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. 

**We are not "hard to reach"**

**Notes from the Thinking Outside the (Tick)box conference**

**November 2022**

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# Introduction

In November 2022 Shaping Our Lives held the Thinking Outside the (Tick)box conference, an event for service users to discuss involvement, inclusion and intersectionality. In one of the workshops, service users and involvement organisers spoke about the concept of people and communities who are seen as/so-called “hard to reach” – those who may face multiple barriers to involvement or are especially excluded.

However, when it comes to involvement, are these communities hard to reach or hard to listen to? Are they seldom heard or, in fact, seldom asked?

As one attendee at our conference put it: “The whole idea between being “hard to reach” should be taken apart and better understood, as individuals are usually not hard to reach.”

Shaping Our Lives does not use the term hard to reach, as we believe that organisers of involvement can find ways to connect and involve people from diverse and marginalised communities. This resource identifies some ways you can do that. We have included quotes and tips from participants at our conference with bullet points throughout this document.

# Seldom asked

Service users at our conference spoke about the importance of how they are approached by involvement organisers. The form in which the invitation is delivered and the content of the message, including the terminology used and the intentions behind it, are both vital to involving as wide a range of people as possible, including those traditionally deemed “hard to reach”.

* The focus should be on the genuineness behind it, rather than the means in which they approached, especially as individuals with lived experience are able to spot tokenistic intentions
* Co-designing and the messaging is equally as important
* Terminology matters!
* The individual touch coming from “real” people from the organisation is often more important than just having the organisation itself reach out – the emphasis here was on authenticity

The format of how you approach service users should vary – think about different accessibility requirements, digital knowledge, and literacy levels. To truly reach out to a diverse group of people requires a diverse group of communications and formats, understanding and respecting that people prefer to communicate and receive information in different ways.

* Email: it offers them the opportunity to reflect on the context before they are required to answer.
* There is a necessity for true co-production - putting surveys together that are not actually accessible goes against that.

One of our speakers, Sheldon Chadwick from [The Showmen’s Mental Health Charity](https://www.showmensmentalhealth.com/), emphasised the importance of curated, informed communications, and how important it was to see organisations that did not start discussions based on false assumptions.

# Hard to reach service users or hard to reach services?

Often the problem is not that service users themselves are “hard to reach”. It’s that they face multiple barriers to having their voices heard. Organisers of involvement activities need to strive to remove barriers so those who are particularly excluded can get involved and share their experiences.

Here are some of the barriers our attendees identified:

**Lack of trust:**

* Discrimination, especially in workplaces, given it often leads to the inability to work with others and feel part of the community. Discrimination can also hinder the relationship between organisers and those they aim to engage with.
* Trust is built around the feedback loop – if you want people to contribute, as an organiser/organisation, it is crucial to feedback.
* Some people are also “hiding” because they do not believe it is safe to do otherwise. It can be challenging to build trust and share vulnerabilities with others, which leads to the question of “how can we make it safe for people to not hide?”

Our other conference discussion paper, [Building Trust, Making it Meaningful](https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fshapingourlives.org.uk%2Fwp-content%2Fuploads%2F2022%2F12%2FBuilding-trust-making-it-meaningful-FINAL.docx&wdOrigin=BROWSELINK), expands on this topic as well.

**Lack of awareness which can lead to exclusion:**

* Assumptions and generalisations about groups of people
* Culturally specific events and activities *–* oneattendee raised the point that some events might involve drinking alcohol or culturally specific foods, which would exclude some people from feeling comfortable or welcomed.

**Bureaucratic barriers:**

* NHS bureaucracy for example, applications and bureaucratic procedures were barriers
* Levels of literacy

These points raised by our attendees highlight that lots of form filling, lengthy application processes, or complex paperwork in order to become involved could exclude people. For example, those who struggle with literacy could be put off by these processes, or it can exclude people if the forms aren’t provided in accessible, Easy Read, or other languages. The process of applying itself can become a barrier before service users have even reached the involvement activity or event.

# Involving everyone

Service users came up with lots of suggestions about things involvement organisers can do to break down barriers and involve those whom they have not reached out to or struggled to reach before.

**Approaching communities**

Attendees particularly focused on developing meaningful connections within the communities you wish to engage rather than approaching them as an outsider.

* Professionals should listen to those coming from marginalised communities, aside from their own knowledge gained through professional expertise.
* If organisers cannot get through to communities by themselves, they should identify and use champions within the communities that they are aiming to engage with.
* Solutions might be professionals reaching out through voluntary and community organisations, centres and through community champions and education.
* Reaching out to different communities and getting different perspectives more than just asking (consulting), influencing, and shaping services and not bombarding people with information.

**One size doesn’t fit all**

When it comes to involving a wide range of people, including those who are seldom involved, you need to be prepared to try different approaches.

“Sometimes it feels that whatever meeting you go to it’s the same service users who are there. This is not our fault but it is bad practice that the organisers are lazy and make no effort to consult with people who might actually mean they have to change their way of running meetings.” ([Making user involvement work (shapingourlives.org.uk)](https://shapingourlives.org.uk/wp-content/uploads/2021/08/Makinguserinvolvementwork_full.pdf))

If you truly want to involve a diverse range of service users, you should provide a variety of means for them to get involved, taking into account different cultures and access requirements, timings of events, and the commitments and responsibilities people may have.

For example, events and meetings need to be culturally sensitive, this could include thinking about the timing, location, and types of food provided:

* When organising outreach events think about timing and type of foods – Timing was really important here so professionals could come in work time 4pm, this approach was more sensitive to the communities’ culture where hot food could be provided.

Make sure to meet with members of a community before organising an involvement activity so you can have their input and a clear understanding of what would work well.

Events and involvement activities, whether remote or in person, must address people’s access requirements.

* Regarding access requirements people to be specifically asked about their (access) needs and for these to be clear from the start of any involvement.

Accessibility is a bigger issue than making sure a venue has step free access. People can have a variety of access requirements and some may not be obvious, which is why it is so important to ask people from the early stages of planning and give yourself time to accommodate those requirements and for the people who want to be involved to have time to organise what they need, for example, support workers, or appropriate travel and accommodation.

We have written tips on accessibility and how to find accessible venues which you may find helpful.

* [Organising inclusive and accessible events: our top tips](https://shapingourlives.org.uk/2023/01/18/organising-inclusive-and-accessible-events/)
* [Accessibility - more than just step-free](https://shapingourlives.org.uk/2022/07/27/more-than-step-free-accessibility/)

Timing, location, and flexibility are all important – these can be barriers to those who are juggling other commitments such as work, childcare, or caring responsibilities. Provide a variety of times and locations, including remote access, and offer alternatives to those who can’t make it otherwise the views and ideas they have to contribute will be lost.

**Knowledge and awareness**

Attendees felt that targeted education, training, and information was needed to break down barriers so involvement organisers had more awareness and understanding of how to engage with different groups of people.

One attendee mentioned specifically about staff wearing badges providing their names and their pronouns - to raise awareness, not make assumptions and also enable follow up on issues, for example, if someone needs help or support, clearly identified staff with name badges are one way of helping people recognise who is available to help.

**Further reading**

We’re thankful to those who attended the conference, both online and in person, to share their valuable thoughts.

We have an extensive list of user-led groups around the UK on our website - this may help you find local groups to connect with for their advice and input. [User-led Organisations](https://shapingourlives.org.uk/user-led-organisations/)

Shaping Our Lives has extensive experience of inclusive service user involvement. To find out more, you may wish to read these resources:

* [Thinking Outside the (Tick)box November 2022 - Conference outputs - Shaping Our Lives](https://shapingourlives.org.uk/report/thinking-outside-the-tickbox-outputs/)
* [Service user involvement report - Shaping Our Lives](https://shapingourlives.org.uk/report/service-user-involvement-report-2022/)
* [Patient participation in lockdown - Shaping Our Lives](https://shapingourlives.org.uk/report/reflections-from-patient-participation-groups/)
* [Disabled Gypsy Roma and Traveller people - Shaping Our Lives](https://shapingourlives.org.uk/report/disabled-people-in-gypsy-roma-and-traveller-communities/)
* [How to involve Disabled service users - Shaping Our Lives](https://shapingourlives.org.uk/report/how-to-involve-disabled-service-users/)
* [Key questions when planning user involvement - Shaping Our Lives](https://shapingourlives.org.uk/2022/08/31/key-questions-for-planning-user-involvement/)
* [Barriers to involvement - Shaping Our Lives](https://shapingourlives.org.uk/2022/04/13/barriers-to-involvement/)

Sign up to our newsletter to keep up to date with our work: <http://eepurl.com/gmQUu9>

And find out more about what we do and how we could help you: [Need help with user involvement?](https://shapingourlives.org.uk/help-with-involvement/)

**Shaping Our Lives**

**www.shapingourlives.org.uk**

**Email: hello@shapingourlives.org.uk**

**Telephone: 0345 241 0383**

**Facebook: @shapingourlives**

**Twitter: @Solnetwork1**

**Linked In: @shaping-our-lives-national-user-network**

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Registered office: 30 St Giles' Oxford OX1 3LE30