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

July 2017

Acknowledgments

Firstly, I would like to thank the Clore Social Leadership Programme (CSLP) for providing me with an opportunity to begin my exploration into an area of great interest, which I hope will be a valuable contribution to the work of the wider social sector. I am hugely grateful to Shaks Ghosh, Louise Drake, Isaac Abraham and other members of the Clore Social Leadership Programme team for their invaluable support and a special thanks to Dame Mary Marsh, Phyllida Shaw and Liz Lowther who patiently supported me through the research process. I would also like to thank the cohort of Clore Social fellows whose support, encouragement and contributions have helped to power this work, with special thanks to Maria Adebowle-Schaffer, Daniela Papi-Thornton, Gareth Dix, Esther Foreman, Eugenie Teasley and Michael Cooke.

Secondly, I am hugely grateful to the interviewees who generously contributed their time and input into this research – your valuable, challenging and thought-provoking insights and reflections have shaped and informed the content of this report. With thanks to:

- Derek Bardowell – during his time as Head of Programmes (Global) at Laureus Sport for Good Foundation
- Rob Bell – during his time as Head of Strategy at the Paul Hamlyn Foundation (UK)
- Rachel Billet – Consultant & Fund Adviser at Futures Advice Fund (a coalition of funders) (UK)
- Jess Cordingly – Director of Social Innovation at Lankelly Chase (UK)
- Laura Furness – Head of Funding (Investment) at the Big Lottery Fund (UK)
- Bharat Mehta – Chief Executive at Trust for London (UK)
- Habiba Nabatu – Programmes Manager Systems Change at Lankelly Chase (UK)
- Michael Pitchford – Assistant Trust Secretary at Joseph Rowntree Charitable Trust (UK)
- Matthew Roache – Head of Funding at the Big Lottery Fund (UK)
- Rebecca Rittgers – Fund Director at the Themis Fund (US)
- Cathy Togher – Head of UK Grant making at Comic Relief (UK)
- Eric Ward, Program Officer at the Ford Foundation (US)

My personal thanks to Jamie Beddard, Ben Gadd and Kathy Evans for their mindful embrace of the sensitive issues this paper surfaces. To Jim Coe and Liam Barrington-Bush for their friendship and guidance throughout. I would like to extend a special thanks to Peter Orr for his unfettered support in helping to edit and proof read this report and bring it over the finishing line. Your generosity and support has been truly invaluable. And to my family, your courage, integrity and strength over the last few years continue to inspire me.

I would like to extend a special thanks to the teams at the Clore Social Leadership Programme, Lankelly Chase, the Big Lottery Fund, UnLtd, The Social Innovation Partnership, Ten Years Time, Koreo and RECLAIM for openly embracing my reflections during this research journey and for recognising its value in inspiring and informing their work to help educate, build and sustain leadership from, and within, all our communities. Thanks to Daniela Papi-Thornton and the Skoll Centre for Social Entrepreneurship at Oxford Saïd Business School, for using my reflections during this research to inspire their social impact education work, likewise for inspiring mine, and for recognising the value this work brings to all social purpose organisations whatever element of the sector they inhabit.

This report was authored by 2014 Clore Social Leadership Fellow Baljeet Sandhu as part of her Clore Social Leadership fellowship and is licensed under a Creative Commons Attribution NonCommercialShareAlike 4.0 International License.

Contents

1 **Definitions and Terminology** 5

2 **Executive Summary** 6

3 **Introduction** 10
3.1 Initial exploration 10
3.2 Interviews with funders 12

PART 1 – LIVED EXPERIENCE IN THE SOCIAL SECTOR 15

4 **The Value of Lived Experience in the Social Sector** 16
4.1 **Benefits for the social sector** 17
4.2 **Benefits for experts by experience** 18
4.3 **Benefits for communities and civic society** 19

5 **How Far is Lived Experience Valued by the Social Sector?** 20
5.1 **The evolution and impact of language** 22
5.2 **Value given by UK funders** 24
5.3 **Value given by social purpose organisations** 26
5.3.1 Common methods used to give agency to lived experience 27
5.3.2 The slow pace of change 30
5.4 **The lack of meaningful and equitable involvement** 31
5.4.1 Tokenism 32
5.4.2 Facilitating versus policing 33
5.4.3 Involvement too late 34
5.4.4 Collaboration vs monopolisation 34
5.5 **Towards a more meaningful appreciation of lived experience** 35
5.5.1 Community Development 35
5.5.2 Mental health and social care 36
5.5.3 Youth Sector 36
5.5.4 Co-production, co-design and co-commissioning 37
5.5.5 Towards a meaningful appreciation of experts by experience and lived expertise 37

PART 2 – BARRIERS TO CHANGE AND THE WAY FORWARD 40

6 **Barriers to Change: Power Imbalances in the Social Sector** 43
6.1 **Power dynamics at play** 45
6.2 **Helping from a distance** 46
6.3 **Imbalances across organisations** 50
6.4 **Privilege at the top** 52
6.5 **Coexistence between learned and lived experience** 53
6.6 **How representative are experts by experience?** 55
6.7 **The struggle to survive** 58
6.8 **Measuring the benefits** 59

Contents

7 **Barriers to Change: Treatment and Views of Experts by Experience** 62
7.1 **Failure to believe** 62
7.2 **Ethical sensitivities** 63
7.3 **Typecasting and pigeonholing** 65
7.3.1 The importance of self-knowledge and self-determination 66
7.3.2 The importance of fluidity 67
7.3.3 Charismatic leaders and 'Founder Syndrome' 69
7.3.4 Visibility of Experience 69
7.4 **Technical expertise and governance** 70
7.5 **Over-professionalising** 71
7.5.1 A preference for the professional 72
7.5.2 Institutionalisation 73
7.5.3 The rise of consultants and intermediaries 74
7.5.4 Lack of remuneration 75
7.5.5 The push to volunteer 77

8 **Barriers to Change: Voice and Storytelling versus Leadership** **79**
8.1 **The benefits of storytelling** 80
8.2 **Limiting and sanitising** 82
8.3 **Perceptions of storytellers** 83
8.4 **An outlet for frustrations** 85
8.5 **Going beyond storytelling** 85

PART 3 – THE NEED FOR ORGANISATIONAL AND LEADERSHIP DEVELOPMENT AND THE WAY FORWARD **88**

9 **The Need for Organisational and Leadership Development** **89**
9.1 **Practices of social purpose organisations** 90
9.2 **The need for transparency and accountability** 92
9.3 **Equity and inclusivity of opportunity** 94
9.3.1 Social and economic equity and opportunity 95
9.3.2 Accessibility and routes to leadership 98
9.3.3 Current leadership programmes 98
9.3.4 Sector-wide access and routes to leadership 99
9.4 **Shifting organisational cultures, attitudes and practices** 100
9.5 **Research and shared learning** 100

10 **Developing organisational practices** **102**
10.1 **Rebalancing our social change equilibrium** 101
10.2 **Equity and inclusivity** 105
10.3 **Towards transparency and accountability** 105
10.4 **Connectivity** 106
10.5 **Sharing learning and raising awareness** 108
10.6 **Encouraging organisations to evaluate their existing practices** 108
10.7 **Developing unique approaches** 108

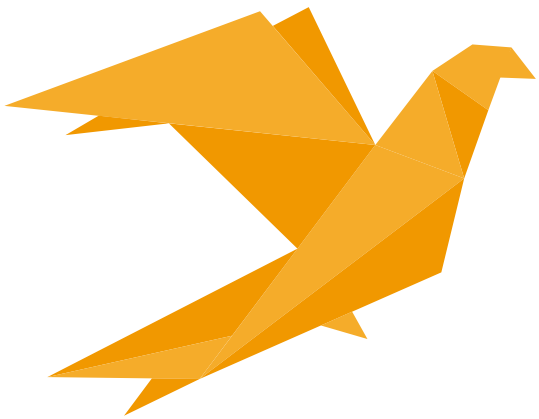
Contents

10.8 Engaging staff from all levels 111
10.9 Promoting co-production and collaboration between organisations 111
10.10 Creating equitable opportunities 112
10.11 Changing and developing funding and investment practices 112
10.12 Developing community leadership 114

11 Celebrating pioneering approaches 115
11.1 Community Development 115
11.2 Disability 116
11.3 Mental health and social care 116
11.4 Age-based sector – youth and the elderly 116
11.5 Social justice sector 117
11.6 Mapping Developments 117

12 Shifting the Paradigm 118
12.1 A Winning Combination? 118

13 Conclusion 121



1. Definitions and Terminology

Some of the terms used in this report may be unfamiliar, ambiguous or just open to interpretation. In order to avoid the trap of loose definitions, here's what I mean by the terms I use.

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

Lived Expertise: Knowledge, insights, understanding and wisdom gathered through lived experience.

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.

Change-maker: Someone who wants to create positive social change in the world.

Service-User: An individual who uses the services of a social purpose organisation. In the global context 'consumer' may also be used.

Community / Communities: Used interchangeably. A group of individuals who share a common attribute, be it the part of the social sector they inhabit (for example, funders, social entrepreneurs, mental health), their membership of a particular social group or groups, or their shared experience of situations or issues.

Social purpose work: Individuals, communities or social purpose organisations working for the wider good of civic society e.g. tackle social inequality, social and/or environmental injustices; or providing services / solutions to address local and/or wider social needs.

Social sector and social purpose organisations (SPOs): Social purpose organisations inhabit the social sector. The social sector is a broad term used to describe a set of values and structures and includes organisations working for the wider good of civic society. The social sector includes individuals, funders, donors, investors, charities, not-for-profits, organisations, social enterprises, the voluntary or third sector, those parts of the public sector that have a primarily social purpose, and enterprises or businesses that trade like any other business but do so for the public good.

Traditional social purpose organisations: Charities, non-governmental organisations and all other not-for-profit organisations.

Community/User-led: A broad term used in the UK to describe a community, social change initiative, campaign or social purpose organisation that is governed and led by experts by experience. In the global context this may equate to terms such as 'consumer-led'.

2. 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?

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?

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?

- **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.

3. Introduction

This research was inspired by the simple notion that all members of society have the power to create positive social change in the world – including people and communities with direct experience of social or environmental issues our wider social sector seeks to tackle.

Indeed, history illuminates the power of individuals and communities who have worked to solve the social problems they have directly experienced. 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; the family from South East London tackling 'institutional racism' following the murder of their son, leading to far-reaching police service reforms – and the list goes on.

Throughout my own career in the social sector I have, and continue to be, inspired by the ingenuity, courage, compassion and leadership of **"experts by experience"**[1] who have ignited, designed and implemented significant social change initiatives on a local, national and global level.

The aim of this report is to explore how, today, the wider social sector currently cultivates, develops and evolves its social impact efforts through the work of such experts by experience, and how it can go further and do better to harness their knowledge and change-making capacity to lead positive social change now and into the future.

3.1 Initial exploration

Today, many working across the social sector recognise the need to include work with, and even led by, individuals or communities with personal experience of the social issues they seek to tackle. It has come to be expected that the 'lived experience'and 'lived expertise' of individuals and communities should form a central part of debates around social change.

However, although there is a growing body of scattered literature around "active citizenship" and "service-user/beneficiary" participation in the work of social purpose organisations[2], there is a marked absence of research and leadership discourse on lived expertise in social change, with little publicly available that addresses this specific sector-wide exploration. I therefore decided to turn to social sector leaders in the United Kingdom (UK) and the United States (US) to explore my inquiry, in the hope that I would be able to use their experiences and insights to celebrate current activities and development in this field.

This took the form of informal discussions with over 80 social sector leaders[3] in the UK and US over the course of 2014 and 2015. I asked how work in their field was led by individuals and communities with lived experience and lived expertise and how they themselves worked alongside these individuals or communities.

[1] A term coined by a community of individuals in the UK who use their 'lived expertise' to effect positive social change. These are change-makers who seek to use their lived experience(s) of particular, or a combination of, social issues to inform the work of social purpose organisations; to drive and lead social change; and/or to drive their social impact work.

[2] Research is often carried out in isolation – focusing on specific forms of involvement; within specific organisations or sectors; and/or addressing specific social or environmental issues. Research also tends to be organisation or institution led.

[3] Conversations were held with founders, chief executives and senior staff of large and medium sized social purpose organisations working in the fields of human rights, community development, health, social care, education and economic empowerment, social innovation and social entrepreneurship. The organisations were a mix of charities, social enterprises, public service providers and housing associations, along with the intermediaries that support them, including social investors, trusts and foundation staff, charity and not-for-profit alliance leads, universities and incubator and accelerator programmes.

My conversations (in a pre-Brexit era) were lively, and the topic hotly debated. I found that although most people appeared to recognise the intrinsic value of working alongside communities with direct experience of social and environmental issues, many were reticent or apprehensive about including these so-called 'beneficiaries' in their organisations' leadership and were often to reluctant to invest in, develop and support those individuals' agency. The concept of lived experience or lived expertise appears to have stagnated somewhat as a key concept in sector-wide organisational and leadership development; it is not exactly ingrained in the sector's DNA. In fact, although the sector is keen to celebrate stories of leaders with lived experience following national or even global acclaim, there remains a widespread lack of understanding and collective acceptance of the value lived experience brings to our wider work – particularly in the UK.

Although a few shared stories of inspiring and collaborative work in the sector, many of my correspondents reported little or no awareness of people or communities with lived experience who are leading change in their field. Other conversations sparked discussions about the need to address *'heropreneurship'*[4]—the sector's focus on the single, heroic entrepreneur—and a concern about the elite seeking to impose their solutions on others.

As a personal reflection, before undertaking this investigation I had expected all elements of the social sector to be thoroughly committed to the value of lived experience and its role in leading positive social change, and my initial aspiration for this work was to celebrate progress and development in this field. I was aware that this broad concept was unlikely to be categorically defined across the wider social sector; indeed, 'lived experience' or 'lived expertise' are not commonly used terms. Moreover, clearly social purpose organisations are diverse in their aims, activities and profiles and the way they operate throughout the world. However, two years on I came to realise that this whole area was greatly contentious. I had been naïve to assume widespread acceptance of this concept throughout the social sector, and unaware of how little traction it held within our broader jurisdictions. Cross-sector consensus on social change approaches can, as we know, be hard to achieve. However, what was most striking about this initial exploration was how consistently problematic this concept was seen to be across the sector.

My discussions provided a healthy supply of insights and viewpoints, along with confusion and questioning the scope to my inquiry. Although reflections on positive 'community involvement' and 'collaboration' were cited by some correspondents, they were few and far between. Six key themes dominated discussions:

- **Who knows best?:**

  "The idea that lived experience brings anything additional to the table is ill-conceived"; "Individuals and communities with lived experience may not necessarily understand what is best for them"; "We have to be careful and not be patronising when we know their ideas may not work"; "It would be naïve to think that by directly experiencing a social issue you can be plucked into organisations and lead change."

- **Can 'beneficiaries' be trusted?:**

  "Someone with the lived experience might be too emotional"; "Some people have fantastic ideas but they can be stuck in their own pain"; "It's difficult…people can find it difficult to focus on other things outside of the awful experiences they have had"; "I can understand the anger but it can be disruptive"; "Victimhood is a reality."

- **It's 'tokenistic':**

  "We try our best to work with communities we support, but it is difficult to get funding to do this work where others think it's tokenistic"; "Try telling others in our field that this work is important and not tokenistic"; "We don't want to be tokenistic"; "We tried it and it feels a bit tokenistic"; "You see many try their hand at it when it is in vogue but we'd rather not play that game."

[4] *http://tacklingheropreneurship.com/*

- **Lived experience is not 'expertise':**

  "Lived experience is one thing but having the technical expertise and skill to design and plan workable solutions and services is another"; "One individual's experience of poverty may give them some insight, but it cannot be said that it can make them an 'expert' in the area"; "It's about getting a person in the job who has the skills needed."

- **It's about merit:**

  "Would this debate suggest that those without direct lived experience cannot, or should not, lead change?"; "What about those of us who don't have any lived experience?"; "I come from financial and educational privilege – would that mean my role as a change-maker is redundant?"; "I benefited from a wonderful education – I also work hard to create positive social change in the sector"; "The gates have to be open for all including those of us with privilege who also have our own lived experiences"; "We need the real deal and not just be tokenistic because we think it is the right thing to do."

- **The reality is that your background does matter:**

  "Funders and investors like people that walk and talk like them"; "If a social cause has any chance of succeeding it needs to pull in people who can persuade people like them to fund it"; "The reality is that we need to have those who know how to play the game."

I would like to thank everyone who responded to my initial inquiry with bemusement, or who challenged it. It helped to shape the eventual design of this initial research and its methodology.

3.2 Interviews with funders

Having learned a lot from these initial discussions, I decided to proceed by interviewing funders. My hope was that their strategic view of the wider social sector, including their understanding of an array of individuals and organisations operating across such a wide field, would help me to further explore:

- the sector's understanding of the role of lived experience in social change;
- if, and how, we are integrating lived experience into our social purpose work;
- the challenges raised during my initial exploration in terms of placing lived experience, and the work of experts by experience, centre stage in our work.

This exploration took the form of semi-structured interviews with twelve senior staff working in the field of philanthropy. Ten of them were UK grant-makers from a range of public funding bodies and charitable trusts and foundations. I also met with two US grant-makers; however, because their operating and funding contexts are so different to those in the UK, I have only highlighted their views where relevant to the UK focus and analysis. All but two of the interviews were face-to-face and lasted on average two hours.

The 12 contributors were provided with a summary of the aims of this report, initially titled 'The Value of the Lived-Experience in Organisational and Leadership Development'.

'Lived Experience' is currently an uncontested term; although its use is not widespread, those who use the term understand it to largely mean **'the experience(s) of people on whom a social issue, or combination of issues has had a direct impact'.** This broad definition allowed me to capture the full range of the contributors' experiences and understanding of the concept and how we currently provide it agency in the operations of the wider social sector. From the outset, I adopted an open and fluid approach to discussions. I also tested out some of the themes that had emerged from my informal discussions with social sector leaders.

Contributors were invited to:

- Share their understanding and views on lived experience as a social change concept within the social sector;
- Comment on the rationale for focusing on it;
- Reflect on how the term was understood across the social sector;
- Set out whether it featured in their grant-making (and if so why);
- Explore the value placed on lived experience within the wider social sector;
- Provide examples of initiatives featuring lived experience in their social purpose work; and raise concerns and doubts about the topic (if any).

This framework provided a good starting point for exploring and understanding whether lived experience featured in social sector practice, whether it was valued, how and why it was valued and the vast and interdependent factors that influence the effectiveness of approaches being used with which it is used in the sector. However, completing this research has also helped me to frame and understand the wider, and more nuanced, issues at play in this field: how experts by experience are currently involved in the sector's operations; how they and their change-making capacity is perceived and treated, the complexity and diffuse nature of practices and dimensions of involvement; barriers and challenges to getting involved; and ultimately organisational and leadership deficits in the sector.

I am incredibly grateful to the contributors for their candid, bold, challenging and thoughtful contributions on the diffuse issues, experiences, doubts and concerns raised by this topic. Contributors kindly provided examples and experiences of their own work and their observations of the wider social sector and funding community, and generously expressed their hopes and aspirations for this piece of work

As this report focuses primarily on the findings from these interviews[5], this research is indeed limited in scope and inevitably not all issues on this large topic will be adequately addressed. However, lessons from these interviews have been profound, and analysis of contributions has provided powerful insights to help map the current landscape in this field, which I hope will enable social purpose organisations, including funders, donors, public service providers and governments at all levels to better understand, support and develop this field of work.

This report does not explore why experts by experience actively participate in the work of the social sector as this fell outside of the remit of this exploration. The overall aim of this report is to empower funders, investors, organisational leads and other key staff in social purpose organisations to help develop a richer and fuller understanding of this field, so that it may help them grow, adapt and develop their own leadership and practices.

[5] References to published research and theoretical concepts are those suggested by contributors. No further academic or theoretical research has been explored independently, beyond these findings.

PART 1

LIVED EXPERIENCE IN THE SOCIAL SECTOR

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. They can be key drivers for social change and purpose-driven work.

Contributors unanimously agreed that an understanding of lived experience, along with the knowledge, insights (and for some the expertise) it brings, is fundamental to the work of all social purpose organisations and social impact initiatives.

"The very core of what we do."

"How can we serve our communities if we don't understand their lives and experiences?"

"Bringing value, legitimacy, and accountability to the work that we do."

"We must understand the knowledge that people have of their own lives, their communities…real life."

Active citizenship such as giving one's personal time and money to charity, volunteering, and participating in public consultations was considered by contributors as fundamental for a democratic and just society. However, there was wide understanding amongst contributors that these participation activities differ from activities that seek to meaningfully involve experts by experience in social purpose work. Some noted that many across the social sector have long grappled with how we meaningfully engage and involve people and communities with lived experience in our wider work.

"Citizenship participation has received considerable coverage over the last decade…but this can distract from the meaningful involvement of people and communities who have direct experience of the social problems and distress we are trying to address in our work."

"There has been some beneficiary and service-user involvement research in the sector…you're attacking this from a very important angle…"

"So simple yet so overlooked."

In this part, Chapter 4 will sketch out some advantages and benefits that arise when the social sector appreciates and acts upon the value of lived experience and its ability to drive social change. Chapter 5 will then look at the question of whether, and to what extent, the social sector in fact effectively values lived experience, how it currently gives it agency and where it goes wrong.

4. The Value of Lived Experience in the Social Sector

Key Points

- There is historical precedent for people with lived experience taking pivotal roles in the struggle for social change.
- There are many recognised benefits for social purpose organisations and civic society.
- These include strengthening the legitimacy and accountability of all social purpose work; improving the effectiveness of existing, and developing new, services and social change initiatives; innovation; the enhancement of community cohesion; and the cultivation of effective partnerships and collaboration.
- There are also a host of individual and unique benefits for experts by experience, particularly for those who are 'service-users' or 'beneficiaries' of a service.

There was a broad consensus among contributors that the term 'lived experience' was uncontested and widely understood within their work. The majority did not want to get caught up in the framing or conceptualisation of the term. They felt that it has not lost its meaning or potency, has not been distorted and does not need explaining.

That said, several contributors noted that the term is not widely used across the wider social sector. Instead its use is mostly limited to specific parts of the social sector, especially those social purpose organisations which 'root' themselves within the communities they serve.

Many felt that that the concept of lived experience had a long historical pedigree: one contributor referenced the 'Poor Distracted People in the House of Bedlam' petition to the House of Lords in 1620, in which patients complained of inhumane treatment, having been physically shackled and forced to entertain the public in exchange for clothing and food[6]. Contemporary examples include Alcoholics Anonymous and The National Domestic Violence Helpline, established and maintained through the vision and commitment of individuals and communities with lived experience.

Although contributors were aware of numerous initiatives which recognised the value of lived experience, some explored below, many of them accepted that such initiatives were limited in scope and that the idea of promoting change through leaders with lived experience and experts by experience remains significantly underdeveloped across the sector[7].

"If you're talking about people and you're working with and for people, then those people surely must be involved."
"Things should not be happening 'to communities' but 'with' them."
"Individuals have the right to be involved not only in service-planning but all decisions that impact their lives."
"Democratically…in terms of individual or community's rights, voices…everything…doing without is morally unsound and surely uncontested."

One contributor noted a slogan often used by experts by experience:

"Nothing about us, without us."

[6] Brandon, D. (1991) 'Innovation without change', England, Macmillan
[7] Significant concerns about this underdevelopment were raised and will be explored in further chapters.

4.1 Benefits for the social sector

Contributors provided a host of benefits that lived experience brought to the social sector and the work of social purpose organisations.

However, most contributors felt that the wider social sector failed to understand or take advantage of these benefits, often to its detriment.

The following list summarises the varying benefits of meaningful engagement with lived experience in social purpose work :

Benefits for the social sector / social purpose organisations (SPOs):

- Ensure that services and activities remain true to the vision and values of the organisation.
- Ensure that the activities and services reflect the needs of communities and benefit the communities they purport to serve.
- Create a sense of service and community ownership.
- Strengthen identity and gain credibility and legitimacy within communities, the social sector, government and wider society.
- Enable organisations to operate equitably, genuinely and authentically.
- Break down organisational hierarchies and avoid stagnation.
- 'Humanise' activities and services.
- Improve equal opportunities, inclusiveness of all members of society, and representation of people from diverse backgrounds and talents.
- Enable organisations to draw upon and make effective use of people's unique skills, capabilities, diverse perspectives, experiential knowledge and insights, allowing this to contribute to all decision-making.
  Improve and enhance the ability of organisations to bring policy issues to life by illustrating e.g. the scale of disadvantage people are facing, the real life and practical challenges in implementing laws, policies and strategies efficiently and effectively.
- Allow organisations to design and develop high-quality, effective and relevant policies, projects, interventions, services and initiatives.
- Add value to service / activity planning, development, delivery and improvement.
- Help all employees and volunteers to develop their skills and knowledge beyond theoretical and text-book learning.
- Increase organisational capacity e.g. through the development of peer support and/or mentoring schemes.
- Improve sense-making and sense checking; inspire innovation and rejuvenate and reinvigorate activities.
- Help set priorities, identify issues and outline solutions which might not occur to or be valued by those who are not experts by experience.
- Give early opportunities to test ideas and make decisions as they arise.
- Help learning and grounding of decision making in that learning.
- Build relationships of trust with communities, increasing the reach, leverage and traction of activities and services; generate social capital.
- Challenge wider discrimination, stigma, custom and practice.

4.2 Benefits for experts by experience

Contributors with experience of working with, monitoring and evaluating services that actively provide agency to lived experience gave clear examples of individual and unique benefits for 'beneficiaries' of a service who actively became involved in social purpose work [8].

The varying benefits to experts by experience can be summarised as follows:

Benefits for experts by experience

- Equality and dignity, self-determination, value and respect, the right to participate in decisions that affect their lives, validity as a valued citizen within society.
- Having a voice; being valued, listened to and appreciated; not feeling that expressing concerns was a waste of time; understanding that their opinions hold value and matter to others.
- Having a sense of purpose, taking the value and benefits of supporting and helping others, creating change with wider benefit to others and communities.
- Developing, improving and/or enhancing professional skills and abilities through meaningful activities, independence and the resources and income to participate in society.
- Developing, improving and/or enhancing personal skills by building confidence, increasing self-confidence/respect/self-efficacy, enhancing self-esteem and self-worth, developing life skills, increasing personal expectations and being the focus of positive attention.
- Social inclusion, along with social support within communities, a sense of connection, shared identity, friendship, development of social networks and connections and the sharing of problems.
- Solutions emerging from group interactions between people who had previously been alienated from each other, bringing people and communities together to achieve mutually agreed and desirable goals and outcomes.
- Connection to community, inclusion in community life and civic society.
- Stability and safe spaces, improved trust in and understanding of services and community, greater hope and optimism.
- An increased role in information sharing, awareness raising, signposting and public education, allowing them to challenge stigma and discrimination.
- Improvements to health (including mental health) and wellbeing through inclusion.
- Movement from being uncertain of their identity and place towards knowing their own value.
- Taking control and separating the sense of self from external situations.

[8] Transitioning into the space of expert by experience.

4.3 Benefits for communities and civic society

Contributors who work with, monitor and evaluate programmes that actively provide agency to lived experience made clear that there were additional benefits for communities and civic society, which are often hidden from view.

Several contributors amplified examples of connections created between different facets of a local community who are working on distinct, although sometimes connected, social issues. The involvement of experts by experience improved trust dynamics between these groups on an instinctive, and instrumental, level. This is helped by the sense of sharing common ground in terms of:

- Purpose and motivation, in creating positive social change for the benefit of the community and their livelihoods;
- Similar, shared and connected experiences (whether direct lived experiences or through family and friends);
- An understanding of community dynamics;
- An understanding of community circumstances e.g. social and/or economic barriers.

Three contributors commented on their observations of successful connections made between organisations involving experts by experience where previous attempts led by social purpose organisations had failed.

Some contributors felt strongly that this underdeveloped area was not only an opportunity to create powerful and transformational change across the sector but also had the powerful potential to heal fractured and fragmented communities. By helping communities to band together to focus on making major societal changes, they could create opportunities for deep, connected, meaningful and lasting change.

Benefits for communities and civic society

- Equality and dignity for all.
- Self-determination and ownership.
- Ensuring that services and activities are relevant to local needs.
- Enabling communities to voice their opinions and identify good practice and areas of concern.
- Raising community consciousness.
- Discovering and exploring community identity, along with distinct and/or connected identities.
- Dispelling community fears and anxieties and promoting social inclusion.
- Improving community cohesion.
- Developing a sense of pride within, and for, communities.
- Strengthening the role of communities in policy change and creating new political accountability structures.
- Promoting collective action.
- Empowering people to effective interventions in their own lives and in their communities.

5. How Far is Lived Experience Valued by the Social Sector?

Key Points

Common practices

- It is hotly contested whether or not lived experience is a form of expertise.
- The language used to describe people and communities with lived experience can have an impact on how they are perceived by others.
- Some funders and social purpose organisations take engagement with people with lived experience very seriously, but others are indifferent to or even wary of the idea.
- The community development, mental health and social care and youth sectors are more developed, but even here progress has stalled or even regressed and is now limited to specific social purpose organisations.
- Even when action is taken, in large part people with lived experience are often viewed more as 'informants' than change-makers.
- Funders are sometimes concerned about the prospect of 'punishing' social purpose organisations which are unwilling or unable to engage with experts by experience.

Progress and development

- The best social purpose organisations appreciate the value of experts by experience and work hard to put them at the forefront of their work, in particular helping 'service-users' or 'beneficiaries' transition into the role of change-maker.
- Doing so successfully involves appreciating the strengths and limitations of individuals, helping them to understand their experiences and respecting their decisions.
- Often, innovative organisations rooted in lived experience, or led by experts by experience, are some of the smallest, and so the least visible.
- Meaningful involvement of lived experience is seen when experts by experience have key decision-making powers in governance structures: equitable and inclusive positions within organisations and the work of the social sector. The sector is currently far from this goal.

Overall

- Progress towards meaningful inclusion of experts by experience has depended heavily on the area of the social sector.
- Lived expertise as a way of leading change, and the role of experts by experience as leaders of change, are not understood or acted upon by the wider social sector.
- Engagement and involvement is largely controlled by social purpose organisations, which means that experts by experience are unable to give the full benefit of their insights, knowledge and lived expertise.
- Equitable and inclusive opportunities are not in place to help people and communities with lived experience to take leadership and change-making roles. There are also many structural and institutional barriers to effective involvement.

As explored above, there was an overarching understanding among contributors that individuals and communities with lived experience of social issues can play a pivotal role in social change. However, nearly all believed that large sections of the social sector failed to actively and meaningfully use it to create and lead social change initiatives.

All but two of the contributors observed that the wider social sector treated experts by experience as 'informants' to their social purpose work rather than as 'change-makers'. Six of the contributors observed that the dimensions and features of methods used by the sector to 'engage' experts by experience supported this view, explored in further detail in chapter 5.

> *"Whose knowledge counts? Largely 'ours'…we turn to communities to inform our work once the work has already started."*

It was hotly debated whether or not lived experience was widely accepted as 'expertise':

> *"We don't trust our communities – their insights or ideas. 'We' think we know best."*

> *"Expertise...a difficult beast…using it can turn many away."*

> *"We can't assume that simply because someone has lived experience they have 'expertise'. One's experience of poverty does not make them an expert on the poverty of others."*

Several contributors observed that, without any sector-wide research on the value lived experience brought to the operations and activities of social purpose work, it was difficult to make the case for wider, meaningful implementation across the wider social sector:

> *"I don't think many elements of the social sector understand the importance of the lived experience, let alone its value…and if this report does one thing I hope it helps achieve that."*

Some noted a lack of cross-sectoral learning from initiatives led by experts by experience, or those that had developed their work in this field:

> *"There is good work happening out there…but it is scattered across elements of the sector."*

> *"Initiatives embedded in communities with lived experience are not visible…rarely celebrated."*

Reflecting on their active experiences of working alongside communities, four contributors observed that there were many individuals and communities with lived experience ready, keen and able to help create positive social change, become change-makers or leaders of change in their own right – experts by experience. However, they noted a pronounced lack of meaningful opportunities or channels to help harness this social capital and 'lived expertise'.

> *"There is extensive social capital that exists within communities, which is there to be unlocked and many just don't recognise that."*

This is fuelled by the sector-wide stigma attached to individuals and communities with lived experience and the failure to understand the value their lived expertise bring to social purpose work.

This was particularly so within the realms of the funding community and larger social purpose organisations which are largely owners or gatekeepers of such opportunities. Structural and institutional reform was called for.

> *"We have a massive supply of experts by experience and not enough demand…And there is a reason why that demand is not out there…Why is it not a part of our structures? Stigma and fear are some of the challenges we have to come to terms with."*

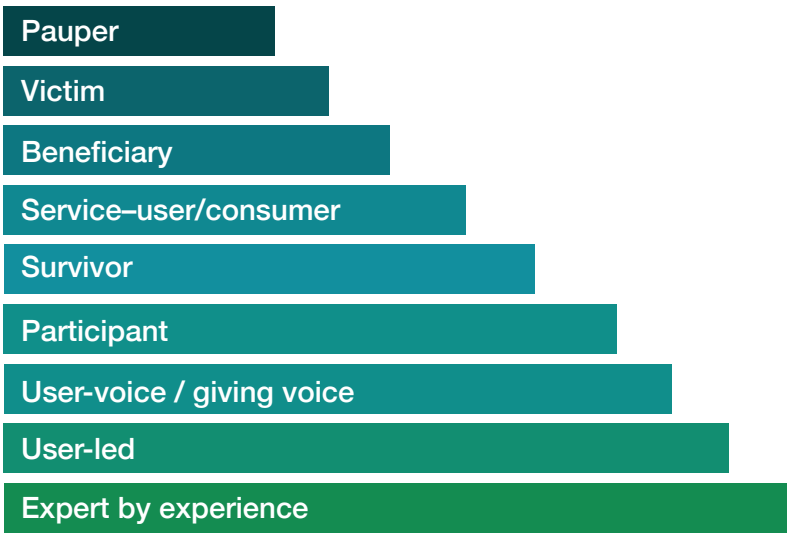
> *"For want of a better word – there is a 'stigma' attached to people and communities with lived experience…that they lack change-making and leadership capacity."*

> *"I'm not sure if organisations even try because they think people facing social issues either don't have the capabilities or will to create change…but is this an elitist viewpoint? And what's actually the problem is that people or communities don't have the capacity and resource to do so."*

> *"We need to stop alienating the very people and communities we say we serve, recognise and value the knowledge, insights and intelligence all people bring to the table and build new systems and structures around that 'expertise' to help create social good."*

5.1 The evolution and impact of language

Some of the contributors reflected on the generational evolution of language used to describe people and communities with lived experience. As language has evolved, so has our understanding of their role in social change and the methods we use to give them agency in social purpose work. An example of evolving language is:



Contributors were highly critical of the language the wider sector used to describe the people and communities they serve. Many believed that language and narrative can frame the approach and the very work of social purpose organisations. Some emphasised that by continuing to use historical or outdated terminologies such as 'victim' or 'beneficiary' we risk stifling progression towards meaningful involvement of experts by experience as social change agents or leaders of change.

Deficit- and problem-based narratives, such as 'disengaged' 'deprived', 'disenfranchised', 'at risk' and 'hard to reach', were noted as being widely used across the sector. These narratives can be

counterproductive and counterintuitive. Contributors observed that the 'labelling' of individuals and communities not only has the effect of 'disempowering' and 'disarming' people but has also, directly or inadvertently, labelled entire communities as 'deficient' and 'unable', thereby devaluing and masking their change-making capacity and instead positioning them as mere bystanders led or controlled by social purpose organisations.

> *"We focus on labels not experiences…treating people as 'the problem' – what about the 'runaway-teen' who has stopped running, 'young-offender'…who is no longer offending; pregnant-teen and I could go on."*

> *"A dominant approach to women who have experienced and escaped domestic violence – when do they stop becoming a 'domestic violence victim'?"*

> *"Surely its demoralising and sees people as passive recipient of services, which forces dependence…and dependency on a service is not what we are trying to achieve."*

> *"We know our services are not reaching communities – but what do we imply when we say 'they' are 'hard to reach'?"*

Contributors were also critical about their own operations and that of the wider funding community. Applicants for funding are often required to conceptualise and characterise their activities as addressing social problems and need, which some felt can perpetuate the 'doing to' rather than incentivising the 'doing with' whilst also supporting outdated 'silo' approaches to social purpose work.

> *"We condition ourselves to think that the communities we serve are 'needy' with the language we use."*

> *"Agendas and services often focus on one aspect of an individual or community – for example, housing, mental health, substance abuse, literacy…This model doesn't approach an individual or community in a holistic way."*

> *"Innovation can happen when you know much about the whole person, community or place. It's in these spaces we've seen innovation flourish and we need to do more to encourage that."*

Contributors accepted that it is therefore important to review the language used across the wider social sector, which may help to unlock or unblock progression in this field.

For two contributors, lived experience was intrinsically linked to service-user or user-led initiatives and both contributors were confused about the wider role of lived expertise beyond service design. By contrast, one contributor noted that the term 'service-user' seemingly described the 'transactional' nature of the relationship between social purpose organisations and experts by experience, thereby devaluing, and deviating away from, individual and collective change-making capacity. Similarly, one US contributor commented on the use of terms such as 'customers' or 'consumers' in the US: although helpful to inform service design, they found it did little to fully appreciate the benefits of lived expertise in wider social change initiatives.

Four contributors working closely with 'service-user' or 'user-led' initiatives commented on the very use of the word 'user' as creating barriers to the effective engagement of communities, inhibiting them from bringing solutions to decision-making tables whilst also allowing implicit and unconscious bias to flourish within sector-wide thinking.

One contributor candidly admitted that they were highly criticised by 'service-users' for using the term – 'it seemed obvious once raised'.

Terms such as 'expert citizen' or 'expert by experience' are increasingly being championed by people with lived experience who consider themselves actively involved in social purpose work.

> *"They were very clear they don't want 'service-user' or 'user-involvement' to be used to describe them…they want to be people, want to be human and not items. As we all do…Important to get it right…to understand their value as expert citizens."*

> *"We're all out for the same goal. We need to level the playing field and value all knowledge and insights."*

Contributors felt that the elements of the social sector that have adopted this terminology have leaped ahead in this field. Arguably, using terminologies such as 'experts by experience' has liberated both social purpose organisations and individuals from the confines of historical labels and definitions that limit the value placed on people's insights and lived expertise.

The shift in language has also produced a shift in behaviour and attitudes; transformed power dynamics and promoted collective ownership and responsibility of initiatives.

5.2 Value given by UK funders

Each of the UK grant makers interviewed was asked to comment on whether and to what extent lived experience is incorporated into their grant-making.[9] In addition to their answers to this, some contributors also provided insights and overall observations of the wider funding community. Their insights included the following:

- One of the ten UK contributors explained that lived experience runs through the heart of the ethos of their organisation. It is a key priority in their funding work, which they score in their overall assessment process. Although it is not a requirement in order to receive a grant, they encourage applications from programmes that actively involve people directly affected by social issues. These applicants are asked to detail how such people are engaged and involved at all levels of the organisation, and the number of applications is actively monitored (although it is still disappointingly low). They also ask organisations to explicitly confirm if they are user-led (led by experts by experience). If so, applicants are asked to elaborate, with the proviso that:

  "By user led we mean those organisations which have users at their heart, most usually where they make up a majority of the board. Where this is not the case, you would need to be able to show how users shape, influence and direct the organisation."

- Two contributors actively embedded lived experience into their funding strategies and have tested, or are currently testing, funding programmes that require involvement and engagement of experts by experience at all levels of a project or programme including proposal, development and delivery.

  One contributor detailed how user involvement in decision-making had featured in a specific grant programme in the past but that this requirement was not prevalent across most of their funding programmes.

[9] Two contributors highlighted the change in language from 'grant-making' to investing, especially when grants were awarded to social purpose enterprises.

- Another confirmed that that they expect all applicant organisations to have mechanisms by which they consult, engage and/or involve the people they serve before and during delivery of a service, project or social change initiative. This was included in funding guidelines but applicant organisations were left to describe how they would achieve this.
- Another stated that there was an internal policy that explicitly states that the fund is interested in applications from people who have 'experienced the issues' but there is little guidance for applicants.

Several contributors commented that although there was no directed approach to supporting user-voice or user-led organisations in terms of their organisation's funding priorities, they felt that it often featured prominently in the minds of individual grant-makers. Some contributors had observed subversive attempts by individual grant-makers to feature lived experience in grant-making, doing so by stealth where there was no strong commitment or position within the funding organisation. Many contributors felt uncomfortable with this.

Others reported positive approaches to awarding grants to social purpose organisations that actively embedded or sought to embed lived experience in their social purpose work.

For some of the funders whose organisations did not explicitly feature lived experience as a funding priority or criterion, they nevertheless felt that it implicitly permeated their funding assessments, or at least they hoped that it did. A few contributors described specific grant programmes where grantees were expected to 'harness' the voice of particular groups or communities targeted by the grant programme.

However, it was noted that many funders who lack a strategy of supporting experts by experience are uneasy about funding community-led organisations. Their primary concern is the prospect of supporting work solely because it was representative of marginalised communities, rather than because of the quality of its overall initiative and strategy.

One contributor highlighted their organisation's focus on tackling systemic change, stating that they work with grantees where experts by experience clearly form part of the staffing body and governance structures. As primary stakeholders, they fundamentally influence decision-making within the organisations they fund. The funder recognises that a power-shift is necessary in grant-making, an understanding that is rare across most elements of the funding community.

Several contributors commented on their experiences of the wider funding community, which not only fails to feature lived experience in their grant-making and management, but barely discusses the issue at all. Where conversations have taken place, there was a desire not to be prescriptive or to 'punish' social purpose organisations struggling to engage and involve communities. For some, user-involvement or user-led approaches were considered to be "leading with the heart," "unfocused" or, as one contributor noted, "for want of a better word, messy."

For some the focus was on the values of the social purpose organisation and examining their track record with the communities they purported to serve. Others were highly sceptical of organisations which provide a menu of superficial processes that simply did not allow for meaningful participation, engagement or involvement. This played heavily on the minds of the majority of contributors and is explored in the following chapters.

Several contributors reflected upon their own lived experience and confirmed that it often, coupled with their learnt experience, helps to inform their decision-making in terms of insight into and

knowledge of an issue or application. This is often an invisible feature of their overall expertise within the organisation (as often such personal experiences are not shared in detail with colleagues) but where it is relied upon in their decision-making, they often comment on it explicitly to describe their decision-making process or views on an application.

One contributor described this as:

> *"Watching the world from the spectacles we wear."*

Four contributors reflected on the dissolution of this expertise as they became 'institutionalised' within the funding community. Many pointed out that although we all bring our own individual lived and learnt experiences to the work that we do, often the 'lived' aspect is barely reflected upon or verbalised, let alone celebrated.

As it stands, there is a glaring shortage of those with lived experience in the grant-making world. Several contributors felt that there was a pressing and overwhelming need for funding organisations to review their own recruitment processes and actively consider the benefits and value of experts by experience in their work. Although a few highlighted gentle shifts in the recruitment processes for grant-makers within their own organisations, the higher up the governance or 'command' chain the more noticeable the absence of experts by experience.

One contributor reflected on recent shifts in their equality and diversity mechanisms and audits, whereby staff and trustees were asked to self-define and to comment confidentially on their lived experience of the issues the organisation tackled. Another highlighted a concerted effort by some in the funding community to recruit trustees with lived experience, although this was admittedly rare.

All agreed that there are many trusts and foundations which simply operate and develop their personnel in a way that actively marginalises or prohibits experts by experience from entering their fold. It is also worth noting that US colleagues felt similarly about the US funding community. Even where attempts are made to actively create leadership channels for particular social groups, they are not always reflective of all the communities: intersections between race and class/socio-economic status were given as an example.

There was a general consensus that much more could be done within the funding community not only in terms of internal processes but also recognition that their organisations as funding bodies are responsible for developing and encouraging the work of social purpose organisations in this area.

However, through personal experiences and observations of the wider funding community, contributors did not feel it was a priority for many colleagues in the funding sector. Many struggled with the concept. This was particularly apparent within the work of private foundations and trusts. Many contributors highlighted new and innovative approaches they are exploring or deploying in this area in recognition of the importance of lived experience in driving and leading social change; this will be explored in more detail in chapters 10 to 12.

5.3 Value given by social purpose organisations

Contributors also had plenty to say about the extent to which the social purpose organisations themselves value lived experience. Their knowledge and insights into this area come largely from decades of experience working within the UK funding community, with some observations from their historical work within the wider sector.

Overall, although the sector recognises the intrinsic value of lived experience in social purpose and social change work, contributors unanimously agree that it is not exactly ingrained in the sector's DNA. In turn, it appears to have somewhat stagnated as a key concept in sector-wide organisational and leadership development. There were many reasons for this, which were hotly debated. These concerns, challenges and barriers to change will be explored in further detail in chapters 6 to 8.

However, several key themes emerged in terms of the value social purpose organisations place on lived experience, which will be explored for the rest of this chapter:

- There is a large degree of variance in the methods and approaches used by social purpose organisations to give agency to lived experience.
- The level of involvement of experts by experience is a key factor in understanding the extent to which social purpose organisations place meaningful value on lived experience.
- Historical and existing involvement processes have helped to develop the role of lived experience as a key concept that informs and leads social change across the wider sector.
- The impact of the concept on social change work has clearly evolved over time, with an increase in the number of initiatives led by experts by experience in some elements of the social sector. In general, however, sector-wide recognition of the concept is convoluted and slow.
- The evolution of the language used to describe individuals and communities with lived experience and the processes used to give them agency in the work of social purpose organisations were called into question. Some believed that roles were limited and restricted to fit the needs of social purpose organisations, with little meaningful appreciation in the wider sector of the role of experts by experience as change makers and social change agents in their own right.
- In turn, many felt that there had been little progression in terms of understanding of lived expertise, resulting in the concept being underdeveloped in organisational and leadership development and theory.
- Similarly, understanding of the social change leadership capacity of experts by experience is a highly underdeveloped area.
- However, small elements of the social sector are leaps ahead compared to others in terms of their development and use of the concept. Unfortunately, there is often little visibility and dissemination of this progress within the wider sector.

5.3.1 Common methods used to give agency to lived experience

Discussions and deliberations brought to the fore a huge variety of engagement and involvement activities that have developed in a myriad of ways over time and across various elements of the sector. The lack of uniformity is inevitable given that the sector itself is extremely diverse. Of course, with that comes complexities, and plotting the different approaches is not easy. It is also subjective. However, it was crucial to unpack and unload some of these methods in order to effectively explore this field.

Here are some of the various methods and approaches that have been used to give agency to lived experience in social purpose work:

- Consultation, participation and/or involvement of survivors, beneficiaries, service-users, consumers and communities (which I will collectively refer to as 'involvement processes');
- Initiatives led by service-users, communities and consumers (user-led/community-led); and more recently.
- Recognition of 'expert citizens' and 'experts by experience', which is a new and evolving area currently recognised by only a few elements of the UK social sector.

As set out at the beginning of this report, many contributors felt that these varying methods give agency to lived experience. However, it is heavily contested whether the involvement processes engaged by the wider sector[10] meaningfully provide agency to experts by experience as drivers or leaders of social change. Often, they are the 'subjects' of the involvement process.

Contributors recognised that in recent times, social purpose organisations have heavily pursued involvement activities with a view to 'consulting' communities that are affected by government or local authority policies, services and decisions in question. As a result, some felt that experts by experience are increasingly and regularly involved in policy and campaign activities, research initiatives, and some elements of service contract consultations. Information from these consultations is fed back to those holding power at all levels, including organisational leads, boards, committees, funders, donors, investors, commissioners and decision-makers. However, the majority of contributors strongly doubted whether these involvement processes meaningfully recognised the value that communities and experts by experience bring to the table.

Many felt that these processes have become simple 'tick-box' exercises, fulfilling the need for organisations to be seen to be consulting with and accountable to their beneficiaries and other key stakeholders. For them, whether involvement was meaningful depended on the level of involvement communities had in decision-making and in the overall governance structures of social purpose organisations.

The majority felt that involvement activities are normally limited and narrow in scope and remain formal despite efforts to make them less so. As such they can be inauthentic and can dissuade or 'kill off' active involvement of people and communities with lived experience:

"People are trying…but a post-it note doesn't necessarily make the event less formal."

"There is 'consultation' fatigue amongst communities. It's not uncommon for organisations and consultants to parachute into communities to 'consult' with them and then hear nothing."

"Communities are sceptical about consultation activities. I regularly hear their frustrations from people and community organisations who feel that consultations are often not genuine."

Government led initiatives that have emerged over the last decade also generated scepticism and concern amongst some of the contributors. The increased outsourcing of public services and initiatives such as the previous coalition government's 'big society' agenda – encouraging people to do more in their communities and arguably championing social action – have also led to further pluralism and confusion of processes. Contributors strongly believed that they 'overshadow' and 'distract' from meaningful and equitable involvement of experts by experience.

[10] Setting aside smaller user-led or community-led organisations

"The mistaken assumption that community participation activities open the doors for all to participate is a myth."

"Social action is great but it's also a buzzword of the day…does it really give agency to all? No. It can overshadow the realities and inequity that remain."

"It's resulted in an industry…yes, engaging civic society is always a good thing, but when those very initiatives seek to marginalise or ignore members of society who are struggling the most…[there is] a focus on digital participation and increasing volunteering opportunities rather than seeking to engage those who lack the resource."

Many contributors felt that processes which genuinely and meaningfully engaged with communities and experts by experience were not widespread across the social sector. There was general consensus that social purpose organisations, across sectors, should be doing much more. The majority of contributors also raised a number of concerns over the value of involvement processes that exist and they were keen to explore alternative methods and approaches.

As two contributors noted:

"There is something very uncomfortable about the people we serve forming part of preconceived 'accountability' structures and mechanisms alone, which are then measured and considered by funders and investors."

"As part of evaluations it's not uncommon to see participatory projects focusing primarily on what their beneficiaries think of the organisation's activities or services. Even where I know models of practice have been designed by organisations without input from the beneficiaries I still find myself searching through the report to discover and learn what beneficiaries thought would work better or what they believe needs changing beyond the work of the service or organisation."

One contributor, when discussing the move of some elements of the social sector towards understanding experts by experience as social change-makers, noted:

"We're on the road to expertise but not quite there."

There was a consensus that whether movement is made from simple involvement processes to meaningful engagement of experts by experience depends largely on the part of the social sector, resources available and networks of support.

It was felt that older social purpose organisations still tend to confine involvement of their beneficiaries to specific issues and areas. It was also acknowledged that social purpose organisations often use involvement processes only to benefit the aims and objectives of their preconceived plans, rather than taking advantage of the expertise on offer to shape those plans.

Some felt that although involvement processes were used by many organisations in order to build movements and campaigns, little was done to try and engage more vulnerable or marginalised communities.

Nearly all believed that entrenched societal issues such as social and economic inequality cannot be divorced from any debate focusing on the meaningful involvement of experts by experience. This is discussed in more detail in Chapter 6

Examples of common traditional involvement processes used by social purpose organisations include:

- Community forums.
- Advisory and reference groups or committees.
- Community / service-user consultation events such as focus groups, roundtable events and reference groups
- Service-user / community / beneficiary presentations and performances (including creative performances).
- Storytelling'.
- Online campaigns / surveys.

Examples of emerging involvement processes include:

- World cafes.
- Innovation camps.
- Hackathons.

The purposes of involvement processes vary but include:

- Raising funds.
- Raising awareness among decision-makers (charity/trustee boards, funders/donors, government officials and policy makers, commissioners etc.).
- Performances and presentations at Annual General Meetings.
- Feeding into research, evaluation and reports.
- Feeding into Strategic Review events.
- Feeding into commissioner consultations / events (although some contributors felt that this only tended to occur with health and social care consultations).
- Feeding into the strategy and creative design work of social purpose organisations, increasingly, social entrepreneurs.

The levels of input represented by involvement processes also vary, for example:

- One-off attendance at an event (such as a focus group, interview, hackathon etc.).
- Regular group meetings.
- Completion of surveys, forms or questionnaires.
- E-mail and web updates and feedback.

5.3.2 The slow pace of change

Contributors recognised the important work of some parts of the sector, mainly those parts working in the fields of disability, community development, social care and health, mental health, drugs and rehabilitation. Social change organisations in these areas have pioneered involvement processes in the UK, along with activities and in some cases employment opportunities for experts by experience. This is discussed further at 5.5 below. Nevertheless, contributors felt that these changes were incremental rather than transformative and a few felt that progress had halted, stagnated or was even in regression.

Contributors recognised the important work of some parts of the sector, mainly those parts working in the fields of disability, community development, social care and health, mental health, drugs and rehabilitation. Social change organisations in these areas have pioneered involvement processes in the UK, along with activities and in some cases employment opportunities for experts by experience. This is discussed further at 5.5 below. Nevertheless, contributors felt that these changes were incremental rather than transformative and a few felt that progress had halted, stagnated or was even in regression.

Some made observations on the wider social sector:

> *"You could almost do a graph – the refugee and migrants sector is pretty bad with some small RCOs (Refugee Community Organisations) with a few trustees but not hugely represented or user-driven; organisations tackling sexual abuse are very driven but heavily constrained; the advice sector doesn't really do it at all."*

> *"Whilst some commissioners purport to have community engagement in certain initiatives they are rare and in regression and there is very little evidence of engagement activities within the public sector…"*

> *"Social purpose businesses may have a much stronger focus on their 'consumers' in comparison to charities and the voluntary sector but products and activities are targeted to specific groups for specific purposes and not necessarily focusing on community expertise and leadership."*

The majority of contributors agreed that meaningful involvement of experts by experience was largely confined to smaller community-focused social purpose organisations and were rare amongst larger organisations including larger national charities. A few contributors noted that their own focus on this area of work had helped to identify a small pool of grantees who actively and explicitly included involvement processes in their social purpose work – smaller organisations which were constrained, with their work was less visible.

Overall, a majority of contributors felt that the existence of meaningful participation, engagement and involvement processes, as well as leadership opportunities for experts by experience, depended largely on the part of the sector and the type and size of the social purpose organisation.

5.4 The lack of meaningful and equitable involvement

For most contributors, the value of involvement processes is directly related to the level of engagement of communities or experts by experience in the decision-making and governance of organisations, projects and/or programmes. For some it also included pathways to inclusive training, leadership and paid opportunities for experts by experience.

Overall, more weight is given to processes that embed decision-making: for example, trustee or board membership, service-user commissioning projects and co-design/co-production projects, where experts by experience are involved from inception and design through to development and delivery of a project.

Many contributors felt strongly that in practice, social purpose organisations were not always applying a meaningful approach to involving communities and/or experts by experience in their social purpose work. The involvement processes they did use were not necessarily able to give agency to communities and/or experts by experience with a view to creating social change or leading change.

Indeed, even where contributors explicitly sought clarification on the involvement processes used by social purpose organisations, as part of their grant-making activities, some organisations were unable to provide explanation beyond 'surveys, feedback forms and questionnaires'. One contributor explained that their organisation did not recognise these as effective and meaningful ways to involve communities, and that applicants would not be accredited in the grant application process if their involvement processes were not considered meaningful.

Some contributors raised heavy criticisms about how meaningful current involvement processes are. These criticisms included:

- Failing to meaningfully include communities.
- Failing to adequately represent the identities of communities and, albeit inadvertently, reproducing inequalities by excluding or marginalising some members.
- Failing to adequately represent or connect with the aspirations and ideas of communities.
- Failing to provide communities with ownership of activities for change.
- Approaches being 'tokenistic' or 'paternalistic'.
- Policing rather than facilitating involvement processes, resulting in 'futile' exercises to feed into pre-planned programmes: as a result, knowledge and expertise of communities or experts by experience was 'lost in translation'.
- Fail to share power, and albeit subtly, disempowering through processes.

Some noted that the intention to involve communities and experts by experience may be well-meaning, but that the levels of involvement in fact illustrated the low value that some social purpose organisations place on lived experience. There is genuine engagement and then there is engagement that happens only because of the structures that exist internally – within social purpose organisations – or externally, e.g. commissioner consultative groups, police consultative committees.

5.4.1 Tokenism

Many contributors felt that involvement processes were often 'tokenistic' or 'paternalistic', with organisations paying lip service to the idea of involving communities and/or experts by experience:

> *"We need to stop thinking that it can only be done in certain ways. It's not just simply feedback forms or quarterly reference groups; AGM performance or volunteering. It's about thinking through how organisations help facilitate effective community engagement."*

> *"It's about helping to move beneficiaries on in every way be it as part of their recovery, to fulfil their purpose and/or their leadership capacity. This is not necessarily being reflected in the work of organisations I see who say they have service-user involvement or say they are user-led."*

However, there were many aspects to the issue of tokenism:

- Involvement processes are crafted to avoid criticism and give the appearance that an organisation is fairly or equitably involving communities and/or experts by experience in its social purpose work.

- This then creates inertia in the social sector. Involvement processes or activities are used to 'tick the box' or 'go through the motions', which does nothing to help the idea that these activities are tokenistic.

- Once involvement processes are labelled as 'tokenistic', this becomes an easy 'get out clause' for some parts of the sector, allowing them to avoid engaging fully with the concept of involving members of their communities as experts by experience. They see it as too messy or resource intensive, or simply low down on the priority list.

- There is a perception that over time, social purpose organisations had stopped investing in or evolving involvement processes because they were perceived, or misconstrued, as being 'tokenistic'. Many observed that involvement processes have been dropping off over the last decade. One contributor with over 15 years of frontline experience as a practitioner working with 'service-user involvement' prior to entering the funding community felt that 'tokenism' had been a fear within the wider social sector for many years and that parts of the sector simply 'hadn't progressed from this notion'.

These concerns were going on internally, subconsciously or unconsciously for those who hold power. Some contributors noted that, in their experience, experts by experience and communities knew when activities were tokenistic and a waste of their time. One contributor highlighted the feedback loop this created between the two environments:

> *"So what do you do? If you know what you say, or your presence is futile, you fight it and the more resistance you get and the more it confirms what people think is a waste of time."*

Another contributor added:

> *"It's about unpicking…why it's so important and you see in some sectors it has got stuck at that level – so gathering feedback or getting surveys is the only practice followed."*

5.4.2 Facilitating versus policing

A number of contributors felt that social purpose organisations were imposing their own value on involvement, with organisation staff taking control of the information and deciding whether, when and how it is shared with experts by experience. Although this may be necessary at times, the risk is that involvement could be sanitised, contained, controlled and kept to the side-lines.

One contributor noted that even where user-forums, user-groups or advisory groups were formed, it was rare to see user-led agendas; there was still a level of control from the decision-makers in social purpose organisations. Involvement was not necessarily equitable and power was not shared. Issues raised by experts by experience could become standing items and not given priority. Many therefore became 'glorified feedback sessions'. Examples raised included:

- Getting individuals to attend to increase numbers in involvement processes rather than targeting and promoting it widely to those who may wish to get involved.
- Asking questions on decisions already made.
- Asking for contributions on issues that don't impact on the organisation.
- Selecting beneficiaries who 'toed the organisation line'; thought palatable for others around the decision-making table; or who did not challenge the status quo.

5.4.3 Involvement too late

Half of the contributors felt that when experts by experience were involved in research and programme design as well as strategic and funding decisions, this helped to shape a social purpose organisation's evidence and innovation work. As one contributor attested:

> *"Incredibly clear as part of our programme – if you're not including experts by experience in your programme you are missing half of your jigsaw."*

A number of contributors felt that the way things are currently structured, often any kind of involvement of communities or experts by experience gets left out, with no full understanding of their role as key stakeholders in social change initiatives and wider social impact work. One contributor noted that parts of the social sector regularly referred to investor engagement, but with no equivalent recognition of the key stakeholder role of communities or experts by experience, giving it 'at best a token nod'.

Having experts by experience involved from inception of a service can help determine what will work and what will not: without involvement, you risk creating a service that does not work by default. One example provided involved services which were only operational between 9 and 5pm. As a result, they were inaccessible or completely at odds with what the specific community wanted and needed. By meaningfully engaging with experts by experience and creating a service from 7 to 11pm, not only did the services become accessible, and save costs, but outcomes improved and beneficiaries promoted the service and felt that it had been designed with them in mind. Such involvement can have a crucial part to play in commissioning and contracting of services to meet the community's needs.

Involvement in strategic planning and decision-making was also noted to provide an early opportunity to test ideas.

> *"By involving experts by experience in the planning, delivery and evaluation of services and initiatives it can help to make sure that the system is taking a community-centred approach and placing people at the centre of systems change initiatives."*

Two contributors felt that current involvement processes were mainly confined to things as they are ('what would you like the service to include' or 'how do you feel about being treated unfairly') rather than things as they could be ('what do you want for yourself' or 'what would a radically reimagined system look like').

5.4.4 Collaboration vs monopolisation

Many contributors agreed that everybody in the social sector has a role in helping to create opportunities for communities and experts by experience, enabling them to be effectively involved in social change initiatives as well as become leaders for change. Partnerships, collaborations and alliances are therefore important ways to effect change in this area, allowing organisations to speak with communities rather than for them and to open up about the challenges, concerns and complexities involved.

However, several contributors commented on the disconnect between smaller and larger social purpose organisations. Two noted that smaller organisations are known for their links to communities, and sometimes larger and national social purpose organisations seek to monopolise on these connections for their own goals, be it research or one-off community-involvement projects, with little commitment for long term support and exploration in this field.

Three contributors believed that larger social purpose organisations can prove resistant to adopting, supporting or working closely with smaller organisations 'unless they fit with the corporate line'. Both US contributors confirmed that they actively facilitate the 'joining-up' of applicants from smaller and larger social purpose organisations to allow them to discuss collaboration and community involvement within an application process for a larger grant to effect change and tackle inequality.

Two contributors felt that often social purpose organisations hid behind the cloak of communities being 'hard to reach,' despite having done little to work closely with communities or reach out to them to begin with. It was recognised that in the short term it could be hard work to initiate and implement involvement processes, but the long-term gains for social change outweigh these short-term challenges.

5.5 Towards a more meaningful appreciation of lived experience

The conversations revealed that over the last several decades, some parts of the sector have been pushing the envelope in terms of developing more progressive ways to include and involve experts by experience in social purpose work. This has at times been a significant feature of some parts of the community development, mental health, disability and social care sectors in the UK, and more recently the youth sector. A few suggested that these parts of the social sector were 'leaps ahead' in terms of progress in providing agency to lived experience. However,

contributors emphasised that work across these areas was fragmented, in regression or at best unique to specific organisations inhabiting the sector-specific space.

Contributors provided some examples of organisations pioneering and leading the way in this field e.g. by incorporating the involvement of experts by experience into their recruitment procedures, governance and decision-making structures – these will be discussed further in Chapter 9. In the meantime, it is important to try to plot these developments and the progress made. It is therefore worth turning briefly to the four key sector areas deliberated on during discussions.

5.5.1 Community Development

The involvement of communities has featured and continues to feature heavily in community development and regeneration work. Involvement varies from surveying and consulting communities through to bringing communities together to design solutions to the issues they face.

Some contributors provided examples as far back as the 1970s, where local councils invested in communities. Recent initiatives include collaborations between communities and civil servants to make decisions on community initiatives and services, including National Community Forum Panels and Truth Commissions. Some mentioned tenants' and residents' associations, which employ and are run by experts by experience in those communities. Such initiatives involve people from the community all the way from inception through to delivery, with members on recruitment panels and involved in decision-making and governance structures. However, several of the contributors expressed reservations about the meaningful and equitable involvement of all members of the community, particularly those from more marginalised backgrounds or those unable to take up unpaid opportunities.

Examples of pioneering approaches in some Asset Based Community Development (ABCD) initiatives were raised by two contributors and these will be highlighted in Chapter 9.

5.5.2 Mental health and social care

Two contributors reflected on significant legislative changes over the last three decades, which have made service user involvement obligatory when planning services. This obligation was relatively nominal until the Community Care Act of 1990[11], which required local authorities to prepare Community Care Plans and to consult service-user groups which used, or were likely to use, their services. The Health and Social Care Act of 2001[12] placed a further duty on NHS Trusts, Primary Care Trusts and Strategic Health Authorities to consult with and involve people in service planning and proposals for change. Some contributors felt that gains were made in these sectors due to the statutory backing. Specialist services, user-led organisations and networks have also grown over the years. Contributors did not reflect over the advancements to legislation in these fields or others areas.

However, overall, many of the contributors again raised reservations over the meaningful and equitable engagement and involvement of experts by experience in this area. They highlighted that although involvement processes may be more developed, gains were not made in distributing decision-making powers effectively with communities and experts by experience. There also remains a shortage of paid opportunities (which is for many contributors the hallmark of meaningful and equitable involvement of experts by experience), including the charity and voluntary sector as well as the public-sector space. One contributor made a similar comment when reflecting on the disability rights sector.

A few contributors noted that historically, drug and alcohol services was another element of the sector where there was strong involvement of experts by experience, which also included employment and leadership pathways for them within social purpose organisations. However, some felt that this was also the element of the sector that was in regression. Some queried whether this was partially down to an injection of resources and support and the emergence of Drug and Alcohol Teams across local authorities over the last few decades. Major public funding supported the creation of targeted initiatives across the UK, but have long since been disbanded due to cuts in funding, taking along with it many staff with lived expertise.

5.5.3 Youth Sector

More recently, some contributors noted some progressive moves within the youth sector. Several highlighted the growth of youth empowerment, leadership and social action initiatives in the social sector space e.g. national youth service scheme.

Many commented on the positive impact such initiatives were having on developing young people's skills and confidence, and galvanising them towards active citizenship, volunteering and social action. However, many critiqued whether they did provide meaningful agency to young experts by experience, and some were concerned that, inadvertently or otherwise, they often marginalised young people from more underserved communities e.g. in rural towns with high unemployment. Some did not believe that they necessarily sought to provide agency to experts by experience.

However, two contributors highlighted innovative youth-led projects and organisations which do actively seek to utilise the lived expertise of young people to drive and lead social change; these will be highlighted in Chapter 9. However, contributors were clear that these initiatives and activities were specific to certain organisations and not widespread across the youth sector.

[11] Section 46
[12] Section 11

5.5.4 Co-production, co-design and co-commissioning

Contributors noted that over the last two decades an increasing focus was put on service design, evolving over the last decade towards co-design and co-production initiatives. They highlighted examples of communities working with public service providers and commissioners to design the provision of public health and social care services to meet the needs of a particular and/or local community: e.g. cancer patients, mental health and social care services. The principle of service-user involvement was said to be intrinsically linked to these sectors.

However, the majority of contributors felt that although this concept was gaining traction in sector-wide discussions among larger social purpose organisations, and partnership initiatives across particular sectors and regions of the UK, and many were using the language and even embracing these concepts, they are not necessarily gaining traction across the wider sector nationally. In fact, overall little was known about co-production and it was rare across many sectors and regions in the UK.

This way of working is still not habitual and relatively few organisations are applying co-(word) approaches and strategies to take forward their work. There's a lot of talk but little by way of practice being adopted.

> *"We're increasingly hearing terms such as co-design and co-production thrown around but event those shouting loudly aren't actually departing from business as usual."*

> *"Co-production is about valuing everyone around the table – sharing power and sharing ownership…we're a long away from that as a sector."*

> *"I think the sticking point for most is the fear of not reaching consensus…or getting it wrong."*

Despite the gains and progress made in parts of the social sector over the years, several contributors felt strongly that there had been regression in the aforementioned sectors. Two contributors commented on the devaluing of service-user involvement and engagement by most commissioners in England and Wales, with some believing it was merely an 'add on' for public bodies which simply pay lip service to the views of experts by experience.

There was general consensus that these approaches were far from 'tested out' or embedded across the wider social sector. Three contributors felt that this had direct implications on overall understanding of the value of involvement processes across the wider social sector, creating confusion that such methods were only deemed valuable in certain parts of the sector or only helpful for informing 'service' delivery.

> *"It's crazy….one could argue there is clearly a push in the health sector to involve people in the design of services yet this doesn't extend to the wider social sector…to help address other social issues…and not just focus around mainstream services."*

5.5.5 Towards a meaningful appreciation of experts by experience and lived expertise

Despite the many reservations and concerns raised over the sector-wide approach to meaningfully and equitably providing agency to experts by experience, deliberations amongst contributors highlighted some key developments and improvements that have been made through the work of the aforementioned sectors. In particular, two key themes surrounding development emerged:

- There was a move away from seeing individuals and communities with lived experience as mere bystanders or informants of change and a towards the recognition of an individual's skills, insights and knowledge. This move was assisted by the use of various active positions and roles, e.g. peer-led initiatives (peer mentors, peer-to-peer support, peer networks, self-help groups) were cited as plentiful across elements of the health and social care sectors.

- By adopting these roles through organisational structures, they give a more meaningful value to lived expertise, taking into account the experiential knowledge, understanding, views and insights an individual holds.

Contributors also identified key features and dimensions that characterise and structure meaningful involvement, including:

- Having carefully structured involvement processes from inception, preferably having experts by experience form a crucial part of the design process.

- Engagement from the beginning to explain why involvement is needed and valued; exploring involvement processes together and undertaking co-design activities.

- Establishing foundations from the start and ensuring that people know what they are signing up to: defining what the activity is for and what involvement will entail and mean; establishing clear roles and responsibilities; acknowledging limitations of both parties; setting expectations of both parties.

More frequent and engaged activities.

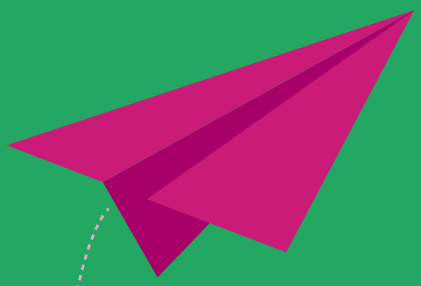
- A level of independence, flexibility and self-sufficiency in the 'running' of involvement activities; aligning it with other organisation activities e.g. social events.

- Support with management and/or coordination e.g. administration, facilitation, negotiation.

- Sharing outcomes – what has and what has not been achieved and why; progress made – what difference have their views and insights made; ideas for further involvement.

- 'Giving voice' to individuals and communities and providing the space to allow individuals and communities to tell and share their 'stories'.

However, some contributors also recognised the limitations of many these processes – particularly around governance structures, relinquishing of power and decision-making, and the lack of inclusive and equitable pathways for further opportunities in the sector for experts by experience beyond participation, involvement and volunteering.



PART 2

BARRIERS TO CHANGE AND THE WAY FORWARD

A clear theme running through all the conversations was the social sector's collective inability or unwillingness to appreciate the full value lived expertise brings to the heart of social purpose work.

The social and cultural resources and wisdom available within our communities and their capacity to benefit and drive our work are clear, yet universal inaction is abundant. For some, civic society's sinking support for the work of social purpose organisations was fuelled not necessarily by inaction but rather the slow pace of action and its failure to keep up with an ever-changing and evolving society.

"Something is not marrying up in the sector…We have to break that down. We've got to break it down."

"People and organisations are too scared, they don't understand it [the value of lived experience], they don't feel they need to or they feel they are on it and they're not."

"What's my part to play here? I think I place an over-reliance on service-user peer groups as the key marker of lived expertise…whilst these volunteering opportunities are vital…it's truly beyond that…you've shaken me up on this…my own implicit bias."

Contributors recognised the pressures social purpose organisations face, with the cycle of government cuts and legal and policy changes aimed towards communities they serve. Nevertheless, many argued that by not meaningfully and equitably involving experts by experience in our work, we are failing to grasp, understand and capture the issues at stake for the communities we purport to serve.

"Are we understanding the detail or even the enormity of what our communities are facing on the ground?...Are we doing it too late?"

"We're disconnected with matters of real relevance to people's everyday lives."

Overall, all but one contributor felt that the wider sector is falling short of where it needs to be to benefit, organisationally and collectively, from lived expertise in social purpose work. Half of the contributors observed that lived expertise has the capacity to create transformational and long-term sustainable change embedded in communities.

"Experts by experience can help design solutions to problems and help bring policy issues to the fore or to life, such as the scale of disadvantage the community is facing."

"They can identify and often articulate very well practical challenges people and communities face day to day…which other professionals may miss or perceive as unimportant."

"It's simple…people with lived experience are fundamental for systemic change…where they have agency, innovation will flourish."

Contributors unanimously agreed that the wider sector is failing to do enough to identify and provide meaningful and equitable change-making and leadership opportunities to experts by experience. For some, the current landscape was 'deeply discomforting' whilst others explored the 'Kafkaesque nature' of the sector's operations and bureaucracy that directly, or inadvertently, exclude the very people we serve, and need, to create effective social change.

Barriers to effect change were entrenched and endemic across the sector. Significant concerns were raised by all, especially those actively engaged with community-led social change initiatives.

> *"You can always look for justification of why something can't or won't work if you look hard enough…or simply don't look at all."*

> *"The benefits and impact massively outweigh the challenges, by far. If you dig deep enough there are always challenges in everything that we do. They are not reasons for why we should not be doing them. Here the challenges are manageable."*

While the sector to a greater or lesser extent recognises that these problems exist, they are not explored adequately, if at all. Chapters 6, 7 and 8 will attempt to sketch out some of the main issues which contribute to these barriers, and Chapter 9 will then start to look at how we can move forward.

6. Barriers to Change: Power Imbalances in the Social Sector

Key Points

- There are various ways in which the social sector's various power imbalances prevent experts by experience from achieving their full potential as leaders of change.
- The social change sector is relatively good at talking about inequalities in wider society, but is reluctant to recognise its own problems and contributions.
- Funders and larger social purpose organisations in particular can be far removed from the problems which they are seeking to help solve.
- Social purpose organisations are overwhelmingly run by individuals from privileged backgrounds who tend to put a lot of emphasis on 'professional' attitude and appearance.
- Resistance to increased power for experts by experience can be motivated by the fear that they will push out or contradict people with 'learned' or 'technical' expertise.
- Experts by experience may not truly represent their communities, and may become 'institutionalised' and less representative over time.
- The increasingly constricted funding and support available to the sector has shifted focus even further away from effectively engaging experts by experience as leaders of change.
- This is made worse by the lack of research in the area.

Contributors unanimously agreed that the wider sector is failing to do enough to identify and provide meaningful and equitable change-making and leadership opportunities to experts by experience. Barriers to effect change were entrenched and endemic across the sector. Significant concerns were raised by all, especially those actively engaged with community-led social change initiatives:

> *"We have to have the 'uncomfortable' conversations. It may not be very British but there is not one person I know working in the sector who wants to be seen to be acting or behaving unfairly or unjustly…these discussions are a must across the social sector."*

> *"We cannot ignore it. I come from privilege and I do not need to apologise for that. What we need to do is talk about those who do not have it…the people we say we serve…only then can we genuinely identify and address areas of concern and effect sector-wide change."*

First and foremost, contributors agreed that an important first step is the need to acknowledge and accept that the sector is not immune to the entrenched and endemic socio-economic inequalities and unequal power structures that exist within society.

> *"We know that we live in a vastly unequal society. One can turn to every single institution, be it housing, health, education and disparities exists within every single field and we are not immune to the status quo of the systems within which we work."*

"Although social purpose organisations are better than average at discussing social inequality, the sector is not immune from the general power structures that exist within society because it operates within the same systems."

"Much of these discussions stagnate when we start widening out the debate around the role of central and local government…we know inequality exists within those structures and many are working hard to address it…what we need to do is turn to the operations of others – public service providers, commissioners, larger charities, social entrepreneurs…ourselves as funders."

Secondly, it is important to recognise the historical background of the sector and its systems, which many argue were not created to tackle social inequality nor to shift power structures and empower communities to address social issues impacting their lives. It was largely built on the wealth of particular members of society – rich giving to the poor – in an attempt to alleviate the worst of poverty and its impact on less privileged members of society.

"It was not meant to deconstruct inequality."

Two contributors also commented on the role of philanthropy within the social sector and how, by its very definition, it could only exist when there is inequality, using the redistribution of wealth to tackle social issues.

"By its very nature it is borne out of inequality and arguably can only ever exist where there is inequality."

Contributors also commented on the concept of 'charity' and the evolution of a third sector[13] that was largely dependent on this distribution of wealth, be it through monetary or in kind support e.g. philanthropy and volunteering. Some contributors also felt that the charity sector, although well-meaning, rarely likes to hear about the degree to which it reinforces the status quo.

"What makes us think the charity sector has a massive halo because it happens to be well-meaning."

"In some areas there is a cultural divide between community-led organisations and long-standing voluntary sector organisations…something you only appreciate when you visit an area in person."

An important third step is to acknowledge and accept that all too often the people who decide how funding is distributed to tackle local, national and even global social issues – be they funders, Chief Executive Officers[14] or organisation board members – do not reflect the communities they serve and have rarely, if ever, lived or personally experienced the very social issues they seek to tackle. It's here where the disconnect to the 'realities' of communities and experts by experience begin to appear. This disconnect is real and cannot be ignored.

Finally, an important fourth step is to then appreciate that the sector is therefore susceptible to the same explicit, implicit and unconscious biases that affect the rest of society. For many of the contributors, shining a light on these, often hidden, biases would help to identify resistance and barriers to change, and ultimately help to drive the sector forward. As noted by one contributor, this approach is well recognised in the Gender Lens Investing Movement.[15]

[13] Traditional social purpose organisations e.g. charities, not-for-profits, non-profit voluntary sector organisations.
[14] In the US context, Presidents and Executive Directors
[15] Mainstreaming Gender Lens Investing Jackie VanderBrug Jun. 12, 2012; Stanford Social Innovation Review

6.1 Power dynamics at play

Contributors explored in-depth some of the power and privilege dynamics at play across the sector. Before delving deeper into the impact such dynamics may have in social sector operations, it is important to turn to some overarching dynamical features contributors observed.

Contributors irrefutably agreed and acknowledged that it was vital that all members of society have an equal part to play in the work of the sector

> *"Rich and poor…we all have a responsibility to talk about poverty. This should not fall on one part of society but be a responsibility for all."*

However, contributors questioned the equitable and collaborative bona fides of relationships between social purpose organisations, communities and experts by experience across the wider sector. The majority strongly agreed that social and leadership inequality permeated throughout our domains. People with decision-making powers, including senior staff, boards, advisers and consultants working in philanthropy or within and for larger social purpose organisations, normally do not reflect the communities they serve.

> *"People who call the shots are people with power and privilege – whether government officials, funders, CEOs and Trustees – they largely tend to come from privileged backgrounds. It's a reality."*

Several contributors argued that to meaningfully and equitably involve experts by experience in social change initiatives, and indeed our leadership, will require a distribution, or sharing of, power. To achieve this requires an understanding of, and significant shifts in, prevailing social norms, attitudes, cultures, behaviours and values inherent across the social sector space. Contributors unpacked this a little further during discussions.

People with power and privilege hold an entrenched entitlement and valued their influencing power, and yet the same entitlement or value was not necessarily transposed to those with less privilege. Many contributors agreed that there was a need for those with privilege and power to, at times, advocate on behalf of those with less privilege but observed that all too often little value was given to communities' power or ability to lead, or even create, positive change. Instead, many still focus on the 'neediness' of communities rather than their change-making capacity.

> *"Undeniably there will be times when 'power' needs to talk to 'power' but this dynamic often infects all our operations."*

Seven contributors emphasised the need for caution when unconsciously or subconsciously we impose our values and ideas on less privileged or marginalised communities. Others warned against the social sector reflex, albeit inadvertent, to choose between deserved and less deserved members of society to help and support.

> *"[We] pick the cause or a profile of a beneficiary who we believe has been hit the hardest or has it 'the worst'…then fail to address the immediate or long-term future for the very same beneficiary…"*

Contributors observed that parts of the social sector work tirelessly in the belief that they have a responsibility and obligation to advocate on behalf of 'disadvantaged' groups and the poor, whilst others understand their role as helping these groups to find their 'voice'. This work is, and will

Always be an important element of the social sector's work. But some contributors noted that care was needed when this dogged belief undermined the very issue the organisation is trying to address:

> *"We are increasingly seeing funders and philanthropists fly the flag of social inequality…but they commonly fail to address disparities within their own operations…worst still, justifying their failure to support community-led initiatives because they are not 'in the game of service delivery'."*

This latter quote was borne out by my discussions with contributors who fund programmes to tackle social and power inequality in society. Although they agreed more accessible opportunities were needed for experts by experience in the sector, they did not believe that their role was to create employment opportunities for them. Conversely, one of the two contributors later returned to this topic when reflecting on the lack of grass-roots community involvement in some of the work they do.

The inequitable involvement of experts by experience as key stakeholders within governance structures across the sector was considered an untenable feature of the social sector by all contributors. For the sector to be sustainable, equal involvement of all members of society in social purpose work was necessary.

All agreed that any genuine debate over the disparities of inclusion across social sector leadership would need a sincere and genuine discussion about the dynamics and distribution of power and privilege across the sector.

> *"Are we forcing experts by experience to start their own charities because we are not willing to let them into our world?"*

> *"People and communities often start their own charities because it is a way to address needs not being met by others…not to be beholden to others…but at the same time we know small charities are finding it hard to survive."*

> *"I often wonder whether it is best to encourage people with lived experience to start their own social enterprises…it's a means of getting outside of the current power systems and structures."*

A few contributors remarked on the importance of elements of the social sector robustly challenging the unequal power relationships that pervade the sector – and the sector's resistance to doing so. Contributors noted some efforts, but such discourse was occasional, infrequent, fragmented and could be connected to major societal events.

6.2 Helping from a distance

To put it bluntly, it was undisputed that power dynamics emanate from those who wield the most influence in social purpose work, those with the funding. This included investors and funders, whether philanthropists, donors, independent trusts and foundations, public sector commissioners or larger social purpose organisations which receive funding and are then left to decide how much to include experts by experience in their work, if at all.

Contributors therefore considered the dynamics at play where decisions around social purpose work are made by those who work at a distance from, and are not rooted in, the communities they serve. Several contributors sought to address the power hierarchy in the governance and leadership structures of the sector which they felt amplified the 'disconnected realities' between those 'at the top' and people and communities with lived experience. This disconnect is further explored at 6.4 below.

However, contributors accepted that it was important to explore their specific role and the power they wield in the sector, often from a distance, and how this may play out in this debate.

Typically, funders assess the merits of a funding proposal to solve a social issue or problem. Although their role is often technical in terms of assessing funding applications and proposals or doing due diligence on a social purpose organisation, amongst other things, they also play other key roles in the sector. One being their capacity to fund and support initiatives and research to help improve the work of the sector and advance social purpose work, including work to give agency to lived experience as discussed in Chapter 5 above at section 5.2.

Many of the contributors critiqued their own role and that of the wider funding and investing community. They examined power dynamics at play in their relationships with social purpose organisations and were also critical of some of the activities they deployed that may stifle progress and development in this field.

Despite it being a well-meaning community, the grant-making and investment world was recognised as being incredibly privileged, holding a lot of power and influence in the social sector arena.

> *"It doesn't relinquish power very easily and even in its own benevolent way it can think it knows more than the recipient of its grants."*

Contributors reflected on their observations of the wider funding community, recognising that often the power and privilege it holds can dictate the social change agenda. Funders and investors may design funding programmes to fit within internal and external political agendas, often with only a theoretical understanding of the social issue at stake. Indeed, its very choice of the social issue to fund may not necessarily align with the needs of communities.

Contributors explored the role of private foundations and trusts during such reflections. One contributor observed some grant-makers trying to 'reframe' the debate around a social issue. They could see the benefit in this if done alongside communities, but often:

> *"It's a million miles away from what is happening on the ground…it feels a bit like politics. Some funders seem to be fascinated by it all, particularly around reframing narratives and debates."*

Others noted the hands-on approach taken by some investors and funders, who like to play a role in strategic decisions such as commissioning, thereby influencing or disempowering decision-making within the organisations they fund.

Others commented on the role of grant managers as gatekeepers for the funding community, advertently or inadvertently denying access to power for communities, with its constant shift of the funding 'ceiling' to suit the aspirations and ideals of funders, leaving communities and organisations at their mercy and forced to 'dance their tune'.

One contributor recognised the tension for funders who are ultimately considering the distribution of often very limited funds. This can place expectations on social purpose organisations to illustrate innovative and cost-saving methods to effect change, including pro bono or volunteering activities.

> *"I feel very uncomfortable when we have discussions around the need for smaller community-led organisations to be able to design and deliver cost-effective methods to the delivery of their work...we tend to forget the limited resources and capacity they are already working with."*

Concerns were expressed about the lack of knowledge and understanding some funders have with regards to the connections larger social purpose organisations have with local communities and community-led organisations. They also often know little about the people involved in funded projects and programmes: it was common for staff within the funding community only to meet with Chief Executives or senior management teams of the organisations they funded. In terms of agenda-setting, often senior teams within larger purpose organisations were invited to roundtable or consultation events with smaller organisations rooted in communities being unrepresented or 'their voice' represented by an intermediary.

Others deliberated on the dangers and risks of such power imbalances, including mission drift within the work of social purpose organisations and/or strategic incoherence within the social sector, including in its relationships with communities.

In addition to issues explored in chapter 5, contributors also considered grant-making practices that may fall short of their own goals of promoting the equitable inclusion of experts by experience in their social purpose work. In some cases, practices may unwittingly perpetuate inequity in this field by inadvertently or otherwise directing funding away from initiatives providing meaningful agency to experts by experience:

- Funding can often be distributed to social purpose organisations known to funders, those they have relationships with and those which pose less risk e.g. healthier financial reserves.
- Although some have made significant efforts to address this issue, technocratic funding application processes and funding guidelines can pose difficulties for those without sufficient fundraising support e.g. understanding sector jargon; defining and articulating activities and outcomes within small word counts and online.
- Funding programmes continue to use deficit based language requiring applicants to focus on 'problems' and 'need' rather than promoting the inclusion of experts by experience and fail to encourage applicants to consider what 'good' things in the community can be built upon.
- There is a lack of incentives for social purpose organisations to develop work in this field, although some, including the contributors' own organisations, encourage the involvement of experts by experience (see 5.2). Overall, there is little to encourage organisations which are new to the field and may require additional start up support.
- There is a lack of site visits to community-led organisations, which could help funders gain a better understanding of their work during the application process.
- Lack of clarity and detail on the types of activity that funders will fund persist across funding guidelines, i.e. what do or could core costs cover e.g. additional governance and communications support if needed.

Many contributors agreed that these practices could inhibit community-led and user-led organisations from applying for grants. They reflected on the funding landscape and the skills needed to make successful funding applications, with many agreeing that a one-size-fits-all approach was long considered outdated in theory, but continued to be applied in practice:

> *"[This is] a difficult and long debated topic in some elements of the funding world…Smaller groups, organisations and start-ups were considered dynamic but lacked know how…lacked the skills to write a strategically coherent two-page document…unable to get through the next [funding] stage…Whereas larger organisations could do that but when we got them round the table…we found they were unconnected to or unrepresentative of the community."*

"It's difficult to make decisions on funding. If you put aside the emotional decision and think more practically – the value of a project is driven by the application you receive…more often than not we rely solely on the information we have before us and with that determine whether the project will meet the outcomes of a programme…if you have the boxes ticked with the indicators and outcomes beautifully outlined and framed to align with the wording of a funding round…it's a skill that wins the day."

Contributors also observed that grant-making practices may also dissuade some social purpose organisations from committing to supporting the equitable inclusion of experts by experience in their work, or distract those who were already committed, in order to appeal to the aspirations and demands of funders. Strategic priorities and even the organisation's strategic direction can be set according to funding levels, or research is instigated on a specific issue only once funding sources become available following a funder's 'interest' in a field. This can all be at the expense of the needs and aspirations of the people these organisations seek to serve.

"[It's] a hidden truth that is tough to navigate but, as there's no policy to intentionally marginalise the marginalised, accountability can be difficult and the route to progress is blurred, bumpy and often lacking in clarity."

"Various developments only serve to widen gaps, shift away from root causes to social issues and make funding even more inaccessible to those who don't know the [funding] game."

"Reports are good but how many times do we need to know something does or doesn't work and instead focus on scaling up what works?"

In contrast, several of the contributors observed concerted efforts by some funders to design and support learning agendas for funding programmes and initiatives, for example through evaluation, with offers of additional support to encourage organisations to better connect with communities they serve and bringing together larger and community-led organisations. However, these approaches were not consistent throughout the funding community and some questioned their effectiveness:

"We often bring cohorts of our grantees together to share learning across a programme…but I don't know how effective these meetings are...often we want them to collaborate but we don't always necessarily make that clear."

"I don't think we have ever hosted an event on how community-led organisations effectively work with and alongside people and communities with lived experience."

Many agreed that sharing knowledge and learning with communities and grantees was a vital role for them to play. However, one contributor noted that even when attempts to share and pass on knowledge to communities are sensitive and well-meaning, they can still be passed down.

"…with a nuanced and patronising double edged sword: 'we think what you are doing is great but actually we think this could work better' – yet another evaluation report with little practical impact and change for communities."

Many contributors considered their own role in addressing power imbalances within the sector and within their own organisations. One contributor highlighted that providing long-term core funding was a traditional and effective way to support the work and growth of social purpose organisations, particularly those that were community-led or smaller organisations rooted in the community. Others were increasingly reflecting on the need for training and support on tackling 'power and privilege' or 'unconscious bias' within their organisations.

Some observed efforts within parts of the funding community to reconsider their internal accountability and monitoring structures, while others considered their capacity-building role in helping to forge shared responsibility, power and leadership within communities. However, eight of the contributors noted the explicit deficit of staff with lived experience working within the funding community.

These imbalances of power are not only a problem for funders. Conversations concerning the power dynamics and hierarchy between and across social purpose organisations, particularly the imbalance between larger and smaller organisations, mirrored these concerns.

6.3 Imbalances across organisations

Many of the contributors emphasised the need to understand the interplay and impact of power dynamics on small social purpose organisations.

Contributors unanimously agreed that the role of small, grass roots and community-led organisations is fundamental in this field. Many root their work in lived experience, often pushing for effective social change through the involvement or leadership of experts by experience. Five of the contributors emphasised that many employ and are even led by experts by experience.

These smaller bodies were often set up and embedded in communities (be they local or sector-specific) to reflect and represent the concerns of their communities and contribute significantly to social purpose work.

> *"They are extraordinarily connected to the community…they understand the day to day challenges they face and help people have personal and collective agency to create change."*

> *"They can identify and spot the real impact that policies and services can have on people's lives and articulate this in a powerfully simple and effective way."*

> *"A senior colleague in the funding community looked at a staff picture of a community-led organisation we fund…said 'it's so great that they have a chance to come together and not be alone'…she didn't know that this community organisation had collectively challenged an unlawful local government policy or worked alongside commissioners to feed into the redesign of local mental health services…it's not that she didn't know that was worrying…it was what she had presumed."*

Contributors cited several examples of community-led organisations creating significant social change in their communities locally and nationally. One contributor cited an example of a small community-led organisation in the north of England that had successfully challenged the accountability of 'pay day loan' providers, helping thousands of people out of debt and poverty nationally.

Three contributors reflected on their transition from practitioner to grant-maker in the social sector.

> *"You have this ridiculous situation where you have this overview of issues and new knowledge but I was alarmed by the lack of knowledge of the work of community groups and grass roots organisations."*

One contributor, who moved from working within grass roots projects in a field to working with a funder on its portfolio in the same field, noted:

> *"I was surprised when I got into the funding world…and I was a little lost…there was a real disconnect between grass roots action and the work we were funding."organisations."*

However, discussions revealed that because of their size the work of smaller organisations tends to be fragmented and less visible, even where they make large gains in terms of wider social impact. Sector-wide learning of their achievements and expertise is low. Reasons for this include limited resources to celebrate successes and share learning. Indeed, many were struggling to survive in the current economic climate and do not have the resources that established larger social purpose organisations in the sector have.

Many of the contributors testified that larger social purpose organisations they have funded have often been tied to the 'traditional' involvement processes explored in Chapter 5 and often rely heavily on the involvement of smaller organisations to provide input into their research or policy-influencing activities. Again, however, this was often barely visible and it was felt that far too often larger organisations failed to recognise, or showcase, the full value experts by experience and smaller community-led organisations have brought to their work.

> *"I went to visit a small youth-led organisation we fund…during the visit young people told me about the meeting they had with staff from [larger national children's charity] and how little they knew about their experiences and work…we funded that organisation too…they referenced their interactions with [the youth-led organisation] in their reporting as 'supporting' them…with nothing the other way around."*

They also observed that it was not uncommon to see larger, more-established social purpose organisations expect access to such resources for little or nothing in return, including funding.

> *"I saw the replication of certain power structures within our own sector and the elitist world of some NGOs and larger charities…I suppose competition for funds highlights this more clearly but I was surprised by how often national organisations, and more recently social entrepreneurs, hold little regard for the work of more local and community based projects and organisations."*

Even more alarmingly, a few contributors observed a resistance or absence of commitment to work alongside or in partnership with local organisations. One contributor acknowledged that 'bigger charities' were sometimes making mistakes but reluctant to learn from smaller organisations which succeeded in areas they find difficult, such as community engagement and involvement. Often, funders sought to bridge these gap by funding intermediaries or consultants to identify, document and even coordinate efforts.

Several contributors plainly felt that smaller community-led organisations, many of whom involve and employ experts by experience, were unequal partners to social purpose work, with their social change-making efforts and capacity disproportionately side-lined or discounted.

> *"You say you're valuing user-experience and you're getting service-users in the room but it's being done within the structure of the organisation and you're effectively saying 'we want you to do this in a way that fits with us'."*

> *"I heard a leader with lived experience describe this relationship as 'service-used'…disturbing but encapsulates what's happening in some parts of our sector."*

There was also a strong feeling that trustees and senior management teams, particularly from larger organisations, need to be closer to the 'coalface', to better understand the work of their organisations and communities on the ground. Over time, like the funding community, many larger social purpose organisations are increasingly helping from a distance and becoming 'disconnected' from the realities of what was happening 'on the ground' for the people they purport to serve.

Four contributors reflected on the funding community's overreliance on larger social purpose organisations as the 'voice' of their sector:

"The reality is we also leave it to larger organisations to set the agenda, tell us what the sector needs…use their 'research' to justify funding to them because 'they know best'."

"How can they (large charities) be the main voice in the sector when we know there's a growing disconnect between them and community-led organisations?"

"Sometimes we know that some of [large voluntary sector organisation]'s solution ideas are outdated and unworkable because it is so far removed from what communities are saying…and asking for."

6.4 Privilege at the top

Assessing the issues raised above, there are clearly many institutional biases that exist within the social sector, but genuine cross-sector discussion was rare and often seen as too threatening. As noted by one contributor:

"There are always barriers to talking about the structural and ideological aspects of inequality within institutions. It can be visible and overlooked but it can also be invisible, hidden and we don't recognise it is happening. This is part of the bias."

Contributors unanimously agree on an undisputed yet often under-discussed fact that the social sector is predominantly led by white, heterosexual, able-bodied, privileged men who generally lead and 'call the shots' on initiatives aimed at diverse communities facing different social issues and different forms of social inequality.

"It's often the big elephant in the room – people rarely want to discuss it."

"Globally, everyone knows this is an issue – our sector is generally led by white English, Canadian or American heterosexual men from privileged backgrounds."

"Discussions around women in leadership sometimes surface."

"It may get raised when major issues of inequality come to the fore…a major societal event occurs such as the 2011 riots…a government report is published…it dies down again…and this cycle continues."

Contributors stressed that leaders within institutions and organisations have their own experience and such experiences undoubtedly shape their ideas of the world, including their understanding and identification of social issues and subsequent proposals for change. They also shape their attitudes and values.

The privilege of education and learnt 'technical' skills and expertise is valuable. Lived and learnt expertise are clearly both needed to drive social change within the social sector. However, views on what constitutes 'expertise' will be shaped by privileged experiences and a natural consequence is to work with people with shared skills and similarities.

"Lived experience? Why is it not 'expertise'? Who decides it is or is not? It may be a different form of 'expertise'…it remains unchallenged."

"The higher up the chain you go the more 'expertise' you are perceived to hold. But the irony is that those who do go higher up the chain often also begin to understand the expertise they don't have…the expertise that people with the lived experience hold."

One contributor noted that the value of expertise from unlikely sources can often be a novelty for many in privileged posts. Another contributor reflected on a meeting among social sectors leaders, predominantly from the public and voluntary sectors:

> *"The idea that ex-gang members could help support change in communities was commended but there was a clear sense that this was considered a novelty rather than a positive indicator that communities could effect change if given the opportunity."*

Many are unlikely to have direct personal experience of some of the social issues and inequalities they seek to tackle. This does not make their contribution or expertise irrelevant – their input is vital to social purpose work – but it's here where the disconnect from the 'realities' of the communities we serve starts to happen.

Contributors went on to acknowledge that this is not true across the sector, but this disconnect is real across many elements and should be openly discussed. Until we do, we will continue to work in 'bubbles bouncing over' and around the people and communities we say we serve.

6.5 Coexistence between learned and lived experience

Two contributors pushed against the idea that experts by experience should be considered 'leaders' of change based on their 'lived expertise' alone. They explored the idea of experts by experience holding leadership positions, founding organisations and their experiences of working with or meeting those working in 'user-led' organisations.

> *"Logically to me, it doesn't follow that lived experience is necessarily the same thing as creativity…"*

> *"Is it the 'expertise' needed to run an organisation?"*

One contributor was anxious about user-led organisations creating 'cliques' or deciding to exclude individuals without lived expertise from their work to preserve the leadership and independence of experts by experience, although no examples of this happening were observed.

Another expressed concern over experts by experience clashing with professional or culturally accepted views on behaviour, appearance and those who do not know the rules on 'professional etiquette' and accepted social norms.

> *"[Expert by experience] was making some very valid points but [expert by experience] was rather abrasive…passion is important but there is a difference when it feels aggressive."*

In contrast, others noted:

> *"[Expert by experience] swore…it didn't matter if it was professionally acceptable…it was considered passionate and a simple demonstration that we need to allow people to be themselves…the views [of the expert by experience] were very powerful and helped influence the room about the social issues we were all there to address."*

> *"Many tend to listen to views and opinions that are more palatable to our ears…we consider them easiest to engage."*

However, most believed that all individuals working in our sector, including experts by experience, should be free to stand by their convictions and opinions, and that challenging the status quo was an important aspect of bringing about change. Nearly all acknowledged that involving experts by

experience in social purpose work may challenge existing work programmes, governance structures and organisational cultures:

> *"There is a fear that people will come in and tell them what they're doing is wrong. They probably will. We don't always get it right. The problem is to continue doing things wrong and continue to do things in ways that aren't effective, not helpful and don't create positive change."*

> *"Surely it's understandable if communities choose not to act on the same issues that organisations and commissioners consider priorities…what I don't understand is why we feel they have to."*

> *"Communities can get frustrated about decisions made…the failures of commissioners…consultative board leads…to act – but these frustrations may be legitimate and cause for action."*

Many of the contributors explored the clash of views of dominant leadership personalities such as leaders with lived experience and senior leads at larger social purpose organisations, where significant disparities may lie between their values and strategic approaches to achieve outcomes for the communities they serve.

> *"Leaders in our sector need to challenge and push for change…it's part of their role…it will involve addressing areas of conflict and tension…we never question it when other sector leaders do it…or is it because they articulate it in a way that feels 'comfortable' to us."*

In contrast, another contributor recognised that a clash of views between different leaders may be a direct consequence of the lack of transparency within the work of the funding community and social purpose organisations, and in particular a lack of clarity around strategy and decision making. To the extent that this is the case, informed knowledge would minimise clashes.

Several contributors felt strongly that there was one rule for those with privilege and another for those without. Authenticity of character was revered as a strong 'leadership' quality and challenging the status quo as a sign of 'courage' within broader leadership learning. However, for experts by experience the goal posts were moved significantly, with a number of contributors recognising that 'user-led' organisations who challenge the status quo can be pushed to the margins and face discrimination for not 'toeing the line' or 'behaving as the sector would like them to'.

> *"Their lack of objectivity or wider understanding of the social sector ecosystem is far too often used to justify under reliance on their expertise and actually what we are doing is using these, often unqualified, assertions to disempower."*

> *"Communication style can 'offend' those with privilege…they hear something that is not within an acceptable frame and so dismiss opinion…or even see opinion as too aggressive."*

For many, the fundamental test of whether the social sector truly puts the views and voices of experts by experience and/or communities at the heart of what they do is whether they give equal weight to those views and voices when they disagree with existing leadership and governance structures.

Some contributors accepted that lobbying work involving local and central government officials may require a specific skill set to help influence change. However, social change work was not all about lobbying for change and in many spheres of social purpose work fundamental challenges maybe needed to 'disrupt' and create new and transformational social change initiatives.

Some acknowledged that there were often knee jerk or presumptive reactions within the social sector that communities lack the technical skills or capacity to 'get it right', and yet:

> *"There is very little in the involvement literature about beneficiary involvement in governance failing."*

Two contributors highlighted the tendency for many 'professionals' in the social sector to have an 'either/or' mentality, assuming that any proposition put forward would seek to replace old sector and leadership structures entirely. One contributor observed several professionals dismissing the idea of community involvement under the assumption that the community 'wanted to do it alone', even though this was never actually proposed.

> *"It's about coming together…the unequal imbalance between what we have now and where people and communities with lived experience currently sit on that scale…we have to begin balancing this out."*

Anxious scrutiny of a proposition is one thing, but this sort of outright 'anxious dismissal' misses the point, stifles change and creates notable barriers to equitable and tangible ideas for change. There was general consensus that this issue is not or should not be about identifying 'deserved or less deserved' 'expertise' but about harnessing our social capital. Not having lived experience does not necessarily mean that individuals will not hold similar values and views to those who do. As a society, we have a responsibility to bring people together to share diverse skills, expertise and knowledge to effect change. Because of these reactions, ideas for collaboration are rarely considered, wasting the expertise of communities and the chance to 'come together' rather than 'other' one another.

6.6 How representative are experts by experience?

An important issue explored by contributors concerned the shifting of power and inequality between people and communities with lived experience, and the risks and implications of placing too much power into the hands of one individual or a specific group with lived expertise or community/user-led organisation. Issues raised include:

- Who then begins to control the agenda?
- Is the individual or group representative of the whole community they purport to represent?
- Do members become 'gate-keepers' for other members of the community?
- Is there co-option, whereby members effectively act for the interests of a social purpose organisation rather than members of the wider community?

However, six contributors were concerned about how involvement processes for people and communities with lived experience may directly or inadvertently marginalise members of a community. One contributor recalled their participation in a community association event largely chaired by men, querying whether they were truly representative of the whole community e.g. single mothers.

Another considered an example of the pitfalls of co-option: the shift in power dynamics and the move from community needs being at the heart of decision-making towards the predominance of the financial interests of an organisation.

> *"I remember them telling tenant members 'your first and foremost responsibility is being a Director of the company'…I witnessed the shift in power and remember being surprised by a decision members made on a voucher scheme, which was less favourable to the community. When I asked why, they said they had to think about the finances of the company. Officers had found a way of getting them to shift their focus from what was best for the community to what was best for the company."*

"This happens in the civil service and public sector all the time. You don't want people to think against the body and so [you get] the shifting of power dynamics to control the agenda."

One contributor raised concerns about family interest groups, with a focus on those working in fields of mental health, the elderly and disability rights:

"Well-meaning and well-intentioned people with the lived experience of a social issue then form an organisation but also start controlling the agenda. It's always difficult. The learning difficulties sector is a classic example. Parents form an organisation and then focus on the interests of family members not necessarily the children."

Meanwhile another cited the work of family interest groups as a dominant cause for scepticism amongst many in the funding community when thinking through the work of user-led organisations:

"Transparency, clarity of mission and accountability is really at the heart of that problem."

Another raised concerns about one individual controlling the agenda: they provided an example of a community organisation where the founder sought to silence or control employees from the community, employing dubious employment practices. They suggested that addressing and challenging such practices required a very hands-on approach by the funder. The contributor admitted that this was an extreme example against a portfolio of numerous user-led and community-led organisations they supported where no such concerns were raised – and one which involved a dubious individual.

Two contributors reflected on the 'transient' nature of lived experience. As time moves on, for how long can an individual continue to rely on their lived experience as being truly reflective of the social issue(s)? Society, systems and structures evolve along with social issues. One contributor reflected on whether lived experience included all members of a particular social group and not just those from disadvantaged backgrounds. Whilst these issues will be explored a little further in Chapter 7, the following contribution is worthy of note here:

"Some people worry about the lived experience…is it only about the poor or marginalised? I can understand why…many of the current engagement approaches focus on 'service-users' or 'beneficiaries'…if you turn to elements of the mental health sector that have really tried hard to involve their communities…I was at an event in Devon…I met bankers, retired builders, academics, a recovering alcoholic…mental health doesn't seem to discriminate [in] who it impacts."

Several contributors were concerned over 'story superiority' or a hierarchy of pain that can create power imbalances. One contributor was anxious about individuals with lived experience lecturing others or transferring their 'story' onto others in a way that may create one-upmanship amongst communities. Another recalled a time where they shared a personal experience of a family member at an event and an event speaker actively, and publicly, dismissing this experience as irrelevant because they had not 'directly' experienced the social issue. One contributor noted:

"What's our collective responsibility? Are we as a social sector, be it indirectly and unintentionally, pushing those with the lived experience to be doing that?…I keep coming back to the power we have placed on story as opposed to experience."[16]

The majority were concerned about the role social purpose organisations played in these dynamics. Many observed professionals within the social sector, including within the funding community, dictating who they felt could or should be included in involvement processes, and who

[16] Discussed further in Chapter 8.

passed the threshold as an expert by experience of a social issue. Others experienced colleagues actively invalidating people's distinct yet connected experiences. Three contributors recalled times where it was 'known' or 'policy' 'not to expect' victims of violence to be involved. Little, if any, regard was given to the fact that some of the leading change agents or organisations in this movement were led by experts by experience and had spearheaded social change in women's rights movement.

One contributor referenced these as

> *"…structural and institutional harms the social sector has created that act against communities…actually against positive change – they are more than just barriers."*

Another noted that

> *"…this mentality is rife across the sector. Why? How have we let this happen and worse still let it continue?"*

The objectivity of experts by experience was also questioned by four contributors during discussions. They observed that some experts by experience become change-makers to focus on a particular social issue that is specific for them at any given time, while involvement processes may also direct experts by experience to work on a specific social issue or combination of issues.

Contributors working with service-users or experts by experience who moved into a position of change-maker observed some individuals who are unable to move beyond a personal perspective, immovably focused on single issues or unable to be objective. Difficulties may arise when trying to determine if a problem is personal or something that impacts a wider population:

> *"Some individuals aren't ready for full involvement and [are] unable to give you their views beyond their immediate situation. So that doesn't always work because people's immediate needs cannot always be translated across…we do have to make sure it's done in the right way and give people the right support."*

One contributor was anxious and uncomfortable about experts by experience 'imposing' their experience or story on others because they are so personally connected to the issue, recalling an episode where they witnessed the work of an expert by experience working in the drug and alcohol sector:

> *"I can remember being somewhere where someone with lived experience was telling someone 'your experience is my experience'. That may be true but their lived experience is valid and it's theirs. I was subtly trying to say to them that this was not necessarily helpful."*

However, during deliberations several countervailing issues were cited by seven of the contributors:

- Some examples were borne out of involvement processes that were heavily criticised by contributors in Chapter 5. This may work against experts by experience if little or no information, support, learning and guidance is deployed to ensure active, fair and meaningful engagement. These processes will be discussed further in Chapter 9.

- Caution was needed when 'public consultation' or 'public participation' events were cited as sole examples of concern in this area. The profile of individuals attracted to and able to take up certain voluntary or 'unpaid' positions and opportunities within communities need to be considered comparatively against those who come from more marginalised backgrounds.

- Four of the contributors, who have worked closely with initiatives meaningfully involving or led by experts by experience, noted that some communities were very mindful of issues surrounding the representation needs of their wider community. There is significant work that has been done by individual, albeit small, user-led organisations, and this learning would help the wider sector to address some of the concerns.

- Two contributors commented on the need for better support and funding for user-led groups that scaled rapidly; often core funding to assist with governance and operations can be difficult to secure, which may help with strategy, mission and accountability structures.

All but one of the contributors agreed that for far too long we have collectively failed to discuss genuine concerns the sector has about the involvement and leadership of experts by experience. Speculation and anxieties are rife but learning and research in this important field is significantly underdeveloped:

"Are communities living through the lens of our fears and anxieties?"

"I recall very little, if any, targeted research to help address such anxieties or think through how we and experts by experience can do better…it's easier to raise concerns than tackle them head-on."

One contributor commented that their involvement in this research had improved some their own understanding of some of the issues, which they hoped to explore a little further within their organisation.

6.7 The struggle to survive

Contributors noted that history has shown that quick-fix solutions or attempts to insert involvement processes into existing structures have failed or are not necessarily working effectively. Complex issues need to be addressed, including better support to work with communities, organisational and structural changes and support for development and leadership.

"It's an area with not enough investment. When I first got involved in the sector 15 years ago we didn't do service-user involvement and then we did [and] it was tokenistic and we haven't really progressed from that. Hopefully we can."

Contributors noted that the current funding crises and the constantly changing landscape of the social sector is having a huge impact on the general work of social purpose organisations. Many are in 'survival' mode or working tirelessly to react to government and funding cuts. Some are reshaping to deliver services the government refuses to, or no longer, delivers while others are trying to create new services and projects or to reshape existing programmes to align with new ideas, data and learning within the sector. Many are therefore working in an increasingly complex and self-sustaining system. With resources focused on meeting the needs of funding bodies or the demands of public service contracts, whilst tackling rising demand, this leaves little room to raise their heads above the parapet. Organisational survival and self-interest can therefore make doing the right thing difficult and limit productive, if any, work alongside communities. Even where it was genuinely on the agenda for organisations, it can easily fall to the bottom of priorities. All of this leads to little or no focus or commitment to creating the necessary involvement and leadership opportunities:

"A few organisations are just so pressed that unless it was embedded in the organisation's work it's dropping off…pressures of surviving more generally."

Two contributors highlighted how elements of the sector are in fact moving away from historical and existing practices of engaging directly with communities, towards digital and triage systems which restrict accessibility and engagement with services, 'minimising human contact for services that are ultimately human services'. Two contributors deliberated over some organisations' decision to move away from community-based work to public sector contracting. Three others noted that

> *"…old sector-wide habits were also difficult to shift and can stifle progress in this field, including being risk averse, silo-working, and having short rather than long-term / early action goals and strategies."*

Several contributors commented on existing community engagement initiatives and organisations led by or working closely with experts by experiences which were under threat. Many have little time and resources to manage work in this area, with some focusing primarily on meeting the immediate needs of communities and beneficiaries as a direct result of cuts. In this way financial insecurity leads decisions, with certain budget lines cuts to meet other demands:

> *"Organisations that feature the lived experience in their work tend to be smaller, low capacity, less organised and tend to not meet all our requirements around administration, governance and financial planning etc…they're not expert fundraisers so find it difficult to fundraise and scale their work."*

Many contributors recognised that long term funding was needed in order to allow organisations to commit to change in this area.

Support was needed to develop and embed initiatives beyond limited engagement and participation processes and towards meaningful involvement processes. However, observations of funding applications highlighted that many social purpose organisations, particularly larger organisations, were not committed to this area of work.

6.8 Measuring the benefits

A significant barrier to change repeatedly raised in conversations was the dearth of research and evidence to justify or qualify the 'success' of organisations, activities and initiatives led by experts by experience or communities; without such research, it is difficult to learn and build on what has gone before or what is currently happening in this movement. Instead, 'success' is currently measured against work, often in competition to, other distinct elements of the social sector such as public service providers and larger charities. There is also little appreciation of what constitutes 'success' in this field:

> *"Immediate metrics may show the high numbers of long-term unemployed accessing work – but what about engagement and growth in confidence and increased self-efficacy and support for their community? The immediate gains and numbers may be small but the sustainable long-term change may be powerful for people, the community and overall society."*

> *"What if an expert by experience, with the right support, identified a solution to a pressing issue with significant impact? How will we know if they have no agency?"*

Several contributors commented on the economic value and costs benefits of involving experts by experience within social change initiatives: in a time of economic decline and a climate of limited resources, perhaps this is a factor which needs to be highlighted. Contributors who work alongside involvement processes that are integrated into the design, delivery and implementation of projects from inception found that overall outcomes where better:

"As part of our programme we have approximately 50 'expert citizens' as part of a user-group. When I have been queried on the value meaningful involvement has for projects, one compelling reason I give for having such experts in the room is – the outcome for you and what you produce will be better…I don't have any published evidence of that but I know that every time I have seen the group involved in a piece of work they have produced something better than those who have not."

"I think I recently heard about a homelessness charity trying to find funding for this…the financial savings of a peer-led initiative…there may be some research out there but I can't think of anything off the top of my head."

One contributor kindly provided feedback from an evaluation of their strategic programmes involving beneficiaries in the design and delivery of projects. One such programme focused on young people, and 16 of the 21 lead partners in that programme reported active involvement of young people in both management and service delivery. When asked if the involvement of young people had either assisted or constrained the development and delivery of their programme, only two partnerships said it had constrained it. Feedback in one case highlighted that

"…skills deficit and a lack of experience in a working environment proved problematic and sometimes hindered progress, however this has also provided valuable learning opportunities for all involved."

Overall the evaluation found the involvement of young people to be the most innovative aspect of the programme, with feedback that such processes had a huge impact on the delivery of activities and services. The scoring part of the commissioning process in one initiative was considered to be

"…extremely valuable as what the young people thought was good to what staff thought was good was worlds apart. Informal feedback was that it led to the quickest decisions and simplest process."

Some contributors felt that not all social purpose organisations made sufficient efforts to consider the economic value and cost benefits of involving experts by experience in their social purpose activities, including policy and influencing activities as well as effective service design. Determining local need and provision may be a pre-requisite for financial investment in some parts of the sector e.g. outcomes based commissioning. However, whether the final service or activity was effective long term or more broadly was an entirely different question:

"It costs £60K [a year] keeping someone in prison. If we spoke to someone and said, what will keep you out of prison – it's a no brainer, no? So why would we not expect that for all our activities?"

The issue of measuring impact is generally a long and drawn out issue for the social sector. How do you measure impact and the value of lived experience in social change initiatives? How do you measure wider societal change? Does everything have to be measured in numbers? Are we sure we know how to define success or understand what we need to measure?

"I am clear in my head that by having the lived experience we are getting the best out of services and activities with communities…But I have no evidence; this is based on my experience from working in the field and on service-user initiatives. The impact will be shown once we can really show what systems change we can and have supported…impact measurement is a huge challenge even then…what proves that it was the work of experts by experience that made the change?"

"It's very tricky…over time we may see evidence of change in the work of the public sector, government and commissioning but how do you measure this?"

"Important learning from the initiatives we have supported is that actually what we define as important often isn't."

"What you can measure isn't necessarily meaningful and what may be meaningful can't necessarily be measured."

The processes of measuring 'impact' within the sector were cited as often being bureaucratic, and the manner in which we describe, monitor and evaluate social impact is difficult to articulate and prove. Smaller organisations in particular find it hard to articulate the complex individual and social needs of the communities they serve, and in turn how they measure and prove the social impact of their work:

"An age-old concern…How do you measure the impact of more nuanced forms of social impact? The organisation that provides an employment opportunity to a young person or one that directly seeks to tackle the wider issues inhibiting and/or stifling the young person's continuous growth including work within their families and communities?"

"As much as I believe monitoring and evaluation is really, really important it also seems that they became a tool to marginalise people and community organisations – a thing that enabled certain sections of the community to be able to bring their expertise in and not others."

"How can we measure the 'true' impact when commissioners, and even some funders and investors, focus on the numbers alone?"

"Some are good at the rhetoric and at times I also see myself wash away with this rhetoric, collaborate with it and then return to my experience – the realities of what creates change on the ground for the people we say we serve."

"What is the metric of success?…Incredibly telling of who gets in and who gets out."

The focus of the sector on market-based, outcomes-based approaches to social purpose work can inhibit progress in this area. The scientific practice of measuring can shift the attention of the social sector away from a systemic critique of structural and social inequality. Over time it can become the rational and accepted mechanism for addressing unequal achievement within social purpose organisations, rather than a way of measuring it.

"An outcomes-based approach carries with it start and end dates – be it for a service, a project, an initiative or for-profit-for-purpose."

"An outcome-based approach to user-involvement has allowed for those with the lived experience to become a superficial add on. Decision-makers are not necessarily led but nor are services defined by 'users'."

One contributor also commented on the use of language by funders and organisations which devalues the social impact of involvement initiatives, which can disempower and disconnect from the work of communities:

"'Soft data' [is] another offensive word like 'too emotional' – what does that mean? Not hard data? This can take away the meaning and validity of experts by experience and can be disempowering. So we revert to measuring what can be measured. The numbers."

7. Barriers to Change: Treatment and Views of Experts by Experience

The previous chapter looked at some of the inequalities and power imbalances in the social sector which prevent it from fully embracing the change-making potential of experts by experience.
This chapter will go into more detail about the ways in which those in positions of power in the sector look upon and treat experts by experience, and how this (often well-meaning) behaviour can further impede progress and moves towards positive change.

Key Points

- The way the social change sector views and treats experts by experience can create further barriers to them taking effective leadership roles.
- People without lived experience can sometimes find it difficult to believe and take seriously the experiences of those who have first-hand knowledge.
- While important, worries about the vulnerabilities of experts by experience can be used as an excuse to avoid genuinely engaging with them.
- There can be a tendency to restrict experts by experience to the area of their learned experience, limiting their potential.
- Putting lived experience on display can be a powerful tool, but there are also potential drawbacks.
- The social change sector right now puts great emphasis on technical and bureaucratic skills, which can deter or impede experts by experience from becoming leaders of social change.
- The sector also has a marked preference for 'professional' types and consultants, and forces experts by experience to adapt to these roles if they wish to be included.
- By failing to pay experts by experience, the sector makes it difficult for them to take up major and leadership roles within the sector, especially given that they are more likely to come from underserved backgrounds.

7.1 Failure to believe

A harsh reality of social inequality and injustice is that members of society, particularly those from more marginalised communities, face extreme hardship and suffering. This can, for example, take the form of abuse, whether interpersonal or a state-sponsored or sanctioned abuse of process.

Sometimes those who have not suffered or experienced the abuse of people, systems, services or indeed power can find it hard to believe or appreciate the realities of what happens when inequality, injustice and/or poverty is involved:

"If it's not been part of your world or part of your reality it's hard to believe and if it's unbelievable how do you make sense of it…in order to make sense of what needs to happen next to create change?"

"There isn't a day that goes by that I don't feel exasperated – on a much more superficial level – with people's inability to understand something unless they have experienced something themselves."

The hard reality is that sometimes people from privilege do not necessarily believe or feel an issue is important. Sometimes they don't believe something because it is so unbelievable…maybe another reason why 'story' is increasingly important in our sector…[is to] help the levels of command understand the issues they are supposedly trying to tackle."

Two contributors turned to the child sex abuse scandals in the UK over recent years as an example of disconnect between parts of the social sector and the underlying realities of people in communities:

"We now know young people and families tried to get help, we now know MPs were also involved in some of the scandals and yet victims were not believed – 'I don't believe you' or 'you're unreliable'. This is hugely damaging and a reason why it went on for so long."

"Of course it is connected to privilege and power and the realities of what some parts of the sector were being confronted with. Because it didn't fit with their understanding of the world or what they thought of the world."

7.2 Ethical sensitivities

Contributors explored the care and sensitivity needed when involving particular communities within social change initiatives, and the ethical issues and considerations this gives rise to. Examples of specific groups affected included children, survivors of violence and/or abuse, the elderly in care settings, those with disabilities and people in recovery.

Several contributors reflected on the role and responsibilities of social purpose organisations: ensuring that they do not coerce or co-opt individuals into involvement processes when it is inappropriate to do so, adhering to standards of transparency and self-determination, and considering the realities of individual's lives and support needs.

"People who have or continue to suffer disadvantage do need support to share their views, their voice, their story that isn't detrimental to their lives, recovery, health…this requires the right processes and structures of support…it may be messy or hard work but if the right environment of support is created, organisations can't be excused for failing to involve communities."

"If you are asking them [service users] lots of questions about difficulties…about where they are…they are at risk because they may not be able to deal with them at that point… and so care and sensitivity is needed."

"There are issues around boundaries and disclosure. Organisational support and supervision of members and employees is paramount and must be factored into structures and processes."

"The reality is that it isn't easy to set up…Organisations do need to think through involvement and employment processes and practices. It can be very easy to get caught up in the idea of involving service-users without thinking through how to support and strengthen their work."

"Working with and safeguarding children and highly vulnerable people is something many across the sector will be well versed in…the very same policies and protocols can be used."

One contributor explored the everyday realities of experts by experience being involved in peer-to-peer initiatives, and the impact on them of working with people who have relapsed following a period of sobriety within a recovery programme. Another contributor highlighted concerns over 'burn-out' and 'stress' amongst people with lived experience working in the mental health sector.

"[We have] a responsibility to make sure that we do not place people at risk whatever we are asking them to do."

In contrast, two other contributors noted that

"…burn out is often raised as a concern by charity leads when we've genuinely tried to discuss this topic in the mental health sector…but doesn't burn-out happen across all of our sector…public service workers…or indeed in any profession?"

"I've witnessed colleagues working in the sector burn out or go on stress leave…it's about poor management and support more than anything else."

However, several contributors felt that far too often social purpose organisations hide behind 'ethical' concerns to defend their lack of effective involvement processes and/or deny equitable inclusion in their social purpose work.

One contributor used the example of colleagues within the funding community who, while well-meaning, pre-determined who they felt should or should not be included in social change initiatives:

"I reached out to colleagues to get their views [on involvement processes] and one person came back to me to say that they did not engage with service-user involvement in offending or domestic violence work…ethical issues were raised but I was also told that service-users could be 'too emotional'."

Two contributors also observed resistance within the sector where victims of violence or trauma were concerned, with engagement often deemed unsuitable. There was little understanding that a key consideration was the individual's choice to engage or enter into social purpose work or become a social change agent:

"I still don't understand why people think it's unsuitable. I can't see any area where it would be unsuitable to involve someone who has a lived experience and wants to create or lead change."

"Choice and motivations for change must be appreciated…No doubt individuals with a personal experience may have a passion and drive that is emotionally connected to self – but it is still drive albeit different to the drive of others within the social sector."

Four contributors reflected on their recent work with experts by experience from 'vulnerable' backgrounds. They highlighted the importance of appreciating a unique journey and providing support where necessary so that individuals can make informed choices with autonomy:

"Their path and motivation for creating change may be very different from others working in the sector…yes emotions may come into it – many bring a heart full of passion, courage and drive."

"In my experience people with the lived experience care deeply about the cause they are involved in and want to give back to their communities in a way that is difficult to sum up in words…yet they often have little opportunities or hit professional barriers and limitations to take this passion forward."

Several contributors also observed that passion and emotion attracted negative connotations within the sector more generally, beyond the work of experts by experience:

"Aren't we all emotional? Is being emotional a negative? Or is it that some of us feel more comfortable about sharing emotions than others?"

"We're in the social sector, surely emotion and human connectedness is important in the work that we do? If you take away emotion are you not taking away passion, drive…and the strength to lead change?"

"There are cultural stigmas attached…we need to be comfortable with emotion and not transfer our baggage onto others."

Many of the contributors commented on the misguided assumption of many across the sector that experts by experience would be 'forced' or 'coerced' into involvement activities, and a lack of understanding that the responsibility to prevent this fell to organisations, rather than using it as a reason, whether directly or inadvertently, to focus on the 'incapacity' of an individual. Involvement processes should not be there to 'coerce' or 'co-opt' people to become change-makers but to give agency to those who want to do so.

"[There's] evidence that people still can't wrap their head around people from more disadvantaged communities wanting to create change."

Four of the contributors also reflected on how such approaches may impact wider perceptions of the leadership capacities and capabilities of experts by experience, understandably even dissuading some from openly sharing their lived expertise. Self-determination and freedom of choice were considered key: whether someone would like to use their lived experiences to effect social change and/or use that expertise publicly or not was their decision.

"Let's not get ourselves in a pickle here…and as a sector we can do that well…this debate is about how WE treat lived experience and value it in our work…that's the crux of it…not why and how people should use and lead with their lived experience, if they wish to."

"There have been lived experience leaders across the sector for generations…the women's and girls' sector is one example…They use their lived expertise to create change…whether they decide to lead with their story…say it publicly…is their choice."

7.3 Typecasting and pigeonholing

There was genuine concern from two contributors that experts by experience were either already being typecast or that they may be typecast if accredited or labelled with the titles 'expert by experience' or 'leader with lived experience'. As such, there was a fear that by labelling experts by experience, we add further invisible preconceived conceptual frameworks and categories around people with lived experience. This then opens them up to further objectification and marginalisation, whereby professionals within the social sector and beyond become unable to see past 'yet another label'. In this way, defining individuals solely based on their lived experiences and not their leadership capacities, capabilities and technical skills could create yet another badge of disadvantag

Other contributors reflected on the transition from 'beneficiary' or member of a community to active social change-maker, the transient nature of their role, the 'label' that they and others ascribed, as well as the transient nature of their lived expertise. These conversations focused primarily on individuals who had either moved from being a 'beneficiary' or 'service-user' to become an active change-maker, or who had visibly used their lived expertise to lead their social purpose work e.g. 'user-led' grantees. There was a marked absence of discussion of less visible experts by experience who may wish to use their lived and learned expertise to enter the social sector as change-makers, but have not had the opportunity.

Some important questions were captured and formulated:

- What if people don't understand their own lived experience and the expertise it brings?
- What if an expert by experience has experience of several social issues? Will they become a change-maker in one or many areas?
- Would expertise of one lived experience necessarily cross over into another field?
- When, if at all, does an expert by experience move away from their identity as an expert by experience?

Although some of the questions are beyond the remit of this paper, many of the contributors explored and reflected on initiatives or programmes they have worked alongside that have actively involved or have been led by experts by experience.

7.3.1 The importance of self-knowledge and self-determination

Reflecting on 'service-users' and 'beneficiaries', contributors emphasised that it was vital to provide opportunities for communities and service-users to understand their lived experiences, their individual and unique journeys. One contributor felt that enabling people to understand their lived experience as a 'social issue' or 'social issues' helped to unlock potential change-making capacity or guide others to become change-makers. This provides an explicit as well as implicit understanding of their potential role in tackling social issues, helps them to connect to and share with others, and assists to open channels of communicating, thinking, belonging and becoming.

> *"Otherwise it becomes invisible private troubles people labour with."*

> *"Communities with lived experience can fall victim to the labels we use to describe them…when you openly value their insights and knowledge it really can be powerful."*

Implicit in conversations with other contributors was the idea that self-knowledge is a powerful tool for change. Contributors commented on initiatives where individuals were given the space, tools and understanding to explore their own journey and come to understand the experiences, insights and knowledge that they bring. Not only does this help people to understand their role and purpose, but it helps to move their position from 'service-user' or member of a community to change-maker.

However, it's important to acknowledge that multifaceted sensitivities and limitations may surface. For example, self-understanding does not necessarily resolve a person's vulnerability, including their ability, or inability, to trust others. Central to the experience of some experts by experiences will be mistrust of public services. Once lost, trust can take time to restore, gain or regain.

Care is also needed to ensure that people are not co-opted into roles in order to meet the needs or activities of social purpose organisations. It's therefore important to appreciate the uniqueness of lives, and the importance of self-determination and choice, along with the need for transparency, flexibility and fluidity in such cases.

However, through active participation within the social sector, understanding of change-making roles and capacity develops and grows and contributors provided a host of examples of the activities of individual experts by experience:

"[Expert by experience] was once a service user…is not only now leading a key programme for the same organisation…is also active in meetings with civil servants."

"[Expert by experience] is training the very service providers who let her down."

"[Expert by experience]'s model of working is being replicated in other countries."

"[Expert by experience] travels around the UK speaking at conferences and events…sitting side by side [with] government officials on panels."

7.3.2 The importance of fluidity

Two contributors reflected on the often transient nature of lived experience and when it did and did not have value. One contributor expressed his confusion around some features and queried whether this debate was about disadvantaged, less privileged and marginalised members of society.

"When does it stop having value…you experience a social issue as a child and then you live your life into adulthood…work, have a family…is it relevant…really…when you are an adult, have learnt skills and expertise in a field?"

"What about the person who has not or does not wish to talk about it…or they have come past their experience?"

Other contributors were less perturbed:

"Lived experience can't have boundaries…I consider myself a social change-maker…I don't stop becoming a change-maker because I move from one job to another across the social sector…my skills may adapt and be enhanced but I will continue to use what I've learnt and indeed lived."

"We all have lived experiences, learnt experiences, a bit of both…we take that with us in everything that we do…but what is different here...is that we have not all personally experienced the social issues we are trying to tackle…combining this lived expertise with learnt experiences or expertise can surely be a powerful combination for social change."

"Ghandi was a lawyer…Did he use his legal skills and expertise in isolation to fight for social change?"

Some contributors felt that the funding community and larger social purpose organisations had an unfortunate tendency to frame, and segregate, lived experience around 'social problems'. The effect of confining people's lives and experiences into 'boxes' in this way is that presumptions and biases can flourish, creating significant barriers to social change and innovation.

A few contributors emphasised the growing recognition that social issues in civic society rarely fit neatly into one policy frame, system or structure. People's lives do not fit into neat boxes and the same is true of people's experiences. For example, people facing complex and multiple needs can experience a combination of social issues such as homelessness, substance misuse, mental illness, extreme poverty and violence and abuse.

"It is important not to see someone as 'A or THE experience' e.g. ex-offender, substance user, member of a BME [Black or Minority Ethnic] community…It's about seeing how they, and sometimes uniquely, experience a social issue or a combination of social issues."

Some contributors felt that the funding community and larger social purpose organisations had an unfortunate tendency to frame, and segregate, lived experience around 'social problems'. The effect of confining people's lives and experiences into 'boxes' in this way is that presumptions and biases can flourish, creating significant barriers to social change and innovation.

A few contributors emphasised the growing recognition that social issues in civic society rarely fit neatly into one policy frame, system or structure. People's lives do not fit into neat boxes and the same is true of people's experiences. For example, people facing complex and multiple needs can experience a combination of social issues such as homelessness, substance misuse, mental illness, extreme poverty and violence and abuse.

> *"It is important not to see someone as 'A or THE experience' e.g. ex-offender, substance user, member of a BME [Black or Minority Ethnic] community…It's about seeing how they, and sometimes uniquely, experience a social issue or a combination of social issues."*

One contributor kindly provided an example of their own experience in the social sector, being typecast with the assumption that they would want to talk about issues around race and migration, when in fact their work in the funding sector was much broader. They were asked to present at an annual social sector leadership conference, and it was assumed they would want to speak about diversity and race simply because they were one of the few people in the room from an ethnic minority background:

> *"Clearly there was an issue around diversity – the room made that clear. When a delegate asked a question about diversity it was a question that needed to be raised. But for it to be assumed by the compère that I would obviously be 'happy' when directing the question straight at me, I simply replied by saying that I thought everyone in the room would be happy the question had [been asked] and added that I was happy about the number of women who were in the room that day."*

Another contributor raised concerns that 'othering' of communities can be disempowering. Experts by experience who excel in their leadership may not want to lead with their story as a means to understand their ongoing expertise and leadership as time goes on. For example, two contributors gave examples of experts by experience: One was the child of a migrant who had witnessed their family in poverty, and who was seeking to forge a career in the social sector to fight social justice and tackle inequality. The other was an ex-offender who was leading social change initiatives beyond just tackling re-offending. Should we expect those people to lead with their experience throughout their work, progression and leadership in the social sector?

Two other contributors made further observations:

> *"Funding could force people to be defined by an aspect of their lives. Although, of course not having your expertise valued is equally bad."*

> *"So when people present we can't seem to get away from these things. It's about us…not them."*

Other contributors felt strongly that systemic biases and prejudices that exist within society and the social sector impose such labels on individuals, and that these are the real issues that need to be addressed.

Some contributors felt that smaller social purpose organisations, particularly those closely connected to communities, tend to have a more flexible and fluid understanding and approach to their work, driven by the learning and experiences of their communities. This allows them to develop social change initiatives to help address emerging as well as existing social issues.

As a result, some UK and US contributors argued persuasively for the more fluid approach more often seen in the USA; they cited initiatives aimed at addressing the intersections between social issues and social groups, such as between race, migration and LGBTQ rights. At the very least they advocated a greater recognition that the boundaries of individuals and community experiences should not be defined by imposed definitions of social issues. Similar approaches were being taken by work in the UK to tackle multiple and complex need. Such spaces were revered for the innovations that have taken and are taking place.

7.3.3 Charismatic leaders and 'Founder Syndrome'

One contributor raised concerns about those with lived experience being at risk of becoming tokenistic 'leaders' or tarnished with the label 'charismatic leader'. They referenced an example of a Chief Executive who was heavily criticised over their management of the organisation, which had significant backing from well-known celebrities and people in positions of power, whilst also receiving funding from the government to deliver services. There was a fear that organisations would be shaped in the image of one person, and that this would be difficult for succession planning. No examples of this happening were noted.

> *"We've recently seen dangers of having a charismatic leader an organization."*

In contrast, two contributors noted the UK media's obsession with and heavy criticism of the idea of the 'charismatic leader', revolving around the same individual as cited by the contributor above.

> *"That individual was neither from nor professed to be someone with the lived experience of those cause[s] they served. Far from it."*

> *"Let's not get this out of perspective. One person in the media. There are a lot of great organisations. There is nothing wrong with having leaders that are charismatic – if they use it in the right way. We cannot belittle all leaders because of one person."*

Several contributors raised concerns over 'founder syndrome' in user-led organisations, providing examples of smaller organisations that had done 'fantastic' or 'ground-breaking' work, but that had collapsed or failed due to 'founders' holding on to the reigns too tightly and not letting the organisation progress. This was recognised as a concern across the wider social sector more generally and beyond the remit of this paper.

Others raised concerns over the routes to leadership within the social sector. For many experts by experience, it was felt that as it stands currently, the only route to create and lead social change was to start their own organisation, be it a charity or increasingly a social enterprise. However, lack of long term financial support, little access to further technical skills and support to help scale the organisations were cited as significant barriers for the success of these organisations. Two contributors observed that, although awards and accolades are important, it was incredibly rare to see such 'founders' or experts by experience expand their leadership within the wider social sector or to reach a higher level of leadership within the broader sector.

7.3.4 Visibility of Experience

A few contributors explored the notion that visibility of experience is vital if experts by experience are to be change-makers. Similarly, it is crucial to ensure they have a voice in leadership development, which provides access and helps them to have influence within a setting. These discussions focused largely on individual change leaders who had used their voice in parallel to their leadership of organisations.

An example was provided of one leader with lived experience who used their authentic 'story' in parallel with the work of their organisation to increase access to people of influence within the establishment. This potentially helped to 'operationalise' that lived expertise into social change initiatives and leadership development (with the caveat that it was unknown whether individuals designed their social purpose work with this approach in mind.)

However, many contributors did not necessarily agree that visibility is necessarily a positive goal. Three gave examples from within the women and girls sector, highlighting that there are many women working in and leading organisations within this sector who have lived expertise of the social issues they are addressing, but who may not be publicly vocal about their experiences. Many of these organisations address a whole series of issues relating to women and girls, and the fluidity to do so is important.

On the other hand, concerns were raised about some organisations which do lead with lived experience stories. The dangers of focusing primarily on visibility and some of the potential barriers for change where organisations are 'stuck' in 'voice' or 'storytelling' mode will be explored in detail in Chapter 8.

It was also seen as important to avoid power imbalances between experts by experience, ensuring that one experience was not seen as more valuable than another, as well as between them and others in the social sector including local communities, the public sector and decision-makers. Blatant visibility was not always conducive to collaboration and engagement with others. An example was provided of a community empowerment network where experts by experience sat side by side with local counsellors, public health officials and members of the local community.

7.4 Technical expertise and governance

Some contributors explored the skills and attributes needed to guide the work of social purpose organisations to success, sustainability and innovation, the lack of which can constitute barriers or challenges to change.

The reality is that social change initiatives work within contexts which require appropriate mechanisms for due diligence, monitoring and accountability, to ensure that funds are used appropriately for the benefit of civic society. There was unanimous agreement on the importance of professional competence and the skills to manage and lead work within these structures. Some also mentioned the importance of the capacity to develop and benefit from evolving and emerging industries and markets.

Many contributors recognised that the credibility and competence of experts by experience as leaders of change is often measured by their level of technical expertise, with two suggesting that technical skills were leading components for success and sustainability within the sector. However, the majority felt that there is an overreliance on technical expertise alone as a way of measuring an individual's capacity to inform, create or lead successful social change initiatives. They believed this approach to be misplaced, misguided or outdated – and at worst, disempowering for communities. They emphasised the role of new approaches to identify, build and support leadership in this field.

One contributor from the US commented on their experience of providing leadership and skills training to community-led organisations:

"Technical skills can be developed within communities…People can move to a position of expertise after acquiring technical skills and knowledge…What we know from such initiatives is that lived experience does count for quite a lot in terms of formulating more permanent and sustainable solutions within the community…and that is where, at least for me, building technical skills, capacity and expertise can empower rather than disempower…but often it is used to disempower the voices that represent those communities."

Contributors working with programmes that provide agency to lived experience deliberated on the need for the funding community and the wider social sector to revisit and radically rethink its approach to initiatives led by lived experience. Unique management and governance structures may be required where traditional governance structures create barriers to change. Citing the work of a local mental health-run initiative, one contributor commented:

"[It was] totally user-led with social and community activities…but in terms of governance structures and management they are considered chaotic…often not in the way funders liked…they really struggle to get funding…no-one would fund them because beyond our understanding others [funders] didn't recognise the value of the lived expertise and with that things may need to be run differently."

Some contributors felt that organisational structures and systems require an organic and human understanding and approach to governance and management activities.

"Chaos and creativity are not necessarily enemies."

"We continue to see businesses launch creative and flexible methods of working for their staff…should it be any different…or do we have an elitist fear that it won't work if applied in our own sector?"

Contributors commented on organisations which have successfully established unique governance and management structures to take forward their work. They cited a national learning disability charity primarily led through the vision of experts by experience, who have established practical changes to working protocols, supervision and training. At the same time, they have worked in targeted and specific ways to recruit and manage staff and their board and trustees, manage governance meetings and ultimately developing experts by experience into leadership positions where they are valued and paid. Others cited exciting and promising emerging ideas such as community-level pooling of personal budgets, which enables coalitions of disabled people to become commissioners.

7.5 Over-professionalising

Many contributors believed that there is a tendency to overcomplicate and over-professionalise the sector. As a whole the sector is guilty of creating bureaucratic barriers, which prevent communities from effectively engaging with social change initiatives, resulting in stagnated progress and innovation:

"We all find ourselves in constant meetings, knee deep in data, research and evaluations…a deep irony is that whilst we work hard to try to escape and minimise such bureaucracy we tend to impose it on others."

Contributors were critical of their own practices, agreeing that bureaucratic funding processes and systems could inhibit experts by experience and communities from applying for grants. This is explored in more depth in Chapter 6 (see 6.2 above).

7.5.1 A preference for the professional

Connected to this is the concern that learned skills and expertise tend to be valued over lived expertise in the 'social sector psyche' as they are across other sectors. There are preconceptions and judgments about the way people present themselves, the language they use and the gravitas or authority it brings; individuals from privilege may present as less risky propositions. Important cultural and social stigmas are at play when considering the profile of change-makers and social change leaders.

> *"We recognise innovation when it comes in the form of three young men with a pitch-deck and we don't recognise it when it is a community group that's just operating in a different way and doesn't have the organisational or structural language to describe what they're doing. We're very much guilty of that."*

> *"A well-meaning social entrepreneur with educational and financial privilege can swagger in with all the trendy buzz words and we expect them to be able to come in and change the world."*

Some contributors observed the style or profile expected of social change leaders entering the social sector 'market' over recent times: an outstanding ability to 'pitch' ideas and eloquently explain their approach and how social impact will be measured and evaluated.

> *"[This is] an attractive and exciting proposition and acceptable face of leadership for funders and investors."*

The language, competencies and technical skills are impressive, but at times style overshadows substance. Contributors shared their experiences of social entrepreneurs and professionals entering elements of the social sector for the first time. Often, there could be little understanding of the realities of social issues and the human distress on the ground. Even where some were positioned to share some experience of working within particular communities, it was often minimal and too often a 'layering' and interpretation of issues from their own positioning and viewpoint. They may relay a compelling 'story' from communities to qualify their proposition or proposal for change, but this often lacks authenticity:

> *"[They have] an excellent ability to grab experiences of communities and articulate them into a frame for change yet little evidence of understanding what has gone before or listening to the needs of communities."*

> *"[They have] an excellent story but when you start to dig beneath the sleek business pitch the cracks can begin to show with little evidence of how social impact or change will happen."*
> *"We decided not to fund big and significant programmes because of a lack of authenticity. We would bring them in, interview them and it just didn't feel authentic."*

Contributors observed that many of their colleagues within the funding community were highly impressed by such pitches, with some having a tendency to impute qualities and skills to individuals even if they are not there, whilst others treated them with high levels of scepticism. Two contributors also observed individuals from privilege having strong networks, and thereby access to the sector, in ways that many communities we serve do not, and monopolising opportunities as a result:

> *"You would see the same people doing the rounds on the funding circuits and networking events and yet hardly anyone from community led projects."*

> *"[You see] the same faces parachuting into spaces sometimes trying to tackle totally different social issues from what you heard they were doing the month before."*

> *"They're often called the serial social entrepreneur."*

Many contributors strongly agreed that the social sector had a very static idea of a 'leader', yet through their experience of work within initiatives providing agency to lived experience, it was in fact very difficult to define 'leadership'. What about communities fighting injustices together, or those providing collective services to marginalised communities where government fails to do so?

Instead, two contributors gave examples of the social sector's fascination with focusing on the 'ground-breaking pioneer' or social entrepreneur. Both raised the example of one organisation created and co-founded by a particular individual (later becoming the Chief Executive) together with experts by experience. The organisation and its services were an incredible success but the organisation faced difficulties following the departure of the individual. The funding community, including grant-makers, investors and commissioners were 'buying in' to this leader as opposed to the work of the organisation that continued to progress following their departure. Concerns over the 'acceptable face of leadership' within the social sector were raised and will be explored further below.

7.5.2 Institutionalisation

A number of contributors feared that experts by experience risk being institutionalised or co-opted as quasi-professionals in order to fit into the culture of mainstream services, inhibiting the effectiveness of their role and lived expertise:

> *"User-led organisations can lack the confidence or financial independence to challenge the status quo and develop radical alternatives…often becoming institutionalised by funding structures."*

One contributor commented on how the sector inadvertently pushes individuals to speak in the language of its own structures and systems, thereby risking a dilution of lived expertise and/or knowledge:

> *"[It] eventually becomes a familiar policy script, bringing little that is original or genuine to the table…In one session with us, for example, one person with lived experience described himself as having 'multiple and complex needs'…not a term previously used to describe their experiences."*

A few contributors deliberated on the varying profiles of experts by experience who acted as change-makers, recognising that people's definitions can become closed off to those who were 'less acceptable' members of society. These discussions explored issues around social worth and preconceived notions that those who have or continue to suffer social ills may be incapable of managing aspects of their lives to address such ills.

> *"We work with people with chaotic and troubled lives. They can be seen as problem-makers rather than change-makers."*

> *"It seems to be more palatable when it's young people. Less stigma attached. But when you're talking about an adult, say, someone who had been homeless for 20 years, stigma increases and less value placed on the insights and capacity that person may have."*

Experts by experience who combine their lived experience with 'professional' experience may have more leverage, be considered less challenging and be taken more seriously than those without. The ability to communicate with the privileged clearly mattered where leadership was concerned.

Some contributors funded projects, initiatives and organisations involving and/or led by experts by experience, but it was not until they 'paid off' that they were taken seriously by others in power.

"If it goes from being a pilot project and then becomes a national project, or it gets some evidence of impact or some level of mainstream or government adoption, then suddenly your voice as a grant-maker is heard and then you have a leverage to show the impact of the value of the initiative."

"They have to work three times harder and prove themselves before they are taken seriously."

Collaborative partnerships between those with privilege and those with less were revered and celebrated. Contributors discussed examples of innovative projects and enterprises jointly created by privileged professionals and experts by experience, or social purpose organisations and communities. This 'sharing of power' helped to progress the learning and skills of both parties.

However, there were concerns over how the power imposed by the social sector on one party to the partnership over the other can have long term implications for such initiatives.

"Funders and investors were buying into [the professional] as an expert rather than the services. They were not buying into the process of true co-design and this posed difficulties in securing future contracts although the service was the same and actually developing successfully."

One contributor reflected on a successful initiative where aligned efforts to address a particular social issue led to the co-design of a project with members of the community. However, following its success, the larger social purpose organisation took unequitable 'control' of the project, which created a disconnect and led to the project's failure.

Another contributor commented on a similar process of power dynamics destabilising projects: one party seeks to limit access to services to particular groups due to 'challenging behaviours', and the other party experiences this as an attempt to marginalise individuals within communities and sort people into categories of 'deserved' and 'less deserved'. In this way, mechanisms for shared responsibility and ownership run the risk of creating a gulf of understanding between communities and agencies.

Alongside this debate over power hierarchy was the need to consider the approach taken by funders and investors:

"If you are coming from investment and aiming for sustainability then you need to show a business model, to borrow, have equity, but if you're an organisation working on the ground supporting communities where it is difficult to make profit out of your purpose – you're considered a lesser outfit."

Understanding the complexities of power dynamics, human relations, cultures and inequalities was not easy.

"Difficult to judge people's lives and what is or is not deemed acceptable in their world."

7.5.3 The rise of consultants and intermediaries

During conversations, contributors also commented on the role of consultants, intermediaries or 'external experts', who are increasingly being hired by social purpose organisations, including funders and investors, to create ideas and strategies for change, to scope, analyse and examine community needs, to interpret and document the voice and insights of those with lived experience and to help facilitate communication between different parts of the social sector.

Rapidly changing landscapes and markets make these experts extremely helpful. Innovation events often rely on their skills, and their focus on uniting and fostering collaboration is considered a positive shift in the social sector. When they lead interactive sessions or attend events and 'write up' findings, this is arguably a positive attempt to get closer to the realities on the ground, particularly when they implement methods such as 'user-centred' or 'human-centred' design.

That said, contributors noted a clear absence of meaningful community involvement in some of their activities even where voluntary sector, citizen and beneficiary participation form part of their core activities. And whilst some approaches to intervention and facilitation sought to embrace and connect with communities, a number of contributors commented on the disappointment of outcomes of such initiatives.

> *"Often they tell you what you already know or are far removed from what you hoped they would explore. I would rather just speak to those with the lived experience who can tell me things that I don't know already or point out things that are missing."*

> *"Care is needed when you pull in people to help facilitate communication, collaboration or build new ideas for change. Is it yet another layer of privilege interpreting the needs of communities?"*

> *"[They have] great technical skills but practice may not necessarily be set up to represent the concerns of communities or individuals may have insufficient expertise in community engagement."*

> *"We have decided to think carefully about the role of consultants. Are we hiring consultants from diverse backgrounds or expecting the consultants we hire to have diversity and transparency in their work?"*

One contributor observed the involvement of one consultant to explore the ideas and work of communities. Although very technically skilled, with notable experience within both the voluntary and public sector, they

> *"…didn't gel with service-users and at times came across patronising. If outsourcing work to experts it's important to understand their background, experience, culture and values. Whether they connect with the people from diverse groups, are actually listening and not just imposing their own views."*

7.5.4 Lack of remuneration

Three contributors noted something stark, which silenced the majority who had not given it prior thought. This was the realisation that in general little, if any, economic value is placed on lived expertise. Despite the many methods and approaches cited in Chapter 5, it is not uncommon for experts by experience to provide their time for free. There is little recognition of the social sector's responsibility to build economic actors out of those they rely upon to drive their social impact work, or those who wish to take forward their lived experience as change-makers within the sector.

Although some (mainly recent) initiatives were cited as seeking to change this inequitable status quo, it was often an issue left unchallenged throughout the sector. Contributors recognised that there is a widespread failure to understand or pay heed to the restrictions and limitations faced by experts by experience due to their personal and financial commitments, despite their aspirations to participate in social change initiatives:

> *"The reality is that we place little economic value on their expertise…we expect communities and those with the lived experience to give their time to us for free…we expect it to come from the heart and yet we would not expect that for ourselves."*

Specific elements of the social sector, for example, the voluntary and charity sectors, rely in part on the unpaid support in kind of individuals who choose to give their time to help support communities and causes; however the majority of the social sector workforce is made up of paid professionals.

Despite this, contributors reflected that few experts by experience are given remuneration for their social impact work, and little consideration is given to whether more communities would become involved in social change initiatives if they were given the financial capacity to do so:

> *"We expect communities to provide us with free consultancy…I'm not sure if they are even given a choice for it to be anything but…"*

One contributor noted that the mental health, disability and drug rehabilitation elements of the sector have moved on more than the rest in the past, and that in these areas it is no longer rare for experts by experience to be paid for their time. However, although not rare, huge disparities across the wider workforce persist. Several contributors explored the role of other experts, for example, facilitators, analysts, researchers, evaluators and academics who were enlisted for support:

> *"We're all paid…we even pay consultants we bring in to assess an issue, evaluate and help design services and/or build solutions…they too may rely on the expertise of communities and use these findings to support their work, which we remunerate."*

One contributor reflected on a community development project they supported involving a large corporate company, which relied heavily on members of the community to co-design a project. Company employees were paid, as were consultants, to facilitate events, asset map and turn enterprise ideas into project proposals.

> *"It became clear that members of the community were not only coming up with all the innovative ideas but they were then going on to implement the ideas within the community…they were the only experts involved that were unpaid."*

In recognition of this inequitable status, a proposal was put forward for the company to fund one to two hours a week of community members' time, in order to value their expertise and contributions. This proposal was criticised and refused. The funder involved felt compelled to come up with an individual grant scheme to reward people involved. The contributor remembered this example clearly because the status quo had never been challenged in their own work up until this point, although they had worked in the community development sector for many years.

Three contributors felt that this attitude and practice permeated across the UK social sector. Two contributors also commented on their unease about the practice of larger social purpose organisations and consultants relying on smaller grass roots charities and user-led organisations to give up their time to aid their work, and in some instances doing the same with non-charitable social purpose organisations. There was an implicit bias that such charities and organisations would or should do it 'for love not money' or because it was the 'charitable' thing to do.

Several contributors felt strongly that the issue around paying experts by experience for their expertise was taboo, and that some social purpose organisations were also fearful of the cost implications for their own work:

"Paid opportunities would drive up project costs and this is something that the funding community and the social sector does not openly admit."

"It's opening the floodgates at a time where funding is constricted."

A few contributors commented on this issue being 'messy' for some, particularly where social purpose work sought to involve experts by experience who were on state benefits. There was some anxiety that payment would impact negatively on individuals' benefit entitlements.[17]

There was also a concern that this approach would mean that organisations would effectively be employing individuals, with the resulting requirements to establish relevant internal processes and operations. Although two contributors recognised that this could be incredibly taxing for smaller organisations, they suggested that there was no reason why larger organisations could not put in place effective mechanisms to pay experts by experience directly or through smaller social purpose organisations which are often conduits for engaging members of the community or experts by experience:

"Larger organisations need to start recognising the responsibility they have and how they value the time and expertise of those with insight, knowledge and expertise they rely on to take forward their own social purpose work."

"As a social sector do we not have a moral and ethical duty to support people with lived experience who do not have financial or educational privilege?"

"We need to make it paid…All well making people feel valued by asking their opinion and [to] share their story but would it not make them feel more valued if we ask for their opinion and then pay for it?…It will make us all feel a lot better."

7.5.5 The push to volunteer

Whilst exploring the routes by which communities and experts by experience became involved in social change initiatives or the work of social purpose organisations, several contributors noted that often the dominant culture in the social sector created an unequal expectation that involvement from such groups will be on a voluntary basis.

Contributors recognised and applauded the important role that volunteering has played in this field. They cited crucial programmes and initiatives that invite, include and provide meaningful agency to communities and experts by experience including peer-led initiatives across elements of the sector such as peer-to-peer support groups and advocacy schemes. Many of these schemes provide vital personal agency and development for experts by experience and some help to advance their role as employees with lived experience within organisations or beyond. However, these opportunities were seen to be sparse and significantly disproportionate in terms of the wider sector workforce.

Although contributors recognised the valuable role that volunteering has, and will always, play in sector-wide work and the importance of active engagement of civic society and its citizens, several contributors explored challenges to these assumptions – where volunteer routes may be inappropriate or may undervalue the role of experts by experience as change-makers. Volunteer routes may also attract particular individuals and block or marginalise others.

[17] However it is worth noting that, in terms of the asset-based community development example above, the contributor confirmed that the proposal would not have interfered with members' state benefits at the time, as it would have involved less than the 16 hours permitted for work under the eligibility criteria.

Two contributors reflected on the overzealous focus by some social purpose organisations on celebrating volunteering opportunities as being of greater value to the individual (e.g. to enhance their individual development or career prospects). As a result, there can be a lack of transparency regarding the value and expertise volunteers with lived experience may bring to the organisation.

In addition, even where volunteering was a preferred route for experts by experience to engage with social purpose work, recognised by some as an integral first step into the social sector for many, some contributors were concerned that the reality is that these opportunities may no longer be available or were at risk.

Several contributors commented on the changing landscape of volunteering in the UK, particularly in rural areas and underserved communities, where people are not necessarily volunteering as they once did. This is fuelled by the closure of community and grass roots organisations and the impact of funding cuts on the declining infrastructure of some small organisations which were previously able to support and manage volunteering and community engagement opportunities:

> *"Often volunteer models are unsustainable in the long term…complex issues within communities cannot be addressed by volunteers alone."*

> *"Over the last two decades the UK government has tried to co-opt, corrupt and incorporate voluntary action into government agendas."*

Four contributors commented on the gulf between current government policies and funding and community needs, with programmes either focusing on involving the voluntary sector in public services or initiatives such as the skills share programme, which seek to expand social impact bonds. Programmes funded largely through the Cabinet Office were being sold as initiatives to improve social outcomes for communities, focusing in the main on youth volunteering, social action, charitable giving and employee volunteering:

> *"Central government is promoting volunteer and new social action initiatives within the regions but they are aimed towards particular members of society, not communities with complex needs or facing hardship and poverty – you have people struggling to make ends meet in disadvantaged towns up and down the country, with long term unemployment, with very little voluntary services and even if they do people can't afford to get involved."*

> *"Some communities are very depressed with little resource, capacity or energy to volunteer…I'm certainly seeing that the voluntary sector in disadvantaged rural areas without a track record of community engagement is almost entirely lacking and finding it much harder to engage people with the lived experience…little thought into the practical and day to day needs of communities…no surprise that those getting most out of these programmes are the more affluent in society."*

> *"Do these opportunities really embrace or engage all members of society…Carer, disabled, refugees?"*

8. Barriers to Change: Voice and Storytelling versus Leadership

Key Points

- The ideas of 'giving voice' and 'storytelling' have gained a lot of traction over recent years.
- They can be powerful tools for experts by experience in their change-making journey.
- Storytelling can be an excellent way of engaging the public, raising awareness and stimulating empathy. It can also help people with lived experience to express their feelings about their experiences.
- However, it can also end up limiting experts by experience, reducing them to their stories and preventing them from growing into leaders.
- Perceptions of experts by experience can be strongly influenced by the stories they tell, leading people to believe them unsuited to leadership roles.
- At the same time, the social change sector needs to look beyond models of storytelling if it is to achieve real and lasting progress.

A key concept running through conversations about the use of involvement processes by social purpose organisations was the idea of 'giving voice' to beneficiaries and communities, and providing the space to allow individuals and communities to tell their 'story'. This chapter will focus closely on the concept of 'storytelling' as a means of giving agency to experts by experience, as many of the contributors considered it to be an approach that was commonly deployed across the social sector.

The power of the 'story' is now well recognised in social change initiatives not only to 'give voice' to communities but more recently as a powerful influencing tool and catalyst for change across the social sector. There is a growing acknowledgement of the political, social and financial capital of storytelling, including an increased recognition across the sector of the prospects of social purpose organisations using storytelling to effectively share their purpose more widely.

As many contributors observed, individuals' stories have helped to start a dialogue with key stakeholders and decision-makers in social change initiatives, be they trustees, board members, funders, investors, commissioners or government officials. They can ignite interest and empathy, and even prompt reflection on how personal lived experiences can drive and influence important dialogues. In several initiatives cited by contributors, the use of voice or storytelling assured experts by experience a seat around the policy table on a local as well as national level.

Several pointed to the growing use of digital platforms. Although recognised by some as an exciting evolution in campaigning and influencing initiatives, others felt that care was needed to ensure that certain communities were not left on the margins because they had little access, capacity or the resources to use this medium for their social purpose work.

Therefore, theoretically, social purpose organisations are using the medium of storytelling to provide agency to those with lived experience to drive social change. Storytelling allows experts by experience to air their lived experiences through an emotional narrative, enables various dimensions of experience to be shared and represented, and can be empowering if done in the right way. It can help experts by experience to own and be the lead actor in their change-making role.

Indeed, as noted by some contributors, storytelling can be a powerful tool for experts by experience on their personal and professional journey as a change-maker.

However, several contributors reflected deeply on the notion of storytelling and some important

- Did social purpose organisations believe that their role in facilitating storytelling alone was enough to give agency to lived experience?
- Is storytelling, as a means to create social change, constraining the value of lived experience in leadership and organisational development?
- Is it limiting opportunities and interventions for social change and/or constraining the capacity and ability of experts by experience to become effective change agents or change-makers?
- Has voice rather than lived expertise taken centre stage?

Arguably, some elements have become stuck on the notion of 'giving voice' to communities, and are no longer making progress in using the knowledge and expertise of communities and experts by experience to effect change more widely.

Some contributors highlighted the commodification of stories by elements of the social sector, reflected by the growing industry focused on branding, marketing and social media initiatives.

"An industry has erupted around this very model of influencing and method of fundraising."

Two contributors observed what could be perceived as a tokenistic search for 'stories' within the sector to fit, suit or complement organisations' internal, external and/or strategic work, with organisations shaping and presenting these stories to help achieve their own aims and objectives – be it for the purposes of research papers, evaluation, emerging policy or consultation responses, campaigning or fundraising efforts. More transparency is needed, as without well-meaning efforts this could reflect negatively on organisations and create scepticism around involvement processes more broadly, including among experts by experience and communities more generally.

The majority of contributors recognised the need to be clear on the varying, and important, dimensions to storytelling and the role it plays in providing agency to lived experience, as well as its impact on the value placed on the change-making and leadership capacities of experts by experience.

8.1 The benefits of storytelling

The strength and impact of 'stories' and 'case studies' is undoubtedly important. Stories can captivate an audience; trigger personal interest and reflection, including on one's own identity and experience; unlock empathy; raise awareness; spread knowledge and educate, as well as change views. This growing social change medium constitutes recognition of the value experts by experience and communities bring to social change initiatives.

The medium of storytelling was recognised by some contributors as an important tool to explore, unpack and understand social issues. It helps communities and experts by experience to convey the realities and varying dimensions of their lives, to be heard, to explain how issues impact their lives and their communities. Equally, it assists communities to understand the value of their voice in

social change initiatives. Three contributors commentated on 'storytelling' as a powerful medium to help experts by experience understand their change-making journeys, own their life stories and build confidence, self-efficacy and self-determination.

Other contributors recognised its power to influence the work of social purpose organisations, including the funding community, helping them to 'feel' or 'connect to' a social issue and/or communities.

> *"Personally, [I think] we need to be closer to the reality of the pain that people feel. Otherwise you are in a sanitised environment – sitting writing cheques to people without understanding the issues."*
>
> *"Funders and senior teams in larger NGOs will sit in their nice offices and can be far removed from the realities of communities and need to be, or feel, closer to the issues."*
>
> *"There's something about a world of data, analysis, evaluation and rationality – people in the workplace miss the human connection. It's a really 'soft' point – people want to connect to other people. Connect with story."*

Three contributors reflected on stories presented by experts by experience at funder-focused initiatives. One contributor co-presented and noted:

> *"[The expert by experience] didn't say anything different from me but it connected in a way that I could never do…[they] spoke from the heart, with passion and enigmatic but [it] was also challenging…very powerful."*
>
> *"When people aren't able to tell their stories and don't get a chance to tell their story we are losing out completely."*

Some contributors recognised the role played by the medium in driving conversations in a particular direction and/or changing the course of pre-existing dialogue on a particular issue. Two contributors highlighted their attempts to engineer activities around storytelling because of its important role in this regard.

In addition to policy and influencing work, further (non-mutually exclusive) uses of storytelling include:

- Deployment as a fundraising tool / a means to generate funds for an organisation or cause / a way to engage supporters / a tick box exercise for funder requirements;
- Service design;
- Giving 'voice' to communities / demonstrating community ownership and leadership;
- Raising awareness of activities and services / changing perceptions and views of social issues and social groups / providing a 'story' for the cause or social purpose organisation to generate engagement among civic society;
- Justifying the services and activities of social purpose organisations, and proving their worth and value;
- Inspiring change more widely, within and outside of particular communities / aiding the work of campaigners and activists;
- Showcasing the role of experts by experience and communities in social change initiatives.

8.2 Limiting and sanitising

However, many contributors explored, and some stressed, concerns about the focus on narratives as a persuasion tool, citing the limitations it places on recognising the overall expertise of communities, the risk of stories becoming 'sanitised' or re-interpreted to suit the audience, the pressures it places on communities and the human consequences of storytelling. Some also questioned its capacity to effect 'real' social change on the ground for communities.

This all leads to the following crucial questions:

- Do personal narratives and stories really change public and political opinion?
- Is there a tendency to focus too much on story in the social sector to the detriment of experts by experience?

Although recognised as important for certain activities and moments in time, including empowerment of experts by experience to lead change with their story, contributors warned against its use where in fact the storyteller becomes the 'subject' of the story for someone's else's agenda.

Contributors felt that there are consequences to the 'chopping' up of stories for the purpose of influencing and fundraising initiatives. Simpler narratives maybe considered easier to understand and absorb by audiences, but they may lead to a loss of deeper meaning and understanding of experiences. Storytelling was seen by some as a specific tool for particular purposes. Three contributors noted:

> *"I think there is a limited impact that stories can have outside of fundraising and influencing work – and if you chop them up – they may not necessarily progress issues."*

> *"The impact in influencing work is important but it might be the newness of it, the initial challenge of it that has impact in a given situation…but they may lose their potency or influencing power. What next?"*

Several contributors, from the UK and US, noted the 'fascination' that some listeners may have with stories – however the fascination with hearing or seeing pain and suffering did not necessarily mean people were moved to act or create change. Two referred to the notion of 'poverty porn'.

> *"People are fascinated – not necessarily moved – by people's pain…it doesn't necessarily shift opinion to activate real change."*

One contributor reflected on their historical work in the field of education with a focus on 'youth voice' and connecting this voice with government officials in order to try and shift culture and effect change. At the time there was high level interest from government to listen, as well as various action plans and funding available. However:

> *"It mainly became a technical exercise – finding ways to connect with young people…it began to decay – people felt that it was a bad transplant or graft into a certain type of institution…It just didn't take."*

Others recognised that although storytelling is an important part of the process of influencing change, it is only that: one part of a process. Several contributors noted that stories may be momentary. The context and background are equally, if not more, important to building up a full understanding of how to identify and create positive social change and drive social innovation.

> *"It brings important insight to the fore but should not simply be a means to give worth or value to a community's cause."*

> *"We need to be careful not to force communities to wash away with the tide of what we need."*

Some contributors explored the limitations of storytelling a little further. Stories can be presented in certain ways to appeal to a particular audience, and be strategically reframed or reinterpreted by social purpose organisations so that experts by experience are pushed to express elements of 'self' in a premeditated way for a specific purpose at a given moment.

One contributor had observed the emergence of sophisticated initiatives focusing on storytelling:

> *"There's a trend at the moment. It's a cliquey thing to do. Clever ways of constructing a narrative to fit around what those in privilege want to hear."*

Whilst another noted:

> *"Is this really about containing communities, making their voice more palatable for us and others in power?"*

Five contributors expressed concern that there were often few routes for unmediated voices to come through. The depth of personal stories, which may include personal and systemic abuses suffered and/or journeys to recovery, could be dismissed, 'cut short' or lost. It was important that individuals had an opportunity to speak their own truth.

Some contributors were concerned about co-option of experts by experience for storytelling purposes alone, and individuals and communities losing control of their voice, message and expertise. Whilst it is certainly important to generate empathy from audiences, care is needed to avoid missing the breadth of wisdom and knowledge available from lived experience:

- Examples of personal successes and triumphs in overcoming challenges and difficulties.
- The manner in which people's lives interact with social and political systems and structures.
- The interconnectedness of social issues, such as the intersections between gender and disability or race and sexuality.

All of these can help to build effective interventions for wider social change beyond the individual.

> *"Stories can be crafted to focus on individual incidents or a group of incidents, but those incidents take place in lives that are governed by social and political systems and structures. The essence and knowledge of those experiences can be lost."*

> *"With the focus on 'story' or 'narrative' alone we are also missing the expertise of communities dealing with complex issues in their lives."*

Contributors also reflected on the potential harm that may be caused by the medium, including perceptions of the 'storyteller' and the impact on the 'storyteller' if that story is devalued, rejected or ignored.

8.3 Perceptions of storytellers

Some contributors noted that by focusing on the value of story we potentially devalue the lived expertise of communities and experts by experience. This focus can cause listeners to doubt whether the storyteller has leadership potential, and whether they are 'professional enough' to lead.

whether the storyteller has leadership potential, and whether they are 'professional enough' to lead. If they are already leading an organisation, it can cause listeners to dismiss them as only a 'charismatic leader', and question whether the work of the organisation is shaped in their image without a wider imprint.

Four contributors observed the social sector's reaction to stories, including the funding community, and they were not always positive. Examples were given of experts by experience telling their story:

"You hear a story being told to people who already have buy in…a risk the story becomes a 'war-story'."

"When you have someone stand up at a conference and they're telling you their story, after 10 / 15 mins you feel like the person needs to be wound up and you can feel the tension in the room."

Contributors also reflected on meetings between experts by experience or 'user-led' organisations with funders and investors. Focusing on story alone did not necessarily hold value as it does in other settings.

"We understand the story and appreciate the cause but what next? How will you create change?"

"[I'm] afraid experience alone does not mean that you can create change. We need to hear more than the story."

"It's interesting…with the emphasis on the 'story' are we unwittingly allowing those with the lived experience to be put in a position where they talk about their story in environments where the emphasis on 'story' is no longer necessary?"

"We can all learn to drive if you teach us when the gears need shifting…but are we helping people to drive?"

Several contributors reflected on their past and current work in the social sector outside of the funding community, witnessing communities trying to get their voices heard inside and outside of the social sector but finding it difficult. Contributors acknowledged that there were many reasons for this, but it is important to note some points raised around the question of voice.

The reality is that change-makers who are outspoken, especially those on the margins, do run the risk of being marginalised within particular forums, since communication is a vital tool for negotiation with and influencing stakeholders and decision-makers.

With storytelling taking centre stage in some social change initiatives, a few contributors questioned whether the need for experts by experience to 'shout out' about their pain and poverty in order to be heard was having a negative and detrimental impact on their role as change-makers:

"The person who cries the loudest and the one who in your world feels the most deserved surely shouldn't be the way we are seeing the world. So many different approaches to human relations – and we need to start to uncover those truths."

"We should not need communities to shout out about their pain and suffering to be heard. It's more about facilitating communication and connection."

8.4 An outlet for frustrations

However, fundamentally people want their voices to be heard. The consequences when voice, message and expertise is not being heard may well include frustration and anger, which may well be considered legitimate. This raises further issues:

- Is the focus of social purpose work aimed at giving voice to communities in fact necessary, or a necessary evil?
- What impact does this approach have for the credibility of experts by experience within parts of the social sector, particularly those parts with power and privilege?
- Do elements of the social sector shy away from the communication style and approaches of particular members of society?

On the whole, contributors struggled with the impact of voice and story. Some felt that visibility is necessary to help experts by experience create change, whilst others felt that this need for visibility was inadvertently being imposed on communities by social purpose organisations. 'Giving voice' and 'storytelling' were clearly seen as important processes in certain settings and for certain purposes, but further discussion revealed negative implications and consequences, including:

- Misgivings about the role and positioning of experts by experience in social change initiatives,
- Concern that 'story' can shape experts by experience, which runs the risk of devaluing their role as experts,
- Fears that stereotypes and stigma may be created or increased, with implications for social change work and the aspirations of experts by experience and communities.

The social sector was commended for understanding the power of storytelling, but at the same time there is an absence of effort to develop this approach into one that values expertise beyond voice.

Some contributors reflected on the hopes of social sector leaders, including their own, for communities to speak out loud about the social distresses they faced. However one noted:

> *"Where is the ceiling for communities? Is it movable? In one sense we want communities to speak out yet in another we shy away if they shout out too much."*

8.5 Going beyond storytelling

Many contributors acknowledged the important role of storytelling in helping communities to explore their role as change-makers, and the fact that some experts by experience had successfully used their lived experience in parallel to their leadership journey within the sector. That said, they felt that social purpose organisations and experts by experience often got caught up in a very narrow view of it all – presuming that voice or story alone would help lead, or activate support for, change.

Many contributors expressed a need for the social sector to move beyond story and shift gears to value expertise rather than story, recognising the importance of lived expertise as an agent for change. By doing so it can open space, and stimulate thought, for effective social change interventions and initiatives that make a real and impactful difference to the lives of communities.

A number of contributors reflected on social purpose organisations or projects actively engaged with, or founded by, experts by experience, and people's own understanding of their lived experience and leadership potential. Some witnessed experts by experience struggling to understand their place and role in the social sector, and reverting to their story which then took prominence and/or precedence in their social change work e.g. 'I am / we are survivors'.

Two contributors observed some excellent work within such organisations, networks and projects, but initiatives became stuck on the concept of storytelling and giving voice as the only medium for change. There was a general frustration that organisations seemed reluctant to move beyond 'voice' and towards ownership and leadership of initiatives or tackling the heart of social issues.

One contributor reflected on a project with great leadership potential, including staff with the skills and qualities to lead on wider change, and struggled to understand why the project could not move on from 'storytelling':

> *"I wonder now whether more should have been done to support them through this change and the role we could have played in supporting and enhancing their leadership."*

Two contributors reflected on the understanding of experts by experience, who are often aware that the wider social sector only values their 'voice' and so are inhibited and forced to stagnate:

> *"[It's a] self-fulfilling prophecy that the story has got them so far. Then that's it. They could not see beyond that and their wider role in the social sector."*

Another contributor commented:

> *"It's exciting when you hear smaller organisations share the expertise of their communities and service users, and as soon as you think discussions are moving towards leading change and leadership they move back to storytelling. It's frustrating. How do we begin to move that towards leadership and ownership of the work and change communities want to see and do?"*

Another contributor reflected on the role of social purpose organisations in shaping the understanding of experts by experience:

> *"[Experts by experience] are allowed to have their views and they're allowed to be engaged but only within distinct parameters around the organisation, the services it delivers and the messages it wants to deliver."*

Contributors also explored the further implications and consequences of letting 'voice' take centre-stage in involvement processes and change initiatives. Some provided examples of how social purpose organisations which address drug addiction, sexual abuse, domestic violence, race inequality and mental health often end up hitting a barrier, with voice taking over to the detriment of other approaches. This can be quite damaging to the image of the organisation and/or the people leading them who are for example 'not seen as professional enough'. Efforts may be made by organisations to assist in the participation of others with lived experience through volunteering, mentoring and peer-to-peer opportunities, but without a sense of these activities ever becoming part of a larger movement for change.

There was widespread acknowledgement that the value of experts by experience as change-makers is in much more than their story. Indeed, some may not wish to share their story, and yet in the current landscape of involvement processes, they may believe that this is the only means to effect change and/or be a change-maker. Some are held back by stigma and shame.

Storytelling can also be harmful, triggering trauma, destabilising recovery or raising self-doubt, insecurity or even resentment and anger. The human consequences and implications of storytelling therefore also require careful and sensitive consideration.

Contributors who actively work alongside initiatives that provide agency to lived experience described 'ownership' and recognising the value of one's own story as an incredibly important phase for experts by experience to make the move to change-maker: for example individuals in recovery, including owning their recovery, and those suffering multiple disadvantage or bereavement recognising the impact this has had on their lives. Benefits of effective involvement processes have been highlighted at Chapter 4 (see above at 4.2), including increased self-respect, confidence and self-esteem.

Contributors highlighted the importance of involvement processes moving away from story and ensuring people were not defined by their story:

> *"Whichever way you come at it there is a phase of being able to own your story. For some it is trying not to go back into it and live that story again…one of the pillars of good support that come out from our work."*

> *"There is a danger that you tell your story so many times that you become no more value than just your own story – the only value you have of self, or the only value you believe others have of you…You are the story and nothing more."*

Contributors stressed the need for involvement processes to help build skills around activities that explore voice. 'Giving voice' is a process that requires systems of support and practice in order to develop over time, and it is hard work. One contributor observed that elements of the women's and girls' sector have worked hard in this area over the last decade, reflecting on organisations and projects which work to address violence and abuse. However, these practices do not cut across the wider social sector or even beyond specific projects within those organisations.

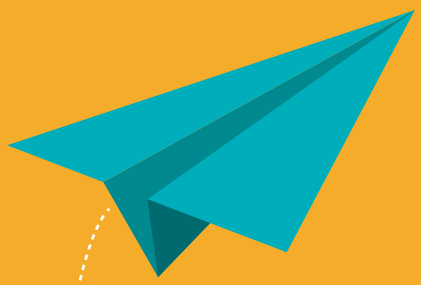
Four contributors reflected on funding applications they had turned down that focused solely on storytelling. One contributor also commented on well-meaning social entrepreneurs who try to create enterprises to help facilitate and/or give agency to the voice of communities:

> *"Storytelling in and of itself is not the whole picture when considering social change initiatives; it is part of a process of change."*

Self-determination, independence of thought and choice were raised as issues, allowing those with lived experience the chance to determine their destiny in the social change arena. At the very least, involvement processes should help to facilitate meaningful opportunities for experts by experience who want to be active change-makers. Two contributors felt that placing communities at the centre of social change initiatives was a start, and could help remove barriers to members of communities engaging with social change activities. As two contributors noted:

> *"We often talk about hard to reach communities – are they always hard to reach or is it that we simply aren't extending our hand far enough for them to participate in the work that we do?"*

> *"Communities will be hard to reach if the communication barriers between them and the social sector have broken down."*



PART 3

THE NEED FOR ORGANISATIONAL AND LEADERSHIP DEVELOPMENT AND THE WAY FORWARD

9. The Need for Organisational and Leadership Development

Key Points

- There has been a widespread failure in the social sector to engage experts by experience in social purpose organisations.
- There is a tendency to push experts by experience into voluntary roles, and not to acknowledge the financial value of their expertise.
- At the same time, experts by experience are put off by the lack of paid opportunities and a focus on learned expertise over experience.
- Even where experts by experience are welcomed into frontline roles, they often find it difficult to get promoted as they are considered invaluable where they are.
- Organisations need to critically examine their own practices and develop strategies to include experts by experience and communities at all levels.
- Funding bodies need to involve experts by experience in designing funding programmes, and should encourage collaboration between larger and smaller organisations working in the same area.

Contributors unanimously agreed that there is a need for the wider sector to revisit, reboot and reimagine its structures and practices to better support the meaningful agency of the lived experience in social change work. They agreed that for far too long, the wider sector has been 'turning the spotlight' on the communities we serve rather than exploring how we can create positive steps in this field.

Eight contributors felt there was a need for wholesale change in the way social purpose organisations work, starting with a full examination of why and how they do the work they do, identifying what is missing, and going on to build mechanisms by which organisations can hold themselves and others to account.

> *"What we need is radical unlearning of the status quo and the way charities have traditionally operated. This should not be too difficult if we are all singing from the same hymn sheet…involving communities to help lead sustainable social change."*

> *"We need to not create a blaming culture, but think through how we can collectively start to change the way we do our work."*

Several contributors called for a fundamental shift in the structures of social purpose organisations across the sector, including investors, funders and the public sector, to harness the active involvement of people and communities with lived experience in all social purpose work. It would ultimately give the wider sector a better chance of creating sustainable social change if work was embedded within the communities it serves. For most, this would yield long-term value for all key stakeholders, including governments and civic society as a whole. Others believed that the social impact could be transformational as well as sustainable in the long run.

Crucial to achieving this is the role of institutional commitment and support. Contributors commented on the importance of engaging experts by experience, as organisation staff, trustees and board members, including within funding and investment bodies, in order to benefit the social sector as a whole as well as the broader social change movement. A key theme that permeated through contributors' discussions is the need for organisational and leadership development in this respect, across the sector.

Contributors working with programmes which provide meaningful agency to lived experience deliberated on the need for the funding community and the wider social sector to also revisit and 'radically rethink' its approach to initiatives led by communities and experts by experience. It was also thought important to consider the political, social and economic context for their work and the wider context of the communities they serve.

Contributors agreed that this work could be extremely challenging, as little cross-sector work has been done previously, and it requires social purpose organisations to focus on issues outside of their primary activities. Structural critiques of systems will be needed. Unique management and governance structures may be required where traditional governance structures create barriers for change.

> *"It will be messy and scary to think through if you haven't done anything like this before…ultimately its vital to everything we do."*

> *"I think everyone is doing their best in their area of work, but actually we're nowhere near to what we need to be doing as a sector to recognise and build leadership within communities – many organisations don't understand what we need to do, their role…and where to even begin."*

Some were concerned that the failure to address this vitally underdeveloped work showed how explicit and implicit biases across the sector prop up social and economic inequality:

> *"Do we not have a broader responsibility in creating change that is equitable?"*

> *"How do those who have suffered inequality become the drivers for change if they don't have a look in to leadership and then in turn have ownership…across the board – mental health, poverty, disability, race?"*

> *"We have to focus on improving our practices…we need to find approaches that secure people's social and cultural progress…also their economic development."*

9.1 Practices of social purpose organisations

Most contributors felt that social purpose organisations across the social sector, particularly larger organisations, generally fail to consider the meaningful role experts by experience and communities could and should play in leading positive social change. Even where efforts were pursued, they were felt either 'insincere' or lacking a meaningful understanding of the wider value and role of experts by experience. Further still, many organisations fail to consider the role they should be playing in promoting leaders of change who have lived experience within their field or indeed on behalf of the wider social sector.

Several contributors felt strongly that organisational approaches needed to move away from an approach focusing on the 'voice' of 'beneficiaries' and communities and towards a meaningful appreciation of 'lived expertise' and 'leadership', facilitating individuals and communities who are

seeking to use their lived experience to create positive social change. This means a shift from traditional involvement processes such as community and service-user participation and consultation towards an approach of seeing people and communities as active change agents and leaders of change.

One contributor recalled an incident during a consultation meeting where a group of voluntary sector organisations were asked to explain how they would involve service-users or communities affected by the social issues they were seeking to tackle:

> *"There was a tumbleweed moment. Frustrated by the lack of engagement I said 'I don't know how we're going to do this and you're going to have to help me,' but I realised that many simply didn't know how."*

Contributors also reflected on the organisational development of funders and investors. They critiqued their role and that of the wider funding community by reflecting on its historical attempts to promote community involvement in social change initiatives and build capacity for change within the sector.

Several contributors reflected on national funding initiatives, including asset-based community development approaches aimed at bringing communities together to use their lived experiences and knowledge to inform the distribution of funds within communities. Many felt that such initiatives had failed to achieve their full aspirations, highlighting the need for reflection and development in this area within the funding sector.

> *"Over the last ten years we've seen initiatives trying to create people-powered change, but in reality is that the case? Have we achieved that?…I don't think so…again I think the procedures and protocols of organisations don't allow for real community-led initiatives."*

> *"I believe some of these initiatives were missing a deep-rooted rationale for providing true agency to those with the lived experience."*

Two contributors provided their observations as volunteers supporting community organisations which apply under such initiatives:

> *"I think the concept was supposed to be about the lived experience – people coming up with the solutions…but I know from my role as a volunteer that those I worked with from truly user-led community groups – yes slightly chaotic but embedded within communities – rarely got through to the next stage."*

> *"I was working with grass roots organisations to help them apply for funds under a programme promoting community-led organisations. I sought clarification from the funder…I didn't even understand the programme's aims…! The rationale lacked coherence and was confusing."*

Barriers to success were also explored, including the use of external experts, a lack of clarity around purpose, the fact that agencies appointed to broker relationships with communities often lack community connections, and a lack of meaningful involvement processes and decision-making powers for communities.

Contributors also noted that it was time to get organisations to 'practice what they preach' and seriously consider the progression routes into paid opportunities for experts by experience within social purpose organisations, beyond involvement in unpaid roles such as volunteering and trusteeships. They cited the need for more sophisticated and innovative steps to inform and build organisational capacity, and leadership pathways for experts by experience.

"We need to radically rethink and reimagine work within and beyond our organisations…the incentive for change in my mind is clear."

"We need to move away from theory and intention towards reform, structure and practice…I think we have an ethical imperative."

Three of the contributors recognised that social purpose organisations are dealing with different social issues, and increasingly a combination of issues. They appreciated that needs and aims of organisations may vary e.g. those tackling environmental issues such as climate change and waste; care services, support and research for cancer patients; organisations tackling social injustices and inequalities for particular social groups. However, for some making these distinctions was often a distraction, and indeed eight contributors robustly argued that they could not see an area or field which did not, or should not, be involving people and communities with lived experience of the issues they seek to tackle.

One contributor commented on a leading tech company which was involved in a piece of their work and their fundamental focus on customer and user experience approaches in the work that they do:

"[Tech company] did some work where they mapped out users' journeys and some of the users went along and it was really interesting…they said they would never develop something without the involvement of their users…of course, designing an app for users is one thing but should we not be applying the same fundamentals to what we do in our work across charities.

9.2 The need for transparency and accountability

The one thing that unites the social sector is its bold assertion that we all, in our different and unique ways, are working for the benefit of civic society. Many believe that such bold assertions should not be taken for granted and those purporting to serve society should be held accountable.

"What if we and our grantees are wholly detached from our intended beneficiaries?"

"I think the funding sector is also behind the game in terms of accountability…we need to be accountable to the people we are supposed to be benefitting, those who are facing disadvantage, you're working to benefit them…so what is your obligation to them?"

Crucially, and in light of the significant findings in Chapter 5 about concerns over the nature of the majority of involvement processes being deployed by the wider sector, contributors unanimously agreed that accountability and transparency of activities and processes was an important factor to meaningfully engage with and retain the involvement of experts by experience.

Many emphasised the need for the development of internal monitoring systems to hold organisations to account in terms of their involvement of experts by experience in their activities and recruitment practices, which for many are likely to be non-existent.

"We are not talking about accountability…there is something very uncomfortable about the people we serve being accountable to us and the services that we provide which is then measured and considered by us…funders."

Credible, workable accountability systems need to be promoted, and for systems and policies to be effective they must be supported 'from the top down' within governance structures and promoted throughout organisations – through to frontline staff.

"We need to make changes to the governance systems not only so that our work is robust and resilient but so that it is representative of and includes the insights and expertise of all our communities."

Contributors observed a significant weakness in the current activities of the wider sector, which were for many insufficient. They have little or no scope for participation, let alone meaningful involvement of the communities they served, and without accountability or transparency it would be difficult to take this work forward. This has likely been the case over the last several decades and a reason why the sector has not developed or progressed in the way it should.

"We need to measure ourselves each year against a set of simple standards – create something that provides me with an opportunity to think through how I can create a level of accountability for our work and hold our grantees up to those same values."

Three contributors commented on the need for greater transparency and sincerity, and the importance of funders, investors and social purpose organisations crediting the efforts, ideas and successes of experts by experience. Transparency in all organisations, across the wider social sector, was considered crucial to building understanding, knowledge and most of all trust.

"We need to do a big piece on transparency within the sector…clear the mist."

"Let's also move towards understanding the role of funders and a framework for accountability."

Some contributors also expressed concern over the 'invisibility' of the impact that meaningful engagement can have on the wider work of social purpose organisations, and emphasised the need to celebrate and raise awareness of initiatives and the depth of the change-making capacity of experts by experience. This would help with universal adoption and commitment across the sector, particularly where social purpose organisations are 'not in the game of service delivery'

"A large charity in one of our programmes is doing some good work…working really closely with experts by experience and creating interesting initiatives to improve policies as well as services…internally all the staff use the term 'expert by experience' but externally they still refer to 'user-involvement'."

During deliberations contributors identified a vast array of involvement processes that seek to give agency to experts by experience as highlighted in Chapter 5. These processes take many forms. They may be 'traditional' e.g. consultations; peer-to-peer volunteering or employment initiatives e.g. support or research; or organisations led by experts by experience e.g. user-led or community-led organisations. Those actively working alongside initiatives also identified that a layering of involvement can occur. This plurality can sometimes confuse and mask meaningful engagement and involvement of experts by experience, and give the impression that overall the sector is engaging with them yet in fact it is not benefitting from the full value lived expertise can bring.

Transparency in this field was therefore considered key by many of the contributors e.g. whilst an organisation may profess to be user-led or user-focused, on further inspection they may engage experts by experience through traditional consultation processes but share little decision-making power or fail to include experts by experience in governance structures.

"When I have worked with experts by experience I have witnessed first-hand the ideas and solutions they come up with…but are charities crediting those with lived experience with ideas? I'm not sure they necessarily are."

"[funding lead] visited a group of smaller funders who actively and proudly support community organisations…as we do not often get out into the communities…turned to them…in hope they would know more than us as a large funder…but none of them had anything different or new to add."

Many deliberated on the overall 'value' placed on lived experience throughout such processes, and concerns were raised around the broader treatment of experts by experience as change-agents and leaders of change. This was borne out by examples of barriers and concerns raised in Part 6 of the report, whereby contributors interrogated the barriers and challenges faced by experts by experience across the sector and involvement processes, fluctuating between the varying involvement processes.

"We need to make changes to the governance systems…not only so that our work is robust and resilient but so that it is representative of and includes the insights and expertise of all our communities".

9.3 Equity and inclusivity of opportunity

Throughout deliberations contributors heavily criticised the extent to which experts by experience are equitably included in social purpose work. They questioned the equitable and collaborative nature of relationships between them and social purpose organisations, from initial engagement and involvement, including the need for information, clarity and purpose, through to power in influencing decisions, practices and policies. For contributors, this debate was not merely about access and participation but about meaningful – and equitable - involvement in the work of social purpose organisations across the board.

Some contributors persuasively argued that without addressing the equitable inclusion of people and communities with lived experience in our work, we also run the risk of vital social and financial capital being redirected towards activities and initiatives that may provide limited or temporary positive social impact, however well-meaning and 'technically' thought-through they are. This could reduce inappropriate or unworkable solutions, free up resources and save costs in the long run.

Some of the contributors emphasised the need to interrogate current involvement processes to better understand whether they meaningfully and equitably engaged experts by experience, involving them directly and/or providing further opportunities within their operations and activities.

"The time of saviour and back-patting philanthropy, charity and service is surely something of the past."

This all raises a number of further questions to be considered by social purpose organisations:

- Are we actively engaging individuals and communities with lived experience?
- Is lived experience being valued and celebrated in our organisation?
- Are we recruiting experts by experience? Or are we creating an environment that ignores, overlooks or disengages from them?
- Are we harnessing the capacity of experts by experience to create and lead change beyond traditional involvement processes? Are we appreciating their uniqueness, autonomy, authenticity and self-determination?
- Are we supporting and enhancing the capabilities, strengths and development needs of experts by experience?
- Are we creating pathways to leadership for experts by experience?

As one contributed aptly pointed out

"A person can only pursue a dream or passion if they know it exists."

These issues were heavily interrogated throughout, and some further issues considered that have not been covered in previous chapters.

9.3.1 Social and economic equity and opportunity

For many of the contributors, creating pathways for experts by experience to get recruited was important. As noted earlier, what was aptly pointed out by several contributors, and which silenced those who had not given it prior thought, was the realisation that there was little, if any, 'economic value' placed on the expertise of those with lived experience. As cited in Chapter 7, it was not uncommon for experts by experience to be unpaid for their time in social change work and the practices of social purpose organisations, including their own, were heavily crticised.

Contributors also highlighted the fact that individuals from 'disadvantaged' or 'underserved' communities or those with little financial or social capital have very little access to opportunities within the social sector. The painful realities for some are the economic and social disadvantages they have or continue to face. Although vital for the social sector, unpaid volunteering, trusteeships and board memberships simply are not an option for some, and many experts by experience may be unable to benefit from internships, volunteering or 'international development opportunities'.

"We must address this inexcusable inequity."

"The sector needs to crank itself around a bit…what's happening to lead organisations that have been there for years and years with settled staff?"

"We need to help build the skills of communities so they can take control of their communities and their own lives…we're going to continue seeing cycles where communities are never moving forward...and disengaging."

"Building economic opportunities within communities will have direct social impact and help influence all our work."

Exploring the critiques of their own recruitment practices a little further. Although a few highlighted gentle shifts in the recruitment processes for grant-makers within their own organisations, the higher up the governance or 'command' chain the more noticeable the absence of experts by experience.

One contributor reflected on recent shifts in their equality and diversity mechanisms and audits, whereby staff and trustees were asked to self-define and to comment confidentially on their lived experience of the issues the organisation tackled. Another highlighted a concerted effort by some in the funding community to recruit trustees with lived experience, although this was admittedly rare. However, through personal experiences and observations of the wider funding community, contributors did not feel it was a priority for many colleagues in the funding sector and glaring shortage of experts by experience within the funding community was stark. This was particularly apparent within the work of private foundations and trusts, which many felt simply operate and develop their personnel in a way that actively marginalises or prohibits experts by experience from entering their fold.

"There are people from working class backgrounds working in the field of philanthropy but it is not common."

Several concerns were raised by contributors over the current equality and diversity monitoring mechanisms that are obligatory for all employers to adhere to. Although beyond the remit of this paper, it is worth noting that five contributors were particularly concerned about the lack of employees from lower socio-economic status, as this was not a protected characteristic under UK equalities legislations. It is also worth noting that US contributors felt similarly about the US funding community. Even where attempts are made to actively create leadership channels for particular social groups, they are not always reflective of all the communities: intersections between race and class/socio-economic status were given as an example. Many struggled with the concept.

> *"Inability to recognise the full layers and merits of diversity has become part of the problem."*

There was a general consensus that much more could be done within the funding community, not only in terms of internal processes but also recognition that their organisations as funding bodies are responsible for developing and encouraging the work of social purpose organisations in this area. For some they felt it was their role to lead the way.

> *"People from poorer backgrounds are likely to have lived experiences of a social issue or be closely connected…poverty being one…yet the higher up the command chain in the social sector the less people you meet from working class backgrounds."*

> *"[We need] to allocate time or resources…to give money and value to someone's lived experience by understanding how they can contribute to our work and aligning it with their work responsibilities."*

Returning to wider sector practices, for several contributors, the continued overreliance on honorary, academic and educational attainment, arguably unavailable to those with the specific lived experience particularly if connected to poverty, creates barriers to equitable involvement and leadership for experts by experience – even where certain social sector professions may not necessarily require them in practice.

As was explored in some depth in Chapter 7 (see above at 7.5) some contributors emphasised that meritocracy and over-professionalising of social purpose work can directly or inadvertently marginalise the very people and communities we seek to serve, and in the minds of four contributors it could prove harmful to the meaningful and equitable involvement and inclusion of experts by experience in our operations.

One contributor observed that there is a 'changing face' to the social sector more widely, whereby change makers entering the social sector are increasingly from privileged backgrounds, and benefit from opportunities due to their background, the university they went to and who they know. Whereas previously change makers from less privileged backgrounds may have had routes into the social sector through other routes e.g. as youth workers, community development officers or support staff, these opportunities are now also highly sought after among those with higher socio-economic status, particularly in some areas of the UK. The current economic climate and decrease in wider opportunities available across the sector were cited as possible reasons.

At the same time, financing may be more readily available to people with existing resources, and opportunities may be more available to those able to invest time for free.

> *"It's kind of the course…easier to set up a social business or social enterprise if you have money behind you or to set up – where people get money from to help them set up."*

> *"Internships can create routes to the job market across sectors e.g. if you want to work in the media you're now expected to do unpaid work – all very well – but there are many who simply cannot."*

While recognising that the social sector is arguably a saturated one in a competitive NGO sector, some agreed that it is too often left to individuals to try to penetrate the sector alone, often with little guidance, support and access to networks that help. Overall, organisations were failing to identify or build opportunities for experts by experience.

> *"We pay lip service to creating 'people powered' organisations – those who face social inequality and seek to serve in a cause they have lived experience of have very little look in to leadership positions."*
>
> *"Yet they can't often be equal or economic actors in the causes that they want to drive."*
>
> *"We want people to take ownership of their communities but at the same time we are not helping to think through how we make that happen, that is viable for them."*
>
> *"Are we setting up people to fail? If there are no sustainable opportunities for them to enter paid work in the social sector and no mechanism for which they can begin a trajectory towards leadership positions."*

There is a need to revisit traditional methods of recruitment, which may explicitly or inadvertently exclude experts by experience from the social sector. There was recognition that in some positions technical skill and expertise was needed, but equally the sector needs to be honest about the way some positions are filled, with connections and networks, for example, often serving as a tipping point for selection. The increased use of 'head hunters' and recruitment agencies by many elements of the social sector was also commented on. It therefore becomes important in certain cases to examine, break and reformulate these networks.

> *"By and large most individuals in leadership positions are hired because they are known or form part of a network."*
>
> *"And the next thing is that much of our sector is perpetuated off of networks – informal networks."*
>
> *"Living wage employers – we now all think that everybody should afford to live and we now value the need to meet those costs for individuals – should it not be the same when we are relying on 'expertise' whatever form it takes?"*
>
> *"Let's start looking at models where people are financially and economically or at least, at the very least, identified, respected and valued for the expertise they bring."*

For many, not addressing the 'inexcusable inequity' represents a serious moral and ethical injustice that may harm the impact of social purpose work and leave communities open to be being reduced to being mere by-standers to the work that we do rather seen as holding vital social capital. The following questions can be formulated:

- Would addressing these social inequalities not be relevant considerations when considering leadership opportunities for experts by experience within our sector?
- Do we truly want to pit young against old, the able-bodied against the disabled, the invested against the disenfranchised in our practices?
- Do we not have a moral and ethical responsibility to eliminate the unequal opportunities frequently created by economic injustices in mainstream society?
- Do we not want to be leading the way in addressing this disparity in order to strengthen the change making powers of all our communities?

9.3.2 Accessibility and routes to leadership

Accessibility of leadership positions for experts by experience played heavily on the minds of several contributors. Some reflected on the emergence of small organisations and charities in areas where communities felt less able to enter larger organisations. A major concern with this approach in the long term was its sustainability while funding continues to be restricted.

9.3.3 Current leadership programmes

Contributors noted that there has been a growing focus within the sector on developing charity leaders. Some felt that these opportunities were aimed at specific groups, with a focus on 'emerging leaders': either individuals who have already been pre-identified within the sector, having held positions of responsibility, or talented graduates. Many such programmes were explicitly aimed at young people, 'millennials' and 'future leaders'. There were also 'elite' leadership schemes for older people, targeted towards city professionals who aspired to become change-makers. Accessing a high-quality graduate training scheme is an increasingly important step in a career trajectory. However, in the minds of many contributors, leadership cuts across sectors, race, disability, health, housing status and age, but such opportunities were rarely, if at all, available across those categories.

Contributors explored the growth of leadership programmes for young people, particularly in the youth sector, in a little more detail. One mentioned an enterprise programme focussing on the 'commodity' of youth leadership. While the emergence of standalone youth leadership programmes, and some embedded in existing organisations, was considered deeply encouraging, contributors expressed concern that the purpose of this focus on 'leadership' in the youth sector was unclear: whether it genuinely focused on young people 'leading their lives' or their progress within the sector, and whether young people themselves are inspiring and driving this agenda or whether this is just a funder-led initiative to try to identify and build leaders early on for the next generation.

Some contributors also felt it was easy to focus on emerging and future leaders as it was more palatable than other elements of society e.g. ex-offenders, homelessness.

> *"It makes sense about focusing on the next generation who are fundamentally different than yourself…Rather than saying you are fundamentally different from people right now."*
>
> *"It's not simply about generation; it's about race, class, gender…"*
>
> *"It's about where you are right now. And that can be much harder to understand."*

Contributors commented on the deficit of any robust mechanism to help members of communities with lived experience into leadership positions across the wider social sector.

> *"What about those who have lived experience, if you don't fall into either of these categories?...And yet I'm driving leaders for the future. This cuts across race, disability, health, homelessness, and all other types of social sector."*
>
> *"How do we make sure there is diversity?…If you focus on existing leaders and leaders of the future – you might be missing a whole pool of people who could be excellent leaders now and in the future but don't get a look in."*

9.3.4 Sector-wide access and routes to leadership

Other contributors explored the lack of specific channels or pipelines for experts by experience, and considered how to create spaces or enter communities to help identify and devise routes to leadership. One contributor highlighted that they had made several efforts to fund 'intermediaries' to identify, engage and support change makers from wider communities. Others highlighted a number of innovative initiatives set up to identify and reach out to change-makers from a host of different communities. However, contributors found that the same individuals ended up 'doing the circuit', and that often the only people reached were those 'in the know', who were already part of relevant networks. Otherwise, these schemes mainly attracting graduates with honours and degrees.

A few contributors also discussed the way that the sector could inhibit leadership progression for experts by experience who were involved at a lower level, due to the need to keep them on as frontline practitioners. Their enhanced ability to communicate with, work with and support communities was invaluable to the organisation, and their loss would impact its workings. One contributor explained that this was apparent in the youth sector where youth workers with learned, as well as lived, experience did exceptionally well at their work but found it difficult to progress up the ladder despite clear leadership aspirations. One contributor felt that this could be said about any frontline organisation dealing with social issues in which service-users required extensive support (e.g. homelessness and youth sectors).

There was a level of disagreement on the topic. One contributor commented that although leadership towards the 'top' may prove difficult, these sectors were making efforts to recruit, train and employ those with lived experience who were previously NEET (not in education or employment). However, another felt that the make-up of the sector was changing due to constraints in funding, which meant that graduates were entering professions at a lower level than previously, and so opportunities for experts by experience or communities had diminished.

> *"If you could get in as a youth worker or community organiser before and then work your way up, may actually not be so readily available as it once was before."*

A few contributors queried whether it was really their role to provide opportunities for leadership, as 'career development' was not a priority or focus of their programmes. However other contributors were determined that funders have a clear responsibility to help build and/or sustain leadership, as a crucial component of enabling communities to lead their own lives, get the change they wanted to see and build community action. They felt that the two could not be divorced.

> *"What are we doing in terms of thinking through leadership of those with the lived experience and equalities in this area as we say it's important – rather than just generic leadership programmes for existing people, which will churn out the same type of leaders."*

Two contributors considered the need for bespoke programmes for leaders with lived expertise, to address the support needed to help prevent 'burn out' and the training and support needs that may not be considered vital for 'emerging leaders' such as finance and business courses. Contributors agreed there was no quick fix answer such as training or mentoring programmes, but much research was needed in an area so underdeveloped. Several contributors added that with some targeted work to scope this may also help alleviate anxieties in the sector and spark attitudinal change across the sector more broadly.

9.4 Shifting organisational cultures, attitudes and practices

In the opinion of many contributors, the availability of decision-making, leadership, employment and training opportunities for people with lived experience largely depends on the value social purpose organisations place on their communities and on experts by experience as change makers.

Contributors agreed that understanding and appreciating the value of lived experience as a change-making capacity was a first step towards changing institutional and organisational culture in this field. This means shifting or moving the debate from 'participation' towards 'expertise'. Only then can we begin to support and create meaningful opportunities for communities and experts by experience.

Some contributors felt that for far too long the focus has been on seeing people and communities with lived experience as services-users, customers or beneficiaries. They felt that what was needed was a move towards organisations increasing their levels of awareness and acceptance of the value and benefit of having experts by experience within their governance, staffing and leadership. This means not simply focusing on the liabilities, but the capabilities of experts by experience. It means pushing and helping organisations, including funders and government agencies, to commit to changing their approaches and practices.

Social purpose organisations, including funders and investors, need to reflect on and evaluate their current role in giving agency to those with lived expertise, as well as their personal and organisational experiences and the presumptions and barriers to entry as discussed heavily in Chapter 8. They need to sweep away any stigmas, biases, be they implicit or unconcius, and prejudices which may exist internally and externally in their field of work.

> *"Do we not have a broader responsibility in creating change that is equitable? If so, we need to explore the hidden biases and prejudices that are propping up all and any forms of inequality."*
>
> *"Until we allow time for reflection, it will be difficult for us to expect those same institutions to come on board with more radical ideas of leadership that go with the lived experience."*
>
> *"People may feel threatened or fear people coming in and telling them what they're doing is wrong. They probably will. We don't always get it right. The problem is to continue doing things wrong and continue to do things in ways that aren't effective and not helpful."*

9.5 Research and shared learning

As we have seen in Chapter 5, the findings highlight that currently approaches seeking to meaningfully provide agency to lived experience are fragmented and scattered. The contributors expressed the need for a sector-wide approach to developing the understanding and practices of social purpose organisations, including funders and investors.

There is also a need to better understand what 'good' and 'effective' approaches look like. Only then did they feel can we move towards understanding how to encourage sector-wide adoption and then eventually measure outcomes of success, which arguably is not as easy to achieve.

> *"It's about increasing awareness within, and acceptance by, organisations because I think organisations see it as a threat rather than a gain."*
>
> *"What we're doing is focussing on the benefits of involving experts by experience and that's important but we also need to expand that…How do we get others in the social sector to listen and get them to commit to it and to help change their approaches, their policies and commissioning practices?"*
>
> *"If people know what is already happening out there they may be less baffled with it all."*

Some contributors noted connected areas of research, available in the UK, which are worth exploring as a starting point:

1. Evaluation reports on beneficiary and service-user involvement[18] (although admittedly this research is largely fragmented and disparate);

2. Historical and emerging service-user / survivor and expert networks, which facilitate links between user groups and individuals with lived experience, broker connections with policymakers, commission research, manage peer support initiatives and provide training in organisational skills, campaigning and leadership; [19]

3. Leadership, fellowship and apprentice programmes and initiatives across the wider sector; [20]

4. Co-commissioning and co-production projects are increasing and there is likely to be a vast array of learning there.

5. Peer-led / peer-to-peer initiatives

Several commented on the lack of any historical or present research on 'lived experience' leaders – moving away from 'participant' towards expertise and leadership. Two contributors felt there was likely historical research in the mental health, health and social care sectors on building the leadership of employees with lived experience.

Several commented on the need for research exploring whether and to what extent social purpose organisations are currently using their resources in the most effective way, and assessing the costs and benefits of involving experts by experience and communities in their work.

"How can they be doing that if those who are most impacted – with lived experiences – are not the anchor component of the solution? Why would you waste resources without first knowing what would work or what is needed?"

"How do we make best of limited resources for highest social impact? Not having communities anchored in creating the solutions and services needed to address social distress is not a good use of resources."

"It's only when we start altering the theory of money that we will begin to change the practice of where the money is going…start to value the money you are giving out not only as a means of building community involvement but a truly 'expert' quality that is being funded."

[18] Making Every Adult Matter (MEAM).
http://www.shapingourlives.org.uk/resources/our-resources/all-publications/beyond-the-usual-suspects
[19] The National Survivor User Network (NSUN) is an organisation led by users of mental health services, which was established in 2007 following the recommendations of the 'On Our Own Terms' report (Wallcraft et al 2003).
[20] Launch 22, a business incubator supported by Catch 22 for less advantaged and underrepresented entrepreneurs of the future.
https://www.catch-22.org.uk/collaborate/current-collaboration/launch22/ - leadership programmes in the health and social care sector

10. Developing organisational practices

Key Points

- There are many ways in which social purpose organisations can develop their practices to support and empower experts by experience in their work.
- Shifts in the language used to describe experts by experience can change attitudes and help to shift practices.
- It is vital to include experts by experience throughout programmes, from planning stages through to evaluation.
- There is no substitute for visiting, meeting with and talking to people and communities with lived experience.
- More needs to be done to highlight the contributions of experts by experience to social purpose work.
- Organisations need to reassess their practices from the ground up, to put experts by experience at the heart of everything they do.
- They should also pay experts by experience for the contributions, to avoid turning away the most disadvantaged communities.
- Funders and organisations need to establish paths to and support for leadership of experts by experience.

Contributors recognised the realities of the varying and diverse practices, structures and environments of the social sector, but shared some insightful and powerful examples of existing and emerging practices from their own work and that of social purpose organisations. The following chapter will share some of these examples with a view to aiding the work of the wider sector. However, contributors stressed that their knowledge was only of the work they were aware of, that there is a need to explore good work happening in other elements of the sector and that they were also keen to learn from others.

Some contributors also stressed the need for constant evolution in practices: given the constantly changing landscape of the social sector, along with government policies, funding, laws and practices, contribution and consultation can easily become more of a process than a project. They stressed that involvement processes should not be one-off events but ongoing, continual and requiring constant review and attention.

> *"As we evolve, society evolves…our works evolves…since we have been working more closely with experts by experience my work has evolved rapidly…revealing new things…resulting in new initiatives and action…sometimes it is messy but the outcomes are powerful and very effective on a national as well as local level."*

10.1 Rebalancing our social change equilibrium

Some of the contributors confirmed that they had started to grapple with questions around their own funding processes and whether the manner in which they operate is 'propping up', driving or feeding into social inequality.

> *"We decided to reject social constructs that do not serve us."*

> *"We need to evaluate and restore the equilibrium of power between us and experts by experience."*

"If we wanted to speak out on behalf of the disadvantaged communities, about equity and about access to opportunity then we also needed to put our money into real practice…learn, understand and connect with the very people we are serving."

One contributor from the US noted the following in their programme to actively support leaders with lived experience and community-led organisations:

"We know, and have always known as a society, that there are leaders within our communities. If you start with that presumption then the next step is…how you support those individuals and communities."

Another referenced a historical disability rights programme their organisation funded:

"We established a funding programme for disability rights…we specified that an organisation must be a user-led organisation at governance level – from top to bottom…it was very brave at the time…it ruled out big nationals…we made clear that they could work with user-led charities."

Two UK funders and both US funders stressed that their organisations had made a conscious and meaningful decision to address 'power' in their approach and embed this in their funding portfolio.

"The intent to do it may be well-meaning, but if you do nothing in practice…your own practice…then you have little impact."

"The impact of not doing anything is to reinforce the disparities."

Several contributors agreed that as a social sector we continue to move towards understanding social constructs within society, some of us more quickly than others, but as two contributors noted:

"We have to understand the role of social purpose work to create social good for society…social good means addressing the social harms."

"We wanted to create social impact that is sustainable and transformational…tackling social inequality and social injustices formed part of that intent…we have done it visibly, some of it indirectly but it cuts across all of our work…when you do that…you have to think about not only including and involving but also funding the very people you have decided to serve."

Two contributors from the US and one from the UK confirmed that they were tackling social inequality more broadly, targeting 'the root causes' with a very systemic structural approach. All three emphasised that using this approach ensures that investment reaches experts by experience and leaders with lived experience. They also funded collaborations, leadership and development training.

They agreed that this was not necessarily an approach taken by many in the funding and investing community. Another contributor admitted that they and others do not necessarily tackle deep structural issues in this way.

One US contributor noted:

"Even if [philanthropy] is not the structure that we need going forward…it certainly can be better managed…and to be better managed it has to be better represented by the individuals who are most impacted."

Commenting of the words of the organisation's lead:

"Are those with the most wealth really going to be able to solve the problems of the least wealthy?...And be able to find those solutions – not likely."

Another UK-based contributor highlighted that they were commissioning research which moves away from simple 'service provision', in an effort to better understand the structural causes of the

social harms that were being perpetuated in the lives of the communities they were funding. Having a service and systems approach was helping them to think through wider and long-term impact for the community:

> *"To understand the broader structural issues…they have to be unpicked for us to fully dissect and understand what social change looks like."*

Several Contributors accepted that a purposeful shift in the language they and others use has had a powerful impact on the practices, relationships and overall power dynamics within their social purpose work.

Moving towards the explicit use of the term 'expert by experience' has created greater value, meaning, equality and ownership of their work. They argued persuasively that it is important to review the language used to describe people and communities with lived experience who have freely chosen to use their experience to drive and lead change across the wider social sector; in their view this would unlock or unblock progression in the work of others as it had in theirs.

Contributors also shared further shifts in organisational language in their work. One contributor highlighted their move from talking about 'grants' and 'gifts' to social purpose organisations (including not-for-profit organisations) to 'investments'. Another explained that language to describe their work with communities and social purpose organisations has since moved away from a 'grantor – grantee relationship' towards a 'partnership'.

One contributor commented on their organisation's purposeful use of the word 'disadvantage':

> *'Disadvantage' was consciously chosen…it implies it is a condition and is not permanent. And it also implies there is a power imbalance – it's a disadvantage and therefore there are people who are advantaged…This therefore almost always necessitates the need for addressing and shifting power and leadership…it is crucial to work with the people who don't have the power at the moment, and how we can then be useful in helping them to take a retake that power…not just their lives but within their communities…for the benefit of wider society."*

Contributors from Lankelly Chase shared their approach to achieving systemic, structural and cultural change,[21] which seeks to place experts by experience at the heart of their work. They also kindly shared some of their practices:

1. We began by evaluating our internal operations.
2. We then went on to consider:
  a. Who are the people we serve and how do we work with those people?
  b. What is the support that they want and need?
  c. What are the systems that underpin this?
3. We then went on to reflect and focus on ourselves as an organisation, noting that for many years evaluation and reflection had been outfacing rather than internal.

Our theory of change is underpinned by five conditions and although it does not explicitly say so, we believe that strong power-shifts are needed. This also underpins what we do:

1) Support is based on mutual accountability,
2) Open trusting relationships,
3) Based on strengths and resources,
4) The presumption of a right to rewarding life – so tackling stigma forms part of that
5) Continual learning and adoption.

With our focus on tackling systemic change, we work with partners where experts by experience clearly form part of the staffing body and governance structures.

[21] *http://lankellychase.org.uk/wp-content/uploads/2015/12/LCF-Theory-of-Change.pdf*

10.2 Equity and inclusivity

Contributors from the BIG Lottery Fund kindly shared their vision of their organisation's People in the Lead[22] strategy, which helps encapsulate a more purposeful move towards equity and inclusivity.

As one contributor noted:

> *"[The strategic framework] embodies the principles of individuals accessing services being the people who influence, lead and review the projects themselves. This fits with the equality principle of 'Promoting participation'. Meaning that our new policies, processes and programmes must be developed on the basis of real need. This means that the people who will be affected by them should be involved in their development."*

However, five contributors stressed the need to ensure that well-meaning initiatives did not fall foul of current and historic sector-wide approaches to 'involvement' and 'participation', concerns which have been cited throughout this report. Involvement must be meaningful and equitable and this includes sharing, and for some owning, decision-making power:

> *"To really have impact, true impact, we have to put people in the lead in a meaningful and equitable way…equity includes shared power…in decision-making and governance structures…from start to end…[and] most of all…ensure people also benefit from economic equity…that they, like us, are paid for their time if they are unable to give their time to activities for free."*

> *"self-determination is also important. For people and communities with lived experience to have full power to drive and lead change"*

10.3 Towards transparency and accountability

Many of the contributors explored this issue in some detail, but ultimately many reached the same conclusion. For the wider sector to move towards effective transparency and accountability, this requires meaningful involvement of experts by experience in all social change work that we do.

> *"Share your plans and work with the people and communities you serve, ask their opinion and views of what you are planning, how and why…not simply consult once something has been delivered."*

> *"Experts by experience should be part of every staffing body, as part of trustee and boards to truly and effectively hold organisations and institutions to account."*

Contributors provided a host of examples of historic, existing and emerging work in funding practices that help them to effectively think through a more meaningful way forward to address transparency and accountability. These are explored further at Chapter 10.11 below.

Contributors kindly shared some example ideas on how to tackle accountability and transparency within social purpose organisations more generally, such as:

1. Including lived experience in planning stages of all social purpose programmes and initiatives.
2. Including lived experience in partnership analysis and application processes.
3. Including lived experience and involvement of experts by experience in funding, evaluation and contract requirements and agreements, to ensure social purpose organisations are held accountable.

[22] *http://lankellychase.org.uk/wp-content/uploads/2015/12/LCF-Theory-of-Change.pdf*

4. Establishing meaningful and equitable involvement processes that allow experts by experience to be involved in governance structures: decision-making from inception and development, through to delivery and implementation.
5. More visibility of lived experience in recruitment and programme literature.
6. Valuing lived expertise in recruitment applications – valuing the interest, knowledge and insights of potential recruits, and appreciating how this will also benefit the work of the organisation.
7. Incorporating and connecting lived experience to the work that the individual and the organisation is doing,[23] and making it form part of their responsibilities and how they can contribute their lived expertise to the work of the organisation.

Several contributors commented on accountability surrounding financial expenditure and for organisantions to consider whether they were wielding resources in the most effective way

"How can we be doing that if those who are most impacted and had those experiences are not the anchor component of the solution? Why would we waste resources? How are we effectively wielding limited resources?

10.4 Connectivity

The connect with social purpose mission yet 'disconnect with realities' of the communities many within the sector serve formed a major part of discussions throughout deliberations, as was explored in some detail in Chapter 8. Many contributors emphasised the need for more human, connected, relationships with communities and across social purpose organisations – particularly between larger and smaller community-led organisations as well as their own. Relationships need to embody trust, respect and autonomy for all people involved, including the communities we serve. This means moving away from old command and control models from the 'top down' and towards understanding the importance of the interconnectedness of humanity in all services and activities.

"The way we do 'business' has fundamentally caused barriers…not connecting on a human level."

"Once you meet, learn and understand from the person who has first-hand experience…you can try to work together to think through what you can aim for…if you fundamentally believe in making that connection…then the rest will follow."

"The value of human connection…something we all to easily forget in our busy lives…yes it takes money to create the space and time…but it is valuable."

"Sometimes it's not until you sit side by side with someone you would never get the chance to meet in your everyday life…to talk, share what you do, what you are trying to do…that you begin to forge relationships to tackle, together, the mundane stuff."

To achieve this shift, several of the contributors highlighted the need for shifts in individual and organisational cultures and to move away from narratives alone as explored in depth in Chapter 8.

"We need to understand the real experiences, life experiences, of people…appreciating they are unique and different to our own."

"Value that those experiences will help us to understand our work better."

"Humility is needed…to know that you may not know something...you can then also appreciate…and actually hear…the ingenuity, energy and power of the community you say you serve."

[23] Following the interview, the contributor confirmed the successful recruitment of a new grants-manager with lived experience to work on a programme aligned with their lived expertise, and noted the contribution it brings to their organisation's work in the same field.

Several of the funders emphasised the importance of visiting, meeting with and talking to people and communities with lived experience about their experiences, the world they live in and the wider context surrounding their lives, in order to fully appreciate what is important and how they can work together to address that.

> *"We lose sight of the context in which their lives are lived…the poverty and inequality that may have affected their community and family life for generations….This leads us to over-emphasise the behavioural aspects of disadvantage, at the expense of structural and systemic drivers. Crucially, it erodes our appreciation of people's core humanity."*

> *"A one-off consultation event does not achieve the deeper connection needed…to get a deep understanding…we need to understand people and their experiences, to start from the beginning, how is there any other way?"*

> *"You soon realise how our silo approach to social change does not work in real life…people rarely view themselves as suffering from one thing…a social issue…but we seem to tackle the issues rather than their lives."*

> *"How can you monitor and hold government to account if we have little understanding of the impact that services, initiatives are or are not having…how can that be done without visiting people, places and organisations…to see what is happening, talking to the community...[to see] what 'life' is like?"*

Contributors highlighted the value of listening to people and communities with lived experience even if they are not speaking in the language that we are accustomed to. Spending time with, and alongside, the communities organisations serve to understand, better at least, the core of the message that the person or community has given. It helps to forge trust and respect, fundamentals for better collaboration. They emphasised the need for smaller and larger social purpose organisations to meet and work together: not to simply meet 'half-way' but to change the way they work 'together'.

> *"We need to stop the 'top-table' culture we have created."*

> *"We need to understand what our communities want and need. It may be different from what we think – we may feel challenged and they may even tell us that what we have been doing is wrong – but we need to embrace that as the long-term benefits will surely outweigh the immediate unease we may feel."*

Several contributors commented on the importance of people and communities having space and opportunities to connect. Many of the human benefits to individuals and civic society as a whole have been captured in Chapter 3, including connection, empowerment and collective action.

Several contributors commented on practical and active steps they have taken to achieve better connection.

> *"We are moving away from the application form, it's going to be about us spending more time with our partners…working for the same vision. Shared learning. Shared strategies."*

One contributor highlighted their concerted effort, determined by experts by experience they were working alongside, to meet the need for better networks for experts by experience. They helped to build connections ('bridges between communities'), create opportunities and pathways for wider participation in activities for more experts by experience, and minimise isolation and fragmentation.

They also help to facilitate communication between experts by experience and the wider social sector. This also improves the visibility and credibility of experts by experience, which has enhanced the chances of successful collaboration and co-production, stimulating strategic thinking and decision-making of social purpose organisations overall.

"We have a network of 50 'expert voices' in our programme tackling multiple and complex need…it truly has bridged communities across the UK and helped to galvanise people, communities, commissioners and organisations together."

10.5 Sharing learning and raising awareness

Many contributors shared their active approach to share learning and raise awareness of the activities and work of experts by experience. They emphasised the importance of doing so in order to bring visibility, credibility and value to the work done by experts by experience.

"Our programme is clearly beneficial, and challenges are heavily outweighed by the benefits to the individual, service and commissioners. Therefore we want to use our experiences to promote, support and influence others so that this becomes a default way of funding."

Contributors also highlighted examples of current and emerging practices they are deploying in their organisations to enhance this field, and consider their role significant in sharing learning within their organisations and across the wider sector.

10.6 Encouraging organisations to evaluate their existing practices

Contributors highlighted the need for social purpose organisations to:

- Self-assess and monitor their current practices and approaches in this field.
- To explore and consider how their practices are currently working.
- Start thinking through how they can start adapting practices in the short term and plan towards what they can and should become.
- This would entail actively exploring and reflecting on barriers and biases such as privilege, access, equitable involvement and opportunity.
- Explore and address operational, practical and financial barriers and plan towards remedying these.

Six contributors highlighted their own efforts to tackle implicit and unconscious bias within their organisations.

"Larger organisations have to examine and address their own working practices…how connected are they to their beneficiaries; what role do they think their beneficiaries play in their work? What prejudices and biases exist within their practices…It's a big balancing act if this is something that has not been done before. This may require time and effort…but see what happens. It's manageable and workable."

10.7 Developing unique approaches

Many things are crucial to this organisational shift, which were highlighted in Chapter 5 (see above at 5,5), but for many contributors the addition to the list – was the need to relinquish power to communities and experts by experience.

Three contributors highlighted that getting caught up in how to conceptualise lived experience may not help and may create barriers to change for social purpose organisations seeking to work with their 'beneficiaries' or 'service users'. The following was encapsulated from discussions:

- A service-user may simply be that, a person who uses a service. They may not transition to becoming an 'expert by experience' simply because they to do not want to.
- However, when social purpose organisations seek to rely on individuals, and those people seek to inform and participate in social change initiatives – be it through various consultation or participation methods described above – the individual becomes an expert by experience. Their insights and knowledge then informs our social purpose work.
- Of course, historical definitions may not be mutually exclusive. An expert by experience may still be a service-user, but when we are relying on their insights and knowledge their role has also transitioned.
- Experts by experience may not necessarily want to lead with their voice or story. They may wish to take a back seat, but this does not mean they do not want to be involved in other activities. The social sector's focus on 'story' and 'voice' can also generate this confusion.
- A person may transition away from becoming a 'service user' but remain an expert by experience.

Some elaborated further on specific approaches that were being deployed by organisations they worked alongside:

Self-knowledge as a powerful tool for change: Creating the space, tools and understanding to allow people to explore their own life journey. To help understand the unique, and connected, experiences, insights and knowledge that they bring. Providing the right support to achieve this.

Understanding the wider context and world around you: Providing support to people to understand the wider work of the social sector; those working in the field they are interested in; what has gone before, what is happening now and what is in the pipeline.

Storytelling: Building skills around activities that explore 'voice' to strengthen individual autonomy and self-determination. One contributor observed that elements of the women's and girls' sector have worked hard in this area over the last decade, reflecting on organisations and projects which work to address violence and abuse. However, these practices do not cut across the wider social sector or even beyond specific projects within those organisations.

Three contributors expressed concern that certain organisational and funder-imposed constraints placed on social purpose organisations may stifle creativity and new approaches in practices e.g. the need for appropriate adults or interpreters to facilitate activities and processes.

> *"Organisations may feel unable to craft approaches outside of the status quo, as they may not always pass due diligence requirements…they may be right."*

By contrast, several contributors explored unique participatory and governance approaches taken by organisations, which involved actively providing jobs and leadership positions to experts by experiences. These included youth-led charities which face the barriers to trusteeship roles due to

their minority. Despite young people not having any legal standing to take up decision-making roles, they are given opportunities to play key roles in partnership with trustees e.g. they are given places on decision-making and recruitment panels for the organisation, and opportunities for trusteeships are opened up to them as soon as they turn 18. Another example given was a disability rights charity, which developed and adapted processes and facilities to aid full participation and involvement in staffing roles.

A similar suggestion involved exploring the sort of innovative and creative approaches increasingly developed by the business sector to support staff creativity, some of which have received awards and accolades for innovation in employment practices: allowing pets at work, providing crèches for parents, permitting flexible and remote working, and testing out new staff facilities including work pods, sports and games within work spaces.

> *"Arguably where innovation is vital we are still playing catch up with business."*

One contributor cited an example of a housing association resident committee's approach of taking over a large housing stock. Recognising that not everyone has the capacity to run their own areas, this allowed them to:

- Encourage people to become members (since membership is not automatic).
- Have a higher level of membership (at the time).
- Get people involved in consultation.
- Enable each estate to get to the stage where it runs itself – an element of devolving decision-making to the estate level.
- Get experts by experience on the board – a group of tenants elected by other tenants.
- Allow people to choose the level of involvement and ownership.

Another contributor noted examples of two programmes they were involved with, which clearly stated that the involvement of experts by experience could not solely be on a voluntary basis.

> *"So we do expect that those who work with experts by experience to also offer paid opportunities. Not all are paid across the programme but many are."*

In the spirit of shared learning, one contributor kindly highlighted key features of a large funding programme actively involving experts by experience and their commitment towards evaluating, enhancing and expanding the work of the programme:

- We are continuing to involve and listen to those with lived experience and challenge our practices.
- We are looking to increase the involvement of experts by experience in existing programmes/projects which do not currently offer active involvement.
- We are providing opportunities for experts by experience and organisations to share learning as to the benefits and impacts of involvement, both internally and with other funders / commissioners / partners, to promote systems change.

- We are advocating for improved involvement programmes, supporting organisations to overcome challenges and barriers they face and help understand the countless positives of involvement.

- We are introducing individuals within projects to partners who may wish to follow their models and encouraging innovative approaches within their own specialisms.

- We are proactively expecting active engagement of those with lived experience in the identification, design, delivery and evaluation of future funding opportunities, including paid employment, training and skills development.

- We are using the skills of expert by experience champions within the funding body in order to bring all of the above together, and keep up to date with relevant policy issues. These champions also work to increase experts by experience internally, to lead by example.

10.8 Engaging staff from all levels

Some contributors commented on the importance of all levels of the organisation engaging with communities, including staff, trustees, boards, funders and donors, in order to help improve their understanding of the support people and communities with lived experience need.

Other contributors reflected on organisations they have worked with which have made shifts or attempts in this field.

"It requires support from all staff…from the top to the bottom…trustee boards and senior management teams to frontline staff and volunteers."

10.9 Promoting co-production and collaboration between organisations

Two of the contributors discussed the emerging role of co-production across some elements of the sector. There was a pressing need to share learning and interrogate processes to consider their wider application.

Three contributors observed the disconnect between smaller grass roots organisations and the larger organisations, recognising that often there is little incentive within the sector to promote collaboration.

"It's not rare for smaller and larger organisations to not know about each other's work."

"There is something to be said about bigger organisations clearly being resistant to adopt, support or working closely with smaller organisations unless they fit with the corporate line."

One contributor used an example in their current work – sifting funding proposals from organisations working to tackle domestic violence – and noted one example in particular:

"There is a small domestic abuse group and a larger one. The big one can clearly tick all the forms and requirements and write eloquently, have all the quality standards, be able to say in a nutshell what they want to do and prove they can handle the funding. And the very small one doesn't tick the boxes at all…but [is] embedded in the community with women leading for women…When you ask the larger one about the smaller one they'll say 'we've vaguely heard of them' and they don't mention each other…Why aren't they meeting and why are they not collaborating?"

10.10 Creating equitable opportunities

Many contributors suggested that there was no reason why larger organisations could not put in place effective mechanisms to pay experts by experience directly or through smaller social purpose organisations which are often conduits for engaging members of the community or experts by experience:

> *"Larger organisations need to start recognising the responsibility they have and how they value the time and expertise of those with insight, knowledge and expertise they rely on to take forward their own social purpose work."*

Contributors noted an improvement in some elements of the sector, two commenting on the mental health sector, that are increasingly including lived experience as a desirable criterion in job descriptions. However, with a few exceptions (including the National Health Service[24]), there is rarely anything visible in terms of recruitment drives whereby social purpose organisations seek out potential leaders with lived expertise or provide leadership opportunities to those with lived experience.

In the opinion of many contributors, the availability of decision-making, leadership, employment and training opportunities for people with lived experience largely depends on the value social purpose organisations place on their communities and on experts by experience as change makers.

10.11 Changing and developing funding and investment practices

Some contributors kindly shared their practices and examples of historical practices to consider in this field, including:

- **Recruitment of experts by experience:** One contributor confirmed their recent recruitment of an expert by experience on their board, and another is planning to an expert by expert as part of their grants team.
- **Providing skills and capabilities support to community-led organisations:** Several commented on their support for skills and training for community organisations. One commented on a large funding programme to support communities with social enterprise development. Another provided an example of media training and support to community-led organisations.
- **Funding organisations with knowledge and community connections:** One contributor highlighted an historical example of funding a small community charity with expertise in a particular field, to distribute funds to smaller groups embedded in communities the funder was less connected to.
- **Funding networks and platforms** run by and for experts by experience with experience of multiple and complex issues.[25]
- **Long-term core and unrestricted funds:** two contributors cited this as a method they had used to support smaller community-led organisations build infrastructures to 'do better' and 'allow them more room to be brilliant' and give them the space to work in partnerships and collaborations.

[24] One contributor recalled a local National Health Service (NHS) Trust deliberately employing support workers with lived experience.
[25] Two new organisations have since been created: Expert Citizens and Expert Link

Four contributors also highlighted current grant programmes that:

- Involve experts by experience from inception and the design phase of the programme,
- Support and encourage smaller and larger organisations to forge partnerships,
- Build a network of 'expert citizen' voices,
- Require organisations to have experts by experience involved in governance structures and recruitment / decision-making panels,
- Fund organisations led by experts by experience.

Contributors shared ideas on how this work could be developed:

- Involving experts by experience and communities with lived experience in designing and developing funding programmes.
- Including involvement of communities and expert by experience in the application processes for programmes.
- Insisting on the involvement of experts by experience from the start of the project through to the end. Contributors working alongside involvement processes observed that this tended to lead to successful outcomes and achievements.
- Building initiatives focused on partnerships and collaborations. This supports grass roots and larger organisations in coming together, and incentivises collaborations that share power and fairly distribute funds across organisations.
- Changing funding application processes which inhibit or restrict communities from receiving funding e.g. simplifying funding processes, visiting organisations to better understand their operations, meeting with experts by experience working within organisations.
- Involving communities in decision-making panels, and/or allowing communities to nominate organisations. One contributor explored the idea of a 'Citizen Jury' with people and communities with lived experience to decide distribution of funds.
- Funding organisations to explore and resource initiatives in this field. This involves appreciating the resource needs of specific organisations e.g. that those led by experts by experience and communities may need more help with administration, governance, fundraising and communications.
- Funding targeted research to understand the "value of money" of the lived experience .
- Funding bespoke leadership and support packages for experts by experience.

10.12 Developing community leadership

The concept of building leadership for communities is not new. Most contributors felt that communities thrived because of their leaders. Fortunately, the sector tends to recognise this and, in some parts, increasingly recognises that leadership takes many forms and that it is about more than just academic honours and professional excellence. However, many called for the whole idea of 'leadership' to be rehabilitated across the wider social sector if it is serious about creating sustainable and lasting change across all social purpose work.

Several contributors highlighted the need to consider a programme to build the leadership strengths of people and communities with lived experience. However, they stressed that like with any other change initiative, careful strategic thought needs to be given before any programme or initiative begins, in order for it to be successful. Leadership programs are not a silver bullet, but some agreed that they could help diversify leadership across the sector.

In terms of structural changes to support leadership, contributors recognised that leadership support is needed beyond funding user-led / community-led organisations. New and bespoke models of leadership development will be needed.

In the US, more sophisticated approaches to leadership development were noted. On example given was an alliance of funders coming together to fund sabbaticals for emerging leaders to allow them an opportunity to learn, reflect 'and recharge'. Another cited an example of secondment placements shared across organisations to enhance learning in a new environment.

Contributors to the research raised genuine concerns over the capacity of some experts by experience, which would require new and novel ways of engaging and supporting individuals and communities with lived experience e.g. trauma-informed services and support.

Three contributors highlighted their own attempts at providing space for experts by experience to widen their role and leadership, and highlighted the need to consider peer-to-peer support, coaching and action learning as well as internal and external supervision:

> *So a project we have called System Changes funded frontline staff to step away from frontline work and sit back and think about systemic influencing of their role in the larger system, and many of those frontline practitioners have the lived experience."*

11. Celebrating pioneering approaches

Key Points

- Progress towards meaningful inclusion of experts by experience has depended heavily on the area of the social sector.
- The community development, mental health, social care and youth sectors provide some examples of change, but even here progress has stalled or even regressed.
- The best social purpose organisations appreciate the value of experts by experience and have worked hard to put them at the forefront of their work.
- Doing so successfully involves appreciating the strengths and limitations of individuals, helping them to understand their experiences and respecting autonomy and self-determination.
- Putting lived experience on display can be a powerful tool, but there are also potential drawbacks.

As set out in the previous chapters, contributors detailed extensive and wide-ranging challenges, concerns and barriers to change. However, the conversations also revealed some parts of the sector pushing the envelope in terms of sophisticated and progressive ways to include and involve experts by experience in social purpose work. This section will highlight those who have pioneered or embraced this paradigm shift – towards experts by experience as change-makers and/or social change agents.

"Lived experiences can be a crucial motivation for social change and purpose driven work."

11.1 Community Development

Two contributors highlighted examples of pioneering approaches in some Asset Based Community Development (ABCD) initiatives, which invest in communities by providing training, leadership and development opportunities, supporting their ability to run projects for themselves. One was celebrated for their pioneering approach, funding thousands of community projects where residents were trained and employed as part of funded projects.

One contributor provided an example of a programme they funded where projects recruited people from communities as community development workers or trained them up to do the work, which was considered to be a critical part of the programme:

"A winning combination if you want to talk in terms of sustainability, added value and lasting legacy…[they were] committed to continuing the work following the end of the initial project grant. Whereas staff parachuted in to deliver a project from outside of the community may not have that same sort of commitment. This added value is rarely discussed in a monetary or economic sense."

11.2 Disability

Contributors commented on organisations which have successfully established unique governance and management structures to take forward their work. They cited a national learning disability charity primarily led through the vision of experts by experience, who have established practical changes to working protocols, supervision and training. At the same time, they have worked in targeted and specific ways to recruit and manage staff and their board and trustees, manage governance meetings and ultimately developing experts by experience into leadership positions where they are valued and paid. Others cited exciting and promising emerging ideas such as community-level pooling of personal budgets, which enables coalitions of disabled people to become commissioners.

11.3 Mental health and social care

The employment of people with lived experience is for many contributors a hallmark of meaningful and equitable involvement of experts by experience. One contributor recalled a local NHS Trust deliberately employing support workers with lived experience.

Three contributors highlighted examples of communities working closely with public service providers and commissioners to design the provision of public health and social care services, in order to meet the needs of a particular and/or local community: cancer patients, mental health and social care services.

Another provided an example of a mental health charity working to employ people with lived experience of mental health issues and openly including this in their recruitment literature. Experts by experience were involved in governance, management, peer-to-peer, campaigning and local and national training initiatives.

One contributor provided an example of a user-led organisation that facilitates links between mental health user groups across England, working on a local and national policy level whilst also providing skills and leadership development training to user-led organisations and providing support and development on peer-led initiatives.

11.4 Age-based sector – youth and the elderly

Despite age being a barrier to holding governance positions, one contributor highlighted the work of one youth charity which actively involved young people in the recruitment of staff and trustees and took roles on shadow trustee boards and youth ambassador initiatives. Recruitment and board opportunities were made available within the organisation at the age of majority.

Other contributors highlighted the fundamental role that young people had played in the design and development of services for young people, which has steadily gained traction with and support from local councils. Examples were cited of individuals and groups spearheading social change through education and training programmes, including awareness raising and anti-stigma campaigns in the mental health and youth sectors (particularly in the areas of care leavers and young people's rights).

Another contributor provided an example of a large charity for the elderly working with employed experts by experience as peer researchers.

11.5 Social justice sector

Contributors provided examples of community-led organisations working across the UK; although working locally and employing experts by experience, their work was having a significant impact on a national level.

One contributor provided an example of a community-led organisation focusing on faith-based child abuse. Leaders with lived experience were challenging abusive practices and promoting the rights of children within the community – training local communities, faith-based organisations and schools. Experts by experts were closely connected to their community, promoting the rights of children and providing safeguarding training to communities from within, while at the same engaging leads of faith-based organisations, training and working closely with national charities and informing national policy work.

Another contributor provided an example of a small local charity working in a deprived area of England, which aims to build sustainable livelihoods and get the voice of people in poverty directly to decision makers. They provide experts by experience with opportunities to work within the community and support those who are financially and socially excluded. Through their work, they bring their communities closer together and have successfully challenged the accountability of 'pay day' loan providers, helping thousands of people out of debt and poverty.

11.6 Mapping Developments

Through the work of these sectors, more sophisticated methods and approaches to providing agency to experts by experience have arisen:

INVOLVEMENT PROCESSES:	PURPOSES OF INVOLVEMENT:	LEVELS OF INPUT:
• Board membership • Shadow trustee schemes (young people) • Expert Citizen Panels / networks • Lived Experience Advisory Panels • Recruitment panels • Monitoring panels (service providers, commissioners, employers etc.) • Employees in social purpose organisations • Community / peer researchers	• Governance and decision-making • Active involvement in management and service delivery • Recruitment of staff / boards • Strategic reviews on diversity and involvement, and future funding design • Engagement in funding spend decision-making • Engagement in identification, design and delivery of services, and local and national evaluation programmes • Co-designing and co-producing services with social purpose organisations (including work with commissioners and social entrepreneurs) • Peer-led initiatives (e.g. peer mentors, peer-to-peer support, peer networks, self-help groups) • Leading on change-making programmes and campaigns • Leading on opinion research	• Day to day • Weekly • Flexible to fit experts by experience

There was a real sense that the social purpose organisations which have pioneered change in this field have embraced the unique and valuable perspective of experts by experience. They acknowledge that such experiences thread through social, cultural, economic and political structures, systems and processes, and that these cannot therefore be entirely understood by someone who – simply put – lacks this experience.

They understood that there are layers of complexities involved in individual lives, and the expertise that complexity brings: experiential knowledge, understanding, views and insights, along with a deep understanding of particular environments, contexts, issues and the surrounding world.

> *"It's skill, knowledge, you don't live through multiple and complex needs without having a wide skill range. Develop such resilience, creativity, innovation to manage experiences, ways to survive. Not to see these human strengths is a complete waste."*

They adopted an organisational awareness of this lived expertise, a valuing of these skills, insights, knowledge and expertise. The result was attitudinal, linguistic and structural shifts within organisations.

> *"People with degrees and learnt skills provide important knowledge and expertise in their field – the lived experience brings other important expertise around the table."*

> *"I entered the funding world thinking I knew a lot about local communities, activism and social policy but it's not until you engage with user-led organisations that you realise much of what you have learnt is theoretical, abstract and very distinct, sometimes far removed, from the realities of life."*

They also embraced an understanding that lived experience is personal, and that it is for the individual to make an informed choice about their capacity or role, whether to be or become a change-maker.

12.1 A Winning Combination?

Contributors from the BIG Lottery Fund kindly provided examples of social impact work which is driven and led by experts by experience involved in their programme – Fulfilling Lives: Supporting People with Multiple Needs – which is having 'powerful local and national impact'.

BIG Lottery Fund programme – Fulfilling Lives: Supporting people with multiple needs

This is a £112 million investment fund, aimed at improving the lives of people with multiple needs – individuals who are experiencing at least two of the following: homelessness, reoffending, problematic substance misuse and mental ill health. The programme recognises that people with such issues often rotate through various welfare and justice systems, which can deepen the problems in their lives at a cost to them and society.

Funding has been awarded for five to eight years to 12 partnerships nationally, bringing different organisations and services together to offer co-ordinated support services that meets the needs of individuals. The ultimate aim is to give organisations the chance to showcase and evidence more effective and efficient ways of designing, commissioning and delivering support services for these people in the future.

In each of the 12 areas, people with multiple needs are central to the plans, including development and delivery. Each of the partnerships do this differently, with strategies including:

- Varying participation and engagement activities.
- Paid and voluntary recruitment of experts by experience within services, such as 'navigators' to help people engage with services in order to make changes in their lives, and 'peer mentors' to provide additional support to individuals.

The creation of a National Expert Citizens Group is also currently supported by the Fund both financially and in practice, with two experts by experience from each partnership (24) meeting together on a quarterly basis. This body acts as a community of interest, allowing members to share learning and influence. It undertakes a broad range of activities:

- Providing honest feedback and advice as this initiative progresses.
- Sharing best practice and supporting each other to embed 'true service user engagement' in the projects.
- Discussing and sharing experiences, and taking learning back to the projects.
- Pioneering and championing initiatives across the country.
- Advising and working with the national evaluation body.
- Getting involved in peer research led by those with lived experience, who independently decided the theme of the first research topic and then led the process.
- Advising and working with Big Lottery Fund on the Fulfilling Lives initiatives and other related policy areas around lived experiences.

Examples of local and national social impact:

- Experts by experience in Manchester's Core group have been influential by the city's move to adopt a Homelessness Charter, committing the Council to a new approach to tackling homelessness, and are involved in reviewing applications to their funding programme.
- Experts by experience in West Yorkshire have produced a video used by the police as part of new officer inductions, to raise awareness of the lives of people with multiple and complex needs and to help reduce stigma. They have also been invited to upskill doctors in the area.
- Experts by experience participated in peer research concerning dual diagnosis on behalf of the Camden Strategic Recovery Group.
- Experts by experience in Nottingham have been involved in the commissioning of drug and alcohol services in the city.
- The Director of Public Health in Blackpool is involving experts by experience in the commissioning of relevant services in the town.
- The North East Core Group and the National Expert Citizen Group have been invited by the Home Office to feed into the Government's forthcoming new Drug and Alcohol Strategy and to contribute evidence to Dame Carol Black's review: 'Drug and alcohol addiction, and obesity: effects on employment outcomes'.
- The National Expert Citizen Group have been approached by national social purpose organisations to feed into their work.
- Experts by experience in Stoke are having a significant impact on the approach of local and national agencies to involving experts by experience in their services and activities.

A UK and a US contributor both provided the same example of a US youth movement of social change-makers – 'The Dreamers' – who they felt epitomised the strength of lived experience to create social change and the power of experts by experience as change-makers and leaders of change.

United We Dream

United We Dream was founded by a group of young undocumented activists in the US in the mid-2000s. It is now the largest immigrant youth-led organisation in the US, with a network made up of over 100,000 immigrant youth and allies, and 55 affiliate organisations across 26 US states.[26]

The network organises and advocates for dignity and fair treatment of immigrant youth and families, running programmes to advocate for access to higher education, to stop the deportations of undocumented youth and their parents, and to strengthen alliances and support for DREAMers at the intersection of queer and immigrant rights.

It is an organisation built and led by experts by experience, and it is seen as a political force within the US. They also leverage their social change capacity to help build and sustain services in their communities across the US, including employment and leadership opportunities.

[26] *http://unitedwedream.org/*

13. Conclusion

Introductory remarks

The aim of this report was to explore how as a UK social sector we cultivate, develop and evolve our social impact efforts alongside experts by experience – individuals using their lived experience of social issues to drive, lead and create positive social change.

This report did not seek to explore why experts by experience actively participate in the work of the social sector but rather if, and how, the wider social sector values their involvement and what opportunities, if any, are created for them, so that lived experience can be embedded as a core concept in thinking around social change.

Despite this study being ultimately limited to 12 in-depth interviews with professionals working in the funding community, the findings are vast, diffuse and rich and cover an incredibly complex terrain. Discussions were lively and challenging, exploring and deliberating upon a wide range of issues, for which I hope this report can serve as a guide for the reader. I also hope that this report can help equip the wider sector with a better understanding of both the importance of lived expertise for social change and why it nevertheless has such limited traction in social change work.

Summary of findings

There was a large degree of consensus about the meaning of lived experience, with interviewees referencing historical, current and emerging approaches used by the social sector to integrate it into their social purpose work. However, there was an inconsistent understanding of its value in driving and leading social change across the wider sector. Explaining why, contributors cited a host of concerns, barriers and challenges captured in detail in Part 2 of this report, which include the power imbalances that permeate the social sector, sector-wide perceptions and understanding of people with lived experience, and our preference for 'story' (for personal testimony as a means to corroborate organisational positions and efforts) over the true substance, insights and knowledge that lived experience can bring to our wider social purpose work.

There was recognition that, to its detriment, the social sector often fails to recognise, cultivate and harness the insights, knowledge and lived expertise of experts by experience relevant to its work. The sector now broadly understands that lived experience is important, but still thinks of experts by experience primarily as service-users and informants, rather than drivers or leaders of change. There was general agreement that commitment to lived experience in our work is far from universal; that this is an underdeveloped and unsupported area and in dire need of better leadership.

Contributors agreed that a fundamental shift is needed in both leadership and organisational development across the sector, and contributors generously shared elements of their current work and views on future steps, which together amount to a powerful call for sector-wide adoption and action. A summary of some examples of how we can lead the way together is encapsulated in Chapter 9 of this report.

Ultimately, we need a powerful shift in our thinking and a significant sector-wide step-change towards understanding the valuable concept of 'lived expertise', the knowledge it brings and the role of the holders of that knowledge within our social sector ecosystem.

Conclusion

Those actively practising community engagement in their social purpose work will likely already be well-aware of the issues raised in this report, and may well have been debating them for years, if not decades. However these issues are not necessarily acknowledged or accepted across all elements of the social sector. For some readers, this report may raise uncomfortable challenges.

But one thing that unites us is our bold assertion that we are all, in our different and unique ways, working for the benefit or welfare of members of society, across the range of issues that the sector exists to tackle. If this is the case, we must embrace the themes raised by this report and demonstrate the commitment and persistence to work through them genuinely, openly and (hopefully) together. We need to liberate ourselves from the current sector stagnation suggested by the findings, and push forward for positive and impactful change.

Without this, we risk undermining the very communities we say we serve, and impeding the ability of our communities and experts by experience to create not only positive social change, but change that is transformational. Ultimately, we do not want future generations to look back at today's social sector and judge it responsible for stalling the growth of the social change-capacity of our communities, and instead forging leadership inequity in its heart.

There will be many who are actively adopting and changing practices in order to put people and communities with lived experience in the driving seat. Some will have been doing so for many years. There has long been an interest in, and an attempt to, understand and deploy effective 'beneficiary' and 'service-user' involvement processes, particularly in the fields of health and social care[27] and more recently, during emerging debates focusing on co-production, co-design and co-creation. Although, some elements of the sector are pioneering change in this field, overall development in the sector is slow and fragmented.

This report argues that key concepts such as user-led or co-(words) mean little without first understanding the essential value lived expertise brings to our social purpose work. The time has surely come for us to move our attention away from focusing primarily on people and communities with lived experience as 'beneficiaries/service-users' – as those who only receive our charity, service or 'kindness', or stakeholders we engage with so that we can consult with them or 'give them voice'. Instead, we must shift towards understanding the potential of lived expertise to lead and drive social change and begin to understand the true value it can bring to all social purpose work.

This report explores how the current plurality of involvement processes have created barriers to understanding the potential of experts by experience as change-makers. At the same time, as we have broadened our social change work to be inclusive of other concepts and approaches, such as storytelling and social entrepreneurship, we seem to have, inadvertently or otherwise, evolved in a manner that has neglected, overlooked and even marginalised the change-making capacity of our key partners in the social sector ecosystem – the people affected by the issues we tackle and the human wisdom they bring to our operations to help create and drive social change.

To change this, we need to create a culture of possibility, in which all members of society can be active creators of change. To achieve this, we need to work towards a number of goals, including:

[27] Branfield, F., Beresford, P. (2006) 'Making user involvement work'
https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/1410-user-networking-knowledge.pdf

- helping lived experience blossom across the social sector landscape,
- considering how to meaningfully and equitably include experts by experience in our social purpose work,
- determining how to tackle the systemic barriers, social stigmas and wider inequalities they face crucial change-agents and leaders of change in our ecosystem, and
- establishing how we can help identify, build and sustain their change-making and leadership capacity in social purpose work, so that lived experience is finally, and firmly, embedded in the sector's foundations.

Only then we can begin to improve the pervasive imbalance that currently exists in our social change equilibrium. It is time to do better and to appreciate the truth at the heart of our sector – that fundamentally it is people who create social change.

Indeed, now more than ever it is crucial to consider the underlying and structural, including historic, causes of the social harms and injustices members of society face, and to reassess how we as a social sector 'do business'. The discomfort and unease shared by contributors about the relationships we – as a wider social sector – have with the people and communities we seek to serve highlights some key and current challenges for the sector. The dramatic political and societal upheavals created by Brexit and the US election results in 2016 have also ignited the consciousness of many within the wider sector, including some who were reluctant passengers during the initial phase of this exploration.

Certainly, many of the correspondents who participated in the early informal conversations leading to this research later reached out to me as I completed this work and have started to re-examine their position, having reflected on the mounting divide between organisations and the communities they aspire to serve, and the disengagement of wider society from the causes we pursue.

With more people in positions of 'power' and influence starting to ask critical questions – and many more now comfortable in doing so – there is clearly a will and intention for change in elements of the sector and we must now unite across sector boundaries and act.

This report argues that to move from this intent to meaningful action we can first begin by recognising the intrinsic as well as instrumental value lived expertise brings to the table, and then rebuild our systems and structures around that expertise, to ensure that it is firmly embedded in our work, in order to help create social good now and into the future.

As highlighted in Chapter 9, to achieve this we need to radically rethink, revise and reform our approaches, practices and cultures. We need to consider and celebrate work underway in this field so that it is more widely understood, and determine how we can develop our organisations, infrastructures and strategies accordingly. Contributors to this report clearly recognised the need to bear in mind the distinct and unique nature of the work and aims of social purpose organisations. Changes to old styles of working will be challenging for some, extra resources to implement change may be needed, as well as careful consideration of local, national and even global priorities. Yet, we also need to carefully consider whether our current operations and the over-professionalising of our work has in fact become wasteful and worse still, become harmful to social change.

Sophisticated and evolving leadership styles will be needed. Moving away from old-school command and control styles where power is held at the top, often inaccessible, guarded and filtered down (within and outside of our organisations) - towards a more proactive, fluid, reflective and equitable approach that helps build connected and collaborative relationships and shares resources and power fairly and equitably. Leadership that also recognises the vital role all key stakeholders play in the social sector's ecosystem – including the people we serve. To this end,

much can be learnt from leadership approaches such as Generous Leadership [27] that help us to reflect on ways that can truly begin to create greater unity and prosperity for all within our society.

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 together, and not in isolation, we can create impactful, sustainable and transformational change.

And by doing so, I hope that we can collectively begin to open our doors and support the social impact careers of all change-makers in society, including courageous individuals and communities who seek to use their personal lived experience to pioneer, drive and lead social change initiatives.

A vital next step is to turn to experts by experience and leaders with lived experience. Their insights and views have not been explored in this work and it is crucial that we hear and learn from them. Preliminary discussions I have had with many such leaders have been insightful and inspiring, and I hope will form the foundation of my developing contribution to this field.

Final words

One of the beauties of this report and the process which led to it has been the conversations that have taken place. These have not only been bold, honest and challenging, but have enabled participants to reflect on their own individual social change journey; lived as well as learnt experience we all bring to our social impact work.

This piece is not about the rights and wrongs or a 'blame game', nor should it be used to recommend one leader above the other. It's about how we as a collective social sector explore leadership and social equality within our own realms and bring about the social change we want to see – whatever our background.

I **end by turning to some of the initial concerns raised leading to this research and giving some preliminary responses:**

- **Who knows best?:** We all do if we work together.
- **Lived experience is not expertise:** It may not be 'technical-expertise' but it is a form of expertise – 'lived expertise'.
- **It's 'tokenistic':** Sadly, that's our sector's fault. In many parts of the sector we make it that way, but it should never be. Let's learn from our communities about how we need to get it right.
- **It's about merit:** Absolutely. Change-makers exist across all our communities and those who use their learnt and/or lived expertise to create positive social change in the world all have merit.
- **The reality is that your background does matter:** If by background we mean 'privilege' (be it finance or education) – and this affects how we treat others and the opportunities available in the field – we are forging inequity in the heart of our operations and we must be held accountable. If we allow it to bed into our systems, our social sector will never be fair, just or sustainable.
- **Can 'beneficiaries' be trusted?** Can we be trusted to act?

[28] Blog post for the Clore Social Leadership Programme by Dawn Austwick, Chief Executive of the Big Lotterr Fund, September 2016 *http://www.cloresocialleadership.org.uk/Generous-leadership-Big-Lottery*