Shaping Our Lives Logo, including the words 'Inclusive Involvement Matters'

Description: The main part of the logo contains an image to the left with the words Shaping Our Lives to the right. Underneath both of these are the words 'Inclusive Involvement Matters'. The image resembles an 'S', formed out of 2 semi circles that overlap. The top semi-circle is lime green and the bottom is turquoise. The words Shaping Our Lives are split over two lines, with Shaping sitting above Our Lives. These words are in line with the two semi circles. Shaping and Lives are in lime green, the Our is in turquoise. The words 'Inclusive Involvement Matters' are along the bottom of the logo. They are in turquoise. 

Building trust, making it meaningful

Discussions from Thinking Outside the (Tick)box conference

November 2022

# Contents

[Contents 2](#_Toc121913288)

[Introduction 3](#_Toc121913289)

[The personal touch 4](#_Toc121913290)

[Language and words 5](#_Toc121913291)

[Consistency and time 6](#_Toc121913292)

[Shared goals 7](#_Toc121913293)

[Unwanted views and experiences? 7](#_Toc121913294)

[You said, we did 9](#_Toc121913295)

[Commitment 10](#_Toc121913296)

[Further reading 12](#_Toc121913297)

[About us 12](#_Toc121913298)

[Appendix 13](#_Toc121913299)

# Introduction

Asking people to share their experiences of care, service access, or health, requires people to share personal experiences and recall sometimes difficult memories. The stories they tell may be extremely private or painful, and speaking about them could invoke traumatic memories or strong emotions. People who have had negative experiences as service users, employees, or volunteers of organisations may develop a distrust of service providers or statutory organisations which can affect their willingness to become involved.

So, when it comes to meaningful, inclusive involvement, building trust with your participants is vital to ensure they feel safe and comfortable to share openly.

Indeed, in our service user research, [Tickboxes and Tokenism](https://shapingourlives.org.uk/report/service-user-involvement-report-2022/) (2022), a number of people raised trust as a concern when sharing their personal stories, and some said that only when they trusted the organisation to make meaningful changes did they feel empowered to speak freely.

In our conference, Thinking Outside the Tickbox (November 2022), we discussed with service users about how involvement organisers can build trust, and ensure activities are meaningful.

We’re thankful to everyone who attended our conference, both online and in person, and shared their thoughts about how to build trust and create meaningful involvement.

Here are the key findings from those discussions.

# The personal touch

Service users at our conference said that developing a compassionate, genuine rapport with people, with an understanding of who they are as individuals, is vital to building trust with them.

*“The friendship I had with them, they were nice, kind people, they really cared about my disability, they cared about my opinions which doesn’t always happen for a disabled young person.”*

*“Understand who you are speaking to and what background people are from.”*

Attendees at the conference also mentioned that sharing your own lived experience is another powerful way to grow that relationship – breaking down barriers of distrust and creating a sense of equality and mutual understanding.

*“When we delivered that training people shared their experiences, we drew from our own lived experience but also examples of when we worked with other patients. People were telling us what they appreciated the most was hearing those experiences; it helps to normalise the challenges that people face.”*

*“Someone mentioned sharing vulnerability that’s something that’s very difficult it doesn’t come easy and I think that does help people to share their own experiences. I find it incredibly difficult to talk about my own and I appreciate that others do too.”*

# Language and words

Language matters – it can be a barrier to communication and trust, or it can open doors. The words and messaging you use can affect people’s willingness to get involved right from the start, beginning with your advert for participants.

It’s not just about making sure your advert and materials are available in different languages and accessible formats, though this too is crucial. Using abbreviations without explanation, and using terminology that is not easily understood by lay people can create a sense of “us versus them”.

*“I don’t like abbreviated words – as a young person I don’t know what that means especially when I have been diagnosed with something they used that a lot and I don’t know what that means, I just want them to tell me what I have or what this means without saying an abbreviation.”*

It goes without saying to avoid language that is discriminatory or offensive, but also ensure you avoid words and terminology that demonstrates a lack of understanding of the people you want to engage with. For example, use “Disabled People” rather than “People with disabilities” – this is something that is highlighted in the [Social Model of Disability](https://www.disabilityrightsuk.org/social-model-disability-language) which rejects negative or medical language in favour of more positive and empowering language.

*“the young people I worked with, building a safe environment was really important, giving them an opportunity and a space to talk with each other. Building that trust in different ways was really important. Language and words - thinking what’s contextual for other people’s experiences - is really important.”*

# Consistency and time

It takes time to build trust with people who are willing to share their lived experience. If the member of staff in charge of the involvement activity keeps changing, this will affect the ability to develop that relationship. How can you build trust with a different person each time?

*“[If] relationships are too transient, it’s difficult to build trust.”*

This can be especially frustrating if people who have access requirements have to keep repeating them, or if participants are required to repeat elements of their experience again and again.

In the research report [The Usual Suspects](https://shapingourlives.org.uk/report/beyond-the-usual-suspects-research-report/) (2013), the importance of consistency to build trust is also raised:

*“Key to ensuring the involvement of ‘hard to reach’ service users is providing on-going opportunities to get involved which over time make it possible to build trust and relationships with them. Such an infrastructural rather than ad-hoc, one-off approach to involvement makes for sustainable arrangements which are likely to attract new people as well as retaining others. This makes it possible to build up interest, experience and expertise.”* p.13

**Tip: When advertising involvement opportunities, make sure to put the name of the person in charge of the project or recruitment. Having a named person, and ideally a direct contact number or email address, takes away that sense of contacting a faceless organisation. This is a vital first step, especially for those who find getting in touch with an organisation difficult due to previous bad experiences or mental health problems.**

# Shared goals

If you’re asking people to become involved, make sure it’s clear to them what you are working towards. Honesty about what you can achieve together is vital to building trust.

Always ask service users to set the agenda with you. That way you can ensure you are working towards shared goals.

*“If you don’t begin from a shared agenda, or a shared understanding of what it is you are trying to achieve, it is very difficult to build trust.”*

# Unwanted views and experiences?

In our research [Tickboxes and Tokenism](https://shapingourlives.org.uk/report/service-user-involvement-report-2022/)(2022), we found that people were disheartened and disillusioned when they felt that their views and experiences were unwanted.

*“A number of people … 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.”*

In the conference, the concept of feeling valued and that views were welcome was a repeated theme in our discussions about building trust.

*“Trust isn’t given automatically; it has to be earned by sharing that space and actually being prepared to be criticised and take criticism.”*

*“Allowing different options and choices, giving feedback, making them feel heard.”*

*“It stands out when there is a service professional who wants to hear your views and wants to act on them. Rather than just ticking the box and saying “we’ve heard the view of a carer / patient.””*

*“One of the messages is to make people feel their views and their experiences are important to us. To say we want to learn from you.”*

**Tip: If you’re involving patients, service users, and experts by experience, be prepared to hear critical views or things you don’t agree with. It’s vital that people sharing contrary experiences don’t feel as though they are sharing something unwanted. Ensure participants feel that their contributions are valued even if they are unexpected or negative.**

# You said, we did

*“Trust is built by action. i.e. if the worker or whoever you come into contact with says this is your care plan and nothing happens, you lose that trust, but if you keep them informed that’s how you build trust.”*

Many people get involved only to have no idea of the outcomes of their time and efforts. Commit to sharing with your participants what happened after their involvement and why. What difference did they make? If certain things couldn’t be achieved, be honest about why not.

*“I think a lot of the time it’s “We’ve got you here, we’ve ticked the box, and goodbye” and that’s where trust leaves. And when I work with service users and underserved groups and I am going in and building partnerships I say that if we can prove that what they have said they have taken on board and the next time we see them we can show them what’s changed, “you said, we did,” - you have listened to them, trusted their ideas and gone on to do something.”*

*“When we have tried to do co-production what we say at the beginning there has to be trust and be honest about how much money there is to do something, there’s no point getting people to come up with ideas that can’t be done if there is no money. If you don’t tell people and they come up with these ideas and you say no you can’t do it that damages trust. It makes people not want to bother.”*

This was also a repeated theme in our research [Tickboxes and Tokenism](https://shapingourlives.org.uk/report/service-user-involvement-report-2022/): “*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.”*

**Tip: Ensure feeding back to people is part of your plan from the beginning of the project, schedule it in and make sure your participants know when they can expect to hear from you about the outcomes of their involvement.**

# Commitment

Doing involvement inclusively and meaningfully requires commitment. It needs time, money, staff. Where involvement is merely a tickbox or rubber-stamping exercise, done with the minimum of effort and time, this will erode service user trust, and their willingness to share this time in the future.

*“I know as a clinician I have more power, but when I do involvement I don’t have enough power – we haven’t got staff, money then I get stuck.”*

You need to budget for good involvement. Not just for staff to run the activities, but also to meet people’s expenses and access requirements, and to pay for their time.

*“They weren’t even paying expenses and I have changed that, slowly I have changed that – an example of where there is trust. Budget now. Meaningful involvement. Good experiences.”*

*“To help build trust you have got to actually have a commitment to co-production to build what you are trying to achieve.”*

Committing to meeting people’s access requirements will help to make your involvement more inclusive. It demonstrates a willingness to break down barriers to participation, helping to foster trust.

Offering to pay for people’s time and effort helps to break down financial barriers to involvement, can provide a sense of equality and value, and shows a financial commitment to including service user voices.

Commitment to service user involvement shouldn’t be championed by one person in the organisation. To put service user voices at the heart of what you do means embedding involvement across your organisation. This creates an atmosphere and a culture in which involvement is valued, enhancing people’s trust that this is an organisation they want to be involved with.

*“I work for a local Mind, when we started people said “John does that bit”. It can’t be a one-person thing.”*

*“200 people in trust and never been in such an enthused group. All clinicians working at hospital trust – from dinner ladies to consultants, everyone so enthused, it’s unbelievable. There is optimism.”*

*“Research organisations need to move away from 1 or 2 individuals responsible for involvement wider strategies.”*

# Further reading

[Service user involvement report - Shaping Our Lives](https://shapingourlives.org.uk/report/service-user-involvement-report-2022/)

[Beyond the Usual Suspects Research Report - Shaping Our Lives](https://shapingourlives.org.uk/report/beyond-the-usual-suspects-research-report/)

[How to involve Disabled service users - Shaping Our Lives](https://shapingourlives.org.uk/report/how-to-involve-disabled-service-users/)

# About us

Shaping Our Lives is a user-led non-profit organisation, specialising in inclusive involvement. We have over two decades of experience in service user involvement. To find out more about us and what we do, visit our website: [Need help with user involvement? - Shaping Our Lives](https://shapingourlives.org.uk/help-with-involvement/)

Every month we share news and resources relating to co-production, involvement and participation via our newsletter. Please sign up here: <http://eepurl.com/gmQUu9>.

# Appendix

**Four essential steps to improving involvement of service user representatives**

Taken from: [Improving Understanding of Service User Involvement and Identity - A Guide for Service Providers and Practitioners Organising Involvement Activities with Disabled People](https://shapingourlives.org.uk/report/how-to-involve-disabled-service-users/) (November 2017)

**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.

**Shaping Our Lives**

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