarded and lessons from their experience learned.

Communication issues

There was strong agreement that it was very difficult for people who communicate differently to get involved. This group includes deaf people, people with speech impairments, people with communication problems like aphasia, people who use a voice synthesizer and other communication aides and people without verbal communication. Many people commented that:

> People who are both Deaf and blind – you don't usually meet them at consultation events.
>
> Sometimes if you can't understand what someone is saying it can be difficult and embarrassing for all concerned.

A woman who used a voice synthesizer said:

> Often people don't wait for me to type out what I want to say. So that by the time I am ready to say it the conversation has moved on.

Others agreed:

> I find it difficult to say the things I want to say because other people are talking. By the time I get to speak the subject's changed.

Another person said:

> You don't often see people who have difficulty talking at meetings. Meetings are always expected to go at a fast pace and if people can't understand what someone is saying they just say, 'Yes, Yes' and move on.

The project organised a one-off group discussion with people with aphasia. This is a condition associated with stroke which creates difficulties in communication and understanding. This group highlighted the difficulties they experienced accessing the telephone. They particularly stressed the inaccessible nature of automated switchboard systems. Members of this group referred to conferences and events that they had attended where the pace was too fast:

> It makes it impossible for me to keep up with what people are saying.
>
> It becomes too confusing.
>
> There is too much going on. I can't follow it.

They all agreed that this made it:

> … virtually impossible to join in and say what we thought.

They talked about a conference at which they had all made a presentation. They talked about how difficult this had been made for them because people in the audience kept talking and other people came in and out of the conference hall. This:

> … made it very difficult to concentrate.

They said that they were often not listened to, people interrupted them and often finished sentences for them. As one person said:

> You start to say something and after you have said three words they start talking and forget you and move on while you are in mid sentence.

The nature of impairments

There has long been talk of a 'hierarchy' of impairments operating in disability, with some groups valued more than others. This has been reflected in provisions for participation (Begum, 2005; Morrow et al, 2012). Most significantly, however, are the particular barriers that still seem to exist in the way of people with multiple impairments, high support and complex needs. These are people who might formerly have been seen as having 'profound handicaps' and written off as having very limited abilities. Particular exclusions still seem to apply to them.

Thus, this comment from one service user reflected a much broader view:

> People with multiple impairments [are especially excluded]. People with more than one impairment. For example, people who have a mental illness but also may have learning difficulties. Or someone who uses a wheelchair but who is also blind. Some

> disabled people have to lie on a bed-like wheelchair; people don't involve them. Or people who feed through a tube. Severely or multiply disabled people are seen as difficult to reach. It tells you a lot really doesn't it?

> I don't think people who fit more than one box, for example if you have a learning difficulty and a speech impairment you don't get invited to join in.

It is perhaps not surprising that people with more complex support needs are deemed 'hard to reach'. When we consider the barriers to access that most disabled people encounter and how difficult it often appears to be to meet the most basic of access requirements, it is understandable also that people with more complex support are also reluctant to attend involvement initiatives. As this person wrote:

> I have learnt through bitter experience that even when intentions are good, people just don't understand. What is so difficult to understand about 'flat access'? I prefer to stay at home now … I have got too tired to ask about hotel hoists. Completely flat access from the car park – that is if I have one where I can reserve parking – surprising how many places you can't reserve a car parking place! They don't tell me of kerb edges – which means its not flat access … Sometimes you get the distinct impression that it is just too much hassle to involve you.

People are also often excluded where they are seen as 'awkward' or 'difficult' a category in which people who see themselves within the range of neuro-diversity are sometimes included.

Routinely excluded groups

> [Also excluded are] those service users who aren't enthusiastic or interested in meetings, or would rather deal with things in their own way, or people who don't feel comfortable or confident with big projects and can only handle light occupation. People who can't control their alcohol or drug use or who have violent tendencies. People who are too housebound/agoraphobic/reclusive to be able to be involved …

It is possible to think of people who don't get involved as excluding themselves rather than being excluded by others. Yet of course, the likelihood of people getting involved is ultimately dependent on how easy involvement is made and what their expectations of it are. The rule of thumb should always be that the organisation or individual seeking to involve people should take responsibility to overcome people's fears and uncertainties about it, rather than just expecting them to turn up.

Many people we spoke to expressed concern about a more recent group of people who they felt were increasingly excluded; those service users who did not, for whatever reason, have access to or confidence in the internet.

> More and more you have to be able to use a computer. They are expensive and libraries are not accessible to a lot of people.

> It is not just about getting to a library to use a computer. Many people are frightened of computers and don't know where to start.

> They are difficult to use for many service users, unless you have the right software. If you are blind or can't use your hand, you need special equipment and where do you get that especially if you are on benefits? How are you supposed to find out about stuff?

> People with literacy problems would not be able to use a computer. Some disabled people never had the chance for a proper education – it was a 52 weeks a year school, mine, but not like an ordinary school. They were special schools that was not about education.

About eight million people in the UK still do not have access to the internet and half of these are estimated to be disabled people (ONS, 2012).

Unwanted voices

Service users frequently expressed the view that some points of view and some groups of service users were more welcome and acceptable than others. As they said:

> I think [for services] it comes down to those groups who you don't have to make any effort on your part to hear.
>
> It's about not being made uncomfortable. You know the nice middle class wheelchair user who's just like them really, knows their corporate language, wears their corporate clothes ... That's what so many non-service users like in a service user. Not some angry, emotional, drooling person whose speech impairment they can't understand. That is far too challenging and makes them feel awkward.
>
> I think there is like a hierarchy of acceptable disabled people. Those of us who challenge them, not necessarily in what we actually say but just because of who we are as disabled people – we are not the cosy, cuddly, disabled people.
>
> They invite you because you are a mental health service user. But if you act in any way that for them means you are a mental health service user, they are really uncomfortable and don't want to know you. If you mention that you hear voices, which in my case I do, they go: 'Oh No! She's a nutter – get her out of here!' Which if you think about it, is quite mad!

While consultative exercises might welcome views that were in agreement with their own, different, more strident points of view might be less well received. Service users also expect from experience that the more confident and assertive participants become, then the more likely they are to challenge proposals put to them or arguments offered.

This is one of the reasons why service user activists are often dismissed as 'the usual suspects'. While involvement should be diverse and inclusive, this should also extend to including these 'usual suspects' – confident and assertive people whose views agencies may not want to hear, but which are a key part of the overall picture. We'll hear more about this and the importance of not excluding activist and experienced service users, later in this discussion.

The complexity of identity

Service users are often anxious to emphasis that their identity is complex and not just simply that of a service user. They may experience discrimination for more than one reason, face more than one set of barriers and come from other marginalized or disadvantaged groups like BME communities, gay, lesbian, bisexual and/or transgendered communities, older people, single parents, refugee and/or asylum seekers, travellers, homeless people and so on. They may be discriminated against because they are service users or because they are a member of another marginalized group or both. People can also experience discrimination from within 'their own' group. So, for example a disabled lesbian might find she experiences discrimination from the disabled community because she is a lesbian, but she might equally find that she faces barriers from the lesbian community because she is disabled.

This project found no evidence to suggest that service users from particularly marginalised groups whose voices were seldom heard did not want to be involved, if lack of access and other barriers were overcome. There is a sense among many service users, that anyone can successfully be involved if they are properly supported to do so. Minority groups within minority groups can face particular difficulties in getting involved. For example, some women from some black and ethnic minority groups, some refugees and asylum seekers do not have the same opportunities to learn English as men do. Equally some women who have problems with alcohol face particular barriers that men who use alcohol do not.

WHY PEOPLE GET INVOLVED

> The best thing about being involved is going along to these meetings and conferences and doing presentations and … speaking up for people with learning disabilities.

The motivating force for most service users for getting involved is wanting to make a difference (Beresford and Croft, 1993; Carr, 2004). They want to make things better and bring about change. They want control and choice over the services they use. They want to be able to influence policy and practice that impact on their daily lives. Often, we found in this study, that their starting point was the past negative experiences that they had had, without involvement.

> Years ago I was in hospital and I wasn't treated so good. I wanted to find a way to redress the balance and get involved. When I started using the Afro-Caribbean services, we did get a chance to speak to the psychiatrists about how we felt. That's how I got involved.
>
> Having gone through the things I've been through in my life, I thought getting involved would help me and help other people.
>
> We've all had bad experiences and it's important to let the people know.
>
> I would like to see better services with people with learning disabilities.
>
> It was about the way I was treated and – more importantly – the way other people were being treated and abused by social care workers and psychologists. I found it quite disgusting. So I wanted to empower and influence people and make sure that people are heard and able to make changes. That's why I got involved.

They aim to improve the services they receive, not necessarily for themselves, but for others in a similar situation. Thus, for example:

> I know why I wanted to get involved [with social services] because I like to help people with learning disabilities to stand up for themselves and take control of their own lives.
>
> I had an axe to grind because I couldn't get my voice heard. I wanted a way to channel my energies because I was assaulted by a member of staff and I tried to take them to court and my efforts to take them to court were useless. So I exhausted that avenue and I needed some way of expressing myself about what had happened to me so I joined the user group, and I've had my voice heard and it's made a difference in some respects.

Because of this, they are most interested in the effectiveness of their involvement and the outcomes it can have.

> Having your views acted on, it's no good having your views heard if they are not acted on.

THE MOTIVATING FORCE FOR MOST SERVICE USERS FOR GETTING INVOLVED IS WANTING TO MAKE A DIFFERENCE. THEY WANT TO MAKE THINGS BETTER AND BRING ABOUT CHANGE.

One regional group summed up 'good user involvement' as being about 'influencing the agenda and achieving change'. Everyone had a view on what involvement should mean:

> Involvement to me means that I am approached and asked my opinion. It means that my opinion is listened to and hopefully is taken on board and used.
>
> I feel cheated if I don't get involved in the process of anything that's happening to me.

Many service users were clear that where there was a lack of user involvement, they felt:

> Powerless and without a voice.

They gave us many reasons for no longer being involved in particular participatory schemes, where once they had been.The main reason they gave was that it felt pointless. Nothing changed as a result of their involvement; they were just 'rubber stamping' decisions that had already been made. This is the worst form of user involvement as it has a negative effects on everybody concerned.

A clear picture emerged from what service users said during the course of the project. They primarily get involved because they want control and choice over the services they use. They want to influence policy and practice that impact on their daily lives.

Participants made the point that some of the changes they would like to see happen were likely to be long-term goals. It was just as important to look at small and achievable goals. As this service user said:

> In the Second World War, in the prisoner of war camps, one person escaping was a good thing. It's the same in mental health: one person escaping the mental health system is a good thing for me; achieving one change is a good thing for me.

However, there are also other reasons why people get involved, but these can vary according to the basis for people's involvement. The project highlighted that there are essentially two different if overlapping routes to involvement for most service users. These are:

1. Getting involved in your own organisations, like a Disabled People's Organization (DPO), a Centre for Independent Living (CIL), or a User Led or Controlled Organization (ULO).

2. Responding to invitations to get involved from services, government and other agencies and organisations.

These two approaches are not mutually exclusive, and similarities as well as differences between the two emerge. However, generally, service users experience some significant difference between being involved with other service users and disabled people on their own terms and participating in external involvement initiatives. One service user tried to explain the difference, by reference to her own experience of a user led organisation:

> Going to a consultation where you know your access needs will be fully met; where nothing is too much trouble and you don't have to constantly feel awkward; where ground rules are read out and stuck to; where it's OK to leave the room if you need too. But it is more than that – there is a shared understanding that we are coming from the same place, we recognize the commonality if you like between us all as service users and as disabled people.

The project confirmed that at present most user involvement is of the second kind, with much fewer opportunities and resources for the first, user-led approach.

Why people get involved in service user and disabled people's organisations

We already knew from earlier work undertaken by Shaping Our Lives that service users valued the opportunity of being able to come together in their own organisations to share experiences and knowledge (Branfield et al 2006). Since the emergence of service users' and disabled people's movements in the 1970s and 1980s, service users and disabled people have recognized the importance and centrality of coming together, sharing experiences and supporting one another to bring about change (Beresford and Campbell, 2004; Campbell and Oliver, 1996; Campbell, 2009). Participants in this project again emphasised the importance of and gains from service users coming together, both in terms of improving the quality of their lives and sustaining a more effective voice and presence to make a difference. They talked about the benefits of meeting with other service users. These included psychological, social, occupational and other benefits:

> I love the group. I like to get involved with it because I love these people.
>
> It helps you to get out of the house to talk with people who are in a better frame of mind.
>
> Sometimes you just don't know things and involvement helps you. You meet with people and get problems off your chest.
>
> On a non-political level, getting involved in steering committees and so on, to me is primarily to occupy myself in what I want to do and occupy myself creatively. That helps me mentally, that helps to keep the mind and body together. I can't do too much but I get the balance right and it helps keep the mind and body together.
>
> My last meeting with a service user organisation, it left me feeling very positive.
>
> Being listened to, being asked your opinion and being allowed to answer the questions. Being involved in setting the agenda, not being told that everything you try to raise isn't on the agenda.
>
> I wanted to be able to meet other service users and make friends along the way.

One service user described how she felt before becoming involved with a local group:

> I didn't think I had a right – I didn't even have a concept of involvement.

Another said:

> Before I joined our group I thought I was alone. I was always made to feel that I mustn't complain, mustn't grumble ... I should be grateful that I got any help. No one said it to me it was how I felt. But now I know I have rights and I feel I have friends and support from others.

One participant highlighted the importance of being able to socialise with other service users by talking about someone she knew who couldn't come to the user group:

> She would like to come. She is a bit lonely by herself; she doesn't have nobody else to talk to. She would like someone to help her.

Two service users articulated what they liked about service user only meetings. They highlighted the sense of commonality and unity that they shared with other service users:

> I like going to meetings where you don't have to explain yourself. This only happens in meetings where everyone else is a service user and service users are in charge. It is quite difficult to say exactly what the difference is. But it is there.
>
> It's like ...If you feel you want to leave the room you can, but if you are the only service user there you can't. Because you would have to explain yourself. It's about that, but more!

Many participants were clear that meeting with other service users was the best way for service users to make their voice heard. By coming together they were better able to influence change.

> The pensioners' group I belong to is a lifeline because it is political. We don't just go and chat. We bring up issues about a better standard of living. We canvass, we go to Parliament, we demonstrated against the war in Iraq and all of those things. It gives a lot of us a new lease of life because some of us were active trade unionist before we retired and suddenly we weren't anything.
>
> … it is about coming together for something we believe in that might be completely separate to our service user identity.

Many participants saw coming together with other service users as a political activity:

> I have become politicized because I've seen what goes on with user involvement and in the mental health system, so you do become politicized once you become involved in user involvement.
>
> I've had so many good experiences, getting involved in the black user group, getting involved in a national service user organisation and attending some brilliant conferences. They took me to a place that I wasn't at before, which is opening my understanding and opening my mind to different experiences and the way different people solve different problems, which is great.
>
> I had what I call my bubble year when everything seemed to be going on around me and I felt very isolated. Fortunately someone burst the bubble and helped me start to get involved. I realised that there were other disabled people there who couldn't speak up for themselves so I became an advocate and that's really helped me to start getting rid of the stigma and the discrimination about what we are.

Getting involved in service user organisations makes possible the crucial link between people's lives and the worlds they live in; between the personal and the political – being able to see the connections and being in a better position to do something about them. Since the emergence of service user organisations and movements, service users have consistently stressed the importance of collectivity – of being able to do things together to bring about positive changes in their everyday lives. A recurring theme in this project was the importance of service users having the chance to work together to bring about both positive changes to themselves as individuals and for service users and disabled people more widely. This was best achieved by getting involved in service user or disabled people's organisation.

For many service users and disabled people, joining a local grass roots disability or service user organisation is the first step to having more choice and control over their lives and services they use.

Why people respond to mainstream invitations to get involved

Most participants in the project who had some history of getting involved, had had experience of working with initiatives and organisations which were not service user controlled These experiences ranged from one-off consultations, going to and speaking at conferences, being a service user representative, to taking part in research and being a member of a social services inspection team. Some of the participants told of good experiences they had had:

> I suppose sitting on recruitment panels gives me the hope that I'm making some kind of difference, so I guess sitting on recruitment panels is my best experience.

> My best experience was the Liberty Festival – performing and shouting out against the whole colonial thing.

> I've had several good experiences really, one of the first was making individual speeches in a conference and being satisfied that I done something useful, another was being elected onto a committee.

Again, it was clear that the motivating force for the majority of the service users for becoming involved in this way was essentially political. They wanted to make a difference. People got involved because they want to improve the services they received, not necessarily for themselves, but for others in a similar situation:

> I know why I wanted to get involved [with social services] because I like to help people with learning disabilities to stand up for themselves and take control of their own lives.

> Taking part and having your views heard.

People pointed to the high degree of personal satisfaction and the sense of achievement that could be gained from being involved in non user controlled initiatives:

> I get stuff out of it and they get stuff out of it. It's a two way process.

> I was a speaker at a conference and it went down really well.

Good experiences of involvement for some service users meant being able to play an active and effective role, as these two explained:

> When we had social services here and we trained them – that was good.

However, participants in the project had much more to say about the negatives than the positives of such external opportunities for involvement. They gave far more examples where they felt that what they said was ignored or undervalued. This reflects findings from other studies (Branfield & Beresford at al 2006; Beresford et al, 2011). They talked about not being listened to and the lack of follow-up action. All this offers insights into why people don't get involved or stay involved.

> I just can't be bothered anymore. You never hear what happens. You think 'what's the point'?

> The one thing that I get disappointed with, is you don't get much feedback from these meetings and that's important to find out if the things that we've discussed are going to come to fruition or not.

> Why do you ask people to get involved and then don't listen to them? And now people don't use the service [set up without listening to people]. It sounds like they are wasting their money.

> Even where I've had good outcomes the experience has not been good of getting to that outcome. I tried to raise an issue at a forum meeting with some of the directors and the chair said it was something for another meeting. It sounded reasonable so I went to the other meeting and they said it wasn't for that meeting. I did not accept this and decided that they were going to listen to me and we did have a discussion in the end. It was a good outcome but it was a disgusting way of having to get there. I don't regret what I did but I do regret that I had to do it like that.

Another participant added:

> We need them to talk to us about making the priorities, not just keep telling us that they don't have enough money.

Some service users have developed a sophisticated understanding of what involvement should – but often doesn't – mean:

> It means being included and when you talk about being included there are several different levels of that; being included in the planning and being included in organisation.

So it's about what level you are coming from. If you are included in the planning you should be there at the start and at each and every opportunity.

There is inclusive involvement and exclusive involvement. Exclusive involvement means that you are only asked about things, you are only giving an opinion which may not be taken on board. Inclusive involvement is where you achieve some change, which means you are part of something that you are contributing to and that influences other organisations.

What works best

Service users told us that getting involved with other service users was generally an empowering and positive experience. They felt comfortable talking with and sharing ideas and experiences with other service users. As they stressed, involving them should not mean inviting one service user to join a meeting or committee. One of the most successful ways of hearing what service users have to say is by asking service users to come together in a facilitated service user only forum.

Thus the most positive experience of involvement that service users reported came from user-led initiatives, that is to say where service users were supported to come together in a service user only situation facilitated by other service users. This was true whether such involvement was sought by a user controlled organisation, a non user controlled organisation or a statutory body. It is the fact of service users coming together with other service users which is most empowering for those concerned. It also seems to result in better, more insightful contributions than when services users are in a minority in a group, or consultations are organised from a non-service user perspective.

What can be most helpful, for people who want to get involved, where this is possible, is to get involved first in a service user group or organization and then from that springboard, to feed into user involvement activities offered by services and other organisations. This makes it possible for service users to link up with others, find out more, gain confidence and skills, as a basis then to get involved in participatory initiatives – from a position of greater strength. It means that they are able to be part of collective action for change as well as developing and expressing their own particular individual point of view.

BARRIERS TO INVOLVEMENT

> 'Hard to reach' groups' – what does that mean? They say young homeless people are 'hard to reach'. You can't walk down this street without tripping over them. How does that make them 'hard to reach?

There are some obvious barriers that can keep people from being involved. They can have particular significance for those seen as 'hard to reach'. These include:

Physical access barriers

For example:

- Heavy fire doors
- Steps
- Entry system.

Organizational barriers

For example:

- Inflexible work style
- Jargon and inaccessible language
- Negative attitudes of professionals/ colleagues (These can be institutionalized organisational attitudes and/or individual attitudes).

Attitudinal barriers

For example:

- Assumptions made about people's abilities
- Disablist humour
- Inability or unwillingness to acknowledge difference.

Structural barriers

For example:

- Lack of accessible transport
- Lack of appropriate communication aids
- Lack of appropriate support.

Barriers can also be more subtle and complex. Participants in this project highlighted many barriers in the way of service users getting involved, particularly in mainstream participatory initiatives. Such barriers take many different forms and operate in different ways and at different levels. External barriers – barriers set in the way of people's participation, could also exacerbate difficulties or obstacles people faced within through their lack of experience or confidence in getting involved. Such external and internal barriers – barriers within us through our make up and experience and barriers we face from outside – clearly operate in complex association with each other. Here we focus on six of these barriers:

- Devaluing service users
- Tokenism
- Stigma
- Confidence and self-esteem
- Language and culture
- Inadequate information about involvement.

BARRIERS CAN BE SUBTLE AND COMPLEX. PARTICIPANTS IN THIS PROJECT HIGHLIGHTED MANY BARRIERS IN THE WAY OF SERVICE USERS GETTING INVOLVED.

Devaluing service users

Many service users felt that what they had to say was not generally listened to, valued or respected in the same way as what service providers, 'professionals' and other conventional 'experts' contributed. In other words, what 'professionals' or 'experts' knew, their knowledge, was prioritized and given greater weight and credibility than what service users knew from their 'experiential knowledge'.

As one service user said:

> At one meeting, the university professor turned round to me and said: 'Well, you are not qualified to have an opinion'. So that put me in my place didn't it?

Another said:

> I've been doing all this research and now have three academic publications, which is a really big deal. ...These academics make me feel like nothing – though I'm sure they don't mean to – while what I've achieved is massive. There's a sort of invisibility.

One service user said that she had been to a meeting to do with involvement in funding universities. She said she hadn't understood any of the meeting and that it was 'boring' and that she 'left early.' Another said:

> I went to a meeting with the social services and they asked me to join in their meetings... They didn't get me involved. They didn't ask me any questions or anything. They just had the files piled up on one another [and were] talking among themselves as if I wasn't there.

All this added to the general sense of exclusion and disempowerment that participants in this project felt service users experienced on a regular, sometimes daily, basis. Such involvement can only be expected to exacerbate any sense of low self esteem and poor self-worth service users may already have.

Tokenism

Service users regularly reported that when they had been involved it often felt tokenistic rather than meaningful. As these service users explain:

> What I hate is when statutory bodies and professional workers are asked to get service users involved, but a lot of the time it's tokenism and it's just about ticking boxes.

> You feel you are just rubber stamping.

> Sometimes you definitely feel that you are wasting your breathe because you don't get the impression that your views will be acted on.

Many respondents clearly felt that their 'involvement' was a mere publicity exercise, so that organisations could say that they had 'consulted' and that decisions had already been made:

> It appeared to be that the outcome of the meeting had already been decided and that the involvement of service users was nothing more than an exercise to 'tick the right boxes'.

> Tokenism – the agenda had already been 'decided' before the meeting. It was a case of 'wheel in the 'expert' service user, tell them what is going to happen', rather than ask them what is required.

> We don't get to discuss the big issues – like means tested charging and eligibility criteria. I have 25 years of participating in user consultation at the council and I have learnt that ultimately the real issues, funding eligibility etc. etc. are decided politically. Users views are irrelevant at such times.

> People usually get disillusioned and don't attend meetings again.

This point is important and has repercussions, not just for individual service users who are left feeling frustrated and disempowered, but more generally it also goes some way to help explain why service users give up their efforts to have their voices heard as it can feels so difficult, even futile:

> There is the sense that you can't make a difference.
>
> We seem to have been saying the same things year after year but no action has ever been taken on our comments.
>
> Nothing seems to happen as a result of these meetings. They seek a lot of information from us to explore what works and what doesn't work and what we'd like but then a big fat nothing!
>
> A lot is discussed in the meetings about meaningfully involving service users but there is no power sharing and subsequently service users loose interest.
>
> When involvement is not genuine but blatant box ticking – this is extremely undermining and frustrating.

It became clear in the project that where service users experienced involvement as unproductive and tokenistic, they felt disempowered, disillusioned and disappointed. This has far-reaching consequences for all organisations striving for good practice and meaningful involvement since it undermines the trust and confidence of service users that they might seek to involve.

Stigma

All participants in the project highlighted the importance of stigma as a barrier to involvement. Interestingly, in the group discussions we carried out, each specific user group thought that issues of stigma had particular resonance and meaning for them. For example, members of the black mental health user group talked about black people's reluctance to take up assistance, such as free passes for bus travel because they did not want to be identified as a disabled person or a mental health service user. One service user went on to explain why it was difficult to involve young, black men:

> Certainly for young men entering the mental health system it was not 'cool' to be 'mad' and have a mental health problem and to reinforce that state of affairs by joining a group might be a bit too much for people.

Others agreed:

> Stigma is a major reason [for not getting involved]. Peer pressure, family pressure and ignorance, prevent people from coming forward to get involved and join groups. They don't want to admit to it [being disabled].

This argument found favour with many people who took part in the project:

> People are too frightened of speaking out, so it is going to be difficult to get them to answer questionnaires and get involved because they feel intimidated by the stigma around them. That means they are uncomfortable and we need to find ways to make them feel comfortable.
>
> Some communities just don't recognise that mental health issues exist.

For some service users the idea of 'coming out' as a service user, of telling your family that you are a disabled person was fraught with stigma:

> I cannot admit to my family that I am gay. That is bad enough. I cannot admit to them that I am living with an incurable illness. The stigma is too heavy. They would not want to know me. So for people like me I think it can be very difficult to become involved in things because we are trying to hide that we are service users.

For some of the people involved in this project, the perceived stigma of being different, of being a disabled person represented a serious barrier to involvement:

> You have to accept who you are to get involved. You have to like mixing with other disabled people and be proud of yourself as a disabled person. Some people don't want

> to spend any time with 'the disabled' and try and distance themselves. You are never really going to get those people involved in a meaningful way, because they always deny there are any barriers to anything.

> Having an impairment is saying you are not 'normal'. It is saying that you are not like other people. Some of us put a lot of effort into trying to pass as normal – that used to be me. But other people see you as different and treat you a bit differently. It might be you are 'an inspiration', or you might be a 'freak', but you are always a bit different from 'normals'. There is always stigma unless you are with other disabled people or service users.

There was concern about the negativity of language and how this reinforced stigma, for example, language around mental health:

> The names of places – you say to people, the 'Crisis Resolution Team' and people run for cover. People don't want to get involved with the whole structure of mental health. It's a no- no, and there is stigma. Coming to these places does affect your standing in the community.

Some people saw the label 'service user' as resulted in them being treated in an unequal and patronizing way. For service users who had used drug and alcohol support services, the stigma attached to the label 'addict', could have even more negative and frightening consequences:

> Women are more ashamed and frightened, especially those with children to lose.

> We are really vulnerable when we are in treatment or dealing with officialdom.

Again this was not just an issue for these women. Such fears were echoed by women with learning difficulties:

> Social services took my boy away, my baby. There was no need. I see him now. I am very proud of him.

The stigmatisation of service users did not only come from the general population, it could come from people working in the service system that is meant to help:

> They [professionals] just talk amongst themselves as if you are not there.

There is also growing evidence that problems of stigma are increasing rather than diminishing *(Strathclyde Centre for Disability Research and Glasgow Media Unit, 2011).* While there are now high profile anti-stigma campaigns, for example, the government funded Time For A Change campaign in mental health, any gains seem to have been lost by a renewed emphasis in political and media campaigning on dependent and 'scrounging' disabled people, living on benefits when they should be in employment (Beresford, 2011). Certainly this is leading to rising fears and anxiety among service users, who are increasingly wary of getting involved and reluctant to put their heads above the parapet (Beresford and Andrews, 2012).

Confidence and self-esteem

Service users made clear in the project how empowering getting involved in a disabled people's or service users' organisation can be. But not surprisingly, many service users, having had limited opportunities, many difficulties and little support, have low levels of self-confidence, expectations and self-esteem. This presents very real obstacles to getting involved effectively, or even thinking it is something that might be open to them. Thus while there may be external barriers to involvement for all service users, for those lacking confidence and who are routinely excluded, their own qualified sense of self worth needs to be recognized as a major problem. Many service users raised issues around confidence and self-esteem. For example:

> I think the barriers are people think they haven't got much to contribute, maybe they think they've got a lack of something and can't cope with the situation of coming to a meeting.
>
> Some people don't have confidence to get involved. Others do but lack sustainability.
>
> Service users are often too nervous to come forward and new surroundings are too unfamiliar.
>
> It can be very difficult to speak at meetings at first. You have to build up slowly, you have to feel secure with the group.
>
> Older people can sometimes have their needs overlooked as some behave in a passive manner.

Getting involved can become more difficult when people are going through problems or crises in their individual lives, yet it is just such difficulties and experience that needs to be listened to:

> It was difficult to have an interest in other things because I was so ill. When you're really vulnerable, you're not interested in having a voice. The way I had a voice then was …taking part in a research project.
>
> At first I was too shocked and worried. How was I going to cope with everything. There was such a lot of things I had to sort and learn. And I was depressed. I did not want to go to anything and I did not think I ever would.
>
> Sometimes we just have off days where doing anything is exhausting.

The failure of non-service user organisations to recognise the difficulties that service users may experience, for example, having bad rather than good days, where they have fluctuating conditions, can lead them to make unhelpful assumptions about the level of commitment a particular service user is showing about getting involved, creating additional barriers.

> Because I couldn't go that day they never got in touch with me again which was a shame because other times I might have been able to go.
>
> I did fully intend to go. But that morning I just couldn't face it. I couldn't face all the hassle to get there and then you are not always supported when you go to these meetings.

Another service user introduced the idea of apathy among service users, as a barrier inhibiting their involvement:

> I think there is a general apathy amongst mental health users regardless of their colour or background and fortunately or unfortunately, you tend to see the usual suspects doing user involvement things.

Apathy, perceived or imaginary, was mentioned by other service users in group discussions:

> Negative involvement can create apathy. First and foremost if I start to get apathetic and then the very people that you are working with and co-represent get apathetic, then that's a bad experience because sometimes you can feel like you are in a wilderness.

But what some called 'apathy' also sounded very much like disempowerment, with service users put in a position of anxiety and fear that made them feel helpless.

> The guilts and fears that people with mental health problems have can be manipulated and it's like in religious cults. They manipulate you through your guilt and fear. People become frightened of what might happen if they persist about something or speak up because they don't want to be mistreated or they don't want to have services removed or think that they are going to suffer in some other way.
>
> A lot of mental health service users are not outspoken and never get listened to at all.

> They don't come, they are not asked to come. Some people need help to come – but nobody ever says to them, 'There's a meeting on and we really want your views and we'd love you to come. Can we pick you up at your house?' A lot of people are scared – to my mind it's the people who should most be listened to that aren't listened to. I know that I say too much but I am conscious of the others.

Thus people's lack of confidence and self-esteem, combined with inadequate arrangements for involvement could create massive barriers to involvement, creating a vicious circle, perpetuating their exclusion.

> We are all at risk of getting pissed off. It is not surprising really is it? It can take an enormous effort with no assurances that when you get there, your access is sorted, or that we will be listened to. And then they say we just can't be bothered to come.

Language and culture

Jargon and inaccessible language are widely recognised as important barriers to the involvement for people with learning difficulties.

> They use jargon words we don't understand. They make it boring.

One woman spoke of her time working with social care inspectors. She said that they used 'too long words' and continued:

> They sent this report and it wasn't easy to understand. Too much long words. It wasn't like pictures and it was all messed up. My supporter wasn't sure [what it meant] either.

Others in the same discussion group raised the question:

> Why are they in the services using too long words? Why are they in the service?

Another person said:

> They must speak more clearly – plain English.

But a wider range of service users in the project talked about similar problems, from their experiences of working with statutory services. It was not only people with learning difficulties who identified language and jargon as a barrier to inclusion. Other participants, in group discussions and individual interviews, made similar comments:

> It's the language that's used. Sometimes the language is so full of jargon that people don't understand it. If you can't explain the jargon to them, people don't get involved. There's a lot of jargon in mental health.

> There is a lot of medical jargon that you have to learn if you want to understand your medical condition, because nothing is ever explained in lay person's terms. But also when you go to meetings like with care services and that ...that is a whole lot of other words and meanings that you have to understand.

> They use all these initials. They say things like 'the APP met with the KRS who needed the DCD and then the PAT said you had to have a P74! I mean how are you supposed to be involved in that conversation!

Initiatives for involvement often seemed to assume a level of education and a familiarity with their particular culture that couldn't necessarily be expected of the general population, let alone service users, who sometimes have been taught in segregated schools and have often had inferior educational opportunities.

> They just seemed to assume we'd understand all these things they said. I was quickly out of my depth. It all made me feel stupid. If I hadn't know other people were thinking the same, I'd have felt humiliated. I didn't need any of that, so I quickly walked away.

> Do they think the world is just made up of white middle class people who went to college like them? Talk about a downer!

Inadequate information about involvement

While the rhetoric of user involvement is that it is for everyone and all are welcome, service users told us that there was frequently a lack of readily available and suitable information to know about getting involved. This lack of information emerged as a major barrier. Many people who answered the project questionnaire responded in a similar manner on this issue:

> If there are opportunities, I'm not tapped into them, I'm not really aware of them.

Time and again what we learned was that service users tended to get involved almost by accident. One participant noted how they had come into user involvement by being in the right place at the right time:

> When I initially got involved in user involvement, it wasn't about a political standpoint, or a political view, or an axe to grind. It was basically being in a certain place at a certain time and being offered a chance to get involved.

This service user explained the haphazard way in which they first 'got involved':

> Well, it was accidental really. I met this woman at the eye hospital and we got talking and she said she went to these meetings and such and just invited me to come along. That was to the CIL [centre for independent living], and then through that I met other people and eventually I got quite political!

The same hit and miss system also seemed to apply with how people became familiar with and then networked into service user organisations and movement.

> I met another disabled person I knew locally and she just suggested I come to one of their meetings. The rest, as they say, is history!

While some local service user and disabled people's organisations make determined efforts to engage with local service users, others because of their lack of capacity and limited funds are less able to engage people in this way. Thus:

> We are always wanting to draw in more blood, but basically the problem is a lack of person power to do so.

KEY PROBLEMS

As has already emerged from what service users told us, there are a wide range of barriers in the way of such inclusive involvement. In this section, we look in more detail at some of these barriers and how they can be overcome. These barriers relate to:

- Gatekeepers
- Financial barriers
- Access issues

Gatekeepers

The importance of 'gatekeepers' as a barrier to user involvement emerged strongly during the project. We use the term 'gatekeeper' to describe people in a position to support or obstruct the involvement of service users. Given the vulnerable position of service users, often located within services, at difficult times of their life, facing both personal and material problems, gatekeepers can play an important, even determining role in their lives. Such self-appointed gatekeepers serve both to prevent service users getting involved themselves and obstructing people and organisations seeking to involve them. They could do this by denying them information or support. We ourselves encountered such gatekeepers undertaking the project. The regional coordinators, working closely with Shaping Our Lives on the project, all saw such gatekeeping as a common occurrence:

> The issue of gatekeepers is very serious and significant. And it happens so much that it is not even really noticed. Certainly a lot of the people doing it, are not even aware.
>
> I have certainly had experience of gate keepers standing in the way of reaching service users.

It became increasingly apparent during the course of the project that in order to involve some groups of service users who were routinely excluded, it was necessary to get past certain people who could restrict access. This could include both paid workers and family members.

Some people with learning difficulties who took part in the project told us that they frequently did not get the support that they needed to enable them to join in activities. Sometimes there was actually direct opposition to people participating in user involvement and those in day centres and

THE FOCUS OF THE PROJECT ON WHICH THIS REPORT IS BASED WAS ENABLING THE EQUAL INVOLVEMENT OF ALL SERVICE USERS, REGARDLESS OF THEIR BACKGROUND OR WHO THEY WERE.

residential homes were sometimes prevented from getting involved:

> Sometimes we want to go to a meeting and there is no one around to take you so I can't go to the meeting always.
>
> There is a lot of people, the staff stop them coming. A lot of people don't get the choice to come … They are not allowed out of the centre.

Some service users thought that this was:

> because they [professionals] don't want to let people out to learn and to get out a bit more.
>
> Service users don't get choices and they [professionals] think they know it all.

Participants spoke of parents of adults with learning difficulties who stopped them from coming to groups:

> Their mum and dad won't let them come – not let them come to the group.
>
> They think they are doing right, but we like to go out and talk with other people and hear what others think. Parents can stop that and think you should stay with them, that you can't do things on your own.

Many service users did not have support workers who could overcome such difficulties. One person told us that their support worker would not take them out in the evening, so that they could not go to meetings or other activities after a certain time. It was not only people with learning difficulties who were 'gate keeped' in this way. Mental health service users on psychiatric wards were not always supported to take part in participation events. One person said that she used to be able to visit people on the wards, ask them how they were doing and keeping them in touch any meetings or events that might be of interest to them:

> Like coming to one of our events and talking with other service users. A lot of people find that good. You know that you are not the only one thinking this or that …But now they stop [our organisation] coming on the wards, so we don't always get the opportunity to tell people things. It depends who is working that day, if they know you or not.

Gatekeeping seems to work against more grassroots, user-led organisations, which are often best at putting service users in touch with each other and which service users often find the most helpful, for example:

> It is very noticeable how staff promoted 'conventional' groups but not necessarily user controlled groups.
>
> If for example you have sight loss people think you should automatically contact an impairment specific charity like the RNIB rather than a service user group. So again information about your group is not given to people but the large charity is supported.
>
> This can lead to a vicious circle that can develop. For example my black mental health user group is not promoted by service providers for service users to join, therefore it doesn't have a high profile and is not funded. Because it isn't funded it doesn't have the resources to raise it's profile therefore more people don't know about it and so it goes, etc etc.

Service users also pointed out:

> that if staff and service providers are not supportive of user controlled organizations it also says something about their own perspective and attitude being 'caring' rather than empowering.

Other groups of service users identified a range of 'gate keepers', also revealing that gatekeeping could be both a passive and an active process.

> I think the main gate keepers are those medical professionals who think they know best.

> I think that parents, centre staff and hospital staff etc. could do more to make it possible for people to be involved if they wanted to be, and to avoid discouraging them.

> GPs [general practitioners] are usually the least well-informed people around when it comes to helping you get involved with other service users.

> If you see your GP. and ask for advice on where to go, if the doctor isn't in touch with the right services for you it is unlikely that they will know of service user controlled groups which might be what you need.

Overcoming the problem

Service users highlighted ways of dealing with gatekeepers. The project's regional coordinators discussed what, from their experience, were the best ways of handling or evading gate keepers:

> A security officer wanted to stop me from going up to visit a ward at a hospital but eventually I was let in but only after seeing someone I knew who 'vouched' for me. The security officers were 'self appointed gate keepers' – so the best advice I'd give was make sure everyone knows you!

> Perhaps we need some kind of security pass. So that if we are visiting people in hospitals they know we have a legitimate business there.

One of the most often mentioned solutions to the problem of gate keepers was:

> To get them on side.

> It is important for such workers to feel that you value what they are doing. Care workers often are not valued. They have poor pay and long hours.

> If you are nice to them and ask for their advice about involving 'their' service user and be interested in what they say, they are often really helpful and have a complete turn-around in their attitude towards user involvement.

> Sometimes it is just ignorance. They see someone who has never been invited to take part in things and they don't think that that person might want to, but has never been invited to.

> It's about training isn't it. I think a lot of people find it easier not to think of us [service users] as ordinary people who just want dignity and respect.

Other service users suggested:

> Well …parents. It's not that they want to be bad with their kids. It is just they think of them as their children, whereas they might be adults with learning difficulties. That does not mean they are kids.
>
> That's right. They're adults. They are not children and they can't keep them like kids.

When one group was asked about this issue, they emphasised the importance of empowering service users:

> You have to stand up for yourself and say. I am an adult. I want to be an adult, not a child. You can't make me like a child. I'm an adult. Speak up for yourself.
>
> You need support at first. But that's what I do now. I speak up for myself. I speak up for people with learning difficulty. I speak up now.

A group of people with learning difficulties gave powerful examples of 'gate keeping' and an effective way they had learned to get round it.

> We decided to have a meeting at a local college so that we could get to know new people. There were many people with learning difficulties that we had not seen or talked to before. It took us nine months to get through the doors of the college. We had to talk to the manager of the learning disability courses and she didn't get back to us for ages. We kept e-mailing her. Then she contacted us and said to talk to Jane [name changed], who is a college tutor. When we phoned Jane, she said she thought it would be a good idea to come to the college.
>
> We went to the college twice; the first time to tell the students [what we were doing] and when we were going to come up and what was going to happen on the day. Then we went up to do a presentation and tell the students about [our organisation] and where to come to see us. We gave them our number in case they want to give us a ring. We got them to do forms, asking them what help they need, what things they like and don't like, what transport they need to get to us. We asked if they wanted us to stay in touch and ring them, so that when we did ring we could say to staff and parents that the students had said they were happy to be contacted by us. Because sometimes when you phone up a residential home they don't understand what we are saying and they won't let us speak to a service user resident.

By getting people's agreement to contact them, this group felt they had successfully side stepped potential gatekeepers and involved more people with learning difficulties in residential homes in their work. As they said:

> Now when we phone, we can say that a service user has asked us to give her a ring and they can't say, 'No you can't speak to her, I don't know who you are'. It was so easy asking people if they wanted us to ring them and then sign something to say 'Yes'.

Financial barriers

Money plays an important part in the inclusion and exclusion of service users. It seems particularly to militate against the involvement of groups identified as 'seldom heard'. Service users in the project highlighted the obstructing effects of money in relation to:

- Meeting service users' expenses
- Paying service users for their involvement
- Problems with the benefit system
- Covering the costs of involvement
- Ensuring support for service user/disabled people's organisations
- Money to make change

Expenses

It's important for service users, many of whom are on low income with limited resources, that user involvement is a zero-cost exercise. This means that where they incur costs, these are recognised and either paid up front if necessary or rapidly reimbursed. Organisations like Shaping Our Lives have considerable experience in addressing this issue and there is no reason for there to be difficulties for service users. Yet service users in the project reported frequent difficulties.

Having to wait an unspecified time to be reimbursed for expenses really inhibits people from getting involved. This story from a service user taking part in a statutory organization's participation initiative is typical of many similar ones we heard:

> I had to pay for my train ticket and my PA's (personal assistant's). I had to pay for taxis. It all mounts up and it was peak travel because they didn't think about the time. And then they didn't pay me expenses for nearly six months. I just couldn't afford it the next time.

For some service users the initial cost of travelling to a meeting can be prohibitive:

> I have to pay for a taxi to pick me up and take me to the station. Then I have to pay for the train ticket, then a taxi at the other end. And sometimes they want to start the meeting so early that I need a hotel. Really if they want the best from me, I need a hotel if any meeting starts before 11.30. That is a lot of money to spend.

> I have to have someone travel with me. I couldn't do it on my own. So I have to pay for that plus all the train tickets and taxis.

> They tell you, all bountiful and 'look how generous we are' that they will pay our expenses. But they want us to travel at peak time that means peak fares and I don't personally have that kind of money just lying around. They have no idea of the reality.

As this service user said, organisations are not always aware of the difficulties this can cause:

> Sometimes you then get behind with paying for other things you need, all because they haven't paid you back for getting to their meeting.

> When you do stuff for the Department of Health, the NHS or any of these statutory bodies you can wait an awful long time for expenses. I've known examples of people waiting six months and even 18 months and they still haven't been paid.

One service user had experienced a two-year delay. User involvement needs to be based on proper and principled practice. This includes recognising and responding to service users' frequent financial insecurity, rather than exacerbating it.

Payment for involvement

The principle of paying service users for their involvement has gained increasing official recognition in recent years. For many service users, it represents a recognition of their contribution and a valuing of their experiential knowledge and expertise. So, for example:

> You can't really feel that you are equal when you know the 'professional' next to you is being paid a large salary.
>
> We should be offered a proper fee, to show they value what we say, as much as any other expert they invite.
>
> The service provider was keen to have service user input ... as long as they didn't have to pay for it.
>
> I firmly think I am an expert by experience, therefore I should get the same rate as any other expert consultant.

One participant in the project was a service user poet and performer who had been asked to perform at involvement events without the offer of payment. He said:

> People just want to be given what they're worth really.

Not everyone agrees with this and not everyone wants to be paid.

> I think some people have such a low level of self esteem and self worth that they are frightened when you offer them money and think that you want something from them that they will be unable to give. So it scares them.

The general view, reflected in the project is that people should have a choice and be paid if they want to be. Many people thought that payments were an important incentive to become involved. Others felt that paying service users could put too much pressure on people.

Payment for getting involved is by no means a universal practice. While official organisations like the Social Care Institute for Excellence have tried to rationalise payment and put it on a clear footing, there are no officially adopted guidelines and when people are paid, rates vary significantly.

> It shows how much they value what you have to say when they pay you £10 for the whole day. And you can be sitting next to some professional who is getting hundreds for the day.
>
> They say that it wasn't in the budget. Well they should have included payment in the budget.

Benefits problems

Payment for participation, however, continues to be a complex and controversial policy, however much it may be valued, because it is still often at odds with welfare benefits policy and practice. Shaping Our Lives undertook independent research (Beresford and Turner, 2003) that demonstrated the difficulties that many service users on benefits experienced when they participating in involvement initiatives.

> If I attend one meeting, where transport has been arranged and I know my access requirements will be met, they see this as me being fit to work. They don't see me the next day when I can't get out of bed and I am in pain. They just think oh another scrounger who shouldn't be on incapacity benefit.
>
> When you go to a meeting you, know if the worst came to the worst, you could leave. It is not the same as a job, where you would have to do it all the time. A one-off meeting is different to a job and I can decide on that morning if I am up to it. People think that you feel the same each day. Well, it's not like that. Some days you can face things, others you can't.

Benefits policy has long been preoccupied with the fear that claimants are trying to defraud the system, this concern seems to have guided its approach to paying people for getting involved. Despite years of campaigning to try and improve policy, this remains complicated and frequently at odds with enabling people's involvement, despite the fact that governments also call for people to get involved. People can put their benefits at risk even through receiving expenses. Even if they don't receive payment for their involvement, they may still be seen as having 'notional earnings' (they could have been paid) and their claim questioned. As a result many service users on benefits are frightened off getting involved or left in fear that they may get into trouble (CSCI, 2007; Beresford, 2007). For example:

> Some people will only accept expenses if no one else knows they are receiving it; I used to pay one person in the toilets to get round this.

Many service users were worried about their entitlement to benefit, if they were paid. They did not want to defraud the state, but equally they did not want to create additional problems by being unnecessarily open about what they were doing. The study suggested that the two policies; benefits and participation policy, were essentially at odds with each other. This problem has important implications for service user involvement. Not only does it mean that many service users are likely to be discouraged from getting involved, but it is also likely to have a disproportionate effect on those most likely to be receiving benefits. They are likely to include some of the most disadvantaged service users. Indeed it even suggests that people on benefits constitute an additional 'hard to reach' group.

Covering the costs of involvement

While involving service users inevitably has costs, these can vary significantly between different individuals and groups. Some service user groups are seen as having higher support costs than others and it can be a short journey between that and seeing them as too expensive. This is particularly true when a professional support worker or interpreter is required to make an event accessible for one service user or additional technology is required. Thus sometimes people who require a palintypist, their own special transport, a BSL (British Sign Language) interpreter, a touch signer or an interpreter in to a language other than English, can be excluded on essentially financial grounds, simply because an adequate budget has not been provided.

> There's often a lack of realism about what it will cost to involve us; the fact we might need a floating PA (Personal Assistant) for example, to help on the day.
>
> You can sometimes imagine the calculations that they are making. 'If we involve this person, they'll effectively need an ambulance to come, they come from far away and for the same price we could get ten other people'. It can be really excluding.

Ensuring support for user led organisations

This can be a difficult issue for many service user organisations who all too often are under-funded and poorly resourced. As a result user led organisations are not always able to be as inclusive as they would want to be. Until they are adequately and more equally resourced, it is likely that they will have to make compromises over involvement, however unsatisfactory that is.

Money to make change

Money also has a role to play in making possible the change that people want from involvement. Offering involvement without any resources for such change to follow from it undermines the whole exercise, as service users told us:

> They said there were no financial resources to put necessary and appropriate services into action.
>
> They invite us along and ask us what we think and then say they haven't got the money to do what we said was needed. What is the point of that exercise?

Overcoming the problem

User involvement like any other policy and practice has financial implications. Sometimes these have been ignored and under-played as it has been treated more as a rhetorical 'good thing' than a practical policy. What this project's findings make clear is that if there is to be broadbased involvement which extends to groups that can now expect to be excluded, then:

- Realistic budgets must be set for participatory schemes and initiatives to be meaningful, diverse and inclusive
- Effective payment and expenses policies and practices must be developed and resourced
- Welfare benefit issues affecting people who want to get involved must be satisfactorily addressed at all levels, from central government policy level through to local user involvement initiatives. This is especially important at a time of major welfare reform when negative stereotypes of service users are being increased by political and media campaigns
- User led organisations need adequate and reliable funding
- Funding must be identified for implementing change following user involvement.

Access issues

The project highlighted that inadequate access continues to be a major obstacle in the way of people's participation. It particularly and directly affects the involvement of many of the groups identified as 'seldom heard voices'. The strong message from service users coming out of this work, is that providing inadequate access facilities to service users who have been invited or encouraged to participate, is a reflection of the low worth and value that they are all still too often held in.

Access is about providing people with equal opportunities to participate fully in whatever is being offered. If service users' access needs are not fully met, then they are being denied full and equal participation in society. Access therefore is essentially a human and civil rights issue. Ensuring access is complex, individual and takes time. It cannot be viewed as separate from the value that is placed on inclusion and diversity. Many service users reported that they have experienced numerous barriers when trying to participate in involvement initiatives, run by professionals and the service system.

Access tends to be narrowly associated with physical access – for example, can a wheelchair user get into this building and move about freely within it. But access is much more than this. The project highlighted three areas of access:

- **Physical access** –enabling people to negotiate the environment, including the built environment on as equal terms as possible
- **Communication access** – including people who communicate differently on equal terms
- **Cultural access** – challenging possible barriers created through class, organisational, gender, ethnic, or other cultural factors.

Access barriers can range from the most obvious, for example the lack of accessible signage, to the most fundamental – for example, an organisational culture that treats service users as inferior, threatening and unwelcome. This may be reflected, for instance, with their first contact being an unsupportive and hostile receptionist.

In some ways physical barriers would appear to be the easiest and most straightforward of barriers for everyone to understand and to sort out. For a wheelchair user a flight of stairs, with no alternative route available (a lift or ramp) is a physical barrier to them gaining access to that level. However service users report many instances of physical barriers left unresolved:

> You go to these meetings to do with service users and while they've invited disabled people they don't have the right facilities.
>
> Things like having fire doors that are so heavy disabled people, like myself, can't open them.
>
> They have a revolving door at the entrance. I can't get through it and have to try and attract the attention of the man behind the desk so that he can unlock the side door for me.
>
> I have a physical impairment and require an office-type chair to sit in. Despite having phoned prior to attending such events this has been disregarded so I am physically unable to stay for the whole meeting time.
>
> Often they expected service users to follow a maze of lifts and corridors unaided.

Here are some of the most common issues that people raised about poor access more generally:

> It's all very well for them to say let's continue the meeting for another half an hour. But I have assistance booked for certain trains. I can't stay an extra half an hour without getting very anxious over my travel arrangements.
>
> Some meetings are too early in the morning which does not give enough time for service users to get ready, have personal assistance or pace themselves if they have limited strength.
>
> Some service users take medications which make them rather drowsy in the mornings, or have poor sleep patterns, which make them tired, so they much prefer late morning or afternoon meetings. Organisers need to find out.
>
> They have meetings in the middle of nowhere that you need to get three trains and two buses to get to. They've clearly never thought through our involvement.
>
> Some agencies think service users have all the time in the world. They obviously imagine we are lords and ladies of leisure. They seem to think our diaries must be empty. So often they just don't give you enough time.
>
> Holding a meeting at 5.30 in the afternoon as they do causes all sorts of access issues. It is not convenient for people who work, people who want to avoid travelling in the rush hour and people with children.
>
> I've tried to get them to change the time but I have failed completely. The reason they give me is they like the staff at the unit to come in for the last half hour and they couldn't be expected to come back later.

This list, emerging from the wide range of service users involved in the project in different ways, highlights the common barriers to inclusion that many service users and disabled people report regularly encountering:

- Lack of basic physical access – including a meeting at a venue without wheelchair access, lack of handrails and steep slopes
- No accessible toilets
- No safe exit from the building for people with mobility impairments in the event of fire
- Lack of accessible information, either prior to a meeting, or at the meeting
- Meetings being held at venues/locations that are difficult to reach
- Meetings starting at unsuitable times, particularly those which incur travelling during rush hours
- Not keeping to agreed times

- Uncomfortable venues – in terms of light, heat, seating, air conditioners
- Background noise
- Use of visual aids with no explanation for people with sight impairments
- Hearing loops not working
- Poor access to food and refreshments – no assistance with buffet food and nowhere to sit when eating
- Lack of comfort breaks
- No facilities for assistance dogs.

No assumptions should be made about access. There are some key points to remember:

- People with one kind of impairment are no more likely to have built-in knowledge of another group's needs than anyone else.
- Non-disabled people are unlikely to have a good understanding of anyone's access needs unless they make real efforts to find out from them.
- One group's access needs can conflict with another's. For example, at a meeting, when people with learning difficulties are discussing what to do with their supporter, the noise they make may make it difficult for people with hearing impairments to follow what is going on at the meeting. Different access requirements have to be carefully integrated with each other.
- Supportive technology is often promised, but doesn't always work! When venues tell you they have a hearing loop, this does not necessarily mean that it is working or that it will work well in conjunction with the particular aids that service users who are coming will need. Technology and all promises about access always need to be checked by people with the necessary expertise and experience.
- There must be a reliable expectation that access needs will be met, otherwise people will not take part, because they do not want to risk all the problems of their needs not being met and being excluded or stranded.

Overcoming the problem

In the light of the frequently reported failure in participatory initiatives to address even basic access issues, it is difficult to accept that such barriers represent no more than minor oversights or practical problems. Instead they suggest a lack of thought and consideration for the situation of service users. This represents a much more fundamental devaluing of them and their potential contribution. Meeting people's basic access requirements is not only a duty under disability anti-discrimination and equalities legislation. The failure to do so makes meaningful and inclusive involvement impossible. Until such barriers are removed, it is hardly to be expected that service users with higher and more complex support needs will either be able or want to get involved to any serious degree.

A helpful and abiding rule of thumb (as yet to be disproved) is that everybody can express themselves, get involved in some way and contribute, if their access needs are properly met. This may be through the use of photography and pictures, through facial expression, through making noises, through movement, through new technology. Certainly it means going far beyond the traditional limited menu for participation of public meetings and consultation questionnaires.
If people seeking user involvement are not sure how best to meet service users' involvement, then they only have to turn to a user led organisation to begin the process of finding out how to do it. There are disabled access experts who are highly experienced in providing audits for accessible involvement for events, buildings and participatory initiatives. There is no excuse for denying anyone's involvement.
In the next section, we look more closely at access and support in their broadest sense, the key requirements for diverse and inclusive involvement.

OVERCOMING THE BARRIERS

Overcoming the barriers that militate against some people's participation is not rocket science. However, judging by the slowness with which some organisations and individuals have sought to address them, they might as well be much more complex than that.

Robson and others (2008), offer a 'practice framework' – a model 'outlining how to enable the participation of seldom-heard groups'. Their basic argument is that participation works when it is an integral part of everyday life. Participation cannot work if it is viewed by managers, practitioners and service users as an 'add on'. They suggest that 'seldom-heard users of social care services can become engaged if practitioners and managers adopt an integrated, 'everyday' approach to participation'. This integrated or systematic approach to user involvement is echoed in other works primarily carried out by the Social Care Institute for Excellence (see, for example Begum 2006; Butt 2006; Stuart 2006).

We have already set out a range of practical ways of addressing the exclusions which continue to have a biased and restrictive effect on the involvement of some service users and service user groups. In this chapter we set out a series of key ways forward. But first as service users who took part in this project were quick to remind us, in their view, there are some essential basics that need to be addressed.

Recognizing the barriers

The first point that they made was that unless organisations recognized that such barriers exist; that they are real and they work to exclude many groups and individual service users from involvement initiatives, then progress will not be made. It is crucial that such barriers are acknowledged and that proactive steps are taken to overcome them.

A realistic response

Participants in this project were clear that if certain groups of people came to be identified as missing and as being excluded, then it was crucial to identify exactly which group or groups organisations want to reach. As one service user put it:

> A general 'let's be more diverse' approach is not going to work.

They can then put in place realistic, workable arrangements to involve such service users and perhaps build on this over time. At the heart of this is starting small and seeking to build trust. Another service user summed this up in the following terms:

> If people have a bad experience at the first thing they go to, you have lost them. They won't come back.

IT IS CRUCIAL THAT BARRIERS ARE ACKNOWLEDGED AND THAT PROACTIVE STEPS ARE TAKEN TO OVERCOME THEM.

Access and support

Before we turn to these key elements for diverse and inclusive involvement, it is important to put them in context. A large national study focusing on person-centred support has highlighted that there are two essentials for participatory, user-led and person-centred support. These are adequate funding and a changed agency culture. (Beresford et al, 2011).

Adequate funding

Lack of money is no excuse for continuing to provide excluding, inappropriate and unacceptable services or stopping service users from having any say in what happens. But all the signs are that if there isn't enough money, then services are likely still to be budget rather than user-led, that is to say, they will be shaped by what money is available, not by what people want and prefer. Unfortunately social care still has low political priority and has long been under-funded.

A changed agency culture

Traditionally welfare services were based on what the people who provided them thought was needed. Often there was a big gap between them and the people who used these services. As a result such services have often been experienced as patronizing and disempowering, making the same narrow range of provision, often segregating service users, lumping them together and institutionalizing them. There needs to be a change in such culture to a much more empowering one, based on involving service users fully and equally and moving from doing things for or to people, to one of working with and involving them.

Both of these elements, adequate funding and a changed empowering culture are important and essential. Neither is enough on its own. A changed culture is unlikely to last long if there isn't the funding to support it. More funding without a changed culture, as we have seen in the past, will probably only mean more of the same services, instead of a shift to more user-led provision.

Two essential for inclusive involvement

Two components seem to be essential if everybody who wants to is able to get involved and all groups have equal opportunities to be involved. These are:

- **Access**
  And
- **Support**

Again, both are necessary. Experience and evidence suggest that without support, only the most confident, well-resourced, experienced, acceptable and advantaged people and groups are likely to become involved. This helps explain why participatory schemes often only involve a few people and leave out a wide range of so-called 'hard to reach' groups. Without access efforts to become involved are likely to be difficult and ineffective, however assertive or experienced people are.

Access

Access means that people have ways into organisations, agencies and institutions that affect them, so that they can influence, advise and inform them. This of course includes physical, communication and cultural access as discussed earlier. In the context of services, access also means providing services which are appropriate for and match the needs of members of different groups and communities, particularly minority ethnic communities who we know have often been badly served, although as we have seen this applies to other 'seldom heard' groups as well. Otherwise people will not be on the starting line of using services which they may then want to have a say in.

If people are to get involved in organisations and services to improve them, there need to be continuing opportunities for them to get involved in both their administrative and political or decision-making structures. That means both where control lies and where policy and practice are developed and carried out. This may include membership of sub-committees, planning groups, forums, working parties and so on, as well as involvement in information gathering and consultation exercises. Another important expression is for people to have access to money or budgets in an organization. Money, like knowledge, can be power. It makes it possible for people to have a direct effect on what happens inside the organization and to do things in different ways. The budget may be large or small. People may have control over funds for training, purchasing services, or research, to develop their own organisations or to employ service user consultants. Again access to such funding needs to be equal between different groups.

Support

The need for support doesn't arise because people lack the ability to participate in society, but because their participation is often made difficult. As we have seen there may be many and different obstacles in their way. People may not know what is possible, or how to get involved or how to challenge prevailing barriers. They may not like to ask for too much or be reluctant to complain.

This project highlights that there are at least five essential elements to support. These are:

Support for personal development to increase people's expectations, assertiveness, self-confidence and self esteem. Assertiveness training and confidence building are crucial here.

Support to develop skills to build the skills people need to participate and to develop their own ways of getting involved. A lot of speaking and writing skills have been involved as we have seen in conventional schemes to involve people. People may want to learn more about these, know how to challenge them, or develop different ways of doing things that they prefer and feel more at ease with.

Practical support to be able to get involved, including information, child care, respite care, transport, meeting places, advocacy (of which more later), expenses, payment for participation and so on.

Support for equal opportunities, key to the focus here of including everybody in involvement. This means the whole gamut of support and provision which we have heard about from this project, including provision for disabled people, deaf people, people with sensory impairments, without verbal communication, non-readers, people for whom English is not their first language, people with intellectual impairments and so on and so on, so that they can get involved on equal terms.

Support for people to get together and work in groups including setting up, office and administrative expenses, payment for workers, training and development costs, etc.

Only when these supports are provided are invitations to get involved real and truly inclusive. If you want to be in the best position to be involved and avoid the sense of banging your head against a brick wall when you try, you may find it helpful to:

- Look for these components in any initiative to involve people
- Press for them in any planned scheme, if they aren't already there
- Make them a condition of getting involved (Croft and Beresford, 1993).

Different ways of being involved

A common, recurring theme from service users throughout the project was the need to find different ways for people to become involved. As participants repeatedly said, involvement for many people:

> …is boring. It's about sitting around a big table with people talking and saying things you are not sure if you understand.
>
> It's what I always imagine it must be like to be a member of a political party. Endless meetings, endless talk about minutes and agenda. Really boring.

What people pointed to was the need for many different ways of getting involved, a kind of scattergun or 'belt and braces' approach, which would mean that there was something that everyone could feel was right for them.

> We're all different. They need to do that if they really want to try and involve us all.
>
> What works for one person, doesn't necessarily work for another. I haven't got an endless attention span. Some people seem to like sitting listening.

Service users were clear that new approaches to involvement were needed:

> Providers need to be more innovative in their thinking and actions rather than being obsessed with tick boxes. They need to get out there and speak to people in ways that allow people to respond and not just sit in offices producing endless policies that do very little to improve relationships with people who use services. They need to be honest – and then service users would trust them more.
>
> A more innovative approach to engage and involve people is needed. They need to effectively market the benefits of being actively involved in decision-making.
>
> Use different means of engaging people and soliciting their opinions and be prepared to take the time and trouble to build confidence etc.
>
> Look at different ways of communicating.

Service users tied in such new ideas and new approaches closely with the idea that involvement must be fully accessible and avoid tokenism. Specific ideas for involvement they suggested included setting up regional forums on social care and education that would be run by disabled people and service users, which would replace other, already existing structures and organisations. Service users stressed that user-only meetings overcame many of the barriers that service users faced, when, for example, they were the only service user or disabled person in a non-service user meeting.

> The best meetings are always the ones where it is run by and for service users and disabled people.
>
> If it is just service users it is better because they are friendlier meetings and less formal.
>
> You can knock an idea round a bit more if you are with other service users. When you are in what can feel like a hostile environment, if you are the only disabled person there. You don't want to speak really. And you certainly don't want to try an idea out like you might if you were with all service users.
>
> Consider having separate meetings, possibly inside a larger meeting. Have pre-meetings to get to know service users – this is important for communication. Use trained facilitators before and during meetings. Consider other ways (of running meetings) – have events that are not as formal as a meeting.

The present picture service users report, however, seems to be one that is far from recognising all these issues. Current opportunities to get involved in services and public policy and organisations, the main routes for involvement, basically depend on two approaches. Both are essentially about service users responding to efforts to involve them. As has been mentioned before these two approaches are:

- Carrying out local and national surveys and consultations to gain their views
- Bringing people together at meetings and events.

We know from the evidence that the former are the most easy to ignore, while the latter tend to get the most limited and biased response (Beresford and Croft, 1978). However while each has inherent limitations, as service users highlighted, both can work to involve a wide range of people, if they are used positively and imaginatively. Thus service users highlighted the importance of surveys and consultations which:

- Were as accessible as possible and highly profiled, so that a wide range of people could hear about them and they met their access needs
- Were carried out and available in the places that service users go to, as well as conventional places, for example, in doctors' surgeries, supermarkets, user led organisations, local community centres and meeting places
- People were kept in touch with the outcomes of such consultations and surveys so that they had a sense that responding to them was worthwhile
- Finally, they were used as a basis for positive change, building trust with participants. Too often service users feel they are ignored in consultations.

> We need to have advertising, send newsletters to all places where mental health users are, so they can see there's things they can get involved in.

Service users also stressed that user involvement meetings and activities, while perhaps not adequate in themselves, could also be greatly improved, with more thought and care, referring to positive experiences that they had had.

> They'd made a real effort to put us at ease. We were met when we got there, shown where to go, introduced to other people. It felt really respectful.

> I'm not good at social things. I tend to get very anxious. They understood and quickly introduced me to another service user who I kept with and helped me feel more relaxed. I felt I could say what I wanted and there was an atmosphere of listening.

It is interesting to note that when the four regional user groups working with Shaping Our Lives on this project wanted to involve the service users that they had identified as missing from their own groups, all decided on holding an event in order to do so. Most other participants also decided on the same approach to draw in previously excluded groups. This is significant, given that they were also aware that trying to bring people together to get involved, has its limitations and certainly doesn't appeal to or feel comfortable to everybody. The groups had mixed success with involving 'hard to reach' groups, although all had some success. But all placed an emphasis on being imaginative and innovative in the events they organised and saw this as crucial if they were to open the doors to wider engagement. Thus they said:

> We should include interesting activities such as music and practical activities such as painting and decorating as a way of attracting people to user involvement.

> Workshops about different relaxation techniques, or herbal remedies – that sort of thing should happen.

> We used picture cards to communicate which was very good.

All four service user groups/organisations who were involved with Shaping Our Lives in this project felt that there were some key features that were central to holding successful and meaningful involvement events. They thought that these would help attract a wide range of service users and not just 'the usual suspects'. They placed an emphasis on:

- Service users having a good time and ensuring that they enjoy themselves
- Providing good, free food and refreshments which are culturally appropriate
- Offering a warm, safe and supportive environment
- People gaining knowledge, awareness and understanding from the events or meetings.

This all makes enormous sense. After all if getting involved is meant to be a positive, then why should the activity of being involved so often seem so dour, so serious and so joyless! The idea of involvement being something enjoyable rather than a challenge is one that many service users in this project signed up to strongly.

It was for these reasons that all the groups/organisations felt it was important to offer participants something more than just the opportunity to voice their opinions and share their experience. Here are some of the things that service users felt encouraged a wider range of involvement and stimulated engagement and discussion:

1. **Entertainment produced by service users themselves, like:**
    - Poetry/performance poetry
    - Drumming
    - Karaoke
    - Music groups/singer song writer
    - Drama/theatre.
2. **Activities which participants could be actively involved in themselves, for instance:**
    - Music workshops
    - Art workshops
    - Drama/role playing
    - Poetry workshops
    - Comedy and sketches
    - Games
    - Writing workshops.
3. **Activities which encouraged networking and making links with other service users:**
    - Cabaret style layout of room with people round tables
    - Small group discussions/activities
    - A long and relaxed lunch break and other informal networking times.
4. **Activities to help people relax and aid communication:**
    - Aroma therapy workshops
    - Yoga/pilates
    - Massage
    - Breathing exercises
    - Reflexology
    - Hypnotherapy
    - Opportunities to be in a quiet, reflection or prayer room.
5. **Supportive and appropriate venues:**
    The importance of choosing the right venue for events was something many service users highlighted. Meetings in service settings, in agency and official buildings are off-putting for many people who see them as stigmatising and don't want to be associated with them. On the other hand, there are a growing range of other settings which service users identify with which add an air of informality and normality and promote a relaxed atmosphere, like:
    - Cafes
    - Pubs
    - Parks
    - Community centres
    - Conference and meeting centres.

Service users stress the importance of treating people with respect if you want to involve them. Perhaps not surprisingly, providing people with good food and refreshments almost invariably gets a mention when people come to comment on what makes for a welcoming and positive meeting:

> The food was excellent.
>
> Everybody loved the food.
>
> I think people were really surprised at how good the food was. They really enjoyed it. It also gave shyer people something to talk about!
>
> Cakes! We loved the cakes!

Outreach and development work

Participants in this project placed a particular emphasis on the importance of outreach and development work if groups identified as 'hard to reach' and 'seldom heard voices' were to be drawn into service user/disabled people's organisations and more general opportunities to be involved. Many service users made this point. The strong message from participants was that these were people that existing arrangements for participation were least likely to engage or be suitable for. Not only were such service users likely to face the most barriers from them, but they were also less likely to:

- Join service user groups/organisations
- Respond to opportunities for involvement
- Take part in events.

Apart from the many other reasons for this that have already been highlighted, this also appeared to be because of many such groups' reluctance or inability readily to 'join in' arrangements which required people to come together in some way. Such arrangements, however, have tended to have a central place in user involvement. As service users said:

> If you aren't a joiner then there's not a lot left except filling in questionnaires.
>
> Not everyone wants to join in things. That's not the norm in our society.

Service users stressed the need for more effort to be put into identifying and reaching the groups of service users who are not getting involved.

> We need to get out and visit service users and let people know who we are, where we are and what we're about. We need to make sure we can support people and meet their specific needs.

For participants in the project, there was an obvious answer. If service users don't come to you, as a service user organisation or involvement initiative, then what you need to do is go out to them. There was a widespread view that this was not generally happening.

Some service users said that some service user groups are difficult to reach and involve:

> They are difficult to find.

One person referred particularly to the situation of travellers, noting difficulties around:

> Their transient nature and not being classed as a member of the local community.

Another made the point that it is difficult to make contact with homeless people as they do not have an address.

However, participants thought that not enough outreach and development work was being carried out to build up relationships with these groups of service users, individuals and communities.

> A concerted effort [needs to be made] to get under-represented users to contribute… Meeting with under-represented groups to hear what they have to say will aid participation.
>
> With some groups it's because we're not getting out there to actually recruit and tell them about it.
>
> Providers cannot be bothered with other communication channels.

> It is very easy to list all the groups who are not usually involved in things. But we and service providers need to be pro-active. We need to be out on the streets engaging with homeless people, or working with social services or whoever to make contact with BME [black and minority ethnic] groups or whoever. We have to be actively working to involve people. People who aren't involved are not going to come knocking on your door saying 'Let me in! Let me in!'.

Service users who took part in the project in a discussion group in a residential home argued that involvement needs to be taken to the service user rather than always being about service users coming to meetings and events. Other participants agreed:

> We could engage people on their patch, rather than them having to come to us.
>
> We need to reach out to people and groups, including people living in institutions and people in prison.
>
> Make sure you have support for people in place in advance and let people know that's the case. People feel empowered if they know that support will be available.

There was a sense that if you want meaningful involvement with service users from minority groups, and those groups deemed 'difficult to reach' then you had to find ways that were meaningful for the service users and that this might be by engaging with people in a new and innovative way.

> It is no good just to say, 'Oh we sent an invitation to a residential home and asked people to come but no one did.'

One service user highlighted the importance of outreach work with black and minority ethnic communities, saying:

> This outreach work would also increase awareness of who is and who is not taking part in user involvement. I don't think we monitor who we are involving very well and I think that is very important. To collect the information.

Others agreed:

> We are not often asked to fill in Equal Opps. [opportunities] forms which we should give out and collect in at every meeting we have. How else can we say, 'We are under-represented and we want to do something about this'.

Service users had specific suggestions to offer about the kind of out-reach work that was needed in order to engage with 'hard to reach' service users:

> They say, and we [service user organisations] are just as guilty as the providers, that young homeless people are 'hard to reach'. Well, excuse me, but just go down any high street anywhere in Britain and they are everywhere… Big Issue sellers, young people sleeping in doorways. They are not 'hard to reach', they are just more of a challenge. That is why we need properly trained outreach workers to go and talk with these people.

In one group discussion, the idea of a register of service users was discussed. People thought that there could be a national register linked to the receipt of Disability benefits. However it was soon agreed that this could become a bureaucratic nightmare that just served to worry service users. Others discussed ways in which a variety of professionals could play an out-reach role by being more informed about involvement opportunities:

> Your doctor or your GP's surgery could make suggestions to patients about ways that they could get involved. They could at least give you a leaflet.
>
> They could talk about it [involvement to children] at schools.
>
> Citizens Advice and places like that should be able to tell you about the involvement opportunities that are available in your locality.

Many participating service users agreed that service providers need to be doing more to reach service users:

> [They] need to revisit how they communicate – and to actively talk to service user/community groups to seek advice on that rather than just thinking they know best.
>
> They've got to put themselves more in service users' shoes and think what might work for them, especially if they are having a hard time or getting involved is difficult for them.

A number of expressions of out-reach work emerged from the project. It can mean:

- **Reaching out directly to service users** – who are less likely to be involved – going to them and offering them positive and purposeful opportunities for involvement. There is no better way of finding out how to involve previously excluded groups than going out and asking them directly.
- **Reaching out to their communities** – for example local black and minority ethnic communities, travellers' communities and so on, to let them know about involvement opportunities which they may able to help such service users link up with. This could also include providers of services for marginalised groups, including residential services.
- **Reaching out to community leaders** – who may have the credibility, links and status to help advance such opportunities for involvement among members of their communities. It is important in such outreach work to include but also look beyond traditional leaders to ensure the impact is as inclusive as possible. They may not reach minorities within their minority (Blakey et al 2006). They can be a key starting point, but efforts shouldn't stop with them. Like any other group, such leaders may hold prejudices and discriminations about particular groups or issues.

It was also apparent from this project, as well as from other studies, that research, particularly user controlled research, has a valuable role to play as a form of out-reach, reaching out to service users to find out more from them, their localities and those close to them (for example, Begum, 2005). This project was an example of this. As service users said:

> We need to find out from service users proactively why they aren't getting involved and what would work to change that – like this project.
>
> Researching with service users puts you in touch with new people, people you haven't had contact with before and can start a process of involvement.

All such out-reach work takes time and effort. It means building and nurturing trust and new relationships, challenging assumptions and finding things out afresh and without bias about different groups and communities. Such outreach work tends to work best when it is undertaken by people with similar characteristics to those they are seeking to engage with, in terms of background, culture, sexuality, gender, impairment and so on. It is also most effective when it draws on and is linked with community work and community development skills and approaches. These have much to offer in making possible diverse involvement and are a key element of effective user involvement schemes more generally. At the same time, they cannot be approached in isolation. Outreach, like other forms of user involvement work must of course follow the essential guidelines for good involvement. These include:

- Treating service users with respect
- Making involvement a zero cost activity for them in every sense
- Feeding back to service users the outcomes of involvement
- Acting on what people say.

Finally, it is essential to remember that outreach work, like user involvement generally, should not only be concerned with involvement that seeks to draw people into group or collective activity, but also operates on an individual basis, where it is possible for people to take part as little or as much as they wish to, in their own space if preferred, to contribute their views and ideas. New technology has created many new ways in which it is possible for people to be able to get involved in virtual and individual ways, particularly through new social networking and social media techniques. We will be looking at this in more detail in the next chapter.

Advocacy

Advocacy is at the heart of good user involvement and is a pre-requisite to make it possible. Perhaps the most important kind of advocacy is self-advocacy. This simply means people speaking and acting for themselves. In a sense getting involved itself, is an expression of such self-advocacy.

Advocacy is especially important for people who have had negative and disempowering experiences and who feel that they lack confidence, knowledge and skills that they need. This is often the situation of people who face the biggest barriers in the way of getting involved. Unfortunately they are also likely to be the people with the most limited access to advocacy. Thus we heard from service users:

> It was learning from other service users how to speak up that turned my life round. I got confidence to say loud and clear what I thought. I know lots of people that isn't true for though.
>
> A lot of people need some help if they are going to get involved. That's where advocacy comes in.
>
> If someone has been disempowered in their life – cut off, on their own, no one to tell them what's possible for them, how will they be able to have an impact without help?

All forms of advocacy are concerned with helping people speak and act for themselves. Five forms of advocacy are identified. These are:

- **Self advocacy** – where people learn how to stand up for themselves. This can be on an individual basis (on your own) or a collectively (with other people in the same or similar circumstances). Service user organisations offer a key form of collective self-advocacy
- **Legal advocacy** – when we are represented in law courts and other formal settings by legally trained barristers and solicitors
- **Professional advocacy** – which includes people with welfare rights and other skills offering people support and advice to deal with services like income maintenance, immigration, housing and social services
- **Lay or citizen advocacy** – when people make a commitment usually on a voluntary basis to support people to be able to stand up for their rights and entitlements
- **Peer advocacy** – where people advocate for others with similar experience.

The most helpful advocacy and that which service users particularly value is that which is:

- **Ongoing** – not just available in a crisis, but whenever someone needs it
- **Based on a relationship** – developing trust over time so that people feel able to confide and have confidence in their advocate
- **Independent** – of service providers and others who may not be on the service user's side, but have their own interests
- **Accessible** – readily available when people need it, taking a pro-active approach to reach them
- **Competent** – through proper training and support for staff
- **Culturally sensitive and diversity aware** – addressing the different needs and shared rights of black and minority ethnic and other communities.

Service users stress the importance of advocacy and also the essentials of advocacy if it is to make a difference and enable everyone to be at the starting line for getting involved, becoming empowered and making a difference.

> My social worker was an advocate for me. It was because of her that I first went to a meeting and met other service users.

> It's horses for courses. As a black mental health service user group we could offer the kind of advocacy that other BME service users would trust and value.

Ensuring sustainable involvement

Key to the success of user involvement is ensuring that it is sustainable. It is not enough to be able to put in place arrangements for involvement on an ad hoc basis, trying to engage people in one-off situations, or if there is a sudden call to hear their views. The evidence has long indicated that effective involvement is on-going involvement (Beresford and Croft, 1993). This has become particularly clear in areas like user involvement in social work education, where such involvement is a requirement and it needs to operate on a continuing basis through professional academic courses. (Branfield et al, 2007; Branfield, 2009). It is also extremely difficult to ensure diversity in involvement where there is not an existing infrastructure, because of the need over time to build trust and reach out to 'hard to reach' service users to ensure their involvement.

Key to ensuring sustainability is making sure that at least some service users who get involved want to stay involved. As has been made clear in this project report, it is crucial that there is a serious effort to be inclusive; to reach out to involve new people and a diverse range of people. However, as with every activity, when the focus is involvement, it is also important to ensure that the body of collective expertise, knowledge and experience is built up. That is why some service user groups and organisations talk about 'apprenticing' new people to get involved and also have put in place mentoring and training arrangements to support the development of new people's skills.

> You don't want it to be like a clique, but often, especially when there's little money, things are down to a few brave souls.

> I remember one group I joined and it was just a clique. I quickly got fed up. They weren't welcoming.

But some participants also reported very different experiences from the last:

> I'd been having a bad time. Lost my confidence. Nervous even being out. People were really welcoming. They knew what it was like, they had been there too!

Without such a core of experienced service users at the heart, it is not only difficult for service user organisations and groups to hold together and draw in new faces. It is also difficult, if not impossible, for them to be fully effective. Thus there is a constant need to balance the mixture of new people and old hands, new participants from seldom heard groups and those with a track record of successful involvement. Inclusivity and effectiveness, especially in the short term, can often be in conflict rather than mutually supportive. A group may be very inclusive, but if it does not have the experience to deal with external organisations, agencies and powerholders, it can be vulnerable. It is unlikely to be able to do much to influence them and is more likely to be tokenized.

While this project has detailed how some groups are more excluded than others, we also heard throughout it from participants who had had a variety of negative experiences around being labelled as 'the usual suspects'. For example:

> It's us as 'the usual suspects' who are being seen as difficult and trouble makers. We are not. We are now more self assured. We have found our voice and we will not shut up. Not everybody wants to hear from us. To be fair some do and they value what we have to say. But others would rather get inexperienced service users who are intimidated by the committee table, the smart clothes and business-speak. For some, these service users are much more biddable and they want to boot us old hands from around the table and replace us with inexperienced, pliable 'safe' service users.

> We need the 'hardcore' people. Without them there wouldn't be involvement. I've been in groups before where they tried to get rid of them and it hasn't worked because these are the people with commitment and drive.

> Twelve years ago I was not the person you see today, but thankfully someone came along and changed my life and I became empowered to be involved in the voluntary sector, national work and doing courses and everything. That has gone right round now because I have a label of being a professional service user and a service user consultant and one of the usual suspects, so people don't let me in – they exclude me and disempower me.

This last service user continued:

> We achieved so much – we had a crisis team in A&E (the accident and emergency ward) and we had two projects to get mental health service users back into employment. Now the management committee or core group is made up of outspoken people and we lost our funding last year. They thought that if we lost our funding, we would all go away quietly. But we haven't and we're now taking legal action. Up until three years ago we were the number one for service user involvement in mental health and I used to go to conferences and everyone would say, 'Wow – what's happening now'. What we did today, everyone else would do tomorrow, but it's been run down by professionals and they thought we would all go away, but we haven't. The strange thing is that we work with national care services groups, but we can't work with any local bodies.

While participants in the project generally agreed that it was important to involve new people and be as inclusive as possible, they also highlighted the problems associated with been written off as 'the usual suspects'.

> But the problem is that they want new people who will agree with them and they want to make us walk away.

A different participant said:

> It would be a travesty if we lost those whose services have had a major impact on progress.

Getting beyond the usual suspects; developing diversity in involvement has demonstrated that the service user movement is not a narrow band of non-representative white middle class wheelchair users as some have suggested. On the contrary service users have recognised who is missing, who has not been included, additional barriers have been identified and strategies have been adopted and suggested for all service user groups and statutory care organisations to adopt in order that we get beyond the usual suspects. At the same time it is important to recognise that there is nothing wrong with 'the usual suspects' who have a wealth of experience and knowledge to offer.

Thus schemes for user involvement need to support and encourage experienced service users alongside others and not devalue them. They need to remember that if involvement is inclusive and effective, today's 'seldom heard voices' will be tomorrow's activists and 'usual suspects, having gained the skills, confidence and experience to make the real difference that service users get involved to make.

Issues of power

At the heart of any participatory, involvement or inclusion initiative lies power. Much has been written about power, but it is a subject that is often ignored or overlooked (Lukes, 2005). Yet it is critical for an understanding of user involvement and who does and does not get involved.

There is a conventional rhetoric which talks of 'empowering the service user'; of 'working in partnership' and of 'shifting the power balance'. But what does this actually mean in practice? Service users who took part in this project were clear that power is about the ability to have an influence over what happens. Power is generally not absolute. The power that a person or a group has in a given situation in relation to other people or groups in that situation depends on who is involved and the circumstances that exist.

The power that any one person or group has in a given situation depends on how both they and others perceive that power, for example:

- How much power, relatively, does one individual or group perceive others to have?
- What understanding do they have of their own and other people's power?
- Do they believe that power will be used to influence and improve the situation?

> Some of them pretend we are all the same. But they call the meetings. They decide when to end them and they make the decisions. Service users are just there to look good for them.

> It took me ages to realise that I could actually do something about things instead of just having stuff done to me.

Certain things increase the likelihood of one group holding greater power, for example the possession of information, levels of education, experience, confidence, understanding of how particular systems or settings operate. From this we can see that:

- Feeling more or less powerful is situation based
- Feeling powerful or powerless depends upon perceived notions of who is holding the power
- Disabled people, as a group, are more susceptible to abuses of power, which may sometimes be unintended. This is because power can be exercised over others without recognition of the power held over them
- How a person feels in relation to power is often dependent upon their past experience
- Power can be conveyed in a look, a glance, in body language and through the spoken word
- We are all experienced at exercising power over others and having power exercised over us. Some of us though, are much more used to being the in latter position rather than the former.

In general, power does not simply belong to one group of people who exercise it over another group of people. Power can shift. If you do not recognize that others perceive you to be powerful then you are likely to be exerting that power and unless you recognize this you may be abusing it. Power is not a zero sum game, that is to say, that increasing one person's power does not necessarily reduce that of another. But it can make for the more fair and equal distribution of power and more equal relationships. User involvement can influence the distribution and balance of power, but it is not always intended to do so and doesn't always serve that purpose.

INVOLVEMENT FROM OUTSIDE

Many service users have become sceptical about being involved with statutory and service organisations:

> A lot of the time its tokenism and it's just about ticking boxes and it's time we got away from that and say that we want people to help to shape the services of the future, and to do this we need genuine user involvement.

> The professionals are really just doing it all themselves. They set the agendas, they've always decided everything and what they're actually going to do. They even congratulate themselves on doing things that they haven't done and modernising the service and giving everyone what they want when they've done nothing. To be truthful I'm absolutely baffled at the way involvement happens, I just can't believe it. They spend money on reports and meetings and discussing what they're going to do, then they make out that they've done things when they haven't and they just ignore us.

> The powers that be just get on their high horses and just do what they like. They say that they want your opinion on something and that they will take it on board, but once you start giving your opinion they start to slag you off and say, 'you can't talk about it, we're not talking about that, we're talking about this', and then they say you haven't contributed anything.

> The way they see it is that they are the people at the top; they are holding the whip and we're supposed to obey them. So they make all the decisions and they don't let us have a say, they don't want us to even make a noise. As a result service users are afraid to speak out because of the amount of abuse they get off social care workers. They don't want to listen to the views of the people.

There seems to be a growing mood among service users and their organisations to challenge such a state of affairs. Increasingly they seem to feel under pressure to find new, more effective ways to do this.

As this project has highlighted, service users have found invitations to get involved from services and mainstream organisations very much of a mixed blessing. They can be a positive experience and result in positive change. But more often, participants talked about less helpful experiences that didn't seem to lead to any positive results. This pattern has undoubtedly worsened more recently. Public spending cuts made in the name of reducing the 'public deficit' have had a particularly adverse effect on disabled people and other long term health and social care service users. They have been particularly badly affected by the loss of mainstream services resulting from major cuts in central and local government spending. They have also reported very negative effects from major programmes of

MANY SERVICE USERS HAVE BECOME SCEPTICAL ABOUT BEING INVOLVED WITH STATUTORY AND SERVICE ORGANISATIONS.

welfare reform introduced by the Coalition Government. These have been accompanied by highly stigmatizing reporting of service users claiming benefits and also the presentation by government of such groups as unnecessarily dependent and avoiding employment (Beresford and Andrews, 2012; Davison and Rutherford, 2012; Strathclyde Centre for Disability Research and Glasgow Media Unit, 2011; Diary Of A Benefit Scrounger et al, 2011).

All this has taken place despite disabled people, service users, their organisations and traditional disability charities evidencing the destructive effects such policies are having on service users. Thus service users have lost even more confidence in being listened to by government. Yet at the same time, government has continued to undertake consultation exercises and user involvement initiatives, asking for their views (Beresford and Andrews, 2012). This has given rise to further distrust and disenchantment. At the time of writing the government has also delayed on resolving the serious funding problems that beset social care, despite the widespread agreement, spreading across all major political parties, that such reform is essential and long overdue.

> Why do they ask us our views, when they take no notice of them?
>
> They must know how much their reforms are hurting us. We keep telling them. But they take no notice. What's the point?
>
> They say they have to make the cuts because we've got to pay back for borrowing. But they are still spending on what they want to.
>
> Everywhere services are closing and people with learning difficulties are being forced back indoors. All we have gained is going.

A key concern of service users has become:

> their 'increasing sense of coming under attack, negatively stereotyped by politicians and media, increasingly marginalised and excluded' ((Beresford and Andrews, 2012, pp7-8).

At the same time, while government rhetoric has long been supportive of service User Led Organisations (ULOs) and Disabled People's Organisations (DPOs), their position is becoming increasingly precarious as many are losing already inadequate funding. Some are closing down, others are more and more financially insecure, so that while some new organisations have been funded by government, generally the picture that is unfolding is a negative one. This means that opportunities for service users to get involved in such organisations, to develop their skills and confidence and gain a more powerful voice are diminishing.

> Our organization of people with learning difficulties has lost almost all its funding. We are trying to keep going, but it is very difficult. It is very sad for a lot of people.
>
> There's no service user organization round here anymore. There's nothing and the big charities are too scared to say much. We are on our own.

Thus many service users are even more reluctant to respond to invitations to get involved and there are now fewer chances to get involved through user-led organisations, because of the difficulties and cuts they are facing.

This does not, however, mean that service users have been silenced. It does though seem to mean significant changes in the nature and form their involvement takes. There seem to be three key expressions to this. These are:

1. Service users seem increasingly to be seeking to get involved to make change outside of formal arrangements for user involvement.
2. They are developing new groupings to do this and new collective ways of doing it.
3. These are often based on the new social media and social networking technologies. These also enable people to get involved in 'virtual' ways which can overcome many of the traditional barriers relating to 'access' and inclusion, requiring people to go to participation, rather than participation coming to them.

Involved from outside

It is hardly surprising if people have become increasingly disenchanted with schemes for user involvement, given that they feel that there is less and less point to them as their views appear to be ignored. But while this has left many service users feeling powerless and even hopeless, with increasing talk of some having suicidal thoughts (Beresford and Andrews, 2012), it has also resulted in a continuing if different challenge to government policy from service users and their organisations. But this has been characterized by an increasing move to service users getting involved outside of consultative arrangements, in more conflict-based and combative roles, explicitly opposing government policy. Over this period, service users have increasing looked for more effective ways of influencing what is happening. The government has talked up self-help and mutual aid, with ideas like 'big society', but these have largely looked to service users like being left to struggle on their own without adequate funding or resources.

This increasing move to more oppositional approaches to engagement is clearly related to people's sense that little is to be achieved any longer by getting involved in conventional consultative ways. The truth is that involvement has always been a complex issue and the history of user involvement has always included both more consensual and more conflict based approaches; approaches from within and without. As one service user said:

> They used to talk about it being better for us to be peeing inside the tent outside, than outside peeing in. Now they don't seem to care that we haven't really got that choice any more. So it's much more a matter now of peeing wherever and whenever you can!!

There has always been ambiguity about user involvement, as governments have talked up voice, choice and the consumer, while responding much more slowly to the liberatory goals of service users and their social movements. But the unprecedented public spending cuts now being made in the name of the 'public deficit' have brought these contradictions into stark relief.

There have always been more oppositional approaches where service users have sought to influence by campaigning from outside rather than getting involved within. There have also been differences between movements. Thus the UK disabled people's movement has been much more associated with campaigning for different kinds of services and support based on the 'social model of disability' and a human and civil rights approach, seeking change through direct action as well as through legislative change from parliament (Campbell and Oliver, 1996; Beresford and Campbell, 2004). The mental health service users/survivors movement, on the other hand, has been more strongly linked with services, trying to achieve change from within through structures for user involvement developed by the service system (Campbell, 2009). Service users have long used both consensus and conflict based approaches to involvement (Simons et al, 2009), but the balance now seems to be changing towards increased campaigning and direct action.
As service users say:

> Telling them isn't working any more, so we are having to find different ways of being heard.
>
> We've just got to keep telling them, making them listen.
>
> There's no point in filling in their forms or going to their meetings. We've got to do what other campaigns do.

Developing new collective forms of involvement

Faced with the loss of benefits, housing and services, service users are finding new voices in opposition, action and protests. Because they have physical and sensory impairments, because they are frail through age, or isolated through mental distress, traditional forms of involvement and campaigning may not be open to them, familiar or comfortable. Over the years they have developed new accessible forms of involvement, creating new meanings to collectivity and community, direct action and protest. They are now working together to campaign with people with shared experience, as well as with allied causes. For instance:

> We're linking in with trades unions. We're linking in with positive professionals with things like the Social Work Action Network.
>
> It's great different groups of service users getting together and fighting for our rights.
>
> We've linked up with carers for the first time. They are attacking us both so it's important to build partnerships like this.

York Faces is a typical local organisation for mental health service users, made up of people with that experience. Although it doesn't have great power, the group does what it can to resist cuts, including leafleting outside hospitals and working to make anti-cuts events accessible and inclusive of people with mental health problems and other 'hidden' impairments. Mad Pride, the mental health service users' group, organised a march to Downing Street last year against housing benefit reforms, following a 'one-day medication strike' against cuts. This was followed by a two-minute 'scream' in memory of those who have killed themselves and others who may do so because of the benefit cuts. They demand a 'Stop to The Suicides, Hands Off Our Benefits' (Beresford, 2012, p75).

The Crutch Collective picketed Atos protesting against their Employment and Support Allowance (ESA) reviews. This is not responding to official consultations, but engaging with the mainstream political process and taking new forms of direct action. As well as developing their own campaigns, service users and disabled people are a visible presence in broader struggles and demonstrations – against increasing student fees, among the tents Occupying cities as part of the '99%' protesting extreme inequality.

One group of people with learning difficulties, People First Lambeth, wrote an open letter to the prime minister to express their dismay that they felt the government was making it harder for them to keep their jobs, homes and independence. They launched a judicial review against their local council for ending their funding. A new year's message from The Broken Of Britain disabled people's campaign highlighted 'the misery' that the Coalition government had heaped on disabled people through its benefits policies, but concluded that 'David Cameron and Iain Duncan Smith had picked the wrong fight' as grassroots protests escalate (Beresford, op cit, p76). This new mood and approach from disabled people and service users has been epitomized by the Spartacus group and their reports, beginning with the report, 'Responsible Reform', challenging government welfare reform (http://wearespartacus.org.uk/spartacus-report/). This was 'entirely written, researched, funded, and supported by sick and disabled people, their friends and carers'. It has gained high visibility and widespread support, ranging from the Guardian (http://www.guardian.co.uk/commentisfree/2012/jan/08/disabled-people-welfare-reform-sham) to less predictably the Daily Mail, which ran the headline, 'We're all desperate for welfare reform, Mr. Cameron, but hiding the truth is not the way to achieve it'. (http://www.dailymail.co.uk/debate/article-2084706/David-Camerons-

Welfare-Reform-Bill-Hiding-truth-way-achieve-it.html#ixzz1jd6gdRUl). The report has 'helped inflict a hat-trick of welfare reform defeats on the government in the Lords (http://www.guardian.co.uk/society /2012/jan/ 17/disability-spartacus-welfare-cuts-campaign-viral) (Beresford, 2012, p66).

New radical groupings of disabled people and service users have emerged like 'Not Dead Yet' (campaigning against assisted dying), 'Disabled People Against Cuts', 'The Broken Of Britain' as well as 'Spartacus'. Service users and these organisations are co-opting the government's own rhetoric of 'co-production' (where recipients are involved on equal terms in designing the services they receive), but in this case to oppose proposals that stigmatise and exclude them. They are seeing that where protest is strong, the government is more likely to listen. As Jaspal Dhani, chief executive of the United Kingdom Disabled People's Council has said: 'If it wasn't for disabled people's energies to campaign and protest against Disability Living Allowance cuts for residential service users, the government wouldn't have done a u turn on that policy' (personal communication, 2011).

New electronic forms of involvement

These new groupings have also taken forward the new technologies and forms of networking now available, making it readily possible for people to join in while still being on their own and even without conventional access. User-led initiatives like the Spartacus group and reports sum up this new development. Inspired by disabled people and service users, they have gained massive interest, powerful and celebrity supporters and made an enormous impact through their effective use of social media (http://www.guardian.co.uk/society/2012/jan/17/disability-spartacus-welfare-cuts-campaign-viral).

Service users are joining mainstream anti-cuts campaigns, linking up with them and forming their own. They are taking to the streets, to the blogosphere, getting support for electronic petitions and are a growing presence on social networking sites. While some service users are still excluded from the new digital and internet age, others are at the cutting edge. As one woman involved in an activist carers organization says:

> Until a few years ago it was very rare I used a computer … I had no idea back then about the world being so accessible at the click of a switch. I had so much experience of caring and the disabilities/illnesses of those I cared for, but we were in a little bubble, the outside world very rarely came in. Then the internet became a learning tool, each day brought new contacts from individuals, groups, charities, politicians and academics. My understanding of disability grew, how a person's life could be affected and how they dealt with it on a daily basis. This was a positive step but the downward side was I learned that the perception among some of the public was vile, something that was fed daily by media and politicians …Then we started to fight back. Not just for ourselves but for our children's future. New social media such as Facebook and Twitter have taken campaigning to a new level. What is new about the above you may ask … well one thing is, most of the people will never meet face to face. Yet they build a network of trust, they learn who their friends are, same way they learn who their enemy is. When under attack they will unite as one. Their voices will grow louder. I am a wife/mother, sat in my dining room and yet through the internet I have been privileged to have met in cyber space the most wonderful of people … They are all as dear to me as my friends at home (Beresford, 2012, p75).

Other service users echoed such views:

> It's difficult for me to get out, but that isn't a problem any more. I have got the world at my fingertips with my laptop.
>
> Having the computer has changed my life. I am in touch with people. I'm not cut off. I keep in touch with people who keep me in touch with what's going on.
>
> Everything's changed with new technology – I'm able to get involved now from the comfort of my armchair, with my phone in a café, whatever.

In recent years disabled people and other service users who might have been isolated, tied to their homes or residential institutions and unable to communicate conventionally, have had their lives and opportunities transformed by new technology. First this was through the creation of the internet, the world-wide web and e-mail. All these opened new avenues for communication, contact and activity, without leaving your own home, wheelchair or even bed. More recently opportunities and means of linking up have multiplied with the emergence of social media and social networking. These have had profound implications for people's participation and the nature of user involvement.

These new progressive service user pioneers are developing their own new forms of inclusive and accessible action and collectivity. One disabled woman wrote to me:

> In the last few months, I have set up a blog that will eventually be a website, called WellFairSystem (http://wellfairsystem.dreamwidth.org/). We are doing our best to reach many in the disabled community and Twitter is an integral part of that. Twitter has been a huge platform for us, simply because you have the ability to reach the corners of the worlds with just a few Tweets. Another platform that's blown up in the last five years is blogging … There really is a sense of community … to connect with people who understand what you're fighting for. That's a very powerful tool when … many of us are unable to attend large meetings or demos or don't have the energy to blog (Beresford op cit, p76).

Such service users are, blogging, vlogging, podcasting, tweeting and have their own facebook groups. More and more they are both a physical and virtual presence, from flash mobs to pickets and demonstrations. These are not isolated expressions, but the vanguard of new kinds of activism and collective action. Other expressions of this to follow-up include Black Triangle, Carer Watch, the Hardest Hit Campaign.

One disabled man living in residential services talked about how he used the law to bring about change:

> Information access as defined under various legislation has certainly been a key tool in fighting my personal corner … Through its enforced frankness, it can disarm and cause institutions, statutory or otherwise, to rethink. If the Department for Work and Pensions suspects a benefits claimant of breaking the rules, they can insist on a Compliance Interview. A scary letter, without any details as to what has caused the suspicion etc. They have absolutely no information on their website. It can be sparked by malicious accusations (increasing due to the state/media blackening of disabled people's character), misunderstandings, genuine mistakes etc. I put in a Freedom of Information Request to find out the rules on this process. This has generated a huge amount of interest from people otherwise unable to find any useful information, left petrified and unprepared as a result. It's made a real difference to benefits claimants (Beresford, op cit, pp73-4).

There are campaigns to save the Independent living Fund and against organisations like the US insurance giant Unum. A disabled war pensioner, talked about how she had come to see knowledge as power:

> I have been doing research now for the last two years, health permitting. Any info I get from all that research is what works. What I do is DEEP research – and then report the evidence I have found, passing it on to as many people as possible via websites etc. Mandela is a hero of mine and whenever I have been tempted to stop I recall his famous quote, 'Never underestimate the power of persistence' (Beresford, op cit, p74).

More and more service users feature on the radio phone-ins and the TV vox pops and 'the public' is beginning to hear what they have to say. In a new digital age, they offer the promise of a new and inclusive kind of involvement that politicians and their policies are increasingly having to address. It has thus now become possible for service users (and indeed carers) to get involved in user-led organisations, to get involved, to have a presence and to exert an influence without going outside their front door or having any actual direct face to face contact with the service system, political structure or activist grouping. For people who have faced big barriers doing this in the past, this represents a major change. It is now much more difficult to exclude particular groups of service users and their perspectives. It is much easier and less demanding to get involved. This is both likely to encourage the involvement of previously 'seldom heard voices' as well as perhaps highlighting new difficulties for them and other groups. Certainly it means that there is new work to be done to ensure that the fullest range of service users have equal access to the new social and networking media. This offers a key way forward for more inclusive and more effective involvement in the future.

RECOMMENDATIONS

- Service user involvement and participation has become increasingly important for social care, health and other public services. Organisations need to review and evaluate their policies, processes, procedures and practices on an on-going basis. This needs to include an evaluation of who they are including and who they are excluding.

- Groups and organisations need to ensure that all their members are committed to equality of opportunities and diverse and inclusive involvement.

- Service user groups and organisations need to be clear about their aims and objectives. For example, if they are a black and minority ethnic group for mental health service users, they should decide if they are for all black and minority ethnic people who have experience of mental health issues and if so, ensure that they are reaching all black and minority ethnic communities, or be clear who their group is for.

- Training and support on inclusion and diversity issues needs to be available to services and service user organisations on a continuing basis.

- Consideration needs to be given to both informal and formal ways of supporting the involvement of service users who are seldom heard.

- Specific strategies to involve people who are often excluded need to be further developed and implemented.

- Training, support and mentoring needs to be offered to new voices to enable them to contribute fully.

- It is essential to be clear on the issue of representation – who is speaking for whom. This is of particular importance when engaging with minority groups within minority groups.

- New, imaginative, flexible and innovative ways of working together need to be explored, which support the involvement of individuals and groups who tend to be excluded.

- It is necessary to identify and develop ways of supporting both individual and group participation.

- More attention must be given to evaluating participation, particularly exploring how inclusive and diverse it is.

APPENDIX 1

Interview schedule for use with individual service users

If you prefer to fill this form in electronically you can find the questionnaire on our website: www.shapingourlives.org.uk

If you would prefer to fill it in over the telephone please contact the office on the number above. Please send the completed form back to Shaping Our Lives in the prepaid envelope or to the email address above. See final page for details of prize draw.

Introduction

Shaping Our Lives is doing a new national project. It is called Getting Beyond the Usual Suspects: developing diversity in involvement. The aim is to enable a wider range of people and more people who want to, as service users, to get involved effectively and have a say in improving their lives and the support that they receive.

As part of this project we would very much like to ask you some questions and hear what you have to tell us about your experiences of getting or not getting involved in different things. We are trying to find out a number of different things. These include:

- Whether there are barriers preventing people getting involved.
- Whether some groups of service users are particularly affected by these barriers.
- Why people get involved in things.
- Why people don't get involved in things
- What makes involvement work?
- What makes it not work?
- If there are some people or groups of people who are often not invited to be involved.
- If there are some groups of people that service user organisations find more difficult to include and involve.
- Who these people are and why is this?
- What can we do about this, so that everyone can be involved in something if they want to be?

We are as interested in hearing from people who have not got involved as from people who have. So we would also like to hear what service users who are not involved in any groups or who do not go to meetings or events around service user issues, have to say. Are there reasons why they do not get involved, or are they happy not to be involved?

If you are not sure what we mean by 'service user' please see the definition at the end of this questionnaire.

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

This project will work to make sure that what people say as individuals is strictly confidential and anonymous. By this we mean that whatever you may say to us will not be linked with 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.

We are trying to find out from people what sorts of things might stop them from being involved with both other service users and/or having a say about their services and involvement initiatives in general. We want to make sure that every service user who wants to have a say in any issue that affects them can have the chance to contribute and be heard, so that we can all say:

'Nothing about us without us'

1. Have you ever been involved in a service user group or organisation?

☐ YES ☐ NO ☐ DON'T KNOW

1a. If your answer is YES, (you have been involved in a service user group or organisation) can you tell me more about this? When answering the following questions please think about the group you have been involved in most recently (if NO go on to Question 2). Was it:

☐ A user controlled organisation
☐ This year
☐ Last year
☐ More than three years ago

1b. Was the user group or organisation you got involved in concerned with:

(Tick as many as are relevant)

☐ Campaigning
☐ Self help
☐ Mutual support
☐ Doing research
☐ Education and training
☐ Other: Please tell us a bit more about it.

2. Have you taken part in any user involvement meetings, events or initiatives set up by service providers/service system for example social services or a local health trust?

☐ YES – please continue.
☐ NO – please go to Question 3

2a. Can you tell me more about this? (getting involved in user involvement meetings, events or initiatives set up by service providers/service system) Was it:

☐ This year
☐ Last year
☐ More than three years ago

2b. From your experience so far in getting involved in such user involvement meetings, events or initiatives set up by service providers/service system, was there anything that you didn't like about it?

2c. Have you experienced any of the following difficulties at such meetings, events or initiatives (set up by service providers/service system)?

Please tick as many as are relevant (if you have been to more than one such meeting or event, please tick if this has happened regularly):

It was:

☐ Difficult to get to
☐ Inaccessible meeting place
☐ Inaccessible language
☐ There was too much to read
☐ I was the only service user
☐ I didn't feel I was being listened to
☐ It was disorganised
☐ It was boring
☐ I felt I had other things to do
☐ I've seen and heard it all before
☐ There didn't seem to be any point to it
☐ It went on too long
☐ It felt disempowering
☐ The food was not good
☐ Other (please tell us more)

2d. From your experience so far in getting involved in such user involvement meetings, events or initiatives set up by service providers/service system, was there anything that you thought was good about it?

2e. Have you experienced any of the following good things at such meetings, events or initiatives (set up by service providers/ service system)?

Please tick as many as are relevant (if you have been to more than one such event, please tick if this has happened regularly):
It was:

☐ Friendly
☐ Accessible environment
☐ Very enjoyable
☐ Organised by service users for service users
☐ I got to meet a lot of nice people
☐ I felt people were listening to me
☐ The food was good
☐ I got paid for going
☐ My transport was arranged for me
☐ I felt part of the meeting/event
☐ We shared our service user experiences
☐ It felt empowering
☐ It felt like it would change things for the better
☐ No one talked for too long or too fast
☐ Other (please tell us more)

3. Are there any groups of service users who you think tend not to be included in user involvement initiatives, meetings and activities set up by service providers/the service system?

☐ YES ☐ NO ☐ DON'T KNOW

3a. If YES, Who do you think these groups are?

3b. Do you think any of the following groups of service users tend not to be included in user involvement initiatives, meetings and activities set up by service providers/the service system?

You can tick as many boxes as you like.

Please tick even if you have mentioned them before.

☐ People seen as having 'profound' or multiple impairments
☐ People who communicate differently (for, example, non-verbally, using communication assistance, etc)
☐ People whose support costs are seen as expensive
☐ People whose access requirements are either not recognised or not routinely met
☐ Older people
☐ People from black and minority ethnic communities
☐ People in the prison system
☐ Refugees and asylum seekers
☐ Homeless people
☐ Parents with small children
☐ Deaf people and people with hearing impairments
☐ People with drug and alcohol problems
☐ People who live in rural/country areas
☐ People who are seen as experienced, 'professional users' and able to speak up for themselves
☐ People with learning difficulties
☐ Others – please give details

3c) Why do you think that these groups are not included/involved in user involvement initiatives, meetings and activities set up by service providers/the service system?

3d) What do you think could be done generally so that a wider range of service users including the groups mentioned above can be included/involved in user involvement initiatives, meetings and activities set up by service providers/the service system?

3e) Do you have any specific ideas for how any of the above groups of service users might be included/involved more in user involvement initiatives, meetings and activities set up by service providers/the service system?

☐ YES ☐ NO ☐ DON'T KNOW
If YES, please give details

4. **Would you like to be more involved with other people who use services?**
☐ YES ☐ NO ☐ DON'T KNOW
If YES, please continue. If NO please go to Question 6

5. **Can you tell us more about why you would like to be more involved with other people who use services?**

5a. **Look at the list below of reasons why people might want to be more involved with other people who use services and please tick as many as are relevant to you and if you want, add any other ideas of your own:**
☐ To share experiences
☐ To make new friends
☐ To campaign together
☐ To gain a stronger voice as service users
☐ To improve our services
☐ To plan events
☐ Other (Please tell us more)

Please now go to Question 7

6. **Can you say why you would NOT like to be more involved with other people who use services?**
☐ YES
☐ NO
☐ DON'T KNOW
If yes please give more details

6a. **Look at the list below of reasons why people might NOT want to be more involved with other people who use services and please tick as many as are relevant to you and if you want, add any other ideas of your own:**
☐ I don't know of any groups in my area
☐ There are no groups in my area
☐ It is difficult for me to get to meetings
☐ Public transport is not accessible to me
☐ I don't like spending time with other service users
☐ I am too busy doing other things
☐ I am not one for joining groups
☐ I used to be more involved in things but I became disheartened
☐ Nothing changes
☐ I don't have the energy
☐ Other (Please tell us more)

7. **Are there any things in your life that you would like to have more of a say about?**
☐ YES ☐ NO ☐ DON'T KNOW
If Yes please continue.
If No or DON'T KNOW please go to question 12.

8. **Can you tell us a little bit more about what things in your life you would like to have more of a say about?**

9. **How would you like to be able to have more of a say about these things in your life (that you would like more say in)?**
Please tell us more

10. **What would make it easier for you to have more of a say about these things in your life (that you would like more say in)?**
Please tell us more

11. **What makes it difficult to have your say about these things in your life (that you would like more say in)?**
Please tell us more

12. **If you are NOT already or currently involved with a service user group or organisation, would you like to be a member of a group of service users that works to make people's lives and services better?**
☐ YES ☐ NO ☐ DON'T KNOW

12a. If YES, can you please tell us why (you would like to be a member of a group of service users)?

12b. If NO, can you please tell us why (you would NOT like to be a member of a group of service users)?

APPENDIX 2

Definition of 'service user'

This definition was developed by a diverse group of service users working on different projects with Shaping Our Lives.

What we mean when we say 'service user'

Shaping Our Lives National User Network sees 'service user' as an active and positive term, which 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 when we may not. Some people still need to receive services but are no longer entitled to them, for many different reasons. This is important since some people and groups who should have access to support services may not actually receive them.
- People may also receive services involuntarily on a compulsory basis, for example, as mental health service users.
- 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, people with physical or sensory impairments, 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 also 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 National User Network means when we talk of 'service users'.

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PROJECT RESOURCES

Shaping Our Lives has produced a range of materials about inclusive user involvement.

Beyond the Usual Suspects:
Towards inclusive User Involvement – Research Report

Beyond the Usual Suspects:
Towards inclusive User Involvement – Practical Guide

Beyond the Usual Suspects:
Towards inclusive User Involvement – Findings

Beyond the Usual Suspects:
Towards inclusive User Involvement – Poster

Beyond the Usual Suspects:
Towards inclusive User Involvement – DVD

You can find out how to get a hard copy or download a copy from: **www.shapingourlives.org.uk/ourpubs.html**

The website will also tell you how to get Word copies of the documents which can be downloaded for use with computer readers or in large font versions.

Electronic resources

We offer a series of links to electronic resources that can offer people additional information and support towards enabling inclusive involvement.

These include examples of Shaping Our Lives' own forms that we use when we are holding events, 'get togethers' or consultations. They have all been developed over time with service users and they are continually being up-dated and changed as we receive feedback from service users. They are not meant to be telling people or organisations how they should do things. They are suggestions of what has worked for us when we are working with a diverse range of service users.

We are happy for anyone to reproduce any of these suggestions but we would like it if you would acknowledge that they were developed by service users working with Shaping Our Lives.

To access **electronic resources** please visit: **www.shapingourlives.org.uk/ourpubs.html**

THE FOCUS OF THIS REPORT IS MAKING IT POSSIBLE FOR EVERYONE WHO WANTS TO, TO BE MORE INVOLVED IN AND HAVE MORE SAY OVER THEIR LIVES AND THE SERVICES THEY USE TO LIVE THEM.

Shaping Our Lives
A National Network of Service Users and Disabled People

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Produced with funding support from the Department of Health.