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BEYOND THE USUAL SUSPECTS

ACHIEVING EFFECTIVE AND MEANINGFUL INVOLVEMENT WITH PEOPLE WHOSE VOICES ARE SELDOM HEARD MEANS EXPLORING, EVALUATING AND MONITORING NEW AND CREATIVE WAYS OF ENGAGING WITH AND INVOLVING THEM.

Main points

Public, patient and user involvement are now a requirement among many areas of public policy and services, particularly in health and social care. Some groups however, tend to be left out of such arrangements, often groups facing some of the greatest barriers and difficulties in their lives, making it even more difficult for their voices to be heard. The Developing Diversity in Involvement Project sought to find out more about who these groups are and how they can be more fully and equally involved.

Some of the key groups that are still often left out of arrangements for user involvement are people with alcohol and drug problems, young people, people who communicate differently, people who use residential services, people with learning difficulties, refugees and asylum seekers, people with complex support needs, older people and people from black and minority ethnic groups.

- The best way of involving such service users is reaching out to them and their communities rather than waiting for them to come to you. Direct contact and word of mouth work best. Don't just rely on 'community leaders', work to reach people themselves.

- Service users and their 'user led organisations' are especially well placed to 'build bridges' with such 'seldom heard voices'.

- Achieving effective and meaningful involvement with people whose voices are seldom heard means exploring, evaluating and monitoring new and creative ways of engaging with and involving them.

- Much user involvement still does not adequately address access issues. This means ensuring that the physical, information, communication and cultural access needs of service users are met.

- Disempowered service users, particularly those receiving residential and institutional services are often subject to 'gate keepers', who can stand in the way of their involvement. Sensitive and effective approaches are needed to avoid or overcome the resistance of such gatekeepers.

- The disempowerment and stigma that some service users face can becomes internalized and then act as an internal barrier to them getting involved. They are likely to benefit from capacity-building to support their empowerment to overcome such difficulties.

- The judgmental quality of public discussion about some groups of service users, particularly around alcohol and drug use, asylum seeking and mental health problems, helps create and sustain negative public attitudes. Other service users do not exist in a cultural vacuum and can also exhibit negative assumptions and attitudes towards such groups of service users.

- Getting involved can mean engaging with service user organisations as well as with formal arrangements for involvement. It can also mean people getting together outside of such schemes to campaign for change in more oppositional ways. There is now increasing interest in such activity and new forms are being developed using social media and social networking sites.

Introduction

We need to be in there setting the agenda, deciding what the priorities are, not flown in after the horse has bolted. It's about equality, isn't it? It's about treating our views as equal to anyone else's views and as worth listening to, because we have an opinion born out of experience.

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 user controlled 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.

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Existing exclusions

*We are not talking about 'hard to reach'.
We are talking about hard to listen to!!*

*When I first started going to these meetings…
I didn't really feel that involved. I was often too
nervous to speak and fearful that something
terrible would happen … At the back of my mind,
I didn't think I deserved anything as a disabled
person. But now I would say that I have found my
voice. And I don't just speak for me. I speak for
a lot of other disabled people.*

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

*I was invited to give the perspective of someone
who uses mental health services, but they didn't
like it when I mentioned the voices I hear. They
seemed a bit embarrassed.*

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, people with dementia). It
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.

People won't get involved if:
- They cannot see any change as a result of their
  involvement
- They feel decisions have already been taken on
  which their opinion is being sought
- They feel they are just 'ticking the box'
- Their access requirements are not met.

Why people want to get involved

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

I love the service user group. I like to get involved with it because I love these people.

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:

- To make a difference
- To gain confidence and experience
- To 'tell it like it is'.

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, it did seem to be widely experienced among some seldom heard groups and individuals.

Key problems

I can feel really good about myself. I'm dressed smartly, I successfully negotiate all the hurdles in my way as I come to London, I feel proud of myself. Then I get to the meeting and when I enter the room everyone stops talking – just for a second – then people either ignore me or rush to help me, with that over-friendly smile and that over-friendly voice. And all the positive things I felt about myself before melt away, as I am patronized, pitied and treated different.

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.

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 offputting 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 fear of losing their benefits
- **Covering the costs of involvement** – where people may have high costs because of the nature of their situation or impairment
- **Ensuring support for service user/disabled people's organisations** – which generally financially insecure and underfunded may not have the funding to ensure as diverse involvement as they wish
- **Money to make change** – funding is often (but not always) needed to make the changes indicated by user involvement and without it such change is unlikely to happen.

Undertaking inclusive user involvement has financial implications and it is crucial that these are recognised and addressed in all arrangements for user involvement if these are to be inclusive of diversity.

Inadequate access

Inadequate access continues to be a major obstacle in the way of the involvement of many of the groups identified as 'seldom heard voices'. 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.

Each of these can take many expressions, work in negative relation with each other and have far-reaching effects in excluding particular individuals and groups. A helpful rule of thumb to use is that everybody can express themselves, get involved in some way and contribute, if their access needs are properly met. Often this will demand innovative and imaginative approaches to improve access.

Overcoming the barriers

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 feel constantly awkward; where ground rules are read out and stuck to, where it's ok to leave the room if you need too ... But it's more than that – there's a shared understanding that we are coming from the same place. We recognise the link between us all as service users and disabled people.

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.

What I find now is that they don't want me to be there. They would prefer a quiet and passive person. Not me, with my 'Hang on a minute there...' and my constant interruptions. I think they see me as awkward now.

Outreach and development work

Sometimes you just don't know things and involvement helps you. You meet with people and get problems off your chest.

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

The pensioners' group I belong to is a lifeline because it is political. We don't go and chat. We bring up issues about a better standard of living. We canvass. We go to parliament.

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, equiring people to go to participation, rather than participation coming to them. Such service users are, blogging, vlogging, podcasting, tweeting and with 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.

The project

Shaping Our Lives (www.shapingourlives.org.uk) is a national user controlled organisation and network. Its aims in this work were:

1. To try to find out from individual service users and from specific service user organisations their experience of truly diverse and meaningful involvement. We wanted to hear from those whose voices are 'seldom heard', what they perceive to be the barriers from their own perspectives and what they thought would be the most helpful ways forward.

2. We also wanted to hear from service users' own organisations, about their experiences of diversity; who was missing from their own organisations, what they understood the barriers to be and what they felt they could do to overcome these barriers to make their own organisations reflect the diversity of service users overall.

The findings from the project were based on individual interviews with 132 service users and just over 100 other service users contributed through participation in group interviews, through the local projects and via the project advisory group. 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'.

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.