

PUTTING PEOPLE WITH LIVED EXPERIENCE IN THE LEAD

Darren Murinas, CEO, Expert Citizens

The idea of ‘user voice’ is gaining traction, but there is a long way to go

In the past two years, more organisations have started to understand that you need to work with people with lived experience. At the moment, user voice is quite trendy. It’s a bit of a buzzword.

I’m not too keen on the terminology of ‘user voice’ or ‘service user’. A lot of organisations even drop the ‘service’ part and refer to people as ‘users’, and to me it’s quite derogatory. It suggests that those in the services are using the people who provide these services. If you’ve been caught up in addiction previously, the term ‘user’ would have a meaning to you. I don’t think we have to label people as ‘users’—actually they’re people with names. ‘Co-production’ is another example of language as a barrier. The idea is good, but the ‘co’ part still suggests that it’s still ‘us’ and ‘them’.

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A lot of this work is often still quite tokenistic. It can be lip service at times. There’s still a big question about whether organisations really are putting people with lived experience in the lead. They might be present sometimes, but are these people really shaping, designing, and developing what that organisation does? I don’t always think so.

Too often, organisations are getting people with lived experience to contribute to the agendas of others. They’re not always given voting rights, for instance. There’s still a big question about how you can identify people with lived experience who can help your organisation and go on to empower them. Real power-sharing is trickier. Organisations need to start enabling the people they work with to set agendas and make decisions. That is supporting and empowering people.

Sometimes people with lived experience have to get this done themselves, because the organisations they want to get involved with don’t believe in them. There can be a lot of fear, people questioning whether service users know what they’re talking about. Well, yes they do. They’re on the end of these decisions and live them every day.

Being person-led is a new direction for many organisations, and this takes time

Engagement and involvement takes people on a journey. But they are still too often being led and not empowered to take things in a different direction. It isn't easy. I've been a trustee for Lankelly Chase¹ for the past two years, and it's only now that I'm comfortable doing it. That's partly because I've received a lot of support from Lankelly Chase. Sometimes organisations, I think, give out all these pages of board papers and expect everyone to turn up having understood them all rather than thinking how they can make that context more welcoming.

We know it takes work for organisations to get to a point where they're better at welcoming people with lived experience of the issue they're working to tackle. Expert Citizens² we've built up a reputation for giving our ideas about how services could be improved and be better for multiple needs citizens. One of our main projects now is an evaluation tool we call Insight. This assesses how services work with people with multiple and complex needs. There are four levels: welcoming, listening, learning, and leading. At the first level, a service can be welcoming to people with lived experience. Then it can listen to them, and even better learn from them and make changes. The fourth level is putting these people in the lead.

It's an appreciative evaluation—we recognise that money is often tight for these things and we try to focus on what's going well as a platform for development. So, it's not the case that if you're at the first level, welcoming, that your service is rubbish. It's all about how you can improve things, how you can make them better and more inclusive for people with lived experience of the issue.

In doing the evaluation we interview frontline staff in those organisations, the people the organisations work with, senior managers, and partners. We then complete a report for the organisation. We see the process as one that builds up over, say, a two-year period. You could have an evaluation every six months, and hopefully you'd move up through the levels. This is a cost effective approach for organisations to take the temperature of their organisation and how inclusive it is of people with lived experience of multiple needs.

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Peer-led research is a key idea for us. We partnered up with VOICES³ and local health researchers to investigate how homeless people access GP surgeries. We found that half of surgeries won't accept homeless people, despite their obligations through NHS England guidance. We produced cards for homeless people explaining their rights, and that surgeries should see them. At the same time, we were able to find out some of the reasons why surgeries turn people away, and to improve that service for homeless people. Our research got a lot of media attention and interest from local Clinical Commission Group's, who recognised that surgeries need to do something about this. It also received support from NHS England.

We've also worked on anti-social behaviour in the city centre, for instance, and we were commissioned by Stoke City Council to work on their homeless strategy review. It was a 75-page report. If you're out of the street, you're not going to read that. So we drew out the key themes and questions and presented those. We posed three or four key questions with craft materials and other stuff around a table—only using first names—and tried to break down barriers and get input from people with lived experience.

¹ lankellychase.org.uk

² www.expertcitizens.org.uk

³ www.voicesofstoke.org.uk

In each case, we challenged the idea that people with lived experience are 'hard to reach' or that they 'don't engage'. Actually, sometimes we don't try hard enough to ask them. Another way to think about 'hard to reach' is that the organisation saying that has 'insufficient skill'. With Expert Citizens, we've been there ourselves, and the people we're trying to engage might even know one or two of us. We have a connection that a university researcher or Council officer wouldn't, and that's important.

There needs to be a focus on creating a partnership of equals

I think a key strength for us at Expert Citizens is that we are part of a pre-existing partnership. We have partners from the City Council, the Police, Staffordshire Fire and Rescue, CCGs, and other charities around the table. Working at the board level has definitely opened doors, and we've been building those relationships for over four years. It is a partnership of equals.

It's crucial that we're supported by these local partners. We see our work as based in relationships of honesty, and explain to commissioners that hearing the voices of people with lived experience is good for them even if it's sometimes uncomfortable. It's also sometimes useful to let them think it was their idea! More seriously, it's about trust and about building relationships with a whole range of people.

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We've not always been successful in our bids to make things happen. Some doors have stiffer hinges than others, but we keep knocking and pushing. I think it's really important to be positive. We're always learning and ask for feedback to keep conversations and relationships going. We're all working on the same side just from different perspectives. For us the outcomes are about saving lives.

I've talked about some of the barriers and some of the opportunities of involving people with lived experience. We now need to recognise the next steps. There's a lot more work to be done. We have come quite a long way from three or four years ago but it's time to start looking at the future. How can we raise the bar even further?

[This essay is part of a series on transformation from the boldest voices in the sector.](#)



About the author

Darren Murinas is chief executive of Expert Citizens CIC, an independent group of people who have all experienced multiple needs using their experiences to improve systems and services. Darren has featured on BBC Radio 4, the Guardian Social Care Network and the Big Lottery Fund website, and he has given evidence to a Parliamentary Select Committee. Darren is also a trustee of Lankelly Chase and has made an enormous contribution to the Big Lottery funded programme VOICES.

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