

Taking Steps to Develop Lived Experience Leaders

TOOLKIT FOR SMALL REFUGEE AND MIGRANT ORGANISATIONS

WHAT IS LIVED EXPERIENCE LEADERSHIP AND WHY IS IT IMPORTANT?

We define Lived Experience Leadership as **people with first-hand experience of seeking sanctuary or migration getting involved in the organisations who are supporting other people experiencing similar issues**. “Leadership” doesn’t just refer to people being in senior staff roles, it also means: having your expertise and knowledge recognised, having a voice in an organisation and being heard, getting involved in delivering and designing services, being involved in governance, influencing decision making or policy and advocacy work.

CAN YOU COMMIT?

In recent years, it has been highlighted that the refugee and migration sector is a long way behind other parts of civil society in including people with lived experience through participation and leadership; organisations and charities working with people who have experience of homelessness, physical or mental health diagnoses, identify as LGBTQ+ etc are seen as far ahead. We believe the refugee and migration sector needs to do more to systematically and meaningfully engage people with lived experience in its work.

Some organisations already do this really well, some have been developing opportunities for Lived Experience Leadership for many years, while others will be at the start of this process. We believe that organisations need to start making changes and accept there will be ongoing learning and reflection, and not let fear of doing it ‘the right way’ hinder change; any step towards inclusion of people with lived experience of the refugee/migration journey is a step in the right direction.

“WHEN YOU’RE EXPERIENCING SOMETHING, YOU UNDERSTAND THE ISSUES AND CHALLENGES, AND FROM THAT YOU CAN WORK TOWARDS THE SOLUTION.”

INTERVIEWEE WITH LIVED EXPERIENCE

WHO WE ARE

We are a group of sector leaders who came together in 2022 through Clore Social Leadership around a common goal of achieving more and better Lived Experience Leadership in our organisations and across the refugee and migrant sector. We do not profess to have particular expertise in this subject. Some of us have lived experience of migration; some of us do not. We all have many years’ experiences of working in the sector. We are all committed to anti-racism, to social justice and enabling and amplifying Lived Experience Leadership where that is what people want. We learnt a lot and wanted to share what we learnt in the hope it will help others who are on the same journey.

Beth Wilson -CEO, Bristol Refugee Rights

Amy Lythgoe - Trustee, Together Now

Jimmy Zachariah - CEO, Baca

Jess Thompson - CEO, Migrateful

Katie Lifford - Head of Client Services , Boaz Trust

Flora Roshi - Deputy CEO, Reading Refugee Support Group

Caron Boulghassoul - Chair, NACCOM

Henry Chango Lopez - General Secretary, IWGB Union

Anna Rudd - Client Support Manager, ASSIST Sheffield

79% of participants at our Workshop for sector leaders said that their organisation needed to do more to ensure good representation in their organisation by people with lived experience

WHERE TO START

People with Lived Experience are not a homogenous group: they are individual people in a diverse group and everyone’s experience of seeking asylum, or migrating to the UK, will be different. Whilst we need to include people with lived experience, we should not expect them to talk on behalf of others. Organisations should not assume that someone with lived experience wants to get involved in supporting or leading organisations that are engaging people of the same background and experiences.

“AT THE TIME WE INTERACT WITH PEOPLE, IT’S A DIFFICULT, UNSTABLE TIME. THEY’RE IN THE MIDDLE OF THEIR ASYLUM CLAIM, OR BEEN REFUSED ASYLUM, AND FACED WITH BEING EVICTED FROM THEIR ACCOMMODATION OR LOSING FINANCIAL SUPPORT. IT DOESN’T FEEL LIKE THE RIGHT TIME IN PEOPLE’S LIVES TO ASK FOR ENGAGEMENT.”

ORGANISATION ON THE CHALLENGE THEY FACE ENGAGING CLIENTS WITH LIVED EXPERIENCE

GENERAL PRINCIPLES OF GOOD INVOLVEMENT

1. **Understand the barriers and the power dynamic; ensure engagement is truly meaningful; challenge negative perceptions of Lived Experience Leadership, including from service users** e.g. ask your service users how they want to be involved; what will help them be involved and what is stopping them.
2. **Commit capacity and resource; commit to change** e.g. seek specific funding to support you develop a plan or implement your ideas.
3. **Tell your service users you are committed to Lived Experience Leadership** e.g. use our leaflet; talk about it to service users; embed it in your literature/publications; include it in your values and strategic plan; celebrate it.
4. **Provide a range of opportunities and ways people can get involved** e.g. people can be influencers, participants, change-makers, volunteers, staff members, leaders, trustees. To really be committed to Lived Experience Leadership is to embed it throughout the organisation.
5. **Tell people the benefits of getting involved and what they will get from you and understand when they don't want to get involved** e.g. think about what they will get out of it right now; think about the skills they will develop that will help them apply for jobs in the future; tell people about your expectations of them and what they will get in return.
6. **Plan for providing the support people need and keeping people and their mental health safe; understand that people may still be "living" their experience** e.g. trauma focused supervision; access to a peer network or peer mentor; training.
7. **Think about language, communication and internal policies and process** e.g. definitions matter, make sure you aren't putting people off with how you talk about Lived Experience Leadership or equity and diversity more generally; write lived experience into your policies; be clear about "what" lived experience you are looking for (is it of a particular aspect e.g. asylum support); be open about your own lived experience (if you feel comfortable to do so) and how it has contributed to and enabled your career.
8. **Take a person-centred approach; recognise the whole person and what they can bring to your organisation, not just their lived experience** e.g. make sure you ask about other skills and think about how they can use them; think about the whole experience of joining your organisation and anything that might act as a barrier, for example staff trips to the pub.
9. **Think about how you will monitor your progress on this journey, continue to learn from it and celebrate success** e.g. have regular review points; build it into your Monitoring, Evaluation and Learning.
10. **It is ok for experience in our sector to be used as a stepping stone to something else; success includes supporting people on their journey to their chosen career** e.g. celebrate this too; recognise that you have supported someone on their journey to building their life and career.

"FOR ME TO GO BACK AND CONTRIBUTE WOULD BE A HUGE OPPORTUNITY. I CAN BE A VOICE FOR OTHER PEOPLE. I DON'T WANT TO STOP HERE!"

SERVICE USER WITH LIVED EXPERIENCE

PLACE LIVED EXPERIENCE LEADERSHIP AT THE HEART OF SERVICE DESIGN THROUGH: PARTICIPATION AND CONSULTATION

- Listen to your service users / ex-service users formally and informally. Provide plenty of opportunities for them to feedback on the service they have/have not received. Think about when the right time will be to ask them for feedback.
- You could set up an advisory or consultation group of current or former service users. We have heard that this can be more challenging for organisations who don't have a long-term relationship with their service users and because service users who are still receiving a service don't always feel they can be honest. You will need to think about these things in your planning.
- Think about whether you can use co-design processes or human centred design to ensure service design is truly collaborative.
- Make sure service users can see that their input/feedback has made a difference – tell them what has changed as a result of them; make sure their feedback is heard by those making decisions e.g. trustees.
- We suggest taking a look at Refugee Action's Good Practice guidance on setting up Experts by Experience groups.

“THE FIRST THING THAT MADE ME WANT TO GET INVOLVED IN COMMUNITY ORGANISING WAS MY OWN EXPERIENCE AND SECONDLY SEEING OTHER PEOPLE NOT WANT TO TALK OPENLY ABOUT THEIR IMMIGRATION EXPERIENCES. I COULD SEE PROBLEMS WE COULD EASILY SOLVE BY TALKING AS A COMMUNITY AND WORKING TOGETHER. I SAW THE INJUSTICE.”
STAFF MEMBER WITH LIVED EXPERIENCE

PLACE LIVED EXPERIENCE LEADERSHIP AT THE HEART OF SERVICE DELIVERY THROUGH: VOLUNTEERING AND EMPLOYMENT

UK systems are different to many other cultures and support is needed to ensure that people who want to apply for roles in this sector have the opportunity to do so. Organisations can say they encourage people with lived experience to apply, but in reality this is largely insufficient and there are additional measures that can be taken to increase opportunities. Making adjustments to be inclusive of everyone's needs is not just good practice in supporting volunteers and employees with lived experience but will support everyone's needs. Some examples of good practice we have seen are:

- Think about where and how you advertise roles e.g. circulating to other organisations in the sector and asking them to share it with their service users.
- Create roles (whether volunteers or employees) that specify or place value on lived experience e.g. valuing language skills. Some organisations, including Refugee Action, are 'ring-fencing' posts for people with lived experience; or weight their scoring in recruitment.
- Be flexible with volunteering opportunities; regular commitment may not be for everyone.
- Think about how you can make your recruitment processes more inclusive and supportive e.g. providing information sessions for people to learn about the role and application process; being flexible on the application and interview process and providing opportunities for people to demonstrate the value they will bring to your organisation in different ways; share the interview questions shortly before the interview so people have a chance to think and also have them written in front of them during the interview.
- Ensure lived experience is represented on recruitment panels.
- Sign up to the [Inclusive Employment Initiative](#) to get ideas and work with other organisations on this journey.
- Think about how you will support people to transition from service user to employee; what additional or different support they might need compared to someone who has worked in the sector before.

“BEING AN EXPERT IN SOMETHING DOES NOT MAKE YOU ENTITLED TO SPEAK FOR PEOPLE. SHARING THE DECISIONS AND GIVING THEM THE CHOICE, SHIFT POWER TO REFUGEES.”
 DIRECTOR WITH LIVED EXPERIENCE

PLACE LIVED EXPERIENCE LEADERSHIP AT THE HEART OF DECISION MAKING THROUGH: SENIOR LEADERS AND BOARDS

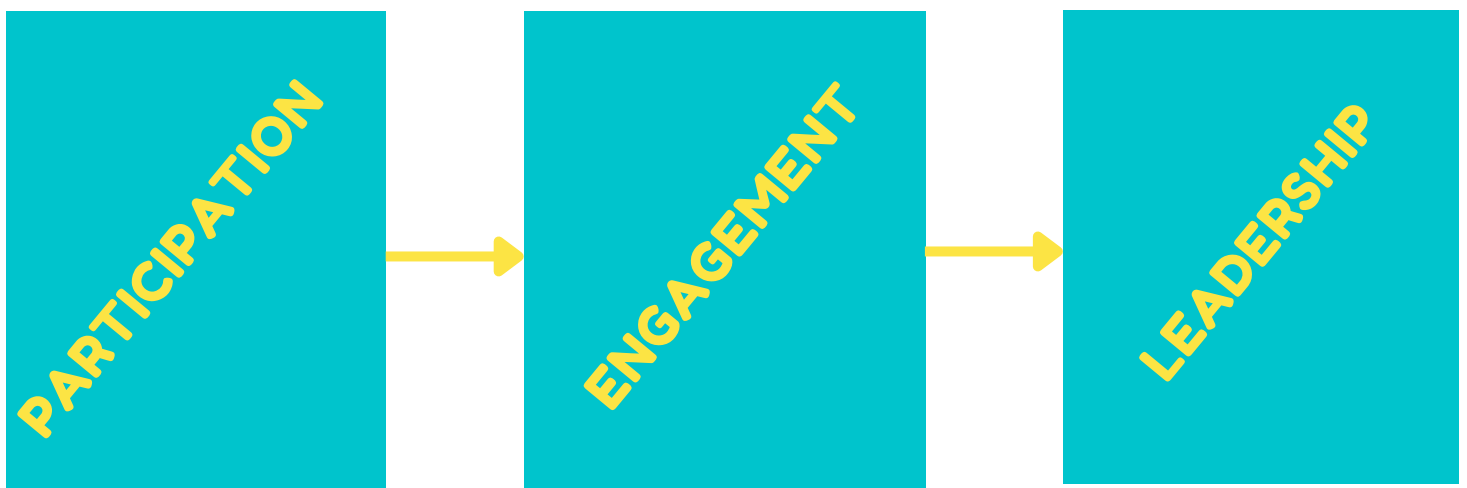
- Support people to overcome barriers and grow into leadership roles. Could you provide training, mentoring, work experience, opportunities to lead projects? You might need to invest in a large number of people being more ready for these types of roles to find the one or two who take them on.
- Provide people with opportunities to contribute to and experience decision making (dipping a toe at first if they prefer) e.g. through sitting on a decision making panel on a particular topic or issue.
- Recognise that it might take time for people to move into senior positions and support might be needed on an ongoing basis.
- Explore power building through membership models if you are or could be a membership organisation.
- We suggest taking a look at Refugee Action’s Good Practice guidance on [Expert by Experience Trustees](#).
- The [LEx movement report \(2019\)](#) is worth a read as is the Bayes Business School report on [Lived Experience on non-profit boards](#).

"I HAVE BEEN THROUGH THE PROCESS AND SAW HOW DIFFICULT THE PROCESS IS AND THE ABSENCE OF LEGAL REPRESENTATION. THERE ARE PROBLEMS WITHIN THE SYSTEM, A BROKEN SYSTEM, BUT THIS IS A DEMOCRACY, AND WE CAN CHALLENGE THE HOME OFFICE WITH KNOWLEDGE AND EXPERIENCE AND IT WILL BE EFFECTIVE."

STAFF MEMBER WITH LIVED EXPERIENCE

PLACE LIVED EXPERIENCE LEADERSHIP AT THE HEART OF INFLUENCING AND POLICY WORK

- Support people to share their experiences in a way they feel comfortable to.
- Make it about the system and not about them.
- Think about the language you use as an organisation and how you portray yourself to others; challenge "them" and "us"; "good" and "bad" migrants' language.
- Make sure they have time and space to debrief about the impact of sharing their story or experiences.



"EMBRACE LIVED EXPERIENCE WITH HAND ON HEART ... IT CAN MAKE THINGS UNCOMFORTABLE BUT THIS IS AN AVENUE FOR GROWTH."

INTERVIEWEE



USEFUL RESOURCES ON LIVED EXPERIENCE LEADERSHIP AND APPROACHES IN OTHER SECTORS

- Unltd's **Leading with Lived Experience** report highlights some of perceptions and systemic barriers that people face, including tokenism and rigid structures and processes. It also includes recommendations such as questioning the power and privilege in your hierarchy and making adjustments to be inclusive.
- **Reports by The Lived Experience (2017) and LEx movement (2019)** contain in depth interviews with social sector leaders who self-identify as LEx (lived experience) leaders as well as funders.
- **Who decides? Supporting Lived Experience Leadership** - Refugee Week's resource, following a workshop of the same title, explores why Lived Experience Leadership is important, questions to consider, and approaches to enabling Lived Experience Leadership in your organisation.
- **Wellcome: Let's talk about lived experiences of mental health challenges:** lived experience in mental health.
- **Leaders with lived experience: breaking down barriers:** a case study of a new initiative to develop a new social leadership programme for those with lived experience.
- **Mind** have a comprehensive influence and participation toolkit that explains how they work, the difference between lived experience influence, lived experience participation and Lived Experience Leadership.
- **DIY Theatre Company**, a company of performers with learning disabilities, have created a video explaining why Lived Experience leadership is important.
- There are many other examples of good practice from other sectors, these just represent a few of the useful things we found.

