



# A decade's worth of lived experience reflections

## Blog three of four: Lived Experience



I have committed to writing four blogs in August to reflect upon my ten years in the gambling support space. I arrived in this sector by accident, having had an addiction to gambling and a desire to use that lived experience of gambling harms for the public good. A quick Google search on the definition of lived experience suggests it is:

'In qualitative phenomenological research, lived experience refers to the first-hand involvement or direct experiences and choices of a given person and the knowledge they gain from it, as opposed to the knowledge a given person gains from second-hand or mediated source'.

Phenomenology is a type of research that seeks to explain the nature of things through how people experience them. This research is used extensively to help researchers or organisations gain insight across human experiences. The challenge with this type of research is a deep, inherent mistrust of the findings as often there is a perception that these may be tainted, depending upon who or which organisation funds the particular research. This is a huge shame, as the insight could be precious if we can look beyond the funding source, especially where great efforts have been made to safeguard any conflicts of interest.

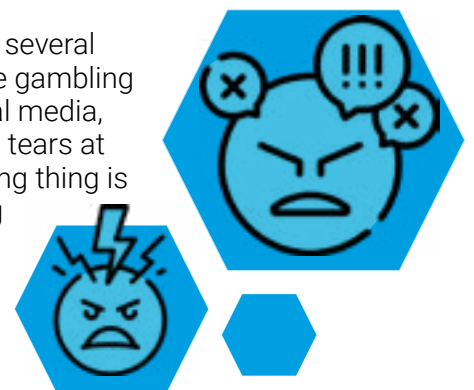


This is the same when establishing an organisation, particularly in the gambling support space. That exact feeling of mistrust and somehow your organisation being tainted, depending upon its funding source, is something I have long experienced in this sector. It is completely misplaced. Despite going to considerable lengths to ensure the funding source doesn't influence or compromise the social impact you seek to create, mistrust remains a challenge. So what does this have to do with lived experience?



Interestingly, much of this mistrust comes from those with lived experience of gambling harms and who have the loudest voices or those campaigning for regulatory change. Yet these same people also accept donations or payments, where the ultimate source of said donation is what you are being criticised for accepting. What a conundrum, a polite word that sums up some aspects of lived experience.

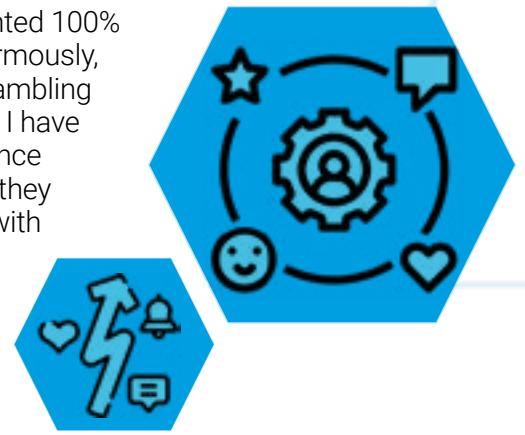
As some people will know, I was a particular magnet for mistrust and abuse several years ago as the first lived experience person to seek direct funding from the gambling industry. After several years of being extensively and unfairly trolled on social media, I came off such media because my family, partner and some friends were in tears at what they were reading on a consistent, almost daily bases. The disappointing thing is that 100% of this abuse came from others with lived experience of gambling harms. These people had replaced their behavioural gambling addiction with a behavioural trolling addiction on social media. If anybody had a view that didn't match theirs, they would hunt and troll like a pack of wolves, and I witnessed this type of behaviour being played out with others on social platforms or in the press. It was despicable activity.



I have no desire to return to some forms of social media, so I have no idea if this behaviour continues; I hope it doesn't. I am fortunate to be incredibly resilient and have a deep desire to deliver social impact. Maybe I should shout more about what is being achieved, but given my experience of being trolled, I have advocated for letting your organisational results speak for themselves.



Therefore, using my lived experience to deliver social impact has been tainted 100% by some who have lived experience themselves. This disappoints me enormously, as one thing we have in common is the absolutely destructive nature of gambling addiction. Thankfully there are a handful of exceptions to this. Fortunately, I have made some good friends with certain people from within the lived experience community, and I deeply admire their contributions and the organisations they have created. Several years ago, some of us tried to bring together those with lived experience, who shared different views to deliver some social impact, but getting synergy was impossible. I would like to see if there is the appetite to look at this again, especially for smaller organisations. Given the pending statutory levy, there could be value strategically in delivering greater, coordinated and cost-effective social impact across several grass-route organisations led by people with lived experience.



My other reflection is the journey that lived experience, as a phenomenon, has progressed within our sector. It's now everywhere you look and has an embedded function in some key organisations in this space. I commend the range of organisations that have embraced lived experience, especially those paying individuals for that insight. That payment wasn't always the case, and it did feel like some organisations would 'wheel out' lived experience to make a poorly thought-through public statement without necessarily remunerating that individual for their expertise. Additionally, it did seem that some good people were almost being used as poster covers for particular campaigns, again with no remuneration. This happens far less now, but if we agree that phenomenology is a type of research that seeks to explain the nature of things through how people experience them, then those providing insight should be paid. It is good to see the Gambling Commission and GambleAware having public statements on remuneration for such people.



The next evolution of lived experience will be exciting, and I sense we are beginning to see some exemplar shoots of positivity here. Firstly I'd love to see a future where lived experience progresses from an advisory role to a governance role within organisations. Example roles include Trustees and Chairs of charities; directors / non-executive directors of Community Interest Companies; non-executive directors of gambling operators and Commissioners / Independent Directors at the Regulator.

Secondly, if we consider lived experience insightful and valuable, we have only listened to one-half (i.e., those who have experienced direct harm or their immediate families). What about consumers who don't experience harm, would their views be insightful too. Well, I think yes and look forward to seeing progress in this area of research too. Naturally, the funding source for such research could be contentious, but an illustration where I think looking beyond funding sources is helpful as the benefits from such research outweigh this. After all, the new Statutory Levy being introduced is ultimately from operators, and as I have mentioned earlier, almost all those who have a more concerned view on industry funding actually accept it in some way for their organisations today.



My final reflection is that all lived experience (both positive and negative) is equal and has the potential to be a real positive force for good. Some with lived experience have tried to divide and conquer, others have been disingenuous with the truth, and others have conducted themselves unprofessionally, causing remarkable upset and pain. However, I take comfort in that a tiny handful of people with lived experience are still in this space a decade on; they have not given up and have remained true to themselves. Those people are modelling the way, and I sense they have much more to give. It is that, coupled with the humble, gracious, and kind lived experience leaders we have today, that really gives me confidence that the role of lived experience within the gambling sector will become less toxic and a be a sector that is welcoming to all, with everybody pulling in the same direction in a positive manner.