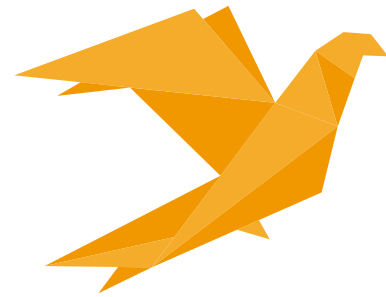
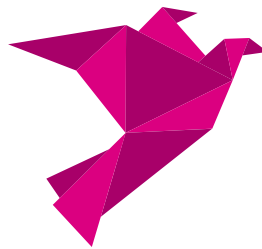
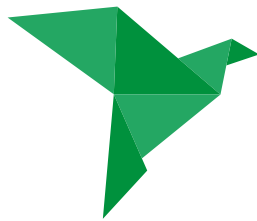
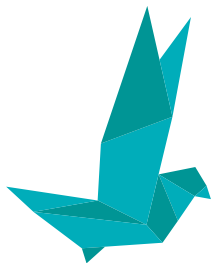




**THE LIVED**  
*Experience*



# **THE VALUE OF LIVED EXPERIENCE IN SOCIAL CHANGE:**

The Need for Leadership  
and Organisational Development  
in the Social Sector

By Baljeet Sandhu

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# Executive summary

## Why do this research?

**Lived Experience:** *‘The experience(s) of people on whom a social issue, or combination of issues, has had a direct impact’.*

**Experts by Experience:** *‘Social change-makers who seek to use their lived experience to inform the work of social purpose organisations, to drive and lead social change, and/or to drive their social impact work’.*

Everyone has lived and everyone has life experiences. These experiences make us unique, but they can also unite us. Whether consciously or subconsciously, hidden or in full view, these very experiences can shape the destinies of social change-makers, and indeed our world.

We have long celebrated inspiring change-makers who have used their lived experiences to drive and lead positive social change in society. Consider the women’s rights movement; the civil rights movement; Alcoholics Anonymous; the world’s first safe house for women and children (Refuge), set up by a child survivor of domestic violence – and the list goes on. But what about today? How does the UK social sector currently cultivate, develop and evolve its social impact work through the work of experts by experience in modern society? I decided to find out.

## How was the research done?

With sector-wide research in this area being very limited, I turned to over 80 social sector leaders in the United Kingdom and the United States to explore their work alongside today’s ‘experts by experience’ and learn more about how they worked together. Although some shared stories of inspiring and collaborative work, the majority pushed back against this inquiry, preferring to focus instead on the characteristics, skills and capacities of these so-called ‘beneficiaries’ and the liabilities of including them in their organisations’ leadership. Others raised concerns over “heropreneurship”—the sector’s focus on the single, heroic social entrepreneur—and about the elite seeking to impose their solutions on others.

I followed this up by conducting in-depth interviews with 12 senior staff working in the field of funding / philanthropy, in the hope that their helicopter view of the wider social sector would help me. This report is primarily based around this second round of interviews and my reflections on them.

## What are the benefits of lived experience to social purpose work?

Along with the knowledge, insights and wisdom which come with lived experience, it is fundamental to the work of all social purpose organisations and social impact initiatives. It brings a whole host of benefits, which include:

- Strengthening the legitimacy and accountability of social purpose work;
- Improving the effectiveness of existing, and developing new, services and social change initiatives;
- Enhancing community cohesion and cultivating effective partnerships, action and collaboration;
- Allowing innovation to flourish.

## How far is lived experience valued by the social sector?

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**Five overarching themes emerged from the research:**

- 1.** Despite sector-wide appreciation that lived experience of social issues can help inform social change initiatives, the wider sector has been slow to recognise the full value and benefit of lived expertise in terms of 'leading change'. In turn, organisational and leadership development in this area is largely unexplored and underdeveloped, and much needed.
- 2.** Commitment to lived experience across the social sector is far from universal. Progress has been made, over generations, but with limited and varying success across different elements of the sector and with little, if any, cross-sectoral learning. Arguably progress has halted or is even going backwards in some fields. Although, today, there are pioneers, their work is largely invisible to the wider sector.
- 3.** The sector now broadly understands that lived experience is important, but even when action is taken, people with lived experience are often viewed more as 'informants' than change-makers and leaders of change.
- 4.** Experts by experience need to be meaningfully and equitably involved in social purpose work. Often, they are not. This is demonstrated by the practices the sector currently uses to involve experts by experience in their work, if at all. Sharing power with experts by experience is rare, whilst excluding them from decision-making processes is common.
- 5.** The barriers, challenges, obstacles, concerns and reservations dominate sector-wide debate and progress in this field.

## To what extent do funders try to give lived experience agency in the social sector?

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Even where efforts are made, and sometimes guidance is given, to encourage the involvement of experts by experience, social purpose organisations (e.g. charities, public service providers, social enterprises) are normally left to shape and control how this takes place in their work. Funders are concerned about 'punishing' organisations for getting it wrong, when it is not an easy issue to tackle.

## What are the major barriers to giving change-making roles to experts by experience?

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- **Policing rather than facilitating:** Too often, involvement processes are reduced to futile exercises to feed into pre-planned programmes; many become 'glorified feedback sessions'.
- **Tokenism and paternalism:** This is a long-held fear and anxiety of the sector. Some of these fears are real because the involvement processes many are using do just that. However, many find it difficult to move away from these notions, and so have stopped trying altogether.
- **Power and privilege:** The sector is relatively good at talking about inequalities in wider society, but is reluctant to recognise its own problems and contributions: failing to provide communities with ownership of activities for change, failing to share power and, albeit subtly, disempowering through its processes.

- **Language and stigma:** The language used to describe individuals and communities with lived experience can still serve to hold them back and pigeon-hole them as ‘victims’ or ‘service-users’ rather than drivers of change. It is also hotly contested whether or not lived experience is a form of ‘expertise’.
- **Meritocracy and over-professionalising:** Social purpose organisations are overwhelmingly run by individuals from privileged backgrounds who tend to put a lot of emphasis on ‘professional’ attitude and appearance, as well as technical and bureaucratic skills, which can deter or impede experts by experience from progressing in the sector. Such practices may be harmful to social change.
- **Attitudes towards experts by experience:** People without lived experience can sometimes find it difficult to believe and take seriously the experiences of those who have first-hand knowledge, or understand that they also want to create and lead social change. And while important, worries about the vulnerabilities of experts by experience can be used as an excuse to avoid genuine engagement and involvement.
- **Lack of equitable and inclusive opportunities:** There is often an expectation that experts by experience will volunteer their time for free for social change. The lack of paid opportunities makes it difficult for them to take up major and leadership roles within the sector, especially given that some are more likely to come from underserved communities.
- **Storytelling:** The sector’s obsession with ‘giving voice’ to people affected by social issues can be a powerful tool to influence social change. However, our preference for ‘story’ may mask the true substance, insights and knowledge that lived experience can bring to wider social purpose work. The medium can also be used as a powerful tool to empower experts by experience. However, perceptions of experts by experience can be strongly influenced by the stories they tell and prevent progression into leadership positions in the wider sector.
- **Lack of funding and collaboration:** Smaller grassroots organisations are vital in this field because they often provide better avenues and opportunities for experts by experience to drive social change. However, many are struggling to survive in the current funding climate. Although larger organisations do tend to rely on smaller organisations to reach communities they rarely fund or support this work and are resistant to fair partnerships.
- **Lack of awareness of the value of lived experience:** There is a lack of research into the ‘value’ lived experience brings to social purpose work. This lack of evidence makes it difficult to justify expensive efforts to enlist experts by experience as change-makers.

## How can we move forward?

A fundamental shift is needed in both leadership and organisational development across the sector, in order to liberate sector stagnation in this field and open the doors for all our communities to join us and become agents and leaders of change.

### Key areas include:

- Embracing the notion of ‘lived expertise’ as a key concept in social change thinking. Valuing this form of human wisdom and the knowledge it brings to our work and the role of the holders of that knowledge – experts by experience.

- Providing meaningful and equitable opportunities and support for people and communities with lived experience who aspire to be change-makers.
- Bringing in experts by experience from the start of social change initiatives and ensuring that they have key decision-making powers in governance structures.
- Commit to determining and tackling the systemic barriers, social stigmas and wider inequalities experts by experience face as crucial change-agents and leaders of change.
- Creating equitable opportunities, funding streams and better recruitment practices in order to benefit from the work of experts by experience, including paid roles and leadership roles.
- Establishing better transparency and accountability structures.
- Providing better funding and investment for social change initiatives led by experts by experience.
- Share and enhance learning around good practice and the value lived experience brings to social purpose work for wider benefit across the sector.
- Developing new funding practices to incentivise organisations to develop and improve, including changing funding practices which inhibit or restrict experts by experience from accessing funding and investment.

As a starting point, there is a pressing need for universal cross-sector commitment to this broad agenda. I hope that this report will help achieve this and strengthen the case for sustained implementation across all social purpose work so that we can collectively begin to open up social impact careers to all change-makers in society, including those who seek to use their lived experiences to drive and lead social change - whether they wish to use their personal narrative publicly or not.

By doing so, we can begin to improve the pervasive imbalance that currently exists in our social change equilibrium. We need to do better. It is time to use the force of our human history and appreciate the truth at the heart of our sector – that fundamentally it is people who create social change.

