



# **Tickboxes and Tokenism?**

**Service User Involvement Report 2022**

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With a foreword by Peter Beresford**

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## Acronyms used in this document

British Sign Language – BSL

Order of the British Empire - OBE



## Foreword

I want to support this excellent report because it is valuable for many reasons. There is a lot of talk about the importance of involving disabled people and social care service users. There is more and more recognition of making sure that involvement is inclusive; that is to say it should include everyone regardless of age, ethnicity, gender, sexual orientation, impairment and so on. Policymakers and services talk the talk. But are they walking the walk? This report offers current evidence in a post-Covid world and the signs are not good. We see that too many people aren't able to get involved with the access and support they need. People say they need to be listened to and their input acted on. Payment issues have still not been sorted out. Some groups are particularly badly affected. But many more want to have a voice and be involved. The report offers recommendations and ways forward.

User led organisations like Shaping Our Lives are frequently asked to come up with the evidence. Well here Gillian, Gemma and Becki have put together important user led research to do just that. It is vital these findings are listened to by government, policymakers and local services. That way we will begin to get the whole picture from disabled people in all our diversity and begin to make the change and difference to people's lives that is now so urgently needed.

Peter Beresford OBE  
Co-Chair, Shaping Our Lives



## Introduction

In 2020 Shaping our Lives was successful in securing funding from the National Lottery Community Fund to develop a national inclusive involvement movement. We aim to enable local service user groups and individuals from marginalised groups to be more influential in service planning and delivery by having a meaningful input. We believe the inclusive involvement of Disabled people and people from other marginalised communities is critical to promote system and social change. We have been talking to service users, Disabled people and those from minoritized communities for several years about how we could support them to be heard in policy and planning and this has influenced these developments.

In 2021 we ran a survey with our wider network to gather views and experiences on service user involvement. We wanted to find out the current situation for people taking part in involvement and to inform the development of our support to individuals and organisations and make sure we were meeting people's needs.

The survey was promoted through our network and beyond, using the website, ebulletins, social media, our members and our partners. It was interpreted into British Sign Language (BSL) and promoted to Deaf organisations. We were conscious the questions were not necessarily accessible to all so we ran a workshop with people with learning disabilities and have been supported by People First England to disseminate the survey to their members.

We received 126 responses, with 9 from the BSL community, and 12 people attended the workshop. No questions in the survey were compulsory. Of the 126 respondents to the



survey, 65% were female, 28% were male, 7% identified as other and neither. Survey participants ranged in age from under 18 to 80 plus. All survey responses were anonymous, and several questions invited people to express additional information.

## Key Findings

- **92% of respondents said they would be interested in finding out about (more) involvement opportunities.** 63% said they currently find it difficult to find involvement opportunities.
- **Only 39% currently have their access requirements recorded.** Of those that didn't, many thought this would be useful so that organisers could find the right people, plan ahead and make necessary adjustments. Some felt it would help diversity and prevent things going wrong.
- We asked people what was important for them **to be able to take part in involvement activities.** 65% said that they needed their access and support requirements organised in advance. This rose to 100% amongst respondents to the BSL survey.
- Besides meeting their access requirements and other practicalities, people said **they needed to be listened to and for their input to have an impact.** They want a meaningful experience and do not want their time wasted. This was a key theme throughout the survey. It showed the importance of feeding back to people involved what the outcomes of the work were.



- **Over half (56%) of respondents have difficulty getting their access and support needs met (rising to 89% for the BSL survey).** There were a range of reasons given: cost, lack of understanding or awareness, invisible disabilities, multiple disabilities or complicated requirements, reluctance to share information, or organisations do not ask or make assumptions.

## Experiences of Involvement

Our survey highlights some of the barriers to inclusive involvement. The first survey question asked respondents whether they had previously shared their story or experience as part of an involvement activity. The majority (69%) answered that they had done so and 82 people shared with us the organisations that they had done this with. It is a wide range and included:

**Local authorities, Universities, Care Providers, Charities, NHS, Research Networks, and Central Government.**

Some participants reported being required to share their stories as part of the process of accessing services and support. Others did so voluntarily through involvement with research, advocacy and awareness raising. Individual stories were shared through various means, such as **filling in forms, surveys, interviews with organisations and researchers, presentations at conferences and talks with groups.**

People's experiences around story sharing were varied. Some described the experience as intrusive and were left feeling invaded. Some were also concerned that they did not know how the information shared would be used which felt unsafe. Others felt empowered to be able to state what they wanted from the service going forward especially when they trusted



the organisation to use the information to inform meaningful changes.

A number of people mentioned concerns about trust when sharing their personal stories and reported that feedback about negative experiences was sometimes unwelcome and prevented by organisations. This left some people feeling used and believing that the involvement process was tokenistic. Participants in the workshop for people with learning disabilities said they were generally not asked about their experiences.

## Finding opportunities to take part in involvement

The wide and varied reports of involvement show a willingness across the disabled community to share their expertise with services and organisations. Many organisations want to improve their service provision by asking service users for their view but matching those with lived experience to organisations that are making improvements has been historically challenging. Most survey respondents (92%) said that they would be interested in finding out about more opportunities to get involved, yet 63% of people said that they find it difficult to find out about involvement opportunities.

## Would a My Involvement Profile tool be useful?

In line with our vision to improve and increase opportunities for inclusion and participation, we are launching a new tool – **My Involvement Profile**. This is a resource where people can record their skills, lived experience knowledge and experience of engagement, involvement, co-production and research.

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Crucially it will also support people to explain their access requirements in advance.

We can support individuals to complete their My Involvement Profile, but there would be no database of this information – it would be held individually. The individual would be in possession of their completed profile and would decide who they share it with.

Across the Disabled and other diverse communities we realise that lived experience knowledge and skills are valuable, and we know that those skills are diverse and varied and can often go overlooked. We also know that to participate fully, individual requirements for support need to be understood and met.

People responding to the survey also told us that the sharing of needs and requirements can sometimes be difficult for a number of reasons.

- They are not always simple to identify
- There are challenges such as location, travel time, access, refreshments
- Organisers don't always recognise that sharing personal information and asking for what's needed is to be taken seriously (many people report having been let down by requests having been ignored in the past).

We asked in the survey if people had their access and support requirements, as well as their knowledge and skills, recorded so that they can be easily shared with organisers of involvement activities. The majority of people (61%) said that they didn't. When asked if it would be helpful to have such a record, many people thought that it would be a great idea and would help organisers find the right people, plan ahead and make necessary adjustments. Others said it would help them recall requirements when asked and think of things they hadn't





thought about. The point was made that it would help diversity and prevent things going wrong. People with learning disabilities who took part in the workshop also said that it is really helpful to have access requirements written down, but that they would need assistance to record access needs. Some people didn't completely understand the concept or didn't think it would be useful for them. A few had reservations of sharing access and support needs up front, in case it leads to stereotyping and exclusion, or because of concerns about data protection.

## Barriers to taking part

Over half of our survey respondents said that they have had difficulty getting their access and support needs met. It's important for organisations to be aware of the barriers experienced by the disabled community so that they can create fair, safe and supportive environments in which involvement, co-production and participation can take place.

A high number of people said they needed reasonable notice of events and opportunities, papers being provided in advance, an accessible venue, the event to be held remotely or remote attendance an option, transport expenses paid, and payments made for participation.

The timing of meetings was also important. Early morning meetings are inaccessible for some; daytime meetings can be inaccessible for those who work.

Our respondents commonly highlighted the following support needs which often go overlooked:

- **Providing accessible information** Captions/subtitles in presentations, easy to read colour in presentations,



appropriate text size in documents using microphones, braille and audio assistance.

- **Facilitating physical attendance** Accessible venues, transport arrangements, realistic allowance of time spent including overnight stays and recovery time, rest and bathroom breaks and assistance with those, dietary requirements, negative impacts of sensory environment.
- **Understanding of other support needs** Recognition of neuro-diversity and hidden disabilities, time to prepare, time to express experiences without pressure, recognition of needs changing over time, understanding complex needs and multiple types of disability, awareness of disabilities that are not commonly recognised such as the inability to sit, psychological support (sharing stories and hearing those of others has an impact), non-judgement when hearing strong and informed views, recognition that people are further 'disabled' by social, economic, communication systems, consideration for carers.
- **Reimbursement** Prompt payment of costs incurred, cost provision for carers and assistance, fair payment in exchange for expertise.

Many people report that complex and less obvious needs remain 'unseen' by some organisers, making involvement feel stressful and sometimes impossible. There were also reports of organisers having little awareness of how much planning, time, and energy it takes for people to attend involvement activities. Many people have experienced having to wait for expenses to be paid. The true costs of participation are also frequently underestimated. Organisers need to be aware that this causes



financial hardship and can leave people unacceptably out of pocket.

One common response to what participants needed was hearing from the organisers **the purpose of the work and how they will use the feedback**. Many people said they needed to know that their involvement would make a difference. They want organisers to feed back to them the changes implemented as a result of the work.

## Improvements and Recommendations

When asked in the survey what might help people to take part in involvement activities many clear recommendations were made, including:

### Before involvement

- Better advertisement of opportunities
- Realistic assessment of and payment of costs, expenses to be paid in advance or at least on time
- Flexibility by offering different formats, physical, online, phone, written, personal one to one interviews etc establishing what works for individuals
- Flexibility of meeting times
- Time for advanced planning
- Clarity about activities
- Clear and concise instructions.

### During involvement

- Supporting and encouraging diversity
- Taking seriously the information shared so it doesn't have to keep being repeated



- Make opportunities varied and interactive for participants
- Increased awareness of individual needs on the part of organisers
- Trust (knowing that the organisation is genuine and cares)
- Making time for personal stories in different formats (poetry, art, storytelling)
- Meaningful experiences, not tokenistic
- Acknowledging expertise by experience
- Open and welcoming entryways
- Don't patronise or infantilize
- Recognising and supporting inconsistent levels of ability.

## After involvement

- Following up involvement with evidence that it has been taken seriously and implemented
- Feedback used for safeguarding rather than treated as 'complaints'
- Relationship building between organisation and expert by experience.

## Conclusions

To bring about real change in the quality of our health and social services, we need to listen to the experiences of those that use them. Many are willing to offer their expertise to organisations to help them to achieve this goal. We realise that involvement, participation, and co-production is complex.

Organisations may need support and assistance to improve the ways in which involvement processes are carried out. The respondents to our survey clearly highlight many of the barriers to meaningful involvement and bring attention to



considerations that would make participation more accessible. Increasing the spirit of true collaboration between experts with lived experience and organisations is achievable through greater communication, access provision, sensitivity, and flexibility, and through listening to the lived experiences of members of the disabled community and their carers.

Shaping our Lives' website has a dedicated involvement opportunities board. This will enable people currently finding it difficult to find opportunities, and support organisations to recruit the right people, i.e. the people affected by the services or change, and increase diversity. We also offer support with making involvement activities accessible and making sure involvement is effective, safe, comfortable and meaningful for those taking part.

We have used the data in this survey to inform our new services. The survey suggests the My Involvement Profile will be useful for service users to record and share their access requirements. It will be a bridge towards this goal of improving access to involvement for those who wish to share their skills and knowledge. Our aim is to pave the way for organisations to connect with people's expertise more easily, to improve the access to and quality of social and health care services for all.



# Shaping Our Lives

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