

# **“Through my eyes and in my shoes”: Putting lived experience in the driver’s seat of change for hearing health**

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## **Abstract**

**Objective:** The objective of this paper is to highlight the critical role of people living with hearing loss in system and societal change

**Design:** This paper is a narrative discussion format.

**Results and conclusions:** Evidence is presented to indicate that people with lived experience of hearing loss can be embedded and partnered with in research, education, and clinical work in the hearing sector. By doing so, our understandings of hearing loss as a whole-person and whole of life experience will be optimised allowing provision of higher quality services, innovative solutions, and a re-framed conversation about hearing loss across society.

## Introduction

Hearing health and well-being do not start nor end in the audiology clinic. The access to, and nature of, social interactions, employment, education, and daily communication far outweighs the impact of even the best hearing healthcare experiences. That is not to say that hearing professionals and technical interventions do not have an important role; rather, as a sector, we must look at the whole person and their whole-of-life experiences from the perspective of people living it. Perhaps you have come across the colloquial saying, “nothing for me, without me”? This saying presents person-centred care in its simplest form. People who live with, and are directly impacted by, health conditions or who are disabled by the way society or a system imposes barriers, are the experts. People with lived experience must be at the table when decisions are made about them. This notion extends beyond service design to how we conceptualise the categories of health and disability entirely. The aim of this discussion note is to highlight that central to changing the narrative around hearing loss, to be one about health and well-being, are individual people and their stories.

### To change a narrative, we need to understand the narrative

Lived experience narratives are evidenced to benefit services and society in many ways, including: service quality improvement and outcomes (Luxford, 2012); design of new interventions or processes (Donetto, Tsianakas and Robert, 2014); improved health outcomes (Luxford and Sutton, 2014); education of key skills to health professionals (Charon, 2008); and, ultimately, improved policy decisions (Robert and Cornwell, 2013; Matthews and Sunderland, 2017). People with lived experience also personally benefit from being enabled and involved (Palmer *et al.*, 2009). Over the last two decades, there has been a surge in qualitative and narrative-based research that seeks to understand lived experience of hearing loss and experience of service delivery (Barker, Leighton and Ferguson, 2017; Edmondson and Howe, 2019; Hallberg and Barrenäs, 1995; Scarinci, Worrall and Hickson, 2008; Grandpierre *et al.*, 2019). While this is a powerful and positive shift, a limitation is that much of this academic understanding about living with hearing loss is viewed and interpreted through the

lens of the journey of help-seeking where the person with lived experience is the research subject, not the collaborator. Moreover, this research is conducted and interpreted by researcher audiologists, educators, or hearing instrument designers – perspectives that are embedded in the system. This lens is a valid one, but it is not the whole picture. There is an opportunity for the sector to gain a deeper understanding of lived experience by including people with hearing loss across all dimensions of our work to ensure we truly understand the narrative – from asking the right questions to interpreting results through alternative lenses. I suggest three ways to extend our understanding of the lived experience of hearing loss.

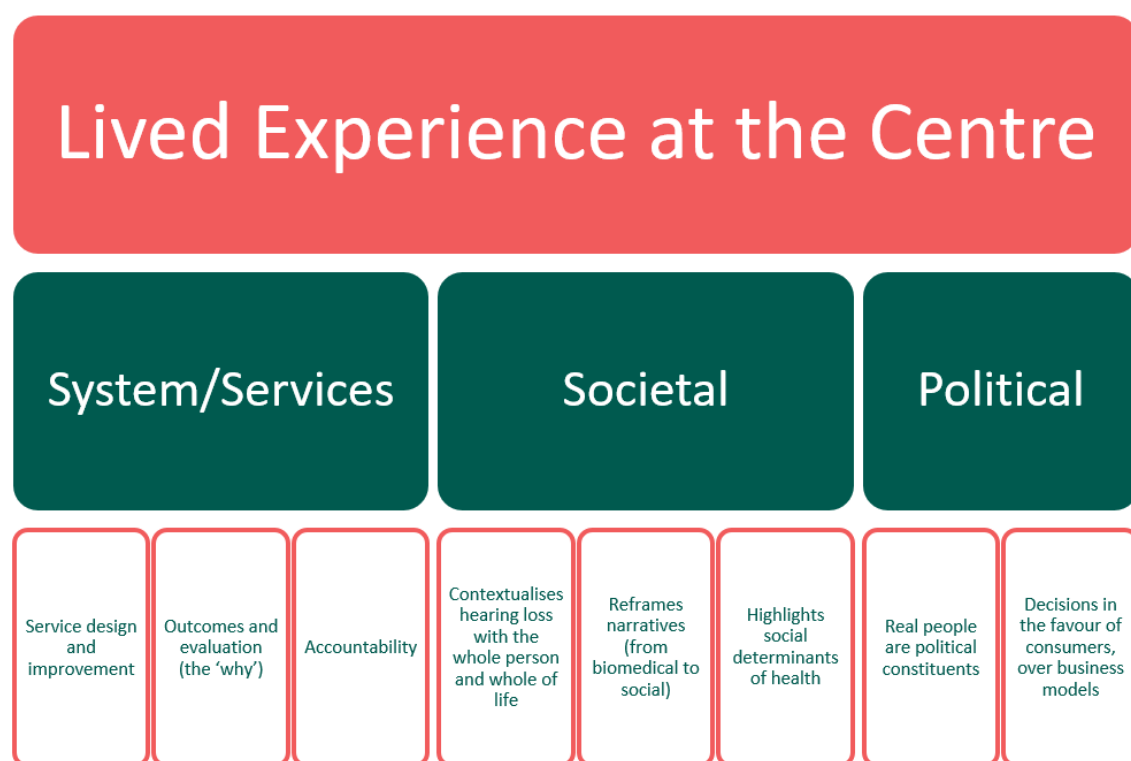


Figure 1. A tripartite model for understanding the lived experience of hearing loss.

### 1. Research

Imagine if people with lived experience were part of research from end to end, moving from being informed of research outcomes, towards partnership and consumer-led directions. Several research funding bodies now specify the need for consumer collaboration. For example, the Australian National Health and Medical

Research Centre (NHMRC) requires consumer involvement in research and states that “guidelines (research outputs) can only meet the needs of the population if they are developed with meaningful and authentic engagement with consumers” (NHMRC, 2020). The notion of embedding consumers and their narratives in research prioritisation, planning, design, and dissemination is slow to gain momentum, and at this stage isn’t widely seen in non-Government funding requirements or smaller research projects; perhaps this is because it is not the simplest path. Having research labs normalise creating partnerships and collaboration with people with lived experience, rather than approaching them as subjects of the research, increases the chances of meaningful outcomes and implementable or ‘market ready’ solutions.

## 2. Education

There is widespread evidence of the important role people with lived experience play in educating health professionals (Towle *et al.*, 2010; Janssen and MacLeod, 2010; Byrne *et al.*, 2013) and especially in developing empathy skills (Heidke, Howie and Ferdous, 2018). Narrative medicine (Milota, Van Thiel and Van Delden, 2019), is considered innovative and effective in teaching student health professionals to approach their patients as whole and complex people. Like with research, it is not without its challenges; however, given the evidence that audiologists (Ekberg, Grenness and Hickson, 2014) and indeed audiology students (Tai, Barr and Woodward-Kron, 2019) tend to focus on technical solutions for their clients’ lived experiences, it is argued that greater partnership with people with lived experience would benefit students. Educational implementation could be as comprehensive as formal utilisation of the narrative medicine pedagogy, or as simple as students being partnered with a person with lived experience as a mentor or throughout their education.

## 3. Clinical services

Lived experience narratives are uniquely well-placed to provide information about health services and system performance. Gathering, analysing and action on lived experience is not as simple as collecting outcomes data. Unlike data commonly used as evidence in health services and systems quality improvement (such as outcomes statistics, patient surveys and other quantitative measures), narratives from people

who are experiencing a condition and who have experienced the 'system', can provide an unparalleled insight into the whole-person, whole-system experience. In outcomes and process analysis (surveys, wait times, health changes), we come to understand the answers to questions that matter to the system, service providers and funders. In contrast, lived experience stories offer information about what matters to the individual as they experience the system - what happens and what this means in people's real worlds (the place where hearing loss intersects with hearing health and well-being).

Embedding lived experience narratives in system and social change means we are able to focus on whole-of-person care, not just the part of the person relevant to that health service, or the part of the service of interest to the provider or researcher. I recently discussed this topic with a member of my organisation who is a consumer advocate; she said: "you're asking me about my experience with the audiologist - but to be honest, my issue is how well I hear at work. If you want to talk about my well-being, then let's talk about my life." How often do clinicians or service managers take the time to ask consumers about their lives? And listen? Outside clinical history taking (which is infrequently narrative based in audiology) or testimonials, few clinics embed lived experience narratives in their service improvement framework. I know of two innovative hearing care clinics that operate a 'consumer partnership model'. In this model, the clinics runs regular and purposeful events with a group of their clients and members of the public with hearing loss to co-design and problem solve service delivery issues and opportunities. Not only does this model lead to exciting clinical innovations, the clinicians are connected to the people they serve, and people with lived experience are invested in advocating for themselves and the service provider.

# Lived Experience at the Centre

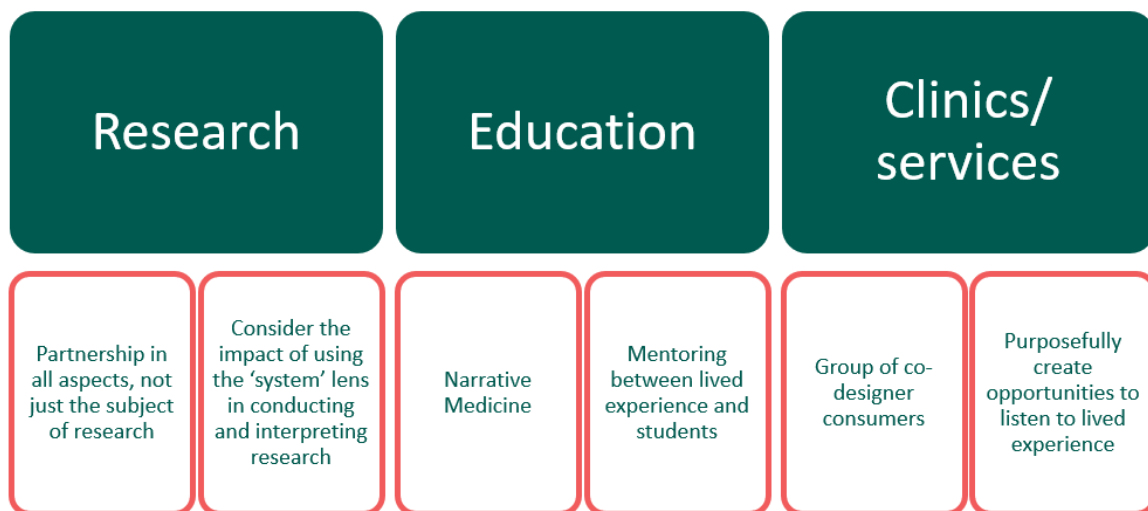


Figure 2. The benefits and opportunities of embedding lived experience within hearing healthcare provision.

## Learning from others: embedding lived experience is not a new concept

There is a need for the hearing sector to move away from the biomedical model of hearing loss towards a conversation about overall health and well-being. This change is an adaptive challenge (Pronovost, 2011), meaning that technical solutions will not suffice and that innovation is needed. Design thinking is one method to approach the complexities of adaptive challenges. The central premise of design thinking or human-centred design is putting the consumer and their functional and emotional needs at the centre by commencing and being anchored in empathy. "...Designers ...consider the wider community (people unlike themselves) during the design process, and it has proven extremely valuable to take them outside their comfort zones, by seeking to develop empathy with the end user for whom they are designing" (Thomas and McDonagh, 2013). In a scoping review of applications in global health, Bazzano and colleagues (2017) noted that despite the clear evidence for the value of designing with the consumer, the central tenets of design thinking are at odds with the

prevailing processes in health – that is paternalism and a biomedical focus on hypothesis testing. Putting lived experience at the centre, requires iteration, comfort with ambiguity and pivots and valuing the quietest voice (Bazzano *et al.*, 2017). Yet, this is the very notion that is needed to make real change in the hearing sector.

### **Some inspiring examples**

Two powerful examples of putting people with lived experience at the centre leading to system and societal change reveal opportunities for hearing sector. Digital storytelling is becoming a popular in health and is particularly strong in highlighting marginalised voices (Matthews and Sunderland, 2017; Matthews and Sunderland, 2013). By utilising digital storytelling, Patient Stories (<http://www.patientstories.org.uk/>) offers the public and health professionals insight into personal experiences of medical error or inadequate care. This extensive library has successfully led to policy change, improvements in systems and protocols, and saved lives. While this example uses lived experiences that were negative, it eliminates the power of excuses and rationale offered by the system, meaning that the hard conversations about change can occur.

Lived experience narratives can equally be used to positively re-frame how health conditions are conceptualised. This has been effectively evidenced in Alzheimer's research, such as Beard, Knauss and Moyer (2009), who explored individuals' lived experience of Alzheimer's to find examples of positive life changes and therefore a positive re-framing of the condition as just one factor in living life well. Another excellent example of using lived experience to re-define a condition are the development of Dementia Cafes (Greenwood *et al.*, 2017). Dementia Cafes are created by and for people living with dementia and their loved ones. The gatherings are social and are focussed on doing activities and tasks that bring out the best in people. The whole person and their well-being is prioritised and dementia diagnosis is left at the door. If we applied this concept to the hearing sector, we might find innovative offerings such as curated social gatherings in acoustically friendly environments or audiologists joining clients for a family dinner to engage in communication coaching on the fly. Examples such as this re-frame living with a hearing loss as just part of

what makes a person healthy and engaged in life in their whole world, not the audiology clinic.

### **What are the barriers and downsides?**

The biggest step forward we can collectively take is to go beyond 'imagining' what life must be with hearing loss, and fully integrate people with lived experience into our work from service and solution design, implementation and delivery, to outcomes and evaluation to how we conceptualise hearing loss. To do this properly, we are talking about system reform and difficult conversations are needed; this includes challenging the assumptions around scope of practice and business models in order to reposition the role of hearing health care within the well-being of a person, not a stand-alone solution to an ailment.

As with many adaptive challenges, changing the narrative (and therefore societal perspectives, systems, and policy) means that some people gain, and others lose. Acknowledging this fact and pre-empting that the losses may pose barriers to change allows us to consider ways to bring those on board who are likely to lose. In the case of the hearing sector, putting lived experiences and the needs of people with hearing loss at the centre will negatively impact certain business models and therefore certain businesses. For this reason, having people with lived experience work alongside organisations and service providers as they transform is critical to success.

Another group who may experience a loss are those who are disadvantaged though social and structural determinants of health. One risk of embedding lived experience narratives is that people who come forward to participate, typically have lower health literacy which is both a barrier to and a health determinant. Health disparities are perpetuated if we do not consciously seek out a diversity of lived experiences from under-represented backgrounds and remove barriers to participation. This requires both intention and investment, but it pays off.

### **Five recommendations and considerations**

To put people with lived experience of hearing loss at the centre of driving change, there are five things to consider in making it happen across research, education, and clinical services:



### 1. Find the right people and protect the quietest voices

Finding the right people is a challenge. Many clinics and researchers have got a group of people who love what they do, or who have high education and literacy levels. Sadly, these alone are not the right people. There is wisdom in the 'no' and in the quiet and most marginalised voices. It takes effort to find the people needed to ensure your engagement with consumers is as powerful as possible. While there are many benefits to working with that client who gave you a great testimonial, when it comes to making positive improvements, you will get less from this person than the person who had a negative thing to say or, often better, the person who said nothing.

### 2. Invest in education, empowering and enablement of your lived experience partners.

It is our duty to empower and enable people to take part in this work. As professionals (clinicians, researchers, or organisation managers), we exist to serve the public. Consumers do not exist to serve us. To this end, to benefit from the wisdom of lived experience narratives and to make the experience effective, we can support consumers by investing in their education, mentoring, or connecting with relevant community organisations who offer training. Though unsaid, the power imbalance introduced by health systems means that effort, education, and opportunity must be offered to consumers, especially to those at high risk due to social determinants of health.

### 3. Do not assume or check or confirm – work with and alongside

The ultimate example of lived experience narrative is if consumers are part of all levels of driving change. Having people with lived experience 'confirm' your ideas or design reinforces the power mismatch and perpetuates the idea that the professionals are the only experts. Professionals are experts, but so are people with lived experience. As mentioned in this article, there are several methodologies that can be used, such as human-centred design, collaborative impact, or experience-based co-design. These methodologies can be done rigorously, or less rigorously, but the underlying values must be adhered to.

### 4. Data does not have to be numbers

In instances where formal re-design or reform is not taking place, oftentimes, a formal methodology is not needed. Instead, data from daily interactions can be used to learn from lived experience narratives. This can include embedding Yarns (as used with Aboriginal or Torres Strait Islander communities in Australia), purposeful non-clinical conversations, focus groups, website visits and social media engagement are excellent data sources, especially if undertaken with the intentional purpose of centring lived experience.

#### 5. Be humble and ready to change tack

If a truly safe environment is created where lived experience narratives are invited, welcomed, and acted upon, it is likely that in time an opportunity to do things differently will present itself. It may be that the 'old way' is revealed as harmful or undesirable, or a better idea comes along. In these instances, it is deep-rooted in us to defend and explain. Commitment to putting people with lived experience at the centre offers an opportunity to be humble and curious, and pivot towards a better service or system.

### Conclusions

This paper overviews the necessity and benefits of putting people with lived experience of hearing loss at the centre of driving societal and system change. It is well established that the value of systematic and sustained focus on lived experience stories and perspectives includes improving health services, policy decisions and societal understanding and narratives around health conditions. After more than 20 years and a century of conversation around moving from treating hearing loss as a biomedical condition, to a critical factor impact on health and well-being – it is time to ensure that the conversation is with and alongside people with lived experience.

#### Additional resources

<https://ahha.asn.au/experience-based-co-design-toolkit>

<https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/e>

#### Acknowledgements

The author acknowledges the input of people with hearing loss in Australia to informing the content of this paper.

## Financial Declaration

I declare no financial interest or benefit has arisen from this work.

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