



**BEYOND  
THE USUAL  
SUSPECTS**

To my much missed sister Maureen Beresford (1942-2000) and to our darling daughter Catherine Jenny Beresford, who was with her towards her end in New York, when I couldn't be there.

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

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# FOREWORD

User involvement is now at the heart of public policy. Across social care, health and beyond – in education, regeneration and the delivery of local services – the ‘citizen voice’ should be at the heart of everything we are doing. New ideas have developed which reflect this, based on the principles of personalisation which emanated from and was led by service users themselves. Whether we call it co-production, co-design, empowerment – citizens and communities need to be central. But although the ambition is to involve all, and the history now goes back decades, some major barriers still remain.

Key among these is the issue of who actually gets involved. Are there equal opportunities for everyone to play a part in shaping their lives, the lives of their communities and contributing to society? Or is it just the same old group of people who are being heard? Is it just the loudest voices who are being heard or represented? Concerns about this have been reflected in the creation of new terms, like ‘seldom heard voices’.

Some groups facing particular barriers in their lives, generally also seem to face additional ones when it comes to getting involved. This can create a vicious circle. The most disadvantaged groups and people are likely to be further excluded by being less likely to be heard and listened to when they try and highlight the problems they face. We can see how this has particular implications for social care and health, which support some of the most vulnerable people, at some of the most difficult times of their lives.

That’s why this guide is so important. Built on a strong body of new evidence, created by service users themselves, which comes from listening to what service users have to say, it offers practical help to make it possible to involve everyone fully. There is real down to earth help here to make that achievable.

As someone with a longstanding commitment to ensuring that everyone in communities can have the help and support they need, I am particularly pleased to endorse such guidance. In my current roles to advance leadership in social care and to speak up for social workers and the value of social work, I welcome this resource as a way to progress these goals.

This is a very practical guide to help us all make real and inclusive involvement more of a reality. I hope everyone will find it as helpful as I have.

## **Jo Cleary**

Chair, The National Skills Academy for Social Care  
Chair, The College of Social Work

Twenty years ago, user involvement was a novelty, an optional extra. It was something we had to campaign and demonstrate for. Now it's become a central feature of good practice across a range of public services, and a core component of much government policy. If you're providing a public service, whether you're a voluntary, statutory or private sector body, you should be involving people who use the service.

The benefits of knowing the views of people who use your services might seem obvious. In the retail world, it's second nature. Holiday firms and hairdressers, cleaning companies and coffee shops, go to great lengths to hear from their customers. They go bust if they don't.

Resistance to user involvement remains in the public services, for all sorts of reasons. People with valuable information, insights and ideas, drawn from personal experience of using services, often find it hard getting service providers to listen.

It can almost seem at times that bodies providing public services don't want to hear what their customers think of them. They don't believe that ordinary people's views count – let alone that they might improve services, or prevent disasters of the kind that happened in hospitals in Staffordshire.

One argument often put forward against user involvement is that the users who do get involved 'aren't representative' – that they're just a vocal minority, they don't speak for the great majority of people using services. I have certainly been accused of this many times throughout my campaigning years. Of course, if this is true of me, it is also true of campaigners like Emily Pankhurst, Florence Nightingale or today, Doreen Lawrence – campaigners who involved large numbers of like minded people, to demand a part in shaping society's future. Where would we be without their loud voices, and others like them? But even essential campaigners like these and their organisations or pressure groups, need constant advice and guidance to make sure the messages are about everyone, not some. This *Shaping Our Lives* guide responds with authority and practical good sense to such people and organisations who continue to fight for the involvement of people who use services.

This guide accepts and understands that the user movement and user-led organisations can and should do more to communicate the views of as wide a range of people as possible. This particularly applies to groups who are often excluded, who struggle to get a hearing, who need help with communicating. It has plenty of ideas for overcoming these difficulties, gathered from the success stories of other service users. But the guide also encourages services to help themselves, by making it easier for users to get their views across. Rightly or wrongly, users often feel their views don't really count. They get the impression the service is just going through the motions, it's already made its mind up, nothing will change. This is frustrating for users, and a missed opportunity for providers. The guide suggests a variety of ways in which service users can be more challenging and more assertive in getting their messages heard, understood and acted on. I am confident it really will make a difference.

**Baroness Jane Campbell, DBE**

‘ Getting involved? It’s changed my life for the better. I’m a different person now, more skills, more confidence, more opportunities.’





# INTRODUCTION

Everyone should have a real say in their life. We know that if people don't they are likely to be unhappy and disempowered. Powerlessness is bad for all of us, just as some people having too much power is damaging. There has been increasing recognition of the importance of people having a say – over their life, in their community, in society. But still some people have tended to be left out – and sadly that is often people who face some of the biggest difficulties and barriers in our world. The aim of this practical guide is to highlight this issue and building on what we know, do something about it. 🍷

## What is 'user involvement'?

User involvement, participation, call it what you want, is a way that all of us can play an active part in getting change and making a difference. Getting involved – in our society and community, in services and organisations, can improve our lives and give us more control. Most important, this is the age of involvement, where everyone is saying it is a good idea, so there are lots of opportunities to get involved. But like everything in life, user involvement can be complicated. If we don't know the ropes, it can create problems.

One of the biggest problems is that not everyone necessarily has an equal chance of getting involved. That can mean that people who face additional obstacles in life, also face additional barriers in getting involved. But if they get left out, that defeats the object of the exercise. Unfortunately this is still what often happens. It means that people who may have the greatest need to be listened to, are still excluded. That's where this guide comes in. The whole point of it is to help deal with this problem. So if:

- **You want to get more involved**
- **You know people who get left out**
- **You want to work with other people to make a difference** – then read on.

## Who this guide is for

“ User involvement? Don’t make me laugh. It’s just the same old people. I guarantee, you go to most meetings, look at who takes part in most consultations and it’s the same folk who do the talking. It’s middle aged, middle class, confident, white able-bodied blokes. What good is that? ”

This practical guide is for everybody, because involvement can and does affect us all. But it is intended particularly to be useful for disabled people and other service users – mental health service users, people with learning difficulties, older people, people with long term conditions and others. This is because we face particular barriers and sometimes have to use or rely on services which can cause us additional problems.

So we need to be able to influence and improve those services so they are more helpful in our lives. And people who work in or provide these services also need to know how to make them better. So this practical guide is for anyone who wants to get better services and better support for themselves or for someone else. That includes:

- Service users who want to make a difference and get involved themselves
- Service users and their organisations and groups who want to involve all service users on equal terms
- Organisations and services that want to involve service users inclusively
- Everybody who wants to know how to make possible truly inclusive and diverse involvement
- Policymakers, educators, service providers and commissioners who want to support that goal.

## What the guide is based on

This guide is based on a lot of service user knowledge and experience about getting involved – and also about being left out. As well as seeking and gaining the views of a large number and very diverse range of service users – including people who get left out, as well as those who get involved, it actively involved service users and their organisations in practical work to try to bring about more diverse involvement. This four year national project was controlled by service users and employed both local service users and service users working to coordinate it at national level. All the comments and quotes included in this guide come from service users.

# BACKGROUND

Like it or not, 'user involvement' now affects us all. Involvement has become a 'buzz word'. It has become increasingly important in public policy and increasingly impacts on our lives. Politicians, policymakers and services talk a lot about it. They often ask people to 'get involved'. They organize meetings, 'consultations', market research, surveys, committees and other activities to 'involve' people as citizens, service users and patients. In recent years, it has become a 'requirement' for many policies and services to involve people. That means they have to involve us, find out what our views are and listen to what we say. This is true of the National Health Service, social care and many other public services.

## Is involvement working?

### ⚡ They ask for our views and then nothing happens. ⚡

Although there are many requests and offers for people to get involved, many service users feel that these don't necessarily mean very much. A frequent message from service users is that much user involvement is just tokenistic or merely a matter of 'ticking the boxes' and doesn't result in really being listened to or things getting better.

## Whose involvement?

But there is something even more basic and perhaps more important than that. We know that many service users just don't get an equal chance to get involved. Some service users are much less likely than others to be asked or have the opportunity to get involved, give their views and for these to be listened to. This is now so well recognized as a problem, that a new jargon has developed to describe it. So terms like 'hard to reach groups' and 'seldom heard voices' have been invented. They are used to describe a wide range of people and groups who tend not to be included or heard when there are consultations or 'listening exercises'. Most often mentioned as excluded in this way are people from black and minority ethnic communities, disabled people with complex and multiple impairments and older people – who ironically are the largest group of health and social care service users. But the fact that some groups have regularly been excluded means that we really don't know enough about the problem.

## Why is inclusion an issue?

### 🗨️ You go to a meeting and it's always the same people. 🗨️

This is one reason why we need to know much more about the limits of who actually gets involved and do something about it. The whole point of user involvement and 'public engagement', is to make it possible for people's voices to be heard so they can have more say in society. This involvement is meant to add to the involvement they are already supposed to have through parliament, their member of parliament and their council and local councillor. Unfortunately we know that MPs and councillors don't always offer people an effective way of being involved in their communities.

That's what makes additional opportunities to get involved so important, particular for groups like older and disabled people, poor and disadvantaged people who face particular barriers.

But if only some voices are included in efforts to involve people, then this is likely to make matters worse rather than better. It simply reinforces the barriers facing some people in having an equal chance to be heard. It means we never really know what they think and policy and practice are not properly informed by their views and so is going to be less use for them – although they may have some of the greatest needs. It adds to the discrimination they face, rather than reducing it. It creates an additional vicious circle. It further excludes and disempowers people who already face disempowerment and exclusion.

So to sum up, it is important to challenged barriers to equal involvement and address diversity because:

- For involvement to be meaningful, it must reflect the diversity of the service user population
- Some rights and needs will remain unmet if they are not voiced because people aren't included
- All service users, regardless of who they are, what services they use or might need to use, have full human rights, including the right to be heard.

## Doing something about exclusion

- **If they were serious about involvement they wouldn't keep asking you how much your travel and support needs are and then finding a reason not to invite you. ↷**

That's why we must challenge the barriers in the way of people participating on equal terms. That is the aim of this guide. Drawing on evidence, it has four main aims. These are to:

- Make clearer what groups of service users tend to be excluded
- Highlight what particular barriers are getting in the way of them having a say
- Demonstrate how these barriers can be reduced and overcome
- The part that each of us can play to do this, whatever our role.

### TOP TIP

At a user group activity or a participatory event, check around and see who might be missing. Then check out these questions:

- Are there individuals or groups that don't seem to be there yet who this really affects?
- Ask yourself, why might it be they aren't here?
- What can and should we do about that?

# WHO GETS LEFT OUT?

🗨️ **The whole point of involvement is to listen to people who don't get listened to. If you get left out of that, then that's saying something!! 🗨️**

Anyone can get left out of user involvement schemes. But we know that some people and groups face particular barriers and are especially likely to be excluded.

It has long been recognized that this particularly applies to older people and people from black and minority ethnic communities. However, the evidence from this project highlights that a much wider range of service users tend to be left out. This seems to be linked with five key issues:

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

## 1. Equality issues

Service users report barriers they face getting involved on the basis of gender, ethnicity, culture, belief, sexuality, age (this can include being young, old or middle aged), disability and class. Such barriers range from their rights and needs not being addressed, to being ignored or discriminated against and not feeling wanted or comfortable.

## 2. Living and housing status

This includes people who are:

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

It also extends to a related group: asylum seekers and refugees; people who do not have citizenship rights and status.

### 3. 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.

### 4. 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' a category in which people who see themselves within the range of neuro-diversity are sometimes included in. A major and growing group of people who have tended to be left out, often because it has been wrongly assumed that they can't be involved are people living with dementia (Weeks et al, 2012; Williamson, 2012).

### 5. 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. The more confident and experienced service users become, the more likely they are to challenge proposals put to them or arguments offered. This can make them unpopular among those organizing consultative or participatory activities.

That's 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' – more confident and assertive people whose views agencies may not want to hear, but which are a key part of the overall picture.

We also know that people can get left out for two sets of reasons that can create a vicious circle which keeps them out. Thus:

- Little effort may be made to involve them or they may be excluded
- They may not be in a good position personally to get involved and because of this may count themselves out. This can arise because they are:
  - Disempowered
  - Isolated
  - Stigmatized.

Essentially there are two kinds of barriers. Barriers we face from outside and barriers these create inside us putting us off getting involved.

## Some key exclusions

Some groups are repeatedly identified as subject to barriers that get in the way of them being involved. They offer important insights with wider applications.

### People who communicate differently

This includes people who might use an interpreter, perhaps for impairment related reasons (for example, a speech impairment that only people who are used to the voice patterns of an individual can readily understand), or it might be that they communicate in another language (BSL or other community languages). Not only may this have cost implications, ensuring suitable translation, but it is sometimes seen to interrupt the smooth running of activities and meetings.

At one advisory group meeting, we heard from a woman who uses a computer aided voice synthesizer, that ours was the first meeting that she had ever been to where other participants waited for her to type her completed comments before carrying on the discussion. We also witnessed and heard of many occasions where someone with a speech impairment would speak and others agree with them, when it was apparent they did not understand what the person has said. It is important to acknowledge that many people are uncomfortable around people who communicate differently. This does not mean people who communicate differently are 'hard to reach', instead it results in their voices being 'seldom heard'.



## People with high support needs

Many service users seem to be aware of the impact that their difference can have on non-service users. Service users can make non-service users feel a bit awkward and unsure of what to do or say. Some service users talk about 'a hierarchy of acceptable service users', with well educated, middle class people who could pass as 'normal' at the top. At the bottom are service users with high and complex support needs. This includes the large and growing number of older people now identified with dementia.

## People with Learning Difficulties

Many of the participants in this research, including people with learning difficulties talked of how their experiences, what they had to say and what they knew, – their 'service user knowledge', was not seen as valid knowledge. People with learning difficulties often said that in meetings with service providers and other non-service users, they were not listened to. People without learning difficulties frequently adopt a style of speaking which is formal and felt to be appropriate for a business-like meeting. They might talk in the abstract to depersonalize the topic under discussion, use acronyms and express themselves in the jargon of their field. Many service users, including some people with learning difficulties, talk from their own experiences and make their points through telling their own stories. This type of knowledge is sometimes dismissed as 'anecdotal' and inappropriate. Again what this may actually mean is that such service users are less 'seldom heard' than 'seldom listened to'.

## People subject to control

Some services restrict people's rights as well as offering them support. This includes social work and mental health services. Groups affected include:

- Mental health service users
- Families whose children might be removed
- People not seen as having 'mental capacity'.

If anything, it is even more important for people to be involved and listened to when their rights are at risk. The two things are not mutually exclusive. But often this doesn't happen and they are not even kept fully informed. It is important to challenge this and to make sure that people who may be subject to control have opportunities to be involved like anyone else.

## WHY PEOPLE WANT TO GET INVOLVED

👉 **Even people coming to the end of their lives say the same thing, they just want to make things a little better for others – even if they won't be there.** 🏹

If we want to involve as wide a range of people as possible, then the first thing to get clear is why anyone is likely to want to get involved. This offers some real clues as to what is likely to work for everyone.

Over and over again, when service users are asked why they get involved, they say the same thing. They talk about wanting to make a difference, to improve the services that they and other people get. They want to improve things for other people and themselves. They want to make change possible. They want to help make something better happen for the future. This is their fundamental reason. Of course getting involved can bring other benefits too, meeting new people, doing new things, challenging loneliness and boredom, offering new challenges and opportunities. But bringing about change for the better is the bottom line for most people.

**Strengthening the user voice.**

**We bring up issues about a better standard of living.**

**It gives me the hope that I'm making some kind of difference.**

**I like to help [other] people with learning disabilities to stand up for themselves and take control of their own lives.**

**Having your views acted on.**

But the opposite also holds. We can also see from this why many people don't get involved. Service users told us of many reasons why they were once, but no longer involved in participatory initiatives. The main reason they gave for stopping being involved was they found they had no meaning. Nothing changed as a result of their involvement. It was seen to be nothing more than 'ticking the box' or 'rubber stamping' decisions that had already been taken. This is the worst form of user involvement, as it has a negative effect on all concerned. In order for this NOT to happen, any organisation interested in taking forward user involvement needs to ask itself some important questions.

## A major lesson to learn

So the critical first lesson that needs to be learned is that if we want to ensure that everybody has an equal chance to get involved and an equal interest in doing so, then there must be the chance for them to make a difference. They must be able to achieve the kind of change that they want.

**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 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.**

## Key question

Think about getting involved yourself. It may have been a time when you needed to complain, comment, or make something happen.

### 1. Think of such time when you didn't do it.

What stopped you?

### 2. Think of a time when you did do it.

How did you feel afterwards?

Finally

What if anything might this tell you about why some people might be reluctant to get involved and how can these barriers be reduced?

# MAKING IT HAPPEN

“ 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. ”

Once we look closely at user involvement, it becomes clear that we will have to address two big issues if we want to ensure inclusive involvement:

1. What makes for good user involvement that attracts and engages with people?
2. What will ensure that everyone will want to be involved and that as wide a range of people as possible can get involved?

We will find ourselves constantly brought back to these two closely inter-connected issues. If we want to make sense of why some people aren’t involved, then we have to know what works to get people involved at all. Equally if we want to involve people who tend to get excluded, we need to look closely at the nature of user involvement more generally.

## Key starting points

“ I sometimes wonder is it really any more than just thinking, now what would make it possible for me to be involved and to think it was worthwhile? ”

User involvement isn’t rocket science. Nor is ensuring equal access for everyone. There is nothing magical about it. It isn’t a science. There is no one ‘right’ way of doing it. There are no crude toolkits for getting it right (although there are lots of non-service user consultants out there trying to sell them!). On the other hand, there are some general pointers for making inclusive involvement work.

We are not saying that they offer an automatic recipe for good practice, but we know of few examples of involvement which haven't been built on them:

- There needs to be a genuine and real commitment to involving people – you've really got to want to do it
- Every effort should be made to build on existing knowledge and experience about involvement, instead of just 'reinventing the wheel'
- Reach out to people where they are rather than expect them to come to you
- Check out with people and groups what kind of involvement is likely to work best for them.

Just as important, there has to be a real commitment to addressing issues of difference. If people are to feel included, then they must be included – and included on equal terms. Equality is not achieved by treating everyone the same. It means respecting and responding to their different requirements if they are to be able and want to be involved. We will only be truly inclusive if we create opportunities for equal and safe involvement.

**If as a service user, you try to talk about different experiences and other forms of oppression, you may then be criticized for causing divisions. You can be silenced and marginalized. It mustn't be like that if everyone – women, gay men, black young people – is to be a real part of it.**

**Treating everyone the same is not equality.**

**You have to be able to talk about gender issues. If you want to talk about women and mental health, that needs to happen in women-only groups.**



‘ 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. ’

# THE BARRIERS

There are some serious blocks in the way of people being able to get involved or decide if they want to. They can be a particular problem for people who already face other obstacles in the way of living their lives as they'd like to. This can create a vicious circle in the way of people getting involved, making it even more difficult for people who face the most barriers.

## Gatekeepers

‘ 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. ’

Gatekeepers tend to be people in the service system, sometimes family members, who get in the way of other people making contact with service users or more important, service users being able to access opportunities for themselves. Gatekeepers can be an especial problem for groups who already face a lot of other barriers, because they can be especially exposed to them. They can be a real problem restricting service users' opportunities to get involved and improve their life chances. Sadly sometimes it's people who are meant to be supporting people to live their lives who act as gatekeepers, restricting what they can do. Gatekeepers can also work to keep service users' organisations out of things, creating barriers in their way too.

### What to do about it?

**Service users and their organisations stress the importance of making it clear to such gatekeepers that they are valued and their work is recognised and of getting them on side. Be friendly, be supportive, build up relationships and listen to them:**

- Be persistent
- Training will help in the long run
- Look for ways round them
- Keep calm!!
- And most of all keep focused on service users themselves.

## Financial barriers

“ I had to pay for my train ticket and my PAs (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. ”

There are many financial barriers operating to exclude people. These include barriers relating 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.

### What to do about it?

The first thing that is crucial is to recognise the problems. There are many things that can be done to deal with them:

- **Make sure service users’ expenses are met fully and quickly**
- **Adopt the principle of paying for service users’ contribution and skills, while ensuring that if people don’t want to be paid that’s ok too**
- **The benefit system often fits badly with user involvement. Seek out expert advice and check with the Advice/Citizens’ Advice Bureau and local benefits agency**
- **Budget carefully and as best you can for inclusive involvement in the activities you carry out.**

There are also big outstanding problems like increasing the inadequate resourcing of service users’ organisations which will only be solved by long term campaigning and changed public priorities.



## Inadequate access

- **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. ʘ**

Three problem areas of access are highlighted:

- 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.

Inadequate access can range from the most obvious to the most subtle – from a lack of accessible signs in a building, to an atmosphere and organisational culture that is unpleasant and unfriendly to service users.

### What to do about it?

**Inadequate access needs to be taken very serious. It points to 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. There are some key messages to highlight here:**

- **Meeting people's basic access requirements is a duty under disability anti-discrimination and equalities legislation**
- **A golden rule for involvement is that everybody can express themselves and be 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.**

**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.**

6 Going to a consultation [organised by a user controlled organisation] 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. 7



# GETTING INVOLVED

Involvement can mean many different things. There are two different but overlapping ways of getting involved. 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 Controlled or Led Organization (ULO).
- 2. Getting involved in consultative or user involvement schemes**  
Responding to invitations to get involved from services, government and other agencies and organisations.

This distinction between getting involved in your own groups or organisations and outside initiatives and opportunities for involvement is an important one to draw. Each of these different starting points for involvement has its strengths and weaknesses.

## 1. Getting involved in a service user organization

### Strengths:

- Chances to gain in confidence and skills
- Opportunities to get to know, learn from and work with people with shared experience – almost invariably an empowering experience
- Strength through numbers, as you won't be on your own but instead will be doing things alongside others, with their help and support.

### Weaknesses:

- There may not be such an organization where you live, or one that works with people with your particular experience or impairment
- Such organizations are often insecure and under-resourced
- You may not be a 'joiner' or keen on doing things with others.

## 2. Getting involved in consultative or user involvement schemes

### Strengths:

- All you may need to do is answer some questions, fill in a form or turn up at a meeting
- You will have a direct chance to meet policymakers and say what you think
- You are likely to meet new people and learn new things.

**Weaknesses:**

- You are likely to be on your own and they will be a lot more powerful than you
- You have no guarantees that they will really listen or intend to take notice of what you say
- You may not feel comfortable having to speak at public meetings or putting things in writing.

**What service users say**

Most service users have positive experiences of getting involved in service user or disabled people's own organisations. But they are much more likely to have negative experiences responding to outside invitations to get involved.

**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.**

**A lot of the time it's 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.**

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

**The best of both worlds**

What can be the best of both worlds is to get involved in a service user group or organization first and then, linking up with others, finding out more and gaining more confidence, using that as a springboard alongside others, to feed into and take part in user involvement activities from a position of greater strength. But as one pioneering member of the disabled people's movement once said:

**Always makes sure that the things you initiate outnumber the things where you respond to them** (Ian Stanton, disabled activist, personal communication).

# KEY QUESTIONS

Ask yourself these questions and think carefully about the answers before you start to organise any user involvement exercise, get-together, or participatory activity.

- What is the purpose of this involvement?
- What change can happen as a result of this involvement?
- Have you the resources to carry it out in line with good practice?
- Have you allowed enough time?
- Are you paying service users?
- Who do you want to involve and why?
- How will you keep a record of what people say?
- How will you deal with sensitive issues which may upset people?
- How will you feed back to participants?
- What are you doing to overcome particular barriers to involvement some people may face?
- What action do you plan to take with what you find out?

For more about these **key questions** see our **electronic resource 1**.



# MAKING ACTIVITIES ACCESSIBLE

Access is about ensuring people have equal opportunities to participate fully. Service users have different needs and these can vary at different times. Different people with the same impairment/condition may have different access needs. Service users have an enormous range of experiences and these impact on them in different ways. They know best – especially with support – about their own individual access needs, so ask them. Never assume you know what someone else's access needs are based on your own experience or having worked previously with 'someone like' them.

Here we can only offer a general guide. It cannot ever be definitive. Service users are clear that for participation to be truly inclusive and effective, then a commitment to ensuring access must be built into all policy, practice and procedures as a matter of course. Access is not an 'add-on' for any particular individual. It has to be built into user involvement. A key reason why some groups of service users are excluded is because their access needs are not met.

## **Listen to what service users say.**

Access issues apply to every aspect of involvement activities. It's good practice to take account of them when planning activities and events. This includes ensuring access in:

### **How you let people know about the event/activity**

**They didn't make things clear. Apparently we were meant to use a side 'accessible' entrance. I never found it and ended up waiting at the wrong place for ages.**

**Everything was spelled out clearly. I had loads of time. I heard about it in different places and it looked interesting.**

## Travel and accommodation

I have to pace myself. I knew that if I went to their meeting I would have to stay overnight before otherwise it would all be too much. They understood and were helpful and that made it all so much better.

You always get a sense that they recognise your access needs. I think that's what comes from it being a user controlled organisation – it's people like you who know what it's like.

## The activity itself

They were friendly. It was nice. I'd been nervous about going.

There was women only space. That was great. We could have our own conversations and then bring that into the bigger group.

It wasn't all 'plenary' with people talking at us. We had lots of small group time and just being able to chat.

## The venue

It was a nice place and I could get around, but the people at the door were so unfriendly and unhelpful. Really put you off. Someone else made a complaint.

Everything was in one place. No having to drag all over the place. And they had floating PAs (personal assistants) to help – if you needed it.

## Timing

I've got a daughter at nursery class. They said they were going to end in time, but it dragged on. I just had to go before it ended and missed being part of deciding next steps. Really frustrating.

Great conference. It wasn't speaker X finishes at 11:00 and you are meant to finish your tea and be at the next place 15 minutes later. They gave you enough time so no having to try and rush about. That is so stressful when you have restricted mobility.

## Communication

You get involved in something and either they send you inches of paper, without even checking that you can read it or you get a whole load of stuff when you arrive with no time to go through it. They just don't seem to think sometimes.

They pay my support worker to go through things before we get together, so I know what is going on. Great!!

For more about these **access issues** see our **electronic resource 2, 5 and 6**.

### TOP TIP

There are some groups of service users who might be excluded from participating if a service user only meeting is the only way of being involved. You might need to consider how you could involve these people in other ways. This can include:

- Service users who do not like attending meetings
- Service users who do not like to travel
- Service users who fear their access needs will not be met
- Service users who are too frail to attend
- Service users who do not speak English
- Service users whose self worth is very low and thus think they have nothing to contribute
- Service users who face exclusion due to where they come from, culture, religion or belief, sexuality and gender.

There can be various reasons why service users might not like attending meetings and it is good practice to make sure you are not excluding them because they fear you will not meet their access needs. Access, as we have discussed, needs to cover much more than level access into a venue.



# THE ESSENTIALS

- 6 We need to get out and visit [other] 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. ➤

## Access and support

Two things are essential if everyone is to have equal opportunities to get involved effectively. These are access and support. We talk a lot about access in this guide. Basically it must be that there are real ways into organisations, agencies, services and participation arrangements that affect them.

The need for **support** doesn't arise because people lack the ability to get involved in society, but because their participation is often made difficult – and sometimes especially difficult. Obstacles may be placed in the way or people may not know what's possible or how to do it. They may be reluctant to ask for too much or complain. There are five elements to such support:

- Support for personal development – to increase confidence and assertiveness
- Support to develop skills – that are needed to get involved – practical day-to-day skills
- Practical support – including information, child and respite care, personal support, meeting places and so on
- Support for equal opportunities – so that all groups can contribute on equal terms, regardless of age, impairment, gender, ethnicity, culture, class, belief and so on
- Support for people to get together – in groups to do things together.

**Access** and **support** are both essential to ensure diverse involvement. Without access efforts to become involved are likely to be difficult and ineffective, however assertive or experienced we are. Without **support**, only the most assertive and confident people are likely to try to get involved.

## Outreach and development

If people aren't getting involved, the only way you will involve them, is reaching out to them. It is important to reach out and be pro-active rather than being reactive and expecting people to come to you. That is a key lesson of efforts to ensure diverse and inclusive involvement. We know that 'hard to reach' service users and 'seldom heard voices' are less likely to:

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

So the simple answer has to be to go to them. This requires outreach and development work. It means reaching out, both to individuals, including the many non-joiners there are likely to be, as well as people's own groups and organisations. Reaching out means using community work and community development approaches as well as research and enquiry to reach out to particular:

- User/impairment groups
- Ethnic groups
- Living situations, for example people in residential services, in the criminal justice system, who are homeless and travellers and gypsies.

It means reaching out:

- Directly to service users
- To their communities
- To their community leaders.

It is important to remember that if their communities and community leaders are a key starting point for making contact with some service users, efforts shouldn't stop with them. All groups have their prejudices and outreach efforts should be geared ultimately to making direct contact with the service users who it is intended to involve. Outreach makes it possible to start the task of building relationships with them. But it is important to remember that doing that and building trust takes time and commitment.

**With some groups it's because we're not getting out there to actually recruit and tell them about it.**

**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.**

## Advocacy

- “ 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. ”

Advocacy simply means supporting people to speak up for themselves. That is why it is so closely interlinked with user involvement. It ensures people have the wherewithal to be involved and exert an influence effectively.

There are many expressions of advocacy. All are likely to have a part to play. But most important of all is self-advocacy – people speaking and acting for themselves and each other. This is something that has by and large grown out of service user movements. Other helpful forms of advocacy include:

- Legal advocacy – where you are legally represented
- Professional advocacy – where people with welfare rights and other skills support people
- Lay or citizen advocacy – when people as volunteers support people
- Peer advocacy – people with shared experience helping each other to speak up.

At a time when abuse and neglect of service users, as well as hate crime, are making too many headlines, all these forms of advocacy are key to ensuring that all service users, especially those made the most vulnerable, can be heard and their difficulties surfaced and acted on.

For advocacy to be most helpful, it needs to be:

- Ongoing – available whenever someone needs it
- Based on a relationship – building trust over time
- Independent – and on the service user's side
- Accessible – there when it's needed
- Competent – based on 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.

## Ensuring ongoing and sustainable involvement

🗨️ **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! 🗨️**

User involvement that works is not a one-off. It means developing arrangements that are a routine part of services, organisations and systems. Involvement that ensures diverse involvement and builds trust so that 'seldom heard voices' are really engaged, is involvement that is ongoing and there for the long term. Such ongoing involvement makes it possible for service users to grow their confidence, skills and interest in influencing what happens.

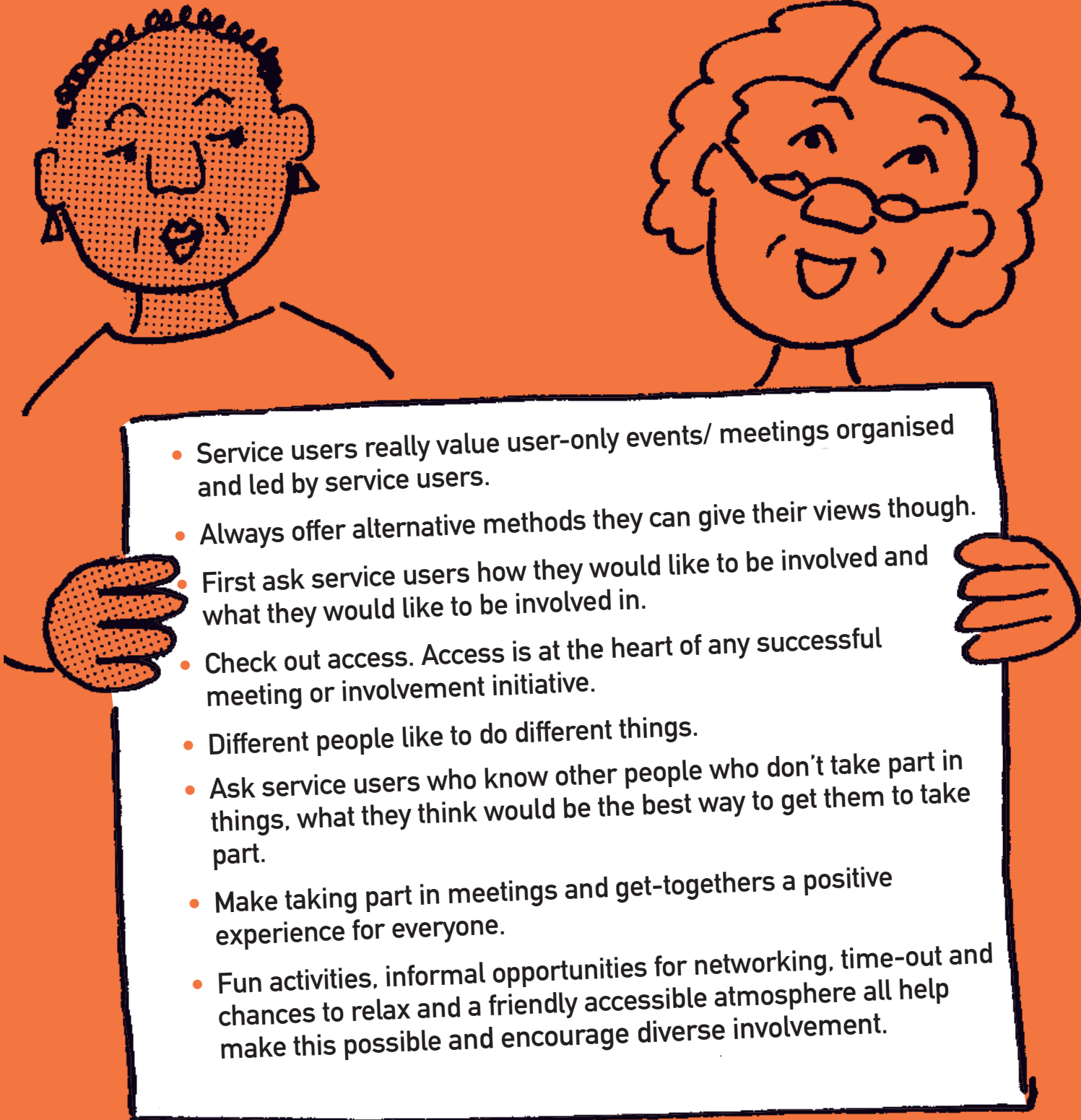
While it is important to involve 'new' people, it is also important to make it possible for others to stay involved. That way there can be a real continuity to user involvement building knowledge and experience, with old hands supporting new recruits, more experienced service users mentoring newcomers and apprenticing them into how best to get involved and make a difference.

Key to ensuring that as wide a range of people as possible want to stay involved is making sure that involvement:

- Is interesting and fun
- Something good comes out of it
- Is manageable.

# Planning inclusive events

Events bringing people together don't reach everyone, but alongside other approaches, they have a part to play – so long as they take account of key issues for addressing diversity.



- Service users really value user-only events/ meetings organised and led by service users.
- Always offer alternative methods they can give their views though.
- First ask service users how they would like to be involved and what they would like to be involved in.
- Check out access. Access is at the heart of any successful meeting or involvement initiative.
- Different people like to do different things.
- Ask service users who know other people who don't take part in things, what they think would be the best way to get them to take part.
- Make taking part in meetings and get-togethers a positive experience for everyone.
- Fun activities, informal opportunities for networking, time-out and chances to relax and a friendly accessible atmosphere all help make this possible and encourage diverse involvement.

Try to think 'outside the box' when planning your event – to make it fun and make sure there is good food!

**TOP TIP**

When you are thinking about user involvement that will include everyone, start by thinking, what would work for you. Then apply that to involvement for others.

This **doesn't** mean that you think about:

- Your access needs
- What you like doing
- Avoiding the kind of things that worry you.

It **does** mean that you think about the importance to you of it being:

- Interesting and pleasant
- Suitable for a wide range of access needs, not just ones you are familiar with
- A zero cost activity for everyone – no strain, no blame, no money needed, no chance of making a fool of yourself
- Complete with accessible information and a helping hand at every point so you know what's happening and can play your part confidently and positively.

**e** For more about **organising events** see our **electronic resource 3, 6 and 7**.

# INVOLVING PEOPLE

‘Everybody loved the food.’

‘We used picture cards to communicate which was very good.’

There are many different ways of involving people. Generally speaking, though, these can be divided into three main ways in which people are encouraged to get involved. These are by being:

1. Brought together to give their views.
2. Asked for information (through consultations and surveys).
3. Recruited and included in representative or participatory roles.

Each of these approaches has its well known strengths and weaknesses. So:

1. Can be ill-suited to those who find it difficult or don't want to join up with others.
2. Is the easiest way to ignore what people say, so it has to be linked with firm commitments that this isn't the case.
3. Can be great for more experienced service users and those who want to commit more time, but not necessarily for many more with other demands and difficulties.

So there is no one best way to involve people. It really is a matter of 'horses for courses'. Different things work for different people. Different people prefer different approaches.

## TOP TIP

It's always best in any user involvement scheme to use at least two methods to involve people. That way it is likely to be more inclusive and leave out far fewer people.

In this guide we try to explore a wide range of ways of involving people that will work for different groups. We want to start, though, with a way that works for people who are ok with coming together with other people. We know this isn't true for everybody, and we will come on to that. So here we focus on what service users seem to find the best way of getting involved which brings them together with other people.

## Service user only involvement

‘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.’

Service users particularly value coming together in service user-only group discussions facilitated by service users, with a report written up to feed back to agencies and authorities. Such meetings are valued because:

- Service users like the opportunity to meet other service users, to talk frankly with people with shared experience, in a supportive environment
- This offers a chance to share experiences in a safe setting without people present who may at other times have power over them
- They makes it possible for service users to develop knowledge and ideas collectively from their unique individual and personal experience
- It enables them to go beyond feeding into other people’s agendas, to explore and develop their own
- Coming together with other service users is inherently empowering
- It helps overcome a sense of isolation and being the ‘only person’ in their situation, encouraging honesty and openness
- It puts them in a position of shaping their discussion and feedback as accurately as possible
- It can offer an effective route to involving ‘seldom heard’ voices, who can be supported to convene such meetings, which also provide a sense of commitment to listening and making change.

There are also major benefits for agencies and services who commission such initiatives. They help:

- Provide accounts from service users that are least likely to be qualified or constrained by concerns to say what services want to hear
- Offer a better understanding of the issues for service users
- Provide a better understanding of the service user perspective
- Service users identify solutions for the problems that they themselves highlight
- Enable service users to meet this way demonstrating respect and trust and a commitment to *meaningful* participation on the part of the commissioning organisation.



## Getting together positively

Often people don't respond to invitations to come to a meeting and get involved, because of their negative expectations. Sadly these are frequently justified, with meetings that are inaccessible, boring and dull. As we have said, service user-only meetings organised by service users can help avoid this. But also crucial for all user involvement that entails people coming together, is that it is interesting, enjoyable and fun. This is no less true for service user-only meetings.

To ensure diverse involvement, service users place an emphasis on enabling participants to:

- Have a good time and enjoy themselves
- Have good, free, food and refreshments which are culturally appropriate
- Be in a warm, safe and supportive environment
- Gain knowledge, awareness and understanding from attending the events or meetings.

They highlight positive ways to achieve this, including:

- User-led performance
- Fun activities
- Encouraging networking
- Aids to relaxation and communication
- Informal, friendly and accessible venues.

Finally, ensure that:

- Service users have a choice over all these activities
- There is a 'quiet' room for those who want 'time out'
- Access issues are given first priority and facilitators/organisers make sure that they work in fully accessible ways.

**e** For more about **positive involvement** see our **electronic resource 2, 3, 5, 6 and 7.**

**TOP TIP**

Here are some practical steps for involving people who tend to be excluded:

- Identify a group who don't seem to be present in what you do
- Identify some people who fit that bill to come together virtually or actually
- Identify someone with the necessary skills who shares that identity to facilitate the meeting
- Fund the facilitator to find out how people see things, what people want to do and their key priorities
- Ask the facilitator to prepare a short report on this.

Work to involve them and their concerns in your activities and to get their priorities recognised and included in the policy process and service system.

**e** For more about **organising positive events** see our **electronic resource 3, 6 and 7**.

**TOP TIP**

People need to be safe when they get involved. But sometimes when people get involved they have a rare chance to tell if they aren't safe, or it comes out that they have a problem. Make sure you have arrangements in hand to deal with this issue if necessary.

**e** For more about **keeping people safe** see our **electronic resource 8**.

# LANGUAGE, ACCESS AND POWER

‘ This is not about political correctness. It’s about treating people with respect. ’

The use of language in user involvement raises issues of both power and access. Both can play a major part in discouraging people from getting involved, particularly members of the most marginalised groups. Language is not neutral. It can be used to keep people down, to keep them separate, to exclude them or to encourage and support them. Language is inseparable from power. It reflects existing inequalities and must change if these are to be challenged. The service system has traditionally controlled the language of health and social care, with talk of ‘the disabled’, ‘clients’ and ‘claimants’. People want to be described in their own terms, just as they want to shape their own lives. While there isn’t really any agreement about language in this field, a good rule of thumb is to go with the words that people seem to feel most comfortable with and be ready to fit in with what they want.

**Talk about them and us! Stop talking about us as if we were aliens.**

**It really annoys me. People should think more before they speak. Words are very powerful and if you litter what you say with words like ‘mental’, ‘mad’, ‘crazy’ and ‘bonkers’ it can have a very negative affect on me.**

Service users, particularly people with learning difficulties, have long highlighted the excluding effects of using jargon and professionals and the service system appear to be awash with it. Jargon can demean as well as exclude. It can make people feel ignorant, stupid and outsiders, when the whole purpose of involvement should be the opposite. User involvement must work to be a jargon-free zone and this is not difficult to do if the commitment is there.

**They have all these letters and words I haven’t heard of. We have to keep asking them to stop. To tell us what they mean. It’s boring.**

Involvement has also raised issues of its own for service users. In recent years there has been much more talk of service users as 'customers' or 'consumers'. Some welcome this and in some countries this is the most common form of description. But others feel uncomfortable with this and don't feel that receiving support as someone with a long term condition or from services which can restrict your rights and liberties has much in common with buying a fridge or choosing a holiday. As the psychiatric system survivor Mike Lawson once put it:

**Describing a mental health user as a consumer of psychiatry is like calling a rat a consumer of Rentokil.**

Or as two service users put it:

**I don't care what people want to call me. Sticks and stones ... so long as they have good intentions they can call me 'spastic'.**

**Some people just don't know what is acceptable. But if they are friendly, it doesn't bother me.**

## Key point

Remember language isn't everything. As one pioneer of advocacy once said, there are a lot of people who can 'talk a good service', that is to say, use the right words and say the right thing, without doing the right thing. Getting the language right is only part of the issue. At the heart of everything is doing the right thing.

The issue of language is one that regularly comes up when people get involved. There can be no doubt that some people are put off getting involved because of the language that is used or their expectations about it.

## And finally...

Language is always changing and people's preferences will change. But don't get tongue tied when talking with a service user, just because you can't think of the right words, or you think you just said the wrong thing. Bear in mind though that words do matter, and can make a difference in how effectively you can communicate with service users. This is about trying to treat people with courtesy and respect.

**e** For more about **language issues** see our **electronic resource 4**.

# At a glance

## Don't say...

The disabled

Confined to a wheelchair

Victim of...

Suffering from...

Crippled by...

Afflicted by...

Person with...

Living with...

Alcoholic and/or drug addict

Speech impediment

Deaf and Dumb

Mental, mentally ill, schizophrenic,  
Manic depressive

Spastic

The old, elderly

Dwarf or midget

Having a fit

The Blind

Disabled toilets

Handicapped

Mentally retarded

Mentally handicapped

## Do say...

Disabled people

Wheelchair user

Person who has...

Someone with alcohol and/or drug  
problems

Speech impairment

Deaf without speech

Mental health service user/survivor

Someone with cerebral palsy

Older people

Person of restricted growth

Having a seizure

People with visual impairments

Accessible toilets

Disabled people

Person who has/with learning  
difficulties/disabilities

# OUTSIDE INVOLVEMENT

**‘They must know how much their reforms are hurting us. We keep telling them. But they take no notice. What’s the point?’**

Getting involved has caught the imagination of many service users because it has felt like recognition at last of the knowledge, expertise and experience they have to contribute and a chance to make a difference. As we have seen, this is the main reason most people want to get involved. But there can also be a negative side to user involvement, which it would be wrong to gloss over. Service users talk a lot about:

- Tokenism
- Being treated like a rubber stamp
- Decisions already having been made
- Just ticking the boxes
- Organisations not really listening
- A lot of pain often for no gain.

This sense of not being listened to has also been increasing, as governments have organised campaigns criticising people on benefits as ‘scroungers’, targeted disabled people and mental health service users for cuts in social care and other services and made them feel less and less part of society and valued for who they are.

All this has happened at the same time as service users have been asked to give their views and say what they think. For many service users as a result, there has seemed less and less point in doing this.

## **Why do they ask us our views, when they take no notice of them?**

As a result many service users are more reluctant to get involved, to respond to consultations. At the same time they are often facing bigger and new problems. So what seems to be happening is that more and more service users are getting involved from outside. Instead of linking with services and policymakers, more and more they are getting involved in outside campaigns to create pressure for change.

New organisations, new groups and new campaigns have been developing.

Sometimes they organize their own activities and initiatives, from petitions, to demonstrations; from marches to pickets:

- Developing their own campaigns
- Sometimes they link up with others, building new partnerships and alliances – with:
  - Carers
  - Trade unionists
  - Professionals
  - Other groups of service users
  - Community and citizens organisations
- Joining in other people's campaigns.

The big difference now is that people feel it is likely to be more useful and effective to try and make change from

## **OUTSIDE**

rather than

## **INSIDE**

They are also finding other ways of challenging what is happening to them, including:

- Producing their own research to prove that what is being done isn't based on evidence and is damaging to groups who are supposed to be being helped
- Using the law to fight their case
- Occupying and organizing sit-ins at services to stop them being closed
- Getting support from councillors and MPs through democratic and parliamentary process
- Using politicians' rhetoric of 'co-production', involvement and empowerment against them when they are ignored and excluded.

## New forms of involvement

“ 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 got really got that chance any more. So it's much more a matter now of peeing wherever and whenever you can!! ”

Not only are many service users now getting involved in an altogether different way – based much more on campaigning than consultation, but this shift has also encouraged the development of wide new avenues for innovation and experiment which enable a much wider range of service users to get involved. This is central to the goal of enabling more diverse, more equal involvement.

Traditional forms of involvement and campaigning have often been problematic to service users, because they have physical and sensory impairments, because they are frail through age, or isolated through mental distress. They may not be accessible to them, familiar or comfortable. That's why over the years they have developed new accessible forms of involvement, creating new meanings to user involvement.

But now they are drawing on and developing a new generation of methods which closely connect with the new need for involvement from outside.

These new groupings have also taken forward the new technologies and forms of social media and networking now available, making it readily possible for people to join in and get together 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 producing blogs and vlogs, podcasting, setting up new websites and Facebook groups, getting support for electronic petitions and they 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 service user who has become an activist says summing it all up:

**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. ... we were in a little bubble, the outside world very rarely came in. Then the internet became a learning tool ... New social media such as Facebook and Twitter have taken campaigning to a new level ... Most of the people will never meet face to face.** (Beresford, 2012, p75).

This has turned some issues of access on their head because now people can be actively involved alongside others:

- In residential services
- Even if they are restricted to their bed
- In isolated rural areas without public transport, as well as in towns and cities.

They are using radio phone-ins and the local press. They don't have to put themselves at risk in crowds, they can exert an influence from the comfort of their own home, while at the same time developing a strong sense of community and collectivity:

- It's now more difficult to exclude certain groups of service users
- It's now much more possible for groups which face additional barriers and who have been excluded to get involved and play an active part in bringing about change with other service users.

For this to be as effective as possible, will need:

- More training for service users in making the most of social networking and media
- Improved access to the internet for service users
- Greater recognition of the key role of disabled people's and user led organisations in supporting people's involvement through these new technologies
- Dedicated funding to make all this possible.

## Key point

Remember whoever we are, however experienced and confident we may be, we all need help to learn and do new things. For many people and groups getting involved is just such a new thing. That's why if our goal is inclusive and diverse involvement, we must put resources into supporting user involvement, so everyone can take part on equal terms.

**There's no point in filling in their forms or going to their meetings. We've got to do what other campaigns do.**

**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.**

**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.**



## HELPFUL MATERIAL

Ahmed, S., Hussain, M. and Vournas, G. (undated) *Consultation with "hidden" and hard-to-reach groups: methods, techniques and research practice*, Trescom Research and Consultancy Limited (available at [www.laria.gov.uk/content/features/68/feat1.htm](http://www.laria.gov.uk/content/features/68/feat1.htm), accessed September 2006).

Begum, N. (2005), *'I'm not asking to live like the Queen': The vision of service users (or potential service users) and carers who are seldom heard on the future of social care for adults in England*, London, The Social Care Institute for Excellence.

Begum, N. (2006), *Doing It For themselves: Participation and black and minority ethnic service users*, <http://www.scie.org.uk/publications/reports/report14.asp> London, Social Care Institute for Excellence/Race Equality Unit.

Beresford, P. and Croft, S. (1993), *Citizen Involvement: A practical guide for change*, Basingstoke, Macmillan.

Coates, J. (1988), *Women Men And Language*, London, Longman.

Beresford, P. & Turner, M. (2003) *Contributing On Equal Terms: Getting Involved and the Benefits System*. London: Shaping Our Lives.

Beresford, P. Fleming, J. Glynn, M. Bewley, C. Croft, S. Branfield, F. and Postle, K. (2011), *Supporting people: Towards a person-centred approach*, Bristol, Policy Press.

Beresford, P. and Andrews, A. (2012), *Caring For Our Future: What service users say*, Programme Paper, March, Joseph Rowntree Foundation, <http://www.jrf.org.uk/publications/caring-our-future-what-service-users-say>

Beresford, P. and Branfield, F. (2012), Building Solidarity, Ensuring Diversity: Lessons from service users' and disabled people's movements, in, Barnes, M. and Cotterell, P. (editors), *Critical Perspectives On Use Involvement*, Bristol, Policy Press, pp33-45.

Beresford, P. and Campbell, P. (2004), Participation And Protest: Mental health service users/survivors, in, Todd, M.J. and Taylor, G. (editors), *Democracy And Participation: Popular protest and new social movements*, London, Merlin Press, pp326-342.

Blakey, H., Pearce, J. and Chesters, G. (2006) *Minorities within minorities: Beneath the surface of South Asian participation*, York: Joseph Rowntree Foundation.

Branfield, F. and Beresford, P. with Andrews, E.J. Chambers, P. Staddon, P. Wise, G. and Williams-Findlay, B. (2006), *Making User Involvement Work: Supporting service user networking and knowledge*, York, Joseph Rowntree Foundation, York Publishing Services.

Branfield, F. Beresford, P. Levin, E. (2007), *Common Aims, A strategy to support service user involvement in social work education*, London, Social Care Institute for Excellence.

Butt, J., (2006) *Are We There Yet?: Identifying the characteristics of social care organisations that successfully promote diversity*, London, Social Care Institute for Excellence.

Campbell, P. (2009), The Service User/Survivor Movement, in, Reynolds, J. Muston, R. Heller, T. Leach, J. McCormick, M. Wallcraft and Walsh, M. (editors), *Mental Health Still Matters*, Basingstoke, Palgrave, pp46-52.

Campbell, J. & Oliver, M. (1996) *Disability Politics: Understanding our past, changing our future*, London, Routledge.

- Carr, S. (2004) *Has service user participation made a difference to social care services?* London: Social Care Institute for Excellence.
- (CSCI), Commission for Social Care Inspection (2007) *Benefit barriers to involvement, finding solutions.* London, CSCI.
- Croft, S. and Beresford, P. (1993), *Getting Involved: A practical manual*, London, Open Services Project.
- Davison, S. and Rutherford, J. (editors), (2012), *Welfare Reform: The dread of things to come*, Soundings On, London, Lawrence and Wishart.
- Diary of a Benefit Scrounger, Campbell, S.J., Anon, Marsh, S., Franklin, K., Gaffney, D., Anon, Dixon, M., James, L., Barnett-Cormack, S., Fon-James, R., Willis, D., and Anon, (2012), *Responsible Reform: A report on the proposed changes to Disability Living Allowance* (<http://wearespartacus.org.uk/spartacus-report/>).
- Dynamix and Save the Children, (2002) *Participation!: Spice it up! – Practical tools for engaging children and young people in planning and consultation.* London, Save the Children Fund.
- Faulkner, A. and Morris, B. (2003), *User Involvement In Forensic Mental Health Research And Development, Expert Paper*, NHS National Programme on Forensic Mental Health Research and Development, Liverpool, National R&D Programme on Forensic Mental Health.
- Hernandez, L. Robson, P. and Sampson, A. (2010), Towards integrated participation: involving seldom heard users of social care services, *British Journal of Social Work*, Vol 40 No 3, April, pp.714-736.
- Kalathil, J. (2011), *Dancing To Our Own Tunes, Reassessing black and minority ethnic service user involvement, Reprint of the 2008 Report with a review of work to take the recommendations forward*, London, The Afiya Trust and National Survivor User Network (NSUN).
- Moriarty, J. Rapaport, P. Beresford, P. Branfield, F. Forrest, V. Manthorpe, J. Martineau, S. Cornes, M. Butt, J. Iliffe, S. Taylor, B. Keady, J. (2007), *Practice guide: the participation of adult service users, including older people, in developing social care*, Stakeholder Participation, SCIE Guide 17, London, Social Care Institute for Excellence.
- Morrow, E. Boaz, A. Brearley, S. Ross, F.M. (editors), (2012), Seldom Heard Groups, in, Morrow, E. Boaz, A. Brearley, S. Ross, F. M. (editors), *Handbook Of Service User Involvement In Nursing And HealthCare Research*, London, Wiley, pp106-119.
- Rainbow Ripples and Butler, R. (2006), *The Rainbow Ripples Report: Lesbian, Gay and Bisexual Disabled People's Experiences of Service Provision in Leeds*, Leeds, Rainbow Ripples.
- Robson, P. Begum, N. and Locke, M. (2003), *Increasing User Involvement In Voluntary Organisations: An exploration of how 11 voluntary organisations increased their levels of service user involvement*, York, Joseph Rowntree Foundation.
- Weeks, D. Wilkinson, H. Houston, A. and McKillop, J. (2012), *Perspectives On Ageing With Dementia*, January, York, Joseph Rowntree Foundation.
- Williamson, T. (2012), *A Stronger Collective Voice For People With Dementia*, October, York, Joseph Rowntree Foundation.

# 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](http://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.

## **e** Electronic resources

In this guide 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](http://www.shapingourlives.org.uk/ourpubs.html)**



**THE FOCUS OF THIS GUIDE  
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TO BE MORE INVOLVED IN  
AND HAVE MORE SAY OVER  
THEIR LIVES AND THE SERVICES  
THEY USE TO LIVE THEM.**



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