How to Centre Lived Experience

A learning summary from Comic Relief's Change Makers Programme

#5 in a series of key takeaways for practitioners & funders

By Emma Pearson and John Williams

FUNDED BY COMIC RELIEF

CONTENTS

Introducing Change Makers **3**

NPC's role as a learning partner 4

What this learning summary covers 4

A few key definitions 5

1. PLAN – Centring lived experience when setting direction **6**

How to include lived experience in design 7

Case Study: Bradford and Craven Autism AIM 8

2. DO – Centring lived experience in implementation **9**

How to embed lived experience in implementation 10

Case Study: Southall Black Sisters 10

3. ASSESS – Centring lived experience in Monitoring and Evaluation (M&E) **12**

How to include lived experience M&E 13

Case Study: Women's Budget Group and the Global Institute for Women's Leadership, King's College London 14

4. REVIEW – Centring lived experience in using learning to improve practice **16**

How to embed lived experience in learning 17

Case Study: Young Changemakers (UK Youth in partnership with The Diana Award and Centre for Mental Health) 18

Case Study: Gatwick Detainees Welfare Group 18

Conclusion **19**

Introducing Change Makers

Change Makers was a £9.1 million programme run by Comic Relief in the wake of the 2019 Coronavirus disease pandemic. It provided up to five years of targeted funding for 20 different partnerships, totalling 45 individual organisations.

From 2020 onwards, the pandemic shifted the voluntary, community and social enterprise landscape. It has been estimated ***that charities lost up to £4 billion*** in income over a few short months at the start of the pandemic, and that ***a third of charities had decreased access to their volunteers***. This direct impact on charities, combined with the general population's restricted ability to access support and need to socially isolate, had a disproportionately negative impact on some of society's more vulnerable populations, whose personal situations had been exacerbated by COVID-19 and their routes to support decreased due to the more unstable charity sector.

Change Makers sought to address some of these challenges and support organisations who work to tackle some of the serious issues that saw increased strain and demand during the pandemic. This list included racial inequality, homelessness, early childhood development, forced migration, domestic abuse and mental health.

The long-term funding Comic Relief provided, as part of its 2018-2023 strategy, gave stability in an uncertain environment. It enabled individual organisations and partnerships to work at a systems change level, exploring the social and structural changes needed in the aftermath of COVID-19 to best support vulnerable populations who had been overlooked or under resourced at local, regional and national level.

Crucially, each of these grants sought to achieve change which would outlast the funding provided by Comic Relief.

FUNDING THEMES

1. Gender Justice
2. Safe Place to be - Forced Migration
3. Safe Place to be - Homelessness
4. Children Survive and Thrive
5. Global Mental Health

KEY STATISTICS

- **20** Partnerships funded
- **5** Years of funding
- **9.1** Million pound programme
- **45** Organisations

Working with organisations across England, Scotland, Wales and Northern Ireland.

NPC's role as a learning partner

NPC were engaged at the start of the Change Makers Programme as an evaluation and learning partner. As part of this work, we co-designed 5 learning questions with the Funded Partners, to frame their collective insights and takeaways.

Learning summary series

1. Building understanding

What do we need to understand about our organisation and the context it exists within before we can create meaningful change (e.g. influence policy and structural decisions) for a broad audience?

2. How to collaborate

How can we create and maintain collaborations with individuals, charities, politicians, service providers and other stakeholders that are effective in creating the long-term change we are seeking?

3. How to monitor and evaluate impact and attribute success

What does short and long-term change look like for our grant? How can we measure and present our achievements in robust, interesting and proportionate ways?

4. How to communicate learning responsibly

How do we tell honest stories in accessible language and formats to our stakeholders whilst maintaining privacy and sensitivity? How can we develop a culture of data curiosity and acceptance of outcomes in a resource-stretched environment?

5. How to centre lived experience

How do we develop and maintain positive relationships with all those with lived experience, including with project staff, service users and other stakeholders? How can we enable open communication within these relationships without putting pressure on them in the context of an ever-changing political landscape?

What this learning summary covers

This is the final learning summary of five in our series, with the first four focusing on **developing understanding; collaboration; monitoring and evaluation; and communicating learning responsibly.** Across these four themes, the importance of centring lived experience was repeatedly highlighted for each stage of projects, including design, implementation, and evaluation.

Centring lived experience needs approaching carefully as it is important to get it right, both for the benefit of the project and to meaningfully and appropriately engage those with lived experience without overburdening or retraumatising them. The lessons shared by Change Makers Funded Partners provide valuable guidance for how to achieve this at each stage of a project.

The specific learning questions we sought to answer on the topic of centring lived experience were as follows: How do we develop and maintain positive relationships with all those with lived experience, including project staff, service users and other stakeholders? *How can we enable open communication within these relationships without putting pressure on people, particularly in the context of an ever-changing political landscape?*

This piece is structured around NPC's *Cycle of Good Impact Practice* (pictured below) which frames impact practice as planning, delivering, making sense of evidence, and using findings to improve. We'll go through each of the four stages (Plan – Do – Assess – Review) in turn.

Figure 1 – Cycle of good impact practice

A few key definitions

In this piece, we'll use the following terms and definitions (taken from NPC's guide *'Centring Lived Experience: a strategic approach for leaders'*).

Lived experience

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

Experts by experience

A person who has first-hand experience of the problem an organisation is seeking to address through its work.

Involvement

Any initiative where an expert by experience has influenced decision-making, or the design or delivery of a programme (some find this word limiting as it places the power with an organisation, but we have used it because it is widely used and recognised).

Service user

A person who has used or benefited from an organisation's intervention or offer (in this case, the Change Makers programmes delivered by Funded Partners).

1. PLAN – Centring lived experience when setting direction

KEY TAKEAWAYS

Start with co-design

Involve experts by experience from the outset to shape priorities, define outcomes, and agree what success looks like.

Understand the needs of target groups

Develop a full understanding of the needs that projects/initiatives are set up to address.

Embed lived experience in leadership

Include people with lived experience in governance and core roles so strategic direction reflects those most affected.

Design for diversity

No single voice represents all lived experience – widen participation, reflect different perspectives, and avoid reliance on a narrow group of contributors.

Resource participation properly

Allow time, funding, and support for meaningful involvement, recognising that co-design takes longer but leads to more equitable outcomes.

Centring lived experience at the 'Plan' stage means co-designing projects, programmes or activities with people from the outset so that project goals, governance, and definitions of success reflect lived realities (rather than assumptions). This requires intentional decisions about who shapes the work, how shared understanding is built, and the conditions under which people can participate safely and meaningfully. Embedding lived experience early helps ensure that both delivery and impact measurements are designed with service users' benefit and insights clearly in mind for added relevance and accountability.

How to include lived experience in design

Co-create your *theory of change*. Planning is most effective when lived experience shapes what matters, how change happens, and what success looks like from the outset, rather than being added later. Across Funded Partners, people with lived experience were involved in co-designing programmes from the beginning. In practice, this meant creating planning processes where people can meaningfully shape activities, define outcomes, and test underpinning assumptions – key elements of a robust theory of change.

Understand the needs of target groups:

As explored in detail in our first learning summary (on building understanding), it was important for Change Makers Funded Partners to develop a full understanding of the needs their Change Makers projects were set up to address. Lived experience was key to developing this understanding of needs, helping to guard against reliance on existing assumptions. However, for some service user groups, involvement in specific types of processes is challenging (e.g. individuals experiencing homelessness being 'hard to reach' in consultations, or very young children), requiring alternative approaches – such as relying on previous research that centres lived experience in its findings and methodology.

Establish shared decision-making structures.

Decisions are shaped by those who hold influence and whose knowledge is prioritised. Centring lived experience therefore requires explicit choices about power-sharing, including setting up steering or design groups with ongoing authority, rather than one-off consultation roles. Funded Partners often created structures where decision-making was shared and, in some cases, progressively shifted towards people with lived experience themselves.

> *"We were able to create a framework of working principles to deliver this project effectively and which kept us on track and focused on our task at hand. These principles included building on existing strengths in the community rather than forcing our own ideas on them [and] listening effectively to the community on an ongoing basis – not just once but again and again."*
>
> *– Change Makers Funded Partner*

Embed lived and learned experience in leadership and governance

This involves including people with relevant experience in core roles – such as staff, trustees, or senior volunteers – so that strategic oversight incorporates their perspectives. This meant moving beyond asking how to involve people with lived experience, towards considering who designs and leads the work, embedding lived experience structurally rather than relying on occasional engagement activities alone.

Overcoming common challenges

Securing buy-in, where people with lived experience may be sceptical that their involvement will lead to tangible change (both in terms of shaping programme design or delivery, but also the ultimate social impact that the Change Makers projects were aiming for).

Communicate clearly and create the right conditions

Meaningful participation depends on how processes are designed and resourced. For Funded Partners, this included using accessible language, being clear about the purpose of people's involvements, and investing early in safe and ethical engagement approaches – factoring consent, safeguarding, and accessibility – while anticipating individual and systemic barriers to participation.

Sustaining fair compensation and resourcing for meaningful participation in resource-stretched, 'firefighting' environments where funding for embedded lived experience can be hard to find.

Be strategic about where to involve lived experience

Identify where it is most relevant and ensure sufficient time and budget for meaningful engagement in the project cycle. For Funded Partners, this often included creating opportunities for people with lived experience to take on leadership roles, such as chairing meetings or acting as advocates.

> *"We successfully choreographed a range of lived experience-led design and advisory sessions / convenings to examine learning from all our programmatic activities with lived experience leaders in the sector to identify critical points of integration enabling us to effectively infuse lived expertise into the design of all our activities."*
>
> *– Change Makers Funded Partner*

Over-reliance on a small number of individuals with lived experience, which can be overburdening and also narrow the breadth of insight incorporated into planning.

Design for diversity

Funded Partners sought to avoid over-reliance on a small number of individuals by designing for diversity – expanding partnerships, building wider networks, and seeking to include underrepresented voices. In practice, this meant engaging different individuals and communities and acknowledging gaps in representation, which helped strengthen both the quality and credibility of insight.

Bradford and Craven Autism AIM

Bradford and Craven Autism AIM works to support autistic adults in their locality who receive little to no funded support from other means. Their Change Makers work was led by several staff members with lived experience of autism, which helped ensure that the insight and understanding that comes from lived expertise was at the heart of their work. They also recognised, however, that the lived experience of key individuals did not represent all autistic people within the community.

> *"This project is autistic-led and it is important that it stays that way. However, we must understand that the lived experience on our team does not represent every autistic voice in the community."*

To address this, they built upon the lived experience of the internal team by partnering at the local and national level, which helped ensure the project was relevant to the broader community.

> *"Growing working partnerships with other organisations will help us understand where we best fit in that community and what the greatest issues are for the people who live there. Additional national partnership work will help us gain a better picture of national trends in Autistic mental health and what has been proven to work across the country."*

KEY TAKEAWAYS

2. DO – Centring lived experience in implementation

Move from consultation to shared delivery

Involve people with lived experience directly in delivering work, shaping outputs, and influencing decisions.

Reflect regularly and refine delivery

Build in ongoing feedback, reflection, and adaptation so work remains responsive to people's needs and experiences in real time.

Create accessible and flexible entry points

Design multiple ways for people to engage – formal and informal – so participation works for different needs and contexts.

Invest in relationships, capacity, and leadership

Build trust and support people to participate in ways that suit them, including developing skills and taking on leadership roles.

Make space for reflection and collective sense-making

Regularly assess whose voices are heard and create spaces for lived experience to shape decision and direction.

Centring lived experience in the 'Do' stage means delivering work with people, not for them, by ensuring they shape implementation, influence decisions, and benefit from participation in ways that are accessible, ethical, and empowering.

How to embed lived experience in implementation

Move from consultation to shared delivery

Many Funded Partners progressed from consultation to co-design, co-production, and user-led delivery. People with lived experience were actively involved in delivering sessions, shaping outputs, and influencing decisions and direction. In practice, this meant that lived experience was not a component of implementation, but fundamental to how delivery happened – through leading events, producing creative outputs, and influencing stakeholders via storytelling and advocacy. Centring lived experience at this stage therefore requires sharing control over implementation, not just contributing to design.

Southall Black Sisters

Southall Black Sisters exists to help Black, minoritised and migrant women live free from all forms of violence and abuse. Their 'No Recourse? No Safety!' programme campaigned to remove the no recourse to public funds condition, which acts as a major barrier preventing migrant women from safely escaping domestic abuse and forced marriage.

Key to the success of the programme was empowering service users to be advocates of change, a catalyst for both personal transformation and wider systems outcomes. This included hosting groups and panels in a range of different spaces, from the UK Parliament, launching international campaigns, and contributing to research.

> *"The participation of women is crucial when advocating for social change and in order to powerfully highlight the systematic failures to provide equal protection to victim/survivors without access to public funds. Women's Voices groups have been hugely positive and successful, and engagement has been strong, and numbers have been higher than anticipated. Feedback from service users has shown that they have increased confidence and have felt empowered."*

Reflect regularly and refine implementation

Effective implementation required continuous refinement, informed by lived experience through methods such as focus/steering groups, feedback surveys, and regular check-ins. Funded Partners adapted projects in response to barriers by using multilingual and hybrid delivery formats and diversifying communication methods. In some cases, this required extending timelines to enable deeper dialogue and reflection. This highlights that centring lived experience requires embedding ongoing learning, so work remains flexible, responsive, and shaped in real time by people's needs and experience.

> *"We will respond to threats by continuing communication with our partners and keeping our finger on the pulse of the needs of the community. One way we will do this is by creating a steering group that incorporates our new regions and to always be asking, "Are we meeting our goals?" and "Are our goals still in line with the needs of the community?"*
>
> *– Change Makers Funded Partner*

Overcoming common challenges

Difficulty reaching people not currently engaged in services, including the most marginalised individuals and communities who would provide important insight.

Create accessible entry points

Design programmes with flexible and simple ways to engage – such as social or informal activities – alongside more time and resource-intensive methods so people can participate on their own terms and at different stages of their journey. Gather service insight and continue to learn and refine approaches.

> *"Our parent/carer Board has been difficult to engage at times. Acting on the suggestions of those who do attend, we are changing the name of the Board to a less formal Group, creating a closed Facebook group for the parent/carers (monitored by [our organisation]) and holding some meetings during the evenings."*
>
> *– Change Makers Funded Partner*

Difficulty maintaining engagement over the duration of a project, including the most marginalised individuals and communities facing the greatest barriers to participation.

Invest in trust-building and relationships

Much Funded Partner delivery depended on sustained relationship-building over time, supported by consistent contact, blended formats, and informal opportunities to connect. Having multiple staff or volunteers with lived experience helped in forming these relationships with service users, as well as guarding against turnover risk when individuals moved on. These relationships were central – not incidental – to enabling meaningful participation.

Invest in capacity, choice, and leadership

Meaningful participation often required sustained investment in service users' confidence, skills, and support. Funded Partners offered training in areas such as facilitation, public speaking, and campaigning, alongside broader personal development opportunities. Importantly, participation was not one-size-fits-all – some individuals preferred visible leadership roles, while others contributed behind the scenes. Where this was done well, people with lived experience developed into advocates, facilitators, and leaders over time, with increasing agency and ownership over different elements of implementation.

> *"The introduction this year of the Alumni project, that provided participants the opportunity for ongoing contact with [our organisation] after completing a cycle of the programme, proved to be greatly valued by young people. In these alternative group spaces (often outside of school settings) young people were seen to flourish, developing communication and leadership skills as well as independence and confidence. This lasting connection with participants and their families embodies the community empowerment ethos that is central to [our] organisational values. It is a recommendation of this report that this is included in future programmes and that every effort is made to continue this provision moving forward."*
>
> *– Change Makers Funded Partner*

5. ASSESS – Centring lived experience in Monitoring and Evaluation (M&E)

KEY TAKEAWAYS

Co-design what you measure

Work with experts by experience to define outcomes, success, and indicators, so measurement reflects what matters in practice.

Make data collection accessible, relational, and proportionate

Adapt methods and formats whilst building trust so people feel comfortable sharing their experiences.

Involve people with lived experience in interpreting evidence

Bring lived experience into analysis and sense-making to strengthen the credibility and relevance of findings.

Share findings in inclusive and meaningful ways

Ethically co-produce materials so that they are accessible and useful to different audiences, including marginalised communities.

Demonstrate value

Use clear communication and visible action on findings to build trust and reinforce the value of engaging in M&E activity.

Centring lived experience in the 'Assess' stage means involving people not only as respondents in data collection activities, but as partners on learning journeys – strengthening the credibility, depth, and usefulness of findings.

This includes working with people as co-designers, contributors, and interpreters of learning, so that measurement goes beyond tick-box reporting and leads to meaningful insight and improvement.

How to include lived experience M&E

Shaping what is measured

Funded Partners co-designed outcomes and measures with experts by experience to define what meaningful change looks like. Funded Partners found that focusing on a smaller number of key M&E activities and refining them over time was more effective than trying to measure many different things simultaneously. Co-designing outcomes ensured that measurement reflected what mattered to experts by experience, shifting away from externally imposed metrics towards shared definitions of success.

> *"We have learnt a lot about effective MEL and are working to make it more consistent, useful and beneficial to participants. This includes working with students at the alternative provision to co-design outcome measures that accurately reflect the impact of the work and adapting our measures for reflective practice to include self-reported questions around cultural sensitivity and professional practice in school staff."*
>
> *– Change Makers Funded Partner*

Collecting data

Funded Partners regularly adapted methods to be accessible and relevant, which included people with lived experience designing tools, and adjusting language and formats. As well, Funded Partners were balancing generating robust evidence while avoiding excessive burden on experts by experience (especially those in a vulnerable situation). They were therefore keen to gather input on data collection approaches to ensure they were robust and proportionate. Beyond design considerations, several Funded Partners ensured that people with lived experience were collecting the data themselves through peer researchers or staff/volunteers with lived experience leading data collection, which improved the quality of insight gathered.

> *"There was also a specific and concerted effort to engage Peer Researchers throughout the design and delivery of focus groups... they co-designed and co-facilitated focus groups which fed directly into the evaluation and allowed us to capture richer and more authentic insights. Co-designing research and evaluation approaches and tools with Peer Researchers was key to ensure the programme was both culturally relevant and trauma informed."*
>
> *– Change Makers Funded Partner*

Interpreting evidence

Lived experience should play a central role in analysing and validating findings. Funded Partners involved experts by experience in sense-making and shaping conclusions, resulting in more credible and contextually grounded insights. This also helped surface ethical concerns, risks, and blind spots that may not have been visible without a lived experience lens, strengthening both the quality and integrity of learning.

Women's Budget Group and the Global Institute for Women's Leadership, King's College London

Women's Budget Group and the Global Institute for Women's Leadership at King's College London joined forces to deliver a full-day event bringing together feminist researchers and women's grassroots organisations to discuss and analyse the 2021 census data. They offered formal and informal data training workshops, bringing together a selected group of activists, academics, policy makers and women's organisations to engage with the census results.

> *"It's crucial that discussions about census statistics are open to everyone and that recommendations drawn from those statistics include diverse viewpoints. Interpreting a large dataset well depends on an understanding of the issues and contexts it reflects. This is especially true when data is used to propose policy solutions for perceived problems. This is why having a mix of different women at the event was so important."*

Special consideration was given to the diversity of viewpoints that went into recommendations and conclusions, ensuring that lived experience was reflected in how findings were interpreted.

> *"We invited a range of women with different backgrounds in terms of academic experience, location, ethnicity, voluntary work, personal experiences related to key census topics, and social class. This way, we could get various perspectives on how to use the data, what factors mattered, and what policies may meaningfully address issues."*

Sharing findings

People with lived experience helped shape how findings were communicated, ensuring outputs were accessible, relevant, and appropriate for different audiences, including marginalised communities. Across Funded Partners, lived experience directly informed communication formats and dissemination approaches. This led to more grounded and practical outputs, better able to inform and influence wider audiences.

> *"We worked with kinship carers to develop streamlined and more impactful policy and campaign calls and developed effective campaign messaging, retaining a positive tone and narrative about the benefits of kinship care and love in their families, without compromising on communicating the challenges and dignity of kinship families."*
>
> *– Change Makers Funded Partner*

Overcoming common challenges

Ensuring findings are accessible to all audiences, particularly marginalised or 'hard to reach' communities that have participated in M&E activities.

Communicate clearly and accessibly

Using plain language, varied formats, multilingual approaches and visual tools made findings more inclusive and easier to engage with.

Demonstrating the value of lived experience contributions, especially for how data will be used, and the impact involvement in M&E activities can have on personal development.

Show tangible value

Clearly demonstrating how lived experience influenced decisions, adaptations, and future plans helped reinforce the value of participation in M&E and acted as a motivator to get involved. In many cases, involvement in M&E also supported confidence-building and skill development over time – demonstrating that evaluation can function as a space for empowerment as well as measurement.

> *"Youth peer research offers numerous benefits for young people who participate and for researchers, including: Development of independent research skills, such as designing surveys and analysing data as well as building skills and increasing employability; increased self-awareness which includes young people reflecting on their own biases and experiences, allowing for a well-rounded research process; greater ability to break down stereotypes and build rapport among young people, specifically young people from racialised and marginalised communities."*
>
> *– Change Makers Funded Partner*

4. REVIEW – Centring lived experience in using learning to improve practice

KEY TAKEAWAYS

Use lived experience to drive change

Ensure lived experience informs tangible decisions regarding programme redesign, priorities, and future strategic direction.

Embed ongoing structures for challenge and reflection

Create mechanisms (e.g. steering groups) where lived experience can shape decisions and question assumptions.

Close the loop and build accountability

Clearly show what has changed, why, and what will happen next to manage expectations and maintain trust.

Prioritise ethics and sustainability

Balance honest storytelling and learning with safeguarding and design approaches that are flexible to people's capacity and roles.

Centring lived experience in the 'Review' stage means using it not only to understand what has happened, but to challenge assumptions, redesign programmes, and guide future strategic direction. The review phase turns findings into actionable insights, guiding future delivery and communicating impact to different stakeholder groups. This stage is crucial for building trust and accountability, especially with those who contributed lived experience.

How to embed lived experience in learning

Drive adaptation and decision-making

A defining feature of the 'Review' stage is how learning informs change. Feedback from people with lived experience led to Funded Partners redesigning programmes, shifting priorities, and changing approaches. Insights also informed decisions about scaling, partnerships, and future focus, often influencing organisational strategy. This demonstrates that centring lived experience in the 'Review' stage means using learning not just to refine work, but to guide how organisations evolve.

Embed ongoing structures for challenge

The 'Review' stage is strongest when lived experience is embedded in sustained mechanisms for reflection and decision-making. Funded Partners established advisory groups, steering groups, and lived experience networks that enabled experts by experience to shape direction over time. Within these spaces, individuals played a key role in questioning assumptions, identifying gaps, and highlighting unmet needs, strengthening the depth and relevance of organisational learning.

> *"The ongoing legacy and sustainability of the work generated through Change Makers is central to how we ensure the impact of the programme is felt for years to come. We will ensure processes enable and empower Co-producers to engage meaningfully to influence the direction of our work. We will support young people's engagement with their next steps through Wellbeing Action planning and Development Pathways to plan capacity and involvement... We delivered a dedicated session for Youth workers to discuss and co-design the evaluation approach in response to feedback asking for more support in delivery."*
>
> *– Change Makers Funded Partner*

Overcoming common challenges

Ethical tension, in balancing honest storytelling with privacy, safety, and non-extractive practice.

Funded Partners highlighted an inherent tension between enabling authentic storytelling and protecting wellbeing, including exposure to social media abuse, re-traumatisation through recounting difficult experiences, and overburdening individuals with repeated requests for participation.

Expectation risk, where involvement raises hopes without leading to visible change

This was of particular concern for Funded Partners towards the end of their Change Makers funding, with concerns that broader systemic changes were not forthcoming, and the impact this might have on people who had been involved: *"There were concerns we were raising hopes without any offer of change to the current system."*

What Funded Partners found helpful

Make safeguarding a priority

This requires trauma-informed and culturally sensitive approaches, careful use of language, and being mindful of the impact of involvement. This meant Funded Partners had to pay careful attention to the ethical risks presented by centring lived experience, including overburdening experts by experience, overexposure, and extractive use of people's stories, which required appropriate support, safeguarding, and informed consent.

Young Changemakers (UK Youth in partnership with The Diana Award and Centre for Mental Health)

Young Changemakers is a programme led by and for young people from Black and Black-mixed heritage communities to reimagine mental health support and services. They adopted an approach to safeguarding on the project under the acronym 'TAB' – Triggers, Avoiding burnout, and Boundaries around overexposure – which sought to address ethical issues thoughtfully to protect the well-being of those sharing their experiences.

> "**T – Triggers:** *Recognise and manage emotional triggers that may arise during sharing.*
>
> **A – Avoiding burnout:** *Establish support and self-care practices to prevent burnout from over-sharing or repeated exposure.*
>
> **B – Boundaries around overexposure:** *Set boundaries to prevent emotional exhaustion from frequent retelling or revisiting sensitive experiences.*
>
> *We recognise that lived experienced based work can be really hard so it's important to ensure that [people with lived experience] know the following: what support they have beforehand; who the designated safeguarding lead is; the power of choice and withdrawal at any point during an opportunity; tools and tips to opt-out (e.g. during a panel talk); where they can have quiet spaces if things become overwhelming; when and where a debrief space will be held; any additional support they have access to after the campaign."*

Close the loop

Clearly show what has changed, why it has changed (e.g. by connecting to the challenges encountered), and what will happen next – particularly to those who contributed. This helps manage expectations of the changes people can expect to see and reinforces accountability on those leading activities.

Gatwick Detainees Welfare Group

GDWG

GDWG works to improve the welfare and wellbeing of people held in detention, by offering friendship and support and advocating for fair treatment. Their Refugee Tales outreach project organises walks in solidarity with refugees, those who have sought sanctuary, and people who have experienced immigration detention, supporting people to share their stories about immigration detention to raise awareness of their experiences.

GDWG paid particular concern to the impact of their communications on experts by experience. This included highlighting the realities of detention without upsetting those who had shared their experiences but also managing expectations about broader legislative change which looked unlikely towards the end of their Change Makers project.

> *"Because our community includes a lot of people sitting on their own in accommodation, in limbo, unable to work with very few financial resources, often very unwell, physically or mentally, and certainly isolated, I had to ensure that the tone of the messaging was such that we were conveying our message, but that we weren't raging and encouraging people to feel even more depressed and isolated... We had to curate our messaging so that there was some hope for people even when legislative change seemed very unlikely towards the end of the last government."*

CONCLUSION

This learning summary has explored Funded Partners' reflections on how to centre lived experience across the project cycle.

Across the varied approaches within the Change Makers programme, relationships were not treated as a by-product of engagement, but as a foundation for delivery. Funded Partners demonstrated that positive relationships are built through recognising lived experience as expertise, embedding it within decision-making, and investing in ongoing engagement rather than one-off consultation. In practice, this meant creating varied opportunities for experts by experience to shape direction, influence implementation, and contribute to learning, supported by appropriate safeguarding and dedicated resources.

Enabling open communication within these relationships depended on creating the right conditions for experts by experience to participate. Practically, this meant combining clarity of purpose, accessible and inclusive communication, and transparency about the influence people can expect to have, with multiple ways for people to engage. Communication was most meaningful when it was two-way and responsive – where Funded Partners not only sought input, but clearly demonstrated how lived experience informed decisions, adaptations, and future plans.

Funded Partners showed that open communication cannot be separated from considerations of power, safety, and context. Avoiding putting too much pressure on people with lived experience required appropriate safeguarding, while ensuring participation reflected people's autonomy. This involved offering flexible routes into engagement, designing for a diversity of perspectives, and avoiding over-reliance on a small number of individuals. When supported in this way, relationships were more equitable, sustainable, and reflective of a broader range of experience.

In the context of an ever-changing political and social landscape, these approaches enabled organisations to adapt and remain grounded in lived realities. Strong relationships and open communication helped respond to emerging needs, navigate uncertainty, and maintain trust with communities over time. Centring lived experience on the Change Makers programme was not a static activity, but an ongoing process of listening, reflection, and adaptation in partnership with those who the programmes were designed to support.

NPC

New Philanthropy Capital is a think tank and consultancy working with individuals and organisations to maximise their impact. For over 25 years, we've worked with hundreds of organisations and individuals who want to turn ambition into impact, from shaping strategy, to supporting delivery, to evaluating what's working and learning what to do next. If you'd like to find out more about our work, please contact us at:

info@thinkNPC.org or visit *www.thinkNPC.org*