



Shaping Our Lives

**Improving Understanding of Service User
Involvement and Identity**

**A Guide for Service Providers and
Practitioners Organising Involvement
Activities with Disabled People**

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Introduction

Shaping Our Lives is a national organisation and network of user-led groups, service users and disabled people. It is a user-led organisation committed to inclusive involvement. It specialises in the research and practice of involving diverse communities in policy, planning and delivery of services.

Listening to and respecting service users' voices and perspectives is increasingly known to be an essential part, and often a statutory requirement, of developing quality services.

Shaping Our Lives has undertaken a piece of research to gather the experiences of Disabled people who have taken part as service user representatives in the policy, planning and delivery of health, social care and local government services.

From these experiences we have produced this guide for professionals. The guide provides essential information for professionals who want to hear the views of Disabled people and use this knowledge to make services efficient and effective for the people who use them. You should aim to co-produce services with your users. The advice and tips for successfully involving Disabled people detailed in this report reflect the principles of the social model of disability, and the adoption of working methods that reflect that the barriers that Disabled people experience are from society and not because of the impairments and health conditions they have.

It may be your role to manage involvement activities in your organisation. You may have been asked to run an involvement activity with little training or experience. If you are reading this guide you are probably thinking ahead to what the task might involve and how to get the best out of it. When you have finished reading the guide you will have picked up some top tips about how to improve the experience for service user representatives.

If you don't understand the following terms or their use in this guide there is an explanation of them on page 15:

- Disability Equality Training
- Involvement activity
- Organisation
- Professional(s)
- Service user
- Service user representative (Representative)
- The medical model of disability
- The social model of disability

Section 1

What makes a good and bad involvement experience?

Getting service user involvement right can be difficult. However, from the research findings there are some clear actions that are commonly mentioned that can make the difference between a rewarding experience and one that leaves both professionals and service users feeling demoralised. Service user representatives say the following things contribute to a positive involvement experience:

- Feeling part of a team.
- If the activity has a clear purpose and role for service user representatives.
- That lived experience and service user knowledge is valued.
- When service user contributions are acknowledged and make a difference.

The following things were commonly mentioned as leading to poor involvement experiences:

- No meaningful outcome from the involvement.
- Inflexible, too long or tokenistic processes.
- Not listening to and acting upon service user views.
- Power imbalances between professionals and the service user representatives.

Top tip!

Build on this research. Ask people who are currently involved in your engagement and involvement activities what makes it a good experience and what makes it a bad one.

Tackle the bad experiences in your actions for change (see section 6)

Do more of the good things!

Section 2

Essential elements for effective involvement

There are seven essential elements for effective involvement activities from the perspective of a service user representative as follows:

1. Equality

When involving service user representatives in involvement activities it is important to value their lived experience and consider them as experts. Power imbalances can be avoided by involving service users at each stage of the process, including deciding what the purpose of the activity is, agreeing objectives and outcomes, setting a time frame and evaluating the outcomes.

Things that can lead to power imbalances are: not listening to service users, using professional jargon, not meeting the access needs of everyone, not providing accessible papers in advance, not sharing all the relevant information, not involving service users in setting the agenda, putting all the service user agenda items at the end (and leaving the meeting when these agenda items are eventually discussed).

2. Mutual respect

Involvement activities should be an opportunity for professionals and service users to listen to each other and gain mutually beneficial knowledge and understanding. There is considerable evidence that when service users become involved in designing policy and services there are improvements in efficiency and often cost savings for services.

However, many service user representatives feel that their knowledge is not respected

“It is diminishing to realise how the service providers see service users. It is frustrating in the meetings to sense how little credence most of them actually give to service user viewpoints. If our view chimes with theirs they are positive and pleased with how things are going; if the service user perspectives challenge their views then they tend to offer platitudes and try to swiftly move the discussion on.”

3. Ownership

If service user representatives are involved equally and shown mutual respect they can become fully involved, play an active role and contribute to the outcomes. If left on the side-lines people will not be able to develop a sense of ownership and contribute to the success of the activity.

4. Structure

There needs to be a clear plan for the involvement activity that has been developed in consultation with the service user group who are represented in the process. This plan should describe the purpose of the activity, state the expectations of people involved and provide the functional details such as frequency, length and duration of involvement activities. It is particularly helpful to develop role descriptions for service user representatives when the involvement activity is an ongoing process.

5. Commitment

Service user representatives often comment that involvement activities are most effective when there is a commitment from professionals, including senior managers, from all the relevant departments. This commitment is interpreted in many ways including the following:

- Providing appropriate funding for the activities – so all access requirements can be met, expenses are funded, service user representatives are rewarded either financially or in other ways such as opportunities for personal development or accreditation.
- An understanding of inclusive involvement of people with a range of impairments and health conditions – all professionals need to have disability equality training, knowledge about inclusive involvement and understand the principles of the social model of disability.
- Provide appropriate support for service user representatives – it may be necessary to provide some training or mentoring for people to be able to complete the required tasks.
- Realistic timescales – by allowing sufficient time for a service user involvement activity it can change the outcome from a tokenistic experience to a meaningful and productive one.

6. Feedback

Many service user representatives say that they do not receive feedback on the outcome of the involvement activities they take part in. This makes people feel worthless and uninclined to take part in future activities.

7. Personal development

Personal development is a key motivator for service user representatives and includes: training, acquiring new skills, gaining knowledge, opportunity for paid or voluntary work, increased confidence, opportunity to network/make new friends, increased self-worth and finding out about services and organisations in the area.

“I think the best one for me used to be the Partnership Board because they had a mentoring system and I was getting some training that helped me be a representative.”

Top tip!

Provide the opportunity for service user representatives to talk to you about what you are trying to achieve, how you are planning to do it and what will be involved for the representatives.

This gives the service user a chance to decide if the involvement activity is appropriate for them and how it might feel to be part of the whole process.

Section 3

Managing relationships and conflict

Service user representatives say that sometimes professionals behave differently towards them when they meet using services compared to when they meet in an involvement activity. It is important to consider that someone taking part in involvement activities may also need to use services and this may cause awkwardness. However, in both situations service users and professionals should be in a collaborative relationship and this is the basis for meaningful involvement activity.

Top tip!

Provide a single point of contact for service user representatives. This person can ensure that any concerns are addressed appropriately.

Make sure you provide contact details for phone, text and email.

Section 4

Ensuring the process is inclusive and accessible

Service user representatives say the most important thing to ensure an involvement activity is successful is to make it accessible.

“It’s about developing inclusive practice. It’s about making them aware that service user representatives are integral to the meeting and they shouldn’t treat us as an add-on. If they were able to do that they would be able to make much more valuable use of the service users and develop much better services as a result of that.”

These are systems to put in place to make activities accessible:

- An overview of the activity, what it aims to achieve and what the outcomes will be.
- Terms of reference for service user representatives taking part.
- Role descriptions for longer involvement activities.
- Clear guidance to the amount of time service user representatives will need to commit and for how long.
- Payment policy for reimbursing expenses with details of how to claim and how long it takes for a claim to be processed.
- Involvement payment policy with details of how to claim and how long it takes for a claim to be processed.
- Including a skills audit to check participants have the appropriate skills for the involvement project.
- Completing an access audit before any activity starts.
- Confirmation of practical arrangements, such as times and places for meetings (although this should be part of the process to agree these details with the service user representatives).

The following things may help service user representatives meet their potential:

- An induction for the service(s) the involvement activity refers to.
- Training on the range of impairments and health conditions that people taking part may have and how this impacts on their participation.
- Professional training that is relevant and can be extended to service user representatives.
- A mentor from the service and/or a buddy with experience of involvement activities.

There is often an assumption that any Disabled person can be an effective service user representative and generally this is true if they have the appropriate skills and knowledge. However, service providers organising involvement activities should do a skills audit or similar to establish any training and support needed for service users to take part successfully.

Section 5

Benefits and advantages for service users

It is useful to consider why service users become representatives. It will help you provide motivational opportunities – and encourage more people to sign up to be representatives.

People become service user representatives because:

- It is a pathway to paid and voluntary roles.
- To make a positive difference to services, to affect change.
- Leads to involvements with other voluntary organisations or to other involvement activities that can expand knowledge and skills.
- Provides new activities and opportunities through increased confidence. For example, people said they had gained enough confidence to write articles, challenge decisions, attend regional/national conferences, do radio interviews - “opening up a whole new world”.
- Is an opportunity to network and join user-led groups or voluntary sector organisations.
- It often also leads to invitations to aspirational events, other consultations and involvement events.
- Finally, some people find that being a service user representative benefits their health and wellbeing; helping them to get well and to manage their impairments and health conditions.

How it helped me

“For me it was a start to getting back out into the world and a step on the journey to being well again.”

Top tip!

Ask for feedback from participants about why they got involved. If you can, offer some or all of those opportunities as incentives on your next wave of recruitment for service user representatives.

Section 6

Good practice recommendations for improving service user involvement

Training

- Provide training in inclusive communication jointly for everyone (staff and service user representatives) who will be taking part in involvement activities.
- Offer opportunities for service user representatives to take part in relevant training and up-skilling activities.
- Find ways of accrediting participation in training.
- Establish accreditation of all service user involvement, for example, a Certificate or Record of Participation will attach merit to the time and effort disabled people give to the role.

Access

- Ensure meetings are fully accessible – involve service user representatives in identifying what the access requirements are.
- Identify a person who is the central point of contact for matters leading up to and following meetings.
- Ground rules – at the start of meetings use ground rules to help establish strategies for ensuring everyone can have their say and these should be used to clearly signal that all contributions will be treated respectfully.
- Everyone should be required to listen carefully and be polite.

Equal participation

- Involve service user representatives in setting the agenda for the meeting.
- Avoid having service user input as the final item on the agenda to ensure service user feedback gets the time and attention it requires.
- Make sure service user representatives have advanced receipt of all papers to be discussed in accessible formats well before the meeting.
- Ensure a welcome and inclusive event – have someone to meet and greet service user representatives.
- Follow through on suggestions and input made by service user representatives and have a strategy for feeding back on this.

Top tip!

If you have not had disability awareness and disability equality training then get some. It will help you to understand simple practical low cost steps you can take to make activities accessible for everyone taking part.

Section 7

Actions for change

Here are some easy actions you can take to immediately set about improving involvement of service user representatives. These are small and doable action steps and habits that will create more respectful and inclusive service user participation and are key to making sure that people who take on the role of service user representation have positive experience and outcomes from being involved. Don't be alarmed: these steps are often small (some will take ten minutes or less to complete!). Over time they will improve involvement of service user representatives in ways that will make it more and more possible to drive through better quality, efficient, cost effective services that disabled people value.

Four essential steps to improving involvement of service user representatives

Step 1 - Profile the service users you currently work with, and build better connections with them

Have you ever written up a list of exactly who the service user representatives are that are giving their time to development of the services you deliver? Building a list of the people you already involve can be a hugely clarifying activity. Understanding who you involve as service user representatives will help you identify essential access requirements for meetings and also help you identify the gaps in service user representation to address missing perspectives. To improve involvement of service user representatives you could get in touch with those already taking part and ask for their ideas on how participation could be improved. Better connections, and building genuine relationships with service user representatives, is a great way to strengthen the impact service users can make to your service and also to ensure the role is positive for them.

Step 2 - Set some 30-day goals for improving involvement of service user representatives

Having identified what needs to change in your practices – hopefully by getting feedback from existing participants – set some goals for change. It might be to let service users know more about how they can get involved, a financial goal to reimburse travel costs quicker, improve access to meetings, a plan to make contact with existing representatives and ask them for feedback on how things are going, a new email update on service user recommendations - those are just a few ideas. We suggest 30-day goals because they are short enough to be manageable and will kick-start real change. In 30 days of focused action you can achieve incredible progress for improving service user involvement based on the rich and varied ideas in the sister report to this guide.

Step 3 - Include a call for service user involvement in any communications you send to your service user community

This is something that will only take a few minutes to write and can be included in every correspondence sent out to service users. Get into the habit of always promoting the value of service user representation, and spell out the benefits for both providers and users who take on the role; this will have a massive impact on raising the value of the activity. Better communication will lead to greater involvement to support service development.

Step 4 - Follow up and ask for feedback

When service user representatives make suggestions follow these through. We know not all suggestions can be fully realised but have in place mechanisms for reporting back on how and whether suggestions have been responded to. Following up with service user representatives, including asking for new suggestions when recommendations get stuck, can be game changing for your service and shows respect for service user representation.

Contact Shaping Our Lives for help from our Service User Involvement Advisory Service.

In conclusion

Service users welcome being able to contribute to service design, delivery and evaluation of the services you provide and the processes you use. Many service users want to do this to help others in the same position as them, to 'give something back'. Service users have valuable lived experience which you and your organisation can benefit from.

However service users cannot automatically become useful representatives – they need induction, training and support just like any paid member of staff would. They need to be valued and motivated and rewarded too.

Good processes and systems for involving service user representatives will lead to better, more efficient and more effective services which are valued by their users. Bad processes and systems will not improve your services; they will put service user representatives off being involved, and in some cases can cause aggravation and distress to the service users who have been subjected to them.

There are simple, practical things you can do to provide inclusive and accessible involvement activities. Be realistic with your goals and make affordable and quick changes to your systems.

Top tip!

Think about all the good practices you have for valuing staff in your organisation. Think about how they can be applied to service user representatives too.

Supporting information

This best practice guide for service user representatives is one of three documents in this series. The other documents are the report of the research findings and a best practice guide for professionals.

You can find these under the heading 'Improving Understanding of Service User Involvement and Identity' in the Resources section of our website - www.shapingourlives.org.uk/resources.

Other resources on our website that may also be of interest are:

- Guide to accessible meetings and events (also included on page 16 of this document)
- Inclusive ground rules
- Definition of a service user written by people who use services
- A series of publications including electronic resources in the 'Beyond the Usual Suspects – Towards inclusive user involvement'.

Or contact Shaping Our Lives about our inclusive involvement service:

Email: information@shapingourlives.org.uk

Telephone: 0845 241 0383

Glossary of terms

Disability Equality Training

Training developed within the Disabled People's Movement which outlines the distinctions between the medical and social models of disability and the implications for professional practice and service delivery of these different ways of understanding.

Involvement activity

An activity, series of activities or group set up by an organisation to engage and involve service users in designing, overseeing and/or evaluating one of the organisations services or processes.

Organisation

A body providing a service. Can be a public body (like a local council or GP, a University), a charity (e.g. drug and alcohol services) or a private company (e.g. a residential home).

Professional(s)

This term is used interchangeably with service provider(s) and practitioner(s) in this document. It is taken to mean someone who is paid to work for an organisation in a particular role, like a social worker, nurse, or commissioning officer. It is used as a noun and not as a descriptive term suggesting particular behaviours.

Service user

A person who uses a service provided by an organisation, often in a social care or health care setting. A service user is not always a Disabled person. However, in this document we have used 'service user' to mean a Disabled person who is a service user. Anyone can self-define as a service user.

Service user representative (Representative)

An individual service user who joins in with an activity to share their lived experiences and sometimes speak on behalf of other service users.

The medical model of disability

Disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being, for example the ability to climb the stairs or walk to the shops (WHO, 1981)
(In other words, disability is an individual problem, a 'condition' caused by physical, sensory, cognitive emotional impairment).

The social model of disability

Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Disabled People's International, 1981)
(In other words, disability originates in the built and social environments, and is a matter of how society responds or fails to respond to physical, sensory, cognitive or emotional differences of people with impairments).

Guidelines for making events accessible

Access is about providing people with equal opportunity to participate fully in whatever is being offered. Meeting people's access needs should be done in a positive and affirmative way, which should be reflected in the language we use when discussing access requirements. All disabled people are individual and will therefore have different needs at different times. People with the same impairment/condition may manage it very differently and also have different access needs. However, here are some guidelines that Shaping Our Lives National User Network suggests are good practice.

Before a meeting/event

As a matter of good practice participants should be asked prior to a meeting/event if they have any access requirements.

It is absolutely essential that anything people ask for is available at the meeting/event. This means that events/meetings need to be planned well in advance as, for example, palantypists, lip speakers and BSL interpreters cannot be booked at short notice. Hearing loops in venues are notoriously unreliable and thus venues must be made aware of the importance of them working and be reminded of this closer to the event, with testing carried out prior to the event.

An agenda should be sent out in advance of each meeting/event. The agenda should include a paragraph under each heading explaining what will be discussed/covered etc. in this item. This will allow people to think about it or discuss it with a support worker if necessary before the meeting. (Funding must be made available to support this).

Getting to the meeting/event

Disabled people who drive, or who are being driven, need reserved, well signposted car parking nearby. People who take enquiries about public transport to the event need to be able to advise on accessible travel arrangements.

Getting in

Entrances to venues should be level or ramped, and if there are steps as well, these need to have a handrail and preferably step edges clearly marked. Some people with walking difficulties prefer steps to a ramp. Revolving doors are not suitable for wheelchair users or for many other people with different impairments. The position of the entry door needs to be clear, with glass doors well identified. It is a good idea if someone can meet and greet people at the entry into the building.

The place

Venues should have natural lighting and be well ventilated without air conditioning, which can be noisy and thus be a barrier for many impairment groups.

A 'quiet room' should be available so that if any participants want to take 'time out' there is a space set aside for this. Make sure all participants know where it is.

Water should be available throughout the event and a supply of plastic drinking straws is useful.

Food should be clearly labelled and not mixed.

During the meeting/event

House keeping: At the start of meetings it should be explained to people where the toilets are (accessible and non), and where the fire exits are. This should be done in an inclusive manner avoiding pointing, for example 'over there', and should take into account different people's access needs. For example, if the meeting is taking place in an upstairs venue how will wheelchair users evacuate in the case of fire, are the lifts operational in fire and so on.

Agendas must be stuck to so people can follow where they are in the day's proceedings.

Timing is an access issue. At the beginning of meetings, (even if they start late due to unreliable public transport) times of breaks, lunch and ending need to be agreed and stuck to.

During meetings 'ground rules' should be agreed (see next page).

If it is intended to include people with Learning Difficulties in a truly inclusive way then it is important that this is taken into account when the agenda is planned, as well in the practice that is adopted in running the meeting/event.

Before the meeting starts it might be a good idea to discuss the need for break times. Some people need regular breaks for a variety of reasons. For example, a break every ten minutes in order for people with learning difficulties to take 'time out', talk with their support worker, talk to each other or whatever they wish, might be necessary. This can be positive and have benefits for the entire group and for some specific impairment groups, for example hearing impaired people who are lip reading or following a sign language interpreter, people with pain who need to move frequently, or those with continence problems. The interpreter themselves may need a break.

It is important that the venue is checked in terms of access. Staff attitudes are a major factor in determining whether a venue is suitable or not. If possible it is advisable to seek personal recommendation from user groups.

It is important to remember that a solution for one group of service users might become a barrier to another impairment group. It is good practice to have more than one option available.

Access is about providing people with equal opportunity to participate fully in whatever is being offered.

Acknowledgements

This report has been produced by Shaping Our Lives in honour and memory of our great friend Patricia Chambers.

Patricia, a prominent member of the black and minority ethnic mental health user/survivor movement and a dear friend and colleague passed away in May 2016. For over 25 years, Patricia worked tirelessly to address issues at the intersections of race/culture and madness, within services, within the wider user/survivor movement and within research and policy.

In 2009 Patricia took over as the Network Manager of Catch-a-Fiya, the only (and now defunct) national network for people from black communities. It is impossible to list all the places and platforms she contributed to/through: BUGS, the Afiya Trust, Shaping Our Lives, Black Women's Mental Health Project, The Forward Project, the DRE Ambassadors programme, NIMHE's Making a Real Difference programme, the Count Me In census, Dancing to Our Own Tunes.... and the many local/informal user groups where she acted as an advocate and friend to people who needed that.

We developed this project from an interest Patricia had in the conflicts for people who use services and who also work to improve them. The project has been funded by the National Lottery through the Big Lottery Fund. All of us at Shaping Our Lives hope it will go some way to keeping the very fond memories we have of Patricia alive as well as bringing about the kind of positive change she worked so hard and wisely to achieve.



The Research Team was led by Becki Meakin of Shaping Our Lives. The team comprised Dr Colin Cameron from Northumbria University, Professor Michele Moore, Ann Nutt and Charley Bell-Moore.

There are many other Disabled people who have given their time and expertise to the research findings and guides in this series. Shaping Our Lives is very grateful for their invaluable contributions.

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Notes Page

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