



Win Win Alliance

Win-Win Alliance Disabled people leading change (Disability Rights UK, Shaping Our Lives, NSUN and CHANGE)

Essential elements for effective involvement and co-production

There are eight essential elements for effective co-production and involvement activities:

1. Equality

When involving disabled 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 timeframe 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. Inclusion

Inclusion is seen as a universal human right. The CRPD recognizes the full and effective participation and inclusion of Disabled people in Society. (Article 3) The aim of inclusion is to embrace all people no matter their gender, ethnicity, disability or other protected characteristics. In order for power imbalances to be addressed and power sharing embraced and embodied, inclusive ways of working are essential. Most of the current systems and ways of working are not inclusive which means that power is not shared. The people who have power keep their power and power and rank in the room is not recognised. In order to change this we need to work differently and we need to risk getting things wrong. We need to explore new ways of holding meetings and activities that embrace our differences, acknowledge and challenge power and really do include everyone in the room.

3. 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 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.”

4. 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 sidelines people will not be able to develop a sense of ownership and contribute to the success of the activity.

5. 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.

6. 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.

7. 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.

8. 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.”

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).

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 involvement activities.

- 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.

Standards for involvement

The [4Pi National Involvement standards](#) were produced by people who use services and carers with the vision of a future where there is ***‘nothing about us without us’***. The framework establishes some basic principles to encourage people to think of involvement and co-production in the following terms:

- **Principles:** Meaningful and inclusive involvement starts with a commitment to shared principles and values.
- **Purpose:** All involvement needs to have a clear purpose that is understood by all and against which it can be monitored.
- **Presence:** Those involved should include people from diverse backgrounds and communities and reflect the groups of people particularly affected by the service or issues under consideration.
- **Process:** The involvement process needs to be carefully planned with engagement, communication, support and training, and other practical issues thought through, in order to ensure that everyone can make the best possible contributions.
- **Impact:** All activity should make a difference and lead to the improvement of services and the mental health and wellbeing of individual service users and carers.