THE STORY OF DRUG USER INVOLVEMENT

What do we really mean when we talk about lived and living experience? In this third part of a series, April Wareham of **Working With Everyone** explores some of the key tenets, and sets out what organisations need to do to get the maximum benefit from both – as well as properly look after the people providing them

Part 3. LIVED AND LIVING EXPERIENCE

Visit any place where people sharing a common experience gather together – a patient group, a peer support group, a forum, a faith group or a food bank – and you'll hear the rallying cry, *'I want to help people like me – I want to use my lived experience to make a difference for people like me.'*

WHAT IS LIVED EXPERIENCE?

First things first. What do we actually mean by 'lived experience'? Obviously, everyone has a lifetime of experiences. So what changes something that's been experienced into 'lived experience'?

Let's consider German measles (rubella). Rubella is usually a mild condition that gets better without treatment in seven to ten days. The rubella vaccine was offered to schoolgirls in the UK from 1970, with antenatal testing and postpartum vaccination for susceptible women introduced later the same decade, and mass MMR vaccination of children aged 12-15 months was introduced in 1988. Maternal rubella infection in pregnancy carries a risk of miscarriage, stillbirth and birth defects, with foetal damage occurring in up to 90 per cent of cases in the first eight to ten weeks. A baby born affected by rubella has congenital rubella syndrome or CRS, the symptoms of which can include hearing loss, cataracts, heart problems, brain damage and damage to the liver, lungs or bone marrow. It can also cause additional health problems later in life.

Rubella and congenital rubella syndrome – Sense

For many people born before 1987 (the rubella vaccine was given to babies aged 12 months from 1988) German measles was just something that happened to them. It might have meant feeling a bit poorly and a week or so spent at home, so as not to infect other people. They might, if prompted, remember missing sports day or a school trip. For the majority of people, German measles was just something they experienced.

However, for people who lost a baby to miscarriage or stillbirth, or people who have experienced CRS, German measles was a life-changing event and may well be core to who they are. It's the basis of their lived experience.

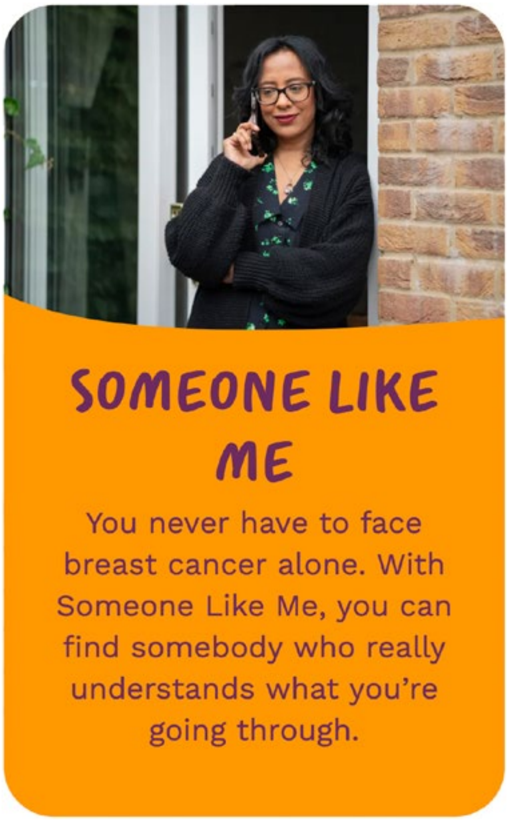
Pic: Drazen Zigic/iStock

MAKING A DIFFERENCE

People with lived experience of bereavement due to exposure to rubella in pregnancy and/or CRS have used their lived experience to do some amazing things. They have provided direct peer support to others, campaigned to make the measles vaccine available and supported initiatives to raise awareness of the benefits of immunisation. They have, both individually and collectively, made a difference to people like them – and continue to do so.

In all parts of health and social care there are people who have a diagnosis, use a service, get what they need from it, and then move on with their life. However, for someone else who has used the same service for a similar reason it could have been life-changing – it becomes a lived experience, rather than just an experience.

Let's think about two women diagnosed with breast cancer. They both undergo a course of treatment.



For both, the outcome is pretty good – the cancer is in remission and their prognosis is positive. They were both supported through the 'Someone Like Me' service offered by Breast cancer Now, and thought it was really helpful.

We're here for you – Breast Cancer Now

One of them returns to her previous employment and continues her hobbies. Other than wearing pink on 20 October and choosing to financially support Breast Cancer Now rather than another charity, their life is pretty similar to how it was prior to diagnosis and treatment. Breast Cancer was something that happened to them; the support group was great, but this is another part of their life experience – at least now the treatment is over.

The other returns to her previous employment but now volunteers for 'Someone Like Me' in her spare time because she wants to support others through their treatment in the way that she was supported. She is using some of her annual leave to speak at a conference about her experience of receiving peer support, and she's also persuaded some of her colleagues to complete a half-marathon to raise funds. Her experience of receiving a diagnosis and treatment (and of the peer support offered) has formed a core part of who she is – it has formed part of her lived experience.

SO WHAT ABOUT LIVING EXPERIENCE?

'Living experience' appears to mean someone who is currently experiencing something. So let's try to apply the same logic.

Everyone alive is experiencing a multitude of things on a daily basis – things that happen, things they do, things they feel, things they think... So for something to go from being just another experience in a lifetime of experiences to becoming a living experience, it needs to be a core part of who someone is and how they experience the world.

Let's try some examples. Almost everyone will have visited a GP surgery in their life. For the majority of the population this is just an experience. Any one visit might be fine or it might be terrible (stigmatising, discriminatory, ineffective or negligent), but for most people it's probably just something that they do sometimes. If challenged they might mention that getting an appointment was frustrating, they'd prefer to see a named GP or they'd like a longer appointment, but overall it's OK – just part of daily life.

But there are also people for whom accessing a GP is disproportionately difficult and/or life-changingly important. Their experience of registering with or accessing a GP

Pic: Someone Like Me is a service run by Breast Cancer Now that seeks to match breast cancer sufferers and their families/supporters to trained volunteers who have gone through similar experiences. Illustration: Blueastro/iStock forms a large part of their life, and is core to their current wellbeing. Trying to find a good GP and negotiate the booking system to get any medical care at all becomes (at least temporarily) a large part of their experience – it becomes part of their living experience.

There's probably a very good argument that people with living experience should, at least in part, be concentrating on their own care. This is reflected in the policies applied by most service providers (statutory and charity) and the majority of patient groups. This isn't because they don't want to include people who are currently needing support, but because it's not appropriate or moral to add additional pressures to people who should be concentrating on their own treatment right now.

PEER SUPPORT

People with living experience contribute to our peer support groups. In fact, it's almost the essence of peer support: *'come along and share your experiences – they might help someone else'* and *'come along and hear other people's experiences – they might help you'*. There probably isn't a peer support group in the world that would stop someone helping out with setting up the room, making the tea, or clearing up afterwards. But the majority should (and in practice do) ask that those taking on a regular commitment, such as opening the building or facilitating, have reached a point in their lives where living experience is becoming lived experience.

From a service improvement perspective – when thinking about service design, delivery and evaluation – people with living experience have valuable, contemporaneous experience to offer. Again, many service providers and patient groups, ask that those who are part of their 'service user council', 'lived experience group', 'coproduction group' – or whatever the current politically popular phrase is today – are not at a point in their lives where their own treatment should take priority, as being part of one of these groups usually involves regular commitment.

ESSENTIAL EXPERIENCE

This doesn't mean that their current experience of care isn't important. In fact it's essential to good service design, delivery and evaluation – in some contexts, more important than someone whose lived experience happened two decades ago.

> The challenge for service providers and patient groups is to know when current experience of care is important, when lived experience is important, and when both are needed.

The second challenge is to work out the right way to capture current experience of care, so that it's not detrimental to the individual's wellbeing. Asking those who are currently using our services (or finding our services don't meet their needs) – and who are, quite rightly, focused on their own care – to fill in a survey, attend an open day, come to a workshop when they can make it, with no consequences for not attending, are all great ways to capture current experience of care.

LIFE-LIMITING CONDITIONS

If someone receives a diagnosis with a relatively short amount of time that they're expected to survive, it would clearly be unreasonable for anyone to expect them or their loved ones to contribute to our support groups in any way not related to directly improving their own quality of life or enjoying the time they have left to the best of their ability.

It would also be both unreasonable and impractical for us to ask them to join our lived experience group, or whatever we call it. This does not mean that people with a short time left aren't welcome in our peer support groups, and it might provide huge comfort to meet others with a similar prognosis. Nor does it mean their experience of care isn't important. For some services such as palliative care or hospices the experiences of people currently using the service are core to their design and delivery. It just means that we need to take care to use appropriate methods to capture that experience. Giving a bereaved (or soon to be bereaved) family member a 27-page survey probably isn't anywhere close to good practice.

PART OF REMEMBERING

Many bereaved families have dedicated their life to helping others like them, once they feel ready. For

Pic: Geoffrey Welsh/Dreamstime.com

many it has been an important part of remembering their loved one. How many times have we seen a fundraising appeal or small charity set up in the memory of someone, often with quotes like *'We want to support hospital ward/charity/hospice by raising £x in memory of …', 'We want to raise awareness in memory of …', 'We want to set up a support group in memory of …'*, or, tragically, *'We want to make sure that this never happens to anyone else. Then we can get closure and, maybe, feel their death wasn't in vain.'* In short, *'we want to use our experience to help people like us'*.

But the important point is that this has been achieved by people after their loved one no longer needs their full support and once they feel ready. The majority of these examples have also been driven by the people who've been bereaved, not the system. When the ask comes from a group or organisation, it's probably better to err on the side of caution rather than put pressure on someone before they're ready.

INSPIRING STORIES

There are some conditions that, even if well managed, will shorten life expectancy – muscular dystrophy, motor neurone disease, Parkinson's, and some of the slower moving, less aggressive cancers. In all of these conditions the time between diagnosis and end of life can often be measured in years. There are many inspiring stories of people with life-limiting diagnoses helping people by fundraising, providing peer support or advocacy, founding charities, taking part in research, campaigning for a change in legislation, using their experience to improve care and a million other things to enable them to *'help people like me'*.

There are many people with life-limiting conditions who choose to become involved in existing organisations – whether directly supporting individuals by becoming a group facilitator or staffing a helpline, or becoming involved in service improvements, design or evaluation – the traditional 'patient experience' roles. Or they might be campaigning to raise awareness or get a legislative change approved – there are many inspirational stories from people with these conditions who have quietly supported others or worked for system improvement.

There are also many people with life-limiting conditions who've become involved with existing groups. This might be directly supporting individuals as a peer supporter or peer educator, or working with organisations to improve services, treatments or access to care. It's been called many different things – PPV partner, expert by experience – in groups with many different names.

EVALUATING WHAT'S IMPORTANT

Because of the nature of life-limiting conditions, there's an acceptance that there will come a time when the person needs to concentrate on their own health and wellbeing, and it might become difficult for them to continue contributing in the same way. Or they may use this as an opportunity to evaluate what's important to them and choose to continue with things that add value to their remaining time.

I vividly remember a conversation with Lucy Watts MBE, who I was privileged to call both a colleague and a friend. Lucy achieved a phenomenal amount in her life – supporting individuals and campaigning tirelessly to improve healthcare for everyone, particularly young people with life-limiting conditions. Here's an overview of some of her achievements, taken from one of her (many) obituaries.

An extraordinary life well lived: a tribute to Lucy Watts – Together for Short Lives

Lucy had just experienced (another) hospital admission and was talking about a potentially permanent deterioration in her health and said, *'Just let me get used to my new normal and I will be back'*. And she was!

That phrase about *'my new normal'* stayed with me. This is what many people with lived experience involved in supporting others across health and social care do. They have an experience, gain or regain their equilibrium, and then start or return to *'helping people like them'*.

Pic: Lucy Watts was born with a severely life-limiting condition. Throughout her life she was a champion for hospice care and the rights of people living with disabilities and complex health conditions. Lucy died in 2023.

When this article was planned there was a section for people with lived experience not directly related to a medical condition – such as experience of homelessness, the criminal justice system or childhood abuse. Again, if we replace the word 'diagnosis' with the relevant term and view the word 'crisis' in the relevant context most of what's written above can be applied. The principles behind it are the same.

Whilst somebody is in crisis, their experience of the topic is invaluable to service design and evaluation and they are welcome participants in relevant support groups, but their attention should be on their own needs. Once the crisis is over and they've reached a point of equilibrium in their life they may make the decision that they want to *'help people like me'*. At which point their lived experience becomes an invaluable asset.

In applying this to lifelong or chronic conditions, it's usual for people who've just been diagnosed to take a bit of time to adapt and accept that their life may be different. There may be regular check-ups or ongoing lifestyle changes or medication needed to manage their condition. During this period of adjustment people will have an experience of care or using services that is valid and valuable, and services should ensure that there are appropriate mechanisms to accurately capture their experiences. Whilst people are adjusting to their 'new normal', they may well benefit from meeting people like them in one of the many wonderful peer support groups available.

It's not uncommon for people to attend a peer support group for the first time and say *'Wow, that was amazing! I want to be involved – how can I help?'* Nor is it uncommon for people to use a service and see a poster on the wall advertising a patient group/service user forum/coproduction group and go along to find out what's happening. They may have had a good experience of care, they may (more usually) have had a poor experience of care – but either way, they'll probably be keen to share it.

And so we're back where we started, but this time from the perspective of a new participant. They hear the great rallying cry, *'I want to help people like me. I want to use my lived experience to make a difference for people like me.'*

SENSE OF SELF

It gives them a renewed impetus and purpose to a life that's been upended. It gives them a new sense of self that has value and worth.

How many times have we heard people with lived experience say things like *'After it happened… after my diagnosis… after my treatment… I didn't know who I was anymore. Using my experience to help others made me feel like I mattered, like I was a person again. It was really important to accepting my diagnosis/recovery and enabled me to start to build/rebuild my life…'* This is true both for those who directly support others and those involved in service design/delivery.

Where involvement becomes more tricky is from an organisational perspective. Whether we are a tiny peer support organisation or patient group, a service provider or even a statutory body, the challenges are the same. We're asking people with lived experience to help us design/deliver/evaluate services, and all of our efforts are directed towards improving the outcomes and experiences of the people we want to help. We're not setting out to cause direct or indirect harm to the people that help us to achieve this.

TIME LIMITS

Many organisations set a time limit – post-diagnosis or post-treatment – before which the way they're asked to contribute is limited. Statements such as *'all of our volunteers are at least 12 months into remission'* are not uncommon. This is done to protect people against becoming involved at a time when it might be detrimental to

Illustration: JellyPics

Illustration: Alexey Yaremenko/iStock

their own treatment. It's contentious within patient engagement, but does at least have the advantage of being clear. Other organisations have a more nebulous *'you can be a peer supporter/ coproduction partner when you're ready'* – more person centred in theory, but less clear and more difficult in practice. The main sticking points are – what do we mean by ready, and who decides when someone is ready?

In practice it's usually the organisation that decides, and it often comes down to one individual. This is obviously open to all sorts of potential pressures regarding recruitment targets and so on, as well as conscious and unconscious bias about somebody's physical or mental health or social situation, not to mention favouring people who may appear more compliant. In the very worst situations, it becomes a decision for the existing group.

APPROPRIATE ACCOUNTABILITY

It's OK, if managed properly, for a group of people with lived experience to work with an organisation to produce some guidelines about recruitment or even sit on an interview panel. It's almost certainly not OK for that group to 'vote' or even discuss individuals' current health status or social circumstances. There should be clear and appropriate lines of accountability – not some sort of poorly managed biased popularity contest.

Once someone with lived experience has met our criteria to become involved and survived our recruitment process, the organisation has a duty to look after them and – at the very least – not cause them direct or indirect harm.

INDIRECT HARM

First let's think about indirect harm. This could (and often does) take the form of people spending their own money for travel or childcare so they can participate. The solution to this one sounds easy, doesn't it? Let's reimburse people for their out-of-pocket costs. In practice we have situations where people have had to wait weeks or months to get the money back. So let's think about how easy and fast we can make our reimbursement processes.

Next let's think about the value we give to someone else's time. If we ask people to become involved in one of our projects it might be as a volunteer, in which case we need to value and respect their time.

We should take care to be thankful and act accordingly – saying 'thank you' and having nice volunteer events, maybe even an award ceremony, in nice venues. It also means we should be understanding when a volunteer with lived experience needs to reduce their hours or, horror of horrors, says *'I can't do that this week'*. When someone is volunteering, they're giving us a gift of their most valuable commodity. It's their time, they can choose how to use it, and they've chosen to give it to us.

LEGAL CONSIDERATIONS

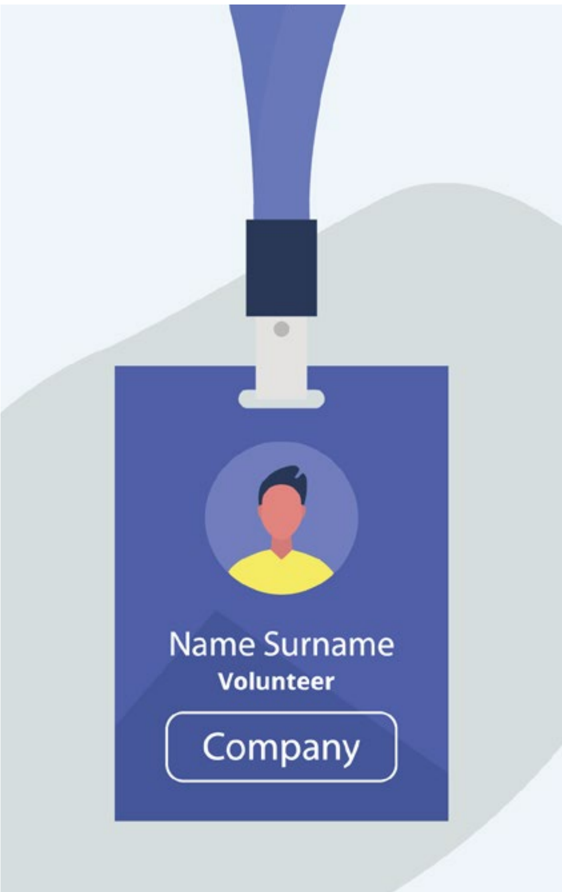
One of the ways we involve people with lived experience – particularly strategically in commissioning, policy and service design – is to offer remuneration as a PPV partner, lived experience rep, service user insight partner, or any of the infinite variations thereof. This does not make someone an employee or contractor, but they do receive a 'token' payment as a recognition of their contribution. This is usually different to the one-off cash voucher payment that someone receives for completing a survey, telling their story or attending a workshop. This is not to belittle the amount they receive – some PPV partners receive a reasonable amount to supplement their normal income, but it is a statement of position under tax and employment law.

Of course there are also many people with lived experience who receive an insultingly low remuneration for their efforts, particularly when the amount is compared to the salary scales of the other professionals on the project. Either way, for employment purposes (whether they're impacted by benefit reductions, need to pay tax or even fall within IR35), they are to all intents and purposes volunteers, with little or no protection under employment law.

HONEST RECOGNITION

These payments are, for the most part, an honest attempt to recognise the value that people with lived experience bring to our endeavours. However, care should be taken to support individuals to find out about the impact that any payment (or indeed offer of payment) might have on any benefits that they receive. This is highly specialised knowledge – there's no one-size-fits-all or easy answer. Unfortunately, however, it's relatively easy to cause immense direct harm here, even with the best of intentions. There are far too many cases of someone receiving a relatively small one-off payment that stops all their benefits, including housing costs. Not a good outcome, by any measure.

Sometimes we employ people with lived experience directly as employees or, more rarely, contractors. This might be as a peer supporter or educator, helping us to deliver support, or it might be as a lived experience partner, a service user coordinator, an insight and voice partner, or any other currently popular designation to help us ensure that lived experience and/or experience of care inform our work. They will usually be employed (or less commonly contracted) on the same basis as any other employee or contractor, with the same rights and responsibilities, the same tax liabilities and the same protection offered under law.



Regardless of designation or payment, to many people with lived experience their 'work' is an extremely important part of their life. It impacts their identity, informs their friendships, and gives them a reason to get up in the morning.

BEFORE AND AFTER

When you talk to many people with lived experience, you can almost hear them dividing their life into before their experience/accident/diagnosis/treatment and after. It may be that after they needed to reassess their priorities, give up their job or move to a new home. It may be that their friendship group changed, because so much of friendship is about shared interests and experience. Life splits into before the rallying cry *'I want to help people like me, I want to use my lived experience to make a difference for people like me'* and after – when that small spark ignites a fire that drives people forward and gives them a sense of purpose.

When dealing with people with lived experience who are experiencing a crisis or deterioration in their condition, it's important that we remember what it means to them – regardless of whether they're a long-term valued employee or our newest volunteer. A crisis or deterioration means that the person may not only need to deal with the implications of their condition, they may also need to reduce or stop their activities related to lived experience.

When this happens it's very difficult for everyone involved, and this is the point at which direct harm can occur. This is a separate issue to someone having done something incompatible with their role (assault, arson, theft and so on – things that would be a sackable offence for employees, and a reason not to invite volunteers back).

A SIDE NOTE ON VOLUNTEERS

It is not possible to sack a volunteer – they are not an employee. The only thing you can do is ask them not to come back. This is an important point of law – although for the person who has just been told they're no longer welcome, it really does feel the same.

If someone is in the middle of a crisis or has just received a difficult prognosis, they are already struggling and it is incumbent on us not to make a bad situation worse. Unfortunately, all too often this is what happens, and there have been far too many stories of the harm caused in this situation.

Illustration: Nadia Bormotova/iStock

THE STORY OF DRUG USER INVOLVEMENT
Part 3. Lived and Living Experience

We need to remember what this role means to people. At a low point, maybe even the lowest point, in their life they began to see hope. They developed a new identity, new friends, a sense of purpose. They achieved something amazing, and they helped others.

DEVASTATING IMPACT

And now because the very thing (their lived experience) that made them so good at what they did has happened again, or has got worse, we're telling them that they can't continue doing the things that are so important to them (and others). This is a devastating attack on someone's sense of self. As a system we're effectively saying, *'thanks for the help but now you're no use to us, too damaged, too broken, and we're getting rid of you'.*

> The feelings of grief and dislocation that people experience when their role is removed are the same regardless of whether they're an employee or volunteer.

In the case of employees, we're also removing their livelihood and ability to pay their mortgage, rent or bills. The shock that anyone would feel after the loss of a job is in addition to the other questions about purpose and identity. In this situation employees are often offered some support, but as organisations we should seriously think about what more we can do. This applies regardless of whether they were made redundant or sacked for misconduct.

FINANCIAL BLOW

For people who are PPV partners or lived experience partners and receiving (sometimes very small) honoraria, there's also a financial impact. That extra twenty quid might be making a real difference to someone's standard of living. If someone has been receiving that little bit extra every week they will have come to rely on it, and it's also a symbol of worth – a tangible sign that someone values you, your experience and your contribution. Don't underestimate the financial – or psychological – impact of stopping honoraria suddenly.

Of course, we have a duty to the people we're providing services for – a facilitator sobbing in the corner isn't able to provide much support. But there are ways that we can reduce the pressure on the individual without abandoning them.

There's no one right answer – but an answer might be for us to be more flexible in the ways that people with lived experience can become involved. At the moment, lived experience is treated a bit like a mini job – you're either 'in' or 'out' – whereas we should look at it more as a spectrum, where people can do more at some times in their lives and less at others.

GO FOR IT!

For those with lived experience who are in a position, and have the desire, to become involved, the biggest challenge is deciding which is the best way for them. But I say go for it – in a way that works for you. You can, and almost certainly will, make an enormous difference.

For organisational and system partners the challenge is to enable people to help others in a way that's appropriate for the organisation, and also enables the person *'to help people like them'* in a manner that supports their goals. But it also needs to acknowledge that the very thing that makes them so valuable – their lived experience – means they may have an ongoing need for care and support themselves.

It isn't easy to do it well – but when it is done well the benefits to the organisation are immeasurable.

So go for it, and try not to cause anyone any harm on the way. It might make an enormous difference to your organisation. And to the people that you're trying to help.

As always, please feel free to discuss anything in this article with me. And if you want to get in contact about policies and processes, give us a shout. WE don't claim to have all the answers but WE can help you work out some pretty good answers that work in your particular situation – or at least point out things that have never worked before and are probably not worth trying.
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Pic: Jacob Wackerhausen/iStock