

'Lived experience' in grant-making practice

Briefing paper, April 2020

Learning partnership



As funders continue to search for ways of improving practice and ensuring that their funds are used effectively, more of them are looking at ways to involve people at grassroots level. Conversations about sharing or shifting power are frequent, and there is a particular interest in working *with* people who have lived experience – to make better decisions.

In light of the Covid-19 crisis, it feels more important than ever to open lines of communication between funders and communities.

Through its 'intermediary funding programme' Comic Relief is partnering with four funders¹ who are rooted in their communities and are well placed to understand the unique challenges and opportunities facing local grassroots organisations. They are, together, exploring how and when to involve people with lived experience in grant-making, and we hope that their thoughts and experiments may be useful to other funders.

IVAR is the learning partner for the intermediary funding programme and is working alongside Comic Relief and the partner funders to draw out and share learning as the work develops. In this first briefing paper, we reflect on how 'lived experience' can be incorporated into all stages of grant-making and make some suggestions for funders who have not yet stepped out on that road. This builds on the first learning workshop held with Comic Relief and its four intermediary funding partners in November 2019, as well as subsequent one-to-one interviews.

What is 'lived experience'?

At IVAR, we hear people talk about experience in lots of different ways and we try to use language that resonates with those we are working with at any particular time. The term 'lived experience' has gained resonance among funders in recent years, but an agreed definition remains elusive. Essentially, lived experience refers to an individual's experience of particular challenges or situations, whether directly or indirectly.

Involving individuals with 'lived experience' leads to better grant-making and shifts the power, so local people can co-create the programmes that are most useful to them. There are three aspects to this:

1. There is a sense of those with lived experience being grounded in their community (whether of shared experience or in a geographical area), which they know and are part of.
2. The term 'lived experience' suggests a *'good, strong understanding of the experience'* as well as the experience itself. Those with lived experience may not know it, but they have a real contribution to make and may already have done so, for example by taking part in consultations.
3. Personal experience is key, though it need not be direct – it may be through caring or supporting those facing challenges, in a personal or a professional capacity, or as a member of a support organisation. One funder used the term *'lived expertise'* and another *'experts by experience'*.

Funders were keen to point out that there is a very wide range of lived experience – this should be recognised and acknowledged. While finding the

¹ Community Foundation For Northern Ireland, The Corra Foundation in Scotland, Wales Council for Voluntary Action and Groundwork in England

right terminology can be a challenge, and its definition must be reviewed regularly, funders acknowledged that language is really important for those we involve to ensure that they are recognised – and it is important to find a way of describing the value that people can bring.

Why is lived experience important in the context of grant-making?

The funders highlighted what motivated them to involve people with lived experience in their grant-making process.

Concern for good practice

Comic Relief chose to work with intermediary funders and to involve people with lived experience in grant-making to ensure they were funding the changes that communities most need. It has also helped funders to review their internal processes:

As an assessment team, we tried to sit in on panels and listen to gain learning for ourselves based on the perspective and experience people with lived experience brought to the room.

The reputation funders hold within a community counts for a lot, so it is important for people at grassroots level to know that their views are being taken seriously: *'To know that we are not just kidding, and we [understand] the meaning of that experience rather than just determining whether their lived experience is right or wrong'.*

One funder described the first time they gave children and parents the opportunity to shape a programme in an area that had a legacy of conflict with the police: *'But since local people and parents [were] involved in the process right from the beginning, the entire community gave permission to have the police come in to give a small talk to the community ... this was a major thing to happen'.* As well as the direct benefit, this was instrumental in giving the funder more legitimacy in the area.

Decision-making based on local knowledge

Local knowledge leads to grant decisions that are more sustainable and have a greater impact:

It is their generosity of sharing their experience and knowledge that adds a lot of value to grant-making processes and by capturing this, we can make better decisions over time that will stick better in the community.

For one funder, it was very much about *'working on each other's strengths: we have the experience of grant-making and they bring in knowledge about the ground realities.'* The relationship between the funder and grantee is also strengthened by the involvement of individuals with lived experience in decision making as it adds transparency. It makes the process more credible locally, and can increase the diversity of funded programmes.

Bad decisions can be avoided, pitfalls can be seen early on and opportunities can be grasped. One funder rejected an application initially, but the panel (made up of people with lived experience) liked the idea. They offered some

suggestions to the applicant, who came back a second time and was awarded a grant.

Sharing power and shifting the dynamic

'Shifting the power for decision making away from [the funder] to other people working at the grassroots or to people with lived experience' was felt to be important. People who are often classed as 'beneficiaries' have been empowered to take control of their communities and are now co-creators in reshaping the aid architecture, making them more equal partners in the process. As another funder said:

The starting point should be about being humble ... to make a real impact we need to shift the power of decision-making into the hands of people [who] know best.

Sharing power with people rooted in local communities also means shared responsibility for grant decisions: 'As funders, we are privileged to have power to make decision[s] about money, yet it comes with a responsibility that the money is spent on benefiting people's lives.'

What have funders learnt about how to involve people with lived experience in the funding process?

A question to think about is how comfortable are you with sharing the power and letting others be involved in decisions over money? Secondly, if you are ready to share power, who do you want to share power with?

Who have funders shared power with?

'There are a number of different ways in which lived experience can exist among individuals, and each one is valid'. Each intermediary funder had a different pool of people they could draw on, depending on their own expertise and existing connections. Some people with lived experience can speak about support they themselves have received – or not received. Others may have supported their peers, or advocated on their behalf. Then there are all those who offer support-parents and other family members, carers, professionals and organisations.

Where in the process can they be involved?

The earlier, the better – and at every stage. More than one funder realised how important it was to have input at an early stage only after involving people in application selection:

The danger is that sometimes you just treat this as a bolt [-on] at the end. There is already momentum, and decisions have already been made and suddenly we say that people with lived experience are in charge. However, the truth is that they haven't designed the process and they were not involved in the discussion right from the beginning.

Here are some ways people have been involved in grant-making:

- **Starting right from the beginning:** Enabling people with lived experience to participate in setting the aims of the grant programme can help to ensure that it is properly focused and tailored for local needs.
- **Developing selection criteria:** Ensuring that the design of grants and selection criteria do not exclude anyone. Also co-creating assessment criteria, for example how funded projects will themselves involve people with lived experience.
- **On decision-making panels** where they can feedback on the initial assessments made by the funders. They are given free space to question, challenge and change recommendations.
- **Visiting projects** once they have started – to check on progress, gather feedback and develop case studies.
- **Developing the application process itself** – as one funder said: *'We [want to] have them feedback into the overall grant process, right from the design of the programme including the application forms and related assessments and the decisions.'*

What are the key things to consider?

Funders found that successful involvement was based on three key factors:

1. Preparation and planning
2. Establishing good relationships and clarifying roles
3. How you work together

Preparation and planning

Learn from other organisations who have involved people with lived experience in their work, before starting your own process of participation.

Build the relationships and trust necessary to get people involved – this can take time. One funder was keen to get people involved as soon as possible after the launch of the programme but found it difficult to do quickly. However, another found that not everything took more time: in relation to selecting applications, *'One shouldn't think that this is a resource intensive process ... it was no different to when we have our trustees make grant decisions, we do papers for them, do lunches etc.'*

Looking at existing processes. If they are set up for funders, they may not be suitable for others, who could find going through written applications *'tedious or overwhelming'*. Hence, funders have adapted their processes to suit panels of people with lived experience. Initial assessments are made by funders, who highlight the key messages in applications, making it easier for the panel to decide which grants to award.

Establishing good relationships and clarifying roles

Make it very clear what you mean by 'lived experience' and clarify the role of participants – as experts. One funder described panel members with lived experience feeling that the experience of professional grant makers was worth more than their own, and *'that they couldn't go against the recommendations to*

reject or approve applications and change the decisions'. Taking this on board, the funder decided to change their language, referring to 'strengths and weaknesses instead of saying recommended for approval or rejection'.

Be open about the decision-making process. Be clear about who makes the final decision. Managing expectations is also important (one funder provided a terms of reference), and being realistic about what can be achieved.

Avoid labelling individuals and be sensitive: *'We are not asking people to fill out forms to tell us about their lived experience, yet we want to be sure we have people with lived experience in the room. In all this we have to be extremely sensitive'.* Funders employed different ways to ensure they were being sensitive to the individuals with lived experience: creating an atmosphere of trust and comfort; understanding when people were prepared to share, and when they weren't; and facilitating conversations on difficult topics.

Confidentiality and conflict of interest. Explain to participants that they do not have to talk about their personal experiences, but if they do, it will be treated confidentially, and that they can let the team know if it is getting too much for them. Tell them that if they have had previous involvement with an organisation whose application is being assessed, they need to be open about that.

Setting up the right environment, where people feel comfortable and safe, is very important. One way to do this is by arranging for groups to meet in their own space. Be aware that face-to-face meetings are not the only means of communication. Joining a discussion by phone or online, or filling in surveys, can be just as effective – particularly for those who may have difficulty travelling.

How you work together

When selecting individuals with lived experience, ask yourself questions like: Why do you want to work with this particular group? Why is their experience important? What do they bring to the table which you want to access to ensure good decisions are made? To ensure that the 'usual suspects' from the community aren't the only ones involved, funders must extend their networks.

While some individuals were known to be activists in a particular field, we [the funders] tried not to just get the best-known names instead we tried our best to find a balance of experiences among the different themes of the grants and the geography they represented.

We were quite aware that, for instance, in choosing the panel, that we are still 'choosing people', even though we started out by saying we want to shift power and make a difference. And there were so many different ways in which we couldn't not be influencing this. However, we did not give up there and thought – let's push ahead.

Preparing participants. One funder allocated staff to discuss roles; another had a member of staff phoning prospective participants to explain what was involved and answer questions; others have included an induction day; and in one case the participants did a trial run looking through applications before starting for real.

Managing expectations. Funders have acknowledged the need to manage expectations, ensuring their panels have a good mix of individuals who share different views and can have useful debates on grant decisions. *'Being careful with who you invite to be panel members, having a good and honest*

conversation with them ahead of time and being clear what role they will bring to the table, helps.'

Being flexible, prepared to constantly adapt your processes and challenge the definition of individuals with lived experience.

It is all about inclusion, reviewing, debating, discussing, changing, amending but the starting point should be about being humble about this and wanting to shift the power. We, as grant makers, are blessed with money to distribute and are in a privileged position to do this, however, to make a real impact we need to shift the power of decision-making into the hands of people [who] know best and this ensures having a more grounded impact.

A strong chair to facilitate panel discussions: One funder cautioned being alert to groups and individuals who come into consultations with their own agendas and can dominate the discussion. Their advice was:

Having a chair who is a good facilitator ... helps to ensure everyone has a chance to speak and some individuals are not left out in the conversation/debates if [they] cannot speak loudly enough.

Valuing your participants. They are giving up their own time to contribute to the process, so as well as making them feel that what they say is valued, it's important to recognise the time they may have spent reading through papers, answering surveys or attending meetings by, for example, helping with travel expenses or offering vouchers as a thank you.

How can other trusts and foundations include people with lived experience in their processes?

'Try it!' That is the first thing our funders would say to anyone thinking of following in their footsteps. Several funders found it didn't work first time but saw enough benefits to continue. One reflected that [our] *learning will help us do this better in the second round of grant making.* Another decided to *'push ahead and do the best we can and be very clear about how we've done it and why we've done it the way we have'*.

'Lived experience' is a broad term. Avoid getting *'too hung up on the differences in lived experience, communities and grassroots organisations, as they are all living through the same thing'*.

Go to where the expertise is. You may have the big picture, but those on the ground have insight and will often spot why a particular idea needs adapting in order to work. For example, a person with experience of mental health provision locally may know that the challenge is not a shortage of counsellors but a shortage of funds to pay counsellors.

Play to your own strengths and knowledge. Use your existing contacts within a community to find people with lived experience. The connections you make can increase your reach within that community and expand the pool of people who can help you. One funder found that some people also had knowledge outside the area that they had been asked to help with.

Empowerment: *'Lived experience being seen as a broad term of personal experience ... is one part in shifting the power in grant-making'*. Shared responsibility for decisions also helps to redress the power balance between funder and grant recipient.

It's a win-win situation. By using existing engagement to get closer to local communities, and establishing trust with individuals with lived experience, it is possible to create a virtuous circle that helps everyone: communities receive focused grants through an application process that better suits their needs and resources; the funder achieves better results and has the satisfaction that through their work they are helping people more effectively.

A final word

The four intermediary funders are each tailoring their approach to involving people with lived experience in their grant-making. For some, the focus is on using the expertise of people who live with the issues the funder is trying to address to help the funder make the best possible decisions. Others are looking at how they can enable local people to make grant decisions, for example, one of the funders is giving local people in four different communities the chance to design a bespoke grant programme – this will include making decisions about who receives grants. We will continue to work with all four funders to reflect on and learn from their approaches.