

Centre for
Mental Health



Humanising health care

The emergence of experiential practice
and leadership in mental health services

David Gilbert

Introduction

These are uncertain, volatile times. Health care has lost its way. The traditional power brokers – ‘professional’ leaders – don’t have all the answers. In mental health, millions of people, particularly the young, poor and marginalised, do not have access to the care they need.

The answer is not only in managing demand or increasing supply – a reductionist, transactional, top-down orthodoxy will not be, perhaps has never been, the fix.

Our mental health is built on trusting relationships and on being connected – within ourselves, with others, in our society, with the planet. Our mental health care system should have that as its primary focus. But the system is itself broken. Perhaps it has been from the beginning. Maybe we are just seeing the cracks more visibly.

People who have been through mental health difficulties bring a laser-like focus on relational aspects of care, and the connectedness of systems. Those who’ve been through stuff are not the problem, but the solution.

This paper charts the emergence of an idea – experiential practice and leadership – that is one route to transformation.

The first part of this paper focuses on what people with mental health difficulties bring: a way of being and seeing that is rooted in the centrality of relationships and connection. It looks at my own experiences, those of other people who use services and the emergence of patient leaders, in the light of failed engagement systems.

The second part argues for bringing together twin forces for change:

- Embedded models of ‘patient leadership’ (patients as partners in improvement, governance and executive levels)
- ‘Lived Experience Practice’ (how people with mental health conditions are working in roles such as peer support).

I propose a fusion of the above and develop the notion of ‘experiential practice and leadership’. The third section explores the implications of this idea at different levels – as a way of creating a new workforce of experiential practitioners, and as a means to transform, democratise and humanise health care.

1. What we bring

The relational and connected self

When I had mental health problems, my relationships and sense of connection were damaged at four levels:

- Within myself – I was lashed by mental and emotional pain, caught between self-judgement and a hurt self, between feelings and cognitions
- With others – my relationships with family and friends were broken, and they did not know how to cope with me, or I with them
- With society – my sense of belonging and purpose was harmed – who I thought I could be was no longer possible and nothing made sense
- With my surroundings – I was unable to enjoy anything about what was going on and no longer able to seek solace in the built or natural environment

Thus, for me, healing relationships are intrinsic to the process of healing and its outcomes. They are the means and the end.

This became reflected in my dealings with the care system – I found it cold, confusing, fragmented: GPs did not talk to psychiatrists and vice-versa; professionals and teams did not seem to communicate with each other; agencies were often unaware of what others were doing; and care varied from one professional to the next.

Communication with and about me, about what was ‘wrong’ with me, what the options were, and what would happen next was often contradictory; with some professionals, this was reinforced by a lack of compassion or listening. All this resonated with and reinforced my sense of isolation.

There were points in the so-called ‘journey’ that were particularly disconnected – between day and night staff on the ward, between being an inpatient and being ‘discharged’ (often with minimal support) and between different agencies (the voluntary and statutory sector, health and housing, educational opportunities, etc).

I know now I was not alone in feeling alone. Those who have been through institutional entrances and exits know what matters: access, explanations as to what’s going on and what will happen, compassion, trusting relationships, continuity, coordination. And beyond the walls, they know the support and connections we need to get back to life.

We know what matters, what works and what doesn’t (Gilbert, 2015a), and have a deep and authentic sense of the ‘domains of patient experience’ and outcomes – particularly those of us with longer term conditions. The digital era has augmented this and spawned vast connective territories of shared knowledge that we must navigate, alongside others. We have skin in the futures game. This is akin to the strategic vision required by leaders.

Most patients I’ve worked with who are fortunate enough to be involved in improvement work, foreground relational and connectedness aspects of care despair of the fractured health care system – “my notes and me were never in the same room at the same time”, as one person commented. Improvement and transformation projects benefit from patients and carers in the room who reframe problems through this lens (Gilbert, 2015b).

Programmes of work become more joined up. Patients and carers are the glue – I’ve seen projects shift from a focus on ‘people who don’t turn up for appointments’ to ‘changing the way appointment systems are managed’. The work then also turns to internal communication between admin staff and clinicians. And, further, to joined-up systems more generally – within and outside a health care provider. This internal relational and connectedness focus is aided, ironically, by the new ‘outsiders-inside’.

True integration will not happen without us.

It is interesting to note that clinical directors (medical and nursing) will focus mainly on delivery of their own performance targets or standards. And while many of them obviously care about what they and their staff do, in terms of providing compassionate care, they become inevitably blinkered – nursing teams may be accountable for ‘the experience of care’ (as well as other components of professional and clinical care) while medical teams will focus on clinical quality outcomes as their main measure.

But nobody is responsible and accountable for the gaps in between. Operational directors who should be doing this are often more caught looking upwards at what the commissioners have set as targets (waiting times mostly) and then hand these down to pressurised managers within the system to deal with.

The relational and connected Patient (Lived Experience) Leader

Without patients having power in the system, these ‘relational and connective’ aspects of the care system are not dealt with as fundamental – there are few metrics or targets concerning coordination or continuity of care, and even fewer directors who oversee them. When I was a Patient Director, I became de-facto ‘Director of Minding Gaps’ – no other director had responsibility or accountability for these facets of relational and connected care.

If this is what the system needs, it is also what patient leaders manifest when they have agency to choose where they place their energy.

The Patient Revolution (Gilbert, 2019) tells the stories of a dozen people who have been through stuff, who know stuff and who want to change stuff – one definition of patient leaders.

Patient leaders can have many roles – entrepreneurs, community development champions, activists, change-agents, improvers and transformers, and partners in decision-making, where they are permitted. All of them have worked hard, suffered and, to some extent, broken free of the cages of traditional engagement mechanisms.

I’ve always been struck by their incredible qualities – courage, tenacity, passion, wisdom, insight, sensitivity, idealism, vulnerability, humanity, authenticity – their leadership qualities. I dub these qualities ‘jewels brought back from the caves of suffering’ – these are their very ways of being and seeing.

These new colleagues are strong by dint of what they have had to face. This is not so much ‘resilience’ as moving through territories of immense danger. This is archetypal. In some senses, people who have been affected by life-changing illness, injury or disability are the ‘wounded heroes’ of myth. This knowledge is akin to shamans and visionaries.

Such experiences mean that we have a deep sense of what it is to be human. This courageous exploration of shared humanity reaches beyond difference, beyond identity – it is at the core of our connective human essence. We are (re)born collaborative leaders.

Brene Brown (2010) identified the power of vulnerability – if so, then patients are the foot-soldiers of such a way of being. Yet this power is disavowed in health care. This deep ‘knowing’ is trumped by ‘knowledge’ gained through the dry territories of professional education and institutionalised ways of providing ‘treatment’. Rather than patients being seen as bringing something to the table, we are seen as voids to be filled.

Of course, we lose as much as we gain during periods of pain. These are the characteristics or capabilities that have been damaged through life circumstances, including ill-health, disability or injury. These are ‘frozen assets’ (Cahn, 2000). And, in my experience, they are usually to do with loss of connection or relatedness.

Thawing out, then, means melting our own feelings of exclusion. This means working on boosting our sense of self, our confidence in social situations, connections to others and safe spaces. This is vulnerable and sensitive work and needs huge emotional labour.

The magic then comes when the wisdom gained during suffering meets the wisdom that had been lost when one got ill in the first place (life experiences, capabilities, professional expertise) – a form of reconnection in and of itself.

Thus, we can harness the potential power of people’s leadership qualities by ‘reframing’ and ‘re-valuing’ the jewels we bring, plus thawing out those frozen assets.

This approach provides the foundation for an asset-based approach to support and development. But building these inherent capabilities – ‘polishing the jewels’ – is one thing; opportunities to manifest them another.

There are systemic barriers to bringing our skills to bear: the system has an in-built set of cultures, systems and processes that prevents a reconnection which could help ‘them’ and ‘us’ to work together. These mirror what happens at an individual level with a person’s care and treatment. Mainly it is to do with power.

The failed engagement industry

We've known for a long time that traditional Patient and Public Engagement (PPE) fails to deliver improvement (Commission for Health Improvement, 2000) and, more deeply, is unfit for purpose. This is partly because it is predicated on two modes – 'feedback' and 'representation' (Gilbert, 2018).

Feedback mechanisms:

- Focus on experiences of services, over what matters in one's life
- Value retrospective experience over what should happen in the future
- Spend time largely on the how – methods of gathering data – over what happens to that intelligence
- Usually value quantitative data over qualitative
- Distance patients from analysis and interpretation of data
- Are led mainly by a cadre of middle management 'specialists' without 'lived experience'
- Often do not inform decision-making.

Meanwhile, 'lay' representatives are brought in; sometimes at governance level, usually into narrowly and institutionally defined committees to provide 'patient or public voice'. Often they are unpaid, have no clarity of role, support or training. I have written about the familiar 'representative traps' in more detail elsewhere. Poorly constructed governance mechanisms lead to representatives being co-opted and tamed, submissive or angry. I liken this to a default 'adolescent-adult' dialogue, whereby power is still maintained, and patient voice is held at arms-length (Gilbert, 2014).

At a systemic level, engagement often fails because it:

- Is based on an 'othering' of people who have health conditions or who use services
- Rests on the notion of a professional or institutional cadre that 'does' the engaging and we, the patients, as objects of 'being engaged'
- Is based upon other assumptions, such as us being 'subjective' or having a 'fixed agenda' that disqualifies our legitimacy
- Maintains the status quo by preserving the institutional authority of professional system leaders who make the final decisions
- Mirrors the paternalism of clinical consultation. I provide you with my symptoms; you analyse and interpret through your professional lens and decide what to do and how to do it.

This is far from the ideals of shared decision-making. I would argue that 'engagement' practices are a form of separation themselves, reinforcing disconnections on many levels, rather than building voices into the system.

2. Twin forces for change

Embedded models of Patient Leadership

In 2016, I was appointed Patient Director at the Sussex Musculoskeletal (MSK) Partnership (Central). Our job was to transform and deliver services for a population of three-quarters of a million people across Brighton and Hove, Mid-Sussex and Horsham and Crawley. We were to receive all GP referrals for people with bone, muscle and joint problems (one in four of the population), have clinicians assess who they should see, and offer them appointments as fast as possible, with the right person, first-time. We wanted to stop the toing and froing between all sorts of professionals that is so common for such patients.

The Partnership also wanted to ‘put patients at the heart of its work’. But, unlike most organisations, it put its money where its mouth was. It created the first ever role of Patient Director, inspired by a GP, Steve Laitner. Steve knew about patient leadership work and was keen to inject a radicalism into the entrepreneurial spirit evident in early discussions.

This was the first NHS executive role created explicitly for someone ‘affected by life-changing illness, injury or disability’. The vision was to embed patient leadership in everyday practice.

The Patient Director role was salaried and at senior decision-making level, part of the corporate executive function and Partnership Board (i.e. very different from a Non-Executive Director position). This included:

- Overseeing operational portfolios (engagement and experience)
- Ensuring co-design in improvement work
- Ensuring patient-centred governance
- Maintaining focus on ‘what matters’ (in particular, relational care and connectedness of systems)
- Modelling collaborative leadership and shared decision-making qualities at executive level.

At any one time, we had a ‘team’ of between six and ten paid, supported and trained Patient and Carer Partners (PCPs), who brought patient leadership qualities to bear on improvement, safety and transformation work. They did not displace our feedback and wider engagement work, but augmented it, and allowed us to shift from traditional modes of interaction and the ‘othering’ of people who used our services.

Our PCPs were at our side every step of the way. It was messy, it was imperfect, we were winging it half the time, but the gist was clear: we were creating meaningful roles and opportunities for people to work with us, and us with them – equal and different. We had begun to break down the engagement industry and create something more akin to an enhanced workforce blueprint.

Their impact was unmistakable. They led programmes on improving access and on shared decision-making, the latter leading to a HSJ award. They helped contribute to a CQC ‘outstanding’ rating, where our model was explicitly praised in the inspectorate’s report. They helped train clinical and admin staff, sat on recruitment panels and multi-disciplinary teams. They did research, helped plan and run community meetings, triggered improvements in waiting rooms, improved our information to and from patients and co-designed improvements in pain pathways. They changed appointment systems to an ‘opt-in’ service that reduced cancelled appointments and became increasingly valued as people who could help reframe problems and identify creative solutions.

This stood us in good stead during Covid-19. With staff on their knees, patient partners became even more valued, and the route became clearer – patient partners were brought in to facilitate staff wellbeing sessions precisely because they had experience of courage through trauma. The gap between staff engagement and patient engagement had broken down.

By the time I left my post we had, in effect, started to create pathways for patient leaders – a nascent career progression for a new sort of workforce. Patient partners were progressing, from inputting into one-off activities (such as training, research or recruitment) through being ongoing improvement advisors, to governance roles and working at corporate level.

Meanwhile in mental health – the rise of lived experience practice

Let’s begin to put things together. If one was to imagine a career progression for service users as a ladder, then one could envisage the very first step being when a person provides feedback, in the shape of filling in a survey, going to a focus group or ‘getting involved’ as an outsider voice.

The second step, or rung in the ladder, might be if a person then supports a fellow service user in some way. This is increasingly common in mental health. But it is less common in physical health pathways.

In mental health, and indeed in other public sector areas (such as probation work and in the criminal justice system), there are many service users, or people with lived experience, who are mentors, advocates, navigators, social prescribers, peer support workers or trainers in recovery colleges, for example. There are 5,500 employed peer support workers in England and Wales.

These practitioners are beginning to be dubbed generically as ‘lived experience practitioners’ (LXPs). These roles are sometimes paid, often at the lower levels of the NHS pay grade system. They have generally focused on someone supporting peers – other individuals or groups of individuals who are also people who use services.

Part of the problem is that there are few opportunities for people to progress.

They may be called into strategic meetings or programmes of work for which they are unprepared for – their role does not cover these responsibilities, and as one person said to me are “beyond my pay-grade”. There’s also now a recognition that peer support workers need to start managing others. Thus, in mental health, there is increasing recognition of the need to create true strategic leadership and operational management roles.

What if a manager of peer support workers who moves into an operational line-management function is seen as occupying a third rung in the ladder?

Over in Sussex, what we had done was formally create such an opportunity for progression, a third step in the ladder, for people who wanted to be in a more strategic role. But as with many physical health pathways across the country (and in contrast to mental health) there are few – if any – peer support roles.

One could then picture an ‘improvement partner’ role, similar to the Sussex Patient Partner role, being an equivalent third rung. A fourth rung might be when someone involved in improvement or transformation work shifts into a corporate governance role. Might a Patient Director be the fifth rung?

Of course, this ladder model is for illustrative purposes only, and it may be more apposite to present it in a less hierarchical fashion – after all, some patient partners in Sussex wanted to be peer support workers. Some people may prefer to be in a governance role only.

In retrospect, one can see that in Sussex MSK Partnership – a provider mainly in the physical health world – we had built a ladder with rungs three, four and five in place. Those in the mental health world have been building a very solid second rung, and have begun to think about that third rung – taking a more strategic leadership or managerial role.

Meanwhile, the engagement industry has kept people on the lowest rung of all.

It’s time to build a proper ladder, with each rung firmly embedded – one which brings ‘lived experience practice’ together with ‘patient leadership’.

However one views a ladder, the point is that we need to create a range of meaningful opportunities by which someone with lived experience can better manifest the qualities they bring, and help transform the service and the system.

3. Experiential practice and leadership

Trailblazers of a new idea

Last year I went to meet Danni Cook and colleagues in the Midlands Partnership Foundation Trust to share learning between us about senior director level roles for people who use services. One of the things she said was that she was considering the title ‘Director of Lived Experience Practice’ rather than ‘Patient Director’.

This subtle but important reframe meant that the ‘Director’ would not be categorised solely by ‘who’ they are (their identity) and therefore seen as representing others, but as leading a ‘type of practice and practitioners’.

In the same way, Nursing Directors are not Nurse Directors, and Medical Directors are not Doctor Directors – they are ‘Nursing’ or ‘Medical’ or more generically ‘Clinical’ Directors. They embody a ‘doing’ word, they are spearheading a form of legitimised, valued and powerful healing practice – ‘clinical practice’.

I have also been aware of the lonely and courageous work of Tamar Jeynes in the field of Mad Studies and beyond. She has pioneered work in the field of Lived Experience Practice that has led to a motion being voted in at the UNISON health conference to support lived experience workers.

To call this work ‘lived experience practice’ provides our field with a domain of legitimacy we have hitherto been expelled from. It restores our rightful place at the table. It also means that if our domain of work is ‘lived experience practice’ then we do not forever have to address the red herring of ‘who’ we represent. Rather, we can embody and articulate the qualities, skills and capabilities of the work being undertaken.

There is one final piece of this reframing that has bothered me since talking to Danni – that is, the phrase and notion of ‘lived experience’. Apart from the semantic problems of this phrase – there seems little difference between a ‘lived’ experience and an ‘experience’ per se – there is a deeper political and systems-rooted problem.

In mental health and in some other sectors (such as criminal justice) the notion of ‘lived experience’ is better received these days. However, ‘patient’ is still the legitimate ‘label’ in wider health care settings, despite its ignoble associations. It should be noted that when we came up with the terms ‘patient leaders’ and ‘patient leadership’, we were as much being mischievous as innovative with our fusion of two contested words.

The birth of Experiential Practice

Over the last year, I have been searching for a phrase that would unite mental and physical health care, that would be a strong, understandable word or phrase for the work we do, and who we are. It struck me that, if our wisdom and insight – those jewels – were discovered through our experiences, then this was not only ‘experiential knowledge’ that we gained, but our work should be dubbed ‘experiential’ too.

What if we called this work ‘experiential practice’?

This adjective ‘experiential’ has the potential to be discussed as equivalent and commensurate with ‘clinical’ practice – it is different yet equal to; it legitimises our journey and lands us in the heart of health care.

The very word ‘clinical’ shapes our thinking about medicine and health care – it is the epitome of narrow and reductionist thinking. ‘Clinical’ is associated with the observation and treatment of patients, but also means ‘cold and calm and without feeling or sympathy’ (Oxford Learners Dictionary, 2022). If experiential practice is about a connected system and the relational aspects of care then it offers a profoundly rebalancing force to health care.

Moreover, if the work is ‘experiential practice’, then to ‘lead’ this work (at whatever level, by modelling the qualities at its heart – relational, collaborative, integrated) is to embody the qualities of experiential leadership.

Most patient leadership roles, or what we can now redefine as ‘experiential leadership’ roles, have developed into ones that foreground humanity and connectedness – from the peer support worker helping someone to reconnect with their life, to link workers who support people to ‘navigate’ and connect a fragmented system around their own needs. My own role as Patient Director was precisely this. We are connectors.

This reframing or change of paradigm might lead to other discoveries. There might be many roles under this umbrella, just as there are many ‘clinical’ roles.

4. Reflections

By reframing patient leadership and lived experience practice as ‘Experiential Practice and Leadership’, we have shifted the agenda to one that is about reforming and reformulating the workforce, rather than one about tinkering with better means of ‘engagement’. We have brought considerations of the value, legitimacy and power of what we possess into the heart of health care delivery – rather than fuss about at the margins.

In my work, this means:

- Providing meaningful opportunities and support for experiential practitioners and leaders
- Getting people in the system to see that this work is now a workforce issue – that a new transformed and transformative workforce of experiential practitioners and leaders are on their way. They need to be recognised, valued, accommodated and supported
- Maintaining a clear view that this way of doing things will not only improve but transform care so that it focuses on what matters – relational care and connectedness of systems.

We have come a long way in ten years. ‘Patient leadership’ did not exist before that, either as a phrase, a set of ideas, principles and values, or a shared understanding of conceptual frameworks. We now have ways of thinking about it and doing it – embedded models have been conceived, implanted and recognised.

The role of Patient Director is now enshrined in NICE guidance – every organisation should have one. The CQC praised our patient leadership model in Sussex during its inspection of our service that led to an ‘outstanding’ rating.

Most importantly, we have thousands of practitioners ready for the next, and perhaps more critical, stage.

Few organisations have taken the work seriously – joining up the ideas of patient leadership and lived-experience practice – to form the whole.

In my work to embed patient leadership and these ideas of experiential practice in health care organisations, I’ve found the work is not a panacea. It is also disruptive – as it should be. It means bringing together patient experience, engagement and lived experience work under a coherent leadership and governance structure. It means providing proper support and training for a new cadre of ‘practitioners’. It means difficult conversations about how to balance the need for such a ‘workforce’ with independent scrutiny and external challenge. We are at the foothills of change.

Meanwhile, investment in support and learning is patchy. National opportunities for ‘patient leaders’ or ‘experiential practitioners’ have been a long time coming. The NHS Leadership Academy was set up, and is still geared primarily for clinical and professional managerial leaders. There are few opportunities in the overall leadership sector for patients, users or carers, let alone programmes that are co-designed and co-delivered.

In mental health, there are a few moves towards developing educational opportunities for peer support workers as they progress into management and leadership roles.

Leadership in health care systems is at a critical juncture. During the Covid pandemic, much was made of collaborative working. And professionals continue to use the rhetoric of collaborative leadership – authenticity, integrity and humanity are the watchwords of every leadership book on the shelves. These sorts of principles are common also to patient leadership and experiential practice. The difference is that these are the leadership qualities we have in spades, as we have discussed.

Yet the pandemic also saw the rise of command and control styles and also the retreat of much patient and public engagement work.

Continued austerity and workforce issues mean the professional leadership sector is deeply challenged. It seems unlikely that ‘experiential leadership’ will be welcomed, without a fight, for many reasons – whether to do with undemonstrated benefits or perceived threat to the status quo. Current policy making continues to deny patient voice – witness NHSE’s recent clumsy attempts to strike patients off waiting lists if they miss their allotted slot twice (Illman, 2022).

On the one hand, then, the soil is unfertile. But, looked at in the longer term, the growth of ‘experiential practice and leadership’ feels absolutely necessary. Rising and complex need, reduced capacity, increased use of digital and the need for prevention mean collaborative solutions are required. We can’t tackle the new problems in the old ways.

In a volatile and uncertain world, where NHS professional leaders prefer to talk about governance and guidance, people, I hope, will come to see the benefits. People will recognise that tough talk, command and control measures, and reinforcement and resources to shore up the old system won’t do it.

We must acknowledge that expanding patient leadership could threaten many in power, who will hide their fears behind ‘concerns’ and erroneous assumptions about the work. But ultimately it could lead to a new era and a new area of health care practice that aligns and is commensurate with clinical practice.

For those of us in the patient movement, experiential practice and leadership will serve to remove sole responsibility for, and jurisdiction over, care provision from professional auspices. It will challenge historical professional privilege and pave the way for a new workforce that will augment roles and opportunities and help humanise health care.

Of course, there will be issues of boundaries to be talked through, of risk-taking, of accountability and governance. And of course, resources – this can’t be seen as a cheap option. But this paper is designed to lay the foundations of a new way of thinking about health care. We have designed and delivered health care services that are systemically unable to be patient-centred because they dismiss the value of the knowledge we bring. This shifts that.

More deeply still, it provides a feasible means of restoring a deeper human connection between mind and body, that critiques of western medicine have long diagnosed, but failed to be able to treat.

As Alastair McLellan, the HSJ editor says, “The patient leadership genie is out of the bottle. Health care systems and traditional leaders ignore it at their peril now” (A. McLellan, September 2022, personal communication).

Beyond my lifetime, we will see ‘patients’ and ‘users’ having greater career choices – either moving into dedicated experiential practitioner roles alongside staff or accessing ‘clinical roles’ more easily than at present. There are exciting possibilities to accredit prior experiential learning that might be applied here, as well as to challenge the need for academic qualifications to always be ‘essential’ to some professional roles.

More deeply still: western medicine has split us from ourselves – the mind as distinct from the body and heart. We have prized objective pursuit of cold fact over the inward (some would say ‘spiritual’) journey. We have privileged those who have therapeutic powers over body, mind and soul.

We have debased illness as weakness or as a problem to be fixed, and inadvertently turned patients away from their own agency. ‘Patients’ – the very name imbues us with servile status – have been by definition recipients of expert healing; devoid of authority (over themselves, their own body, mind or soul, in the system, in society). Knowledge and understanding resides in the professional – we are an empty cup, an empty cracked cup at that, waiting for the beneficence of medicine to fill us up.

While some therapeutic traditions seek to rebalance this view, the mainstream medically dominated model still holds sway. Experiential practice and leadership helps to rebalance power by creating a legitimate counterweight, within as well as outside of the system, to professional hegemony.

What if a reconstituted workforce, centred around the equal but different forms of expertise embodied by clinical and experiential workforces, is the answer to modern health care? What if this way of being and seeing helps to humanise and democratise health care, bringing us wounded healers back to where we belong? We can do more than hope now: we can work on it.

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